

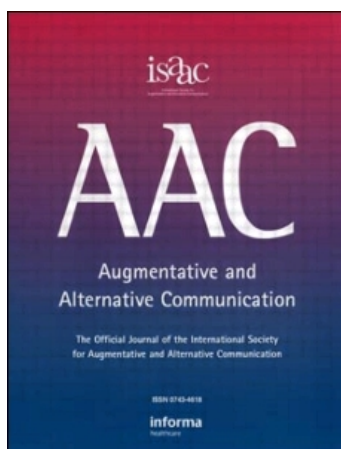
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An AAC Personnel Framework: Adults with Acquired Complex Communication Needs

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A personnel framework designed to support people who rely on augmentative and alternative communication (AAC) because of acquired medical conditions and those who assist them is described. The roles of AAC finders, general practice clinicians, AAC intervention specialists, AAC facilitators, and AAC experts are summarized. These roles are described in detail for people with amyotrophic lateral sclerosis, brainstem impairment, and severe chronic aphasia. The personnel preparation needs for each of these support personnel groups are identified.

Keywords: AAC; Personnel; Amyotrophic lateral sclerosis; Aphasia; Brainstem impairment

INTRODUCTION

On 16 August 1990, David Beukelman was invited to the ISAAC Conference in Stockholm, Sweden to deliver the Phonic Ear Distinguished Lecture. The title of the talk, “The Magic and the Cost of Communication Competence,” focused on the “magic” of assisting people with complex communication needs to communicate, but acknowledged the cost experienced by people who relied on AAC as they attempted to develop sufficient communication competence to demonstrate this AAC magic (Beukelman, 1991).

We have decided to focus this article on the essential people who surround and support those with acquired complex communication needs, rather than on those who rely on AAC, as was done in Stockholm. This focus is consistent with an article by O’Keefe, Kozak, and Shuller (2007) that identified research priorities in AAC from the perspective of people who rely on AAC and their facilitators. They stressed “... the need for new models of communication training for those who are closely related to people who use AAC,

including doctors, nurses, attendants, transport workers, and other caregivers” (p. 94).

In 2008, we are surrounded by remarkable AAC magic, as those who rely on AAC interact with friends, family, and strangers in multiple settings. They volunteer and participate in both education and employment. They write articles and chapters, give speeches, talk on webcasts, are interviewed on television, and participate in advisory groups. They e-mail, send text messages, search the Internet, and play video games. In fact, a review by Beukelman, Fager, Ball, and Dietz (2007) reveals that this list is far from complete, as the magic is much, much better than it was in the early 1990s. And we anticipate even better magic in the future.

However, “... one aspect of magic is its improbability, another is its deceptiveness” (Beukelman, 1991, p. 3). Great magic just looks easy, but typically there are hidden costs that are only recognized by those with complex communication needs their families, and those who assist them. For people with acquired complex communication needs and those close to them, the costs and limitations of the magic are starkly apparent,

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because for years they were able to speak effortlessly and listeners were able to understand them with ease. In fact, most of them do not even remember the effort they initially expended as infants and toddlers learning to speak and be understood. They may have a slightly better awareness of learning to read and write; however, for most, even these activities had become largely automatic prior to the onset of their acquired medical conditions. Now, later in life, because of an injury, a stroke, a degenerative disease, or cancer, they are left with potential, emerging, or actual complex communication needs. As a result, they and those close to them abruptly enter the “world of AAC” about which they know very little; they find that they must learn about AAC and make decisions very quickly (Beukelman, Garrett, & Yorkston, 2007; Yorkston, Miller, & Strand, 2004).

The 1990 presentation focused on the AAC-related costs incurred by people who rely on AAC and their AAC communication partners. Of course, there was awareness that other persons played important roles in the development of communication competence, but that talk did not focus on the need to prepare a range of individuals strategically to support the AAC effort. During the past few years, we have begun to think of AAC-related personnel somewhat differently (Beukelman, et al., 2007; Beukelman & Wallace, 2007), and the remainder of this article will focus on their identity, roles, preparation, and maintenance of knowledge and skill. In addition, we will consider the cost of both pre-professional and continuing education that is required to prepare personnel to implement a more seamless AAC service delivery system.

PERSONNEL FRAMEWORK

The personnel framework for persons with acquired complex communication needs differs considerably from the framework for those with developmental complex communication needs because those with acquired conditions do not have structures such as educational agencies, personnel, and policies to support them over an extended period of time. Rather, they must depend upon informal collaborations, often formed out of convenience, to provide AAC-related services. For successful AAC interventions to occur, several categories of individuals in addition to those who rely on AAC, their communication partners, and AAC technology manufacturers are critical. These categories are introduced in the upcoming section, and are then described in more detail within the context of

three acquired medical conditions: amyotrophic lateral sclerosis, stroke/chronic aphasia, and brainstem impairment. Table 1 (based in part on Beukelman & Wallace, 2007) presents an overview of some of the key activities involved in AAC service delivery as well as the roles and responsibilities of personnel with respect to these activities. As is apparent from a review of this table, responsibilities vary somewhat depending upon the particular situation, and at times are shared, as collaborative relationships among personnel groupings are developed.

AAC Finders

AAC finders for people with acquired medical conditions include general practice physicians, neurologists, rehabilitation physicians, physician assistants, nurses, social workers, general practice speech-language pathologists, and family members. To be effective, these finders require information; to date, however, AAC professionals and others in the field have not been able to systematically prepare and support AAC finders. The importance of well-prepared finders cannot be underestimated, since these individuals often play critical roles in preparing people with acquired complex communication needs and their families to accept and use AAC strategies and technologies.

AAC finders fulfill a number of critical roles (see Table 1). First, they identify people with potential and actual complex communication needs. Typically, their professional preparation provides them with information about the symptoms, including communication, that are associated with various medical conditions. However, their pre-professional preparation probably does not fully prepare them to understand the course of each condition with regard to communication. In particular, they often are not prepared to identify those who may or may not recover functional speech and language in conditions where recovery and restoration are possible.

