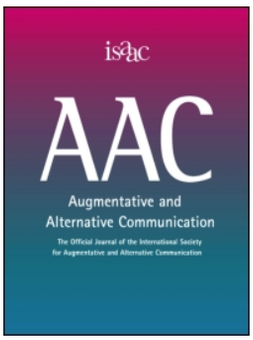

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RESEARCH ARTICLE

Building capacity in AAC: A person-centred approach to supporting participation by people with complex communication needs

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ABSTRACT

Effective communication is based both on the capacity of the person with complex communication needs, and of other key stakeholders (including communication and education professionals, family members, community partners, and healthcare professionals), to ensure that appropriate AAC supports are provided. In this paper, we describe strategies to build awareness of AAC and to assist people with complex communication needs in obtaining needed services; to build the knowledge, skills, and attitudes of AAC service providers; to provide instruction for people with complex communication needs, as well as communication partners and advocates; and to develop communication supports in society more broadly. We also provide an agenda for building capacity in research and development activities to support full participation by people with complex communication needs throughout society.

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> AAC is my bridge to the world, and a window for the world to see the real me. It supported me in moving from frustration to communication, and from isolation to relationships with others. AAC has given me the tools to live independently, to participate in society, and to contribute to the lives of others as a husband, teacher, and friend. (C. Klein, personal communication, May 10, 2018)

The use of augmentative and alternative communication (AAC) has been likened to magic in its ability to surprise us with unexpected outcomes (Beukelman, 1991), as illustrated in the quote by Chris Klein, an individual with severe cerebral palsy. As a child, Chris had limited access to AAC supports and was frequently frustrated by breakdowns in communication at home and at school. He is now an expert user of AAC technologies, and, with the use of his AAC devices, teaches in college classes and interacts with pre-service education and communication professionals across the US (Klein, 2012).

The effective use of AAC has enabled both children and adults with severe disabilities to communicate and participate in a wide range of environments and activities (Light & McNaughton, 2012; von Tetzchner et al., 2018). Clinicians and researchers have demonstrated the successful use of AAC by individuals who have received limited services in the past, including children as young as 9-months of age (Hemmingsson, Ahlsten, Wandin, Rytterström, & Borgestig, 2018) and elderly adults with dementia (Lanzi, Burshnic, & Bourgeois, 2017). There is growing evidence of the successful use of AAC to support participation in key community activities, including education (Chung & Carter, 2013), employment (McNaughton & Arnold, 2010), and independent/supported living (Blackstone, Beukelman, & Yorkston, 2015).

As Beukelman (1991) noted, however, "As with magic, the supports needed for success are not always apparent. The equipment and material costs are obvious; however, the instruction and learning costs are not" (p. 4). There are now increased AAC options available, and a richer understanding of the ways that these options can be of assistance. In some ways the availability of more choices has increased the primary challenge during the AAC assessment and intervention process: to ensure the appropriate identification and development of an AAC system (including not only AAC strategies and techniques but also instruction for stakeholders) to support communication and participation for the individual with complex communication needs across a range of environments and partners (King & Simmons-Mackie, 2017; Light & McNaughton, 2013).

Changes in technology and intervention techniques and a growing realization that AAC can be of benefit to many individuals not traditionally considered for intervention pose special challenges for professionals who may have received limited pre-professional training and have limited experience with clinical decision-making (Dietz, Quach, Lund, & McKelvey, 2012; Lund, Quach, Weissling, McKelvey, & Dietz, 2017). Additionally, many individuals who could benefit from AAC may not be aware of the potential impact of AAC intervention nor receive the supports needed for full participation in society (Light & McNaughton, 2013). Effective use of an AAC system requires not only identification of the

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components of the AAC system, but also supports for learning for both the person with complex communication needs and his or her communication partners (Beukelman, 1991; Kent-Walsh, Murza, Malani, & Binger, 2015).

