AAC, Mobile Devices and Apps: Growing Pains with Evidence Based Practice

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For more than 20 years the field of augmentative and alternative communication has embraced a 'person first' approach that focuses on identifying current and anticipated strengths, abilities and needs of those with complex communication needs (CCN). These characteristics are then matched to the feature set offered by available augmentative communication hardware, software and strategies. This process, dubbed "feature matching" by Shane and Costello in the 1990's provides a framework for clinical decision making based on a set of rules and pertinent questions that cuts across several assessment domains that includes patient, family, medical, motor, cognitive, sensory, linguistic, social, cultural, educational, behavioral and financial areas (Shane and Costello, 1994). When successfully executed, this process yields clearer insight into AAC tools and strategies needing further investigation through a strategic evidence-based, clinical trial. The trial itself is meant to predict adoption or reconsideration of the initial decisions. Since first introduced in the 90's, other tools that match human characteristics to features of AAC technology have been described (see Mineo, et.al 1996, Dodgen, 2004, AAC Tech Connect, 2005). Meaningful use of such a logical clinical processes presupposes the practitioner brings knowledge and expertise into the assessment and implementation of augmentative and alternative communication.

Mobile devices

The growing number of mobile devices accompanied by a myriad of applications or apps marketed as augmentative communication tools portends a clear and concerning shift from a systematic feature matching approach towards a "platform first" approach. In such a platform first model, the communication technology decision is based far less on a consideration of available tools, strategies or needs. Furthermore, as first suggested by Shane and restated in the AAC-RERC white paper on mobile technologies (AAC-RERC, 2011) the mainstream availability and attraction to the mobile device platform has given way to a 'democratization' of AAC system selection.   This is apparent because practitioners, family members, and others, with little or no previous AAC experience, are making selections based mainly on the popularity of certain apps and devices and not according to a set of well-defined clinical principals.   Often such impractical decision-making disregards motor, cognitive, linguistic, sensory, social or environmental needs.

Democratization has led to the fitting of a person with complex communication needs to a specific tool, which effectively turns the feature match process upside down by imposing features of a platform and apps to the individual. Furthermore, the platform first model often leads to practitioners being strongly advised to find ways for apps and devices to work for the person with complex communication needs.   Our clinical experience at Boston Children's Hospital reveals that in the six-month period of Feb 2012 – August 2012, with data provided by eight full time clinicians who provide AAC assessment and intervention services, nearly 78% of all patients or families initiated a discussion regarding possible use of a mobile device platform. Nearly 40% brought a mobile device to the clinical evaluation and a third of those had pre-loaded an AAC application. (Caron, 2012). This is not to suggest that a mobile device and

accompanying app would not ultimately be viewed as the best match to the needs and skills of a person.   Indeed, many who have resisted AAC or for whom a good match to a more traditional AAC platform or strategy has been elusive have had clinically significant success using a mobile device as an expressive communication tool.   Undoubtedly, mobile devices and a plethora of available communication apps need to be part of a broad arsenal of AAC options that enable a comprehensive clinical feature match. In order to help support the decision making process, the Augmentative Communication Program at Boston Children's Hospital has created and made available a systematic set of materials or charts that narrow the key features of available communication apps as a way to compare and then match the user's needs to an app's specifications (Gosnell-Caron, et.al. 2011). To review this feature matching decision chart, the reader is directed to:
(http://www.childrenshospital.org/clinicalservices/Site2016/mainpageS2016P19.html)

 Our clinical experience at Boston Children's Hospital and described in the RERC Whitepaper *Mobile Devices and Communication Apps* (March 2011) suggests the outcome of an evaluation, when a patient arrives at our Center already armed with a mobile device and app, generally fits into one of several categories.

1. Feature match outcomes supports the chosen mobile device and app as a clear match to the strengths, skills and needs of the person with complex communication needs and is expected to serve as a primary communication tool for the person with complex communication needs.
2. While a more traditional AAC device may be a better match, as identified through a clinical feature match and trial, the mobile device and app is a strong match as a backup communication tool that ensures opportunities for success when the primary device use is less likely due to positioning, mounting, lighting,

environmental factors, etc.

3. There is not evidence that the mobile device and chosen app will be an appropriate primary expressive communication tool in the future but currently the platform is valuable for focusing on foundations for future success. Examples of which may include: representational knowledge, linguistic skill, navigation of pages, socio-relational competence, scheduling and visual scripts, switch scanning, familiarity and tolerance of voice output.

4. The mobile device platform and app are not found to be the best match but the platform is highly motivating to the person with CCN to the exclusion of tools and strategies that may offer more immediate or robust communication success. Therefore, apps that can most closely meet the client's needs are suggested.

5. An appropriate mobile device match is not identified but family or user suggest that since they own the platform, it is the only option they are interested in using. In this case, outcomes of the feature match are still presented but applications that may target areas of skill development (vocabulary; target selection; physical access considerations such as scanning, dwell, release, swipe, etc.) are recommended.

