The Urgent Need for Augmentative and Alternative Communication Research, Technology Development, Training, and Services to Support Individuals with Complex Communication Needs

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> *The silence of speechlessness is never golden. We all need to communicate and connect with each other – not just in one way, but in as many ways as possible. It is a basic human need, a basic human right. And much more than this, it is a basic human power*. (Williams, 2000; p.248).

Bob Williams[1], the author of this quote, is one of more than 5 million Americans and 97 million people worldwide who have severe disabilities resulting in complex communication needs such that they are unable to rely on their natural speech and/or writing to communicate (Beukelman & Light, in press). For these individuals, the silence of speechlessness is a daily reality. Many live their lives unable to communicate effectively to express needs and wants, build social relationships, and exchange information at school, at work, in medical settings, and in the community. They are denied the essential human right of communication. Without access to speech, individuals with complex communication needs (e.g., children and adults with autism spectrum disorder, cerebral palsy, intellectual /developmental disabilities, traumatic brain injuries, aphasia, brainstem stroke, ALS, etc.) are severely restricted from participation in all aspects of life: education, employment, healthcare, family, and community living.

The development of augmentative and alternative communication (AAC) techniques, strategies, and interventions has offered the potential for improved communication for individuals with complex communication needs (e.g., Beukelman, Hux, Dietz, McKelvey & Weissling, 2015; Beukelman, Fager, & Nordness, 2011; Brady, Bruce, Goldman, Erickson, Mineo, Ogletree, et al., 2016; Branson & Demchak, 2009; Ganz, et al., 2011; Holyfield, Drager, Kremkow, & Light, 2017; Kasari et al., 2014; Romski et al., 2010; Snell, et al., 2010). Substantial strides have been made in the research and development of assistive technologies and services to support communication, but the full potential of AAC has not yet been fully realized (Light, McNaughton, Beukelman et al., 2019). Many individuals with complex communication needs:

- are unable to access and use current AAC technologies effectively and efficiently due to the lack of fit with their motor impairments and/or cognitive /linguistic challenges (Baxter, Enderby, Evans, & Judge, 2012; Fager, Fried-Oken, Jakobs, & Beukelman, 2019; Johnson, Inglebret, Jones, & Ray, 2006; Light, McNaughton, & Caron, 2019);
- struggle to use existing technologies effectively due to the substantial learning demands (Light & McNaughton, 2012; Light, Wilkinson, Thiessen, Beukelman, & Fager, 2019);

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- fail to receive the evidence-based AAC technologies and services that they require due to a lack of knowledgeable and skilled service providers with competencies in AAC (Beukelman, Blackstone, et al, 2012; McNaughton, Light, Beukelman et al., 2019).
- face substantial barriers to their participation in society due to policy, practice, attitude, knowledge, and skill barriers imposed by communication partners (unfamiliar with AAC) who preempt them from communication opportunities (Kent-Walsh, Murza, Malani, & Binger, 2015).

There is an urgent need for high quality research, innovative technology development, state of the art training, and broad-based dissemination and technical assistance to meet these needs and advance AAC strategies, techniques, and interventions. Communication is a fundamental prerequisite to successful education, employment, health and function, and community participation. It is critical to ensure that **all** individuals, including those with the most complex needs, have access to effective AAC to realize the basic human need, the basic human right, and the basic human power of communication.

Scope of the Challenge

The population of individuals with complex communication needs spans a wide spectrum of ages, disabilities, cultural /ethnic backgrounds, and socioeconomic classes. The population includes children and adults with developmental disabilities (e.g., autism spectrum disorder, cerebral palsy, Down syndrome, intellectual developmental disabilities), those with acquired conditions (e.g., disabilities resulting from traumatic brain injury, spinal cord injury, stroke), and those with degenerative neurogenic conditions (e.g., ALS, muscular dystrophy, dementia, Alzheimer's disease). Table 1 below provides data on the prevalence of key groups of individuals who would benefit from AAC to enhance their communication and participation.

