Access to communication technology for children with cerebral palsy

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Published in:
Paediatrics and Child Health

DOI:
10.1016/j.paed.2017.06.005

Publication date:
2017

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Abstract

Children with a diagnosis of cerebral palsy (CP) may experience difficulties in producing clear speech and may benefit from the use of augmentative and alternative communication (AAC) systems. Such systems may include the use of high-tech hardware and software to allow the selection of words or symbols, to be transmitted to a communication partner through digital or synthesised voice. Children whose movement disorders are more severe may experience difficulties using standard human interface devices such as a mouse and keyboard and may require modified or specialised solutions to access and control their AAC systems. This review discusses contemporary definitions of access and outlines considerations for assessment and selection of such systems. The International Classification of Functioning, Disability and Health (ICF) is suggested as a helpful framework for decision-making. Given the complex presentation of many children with CP, a multi-disciplinary approach is emphasised.

Keywords assistive technology; augmentative and alternative communications systems; cerebral palsy; International Classification of Functioning, Disability and Health

Introduction

Children with communication difficulties affecting the production of clear speech may make use of a range of equipment, techniques and strategies, collectively referred to as augmentative and alternative communication (AAC), to support their expressive and receptive communication. The American Speech-Language and Hearing Association (ASHA) defines AAC as "a set of procedures and processes by which an individual's communication skills (i.e., production as well as comprehension) can be maximized for functional and effective communication". Studies have suggested that communication impairment may well be linked to more general restrictions in children's participation. Therefore the goal in identifying an AAC system is to increase the participation of children in a range of life situations, by allowing them to convey information, make choices and control and influence the world around them.

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AAC systems are commonly classified as falling into three categories: "no-tech" systems such as formalised manual signing systems and natural gesture, "low-tech" systems including printed resources such as communication books and boards and "high-tech" systems such as digital recording devices and complex voice output systems based on computers or tablet devices. For children, whose communication difficulties are part of a broader description of physical disability such as cerebral palsy (CP), the use of manual signs may be precluded by difficulties with gross and fine motor control. For such children, the use of high-tech communication technology is therefore often considered as a way of supporting their expressive language. However, where accurate and controlled physical movements are impaired, it may be necessary to identify an alternative way for a child to make selections on these high-tech systems. This is commonly referred to as identifying an access method.

This article will discuss the principles of assessment that underpin selection of an appropriate access method, proposing the International Classification of Functioning, Disability and Health (ICF) as a framework for decision-making. Within this framework, a review of contemporary definitions of access is also presented.

Voice output communication aids

This paper focuses on "high-tech" AAC, taking this category to include powered AAC devices, which make use of digital (recorded) or synthetic (artificially generated) voice output. In the AAC literature, such devices are commonly referred to as voice output communication aids (VOCAs) or speech generating devices (SGDs). Producing a message with a high-tech AAC device will require the selection of one or more items from an array to construct a message and transmit information. Increasingly, these systems are based on mainstream technology such as tablet computers and desktop or laptop PCs. Such systems can support individuals not only with communication, but with a range of other functions including recording work, accessing social media and web content and interfacing with environmental control systems to facilitate independent living.

Access methods

In the field of AAC, the technologies that allow children to interface with an AAC device and make selections are commonly referred to as "access methods", and fall under the broader category of assistive technologies. Access methods can range from changing or adapting the traditional components (a larger keyboard or a trackball mouse, for example) to the use of less standard inputs such as eye-gaze access technology or mechanical switches.

Evidence for the use of specific access methods with particular client groups is not yet robust, and tends to be based on case study or case series reports. Therefore, the selection of an access method can be seen as a highly individualised process. Research into the functional profiles of children with cerebral palsy reveals potential correlations between the severity of their speech disorder and their level of gross motor impairment. It follows, therefore, that children whose speech is most affected may also be those who would have difficulties using high-tech systems without adaptation or modification.

Global need for AAC and access solutions

In 2016, the World Health Organisation (WHO) published the Priority Assistive Products List (APL); the first stage of the Global Cooperation on Assistive Technology (GATE) initiative, which aims to improve worldwide awareness and use of assistive products and technologies. The list comprises 50 items selected on the basis of widespread need and impact on a users' quality of life. The list contains both communication software and a range of access methods, including keyboard and mouse emulation software. The WHO recognises that use of assistive products and technologies such as these can "enable people to live healthy, productive, independent and dignified lives; to participate in education, the labour market and civic life".

