

Augmentative and Alternative Communication (AAC) and Life Care Planning

Part 2 of 2

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Editor's Note: This article is the second article of a two part series. The reader is referred to Part I of the series in the previous edition of the JLCP for a basic overview of AAC and key components as well as evidence-based practice principles (Hill, 2003).

Abstract. *This is the second of a two part series on augmentative and alternative communication (AAC) and life care planning for individuals with significant speech disability. The purpose of Part II is to provide a case study which applies the principles of evidence-based practice (Hill, 2003) to the AAC assessment process. The article traces the steps leading to a decision about a high technology speech output AAC solution, and provides a case study that can serve as a model for life care planners in addressing similar issues. Part II also includes a list of AAC resources to support life care planning involving AAC which requires performance and outcomes measurement to lead to the most effective communication. Life care planning for AAC should provide a framework of services and supports that measure outcomes in terms of quality of life for the clients we serve. The article ends with a list of ten "AAC Rules of Commitment" on choosing and using augmentative communication systems.*

Key Words: Augmentative and Alternative Communication (AAC), evidence-based practice, performance measurement, outcomes measurement

"Assistive technology without training is not assistive."

-Rick Creech, augmented communicator

Introduction

Life care planning provides an organized framework of services that recognizes the rehabilitation needs of an individual in terms of quality of life (Blackwell, Weed, & Powers,

1994). Similarly, the values of augmentative and alternative communication (AAC) are compatible with quality of life issues. For individuals with speech disability who use AAC, quality of life may bear a direct relationship to communication skills and AAC planning requires a similar framework to address these issues. Quality of life can be dramatically enhanced when AAC teams desire the most effective, independent communication possible for an individual with significant communication disabilities. Practitioners who recommend AAC and individuals who rely on AAC believe that the fundamental, desired AAC outcome of independent communication can be achieved with appropriate technology and appropriate long-term, often intensive intervention strategies (Creech, 1995).

Life care planners are involved in advocating for a systematic, principled framework in making AAC decisions to ensure that the communication needs of an individual are addressed in terms of quality of life. AAC interventions should enhance the quality of life by allowing exposure to, contact with, and interaction among greater numbers of settings, experiences, and people (King, 1999). The benefits of achieving effective, independent communication include widening social networks, increasing social interactions, boosting self-direction, and enhancing both the potential for independent living and educational and employment opportunities. Evidence of how high technology AAC systems have maximized potential and enhanced quality of life can be observed at the Pittsburgh Employment Conference for Augmented Communicators (PEC), the largest gathering in the world of individuals who rely on AAC (for information on PEC, look up <http://mywebpages.comcast.net/amiprofeta/index7.htm>). Conference presenters and moderators include individuals who rely on AAC discussing issues related to transitions from high school to college, from education to employment, from being single to being married, and the quality of adult life.

Case Study

Brent was a 22 year old sophomore in college when referred for AAC services to explore interventions to improve communication, particularly related to college academic performance. Brent was having difficulty completing communication tasks typical of classroom interactions, group projects, and faculty conferences. He was diagnosed with cerebral palsy characterized by severe spastic quadriplegia and had limited vocalizations with no intelligible speech. Brent used a power wheelchair with joystick control for mobility. A high technology AAC system which was recommended in high school was mounted to his wheelchair. Although a University program for students with disabilities made the referral for an AAC re-evaluation, Brent recognized that his current methods of communication were not meeting his needs and were not reflective of his abilities and potential. University officials and Brent feared that withdrawal was unavoidable. Brent became the central team member driving and approving the AAC services. His active participation in the assessment process was reflective of the AAC consumer-centered service delivery model discussed in Part I of this series (Hill, 2003).

In the author's opinion, the AAC assessment may be the single most important event in the life of an individual with significant communication disabilities and needs. Therefore, exemplary assessment becomes an ongoing process in which data are collected and information is gathered to make intervention and management decisions (Lloyd, Fuller & Arvidson, 1997). Figure 1 depicts the AAC language-based model for assessment and intervention that provides an organized framework based on the goal of AAC (Hill, 2001). The principles of AAC evidence-based practice (EBP) are applied at the different levels of the

model. According to evidence-based medicine, teams are expected to conscientiously and judiciously use the best evidence or data to support decisions (Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996). EBP places the client's benefits first when applying evidence of direct practical importance to planning (Gibbs, 2003). AAC teams use evidence at each level of the model for planning the process. The basic steps for applying EBP include: (1) characterizing the person; (2) asking the most appropriate questions; (3) searching for and appraising the field (research and case study) evidence; (4) implementing the intervention; (5) monitoring (measuring) change; and (6) evaluating the results (Hill, in press).