Table 1. Prevalence of individuals with specific disabilities and percentage that have complex communication needs

Disability	**Prevalence in the United States % who have complex communication needs & would benefit from AAC**
Examples of developmental disabilities that result in complex communication needs	
Autism spectrum disorder (ASD)	• 1 in every 59 children has ASD (Centers for Disease Control and Prevention, 2018) • 50-60% of individuals with ASD have substantial difficulty with communication & would benefit from AAC supports (Andzik, Schaefer, Nichols, & Chung, 2018; National Research Council, 2011; Noens, et al., 2006)
Cerebral Palsy (CP)	• More than 764,000 individuals have CP (Cerebral Palsy, 2018). • 95% of those with CP would benefit from AAC (Hustad & Miles, 2010)
Down syndrome	• More than 400,000 people have Down syndrome (National Down Syndrome Society, n.d.) • More than 80% would benefit from AAC, as they are late to develop speech and experience significant intelligibility difficulties (Light & Drager, 2012; Wilkinson & Finestack, in press)

Intellectual developmental disabilities (IDD)	• 6.5 million Americans have intellectual /developmental disabilities (National Dissemination Center for Children with Disabilities, 2014). • 55% of these individuals communicate with difficulty and would benefit from AAC (Mirenda, 2014; Stancliffe et al., 2010; Andzik, Schaefer, Nichols, & Chung, 2018)
Examples of acquired disabilities/ chronic conditions that result in complex communication needs	
Severe traumatic brain injury (TBI)	• Over 2 million Americans annually have severe traumatic brain injuries resulting in emergency visits, hospitalization, or death (Centers for Disease Control and Prevention, 2018) • Many of these would benefit from AAC during recovery; 20% may benefit from AAC long term
Cerebral vascular accident (CVA)	• More than 1 million people live with aphasia (National Institute on Deafness and Other Communication Disorders, 2017) • Approximately 40% experience severe language impairments & would benefit from AAC (Helm-Estabrooks, 1984)
Brainstem stroke	• 100% of individuals with brainstem stroke require AAC initially (Culp, Beukelman, & Fager, 2007) • 75% require AAC throughout their lives (Culp et al., 2007)
Spinal cord injury (SCI)	• 288,000 Americans are living with spinal cord injuries (National Spinal Cord Injury Statistical Center, 2018) • More than 11% have complete tetraplegia & require AAC for speech and/or writing (National Spinal Cord Injury Statistical Center, 2018)
Examples of degenerative disabilities that result in complex communication needs	
Amyotrophic lateral sclerosis (ALS)	• 30,000 Americans have ALS; an average of 5,600 people are newly diagnosed each year (Centers for Disease Control and Prevention, 2014; ALS Association, 2018) • More than 95% are unable to speak by the time of their death & require AAC (Beukelman et al., 2011)

Changing Demographics

As Table 1 demonstrates, more than 5 million people in the United States and more than 97 million worldwide would benefit from AAC. Furthermore, historical trends show that this number is increasing rapidly due to a range of factors, including, for example, (a) improved neonatal and trauma interventions resulting in increased numbers of individuals who survive but experience lifelong disabilities; (b) increased incidence of specific populations (e.g., autism spectrum disorder); (c) increased life expectancy among individuals with disabilities; and (d) aging in the general population with associated cognitive, language, motor and/or sensory perceptual impairments resulting in complex communication needs (Beukelman, Blackstone et al., 2012; Light & McNaughton, 2012a,b). Over the past 30 years, there have also been substantial changes in identifying individuals who would benefit from AAC intervention. Historically, AAC interventions were considered to be a last resort when all else had failed (Romski & Sevcik, 2005). With strong scientific evidence of the positive benefits of AAC to enhance communication and participation, the need for AAC intervention is now recognized not just for children and adults who have no functional speech, but also infants and toddlers who are at risk, individuals who are experiencing speech/language loss, and those whose speech is difficult to understand (e.g., Braddock, et al., 2012; Calculator & Black, 2010; Baumann Leech

& Cress, 2011; Hanson, Beukelman, & Yorkston, 2014; Light & Drager, 2012; Romski, et al., 2010; Sigafoos, et al., 2011; Fried-Oken, Beukelman, & Hux, 2012). AAC interventions are now being implemented with individuals with complex communication needs previously excluded due to their age or the severity of their disabilities (Romski & Sevcik, 2005). Every child or adult who has complex communication needs has the right to receive the high quality, evidence-based AAC services required to enhance communication and support participation in all aspects of life – education, employment, family life, healthcare, and community living. No child or adult should be excluded from AAC services on the basis of being "too something" — too young, too old, too cognitively (or motorically or linguistically) impaired (Beukelman & Light, in press).

