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## “Reach for the Stars”: Five Principles for the Next 25 Years of AAC

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### ABSTRACT

Basing our work on the published writings of individuals who use augmentative and alternative communication (AAC) and their family members, we offer five principles to guide AAC assessment, intervention, research, and development: (a) The time for AAC is now; (b) One is never enough; (c) My AAC must fit my life; (d) AAC must support full participation in all aspects of 21st century life; and (e) Nothing about me without me. These five principles are individually important, but also interconnected, and are meant to provide clear goals for the field of AAC as we work towards the achievement of communication and participation for all.

**Keywords:** Augmentative and Alternative Communication, Assistive Technology, Advocacy, System Change

As a young man in the 1960s, Michael B. Williams worked as a news copywriter at a radio station in California. Michael has cerebral palsy, and because speech was difficult, he limited his interactions with others. In “How Far We’ve Come, How Far We’ve Got to Go: Tales from the Trenches” (M.B. Williams, 2005), Michael described his communication system at the time:

I drew the letters of each word in the air with my finger, while my would-be linguistic interlocutor winked, blinked and performed all manner of mental gyrations trying to figure out what the hell I was saying. My really, really important thoughts were typed on my standard manual typewriter at home, carried to the place of conversation and presented to my listeners with the gravest solemnity, as if they were the Ten Commandments. Needless to say,

with communication methods such as these, one has few friends.

In the 1960s there were no speech-generating devices (SGDs), no portable computers, in fact there was very little awareness of any alternatives to speech. Michael described his experience with his first low tech AAC system, introduced by a work colleague, Art.

I am in my mid-twenties during the time this story takes place. And to my twenty-something eyes, Art looks ancient, about fifty. I notice another thing about him. He’s a post-polio guy with long leg braces who drags himself around on a pair of Canadian crutches. Art and I often have short conversations with each other. He can decipher my air writing pretty well, but he always walks away after a few interchanges. One day, he comes in and throws something at me. “Here, try this,” he says in an irritated voice. I look at what’s on the table beside me. “A checkbook cover? Why is this old fool giving me a checkbook cover?” I wonder to myself. Art deigns to endure my blank stare a few milliseconds. Then he comes over to the table, grabs up the object in question, opens it and slams it back down in front of my face. “The next time you talk to me,” he snarls, “use this!” Then he calmly walks away. By this time, my heart is pumping harder and faster than a Thompson submachine gun in full cry. “Damn,” I said to myself, “what have I done to deserve this?” Slowly, I pull myself together and look at what’s on the table. Yep, it’s a checkbook cover all right. But instead

of the usual check pad and register inside, I find the letters of the alphabet neatly pasted in rows. Now, some of you older moviegoers will remember that long opening sequence of Stanley Kubrick's *2001* when the apes discover the concept of tools and their ability to make them. This is exactly how I felt looking at that rudimentary letterboard. Holy Batman, you mean I could use this instead of air writing?

Michael's limited access to alternatives to speech and his first experience with a "formal" AAC system in the 1960s closely parallels the experiences of many individuals with complex communication needs today. Individuals with complex communication needs often have limited information and limited access to AAC options, and are restricted in their communication partners and communication opportunities, because they do not receive the technology and supports needed to participate. While the checkbook certainly was an improvement over air-writing, it did not support full participation in life in the 1960s – for example, Michael could not interact with groups of people or use the telephone. Finally, while Art had thoughtfully developed a system that helped Michael communicate in specific situations, failing to include the individual with complex communication needs in the identification of the communication goals and development of the communication system, and introducing a system with a command to "use this!" may not always lead to such positive results!

In writing this paper, we examined much of the past 25 years of published writing about AAC by individuals who use AAC and their family members. We reviewed books, conference proceedings, and articles. Happily, today more information about AAC written by individuals who use AAC is available than was 25 years ago. Sadly, there are still large numbers of individuals with complex communication needs who do not have access to AAC technologies or services, and whose voices are not part of this review.

In considering what individuals who use AAC have written about AAC over the past 25 years, we identified central themes – presented as five principles – that we believe will be individual and societal challenges for the next 25 years:

1. The time for AAC is now: The right to communicate is a basic human freedom.
2. One is never enough: Individuals with complex communication needs require more than one device, one communication partner, one communication strategy, one communication environment.
3. My AAC must fit my life: AAC systems must be highly individualized and appropriate to individual needs.
4. AAC must support FULL participation in ALL aspects of 21st century life: AAC must support a wide variety of interactions across all ages and interests.
5. Nothing about me without me: Individuals who use AAC have a right to be meaningfully involved in every aspect of AAC research, development, and intervention.

