EC+: APP FOR PEOPLE WITH PROFOUND INTELLECTUAL DISABILITY (PID)

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Augmentative and Alternative Communication (AAC) is defined as an area of clinical practice and research that seeks to compensate (temporarily or permanently) problems within the scope of expressive communication (i.e. severe damage in spoken or written production or in reading processes) or as an alternative to non-functional speech (NSW Government Clinical Guideline, 2016). Following the classic classification of Lloyd & Karlan (1984), which differentiates between AAC systems with or without aids.
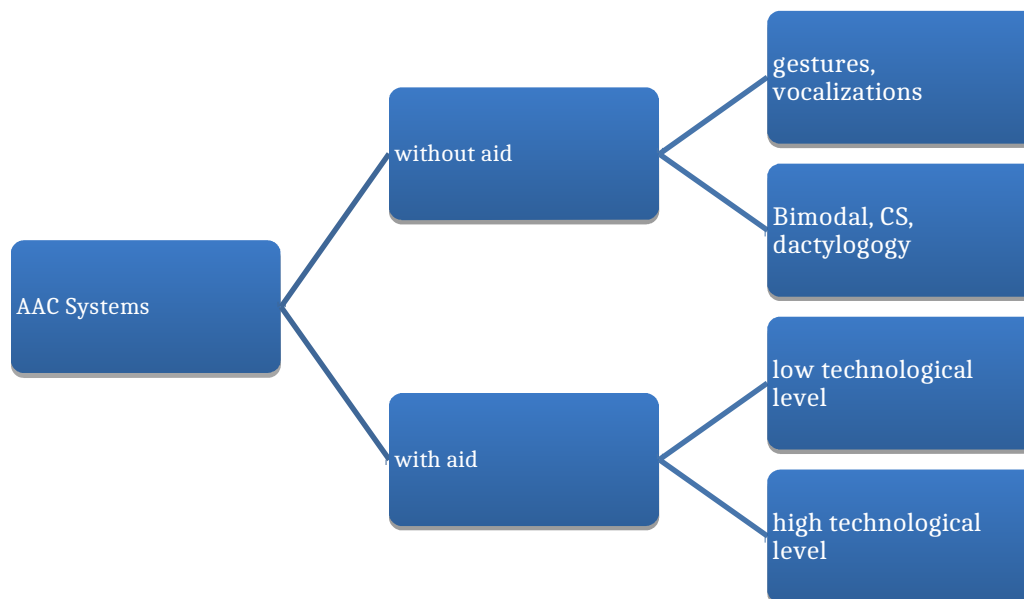

Figure 1: by Marina Calleja

AAC Systems without aids (AAC-a) are those that are composed of forms of natural non-verbal communication (including gestures and facial expressions, in addition to signs). AAC-a systems (using their own body, not resorting to additional devices e.g. electronic equipment).

AAC systems with aids (AAC+a) are those that require the use of equipment, devices or additional material to the body itself, through which a person can communicate with the environment. The AAC +a refers to any element external to the subject itself such as, for example, object symbols, communication boards,

cards, speech generating devices, computer, mobile phone, tablet, … The AAC +a includes high and low technology systems.

The difference between AAC + high and low technological level is that the first are electronic devices and need energy to be used, while seconds do not.

USERS OF THE AAC

Potential users of AAC are those who have serious difficulties communicating through speech throughout their lives (from childhood to adulthood). The causes of Complex Communication Needs (hereinafter CCN) may be physical, sensory, cognitive and environmental (for example, they may be caused by a hearing, cognitive or motor disability). Sometimes this limitation is permanent (e.g. in the case of some modalities of Cerebral Palsy and Intellectual Disability), while in other circumstances the limitation is temporary (e.g. after a surgical intervention on the vocal cords the patient cannot communicate through speech, but after the rehabilitation period, the patient can use speech again).

CCN usually refers to the fact that they cannot use speech as a means to communicate with other partners. However, in some cases, the subject can use speech (understood as vocal and verbal productions), although the degree of intelligibility achieved is so low that it fails to carry out functional communicative exchanges efficiently. In any of the cases cited, it is necessary to resort to strategies not based on the natural resource of speech, that is to say, in some AAC modality (Calleja & Rodríguez, 2018).

Within the AAC users group we find people with intellectual disability (ID). This group has been excluded for decades from intervention programs with AAC. The reason was that they did not meet the minimum cognitive prerequisites. But even those unintentional communicating subjects can be perceived as potential communicators since their behavior must be interpreted by the interlocutors (teachers, caregivers, assistant, healthcare staff, family…) as a communicative act (Brady et al, 2016).

ID is conceptualized as a disability characterized by significant limitations in both intellectual functioning and adaptive behavior, which encompasses many social skills and daily practices.

This disability originates before the age of 18 (Retrieved from http://aaidd.org/intellectual-disability/definition#.WpRKsHyCHIW) (Luckasson and Cols, 2011). The classification system has migrated from a model based on the deficit to another in which this disability is conceived as a situational construct, mediated by the communicative, sensory, motor and behavioral characteristics of a person as well as the demands and supports associated to the contexts with which it interacts (Brady et al., 2016)

DSM-5 (APA, 2013) assumes the guidelines of the definition of the AAIDD and defines intellectual disability as "a disorder that begins during the period of development and that includes limitations of intellectual functioning as well as adaptive behavior in the conceptual, social and practical domains ".

ID is organized according to the DSM-5 depending on the adaptive functioning of the subject and we can distinguish between mild, moderate, severe and profound. Profound Intellectual Disabilities (PID)(some authors continue to use the term Severe Intellectual Disabilities) is present in the social area and entails a limited understanding of symbolic communication. Therefore, these people can understand simple gestures and generally make use of non-verbal communication (American Psychiatric Association, 2013).