Prevalence of need

Precise estimates of the number of people requiring adapted or alternative access methods to make use of VOCAs can be difficult to ascertain. However, incidence of CP and knowledge of the subsequent motor difficulties experienced can assist in estimating the proportion of individuals within this sub-group who might benefit from the provision of alternative access solutions for AAC.

CP describes a group of permanent, non-progressive neurological disorders of movement and posture, secondary to lesions or anomalies of the infant brain, the prevalence of which ranges from 1.5 to 2.5 per 1000 live births. However, it is also understood that what is often described primarily as a motor disorder is frequently accompanied by disturbances of cognition, communication, perception and sensation, and frequently co-occurs alongside other neurodevelopmental disorders such as intellectual disability, and medical conditions such as epilepsy.

A report compiled by Manchester Metropolitan and Sheffield Universities for the UK charity *Communication Matters* conducted a systematic literature review to identify clinical groups who may make use of AAC, before collating data on the occurrence of each condition. Through investigating existing data sets and interviewing clinicians working in the field, estimates of the percentage of people likely to make use of AAC within each diagnostic group were generated. This report estimated that approximately 20% of children and adults with CP may benefit from the use of some form of AAC, although this does not differentiate between the uses of low- or high-tech AAC.

Assessment

International Classification of Functioning, Disability and Health

Since the introduction of the World Health Organisation's International Classification of Functioning Disability and Health in 2001, the conceptualisation of a bio-psychosocial model of healthcare has resulted in a paradigm shift away from medical descriptions of impairment and towards functional descriptors which complement diagnosis. As a result, the increased use of the Gross Motor Function Classification System (GMFCS), Manual Ability Classification System (MACS) and the Communication Function Classification System (CFCS) provide clinicians with a universal language to represent the functional abilities of individuals with CP. It has been suggested that the ICF, as a framework of inter-related domains, can support clinicians to consider all aspects of the individual, their environment and personal preferences. This paper considers the assessment of children for an access method, proposing the ICF as a framework for clinical decision-making.

Body functions and structures – CP and communication

Research indicates that disabilities in expressive and/or receptive communication are present in 50–75% children with CP classified as GMFCS levels I–III, and that this increases to 100% in children classified as GMFCS level IV or V. Individuals with these higher GMFCS levels (i.e.: IV–V) often have severe dysarthria (unintelligible speech) or anarthria (absence of speech) and will require access to an AAC system to engage in meaningful occupations and communicate within wider circles, which include unfamiliar communication partners; the opportunity to make choices relating to occupational engagement provides autonomy and precipitates participation even when the physical aspect of 'doing' is carried out by another person.

Making use of the functional classification systems described above not only helps to identify the possible need for the use of AAC, but also assists clinicians in establishing a starting point for assessment of an access method. For example, restricted use of hand function is likely to impact on the use of 'no-tech' AAC systems including signing or low-tech paper based systems. Individuals with a MACS level of IV who can handle a limited selection of easily managed objects in adapted situations, are likely to require an alternative access method to control an AAC device. Those who have a MACS level of V who cannot handle objects and require total assistance may need to use an access method requiring limited active movement, or one controlled using eye movements.

However, whilst there is some evidence to suggest a correlation between these classification systems i.e.: the higher the GMFCS level, the greater the likelihood that the individual's MACS level will also be high, some studies have demonstrated that gross motor function and manual ability are often discrepant in children with CP. Such research suggests that the patterns seem to vary across subgroups based on the predominant neurological findings. For example, in children with spasticity and no dyskinetic movements, when hand function is better, gross motor function is often worse. Equally, whilst we might frequently work with children whose motor abilities are comparative to their communicative skills, there are children who have severe physical limitations but who can demonstrate receptive and expressive language and communication skills within the average range.

Body functions and structure – establishing and using an access point

From a physical perspective, children with CP are more likely to have difficulties controlling their movements, which will impact on their ability to control any technology that might otherwise be used to compensate for their physical disability. Impaired transmission of information from the tactile, vestibular, and proprioceptive systems, retained primitive reflexes, atypical muscle tone (low, high, fluctuating tone and rigidity), subsequent involuntary movements and posturing will all impact on a child's ability to access an AAC system. Clinician's knowledge of a child's physical abilities at a component task level, understood within the context of environmental barriers and facilitators, is therefore central to identifying how a child might conceivably make selections from an array presented on a high-tech device.

Key to selecting an access method for an individual is the identification of one or more points of control or 'access points'. This term refers to a part or parts of the body where an individual can execute purposeful, accurate, graded and repeatable movement(s). Whilst there exists no evidence for a "hierarchy" of control points, starting with options that are physically intuitive, direct and non-complex from a cognitive perspective is recommended. However, establishing an effective access point for a child with CP is a highly-individualised process due to the variability of physical abilities observed within this population group. Once potential access points are identified, further consideration of fluidity and accuracy ensures that the most reliable, consistent and therefore effective movement is chosen, although clinicians must also be mindful of possible long-term impacts of repetitive movements.