Second, finders need to be aware of the potential of AAC strategies to support communication, personal care, and participation. Current pre-professional preparation for common finders such as physicians, physician assistants, nurses, and social workers does little to familiarize them with these strategies.

Third, finders often play an important role in preparing and supporting those with actual or potential complex communication needs and their supporters to make decisions related to communication needs and intervention options. Typically, finders are prepared to assist individuals and their families to make medical

TABLE 1 Roles of selected AAC personnel: AAC finders, general practice clinicians, AAC facilitators, AAC specialists, and AAC experts.

Personnel	Potential roles
AAC finder	<ul style="list-style-type: none"> Identify persons with complex communication needs Be aware of current, appropriate communication options for individuals with complex communication needs Prepare potential decision makers Organize decision-making process to seek AAC assessment Refer to appropriate AAC intervention provider(s) Certify AAC prescription(s) (when appropriate)
General practice clinician	<ul style="list-style-type: none"> Implement multi-modality interventions Integrate low-tech AAC materials in restorative/developmental and compensatory interventions Implement appropriate low-tech AAC options Implement routine high-tech AAC options Monitor impact of individual AAC interventions Prepare and support AAC facilitators Instruct communication partners
AAC intervention specialist	<ul style="list-style-type: none"> Implement multi-modality interventions Integrate low-tech AAC materials in restorative/developmental and compensatory interventions Implement appropriate low-tech AAC options Implement complex or unique high-tech AAC options Monitor impact of individual AAC interventions Obtain funding for intervention technology Prepare and support AAC facilitators Support general practice clinicians Instruct communication partners Provide continuing education to AAC finders Collaborate to support technology transfer Collaborate to support AAC research Support AAC professional organizations and activities Provide expert testimony for legal and policy proceedings
AAC facilitator	<ul style="list-style-type: none"> Support implementation of multi-modality interventions Instruct communication partners Support unfamiliar listeners Maintain AAC technology Prepare low-technology materials Serve as a liaison with other AAC personnel and commercial company
AAC expert	<ul style="list-style-type: none"> Promote, sustain, and enhance AAC services at program or agency level Pre-professional preparation of AAC finders Continuing education of AAC finders Pre-professional preparation of general practice clinicians Continuing education of general practice clinicians Pre-professional preparation of AAC intervention specialists Continuing education of AAC intervention specialists Pre-professional preparation of AAC experts Continuing education of AAC experts Development of AAC policies Execution of AAC research Collaborate to support technology transfer Prepare AAC educational materials Participate in the leadership and management of AAC professional organizations Support AAC professional organizations and activities Provide expert testimony for legal and policy proceedings

decisions; however, AAC decisions associated with a particular medical condition are somewhat unique. Finders may not be well prepared to assist with these unique AAC decisions.

Finally, some finders support AAC funding applications for technology and intervention

services by certifying the medical diagnosis and signing prescriptions for these technologies and services. These individuals may be familiar with the general prescription process, but they may need updated information regarding specific funding practices for AAC.

Clinicians in General (Integrated) Practice

Clinicians in integrated or general practice include those who provide a range of clinical services as part of their daily practice. Although they do not specialize in AAC intervention services, the agencies where they work regularly serve children and adults who cannot meet their communication needs through natural speech alone. Many individuals with medical conditions receive ongoing services from these generalists, and people with complex communication needs face a crisis if these general practice clinicians or the agencies for which they work choose not to provide AAC services. General practice clinicians need information similar to that mentioned earlier for AAC finders, and they also need information about low-tech AAC options for the persons whom they serve. In addition, they need some level of operational competence with AAC technology that is typically used by the populations they serve (see Table 1).

AAC Intervention Specialists

AAC intervention specialists are those professionals whose workloads include providing direct AAC intervention services (e.g., assessment, recommendations, instruction, funding assistance, and follow-up) to people with complex communication needs at least 50% of the time. These professionals require the same AAC-related knowledge as AAC finders and general practice clinicians. In addition, they must possess a level of intervention expertise to instruct and educate other personnel about AAC services and to provide unique intervention services that others are not able to offer. Their intervention roles are summarized in Table 1. Some intervention specialists focus primarily on fulfilling these intervention roles, whereas others also serve in the role of AAC experts.

AAC Experts

AAC experts include a range of individuals who focus their efforts on developing and maintaining the knowledge, technical, financial, policy, and service bases of the AAC field. They include university faculty, consultants, researchers, technology developers, policy-makers, and administrators of specialized service programs. Obviously, some AAC intervention specialists also fulfill the role of AAC experts, as they participate in research and contribute to the AAC knowledge base through their presentations and writing.

AAC Facilitators

AAC facilitators typically assist a specific individual who relies on AAC by instructing new communication partners and caregivers, programming new messages into an AAC device, maintaining low- and high-tech AAC options, and maintaining relationships with AAC specialists or representatives of AAC manufacturers. The identity and role of an AAC facilitator depends on the needs, capabilities, and expectations of the individual with complex communication needs, the setting in which he or she resides and/or participates, and the range of available personnel. Facilitators may include family members, agency personnel, friends, and/or volunteers, depending on their availability and relationship to the individual with complex communication needs.

The personnel described in the framework (i.e., AAC finders, clinicians in general practice, AAC intervention specialists, AAC experts, and AAC facilitators) are all essential for successful AAC interventions to meet the needs of individuals with complex communication needs and their communication partners. We will now describe the roles of these key personnel within the context of AAC interventions associated with three acquired medical conditions: amyotrophic lateral sclerosis (ALS), stroke resulting in aphasia, and brain stem impairment – each of which has differing AAC personnel needs.

AMYOTROPHIC LATERAL SCLEROSIS

Introduction

ALS is a rapidly degenerative neurological condition that attacks the nerve cells that control voluntary muscles. ALS type is diagnosed by the region of the onset of symptoms. There are generally two types: the bulbar type, which initially involves the cranial nerves, impacting speech and swallowing; and the spinal type, which initially involves the spinal nerves, impacting limb movement. Two recent reviews describe AAC intervention and decision making for persons with ALS (Ball, Beukelman, Anderson, Bilyeu, Robertson, & Pattee, 2007; Ball, Beukelman, & Bardach, 2007).

