

“We Bought an iPad”: Considering Family Priorities, Needs, and Preferences as an AAC Support Provider

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Abstract

A growing number of families are adopting and embracing the use of iPads and other mobile technologies as augmentative and alternative communication (AAC) systems. Merely having access to this technology does not guarantee its success, as supports for customization and learning are almost always needed. Team members need to work effectively with families to maximize outcomes. Consideration of individual and family priorities, preferences, and needs will play a critical role in ensuring positive AAC experiences and successful outcomes. This article describes key strategies for supporting and collaborating with families and illustrates these approaches with case examples.

The populations of individuals who require the use of augmentative and alternative communication (AAC) and their families are highly heterogeneous (Light, 1999). Individuals and their families present with a range of skills and needs (Beukelman & Mirenda, 2005; McNaughton et al., 2008), and therefore interventions are not often precisely identical (Light, 1999). The impact of the introduction of AAC is likely to affect the entire family system (Angelo, 2000), yet parents are particularly influential in achieving positive and successful outcomes in AAC (Huer & Lloyd, 1990).

A growing number of families are adopting and embracing the use of iPads and other mobile technologies as AAC systems (Caron, Costello, & Shane, 2014; McBride, 2011). The availability and awareness of these mainstream systems as AAC options have increased consumer empowerment and acceptance, including expansion of support to many who may not have previously considered AAC (Caron et al., 2014; McNaughton & Light, 2013). Despite the excitement and potential benefits surrounding mobile technology use, merely having access to this technology does not guarantee its success, as supports for customization and learning are almost always needed (Caron et al., 2014; Gosnell, Costello, & Shane, 2011; Shane et al., 2012;). As McNaughton and Light (2013) said:

Now is the time to develop new models of service delivery that bring together the best of both worlds: effective AAC assessment and intervention spearheaded by knowledgeable teams, working in close collaboration with consumers who require AAC and their families, to empower them with the knowledge and skills to make appropriate decisions to maximize communication and participation. (p. 111)

In order to collaboratively maximize communication, families' values, routines, and resources must be considered (Parette & Angelo, 1996). In addition, Angelo (2000) indicated that positive outcomes in effective service delivery have been observed when providers pay attention to three key components: family priorities, needs, and preferences. This article focuses on these three components as they pertain to mobile technology prescribed for AAC use by individuals with complex communication needs, specifically (a) the selection of appropriate AAC supports, (b) implementation of AAC across multiple contexts, and (c) support of changing AAC needs (Parette & Angelo, 1996).

The family's role and perspectives in each of these processes are discussed. This article draws on both the literature addressing family-centered intervention and family experiences related to technology. In addition, the article describes three case examples to illustrate the ways family priorities, needs, and preferences have been addressed for individuals with complex communication needs who are using mobile technology as AAC supports. The cases include Grant¹, who is participating in early intervention; Brian, who is in elementary school; and Jill, who has recently transitioned from high school to an adult day program.

Prescription of Appropriate AAC Devices

At the time of the initial evaluation, Grant was a 2-year-old boy who presented with complex communication and physical needs secondary to right hemiplegia following a perinatal stroke. He communicated using a small number of sounds (mostly vowels) and unaided strategies such as gestures and facial expressions. He pointed using his left hand. He appeared motivated to interact with peers and easily transitioned between activities and environments. He had received early intervention services for about a year at the time of the first consultation with the family. Early intervention had worked on his ability to make choices using photographs. The family was overwhelmed by the management of low-tech supports and therefore decided to purchase an iPad (with an AAC application) to try and meet his communication needs.

Family Priorities in the Assessment

Given that mobile technologies and AAC apps are often purchased without input from knowledgeable professionals, the field has experienced a paradigm shift in service delivery (Gosnell et al., 2011; McBride, 2011). Caron et al. (2014) reported that 57% of families who owned iDevices prior to assessment also had purchased a communication application prior to an AAC assessment. These findings were similar to those of Scherz, Dutton, Steiner, and Trost (2010), who reported that only 54% of individuals who used an iPod or iPad for AAC had received an AAC evaluation to determine the most appropriate communication system. By sidestepping the AAC assessment, individuals with complex communication needs could end up using technologies that do not match their needs and skills (Gosnell et al., 2011; McBride, 2011). As the field continues to manage the impacts of the paradigm shift, an additional consideration should include the message the family is sending when they prepurchase applications prior to assessment. At the very least, these actions may be saying something about the family's priorities, needs, and preferences.