The population of individuals who would benefit from AAC represent a wide range of ages, disabilities, and cultural, linguistic, and socioeconomic backgrounds; they seek to participate in a wide range of environments (home, school, work, healthcare, family, and community); and they require services across their life span as their needs and skills change over time (Light & McNaughton, 2012a,b; Light, McNaughton, Beukelman et al., 2019). Moreover, it is now well recognized that many others benefit from AAC when they face communication challenges due to temporary conditions (e.g., intubation after surgery)(Costello, Patak, & Pritchard, 2010; Blackstone, Beukelman, & Yorkston, 2015). These changing demographics have brought substantial new demands for research, technology development, training, outreach, technical assistance, and dissemination to ensure effective AAC strategies, techniques and interventions to reduce communication barriers and improve outcomes (Light & McNaughton, 2012a; Light, McNaughton, Beukelman et al., 2019).

Impact of Complex Communication Needs

Communication is a prerequisite for all of life's major activities: "Communication is the essence of human life" (Light, 1997). Communication is essential to the goals articulated in the Rehabilitation Act of 1973: "…the right of individuals [with disabilities] to live independently, enjoy self-determination, make choices, contribute to society, pursue meaningful careers, and enjoy full inclusion and integration in …society." (Rehabilitation Act of 1973). Severe communication disabilities have profound negative effects on all aspects of life – education and employment; health and function; and community living and participation. These negative effects include the following:

- Many individuals with complex communication needs are denied the opportunity to participate in general education due to their limited communication skills. For example, 61% of children with autism spectrum disorder, 84% of children with intellectual developmental disabilities, and 87% of children with multiple disabilities are excluded from general education classrooms (U.S. Department of Education, 2016).
- Up to 90% of students with complex communication needs enter adulthood without acquiring functional literacy skills (Foley & Wolter, 2010), undermining their participation in all aspects of life - education, employment, healthcare, and community living.
- Less than 5% of individuals with complex communication needs are employed full time due, at least in part, to lack of effective and efficient communication and lack of functional literacy skills (McNaughton, Light & Arnold, 2003; McNaughton, Light, & Groszyk, 2002). For example, only limited numbers of individuals with ASD secure work after school (Shattuck et al., 2012) and these positions typically involve part-time, low wage jobs (Taylor & Seltzer, 2011). Furthermore, many of these individuals are unable to maintain these jobs; employment rates drop significantly for each year post-high school (Shattuck et al., 2012).

- The overwhelming majority of individuals with complex communication needs who are patients in hospitals have no access to appropriate AAC and struggle to communicate basic needs and medical information. Individuals with complex communication needs experience three times more preventable adverse medical events (e.g., medication errors) compared to individuals without a communication disability (Bartlett, Blais, Tamblyn, Clermont, & MacGibbon, 2008), leading to poorer patient outcomes, increased patient suffering, decreased patient satisfaction, longer hospital stays, and increased health care spending (David, Gunnarsson, Waters, Horblyuk, & Kaplan, 2013; The Joint Commission, 2011).
- 54% of patients in intensive care units (ICU) are unable to communicate effectively with their healthcare providers (Zubow & Hurtig, 2013). A lack of effective AAC in hospitals puts these individuals at substantial risk for poor health outcomes and mortality (Happ et al., 2015; Hemsley & Balandin, 2014; Mobasheri et al., 2016). Reducing communication barriers for individuals with complex communication needs in acute care facilities would prevent over 600,000 adverse events annually with projected healthcare savings of $6.8 billion per year (Hurtig, Alper, & Berkowitz, 2018).
- 91% of adults with severe intellectual developmental disabilities do not have access to AAC and have no means to participate within activities of daily living, commerce, leisure, and community living (Stancliffe et al., 2010). 77% of individuals with multiple disabilities do not engage in any type of community activity due to communication barriers (Wagner, Newman, Cameto, Garza, & Levine, 2005).
- Restrictions in social participation and community integration result in limited social networks for individuals with complex communication needs, leading to greater isolation, increased loneliness, reduced quality of life, and greater risk for mental illness (Balandin, 2011; Ballin & Balandin, 2007; Hamm & Mirenda, 2006; Light & McNaughton, 2015).
- Individuals with complex communication needs are highly vulnerable to crime, maltreatment, and neglect: 45% of adults with complex communication needs report that they have been victims of crime or abuse; 71% of these individuals have been victimized multiple times and 97% knew the perpetrators (Bryen, Carey, & Frantz, 2003). The majority had no effective way to report the crime or abuse (Collier, McGhie-Richmond, Odette, & Pyne, 2006).