The AAC “magic” for people with ALS has improved considerably within the last decade, as precise, absolute head-tracking technology has provided options for persons with even the most limited head movement; and eye-tracking technology has become more accessible and dependable. Access to phone and Internet technology

has allowed individuals with ALS to continue to work; maintain their social networks; and participate from a distance in education, commerce, and employment (McNaughton, Light, & Groszyk, 2001); and the quality of speech synthesis has been improved considerably. AAC intervention is widely accepted among individuals with acquired complex communication needs due to ALS and likewise by their families and the personnel who assist them. When AAC intervention breakdowns or failures occur, they typically result from problems at a personnel level, where even a single person can have an impact on success (Ball, Beukelman, & Bardach, 2007).

AAC Finders and ALS

Ball, Beukelman, and Bardach (2007) described three phases of AAC need/intervention. Phase I (known as Monitor, Prepare, and Support) involves monitoring speech performance, preparing AAC decision makers, and supporting decision makers as they decide to move forward with an AAC assessment. Phase II (Assessment, Recommendations, and Implementation) includes AAC assessment, recommendation of AAC strategies, and implementation of these strategies. Phase III (Adapting and Accommodating) involves ongoing adaptation and accommodation of AAC strategies to meet the changing communication needs and capabilities of people with ALS as the disease progresses.

AAC finders play a particularly important role in the provision of AAC services to persons with ALS during Phase I of intervention. The degenerative course of ALS often requires a decision about AAC assessment and intervention while individuals with ALS continue to be able to effectively meet their communication needs through natural speech. Given the degenerative course of the disease, and the range of issues faced by persons with ALS and those close to them, it is tempting to not deal with AAC issues early in intervention in a timely fashion. However, it is important for finders to be aware of the importance of AAC for individuals with ALS. These finders need to know that 95% of people who continue to live with ALS will eventually lose the ability to meet their communication needs through natural speech. Of this group, nearly all (96%) accept AAC when it is provided in a timely manner and when they are prepared for AAC-related decisions (Ball, Beukelman, & Pattee, 2004). No differences in acceptance rate have been found for males versus females. This acceptance rate is considerably higher than it was 12 years ago (Guttman & Gryfe, 1996). In a recent report (Ball, Beukelman, Anderson et al.,

2007), 100% of individuals with ALS who accepted AAC technology used it until within a relatively brief period (a few days to a month) prior to their death. On average, persons with bulbar ALS use their AAC technology for 25 mos and those with spinal ALS use their systems for 31 mos (Ball, Anderson et al., 2007).

It is important, then, to begin discussions about AAC prior to the actual loss of functional speech, in order to ensure that individuals with ALS are able to realize the maximum benefits of the technology. It is essential to monitor the individual with ALS to predict the loss of functional speech. Speaking rate is the most effective metric to predict the loss of functional speech of persons with ALS; however, traditional clinical thinking tends to focus on speech intelligibility instead, despite the fact that the measures of speech intelligibility tend to be relatively ineffective in predicting loss of functional speech. Typically there is too little time between intelligibility reductions and the time when speech becomes inadequate to meet communication needs. Reliance on intelligibility (particularly *estimated* intelligibility) to assess individuals with ALS means that, by the time the initial AAC evaluation takes place, the individual is likely to have much more substantive complex communication needs. This can result in significant delays in the timing of recommendations, obtaining a prescription for the recommended technology, procuring the technology, and teaching individuals to develop operational competence. Ball, Beukelman, and Pattee (2002) evaluated the speech performance of 158 people with ALS at 3-month intervals from diagnosis to death. They recommended that individuals with ALS be referred for AAC assessment when their speaking rate is measured at 100 wpm to 125 wpm on the Speech Intelligibility Test (Sentence Version) (Yorkston, Beukelman, Hakel, & Dorsey, 1996; 2007) or when intelligibility is below 90%. For comparison, the mean speaking rate on the SIT for adults without disabilities is 190 wpm. In addition to monitoring performance, AAC finders also assume roles in supporting and preparing. AAC finders communicate with individuals with ALS and their decision makers about initiating an AAC assessment in a timely manner to give them sufficient time to become proficient users of the new technology. The finder also prepares them to move forward with an AAC assessment while their natural speech is still quite understandable. This is a rather unique decision-making strategy that is specific to ALS; usually, people seek medical or allied health interventions when their symptoms are obvious and result in significant impairments. By sharing their past experiences

working with people with ALS, AAC finders can help persons with ALS and their families to feel confident about their ability to master and benefit from this new form of communication.

AAC Intervention Specialists and ALS

AAC intervention specialists become particularly active during Phase II of the AAC intervention (Ball, Beukelman, & Bardach, 2007) when the key activities are to Assess, Recommend, and Implement AAC strategies. With assistance from the general practice clinician, the AAC specialist works with persons with ALS and their key decision makers to identify communication interaction and participation needs. Some individuals with ALS choose to focus their social networks on a relatively small group of family and friends who tend to meet in their home. Others choose to maintain a large social network and remain engaged in the community. In fact, some expand their social networks to include former colleagues, friends, other individuals with ALS, and their extended families.

As with determining participation needs, those involved in the AAC assessment and recommendation process should also consider decisions that the individual is making about medical care and support, such as artificial ventilation, that will extend the duration of life. Undoubtedly, these decisions will increase the length of time that the person with ALS will use AAC technology, while surviving with minimal movement capability (Ball, Beukelman, & Bardach, 2007).

During Phase III of the assessment the AAC specialist collaborates with general practice clinicians and support staff of people with ALS (Ball, Beukelman, & Bardach, 2007). This phase involves Adapting and Accommodating AAC options to the individual's changing lifestyle and needs. Activities include optimizing the use of the AAC device in locations where its use is preferred (e.g., moving about in a wheelchair, at the kitchen table, at an office desk, or in bed); and developing low-tech communication supports to meet needs for which high-tech options are not suitable (e.g., while in the bathroom, dressing, eating, and resting).

