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 organized on high-tech and low-tech communication aids. 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 for Children and Youth (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.

Keywords augmentative and alternative communication; AAC; cerebral palsy; children; children with disability; communication; communication aids; communication disorders; disability and health; dysarthria; international classification of function

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 unintelligible vocalizations 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 formal augmentative and alternative communication (AAC) systems such as sign systems and communication aids. 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, and formal systems such as communication aids. Most commonly however, AAC is used to refer to formal systems (signing and/or communication aids) 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 that 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 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.

Types of AAC: signs and symbols

Typically, AAC is classified as *manual signs* and *symbols*. Manual signs refer to prescribed systems of hand shapes and movements, body positioning, and facial expression, to include formal sign languages as used by people with hearing loss. Depending on the severity of motor impairment, children with CP can be precluded from the use of signing 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 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 provided with picture and/or photo-based symbol sets or 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 linked to generate 'grammatical' language units.

Children with profound learning disabilities who have not developed understanding of the symbolic nature of graphic symbols may be supported in their understanding of language and their expressive communication through the use of tangible objects of reference in frequently occurring everyday activities.

Symbols are organized on *high-tech* and *low-tech* communication aids. High-tech communication aids are electronic devices that produce spoken voice. These can be PC-based or dedicated communication aids also known as speech generating devices (SGD) or voice output communication aids (VOCAs). Professor Steven Hawking is an example of a successful adult user of high-tech AAC. In recent years, there has been a growing trend for the

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use of communication aid software on everyday portable devices such as mobile phones, portable games consoles, and hand-held tablet computers. It is possible that children and young people may view such mainstream and apparently 'desirable' devices as more acceptable than other systems, for example 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, symbols and words. The introduction of light-tech systems is a common starting point for exploring AAC intervention with children, families and schools. Despite the provision of high-tech aids, children will need to maintain and develop a low-tech system, to ensure availability of a communication system at all times.

Prevalence

Reported prevalence figures for the proportion of children with communication disabilities related to CP vary, and there is currently a lack of knowledge about AAC provision specifically for this population. Some general guidance is available from published work. For example, the 2009 Report of the Australian Cerebral Palsy Register states that at the age of 5, 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 0.05% of children and young people (with CP and other conditions) are likely to benefit from high-tech AAC.

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 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.

Theoretical issues

Children with CP are known to experience a diverse range of neurodevelopmental impairments that co-occur with their primary physical disability including cognitive, sensory, behavioural and communication impairments. In addition, for children with severe motor impairment who are unable to produce intelligible speech, the course of development is likely to differ from children with CP who have intelligible speech, and 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 tools 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 the 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. However, the use of models of typical development may become increasingly questionable when applied to older children and children with more uneven profiles of cognitive and receptive language ability typical of the population of children with CP.

International Classification of Function, Disability and Health

In recent years the World Health Organization'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 recognizes the potential impact multiple inter-related factors on AAC intervention.

Assessment

For most children, 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 no functional speech are outlined here.