The population of individuals who have complex communication needs are at substantial risk for limited education, unemployment, poor health outcomes, poverty, and low quality of life. The psychological, social, and financial costs to these individuals, their families, their communities, and society are substantial. Without access to effective communication, children and adults with complex communication needs remain dependent on others to meet their daily needs throughout their lives; they are unable to attain their full potential, exercise choice, and make a positive contribution to society. The economic drain on families and society is devastating, extending from the direct and indirect contemporaneous costs incurred by families to the costs of public care to the loss of future economic success (Stabile & Allin, 2010). Compounding these economic costs is the substantial loss to society when individuals with complex communication needs lack the communication skills to fulfill meaningful social roles, contribute to society, and attain their full potential (McNaughton & Bryen, 2007; Williams, 2000).

Beneficial Impact of AAC

The research has clearly demonstrated that, with appropriate AAC technologies and interventions, individuals with complex communication needs can improve their functional communication, enhance language skills, improve literacy skills, increase educational achievement, secure successful employment, decrease challenging behaviors, manage health care needs, and enable community living (e.g., Bopp, Brown & Mirenda, 2004; Branson & Demchak, 2009; Ganz, et al., 2011; Ganz, 2015; Holyfield et al., 2017; Machalicek et al., 2010; Mandak, Light & Boyle, 2018; McNaughton, et al., 2002; Romski, Sevcik, Barton-Hulsey, & Whitmore, 2015; Therrien, Light & Pope, 2016). Furthermore, the research demonstrates that the positive effects of AAC interventions on communication, language, and literacy skills come at no risk to speech development or recovery (Millar, Light & Schlosser, 2006; Schlosser & Wendt, 2008; Beukelman & Mirenda, 2013; Fried- Oken, et al., 2012).

Barriers to AAC Intervention

Despite the potential of AAC, these benefits have not yet been fully realized. In 2018, the current Rehabilitation Engineering Research Center on AAC (The RERC on AAC) convened a State of the Science conference that brought together the major stakeholders (e.g., individuals who rely on AAC, family members, rehab engineers, rehabilitation scientists, clinicians/ service providers, assistive technology and mainstream manufacturers /app developers, government representatives, professional /consumer organizations, etc.) to evaluate the state of the science and define future priorities. Based on the state of the science and stakeholder priorities, the following barriers were identified that currently limit access to effective AAC supports and services:

- Many individuals with complex communication needs do not receive an appropriate education, enter adulthood without functional literacy skills, and struggle to participate effectively in vocational and community settings. There is an urgent need for **high quality research to develop and evaluate new and improved AAC interventions** to foster language and literacy development, improve educational achievement, and maximize communication and participation across the life span.
- Although some individuals with complex communication needs benefit from current AAC technology, many individuals struggle to use current AAC technologies effectively and efficiently due to the significant motor, visual, and cognitive/linguistic processing load, negatively impacting their communication. Many current AAC technologies are not research-based and do not meet the motor, cognitive, linguistic, and sensory perceptual needs of many individuals who require access to AAC (Light & McNaughton, 2013; Light, Wilkinson, Thiessen et al., 2019). There is an urgent need for **innovative R&D to improve AAC technology solutions** to better meet the needs of those individuals with the most complex needs.
- Many mainstream technology developers and manufacturers are unaware of the needs of individuals who rely on AAC. As new technologies emerge, they often create new barriers for individuals with significant motor, sensory perceptual, cognitive and linguistic impairments who require AAC. As a result, these individuals are unable to realize the benefits of these mainstream technologies; they experience a substantial digital divide from the rest of society. There is an urgent need to increase awareness of the needs of individuals with complex communication needs and to facilitate **increased**

collaboration among individuals who rely on AAC, families, AAC manufacturers, AAC researchers, and mainstream technology developers.