General Practice Clinicians and ALS

General practice clinicians often work with AAC specialists during assessment, recommendation, and prescription-obtaining activities. Importantly, these practitioners typically play key roles with respect to instructing persons with ALS, their AAC facilitators, and some of their communication partners. In addition, general practice

clinicians are active in adapting AAC options to meet an individual's changing physical and communication needs. In particular, they play an important role in supporting the development of multi-modality communication options that include low technology as well as high technology options. Of course, the type and level of support the general practice clinicians are able to provide varies, depending on the specialized services that are available in the particular geographic region. Generally speaking, the fewer the specialized services available, the greater the general practice clinician's role in implementing AAC services, instructing AAC facilitators, and providing follow-up services.

AAC Facilitators and ALS

AAC facilitators play a key role in supporting successful communication for individuals with ALS. Ball, Schardt, Kim, and Beukelman (2005) reported that, of 47 individuals with ALS, 100% had AAC facilitators who supported them. Of these facilitators, 96% were family members, friends, or caregivers; with only a few professional clinicians (4%) filling this role. Facilitators typically ensured that the AAC technology was maintained, fully charged, and properly programmed. In addition, they instructed communication partners and listeners who experienced difficulty with the technology and/or communication. When problems occurred, the facilitator usually contacted the relevant manufacturer or commercial company, the general practice clinician, or the AAC specialist for assistance. Facilitators in the Ball et al. study (2005) reported that they received, on average, 2.5 h of instruction in the technical operation of the AAC device, an amount which they said was adequate for their needs. In addition, many facilitators observed the instruction that the individual with ALS received from the AAC specialist, general clinician, or manufacturer's representative.

Individuals who communicate frequently with persons with complex communication needs typically learn unique communication strategies that are not utilized by the average listener. These include implementing a range of different high and low tech communication options as well as establishing reliable nonverbal signals, knowing how and when to provide appropriate options to resolve communication breakdowns, and assisting listeners who are unfamiliar with the individual's communication strategies. Communication partners are usually instructed in these strategies by the individual with ALS, the general practice clinician, or the AAC facilitator.

AAC Experts and ALS

AAC experts fill a number of different roles with regard to AAC for persons with ALS, including conducting research; preparing instructional materials such as webcasts, textbooks, and clinical books; and developing new technology. Some may also instruct AAC intervention specialists and general practice clinicians. Many AAC experts teach at universities, where they provide pre-professional preparation in AAC as it relates to a variety of populations and/or as it relates to individuals with ALS. They may also help shape and implement public policy; and, at times, may fill the dual role of AAC intervention specialist and AAC expert.

STROKE/CHRONIC APHASIA

Introduction

While people with ALS have relatively long and well-documented histories of AAC use to meet their communication needs, the story for those with severe chronic aphasia is quite different. Typically, the initial phase of communication intervention for persons with aphasia involves intensive efforts to restore communication effectiveness through interventions focused on reducing the language impairment. When it becomes apparent that unmet communication needs persist, AAC strategies are considered. The information about AAC support for individuals with aphasia is increasing and has been documented in a number of recent summary articles and chapters (Garrett & Lasker, 2005; King, Alarcon, & Rogers, 2007; Lasker, Garrett, & Fox, 2007). However, the general communication support of persons with severe chronic aphasia is of concern. Aphasia restoration intervention has received considerable attention for nearly 70 years; to date, however, AAC strategies have not been widely and/or consistently implemented with persons with severe chronic aphasia.

Aphasia intervention can be considered in two distinct phases: *restoration* and *compensation*. Restoration strategies are widely implemented to “restore” language functioning that became impaired at the time of the stroke. Many persons with aphasia do experience some restoration of language function. Some are able to meet their communication needs again through natural speech. Others experience some restoration, but remain limited in their ability to meet all of their communication needs via natural speech. Often, their social networks

shrink to include only their immediate family and a few close friends who are willing to continue to make the effort to communicate with them. Finally, the most severely limited persons with aphasia may experience minimal, if any, restoration of language function and must live with extensive unmet communication needs and very limited social networks.

In the United States, individuals who leave inpatient rehabilitation therapy with AAC support have usually been given a communication board or photo/symbol book designed to assist the medical and rehabilitation teams to address medical needs. Upon discharge from restorative intervention, most do not receive additional intervention unless they are connected with a long-term program at a university or an aphasia support program or project. Often the focus of such programs remains restorative, although at times the focus may be compensatory or a combination of the two.

AAC intervention for persons with aphasia is at quite a different stage than intervention for persons with ALS, where AAC is now considered to be accepted practice. Aphasia case reports describing low-technology interventions date back nearly 30 years and include use of communication and remnant books, drawing, photography, written words, messages, and written choice (Beukelman, Yorkston, & Dowden, 1985; Garrett & Huth, 2002; Garrett & Lasker, 2005; Hos, Weiss, Garrett, & Lloyd, 2005; Lyon, 1992, 1995; Lyon & Helm-Estabrooks, 1987). Reports of high-technology speech generating device (SGD) AAC interventions for individuals with severe chronic aphasia have also increased over recent years. However, most of these interventions focus on supporting specific communication tasks, such as answering the phone, calling for help, ordering in restaurants or stores, giving speeches, saying prayers, and engaging in scripted conversations (Garrett & Lasker, 2005). Lasker, Garrett, and Fox (2007) have summarized recent technology developments that are useful to persons with chronic aphasia.

During the past few years, a number of the commercial companies serving the AAC field have made it easier to incorporate personalized contextually relevant visual scenes (actual photographs) as well as iconic scenes into their technology. Discussion of the exact implementation strategies used is beyond the scope of this paper (see Beukelman, Fager, Ball, & Dietz, 2007); however, the use of images to reduce the cognitive and language load of persons with severe, chronic aphasia will be an important AAC theme in coming years.