We discuss these principles below, and provide illustrations for each, drawn from the published writings of individuals who use AAC.

#### **The time for AAC is now**

##### *The Right to Communicate is a Basic Human Freedom*

If I could not express myself clearly and accurately, I could not tell my physician and others how I feel or describe the health problems I may be having. Similarly, I could not let others know what I know or what I am capable of learning. Nor could I go to work or vote. Furthermore, if I could not express myself, I would become like the tree in the forest – the one for which it does not matter if it makes a sound when it comes crashing down, because there is no one around to hear it. Unfortunately, there are still a great many silent fallen trees all around us if we stop and look (B. Williams, 2000, p. 250).

Individuals who use AAC have spoken clearly to the importance of communication in supporting participation in the community, school, work, and personal relationships. As Jim Prentice (2000) wrote:

Augmentative and alternative communication can provide a person with the ability to have and develop strong and rewarding relationships with others. Deny a person the ability to articulate intelligibly, and that person is sentenced to live in social, intellectual, and emotional isolation (p. 213).

There is also compelling evidence of the close connection between access to communication and intellectual development (Hart & Risley, 1995) and self-determination (Wehmeyer, 2005). Clearly, the right to communicate is both the “essence of human life” (Light, 1997, p. 61), and a basic human freedom.

The past 25 years have brought an increasing recognition of the importance of early intervention with AAC, the development of technologies that more individuals with complex communication needs find useable and effective, and the promotion of a multi-modal approach to communication. While some have benefited from increased access to AAC technology and services, significant segments of the population are still excluded from even basic services and may have no idea AAC treatment options exist. As one parent of a child with complex communication needs commented, in describing his experiences with his 6-year-old child: “Unfortunately, even though my child was making NO progress at verbal speech, an AAC option was NEVER mentioned by the school or any professionals” (McNaughton, Rackensperger, Benedek-Wood, Krezman, Williams, & Light, 2008, p. 6).

Very young individuals and individuals with intellectual challenges are often denied access to AAC technology and services because of misdated beliefs about the need for the demonstration of “readiness skills” (Mirenda, 1993). As Gus Estrella (2000) has so logically written:

Some speech pathologists have, in my experience, some odd expectations. The first and perhaps the most poisonous is that we have to master and demonstrate the mastery of certain language concepts before we're allowed to try communication aids with the kind of power that might help us really talk. Umm, how can I master a language if I can't talk with my own voice, and you

won't give me a communication aid? (p. 38). Even when technology is provided, the services needed to support effective use are often unavailable. As one parent described her son's experiences (McNaughton et al., 2008): When my son went to school so many opportunities were missed ... The teachers knew nothing of the AAC, and wanted to know nothing. There is no acceptable reason that he was not expected, encouraged, or allowed to use the device in school. So many missed opportunities (p. 49).

As individuals who advocate for AAC services for individuals with complex communication needs, we believe there should be no waiting for speech to develop, return, or become completely unintelligible. There should be no waiting for readiness for AAC strategies or tools, and no waiting for speech training to fail. As a society, we need to commit to the goal that there should be NO waiting for funding, appropriate services, provision of technology, or technology repairs.

While we have evidence of the life-changing benefits of AAC for a wide range of individuals (Beukelman & Mirenda, 2005), there is a continuing need for research that will effectively document the positive impacts of AAC interventions for individuals who traditionally have been excluded from consideration for AAC services. There is a need to educate service providers and educational systems, in many countries and in many languages, on effective strategies for providing AAC services for individuals who may present special challenges, but who are in need of AAC interventions (Alant, 1999; Granlund, Björck-Åkesson, Brodin, & Olsson, 1995; Hamm & Mirenda, 2006; Patel & Khamis-Dakwar, 2005). Perhaps most important of all, there is a need for public advocacy by everyone with an interest in AAC to clearly communicate to service providers and funding agencies that the time for AAC is NOW.

### **One is never enough**

*Individuals with Complex Communication Needs Require More than One Device, One Communication Partner, One Communication Strategy, One Communication Environment*

“I use the Liberator, Lightwriter, and letterboard everyday at various times during the day. Why do I need three devices? Isn't one sufficient? In a word, no” (M. B. Williams, 2004, p. 6).

In a paper entitled, “Confessions of a Multi-Modal Man,” Michael B. Williams described the communication devices he uses throughout the day. In addition to these technologies, he uses speech, signs, gestures, air-writing, body language, facial expressions, “growls”, and laughter to communicate with familiar and unfamiliar partners in a wide range of situations. No one approach could appropriately support communication with a loved one in a quiet restaurant, a curious 7-year-old stranger in a coffee shop, and a potential employer in a job interview. AAC should not be thought of as an attempt to create some minimal approximation of speech – it is a collection of techniques and strategies meant to support participation in a wide range of communication activities in a wide range of social and physical environments, each with its own unique challenges and demands.