Evidence Based Trials: Testing Efficacy of Feature Match Outcome
Good clinical decision making in AAC requires practice-based evidence through functional clinical trials. An assessment environment is typically characterized by one-to-one or small group attention in an environment with minimal or controlled distractions. Communication partners are few and often mostly unfamiliar while communication opportunities are artificial, engineered for a specific topic and frequently rhetorical. Successes in such an environment must be characterized for what they are – clinical demonstrations. The successes achieved in an evaluation setting can vanish once the tools or strategies are introduced in the 'real world'. In other words, feature-matching outcomes can only be appraised by evaluating their

effectiveness in a patient's real life settings. Real world implementation based on functional clinical trials, often yields objective and subjective data related to *linguistic considerations* such as symbols, organization and encoding strategies; operational *considerations* including volume, battery life, brightness and ease of portability; strategic *considerations* such as learning when, how and with whom to use the AAC device or *social considerations* including developing skills in interpersonal aspects of communication for a range of communicative purposes.

For traditional (or non-mobile) based AAC devices, a trial can be easily arranged. This is the case since many AAC manufacturers provide a loan or rental program often allowing for a 30-day trial period. In addition, the manufacturer's funding department often will assist with coordinating the funding application for such rentals. The funding of trial equipment varies by state and by insurer. Also, some insurance companies only fund the purchase following a successful clinical trial. In many states resources such as the State Tech Act Program funded by the US Department of Education, provide a lending library to support evidence-based trials.

Evidence based practice for mobile devices and Apps

Currently there are few provisions for offering a clinical trial period for a mobile device and accompanying app. This is the case because mobile devices do not currently fall under the same insurance funding guidelines as traditional speech generating devices. Accordingly, the mobile device platform is typically only available through a self-purchase and not a third party purchase model, through a lending lab (such as a state tech act program or a hospital/school based tech lab or a non-profit organization such as a United Cerebral Palsy the MDA or ALS Association), or available by some benevolent grant.   A further complication is that, even when a mobile device is available to borrow, the app that best meets the needs of the user may not also be

available.

Accessing an app for trial purposes is complicated as there are few provisions to borrow an app. Generally, apps are available only if they are purchased and then can only be updated and saved when synced to the account of purchase. Once purchased, an app cannot be 'returned' following an unsuccessful trial period. A plausible solution might be for AAC communication app developers to offer a 30-day full-featured version of the app that would automatically decommission at the end of the designated time. This option is not an easy solution, however, according to the developers of AAC apps contacted by these authors. While the overwhelming response was that a fully functional time-limited app would be an ideal solution that would improve the evaluation of the feature matched selection, there is no mechanism available currently through iTunes or Google Checkout for this to occur. These developers agreed that a full functioning trial would meet the needs of many end users, as it would:

1. thwart a pattern of users purchasing an app only to discover that the app is too complex/too full featured.
2. minimize the waste of resources reported when users have purchased multiple simple and inexpensive apps, only to discover that none of them meet the user's needs.   Often the same resources could have been used to purchase a more expensive full-featured and appropriate app.
3. Discourage people from purchasing an app that is more sophisticated than the client currently needed just to 'be on the safe side' when a lower cost and less sophisticated app would have better met the needs of the user.

One alternative is to conduct a trial using a free 'lite' version – an option offered by some developers. That said, a lite version offers a limited feature set (e.g., no voice output, no editing options, limited word prediction, a limited vocabulary, etc.).   Developers also told us

that a potential danger of relying on a 'lite' version is the potential to adopt the limited version believing it is sufficient. Another unfortunate outcome of adoption of a lite version is a tendency to discontinue the search for the best feature match to the strengths, skills and needs of the person with complex communication on the assumption the lite version is sufficient.

Conclusions:

New mobile technology and accompanying access strategies are emerging at an unprecedented pace. Mainstream availability of mobile device platforms and relatively low-cost apps suggests that the days of the speech-language pathologist being the presumptive expert with priviledged knowledge of the most current AAC options is a thing of the past. Today families and other team members often present ideas and tools they have discovered through an online list serve, found on a blog or read in the newspaper. As a result, they often purchase, experiment with and functionally apply the platform and app, frequently leading to critical insight about its potential. While some professionals may view this as a challenge to their clinical process, we suggest it be embraced as it offers the opportunity to collaborate with more engaged families and colleagues. The challenges to evidence base practice are unavoidable 'growing pains' associated with the onslaught of mobile device technology and apps. At the same time, improved options to insure the best match for persons with complex communication needs must be part of this evolving process and one that should include all stakeholders. We anticipate that, as occurred in the decades of the 80's and 90's, the demand for clear evidence and the minimization of wasted resources coming from the selection of an inappropriate tool, will force a systems change to support funding and availability of platforms and apps for functional evidence-based clinical trials.

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