AAC Finders and Aphasia

Typically, people with severe aphasia are rapidly transitioned out of the care of medical specialists in neurology or rehabilitation medicine unless they have ongoing health problems. In most cases they return to the medical care of their general practice physicians, physician's assistants, or nurses, who usually have little or no awareness of AAC. Speech-language pathologists, physical therapists, and occupational therapists who work with people with severe aphasia are also likely to be generalists with limited knowledge of AAC. Speech-language pathologists are commonly much more oriented to work on restorative rather than compensatory strategies. Family members probably are dealing with aphasia for the first time and they usually do not have much, if any, experience with AAC. As a result, individuals with severe aphasia are often not referred for AAC services. Our experiences suggest that, when individuals with severe aphasia are provided with AAC services, it is because of contact with an AAC finder who had personal knowledge of AAC specialists. As such, much remains to be done with regard to preparing and maintaining sufficient numbers of finders who themselves are familiar with AAC strategies for people with chronic aphasia.

Research by Lasker and Beukelman (1999) revealed that families of persons with aphasia have considerable reservations about AAC interventions, apparently because they are reluctant to shift way from the restoration goals that have been emphasized since onset. For successful AAC interventions to occur, the types of individuals described previously above are all essential, in addition to the individuals who rely on AAC and their communication partners. Anecdotally, we have observed family members who have been reluctant to focus on functional communication even after the person with aphasia is 3, 4, or even 5 years post-stroke. AAC finders must be introduced to current AAC strategies that have been shown to be useful for individuals with aphasia. In particular, they need to be aware of how various strategies are designed to meet communication needs, the reduced learning costs of visual scene (digital image) strategies, and the improved quality of synthesized and digitized voices (e.g., Beukelman, Garrett, & Yorkston, 2007; Beukelman, Hux, Weissling, Dietz, & McKelvey, 2006).

AAC Intervention Specialists and Aphasia

There are a growing but still limited number of AAC intervention specialists who are prepared to

support individuals with severe aphasia. Many AAC specialists are accustomed to serving individuals who have complex communication needs as a result of primary physical or developmental conditions, and so they are typically not confident in their ability to also serve people with aphasia. In our view, the next step is to prepare a cadre of AAC specialists in aphasia with whom generalists can consult as we have observed repeated efforts to instruct generalists to provide AAC services and have found that, without an AAC specialist to consult, limited effective AAC intervention occurs.

General Practice Clinicians and Aphasia

General practice clinicians often focus initially on restorative interventions for individuals with severe aphasia; however, as time passes and functional communication is not restored, there may be increased emphasis on compensatory interventions. A growing number of general practice clinicians, with the support of AAC specialists or experts, are implementing compensatory AAC interventions for those with chronic and severe language impairments.

AAC Facilitators and Aphasia

AAC facilitators for individuals with aphasia are essential. The operational demands of AAC technology often pose challenges for both facilitators and people with aphasia. In our current work with visual scene display technology, we have implemented some "just-in-time" content management features, such as "drag and drop" digital pictures, onscreen keyboards to enter text without saving, and hiding and revealing pictures and texts. These features allow for the creation of customized interfaces while at the same time eliminating the need for users to be knowledgeable about or proficient in program management. These types of features are important so that AAC facilitators with minimal AAC background can efficiently support individuals with aphasia who use AAC technologies. AAC facilitators also play a vital role in identifying and collecting content for AAC technology, communication books, remnant books, and other low technology AAC strategies.

In addition to providing low-and high-tech support to people with aphasia, AAC facilitators also support them through instruction, practice, and problem-solving assistance. They also provide technical support and serve as liaisons with AAC specialists and manufacturers.

Regular communication partners of persons with chronic aphasia play such essential roles in

successful communication exchanges that they could also be considered a type of AAC facilitator. These partners learn to co-construct messages by creating shared communication environments with pictures, remnants, drawings, or simply print (Lasker, Garrett, & Fox, 2007). They provide written choices (Garrett & Lasker, 2005) so that persons with aphasia can communicate using multiple-choice strategies. Once again, we know little about how communication partners are prepared for this role, and more research is needed to learn more about their educational needs and effective training strategies.

AAC Experts and Aphasia

AAC experts have a massive task ahead of them with regard to the development of new technologies for persons with aphasia; this must remain a priority. Of particular importance is the need to better understand how features of technology focused on restoration of impaired language compare to those of technology focused on compensation; an effective combination of restoration and compensation technologies might be a worthy goal for future research. As it now stands, decision-makers are often so committed to restoring an individual's speech/language that they have difficulty accepting functional communication approaches. Even when the person with aphasia is clearly interested in compensatory support, decision makers may still resist compensatory measures (Lasker, Garrett, & Fox, 2007). AAC experts need to learn how finders, restoration-oriented clinicians, and AAC specialists can prepare decision makers to accept AAC and integrate it into a multi-modal communication strategy. There is also a need for policy changes so that intervention services are not terminated when the restorative process plateaus, but rather services continue into the compensatory stage. Perhaps the most pressing issue for AAC experts in aphasia is to help the larger aphasia community understand that the overall intervention goal is to assist persons with aphasia to be functional communicators who can participate in ways that enhance their autonomy and maintain or even expand their social networks. For some individuals with aphasia, this will mean implementing interventions that will reduce their language impairment and thus allow increased communication effectiveness. Others will require compensatory support using a variety of communication modes that, in turn, support participation.

The aphasia community may benefit from considering the motor speech community as a model. Nearly 30 years ago, an expert in motor speech disorders confronted David Beukelman

with the following accusation: "If you insist on giving that man an AAC device he will never speak." Since that time, the motor-speech field has gradually adopted a multi-modal view, understanding that residual natural speech and AAC both contribute to communication interaction (Hustad & Weismer, 2007). We invite the aphasia community to also move to an intervention model that acknowledges the need to provide communication options for today, while assisting the individual to develop the capability to communicate even more effectively in the future.

BRAINSTEM IMPAIRMENT

Introduction

People with complex communication needs that are the result of severe brainstem impairment experience issues that are very different from persons with severe aphasia. Many individuals with brainstem stroke who often have relatively preserved language function but minimal or no motor ability to support mobility, self-care, or communication, and therefore they usually require long-term care in settings that do not have specialized AAC personnel.