In the case of Grant, considering the family's priorities in this light contributed to a successful outcome. During Grant's first months of early intervention, his team focused on his ability to make requests. Aided and unaided strategies were introduced. He learned to recognize and use a number of photographs for people, food, and toys. He also began to initiate and consistently use a small set of modified signs (e.g., *more*, *done*, *bathroom*, and *car*). The team learned that Grant was motivated to communicate and was quickly learning new concepts. The family was diligent in continuing to provide opportunities within their daily routine for Grant to make choices. Although Grant appeared to be making progress, his family was struggling to implement use of the photographs in other contexts (e.g., playgroups, play with his brother) and reported that "managing his growing interests is overwhelming." The family purchased an iPad with an AAC application (Proloquo2Go) to try to meet his growing interests and needs. Although the family switched to use of technology, the underlying purposes for communication intervention and activities for use remained the same. Similar to other parents who support children using high-tech AAC, Grant's parents expressed frustration with the time requirements for upkeep and programming of the iPad and communication application (Bailey, Parette, Stoner, Angell, & Carroll, 2006; Goldbart & Marshall, 2004; McNaughton et al., 2008).

¹Patient names have been changed to ensure confidentiality.

Through observation and discussion with the family, it became clear that their communication priorities centered on social contexts. Although the family understood that providing choices was important, their priorities were to get Grant playing with his brother and participating at playgroups. The family was provided with information, choices, and opportunities to trial other communication modes and applications. The decision was collaboratively made to continue using low-tech supports for choices and to switch from the application they had purchased to one designed to support the use of visual scene displays (GoTalk Now).

Visual scene displays may offer several advantages for beginning communicators like Grant. The advantages include maximization of meaningful representation, presentation of language in contexts, and organization of language according to event experiences (Light & Drager, 2007). In addition, scene-based applications have supported children to participate in social interactions and increasing turn taking, while reducing learning demands (Light & Drager, 2007).

AAC technologies must not only be appealing and meet the breadth of growing communication needs and context of young children like Grant, but they must also be easy to learn and use for both the individual and the family (Light & Drager, 2007). The built-in camera and portability of the iPad allows for more “real-time” capturing of events and moments. This “on-the-fly” way of capturing events and adding vocabulary within the application can reduce the programming demands and upkeep. It also allows families and other partners to respond to the child’s interests by adding new vocabulary (Light, Drager, & Currall, 2012).

Although the hardware remained the same from the initial purchase, a change of AAC application and intervention focus (shift away from choice making to social participation) allowed the family to support Grant’s communication growth. As demonstrated by the case of Grant, there is a fundamental importance of support providers knowing family priorities with respect to (a) goals surrounding communication development, (b) use of AAC supports, and (c) strategies that best support their family. This knowledge can start successful collaborations and lead to greater intervention satisfaction by the families (King, Batorowicz, & Shepherd, 2008).

Implementation of AAC Across Contexts

At the time of the first consultation for Brian, he was a 9-year-old boy with a dual diagnosis of cerebral palsy and pervasive developmental disorder—not otherwise specified. He demonstrated the ability to navigate and use high-tech AAC devices with multiple pages of picture vocabulary. In an evaluation by a speech-language pathologist, a communication application for the iPad (TouchChat HD) was recommended. Brian’s school relied heavily on use of the iPad and AAC application throughout the day. However, for communication at home, he made use of word approximations and gestures.

Family Preferences in the Implementation of AAC

Each family has unique expectations and personal preferences for the course of intervention for their child. As stated by Bailey and colleagues (2006), “Family voice is often quite different from that of professionals. When the family voice is not valued . . . partial or complete abandonment of AAC in home and community settings may result” (p. 51). That said, clinicians and families might share some reservations and perspectives in the intervention process, but recognizing that common ground can be a place to start (Cress, 2004). Developing the common ground with families requires a deeper understanding of what they perceive as successful communication outcomes and their child’s current strengths and challenges. In Brian’s case, this common ground included the recognition that Brian benefited from visuals (picture or text based) and that Brian was very motivated to use technology to learn to communicate.

