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Augmentative and alternative communication for children with cerebral palsy

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Abstract: Children with cerebral palsy (CP) can experience a range of significant speech, language and communication difficulties. Those children with little or no intelligible speech can benefit from the provision of augmentative and alternative communication (AAC) systems. AAC approaches include training in the use of manual signs and/or symbol systems, as part of a 'total communication' approach, whereby all possible communicative modalities are considered as potentially useful. For children with severe motor impairment where the potential for signing is limited, intervention typically focuses on supporting symbol use through the provision of high-tech and low-tech communication systems. This review describes the categories of AAC systems available to children with CP, and outlines AAC assessment and intervention principles, drawing on the World Health Organisation's International Classification of Function, Disability and Health (ICF-CY). Given the complex health, motor, sensory, learning and communication needs of children with CP, AAC related assessment and intervention requires a multi-disciplinary perspective.

Key words: Cerebral palsy; children; communication; communication aids; augmentative and alternative communication; AAC; communication disorders; children with disability; dysarthria; international classification of function, disability and health

Augmentative and alternative communication for children with cerebral palsy

Introduction

Children with a clinical description of cerebral palsy (CP) who have little or no functional speech, and who may have a poor prognosis for speech development, face significant barriers to communication with others. Such children are heavily reliant on the use of communication modalities such as vocalisations and kinesic resources (e.g. gestures, facial expression, use of eye gaze) in their interactions with others. However, use of these modalities alone provides only limited opportunities for self-expression. Consequently, children may also be introduced to augmentative and alternative communication (AAC) systems. In its broadest sense, the term AAC refers to any mode or channel of communication that supports speech and/or writing, including intrinsic modalities such as gesture, sign systems and communication aid technologies. Most commonly however, AAC is used to refer to formal systems that are explicitly introduced and taught. In this paper, the term AAC will be used in this latter sense. Importantly however, AAC intervention cannot be considered in isolation from the full range of communication methods used by children with CP. Consequently, the term total communication is a helpful one can be used to capture the diversity of communication resources used by such children.

This review outlines the broad categories of AAC systems and tools available to children with CP as part of a total communication approach, and the principles of AAC assessment and intervention. The review focuses on support for face-to-face interactions involving children for whom speech is not a useful communication resource in the short or long term. This includes how children for whom AAC may support the understanding of language as well as expressive communication. The evidence increasingly available in this field should guide clinicians in their interventions to best support the development of children with CP.

Types of AAC: Signs and symbols

AAC can be classified as *manual signs* and *symbols*. Manual signs refer to prescribed or agreed systems of hand shapes and movements, body positioning, and facial expression, and include formal sign languages often used by people with hearing loss. Depending on the severity of motor impairment, children with CP can be precluded from the use of a full sign language as an effective mode of communication, although they may still use a range of approximated signs in corporation with other communicative modalities. More typically, intervention with children with severe motor impairment aims to establish the use of symbols to support communication.

Symbols refer to graphic or object representations of language. Examples of symbols used by children with CP include pictures and photographs, with orthography representing the most advanced

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graphic symbol system. By selecting and signalling their choice of symbol, children are able to communicate meaning to their communication partner(s). Children who have yet to develop literacy, or who experience difficulty in this area, are commonly provided with symbol sets or symbol systems. A symbol set is a vocabulary or glossary of language terms represented in graphic form. Symbol systems tend to be more complex and have their own structural rules where, for example, different combinations of symbols or symbol elements can be combined to generate 'grammatical' language units.

Children with significant learning disabilities who have not developed understanding of the symbolic nature of pictures, photographs or graphic symbols may be supported in their understanding of language and their expressive communication through the use of 'objects of reference' in frequently occurring everyday activities. An object of reference is a tangible symbol which can have particular or individualised meaning associated with it. The symbol, often an object, can give the child information about activities, people, events which may not otherwise be available to them. For instance, smelling a certain air freshener may signify an imminent car ride, or feeling a spoon can signal time for dinner.