Body functions and structure – seating and positioning

It is well documented within the literature that an optimal seated position can promote trunk control and subsequent upper limb function, including that utilised for accessing AAC. However, although it may be intuitive to imply that the use of specialist seating systems will also support alternate access points including the eyes in the case of eye-gaze access technology, this has not yet been established through empirical research. Nonetheless, knowledge relating to the development of motor patterns and executive functioning skills would suggest that if repeatable physical movement at the access point can be promoted through consistent positioning of both the child themselves and the peripherals used to control the device, they will experience a decrease in the need for effortful control over performance, leading to the development of automaticity. Reduction of the cognitive load associated with physical access will allow the child to focus on the navigational and linguistic complexities associated with using an AAC device.

Activity – enabling control

After gaining an understanding of an individual child's motor abilities, a clinical team can then begin the process of selecting equipment that will allow independent movement to be translated into control of an AAC system. Whilst it is beyond the scope of this paper to provide a full overview of all available access technologies, all access methods can be seen as having several common, inter-related components: an input device, a selection method, an array of items from which to choose and a method of providing feedback to the user. In selecting a reliable and efficient access method, all components should be considered, with adjustments made to each according to the specific needs of the person controlling the AAC device.

In selecting an access method, clinicians should be mindful that the eventual system balances accuracy of selection with speed, whilst considering the cognitive load and learning requirements of the individual access method.

Input device: perhaps the most crucial element of an access system is an appropriate input device, which is a peripheral or piece of hardware which performs the function of providing control signals to an AAC device or computer. Familiar examples of such devices would include a keyboard, mouse or touchscreen. Within the field of assistive technology, there exists a large range of modified and adapted keyboards, pointing devices and touchscreens, which may be suitable for many children. In addition, more specialist technologies such as switch interfaces and eye-gaze access technology provide other alternatives for children and clinicians.

An input device can provide either discrete input (such as a key or switch press) or continuous input (such as the movement of a cursor controlled by a pointing device). The input device can generate any number of individual signals, ranging from one (such as a single switch) through a variety of whole numbers (such as keys on a keyboard), to a theoretically infinite number of signals available on a touchscreen or via a pointing device. As the number of inputs increases, so too does the level of accuracy required to control the input device.

Selection of an input device will therefore be determined by the type and range of movement that a child can make reliably, repeatedly and accurately. For example, a child who has one reliable access point using the movement of their head, but does not have enough accuracy with this to select directly from an array, may be a good candidate for the use of a switch to access an AAC device.

For children requiring switches, a wide range of options are available, including mechanical switches of varying activation pressures, electrical switches and proximity switches which require no physical contact to activate. Some switches are designed for specific access points, such as pneumatic ("sip-puff") switches which can be controlled by changes in air pressure within the mouth. Recent developments in switches using electromyography (EMG) have provided the possibility of "on body" switching requiring very little physical movement, where electrical activity in muscles can be turned into digital signals for control of a device.

Selection method: the choice of an input device is closely linked with the second element of an access system: the selection method. Within the fields of AAC and computer access, selection methods are described as being either direct or indirect. In simple terms, a direct selection method is one where a user controls an input device to directly select their choice from an array, without the need to navigate through other items present in that array. This is typically achieved by pointing to an item – either on a display screen or on a physical array such as a keyboard – and selecting it using a press or tap, or by holding the cursor stationary for a pre-defined period. An indirect selection method is one where the user "scans" through the options in the array in a systematic way in order to reach a target item, which can then be chosen using the input device. Where the physical skills exist to make use of them, it is generally recognised by professionals that direct selection methods are faster and more intuitive. Comparative trials suggest that selection rates with indirect selection methods are significantly lower than with direct selection, with rates of 1–5 selections per minute commonly reported across the literature and highly competent users still producing under 8 selections. By comparison, a direct access user might achieve speeds of 40–60 selections per minute.

Research looking at access methods has tended to suggest that there is an inverse relationship between the cognitive and physical skills required for direct and indirect selection methods. For direct selection, the process is more intuitive, with a transparent one-to-one relationship between the input device and selection method. Direct selection does, however, require the highest degree of motor control. Conversely, whilst the motor control requirements to make use of scanning are lower, the requirements placed on other component skills such as attention, visual tracking and working memory will be higher.