- There is currently a substantial gap between research and practice. Many individuals with complex communication needs do not receive the evidence-based AAC interventions that are known to improve outcomes. There is an urgent need to bolster **implementation science to investigate effective strategies to translate current research to everyday practice** and to ensure that what is known to be possible for individuals with complex communication needs becomes the daily reality for these individuals.
- There are extreme shortages of researchers with expertise in AAC. In fact, there were only 7 researchers who published more than 7 research papers in the past ten years (Web of Science, 2017). This extreme shortage limits the generation of new research and technology development that is essential to identify effective practices and technology solutions for individuals who rely on AAC. Without the evidence to guide practice, individuals with complex communication disabilities cannot be served adequately. There is an urgent need to **build capacity in research and development in AAC.**
- The shortage of university faculty with expertise in AAC also severely restricts the quality and quantity of preservice training for future speech-language pathologists, educators, occupational therapists, and other AAC professionals. For example, of more than 270 university preservice programs in speech language pathology across the nation, less than 15% of these have even one faculty member with expertise in AAC. National surveys of preservice training in AAC (e.g., Costigan & Light, 2010; Ratcliff, Koul, & Lloyd, 2008) found that 18-35% of the universities surveyed did not offer any coursework at all in AAC. Furthermore, many of the programs that did offer training in AAC did so on a very limited basis (i.e., a total of 1-4 hours on AAC). As a result, most rehabilitation and educational professionals do not receive high quality preservice training in evidence-based practices in AAC, leaving them ill-prepared to meet the needs of individuals with complex communication needs. There is an urgent need for **comprehensive, evidence-based, multidisciplinary preservice training in AAC**.
- At least 55% of speech language pathologists regularly serve individuals with complex communication needs who require AAC (American Speech Language Hearing Association, 2016). Yet 81-93% of practicing professionals report that they did not complete even a single course focused on the needs of individuals who require AAC (Costigan & Light, 2010). Lack of training in AAC has been identified as the "greatest professional challenge" by speech language pathologists (American Speech Language Hearing Association, 2010). The lack of qualified service providers has wide ranging and devastating consequences for individuals with complex communication needs. Many fail to receive any AAC services at all; others receive sub-optimal services from poorly trained professionals. For example, in a recent Pennsylvania survey of 1,900 adults with developmental disabilities who did not speak, 72% had no AAC system to support communication. Lack of access to essential AAC services has a profound lifelong impact negatively affecting education, employment, healthcare, mental health, and overall quality of life. Clearly there is an urgent need for **high quality, evidence-based inservice training in AAC for educational and rehabilitation professionals** to ensure that children and adults receive the evidence-based AAC services and supports that they require.

- Even when individuals with complex communication needs have access to AAC services and supports, they face substantial policy, practice, attitudinal, knowledge, and skill barriers to their participation due to communication partners who are unfamiliar with AAC who preempt their communication opportunities and limit their self-determination. There is an urgent need to develop and evaluate **evidence-based training and technical assistance for communication partners, including AAC technologies that support just-in-time partner training, to reduce partner and societal barriers and empower individuals who rely on AAC**.

Summary

The research evidence is clear: AAC strategies, techniques, and interventions enhance communication, and increase participation in education, employment, healthcare, family life, and community living for individuals with complex communication needs. Despite strong evidence of the benefits of AAC, many individuals with complex communication needs do not have access to effective, evidence-based AAC services and supports. There is an urgent need for rigorous research to advance knowledge, innovative development to improve technology solutions, evidence-based training to build capacity in the field, and strong outreach and dissemination to effectively translate research to practice in order to improve outcomes for children and adults with both developmental and acquired disabilities across the life span (Light, McNaughton, Beukelman et al., 2019). This research, development, training, and outreach will advance AAC technologies and interventions to ensure that individuals with complex communication needs have access to the communication supports they require to attain an appropriate education, secure successful employment, maintain health and function, and participate fully in their communities. The goal is to ensure that all individuals, including those with the most severe disabilities, have access to the basic human need, the basic human right, and the basic human power of communication.

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