Symbols are organised on *high-tech* and *low-tech* communication aids. High-tech communication aids are electronic devices that produce either digital (recorded) or synthetic (artificial) voice output. These software- or hardware-based communication aids are also known as speech generating devices (SGDs) or voice output communication aids (VOCAs). Professor Steven Hawking is an example of a successful adult user of a high-tech VOCA. In recent years, high-tech AAC has mirrored wider technological trends, with increasing use of specific communication aid software on commercially available devices such as mobile phones and tablet computers. Such devices may require some modification (louder speakers, protected screens, rugged cases etc.) for use as AAC devices, but it is possible that children and young people may view such mainstream and apparently 'desirable' devices as more acceptable than other systems in relation to their self-image. For an extensive and independent search and comparison website for high-tech AAC systems the reader is directed to: www.speechbubble.org.uk. Low-/light-tech systems are paper-based books or charts of pictures, photographs, graphic symbols and words. Such systems can be created by hand or with the aid of specific software and templates designed for this purpose. The introduction of light-tech systems is a common starting point for exploring AAC intervention with children, families and schools. Where a high-tech aid is provided, it remains important to maintain and develop a low-tech system, to ensure availability of a communication system at all times, including those times when the use of the high-tech aid is not possible or practical.

Prevalence

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Reported prevalence figures for the proportion of children with communication disabilities related to CP vary, and there is further variation in reported need for AAC provision specifically for this population. A report compiled for the UK charity Communication Matters by the University of Sheffield in collaboration with Barnsley Hospital used a combination of a systematic literature review and practitioner survey to estimate the prevalence of need for AAC in adults and children with a range variety of communication impairments. This report estimated that approximately 20% of people with CP (including both adults and children) could benefit from the use of some form of AAC. The 2009 Report of the Australian Cerebral Palsy Register states that at the age of five, 35% of children with CP had some speech impairment, with 24% described as non-verbal. Also, in a recent whole population study of 152 Icelandic children with CP, 84% were reported to communicate verbally, and 16% of children were described as non-verbal. Twenty-one children were understood to use AAC methods, most typically signing and gesture. No children were reported to use high tech AAC systems. In England, the Office of the Communication Champion report estimates that 0.5% of the total UK population (approximately 1 in 529 people) may require some form of AAC, with approximately 0.05% requiring high-tech communication aids.

Functional communication groups

Given that the population of children with CP is heterogeneous, consideration of the *functional aims* of AAC provision can prove informative to decision making. Three broad groups have been proposed:

Expressive language group: these children experience a marked difference between their ability to understand language and their ability to express themselves because they lack intelligible speech. These children are likely to use AAC systems and tools as part of a total communication repertoire throughout their lives.

Supportive language group: these children may be provided with AAC intervention to maintain and develop communication skills in the relatively short term, with the expectation that speech intelligibility will respond positively to intervention and maturation. Alternatively, children in this group may only aim to use AAC systems in specific interactional contexts where their use of speech is not effective. For example, such children may not be expected to use AAC with familiar adults or friends who have 'tuned into' their partially intelligible speech, but may find AAC useful when interacting with less familiar people.

Alternative language group: children in this group experience significant difficulties both in understanding language and expressing themselves in conventional ways (e.g. children with significant learning disabilities). AAC systems and tools for these children aim to support best possible communication throughout life.

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Theoretical issues

Children with CP are known to experience a diverse range of neurodevelopmental impairments that co-occur with their primary physical difficulties including intellectual, visual, auditory, behavioural, and social communication difficulties. In addition, for children with severe motor impairment who are unable to produce intelligible speech, the course of all development is likely to differ from those children with CP who have intelligible speech, and from non-disabled children, both as a consequence of neurological differences in the maturing brain and the impact of intrinsic impairments on interaction with their caregivers, peers, teachers etc.