Brian quickly learned new icons within his communication application on his iPad. He used topic displays with photographs and symbols (Symbolstix) throughout his day. With these AAC supports, he was able to participate in school activities and routine-based social exchanges

with peers. The school team was thrilled with his progress. Brian was also included in regular education for language arts (specifically, spelling and reading).

Brian's parents were happiest with his success in participating in regular education. The family often discussed their desire to have Brian included in mainstream education for more subjects. At home, his family spent time supporting Brian and his brother with academics through worksheets and flashcards. They also diligently worked through Brian's oral speech drills provided by their private speech-language pathologist. However, they did not feel as though the iPad was necessary to support communication at home, which was a point of contention between the school and the family. The school was seeing progress with the iPad and therefore could not understand why the parents did not want to be a part of that progress.

It would be easy to view Brian's family as unsupportive and resistant to AAC, when, in fact, they preferred to focus on supports that fostered literacy development as opposed to using photographs and symbols. Seeking situational understanding is a strategy that can be used when working on complex tasks (King et al., 2008). Implementing the use of AAC across environments is a complex task. Each environment (home, school, community) can bring different challenges, partners, and topics. Subsequently, it is important to understand the support needed for different situations. Cress (2004) suggested that AAC might be more effective if parents discover and have ideas for strategies that can promote their child's communication on their own. In Brian's case, because of his interest in books and emerging letter and sound knowledge, his family came to the conclusion that he would learn to communicate using spelling and writing. They were therefore interested and invested in working toward this goal.

Through effective and collaborative teamwork, Brian's iPad and communication application were updated to include literacy-based pages (e.g., letter sounds page, sight words page, consistent access to the keyboard). The school team had success with topic displays, and these were continued at school, adding text-based topic displays that included all the words Brian had learned to read. The photo library of the iPad was also used with Brian. It was organized with albums containing simple decodable books, letter cards, and sight words. Mainstream literacy applications were used to provide additional motivating literacy contexts (e.g., Word Wizard, Starfall, Tumblebook Series). The iPad was then used both at home and school. To have Brian communicating through traditional orthography was a goal all team members were able to support. As illustrated by the case of Brian, it is essential to seek situational understanding and validate each family's preferences. This knowledge can lead to maximized communication outcomes for the individual and stronger collaboration between all support providers.

Support of Changing AAC Needs

At the time of the initial consultation, Jill was a young woman (22 years old) with autism. Her family supported her use of augmentative communication since early intervention. Jill communicated through physical contact (e.g., pulling parents to what she wanted) and by using approximately 20 words or word approximations and an iPad with a communication application (Proloquo2Go). Jill had previously used a Dynavox speech-generating device for a number of years. When the iPad became an available option as an AAC support, the family expressed interest in it because of its portability, ease of photo capturing, and motivating leisure activities (e.g., videos, music, puzzle apps) all in one platform. Jill had been using an iPad with Proloquo2Go for 2 years and had recently transitioned from school-based services to adult day services. In this transition time, the family's needs changed.

Family Needs in Times of Change

Parents of children with disabilities juggle many roles, from loving caregivers to teachers, playmates, advocates, coordinators, and programmers (McNaughton et al., 2008; Parette & Angelo, 1996). Knowing the roles the parents play is important for sustaining family involvement.

Supporting the use of AAC (both low- and high-tech) can be stressful and overwhelming, especially when roles and responsibilities are changing (Angelo, 2000). For families of adolescents and young adults, the end of school services can be a distressing time. Even when families know that changes will occur, it can be difficult to plan for life after school (Goldbart & Marshall, 2004).