In the early years of AAC, individuals were often expected to rely on one AAC technique, which may have only been understood by one communication partner, and may have been effective in a single, quiet, well-lit environment. There were limited expectations for the range of social and physical environments in which an individual with complex communication needs would participate. Today, there are increased expectations for participation in a range of communication environments with a wide range of communication partners. It has become increasingly clear that having only one communication technique, or one communication partner who understands the technique, or one environment in which the AAC system can be used, is never enough.

The challenge of providing access and support for an appropriate range of AAC techniques and strategies should not be underestimated. For example, Beukelman (1991) reported that in order to support the participation of a young child with complex communication needs in an inclusive educational environment, 16 teachers and educational personnel needed to learn how to program and support the child's use of an AAC device over a 5-year period. As adults living independently, some individuals who use AAC estimate that they have been responsible for

hiring and training over 50 personal care attendants over a 25-year period (Johnson, 2000). As participants in society, individuals who use AAC have the legitimate expectation that AAC technology will support communication with familiar partners and strangers, and enable participation in a range of educational, social, and employment activities.

Ensuring societal acceptance of the importance of multiple communication modes is often a hard-fought battle. Some individuals experience societal rejection of their preferred mode of communication, and feel pressure to use a particular approach. As Joyce (2005, p. 91) commented, “I know my speech is understandable to some people if they take the time to listen. But the fact is, most people don't take the time and don't know how to listen.” Seals (2005) described the reaction of her teachers to her new speech-generating device:

Not everyone at my special school liked my new talker—especially the teachers! During one lesson, the teacher took my talker off my chair. The classroom assistant put it back. They argued, moving the talker up and down like a yo-yo, until the classroom assistant got her way. I found this battle of wills amusing at the time, but thinking back on it, that teacher was trying to take away my voice (p.73).

Other individuals have described the unwillingness of service providers and teachers to learn the skills needed to be competent communication partners and to support an individual in learning a new communication strategy. As the parent of a child who used sign language described her situation (McNaughton et al., 2008):

Unfortunately, no one helped him [son] learn signs but me, and he had little support in this until about sixth grade, when they hired a classroom aide that knew sign language. To have AAC not be integrated into a child's life until middle school is sad and [makes it] very difficult for them to adjust (p. 49).

Without appropriate supports and a wide range of communication partners, a child with complex communication needs may have an opportunity

to communicate with only a very small number of adults, providing minimal opportunities for peer interaction and the development of communication and interaction skills (Simpson, Beukelman, & Sharpe, 2000), limiting the possibility (or right) to a rich social life as the child grows into a teenager and adult.

The development of a rich and dynamic collection of AAC strategies and technologies has many benefits. First, access to a variety of communication techniques helps to ensure that an individual can have access to an appropriate tool for a desired goal: We need AAC techniques to support delivering a lecture in a high school social studies class and to communicate raucous joy at a sporting event; to send an emergency message when a bus is delayed; and to share the good news when a job is obtained.

Access to multiple techniques also helps create redundancy in case any one technique fails. Bob Williams, in his work as deputy assistant secretary of the Department of Health and Human Services, famously kept two high-tech communication devices available so that there was always a quick back-up available. At a minimum, there should be a low-tech back-up to the high-tech system, and preferably, as has been suggested, a “back-up to the back-up to the back-up” (McNaughton, Light, & Gulla, 2003, p. 249).

Future research should document the communicative richness of the AAC systems and strategies used by individuals who have experienced with a variety of AAC techniques to make clear that no simple count of the use of a single communication device can be treated as a measure of communicative competence. Education and training activities should include helping individuals who use AAC to learn how to make decisions about the effectiveness of particular AAC strategies and technologies in particular situations (e.g., When would it make sense to use brief telegraphic messages? When would it be more appropriate to use complete sentences?), as well as training professionals and family members in how to provide appropriate support and intervention for a wide variety of modes, technologies, and strategies. Perhaps most importantly, individuals who use AAC and individuals who care about them need to advocate for a wide range of needed changes in public policy. At present, funding agencies for

AAC often dictate that an individual may only have one speech generating device (SGD), that an SGD can only be used for a limited range of communication activities, and that only minimal training for the individuals and communication partners shall be provided. As Dickerson (1995) has suggested, we must “celebrate diversity” (p. 27) in human performance and provide the supports needed for individuals to learn and use a wide range of communication techniques with a wide variety of partners.