To date, practitioners lack conceptual models of communication development to guide intervention decision-making for children with motor impairment who rely on total communication strategies and equipment including AAC. Consequently, intervention practice has drawn on methods and findings from a range of disciplines including developmental psychology and linguistics. It has been suggested that application of models of typical development in guiding intervention practice may be relevant for very young children with CP with cognitive and receptive language abilities commensurate with non-disabled children. Interventions based on models of typical language development that include exposure to complex language and language scaffolding which may support ongoing learning in older children and children with more uneven profiles of cognitive and receptive language ability.

International Classification of Function, Disability and Health

In recent years the World Health Organisation's International Classification of Function, Disability and Health (ICF), and the later adaptation for children and youth (ICF-CY), have grown increasingly influential in AAC assessment and intervention practice. The ICF-CY provides a basis for reporting sociological, psychological and biological aspects of health and health-related functioning. The model describes theoretical relationships between body structures and functions (e.g., mobility, sensory abilities), personal factors (e.g. age, gender), environmental factors (e.g., attitudinal environment, provision of assistive technology), and activity/participation (e.g., communication and interpersonal interactions). While there is discussion in the literature concerning the ways in which concepts like activity and participation may be differentiated and measured, practitioners can usefully draw on the ICF-CY framework to support structured clinical reasoning that recognises the potential impact of multiple inter-related factors on AAC intervention.

Assessment

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For most children with CP, AAC use takes significant time and effort to master, and requires a combination of motor, sensory, learning, and communicative skills, which the practitioner will need to consider. Given the complex health, motor, sensory, learning and communication needs of these children, AAC related assessment requires a multi-disciplinary perspective. Aspects of assessment of children with CP who have little or not functional speech are outlined here.

Body structure and function

Oro-motor examination

Range, speed, consistency, accuracy, strength and steadiness (rhythmic, arrhythmic, tremor) of oro-motor function will be assessed. This will involve observation of voluntary movements of the articulators (lips, tongue, and mandible); examination of the oral cavity, and neurological assessment of oral reflexes.

Children may be asked to produce movements related to single muscle groups, or sequences of movement involving multiple muscle groups. Assessment will also consider respiration, phonation (ability to produce voice), resonance (e.g. hypo / hyper nasality), and prosody. For children with CP, assessment of the child's subsystems for speech (respiration, phonation, resonance, articulation) will require the child to adopt physical positioning that best supports controlled respiration and phonation. Assessment protocols are available, such as the Diagnostic Evaluation of Articulation and Phonology or informal structured observation may be preferred. Assessment of speech intelligibility, may be informal and subjective (e.g. recording the proportion of speech that is understood), or more usefully will involve objective measurement using published procedures such as the Children's Speech Intelligibility Measure. The Viking Speech Classification Scale also offers a framework for classification of speech production.

Although oro-motor behaviours for feeding such as chewing and swallowing share neuroanatomic structures with speech, they are understood to develop under separate neural control. A description of such assessment falls outside the scope of this paper.

Sensory functions

Symbol-based AAC systems require a degree of functional visual skills. Therefore, knowledge of acuity, in particular near vision, and visual fields, will inform decision making. Effective functional gaze control is also critical for children provided with AAC. For many children with CP, AAC symbol displays are first accessed by directing gaze toward and selectively attending to a symbol array. In identifying a target symbol, children are required to fix gaze, to disengage and transfer gaze in order to search and to

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selectively attend to specific items. Children with cerebral palsy require careful assessment of these functional gaze control abilities. Failing to appreciate the extent of performance of this core skill set will significantly hamper the development of carefully focused and individualised intervention. For children who are not expected to use vision for learning and communication, auditory scanning techniques may be used, wherein vocabulary items are spoken aloud, either automatically by a high-tech aid, or by a supportive communication partner, and chosen items are indicated by the child using a recognised purposeful movement or vocalisation.