Brainstem impairment occurs as a result of stroke, traumatic injury, or surgical treatment for cancer. The extent of the impairment ranges from moderate weakness to locked-in-syndrome, in which the individual is unable to move his or her body, with the exception of vertical eye movement. A recent review of AAC intervention strategies for persons with brainstem impairment has been provided by Culp, Beukelman, and Fager (2007). A review of this chapter, as well as a recent article by Fager, Beukelman, Jakobs, and Karantounis (2006), reveals that AAC "magic" for individuals with limited movement has improved in the last few years.

Historically, many individuals with brainstem impairment had to rely upon partner-dependent communication strategies that placed a heavy burden on their communication partners. For example, dependent scanning, requires a partner to provide communication options while the individual signals yes/no through eye movement. Eye pointing and eye linking have also been used with the partner co-constructing messages by interpreting eye movements. In the past, many people with severe brainstem impairment had to rely on electronic scanning in order to access AAC technology. Recently, head-tracking and eye-tracking technologies have improved considerably and, along with improved language modeling and synthesized speech output, have allowed

individuals with severe, chronic brainstem impairment to communicate more independently, access the world through the Internet, and reduce the demands on caregivers, communication partners, and others. These changes in the “magic” have also changed the roles of AAC personnel.

AAC Finders and Brainstem Impairment

Finders play a particularly critical role for people with brainstem stroke because these individuals often bypass the medical or rehabilitation settings where they might be likely to encounter AAC specialists. Due to the severity of physical impairment that often accompanies brainstem stroke, along with the limited prognosis for recovery, many transfer from acute hospitalization directly to long term settings (e.g., skilled nursing facilities, care homes). Some people with brainstem impairment may spend a brief time in active rehabilitation and then transfer to care facilities that are selected based on their level of care requirements (e.g., ventilator support, artificial nutrition) or based on proximity to family members. Fager, Beukelman, Jakobs, and Karantounis (2006) attempted to locate individuals with chronic, severe brainstem impairments as part of an ongoing research project and found that typically they had been placed in long term care facilities.

Many individuals with severe brainstem impairment must rely on dependent scanning and eye pointing strategies for communication. Long term care settings often have limited access to general practice clinicians trained in speech and language who can assist in these AAC interventions. Especially in remote locations, the availability of general practice clinicians may be sporadic at best. Not only is there a lack of general practice clinicians, there is also little to no availability of AAC specialists.

As such, it is AAC finders who have the greatest possibility of “discovering” these individuals and identifying the possibilities in terms of AAC interventions and where they can be procured. As AAC options for persons with brainstem impairments continue to increase, so too will the need for well-prepared finders able to identify service providers and initiate services. One possible model could be to utilize trained clinical liaisons who would (a) visit acute- and long-term care facilities to evaluate individuals for clinical rehabilitation and assistive technology services; (b) maintain direct connections with those at the facilities who serve as AAC finders (e.g., nurses, case managers, physicians, general clinicians, or family members); and (c) provide education regarding the types of specialized

services that might benefit persons with brainstem impairments. Keeping these liaisons up-to-date on current advances in AAC technology will help to increase the knowledge base of AAC finders.

General Practice Clinicians and Brainstem Impairment

Unique to this population (compared to ALS and aphasia) is not only the impact of well-prepared AAC finders, but also the impact of general practice clinicians. Our research has revealed that general practice clinicians who serve in long-term care settings often identify individuals with locked-in syndrome or severe physical impairment due to brainstem involvement. Many of these clinicians have commented that they had been “keeping their eye out” for new technology that might help these individuals. Given that general practice clinicians do not have ongoing access to support from AAC specialists, it is crucial that education about new technology options and services be directed toward them – especially since they may serve as the only link between new technology options and individuals in long-term care settings who have not been able to communicate for many years due to brainstem impairment.

Providing education for the general practice clinician is crucial. Some of the authors’ clinical sites feature multidisciplinary educational models that utilize AAC specialists to educate diverse audiences across the region and expand awareness of AAC possibilities and technological advances. General practice clinicians (e.g., speech-language pathologists, physical therapists, occupational therapists, nursing staff) are specifically targeted. The presentations are designed to inform participants about (a) continuing education requirements for many licensed professionals, (b) technological advances, and (c) how to access support to address the AAC and assistive technology needs of individuals with brainstem impairment.

AAC Intervention Specialists and Brainstem Impairment

Many viable high-tech AAC options are available today for individuals with severe impairments following brainstem stroke (e.g., eye-tracking and head-tracking technologies). The major challenge for AAC intervention specialists is to provide education and support to the AAC finders and general practice clinicians so that individuals with severe brainstem impairment can benefit from these AAC advances. As noted earlier, many individuals with severe brainstem stroke by-pass

acute rehabilitation care and transfer directly to long-term or skilled nursing facilities due to the severity of their deficits and poor prognosis for recovery of functional motor control (e.g., upper and lower extremity use for daily living activities). Once they become long term residents in these facilities, they may lose access to funding that could be used to purchase AAC devices. It is crucial for AAC specialists to intervene early in these cases to secure AAC technology that will support the individual's communication needs "today."

While some individuals with brainstem impairment do recover a degree of natural speech (Culp & Ladtkow, 1992), this often occurs only after many years and may not be sufficient to meet all daily communication needs. Early identification of communication needs by AAC finders and general practice clinicians, and early collaboration with AAC specialists, is essential for these individuals. Education of and collaboration with AAC finders and general practice clinicians today will benefit other individuals with brainstem impairments in the future. However, many individuals with brainstem impairment do not receive AAC services early in their recovery; the AAC specialist may only be contacted after many years. It is essential for AAC specialists to collaborate with general practice clinicians and AAC finders, making themselves available to help at any stage of recovery and at any level of care. This ongoing, close relationship with general practice clinicians and AAC finders also serves as a mechanism to provide education on advances in AAC technology that may benefit other individuals with brainstem impairment in the future.