### **My AAC must fit my life**

#### *AAC Systems Must Be Highly Individualized and Appropriate to Individual Needs*

Imagine sitting in a nice fancy restaurant. The waiter comes to take your order. You order a juicy steak, medium rare. After 30 minutes the waiter returns with a fully fluffy salad. You confront the waiter stating that you ordered a steak not a salad. The waiter responds back that a survey was given to 1,000 brother in-laws of people with disabilities and the results were that people with disabilities need to eat salad, so ... Adults with disabilities have experienced this situation all of their lives from make and model of wheelchairs to one's augmentative communication devices (Watson, 1999, p. 36).

When AAC technologies were first being developed, the choices were few and sharply constrained by the technology available at the time. Rick Creech (2004) described learning to use one of the first AAC devices:

It was about the size of a large shoebox, weighing six to eight pounds. It was operated with a numeric keyboard. It had over nine hundred words, some sentences and phrases, and forty-five phonemes, pre-programmed into the thing. Each word, or sentence, or phrase, or phoneme was stored and accessed by a three digit code, for example, “hello”, was 010. For me to say, “Hello, my name is Rick,” it took six of those three digit codes. It took only six because, “my name is”, was a pre-programmed phrase, requiring only

one code. However, “Rick” was not a pre-programmed word. It took three codes to say “Rick”—that was nine numbers. Now if you think that’s bad, let’s go for the simple sentence, “Hello, this is Rick Creech speaking.” This would have taken fifteen, three-digit codes, for a total of forty-five numbers.

During the past 25 years, an explosion of technical development has resulted in many benefits for individuals who use AAC technologies. Current AAC technology has supported improved outcomes for individuals with complex communication needs in the community (Dattilo et al., 2007), school (Hunt, Soto, Maier, Müller, & Goetz, 2002; Luciani, Horochack, & McNaughton, 2007), employment (McNaughton & Bryen, 2002, 2007), and personal relationships (M.B. Williams, 2004). Access to communication is fundamental to the expression of self-determination and the exploration of options for a full and rich life.

In spite of this progress, much work still remains to be done in developing AAC systems that better fit the lives of individuals who use AAC, who have clearly communicated that “AAC must fit my life,” in terms of both ease of use and learning. More attention must also be given to factors that determine the appeal of the device. Children typically want devices that look fun and interactive, while adults want devices appropriate for their academic, employment, and social environments (Light, Drager, & Nemser, 2004).

AAC techniques must be made easier to use, because the physical operation of AAC technology continues to present significant barriers. For individuals who are not able to make use of direct selection, alternate access methods are frustratingly slow. A parent of a child with severe physical disabilities described her son’s use of a scanning system (McNaughton et al., 2008), saying,

The scanning was accomplished by a head switch, and was about as slow as chiseling on stone with a toothpick. This problem was further complicated by the computer’s hard drive crashing about once a week. Needless to say, desire to communicate plummeted (p. 50).

Individuals who use AAC technology are often severely limited in the positions in which they can access the device. As Rick Creech, an expert and fluent user of AAC technology wrote, “My use of my Pathfinder1 is limited to when I am in this chair. Put me in another chair, and I am muted. Lay me in bed, and I am muted” (Creech, 2004).

Even when an AAC system is accessible, a slow rate of participation can have a damaging effect on the interaction. Bauby (1997) described his use of an eye-gaze alphabet system after a stroke resulted in near-complete paralysis:

My communication system disqualifies repartee: the keenest rapier grows dull and falls flat when it takes several minutes to thrust it home. By the time you strike, even you no longer understand what had seemed so witty before you started to dictate it, letter by letter. So the rule is to avoid impulsive sallies. It deprives conversation of its sparkle, all those gems you bat back and forth like a ball—and I count this forced lack of humor one of the great drawbacks of my condition (p. 73).

AAC devices must be made easier to learn. Many of the current approaches place significant learning demands for device operation on young children at a time when we are also hoping that they can be directing their attention to the interaction itself (Light, Drager, McCarthy, et al., 2004). Even adolescents and young adults report the need for up to 2 years of organized study to become fluent in the operation of a device (Rackensperger, McNaughton, Krezman, Williams, & D’Silva, 2005). We need AAC technologies that provide built-in supports for learning and participation across the life span. These supports should be seamless and confidential: Adults who use AAC must already deal with low societal expectations, so their devices should clearly meet current adult expectations for technology and not make adults appear to be involved in a training activity or children’s game.