Motor ability

Assessment of motor ability will influence decision-making concerning methods of access to both high and low-tech AAC systems. In general, access can be direct or indirect. Direct access to AAC systems includes strategies such as direct activation of a touch screen or a standard or adapted keyboard using an isolated and targeted movement of a body part (e.g. finger, knuckle, toe...), or using a pointing device such as a stylus or light source. Direct access will also include the use of both standard and specialist pointing devices (e.g. conventional computer mouse, joystick or rollerball mouse, head-mounted pointing system, trackpad or integrated wheelchair control). In recent years the use of eye-control technologies has increased, offering another method of direct access to a high-tech system. Indirect access to AAC tools may be achieved through any reliable and repeatable physical movement that may be used to activate one or more switches. Navigation through various options and the selection of vocabulary items may be conducted manually, with each new activation of the switch highlighting a new option until the target item is reached. The target item can then be selected by either a press of a second switch, a long-hold of the original switch or a dwell of a pre-defined amount of time. Alternatively, the device may automatically scan through various options which may be selected by switch activation. Automatic switch scanning procedures reduce the number of switch activations required to access the device, but the time required to access vocabulary may be increased. Automatic scanning may also present increased challenges for users with involuntary movements triggered by intention or anticipation.

Cognitive ability and language understanding

Attention, memory, and executive function (e.g. cognitive skills to plan, prioritise, and organise mental activities), have been identified as important aspects of cognitive functioning to examine in children with CP; both to develop a general profile of cognitive functioning, and specifically in relation to decision making concerning AAC options. Assessment of cognitive ability in children with complex motor disorders can be difficult. However, if professionals and parents are confident that they have established a clear

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understanding of the child's preferred purposeful and repeatable selection method (e.g. fist pointing) then assessment can be informative. Children who are unable to use gross motor movements to indicate choice, are reliant on their use of gaze as a selection method. The term eye-pointing is most often used to describe the use of gaze behaviour to indicate choice. However, practitioners' use of eye-pointing may vary in the absence of an agreed method of description. For example, in assessment, direct fixation on an item from an array may indeed be a signal that the child has made a selection. Alternatively, they may simply be looking at the item because it is interesting to them. Arguably, the most unambiguous realisation of eye-pointing giving maximum confidence to communication partners occurs when the child looks between the assessor and the selected item (or vice versa).

Environmental factors

The ICF-CY taxonomy documents a host of environmental factors that are of potential influence for AAC assessment and intervention. Of particular relevance in the context of AAC provision to children with CP are factors relating to the family and school. Parents and carers of children with disabilities can experience heightened levels of stress and periods of difficulty coping. Gaining insight into current parental stress and adjustment will influence the extent to which it may be appropriate to discuss AAC options, for example, in cases where the introduction of AAC is linked with poor prognosis for the use of natural speech.

It has long been recognised that the effect of AAC provision is influenced by parental and professional attitude towards AAC. For instance, parents' experience of and attitude toward technology in general may influence discussion concerning the introduction of high-tech AAC, with parents who lack confidence with technologies possibly, unintentionally, limiting the potential impact of high-tech devices. The converse may also be true, however, with the increased use of software on familiar, mainstream devices, coupled with increased internet literacy meaning that parents now have increased access to information about AAC devices / systems and increased familiarity with the hardware running such systems.

Although the use of AAC tools has the potential to provide a voice to children who might otherwise lack opportunities to express themselves, interpersonal interaction involving the use of AAC systems can vary in particular ways from conversation between natural speakers. For example, conversations between non-speaking children with CP and adults and their peers are commonly characterised by distinct patterns of turn-taking interaction whereby naturally speaking participants take the role of initiator of conversational interactions, asking multiple questions to which the answer is typically already known). Children with CP are often seen to adopt a respondent's role, predominantly responding to their partners'

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yes/no questions with relatively simple affirmations or rejections/denials. Such contributions are typically communicated non-verbally without recourse to AAC use. While the use of questions by natural speakers can be an effective communicative strategy, concerns are raised that the extensive use of this technique by these children's communication partners can have a detrimental effect on opportunities for children to develop language and self expression, leading to long term problems with isolation and mental health. Assessment will therefore want to document commonly observed patterns of interaction between children with CP and their peers, parents and professionals.