AAC Facilitators and Brainstem Impairment

AAC facilitators also fulfill a crucial role for those with severe brainstem stroke (particularly when they are moved quickly to skilled nursing environments), because facilitators are often the ones with direct access to skilled nursing staff. Thus, they can help to train new staff and advocate for persons with brainstem impairments. This would be especially beneficial in facilities with high staff turnover rates (which is common in long-term care settings). While a general practice clinician may be able to provide some level of education and support over the long term, because the condition of the person with brainstem impairment is typically chronic and does not change significantly over time. However, the involvement of general practice clinicians may be limited to yearly screenings or therapeutic interventions only when obvious changes in condition have been noted.

Given the limited availability of general practice clinicians – particularly in remote locations – it is vital that AAC facilitators be incorporated into the intervention process early. As previously noted, individual facilitators (or groups of facilitators) can come from a variety of sources, depending on level of care required, availability of personnel, etc. In some cases, family members may not be able to act as facilitators because they may live a great distance away from the facility. In some cases, facilitator roles are filled by volunteers from the community, as well as staff whose schedules allow them to be actively involved in AAC education and monitoring (e.g., a departmental assistant, a rehabilitation nursing aide, or a case manager). Creativity in identifying key AAC facilitators is needed, as they can come from unexpected places.

AAC Experts and Brainstem Impairment

AAC experts are charged not only with developing new technologies that benefit persons with severe brainstem impairment, but also with disseminating this information outside of the AAC specialist community in order to reach AAC finders, general practice clinicians, and AAC facilitators. Particular attention needs to be given to supporting these individuals over time given the long term, chronic needs of persons with brainstem impairment and give the fact that their AAC facilitators are often not general practice clinicians or AAC specialists. In this, it will be important to develop technologies and training materials that are easy to access and are similar to standard computer applications that are already familiar to the general public will be essential. Online and telephone technical support also must accompany technological advances, in order to allow AAC facilitators and general practice clinicians to successfully troubleshoot when needed.

LOOKING TOWARD THE FUTURE

People with complex communication needs are found in all age groups and in all geographic locations, and they have a wide range of developmental and acquired conditions. Through the years, AAC intervention strategies and technologies have improved considerably, and funding support for technology as well as AAC services continues to expand internationally. Consequently, there is an extensive need for a range of personnel to support those who rely on AAC.

In emerging fields such as AAC, an initial focus on the preparation of specialists and experts is quite common; over time, however, it becomes important to support the dissemination of expertise throughout the multiple levels of general intervention practice. Since 1990, the number of pre-professional programs in colleges and universities designed to prepare AAC-related personnel has increased considerably. Ratcliff, Koul, and Lloyd (2008) conducted a 2006 survey of 290 individuals associated with speech-language pathology pre-professional preparation programs across the United States. They reported the following: Of the 168 surveys that were returned, 68% of the respondents reported that the AAC courses they took were taught via on-site lectures with or without Internet-based supplemental information; 11% said AAC coursework was offered via the web; 52% indicated that an AAC course was required, 48% indicated that courses were electives; and 80% reported that AAC content had been fused into other courses. Costigan and Light (2007) reviewed preservice training in AAC for special education teachers and occupational therapists as well as speech-language pathologists. They reported that the limited research that had been conducted revealed few opportunities for preservice training for special education teachers and occupational therapists. Personnel preparation in AAC is increasing internationally; however, there is still limited information on the roles universities and colleges world wide are playing in training individuals to provide AAC services for adults with acquired complex communication needs. There is a continuing need for university pre-professional programs to provide all students who are preparing for general practice to receive sufficient instruction in AAC.

The availability of print material for AAC personnel preparation has also expanded considerably over the past two decades. In 2008, there are a variety of AAC and assistive technology textbook choices to support the preparation of AAC specialists, experts, and generalists. In addition, there are individual books and book series targeted for AAC specialists and experts; however, print or Internet materials for AAC finders remain extremely limited.

A review of the literature reveals little information about preparing AAC finders to support persons with acquired complex communication needs. Such instruction may be offered informally, in medical and allied health personnel preparation programs. We are also aware of ongoing in-service and staff development workshops occurring at several centers. Gradually, websites, webcasts, and Internet video presentations are being developed to

provide information to the public and to AAC finders; however, this information does not appear to be strategically prepared or presented. There is a pressing need for research to investigate the effectiveness of various types of strategies to prepare AAC finders to fulfill their role and to maintain a level of currency.

This article has documented the critical roles of AAC facilitators. At this point in time, facilitators tend to receive training and education from AAC intervention specialists, general practice clinicians, and AAC manufacturers. Although facilitators may access the manuals, help screens, and onboard video instruction that are available for some AAC devices, these focus primarily on how the devices operate. There is a need for research and development that will assist the AAC field to identify effective methods for preparing AAC facilitators for the range of essential roles that they fulfill.

So, how does the information presented in the current article influence goals for the field of AAC? In order to continue to create "magic" with persons who rely on AAC, we suggest structuring future instructional endeavors to target specific needs at each level of the personnel framework to include AAC finders, general practice clinicians, AAC facilitators, AAC intervention specialists, and AAC experts. Doing so will help to ensure that individuals with acquired complex communication needs receive the support they need to communicate.

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References

- Ball, L., Beukelman, D., & Bardach, L. (2007). AAC Intervention for ALS. In D. Beukelman, K. Garrett, & K. Yorkston (Eds), *Augmentative communication strategies for adults with acute or chronic medical conditions* (pp. 287–316). Baltimore, MD: Paul H. Brookes Publishing Co.