Finally, AAC devices must also fit the personality of the individual who uses the device. For young children, devices should contain characteristics and features that would make them desirable to peers in play activities

(Light, Drager, & Nemser, 2004). For adolescents, AAC devices should be durable and useable on a sunny day outside or at a noisy rock concert with minimal lighting (Smith, 2005), and expressive of the adolescent's individual style. For adults, AAC devices should be easy to learn for the large number of communication partners who may interact with the individual. Ideally, how to communicate with an individual who uses AAC becomes nearly transparent: simple, direct, and obvious. For all individuals, AAC devices must protect privacy and carefully distinguish between what information is and is not to be shared with others.

There have been enormous positive changes in AAC technology since the early large, slow devices described by Creech (2004); however AAC systems still remain "far too complex, stigmatizing, and costly" (M.B. Williams, 2000, p.6). AAC researchers and device manufacturers must become better attuned to the needs of individuals who use AAC and their families and caregivers. This has the potential to benefit both consumers and manufacturers. Although an estimated 11,000 AAC devices are sold each year in the United States, only 2–3% of all individuals with complex communication needs have access to needed technology and services (Assistive Technology Law Center, 2006). Continued research, education, and advocacy work is necessary to ensure that all individuals in need have access to appropriate technology and support.

### **AAC must support full participation in all aspects of 21st century life**

#### *AAC Must Support a Wide Variety of Interactions Across All Ages and Interests*

A week before the start of school, my family and I met with the principal and the school nurse. They looked me up and down real good, and the principal asked: "Michael, do you REALLY want to go to this school?" The air was tense; we were locked on to each other's eyes. "Yes, Sir," I said in my firmest, clearest voice. To make myself perfectly understood, I nodded my head up and down (M.B. Williams, 1998, p. 2).

When Michael Williams sought to become the first individual with severe disabilities to attend

John Muir High School in Pasadena, he had evidence of his academic achievements, the encouragement of his teacher and parents, and a community that was re-evaluating their values during the economic and social change that led to the 1960s; however, he did not have an AAC system that let him demonstrate his intellectual ability, or effectively advocate for an equal educational opportunity. Michael was dependent on the good will of the school administrators and the recommendations of others in his fight for an education; in the end, the principal approved a "trial period." Although Michael was very successful as a student, his high school education, and, in fact, his pursuit of post-secondary education, was dependent on his refusal to be ignored and his confidence to go where he was not wanted even though he was not able to fully communicate his ambitions, explain his reasons, or verbally advocate for his goals. With a few words of speech, gestures, and countless pages of typed notes to supplement his air writing, Michael was able to obtain an education and graduate from high school, but no one would claim this was full participation in high school life. Full participation is unobtainable whenever communication with unfamiliar partners is restricted.

Due to the individual activism of many people who use AAC and their family members and to changes in government legislation and public policy, there are now more opportunities for individuals who use AAC to participate in a wide range of community, academic, and employment opportunities and to fulfill a wide range of adult roles. In many countries, laws protect the rights of individuals with disabilities to obtain a free and appropriate public education, appropriate housing, and a barrier-free workplace. A meaningful education, satisfying employment, a home in the community, and adult relationships are all attainable goals; however, these goals require skillful use of AAC systems that support full participation in all age-appropriate activities at all stages of life.

Robin Hurd (2005), the parent of two children who use AAC, has written that children who use AAC must have the ability to form and express their own opinions if we expect them to be independent, self-determined adults. As children grow up, we must ensure that they have access not only to the things that we want them to say, but also the wide range of vocabulary typically



used by children as they negotiate adolescence, regardless of an adult's view of the appropriateness of this vocabulary (Smith, 2005).

Many young adults who use AAC are looking to the day when they will live independently, and are acquiring the communication skills that will help them learn to plan and manage their personal care. Rick Creech (1992) wrote:

Another factor in my decision to attend and graduate from college was my fear of dependency. I am not sure that my parents knew about this. I never said, "Hey folks, I know that you aren't going to be able to take care of me forever, and I don't want to get stuck in nursing homes with a bunch of old people; therefore, I have to find a way of living my life without you." I accept that I am dependent on others. However, I had to create a situation in which I decide how much I am going to depend on a person and where that dependency ends (p. 26).

A decision to live more independently means that the individual will need the support and vocabulary necessary to make decisions about new adult roles. Ruth Sienkiewicz-Mercer (1989) spent much of her life in state-run institutions, with minimal communication or educational opportunities. When she first ventured out into independent living, she wrote:

I had never had a place of my own. As a result, I had never worried about buying groceries and planning meals, paying the rent and the phone bills, balancing a checkbook, making appointments, figuring out how to keep the appointments I made – all of the things adults just do. But starting out in society at the age of twenty-eight, after living at a state institution for the mentally retarded for 16 years, I found these everyday tasks confusing, and wonderful, and frightening (Sienkiewicz-Mercer & Kaplan 1989, p. 202).