Contributions to conversation that are mediated via communication aids are produced significantly more slowly than speech, and may be relatively limited in propositional content and grammatical form. Overwhelmingly, children using communication aids and their co-participants in conversation are required to work together to actively negotiate the intended meaning of the child's turn. This requires additional 'work' on the part of the natural speaker. Consequently, individuals' attitude toward the child, the AAC system, and to issues concerning disability, can significantly affect the outcome of AAC provision, and children's ability to take part in conversation and inter-personal interaction more generally.

Personal factors

Child age and gender are important factors to consider. Establishing the relative correspondence between developmental and chronological age will have important implications for intervention. Developmental age can be determined via a range of indicators including level of the child's language understanding, and non-verbal and social cognitive abilities, as well as their preferences, interests and motivations.

Participation

Children with CP who have complex communication needs and are provided with AAC tools experience restrictions in their participation in everyday activities. In ICF-CY terms, participation is referred to as "involvement in a life situation". Practitioners working with families will want to establish the child's profile of participation, while bearing in mind the fact that for young children, child participation is likely to be linked closely to family participation. A profile of participation is likely to include the range, type and frequency of engagement in activities in community and school contexts. Assessment of participation may be informal or use established measures such as the *Children's Assessment of Participation and Enjoyment*. Assessment will include determining the role of assistive technologies, including AAC, in supporting participation. For example, for children with severe motor impairment, AAC systems may support opportunities for increased participation in play and leisure activities. Further, the increased connectivity of

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high-tech AAC systems (via Wi-Fi, Bluetooth and infra-red technologies) has allowed the integration of environmental and computer control into AAC software, which can in turn promote independence for some children with CP. Where appropriate, gaining insight into children and young peoples' subjective experience of their participation will illuminate the relative importance that children and young people themselves ascribe to aspects of participation and use of AAC tools. Establishing a profile of participation will support families and practitioners in identifying potential intervention goals with strong ecological validity.

Intervention

The provision of AAC to children is not an end in itself. Rather, AAC provision is one aspect of broader intervention practice aimed at supporting and developing the child's total communication repertoire. Intervention may take varied courses at any one time given the relative significance of multiple factors that can influence AAC related support: these factors will include child characteristics, environmental and participation related factors, family and child motivations and preferences, and the perspectives of the clinical care and school education teams. In addition to supporting children to develop their skills in the operation and deployment of AAC tools and strategies alongside their other intrinsic communication skills, intervention will seek to develop the communication skills and sensitivities of these children's communication partners (parents, peers, educationalists). As noted, interactions between children with little or no functional speech using AAC systems can differ from the normal expectations and practices observed in interaction between naturally speaking participants. Intervention with communication partners commonly aims to establish sensitivity to, and engagement with, the total range of communicative modalities used by children with CP. Intervention with children's communication partners will also seek to alter and develop the commonly observed communication strategies used by natural speakers (e.g. excessive use of yes/no questions), which can lead to impoverished communication experiences for children with CP and hence impede children's language, communication and cognitive development.

Intervention practice may also be informed by the published evidence base relevant to AAC. There are often difficulties with interpretation; given the heterogeneity of the population, where evidence is available, it may not reflect practitioners' caseloads, or participants in research may not have been suitably described. Equally, intervention aims from published studies may not mirror priorities identified by children, families and professionals. Therefore, as well as seeking out evidence relevant to multi-modal communication support, intervention is likely to benefit from evidence drawn from strategies common to a range of paediatric populations with communication difficulties.

Further reading

Australian Cerebral Palsy Register Group. Report of the Australian Cerebral Palsy, Register Birth Years 1993-2003. <https://secure.cpregister-aus.com.au>; 2009.

Clarke MT, Wilkinson R. Interaction between children with cerebral palsy and their peers 2: Understanding initiated VOCA-mediated turns. *Augmentative and Alternative Communication* 2008;24(1):3-15.