Where indirect selection methods are required, a variety of methods to increase speed of selection are available. For example, if the user can access an input device with four switches, directional scanning may be a possibility, allowing the horizontal and vertical movement of the scanning highlight. Group-item scanning, where the scanning highlight moves through groups (for example rows or columns in the array or groups of icons arranged by meaning), can reduce the number of switch presses. Similarly, elimination scanning uses two switches, allowing the user to eliminate non-target items until only the target item remains can also reduce the number of switch presses required. Although evidence regarding the cognitive skills required for group-item scanning is unclear, most studies suggest that this method of selection is harder for children to learn.

Within the past decade, the increasing availability of eye-gaze access technology (a group of technologies that allow users to control an AAC device using the movement and rest of their gaze) has provided new opportunities for some children who may have previously relied on indirect selection methods. Whilst the use of eye-gaze technology can be an abstract concept for some children, and preliminary evidence suggests that the time needed to learn to use this technology efficiently may be longer than other direct selection methods, it may offer others a way to use direct selection when no other physical access point can be identified.

Selection set: the selection set is comprised of the items which are presented to the user from which they can make a selection. These choices might include letters, words, phrases or graphic symbols as well as navigational cells and functional commands (such as *speak*, *clear display* etc.). The layout and presentation of items can play a key role in ensuring that an access method allows the user to make choices quickly and efficiently, with minimum effort and fatigue. For example, where a child is using indirect selection with switch scanning, it will be important to place frequently used items high up in the scanning order, so that they may be selected in a shorter amount of time and with fewer switch presses.

User feedback: in order for an access method to be useful, it must provide feedback to the user, indicating what options are available and which are being targeted for selection. In many cases, a feedback system will comprise a visual array of letters of graphic symbols on a screen, with a visual or auditory indicator that a selection has been made. A feedback system may include auditory-only cues for children with severe visual impairment, although comparative trials suggest that this method is slower than visual cues. In addition, haptic feedback such as the click of a key, mouse button or switch can provide feedback to a child that they have activated the input device.

Environmental factors

Adaptive seating systems and wheelchairs, whilst promoting optimal positioning for the child, also provide a mount point at which a mounting system for an AAC device can be clamped. Mounting provides a secure and adjustable position for the device itself, which is essential when using specific access points. However, complications may arise from the fact that whilst the contemporary paradigm view of disability identifies the ultimate health outcome of intervention as participation, seating and mobility equipment is also provided to meet anatomical and physiological needs; whilst these two goals may appear to be mutually supportive, in reality it may be extremely difficult to find one seating system that meets the child's physical and postural needs whilst also enabling the effective physical control of an AAC device required to make meaningful choices and engage in interactions. The use of family-centred practice will be vital in ensuring that any compromises made are done so with the child and family's opinions and goals in mind.

Children functioning at GMFCS level IV–V who require physical assistance to mobilise or who use powered mobility in most or all settings may also require additional consideration regarding portability of any AAC device or peripheral control system. Whilst the provision of a mounting system to support an AAC device can range in complexity, those who require a system integrated with their powered wheelchair controls are likely to need specialist assessment by several professional teams.

The complex nature of communication via AAC means that active participation from the communication partner is essential, with parental and professional attitudes towards the use of AAC greatly affecting the child's use of the device. Children who have a higher MACS level will require support at the initial set-up phase, to position the device for use. Children who require symbol-based systems will require additional support to ensure that specific vocabulary required for them to engage in meaningful occupations is available to them on the device. The fact that learning to use an AAC device is not necessarily an intuitive process also means that all children using AAC will need specialist intervention to teach them how to use it. The communication partner is responsible for supporting the child's development of independent navigation through the software, pragmatic communication skills (e.g.: turn-taking) as well as semantic and grammatical linguistic skills. Modelling how to use the device across contexts is essential in supporting functional communication skills.

Personal factors

It is recognised that personal factors play a key role in the adoption and use of AAC. As discussed above, access methods can place differing cognitive loads on a user, meaning that it is important for clinicians to understand the developmental age of the individual child. Access methods should wherever possible be intuitive and should minimise the amount of learning required to use them, allowing children to experience success in their use of the device. The child's motivation to use the access method