Support for a child to grow into an adult requires not only the opportunity to make personal decisions and the development of self-determination skills, but also access to the

vocabulary that supports full participation in 21st century life; in medical, legal, and financial decisions; in situations involving adult relationships; and in "outsider" activities and "adult fun." As Sarah Lever (2003) has written, it is often difficult for professionals to anticipate or recognize these needs.

Most of the speech-language pathologists I have worked with wanted to stay with basic core vocabulary. That was okay until I was 18 years old, which was when I wanted to have some adult words so I could express myself with vocabulary appropriate for my age ... A part of growing up and being an adult is saying what you want and expecting others to respect your decisions about yourself. It is very frustrating for the non-verbal person and the personal assistant when the AAC device doesn't have enough adult words to discuss some of the more personal aspects of personal care (p. 4).

Too many individuals who use AAC have been left without a way to communicate effectively and appropriately in adult situations; to refuse to be victimized, for example, and report the inappropriate behaviors of others, as needed, in a precise and confidential manner.

Sometimes even when we want to speak out, we don't have the right words to do so. Most communication aids don't come with vocabulary necessary to end the silence about crime and abuse. Many of us don't have easy access to the right vocabulary in our communication devices. Not having adequate vocabulary raises the risk of people who rely on AAC being victimized because we are identified as unable to tell anyone when crime or abuse occurs. It allows those who would commit crimes against us to continue undeterred. We need adequate vocabulary to talk about crime and abuse, and we need to know how to use that vocabulary (Lever, 1998, p. 4).

Full participation in society requires access to, and the ability to use a full range of vocabulary at every step of an individual's life. Failure to provide appropriate AAC technology and

services means not only that the individual loses an opportunity to be involved, but also, that society loses the contributions that individual would have made. Scott Palm (2007) has clearly communicated how using AAC can change both an individual's perception of himself or herself and how society views that individual:

My job developer came up with the idea of me giving a speech to the city council about my job. I was scared to death. I had just put the speech-giving program into my Liberator but I did not know if it would work when I needed it. My job developer and I wrote a speech about my job in my notebook in my Liberator. Then the night of the speech came. My scared feeling was replaced with a blend of emotions. I was excited but nervous. I was excited because I knew I could do it. I was nervous about how it would turn out. I invited my speech-language pathologist to be there, and she was in the audience. After some technical issues with the mike, I did the speech. Something started to happen. I began to have the feeling that I was in charge of the entire room. Everybody was listening to me. It was really intoxicating. I never had a full room of people listening to me before. The speech was a huge success (p. 70).

Change will require recognition by AAC professionals, service providers, and funding agencies that individuals who use AAC have the right to appropriate support throughout the life span. At age 39, Randy Horton (2001) obtained funding for and worked to complete over 96 hours of training to master an AAC device. He wrote:

Teaching is the missing key. During most training for professionals specializing in assistive technology, there is no focus on implementation. Courses just address choosing the "right device", usually based on what the person can do in a one-hour session ... People without disabilities receive 12 years of writing and language teaching during school ... Usually the consumer is given two to six hours of teaching how to use the device. Extensive, intensive

teaching during implementation is the key to success (Horton et al., 2001, p. 49).

Serious consideration must be given to the limitations and lowered expectations that have taken root in AAC practice. A more realistic view of the untapped potentials, unmet desires, and squandered abilities of individuals with complex communication needs to participate in society from birth to death must inform 21st century AAC research and practice.

### **Nothing about me without me**

*Individuals Who Use AAC Have a Right to be Meaningfully Involved in Every Aspect of AAC Research, Development, and Intervention*

I have known gentler awakenings. When I came to that late-January morning, the hospital ophthalmologist was learning over me and sewing my right eyelid shut with a needle and thread, just as if he were darning a sock. Irrational terror swept over me. What if this man got carried away and sewed up my left eye as well, my only link to the outside world, the only window to my cell, the one tiny opening of my diving bell? Luckily as it turned out, I wasn't plunged into darkness. He carefully packed away his sewing kit in padded tin boxes. Then in the tones of a prosecutor demanding a maximum sentence for a repeat offender, he barked out: "Six months!" I fired off a series of questioning signals with my working eye, but this man – who spent his days peering into people's pupils – was apparently unable to interpret a simple look ... he was the very model of the couldn't care less doctor – arrogant, brusque, sarcastic – the kind who summons his patients for 8:00 a.m., arrives at 9:00, and departs at 9:05, after giving each of them forty-five seconds of his precious time (p. 53).