When the presence of NCC is added to the PID, the clinical intervention becomes extremely complex unless it is used for Aumentative and / or Alternative Communication Systems (AAC) (Romski and Sevcik, 2005).

In the 1980s, subjects with PID were excluded as potential users of the AAC. As we mentioned before, the reason for this exclusion was because they either did not show the cognitive skills needed to correctly use the AAC Systems or they had some actual or potential speech skills, and it was thought that the use of a AAC System could interfere with a supposed potential development of speech to be achieve in the future with stimulation (National Joint Committee for the Communication Needs of Persons with Severe Disabilities, 2002; Snell, et al., 2003)

However, recent studies have shown that the use of one or several AAC systems not only does not reduce the development of speech skills (Millar, Light and Schlosser, 2006), but also the use of VOCA-type devices or the visual scenes, allow people with PID to increase their participation in class, at home and in social environments (Wilkinson and Henning, 2007); enable them to make choices

(Cosbey and Johnston, 2006); help them improve their communication skills (Cheslock, Barton-Hulsey, Romski and Sevcik, 2008); and even, they contribute to modify the stereotypes and the perceptions that others have about them (Wilkinson and Henning, 2007).

Lund, Quach, Weissling, McKelvey & Dietz (2017) suggest that before proposing a AAC device we would have to carry out: a) an evaluation centered on the individual with CCN, b) an assessment of the skills of the communication partners and c) an analysis of the characteristics of the device.

In relation to the characteristics of the individuals, some information about their communicative skills must be available for researchers or speech language therapists. These professionals must be aware of which are their needs and their communication objectives; assess the strengths of the communicative ability of the individual, the barriers that can limit the communicative exchange as well as the preferences. For the specific case of subjects with ID, decision making about the AAC is made according to the subjects' needs. In this sense, Reichle, York, York-Barr & Sigafoos (1991) proposed that we must pay attention to the way in which the subject carries out communicative exchanges so we must know which are the vocabulary needs to meet their communication needs according to their activities and routines, we must know which communicative attempts the subject should learn. We would even have to assess whether the best option is an strategy with or without aid. Given the possibility of choosing the option of AAC without aid, we would have to assess the user's motor skills as well as the type of vocabulary he or she needs to learn. While in the modality of AAC with aid (AAC+a), it would be necessary to evaluate the type of symbol (photograph vs. drawing), the size of the symbol, the representation of the message (nature and length), the way to access to the message (through direct selection, scanning or eye movements), the response options (visual presentation or synthesized speech), the portability of the device and the ability to initiate episodes of social interaction (ability to call attention to a communication partner or the possibility of starting communicative exchanges) (van der Meer et al., 2011)

In relation to the skills of the interlocutors (professional team, staff, family, ...) that are going to communicate with the PID, it is important to know if they have had previous experience with the use of AAC devices, to know their

acceptance or rejection attitude for the use the AAC devices. Even Thistle & Wilkinson (2013) pointed out that sometimes before opting for a device, clinicians have to add vocabulary related to the preferences of family members, the courtesy formulas they usually use...

Finally, when opting for an AAC system, we know that this system can take many forms including gestures and manual signs of sign language, visual symbols inserted in boards or communication books, written words, drawings or electronic devices that provide vocal answers (Beukelman & Mirenda, 2015). Among the AAC systems with electronic assistance are computers, artificial speech generation devices or mobile technologies with applications for communication (Thistle & Wilkinson, 2013).

EC+ APP

EC + (Chicano, Postigo, Luque & Calleja, 2018) is an app for tablets and mobile phones for IOS and Android developed at the University of Malaga for people with DIP and the interlocutors of their environment, whose purpose is to increase communication exchanges. The mobile application is based on the API (Application Programming Interface) in version 4.0.3. of Android (Ice Cream Sandwich) so that it can be used in most of the existing mobile devices in the market.

The acronym EC+ comes from the full English name of the Erasmus + project where this app has been developed, *Enhancing Communication or Improving Communication*. Its purpose is to serve as an AAC device of high technological level based on the assumptions of the multi-modality (simultaneous presentation of visual, gestural and acoustic stimuli such as pictograms, hand signs, photographs and words-spoken and written-).

The approach of EC+ is multimodal. When you access to the interface, to select a certain symbol it is enough to click on the desired icon and the symbol appears in five different modalities (manual sign with linguistic value, verbal-vocal production, written presentation, pictographic representation with drawing and pictographic representation with photographs and video). The process to go from one screen to another can be done by sliding one's finger.

In addition, the app has a series of medical and intervention guides for diseases and syndromes that deal with PID + NCC, as well as instructions to carry out communicative exchanges.

The contents of the app are presented in five different languages (Spanish, English, German, Dutch and Catalan).

WHERE DOES EC + ARISE?

The app has been developed from the University of Malaga, within the framework of a European Project within the Erasmus Plus program called Enhancing Communication: Research to Improve Communication for People with Special Needs and Development of ICT Resources and Tools. It is funded by the European Union and involves various academic institutions (University of Malaga, the University of Ghent (Belgium), the University of Klagenfurt (Austria) and a specialized center Parc Taulí Hospital (Sabadell).

AIM

The purpose of the app is to serve as an AAC device with a high technological level based on the assumptions of multimodal communication (pictograms, manual signs, photographs and words) for people with PID+ CCN as well as caregivers and their relatives. Also the app was conceived as an instrument to reduce anxiety on the part of professionals from different fields (healthcare, education, interpreting, leisure...) when they have to interact with PID and CCN people and they have not previous specialized knowledge of intellectual disability.

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