The biggest stressor for Jill and her family during the transition to adult day services was losing communication with familiar partners. Jill was in the community more and therefore was required to interact with more people in society and in unfamiliar contexts (McNaughton & Kennedy, 2010). The communication opportunities were not as routine based as she was used to, and partners were no longer co-constructing her output. In addition, the family lost communication with familiar partners who were key to keeping the family in the loop. They felt that they needed to establish a way to communicate with the day program about both what was happening at home and when Jill was away during the day. The family decided that Jill could be involved in this process as it would be beneficial for her to share what she did at home with her communication partners at the day program, and visa versa. New pages were added to her current communication device organization to support this exchange. Originally this communication was more routine based (e.g., part of her morning meeting) and then was generalized to more contexts and partners (e.g., responding to questions like “What did you do today?”).

As the family worked out this new communication goal and worked to find a way to communicate with the new service providers, it was clear that training needed to take place. The family was used to having the school support the programming and upkeep of her communication device. The staff at the day program did not have any experience with the iPad as a receptive or expressive communication support. The family now took on the role of becoming trainers.

The family needed to be supported in this new role as they shifted from being supported by trainers (i.e., the school team) to supporting others (i.e., the day habilitation staff). Using instructional components outlined in “Communication Partner Instruction” by Kent-Walsh and McNaughton (2005) as a guide, the family participated in training. These same training principles were then applied to the staff that works with Jill. The training was able to capitalize on the staff’s current knowledge of mobile technologies and then was expanded to the use of the iPad with Jill and identification of other routine-based communication opportunities (e.g., Jill asking a peer a question and responding to the question with a comment).

After the staff had success implementing communication exchanges in the morning meeting, generalization of the iPad as a communication support occurred. The staff expressed interest in expanding use of the iPad for other functions, like supporting comprehension of tasks within activities of daily living (ADLs). Jill’s family had been working on her independence and ADLs at home, using the iPad to support her receptive and independent life skills. Using the Communication Partner Instruction approach, the family was able to teach the staff how to use a visual schedule application (Choiceworks). After participating in the training, the staff were able to independently make new visuals for Jill and generalized the use of the application to other activities that happened in day habilitation (e.g., jewelry making, cooking, and packing her own backpack for outings).

The last addition occurred in sharing and documenting the outings the day habilitation took. Jill’s day habilitation took weekly trips to historic sites, beaches, and other local establishments as part of community outings. Jill enjoyed taking pictures on these outings and had been observed independently looking through her photo library at the pictures she had taken. The family needed a way for Jill to share these experiences without putting too many demands on the staff. A story creation application (Pictello) was used to create stories with the photos she took on her outings. The family trained both staff and other individuals in the day habilitation how to create stories within the application. The application’s wizard feature and the familiarity with the platform allowed for rapid training and implementation of experience sharing.

An individual who uses AAC requires lifelong support. Participation in society changes for the individual as he or she journeys from childhood to adulthood. The role of the individual, as well as the family, changes in this journey. As Jill's parents said:

This transition made us more invested. We needed to be more involved. Instead of relying on others, we had to do things ourselves [learn the applications, seek supports]. . . . In a time where many expect little progress or change . . . we have seen some of the biggest changes in engagement, motivation, and communication. So that's exciting that our investment and involvement are paying off.

Jill's case demonstrated how AAC must support a wide variety of communication functions, across ages, and interests (Williams, Krezman, & McNaughton, 2008). Because of this, AAC supports should be continually updated to meet these changing needs. Understanding what the individual and family need during transition times and supporting their changing roles can allow for more successful outcomes.

Summary

The advent of mobile technologies has created lots of excitement in the field. Mainstream technologies have brought many advantages to the field of AAC (e.g., interconnectivity, portability, greater functionality). Yet challenges remain in supporting individuals with appropriate AAC intervention. Effective AAC assessment and intervention involves knowledgeable teams that work in close collaboration with those who require AAC and their families (McNaughton & Light, 2013).

During the process of maximization of communication outcomes, families and service providers take on many roles (Parette & Angelo, 1996). Moving forward, it is important to remember that family goals and priorities are the key to AAC intervention and that support team members may need to shift their priorities in response (Cress, 2004). The access to mobile technology and AAC applications does not guarantee communication competence. Team members need to work effectively with families to maximize outcomes. This collaborative relationship involves understanding what families want and expect from AAC services, being aware of and sensitive to their situations and perspectives, and striving to meet their priorities, preferences, and needs (King et al., 2008).

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