In Brent's case, the first step required gathering information about his values and needs and collecting performance data about his communication. Brent's values were consistent with the goal of AAC, since he desired to be a "faster, more efficient" communicator, with preference for using his own words rather than pre-stored sentences. Brent's performance on his current AAC system showed that he used spelling as his primary method to generate messages, averaging three (3) words in length, and his average communication rate was one word per minute (see Table 2). Communication partners frequently completed or attempted to complete his messages. Once the team confirmed consensus at this level, the next step or Step 2 required formulating a question to search for field evidence to support decisions. The EBP question was based on Brent's desire to acquire a high performance AAC system that would match his abilities, needs, and goals. As professionals identified research to support decisions (required by Step 3), Brent was involved in searching for and appraising evidence from other sources, which included Internet resources. He joined ACOLUG, the Augmentative Communication On-Line User Group (listed as a resource in Table 3) and observed other adults who rely on AAC.

The fourth step involved implementing the intervention. This step involved using the evidence to support moving through the next levels on the language-based model which included identifying the various language representations methods (LRMs) used to generate communication using AAC systems, determining specific outcomes based on selected LRMs, and evaluating how specific LRMs were supported on available technologies. Refer to Part 1, Table 1 for definitions and examples of LRMs (Hill, 2003). Considerations of LRMs, outcomes, and technology issues were discussed and demonstrated before any AAC devices were introduced. Since Brent already had an AAC device, his current system was used first to demonstrate these components and then compared with alternative AAC language application programs and technology features. Step 5 involved monitoring or measuring Brent's performance by collecting quantitative data. Performance measurement provided a systematic and scientific approach for trial comparisons among AAC systems. Brent required three trial periods to make a decision about a possible recommendation for a new AAC system: 1) his current AAC device with modifications; 2) an upgraded dynamic display AAC system; 3) a hybrid AAC system. Figure 2 is a photo depicting a typical therapy session with Brent working on optical heading in which performance data are collected using automated language activity monitoring.

Table 1 compares the technology features between Brent's original AAC system and the recommended AAC system. In reviewing the results from the trial periods, Brent advocated for an AAC system that supported all three language representation methods. In addition, he selected the hybrid display which included both a static keyboard and a dynamic display touch screen rather than the full touch screen only. Brent also wanted the option to switch between direct keyboard selection and optical head pointing depending on his physical status during the day. Other features or options on the new system that enhanced Brent's perceptions of the

effectiveness and efficiency included: activity row on touch screen, infrared control for computer access and environmental control, language activity monitor, icon prediction, icon tutor, and easy access to display status and tool box. Finally, considerations about the services offered by the manufacturer were included in Brent's choice. He favorably rated services such as access to technical service, regional professional support, and Internet training opportunities as being important to him.

Step 6 of EBP involved evaluating the results of the process. Brent was referred for an initial assessment session in the late fall. The trial period lasted through the winter months, with a significant break occurring between semesters. The funding request for his new AAC system was submitted in the early spring with training immediately occurring on a loaner system. Brent attended one one-hour therapy sessions a week for three months. By the end of the spring semester, performance and outcomes measurement showed that Brent was a more effective communicator. Within three months he had learned his new language application program and was selecting words using semantic compaction 90% of the time with an average communication rate of 6.7 words per minute and peak communication of 21 words per minute with direct keyboard selection. For Brent, use of semantic compaction was 16 times faster than spelling. Table 2 compares Brent's performance on his original system with his performance on his new system. In addition to improvements in Brent's communication performance in various social environments, his communication in classes was also considered to be improving. With an improvement in his grades, withdrawal was no longer considered necessary. Two years later, Brent graduated from the University majoring in Speech Communication Studies.

AAC and Life Care Planning Considerations

Consideration of financial issues should be of interest to life care planners. The costs associated with the assessment and intervention process for the case study example include the diagnostic and therapy sessions and AAC system and accessories. In Brent's case, the University provided reduced fees for the AAC assessment and intervention; however, this is not typical of most clinic settings. Life care planners could expect the cost associated with an AAC assessment to range between \$60 and \$250 per hour. Therapy services generally range between \$30 and \$80 per hour. The cost of Brent's AAC system, infrared receiver, optical head pointer with customized headset, carrying case, and wheelchair mount totaled \$10,435. Additional cost considerations in a life care plan for AAC should include possible interventions as abilities or needs change (such as employment), extended warranties or costs for any repairs, and the likelihood that an AAC system should be upgraded on average every five or more years, depending on effectiveness and advancement in technology. Extended warranties are generally in the better interests of the individual than paying for repairs on a case-by-case basis. Additionally, service loaners may be available under warranty and the delays and administrative process relating to funding are eliminated.