Clarke MT, Newton C, Griffiths T, Price K, Lysley A, Petrides KV. Factors associated with the participation of children with complex communication needs. *Research in Developmental Disabilities* 2011;32(2):774-80.

Communication Matters (2013a) *Shining a Light on Augmentative and Alternative Communication* <http://www.communicationmatters.org.uk/shining-a-light-on-aac> [Retrieved 22/12/15]

Communication Matters (2013b) *Beyond the Anecdote: Examining the need for and provision of, AAC in the United Kingdom*. <http://www.communicationmatters.org.uk/beyond-the-anecdote> [Retrieved 22/12/15]

Dodd B, Hua Z, Crosbie S, Holm A, Ozanne A. *Diagnostic Evaluation of Articulation and Phonology (DEAP)*. London: Pearson; 2006.

Gerber S, Kraat A. Use of a developmental model of language acquisition: Applications to children using AAC systems. *Augmentative and Alternative Communication* 1992;8:19-32.

Granlund M, Bjorck-Akesson E, Wilder J, Ylven R. AAC interventions for children in a family environment: Implementing evidence in practice. *AAC: Augmentative and Alternative Communication* 2008;24(3):207-19.

Griffiths T, Price K. A proposed framework for decision-making for assistive communication technology support: many perspectives, but one common goal. *Journal of Assistive Technologies* 2011;5(4):242-8.

King G, Law M, King S, Hurley P, Rosenbaum P, Kertoy M, Young N. *Children's Assessment of Participation and Enjoyment*. San Antonio, TX: Harcourt Press; 2004.

Paediatrics and Child Health

Murray J, Goldbart J. Cognitive and language acquisition in typical and aided language learning: A review of recent evidence from an aided communication perspective. *Child Language Teaching and Therapy* 2009;25(1):31-58.

Office of the Communication Champion (2011).

https://www.thecommunicationtrust.org.uk/media/9683/nwm_final_jean_gross_two_years_on_report.pdf [Retrieved 22/12/15]

Pennington L, Virella D, Mjølten T, da Graça Andrada M, Murray J, Colver A, Himmelmann K, Rackauskaite G, Greitane A, Prasauskiene A, Andersen G, de la Cruz J. Development of The Viking Speech Scale to classify the speech of children with cerebral palsy. *Research in Developmental Disabilities* 2013; 34(10):3202-10.

Sargent, J, Clarke, M. T., Price, K., Griffiths, T., & Swettenham, J. (2013). Eye-pointing in children with severe cerebral palsy: What are we looking at?. *International Journal of Language and Communication Disorders*, 48, 477-485.

Sigurdardottir S, Vik T. Speech, expressive language, and verbal cognition of preschool children with cerebral palsy in Iceland. *Developmental Medicine and Child Neurology* 2011;53(1):74-80.

Schlosser R. *The Efficacy of of Augmentative and Alternative Communication*. Boston: Academic Press; 2000.

von Tetzchner S, Martinsen H. *Introduction to Augmentative and Alternative Communication*. London: Whurr; 2000.

Wilcox K, Morris S. *Children's speech intelligibility measure*. San Antonio: Harcourt Assessment; 1999

World Health Organisation. *International Classification of Functioning, Disability and Health – version for Children and Youth*. Geneva: World Health Organization ; 2007.

Practice Points

- Children's ability to rely on speech as a primary mode of communication can be compromised by cerebral palsy;
- Children with communication difficulties face many barriers to participating in everyday life and are at heightened risk of social isolation and mental health problems;
- Children may benefit significantly from the provision of augmentative and alternative communication (AAC) strategies and tools;
- AAC is classified into manual signs and symbols;

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- The provision of high and low-tech communication aids form part of a total communication approach whereby all potential modalities of communication are explored and supported;
- The World Health Organisation International Classification of Function, Disability and Health for Children and Youth is increasingly being used to support decision-making.