In "The Diving Bell and The Butterfly," Jean-Dominique Bauby (1997), described his experience following the onset of locked-in syndrome. He writes with honest affection and respect for those who worked to understand and

support his communication. He writes with clear contempt, however, for those who ignored his efforts to communicate. For a man with minimal physical movement, who used an eye-gaze system to communicate with others, having one eye sewn shut as a preventative medical procedure was a uniquely terrifying experience; however, the unwillingness of medical, communication, and educational professionals to provide information or answer questions is, sadly, not an isolated event.

Perhaps not many individuals who use AAC can describe a particular assessment or intervention episode as dramatic as the one experienced by Bauby. Many, however, have described situations in which they felt just as powerless in seeking information or attempting to provide input to decisions about obtaining, learning, and using AAC systems. Individuals who use AAC and their families frequently describe the frustration expressed by the following parent, as she described her assessment experiences with her daughter:

They [evaluation team] said it [the device recommended by evaluation team] was the most sophisticated on the market and that she was a good candidate for it. We really didn't have anything to compare it to, so we went along with their decision ... right away my daughter was having trouble using her head wand trying to hit the keys without constantly hitting the "erase" button that was right next to the "enter" button. Not to mention the device was ugly and not friendly looking (McNaughton et al., 2008, p. 47).

Even when individuals who use AAC have investigated available options and know what they want, it is often difficult to find professionals who will respect and support their decisions. As one adult who was ready to learn a sophisticated AAC device wrote:

My Mom and I had a hard time finding an SLP who was willing to learn the Minspeak Applications Program. They didn't understand its importance and value. They didn't want to take on the challenge of understanding and memorizing the vocabulary, and they broke out in a sweat when we showed

them the thick Unity three ring binder (Rackensperger et al., 2005, p. 174).

Beyond the level of decision-making about their own personal AAC systems, individuals who use AAC also have a right to be present, receive clear information, and provide input regarding best practices in training for AAC professionals and the research and design of new systems. A few individuals who use AAC have prepared for and obtained leadership roles in research activities (Rackensperger et al., 2005), and mentorship programs (Light et al., 2007), or are active participants in device development and technical support (Isakson, Burgstahler, & Arnold, 2006). At this point, however, the participation of individuals who use AAC in AAC service delivery professional training, policy-making, and research activities can only be described as minimal. This is a lost opportunity for everyone in the AAC field and for each individual who uses AAC. Denial of an opportunity to participate can lead an individual to believe that he or she has little to say. As Jan Staehely (2000) wrote, "I had become so used to not being able to say something in depth to a person that I started to believe that I was a person who didn't have much to tell people" (p. 9).

For those of us in the AAC field, the silence of individuals who use AAC means a loss of access to the first-hand knowledge about AAC that these individuals can share. Individuals who have lived with a disability can substantively and subtly influence the decision-making process. Their opinions, rooted in lived experience, may be profoundly different from those of professionals. Individuals who use AAC typically have no agenda other than to ensure technologies and services are effective (they are not concerned with setting precedents or following protocols) and can speak strictly as advocates for individuals with complex communication needs. In order to do their work well, researchers, manufacturers, and policy-makers need to interact with individuals who use AAC. Finally, there is an ethical responsibility to involve individuals in decisions that will affect them, and to support self-governance and self-determination for individuals who traditionally have been excluded from the decision-making process.

Change will require both a “push” by individuals who use AAC and their families, and a “pull” by AAC service delivery agencies, training institutions, researchers, and device manufacturers. Individuals who use AAC and their families must regularly ask about participation in all aspects of AAC and make clear to all their interest in the meaningful involvement of individuals who use AAC. . . Some of this advocacy can be done on an individual level and may be as simple as increasing society's awareness and expectations for individuals who use AAC. As Michael B. Williams (personal communication, 6 February 2008) has suggested:

Every time you step out of your home, cruise down the street, catch the eye of a stranger, make a purchase, attend a ball game, or say hello to a child, you are making a significant change in the expectations the world has of augmented communicators. Interacting with people as you live your life is a major contribution to society.

There is also a clear need for individuals who use AAC to form advocacy groups and work to speak with a united voice. One notable example of this, the Pittsburgh Employment Conference (SHOUT, 2007), is held bi-annually in Pittsburgh, Pennsylvania, and has served as an important gathering event for individuals who use AAC, their families, and caregivers. Rick Creech (1997) described the empowering experience of seeing other individuals who use AAC gathered to advocate for change:

When I look out and see the audience filled with augmented communicators, many of whom I know and admire, it tells my soul that it's okay to be disabled, it's okay to be non-speaking, it's okay to use a communication aid, it's okay to speak out and be myself. Speak out and speak up we must (p. 40).