If a life care planner with appropriate knowledge had been involved in Brent's case early on, he may have been able to start with the more effective AAC system from the beginning. This could have saved him the time and anxiety of working through the process described. It also could have saved the funding agency the cost of the initial AAC system. While speech-language pathologists are expected to lead the AAC service delivery process, many SLPs are not yet familiar with recent developments in the tools, methods, and evidence to support practice. The life care planner can serve as educator and can also coordinate the referral to a

trained and qualified SLP for evaluation.

AAC Resources

Becoming familiar with resources and supports that promote exemplary AAC practices provides the information necessary for individuals to measure and evaluate the outcomes of rehabilitation services and the assistive technology. In Brent's case, after he was shown video clips of individuals using AAC systems, he shared that he had never met another person using a device. The team conducting his previous evaluation had never performed an assessment for an AAC system. During separate conversations, Brent and his mother both related that they had no idea that persons with disabilities like Brent were communicating so effectively and fast using a voice output AAC system. They also shared that they were surprised at the number of individuals using high performance AAC systems similar to Brent or with even more significant challenges. At the first assessment session, Brent was introduced to various Internet resources and was encouraged to join as well as participate in ACOLUG discussions (see Table 3). He was encouraged to post questions about the AAC assessment process to members of ACOLUG to be a better advocate for himself. Internet resources can provide access to information that is current and useful when sources are carefully and prudently evaluated. Examples of useful Internet resources available to life care planners seeking to explore AAC possibilities and options for individuals and families are found in Table 3. The resources include information on AAC evidence-based practice, methods and tools to support performance and outcomes measurement, online AAC courses, information on conferences about assistive technology, directories of resources, and online discussion groups. Various professional organizations also provide information on exemplary rehabilitation practices to support consumers and advocates through web sites and/or email correspondence. Life care planners can help build the sense of commitment by sharing and confirming with AAC team members the *AAC Rules of Commitment* (Appendix A, also available at the AAC Institute website, www.aacinstitute.org).

Summary

Improvement in quality of life is often stated as the ultimate goal in rehabilitation services (Pain, Dunn, Anderson, Darrah, & Kratochvil, 1998). Individuals and families frequently regard maximizing potential and independence as a quality of life issue. When surveyed, individuals with disabilities and family members expressed a clear sense to be "the best they could be" (Pain, et. al., 1998). Individuals with significant communication disabilities desire the same goals through achieving the most effective, independent communication. However, quality of life is defined by outcomes; outcomes which compare interventions in order to make informed decisions regarding treatment (Ninni & Brownstein, 1999). This article focused on a model of AAC service delivery that incorporates the principles of evidence-based practices to compare AAC interventions and measure performance and outcomes. By providing a systematic framework and opportunity to compare AAC systems using evidence (research and quantitative data), the life care planner can ensure that resources are used most effectively and efficiently to achieve the best results. This avoids the "wish list" look to the life care plan, where every possible kind of equipment is included without knowing what the client will really use (Preston, 2003). Life care planners can feel secure that the client's benefits are placed first when evidence is used judiciously and conscientiously within an organized

framework.

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Table 1. Feature Comparison of Original and Recommended AAC Systems (case study)

Technology Features	Original AAC System	New AAC System
Language Representation Methods (LRM)	Spelling, word prediction, single meaning pictures	Semantic Compaction, spelling, word prediction, single meaning pictures
Language Application Program	None; standard alphabet display and customized pages	Unity 128 sequence
Display Type	Full dynamic display	Hybrid, static & dynamic displays
Primary Voice Output	DecTalk (synthetic speech)	DecTalk (synthetic speech)
Selection Method	Direct keyboard	Direct keyboard and optical head pointing

Table 2. Performance Data Comparing Original and Recommended AAC Systems (case study)

Performance Data & Outcomes Measurement	Original AAC System	New AAC System
Frequency of LRMs:		
Spelling	97%	6%
Word prediction	2%	3%
Single meaning pictures	1%	1%
Semantic compaction	not available with system	90%
Mean length of utterance in words (MLU-w)	2.8	5.5
Average communication rate: Direct keyboard	1.0 wpm	6.5 wpm
Peak communication rate:		
Direct keyboard	Not able to calculate	21 wpm
Average communication rate: Optical headpointing	N/A	5.3 wpm
Peak communication rate:		
Optical headpointing	N/A	17.39 wpm