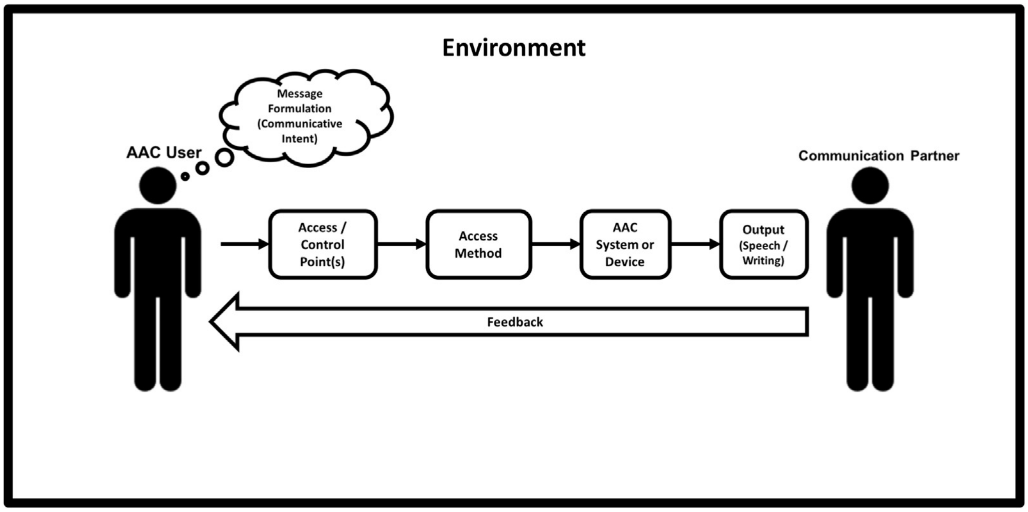

Figure 1 A schematic diagram, presenting the access method in the broader context of engagement in a communicative interaction.

will also be a key factor, particularly as many access methods require practice and explicit teaching.

Participation – access in a broader context

It has long been accepted that the optimal functional outcome of implementing AAC is not the use of symbols or devices, but participation through communication. In keeping with this we understand that, whilst the selection of an access method is an important part of the successful implementation of an AAC system, that the use of an access method is not a goal in itself. Clinical experience suggests that the use of an access method should be practiced in context wherever possible, with the focus on functional goals and tasks. It is therefore helpful to cite the access method within a broader definition of access.

Contemporary characterisations of access recognise that the term must encompass not only the physical and technological aspects of how a user controls an AAC system, but also the cognitive and linguistic abilities of the individual user. Consideration of the communication task, environment, context and the skills of the communication partners involved are also required. Several conceptual models of access have been proposed, with many common elements, and a model for access to a communication exchange is presented in Figure 1.

A more complete definition of the term "access" is understood to refer to a non-speaking individual's participation in an interaction: encompassing the use of an AAC device, any changes made to the way in which the user controls that device, as well as any adjustments or constraints present in the interaction. For example, an active communication partner who can interpret the utterances of an AAC user, and who is aware of the complexity involved in constructing a message, will facilitate the AAC user having better access to the interaction. Modifications to all aspects of an interaction should therefore be considered to support the best possible outcomes for a child using an AAC device.

Since access can be considered as made up of inter-related factors, it is recognised that the selection of a functional method of access should be the result of multi-disciplinary assessment and intervention, with the professional competencies of Speech and Language Therapists, Occupational Therapists and Clinical Scientists or Assistive Technologists adding to the opinions and preferences of the user and family.

Conclusion

Many children with CP experience difficulties producing speech. Whilst the physical aspects of CP are frequently described as the primary difficulty, the potential for individuals with this 'movement disorder' to experience other component skill difficulties within the areas of language acquisition, cognition and social interaction complicate assessment. The need for a multidisciplinary assessment is therefore paramount and the ICF provides a framework to assist clinicians in their consideration of the multifactorial nature of access in its broadest context.

The ICF, in providing a universal language to describe all aspects of an individual within the context of their environment, can offer clinicians from different fields and backgrounds a common framework through which the functional implications of communication difficulties can be understood. As acknowledged in this paper, the goal of selecting an access method is not simply to enable access to an AAC device, but rather a means to enable children to interact and actively engage in activities. The ultimate goal of assessment, selection and provision of an AAC system is, therefore, participation in a range of life situations. ◆

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Practice points

- Children with cerebral palsy whose movement disorders are most severe also have the highest rates of expressive language impairment and, by extension, are more likely to require an alternative form of communication
- Identifying a method for children to access a computer-based communication system is a highly individualised process – access is not a unitary skill
- A thorough understanding of the child's motor, cognitive and linguistic abilities is essential
- Identification of one or more access points should form the basis of any assessment for an access method
- Direct selection is likely to be faster, although the motor demands of these access methods are higher
- Access in its broadest context includes not just the physical skills of the AAC user and the technology they are using, but also the task, environment, context and the skills of the communication partners