Professionals must also work to develop a better understanding of the perspectives of individuals who use AAC and their families, by immersing themselves in the growing body of published first-hand experiences and analysis, and by making a clear commitment to support the principle of “nothing about us without us” (Charlton, 1998, p. 3). In light of the growing number of examples of creative approaches that

support the full and equal participation of individuals who use AAC in all aspects of AAC, it is time for a clear commitment from everyone in the AAC field to expect the full participation of individuals who use AAC in all of the work of AAC: research, policy-making, system development and manufacturing, and practice.

### **Discussion and conclusions**

Why are so many people consigned to lead lives of needless dependence and silence? Not because we lack the funds, or because we lack the federal policy mandates needed to gain access to those funds. Rather, many people lead lives of silence because many others still find it difficult to believe that people with speech disabilities like my own have anything to say or contributions to make (B. Williams, 2000, p. 250).

In 1982, the year in which the International Society for Augmentative and Alternative Communication (ISAAC) was formed, most people with severe disabilities and complex communication needs were forced to live in large government institutions. Few received appropriate educations, and even fewer were employed or had any social contacts outside the institutions. Some 25 years later, increasing numbers of individuals with severe disabilities live, work, and play in community settings. Children with severe disabilities are expected to participate in the general education curriculum, and school administrators opposed to inclusion must justify why a child with disabilities should not receive services alongside a non-disabled peer. With the support of civil rights, disability rights, and human rights legislation worldwide, individuals who have access to AAC systems are finding education and meaningful employment to be increasingly achievable goals. They are also finding opportunities to take on adult roles and satisfaction in activities that support their interests, hopes, dreams, and desires.

During the past 25 years, there have been exciting breakthroughs in technologies and services for some individuals with complex communication needs. In quantum leaps from the “alphabet board in a checkbook” that Michael received, AAC technology now can provide access to communication for very young children (Light & Drager, 2007), individuals with very limited physical movements (Beukelman & Mirenda, 2005), and individuals

with serious linguistic challenges (Beukelman, Fager, Ball, & Dietz, 2007).

It is not enough, however, to know about the possibilities. The challenge for each of us is to make access to communication a reality for all. At a time when so many potentially beneficial technologies and services exist, it is truly disheartening that the vast majority of individuals with complex communication needs have shared in only a little of the progress of the past 25 years. Many individuals with severe physical disabilities and/or severe cognitive disabilities do not have access to basic communication supports and services, are restricted in their communication partners and opportunities, and do not have individualized services or technologies. Many individuals with acquired disabilities or degenerative disorders are never introduced to the powerful support for communication that can be provided by AAC, and are functionally excluded from important life decisions. A lack of information and resources serves to limit access to AAC systems and services in both industrialized and developing nations.

As a society, we would be appalled if a broken leg meant that an individual spent 6 weeks in bed; we would demand that a crutch or a wheelchair be provided to support access to school and employment and continuing participation in society. It is puzzling that none of this same outrage occurs when an individual goes through an entire lifetime with little effort made to help him or her find a means to communicate, interact with peers, share social closeness, and influence others – all of which should be recognized as basic individual rights. At a time when highly sophisticated options and services exist for some, the most basic technologies and services are denied to too many (Hamm & Miranda, 2006).

These ambitions seem very pedestrian, but are so far from reality for so many individuals that it

seems hollow to describe them as realistic goals. We have seen progress for some over the past 25 years, due in part to the important work that has been achieved in research, education and training, and public policy. Therefore, we ask our readers – whether they are individuals who use AAC, family members, or professionals – to remember and join us in working to achieve the five principles we have described in this paper: that the time for AAC is now; that one is never enough; that AAC must fit the life of the individual who uses AAC; that AAC must support full participation in society; and that individuals who use AAC must be meaningfully involved in every aspect of AAC research, development, and intervention.

Most of all, we encourage our readers to set ambitious goals for themselves as individuals, as members of ISAAC, and as participants in society; and to work towards the day when access to communication is a realized vision for all: children and adults, individuals with developmental and acquired disabilities, citizens of industrialized and developing nations. We accept that this is a big dream, but we close with the words of Michael B. Williams (1998), an individual who advocates for the communication rights of others, and who has seen incredible progress in the past 25 years. He also realizes the continuing importance of big dreams:

If we are going to dream, let's do it big. Let's not be limited by what we think we can do, let's consider possibilities that may be beyond our grasp. Let's reach for the stars. We won't touch them, but we may find something worth keeping along the way (p. 7).

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