- Ball, L., Beukelman, D., & Pattee, G. (2002). Timing of speech deterioration in people with amyotrophic lateral sclerosis. *Journal of Medical Speech Language Pathology, 10*, 231–235.
- Ball, L., Beukelman, D., & Pattee, G. (2004). Acceptance of augmentative and alternative communication technology by persons with amyotrophic lateral sclerosis. *Augmentative and Alternative Communication, 20*, 113–123.
- Ball, L., Beukelman, D., Anderson, E., Bilyeu, D., Robertson, J., & Pattee, G. (2007). Duration of AAC technology use by persons with ALS. *Journal of Medical Speech Language Pathology, 15*, 371–381.
- Ball, L., Schardt, Kim, & Beukelman, D., (2005). Primary communication facilitators. *Augmentative Communication News, 6–7*.
- Beukelman, D. (1991). The magic and the cost of communicative competence. *AAC: Augmentative and Alternative Communication, 7*, 1–15.
- Beukelman, D., Fager, S., Ball, L., & Dietz, A. (2007). AAC for adults with acquired neurological conditions: A review. *Augmentative and Alternative Communication, 23*, 230–242.
- Beukelman, D., Garrett, K., & Yorkston, K. (2007). *Augmentative communication strategies for adults with acute or chronic medical conditions*. Baltimore, MD: Paul H. Brookes Publishing Co.
- Beukelman, D., Hux, K., Weissling, K., Dietz, A., & McKelvey, M. (2006). *AAC for Aphasia: A Review of Visual Scenes Display Project*. Retrieved 3 April 2008 from: <http://mcn.ed.psu.edu/dbm/Aphasia/index.htm>
- Beukelman, D., & Wallace, S. (2007). Preparing pre-professional students in evidence influenced decision-making. *Perspectives on Augmentative and Alternative Communication, 16*, 20–23.
- Beukelman, D., Yorkston, K., & Dowden, P. (1985). *Communication augmentation: A casebook of clinical management*. Austin, TX: Pro-ed.
- Costigan, F., & Light, J. (2007). Preservice training for AAC team members. *ASHA 2007: Session Guide*. 158.
- Culp, D., Beukelman, D., & Fager, S. (2007). Brainstem impairment. In D. Beukelman, K. Garrett, & K. Yorkston (Eds.), *Augmentative communication strategies for adults with acute or chronic medical conditions* (pp. 59–90). Baltimore, MD: Paul H. Brookes Publishing Co.
- Culp, D., & Ladtkow, M. (1992). Locked-in-syndrome. In K. Yorkston (Ed.), *Augmentative communication in the medical setting* (pp. 59–138). San Antonio, TX: Psychological Corporation.
- Fager, S., Beukelman, D., Jakobs, T., & Karantounis, R. (2006). Use of safe-laser access technology to train head movement in persons with locked-in syndrome: A series of case reports. *Augmentative and Alternative Communication, 22*, 222–229.
- Garrett, K., & Huth, C. (2002). The impact of graphic contextual information and instruction on the conversational behaviors of a person with severe aphasia. *Aphasiology, 16*, 523–536.
- Garrett, K., & Lasker, J. (2005). Adults with severe aphasia. In D. Beukelman, & P. Mirenda (Eds.), *Augmentative and alternative communication: Supporting children and adults with complex communication needs* (pp. 467–504). Baltimore, MD: Paul H. Brookes Publishing Co.
- Gutman, M. & Gryfe, P. (1996). The communication continuum in ALS: Client preferences and communication competence. *Proceedings of the seventh beinnial conference of the International Society of Augmentative and Alternative Communication (ISAAC, Vancouver)*.
- Hos, K., Weiss, S., Garrett, K., & Lloyd, L. (2005). The effect of remnant and pictographic books on the communicative interaction of individuals with global aphasia. *Augmentative and Alternative Communication, 21*, 218–232.
- Hustad, K., & Weismer, G. (2007). A continuum of interventions for individuals with dysarthria. In G. Weismer (Ed.), *Motor speech disorders* (pp. 261–303). San Diego, CA: Plural Publishing.
- King, J., Alarcon, N., & Rogers, M. (2007). Primary progressive aphasia. In D. Beukelman, K. Garrett, & K. Yorkston (Eds.), *Augmentative communication strategies for adults with acute or chronic medical conditions* (pp. 206–242). Baltimore, MD: Paul H. Brookes Publishing Co.
- Lasker, J., & Beukelman, D. R. (1999). Peers' perceptions of storytelling by an adult with aphasia. *Aphasiology, 13*(9–11), 857–869.
- Lasker, J., Garrett, K., & Fox, L. (2007). Severe aphasia. In D. Beukelman & P. Mirenda (Eds.), *Augmentative and alternative communication: Supporting children and adults with complex communication needs* (pp. 163–206). Baltimore, MD: Paul H. Brookes Publishing Co.
- Lyon, J. (1992). Communication use and participation in life for adults with aphasia in natural settings: The scope of the problem. *American Journal of Speech-Language Pathology, 1*, 7–14.
- Lyon, J. (1995). Drawing: Its value as a communication aid for adults with aphasia. *Aphasiology, 9*, 33–94.
- Lyon, J., & Helm-Estabrooks, N. (1987). Drawing: Its communicative significance for expressively restricted aphasic adults. *Topics in Language Disorders, 8*, 61–71.
- McNaughton, D., Light, J., & Groszyk, L. (2001). "Don't give up": Employment experiences of individuals with amyotrophic lateral sclerosis who use augmentative and alternative communication. *Augmentative and Alternative Communication, 17*, 179–195.
- O'Keefe, B., Kozak, N., & Shuller, R. (2007). Research priorities in augmentative and alternative communication as identified by people who use AAC and their facilitators. *Augmentative and Alternative Communication, 23*, 89–96.
- Ratcliff, A., Koul, R., & Lloyd, L. (2008). Preparation in AAC: An update for speech-language pathology training. *American Journal of Speech Language Pathology, 14*, 222–227.
- Yorkston, K., Beukelman, D., Hakel, M., & Dorsey, M. (1996). *An AAC Personnel Framework: Adults with Acquired Complex Communication Needs Sentence Intelligibility Test*. Lincoln, NE: Madonna Rehabilitation Hospital.
- Yorkston, K., Beukelman, D., Hakel, M., & Dorsey, M. (2007). *Speech Intelligibility Test*. Lincoln, NE: Madonna Rehabilitation Hospital.
- Yorkston, K., Miller, R., & Strand, E. (2004). *Management of speech and swallowing in degenerative diseases* (2nd ed.). Austin, TX: PRO-ED.