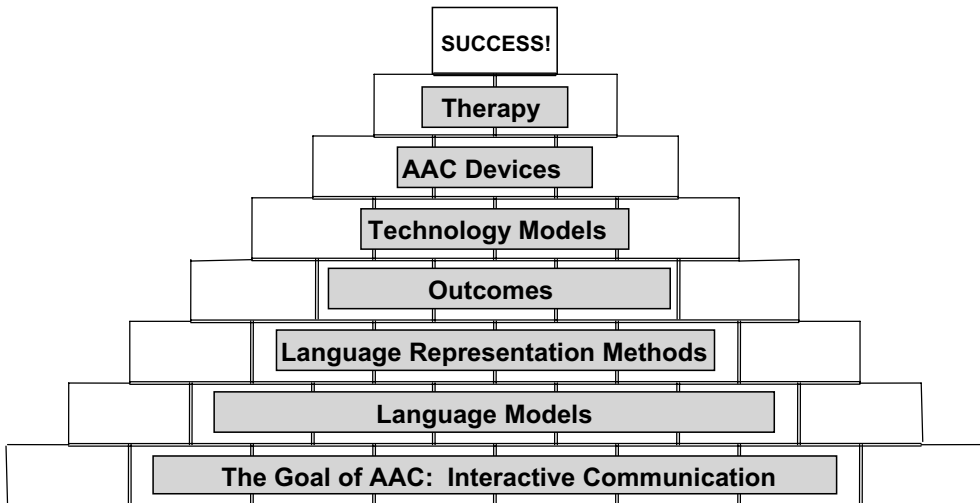
Table 3. AAC Internet Resources

Organization	Website	Description
AAC Institute	http://www.aacinstitute.org	Not-for-profit charitable organization dedicated to the most effective communication for people who rely on augmentative and alternative communication (AAC).
ACOLUG – Augmentative Communication On-Line Users Group	http://disabilities.temple.edu/programs/assistive/acolug/tacolug.html	A listserv created to exchange ideas, information, and experiences on augmentative communication by people from all over the world. By using e-mail, people who use augmentative communication and their friends and families discuss issues related to augmentative communication, such as equipment, funding, learning techniques and supports. Anyone can join and there is no cost.
ASHA – American Speech, Language and Hearing Association	http://www.asha.org	The professional organization of speech-language pathologists (SLPs) and audiologists. SLPs are the primary service providers for people who rely on AAC and are generally the best resource on an AAC team for addressing language issues. ASHA has a Special Interest Division, SID-12, that addresses AAC.
CAMA – Communication Aid Manufacturers Association	http://www.aacproducts.org	Not-for-profit organization of the world's leading manufacturers of augmentative and alternative communication (AAC) software and hardware products. CAMA conducts more than 30, 1-day workshops throughout the United States each year.

Table 3. AAC Internet Resources

ISAAC – International Society for Augmentative and Alternative Communication	ttp://www.isaac-online.org	Membership is open to anyone interested in AAC. ISAAC activities include a biennial conference and sponsorship of AAC Journal. Many ISAAC national chapters address more local interests.
PEC – Pittsburgh Employment Conference for Augmented Communicators	http://mywebpages.comcast.net/amiprofeta/index7.htm	The largest gathering in the world of people who rely on AAC. Topics of interest to employment-age individuals are addressed at the annual conference.
RESNA – Rehabilitation and Assistive Technology Society of North America	http://www.resna.org	An interdisciplinary association of people with a common interest in technology and disability. Their purpose is to improve the potential of people with disabilities to achieve their goals through the use of technology. They serve that purpose by promoting research, development, education, advocacy, and the provision of technology and by supporting the people engaged in these activities. RESNA was founded in 1979 as a not-for-profit professional organization.
USSAAC – United States Society for Augmentative and Alternative Communication	http://www.ussaac.org	United States chapter of ISAAC.

Figure 1. AAC Language-Based Model for Assessment and Intervention



ã Hill 2000

Figure 2. Photo of Therapy Session Showing Language Activity Monitoring of Client's Performance



Appendix A

AAC Rules of Commitment

Compliance with the following rules will distinguish those who hold in the highest regard the interests of the individual who relies on AAC.

Rule 1: Be committed to the most effective communication system for the individual being served.

Rule 2: Be committed to following your professional code of ethics.

Rule 3: Be committed to involving the consumer and family in the service delivery process.

Rule 4: Be committed to achieving the maximum outcomes for the individual.

Rule 5: Be committed to advocating for language.

Rule 6: Understand the merits of ALL language representation methods.

Rule 7: Support the language representation method(s) for core and extended vocabulary access that best serve the interest of the individual.

Rule 8: Advocate for the AAC system that supports the chosen language representation method(s).

Rule 9: Be committed to using AAC performance measurement to support clinical intervention.

Rule 10: If unable to adhere to any of these guidelines, be truthful about it to the individual, family, and advocates.

The AAC Rules of Commitment was first published in a three-part series in *Exceptional Parent* magazine (Hill & Romich, 1999) on choosing and using augmentative communication systems.

About the Author

Katya Hill, Ph.D., CCC-SLP, is assistant professor in speech-language pathology at Edinboro University of Pennsylvania where she teaches AAC courses and supervises AAC clinical activity. She also serves as Executive Director of the AAC Institute, a not-for-profit charitable organization dedicated to providing the most effective communication for people who rely on AAC through evidence-based practice and outcomes measurement.