As part of the special issue on the state of science and future directions, this paper addresses the supports required to provide person-centred AAC services for people with complex communication needs to enable them to achieve full social participation. The term *person-centred planning* is used to emphasize the importance of the person who uses AAC in all phases of the AAC assessment and intervention process. This may involve the formal development of a documented vision plan with short- and long-term goals (O'Brien & Pearpoint, 2007) or, more simply, the regular recognition of the central role of the person who uses AAC in all planning and decision activities (Williams, Krezman, & McNaughton, 2008). In describing the goal of participation, we draw upon the International Classification of Function, Disability and Health (ICF) model from the World Health Organization (2001), and its emphasis on intervention (e.g., therapy, public education) and prevention (e.g., accessible services) to address activity limitations and participation restrictions. As noted by Fried-Oken and Granlund (2012), the ICF model encourages the recognition that the optimal functional outcome of AAC intervention is not simply the use of symbols or AAC devices, but also involvement and the sharing of meaning in everyday life situations.

The determination of needed supports is an individualized process that may include assisting people with complex communication needs in obtaining needed services; developing the knowledge, skills, and attitudes of AAC professionals; providing instruction for the person with complex communication needs, as well as communication partners and advocates; and developing communication supports in society (including community partners and healthcare professionals).

We also provide an agenda for building capacity in research and development activities that will be needed to create and sustain change not only for traditional AAC team members, but also throughout society.

Assisting people with complex communication needs in obtaining needed services

Dana Nieder is the mother of Maya, a young girl with complex communication needs who was introduced to AAC before she was 2-years old. In the passage below, Dana described her daughter and the importance of early access to AAC:

> My daughter, Maya, is almost 5 years old. She can clearly speak approximately 15–20 words. With her talker (an iPad with a communication app) she can speak approximately 700 words, with thousands more available at the touch of a button if she needs them. With her voice, she can say "Mommy" and "Daddy". With her talker, she can tell me that today is Friday and she's going to the therapy gym in the afternoon and she wants to ride on the big swing and the tire swing and do an art project. … As we have spent the past three months searching for an ideal kindergarten for Maya, we have seen many (many) schools and met with numerous doctors and therapists for evaluations. We have heard, over and over again, "I've never seen a preschooler use a communication device the way that she does". I have seen (too many) K/1/2 classrooms populated by non-verbal kids where I am told that certain children "*are learning* to use communication boards" or "*have just started* learning how to use an iPad app to communicate" or "*will soon be evaluated* by the assistive technology team and *will probably start* using a communication device *in the near future*". This is not because these children needed to wait until K/1/2 to be ready to use a communication device. This is not because preschoolers aren't capable. This is because most preschoolers (and pre-preschoolers, frankly) don't have the access to the augmentative and alternative communication (AAC) that they need (Nieder, 2013).

In order for individuals with complex communication needs to receive appropriate AAC assessment and intervention services, they must either self-identify to service providers or be "found" and assisted in accessing services (e.g., a referral). Furthermore, there is a need for everyone involved in the process to know what they do and do not know and be aware of when to act independently and when to seek additional assistance. For many people with complex communication needs, the first step in the AAC assessment process involves a "Finder"—a person who is familiar with the potential impact of AAC and helps people (who would benefit from AAC) contact service providers (Beukelman, Ball, & Fager, 2008). Finders may include early intervention personnel, general education teachers, physicians, nurses, and family members (Beukelman et al., 2008; Binger et al., 2012).

Finders play a critical role. At present, as noted previously by Nieder (2013), too few individuals understand the potential of AAC to have a positive impact on the communication of individuals with a broad variety of disabilities (and across a broad range of ages). Increasing the number of Finders and their level of awareness is one of the greatest challenges faced by the field of AAC. As noted by Binger et al. (2012), Finders do not need to know the full range of AAC solutions, simply that AAC exists, and to help connect the person with complex communication needs with AAC professionals (see Table 1).

There is evidence, however, that this first step in accessing assessment services is sometimes the most difficult. Based on an analysis of the National Core Indicators data from 26 states in the US, Stancliffe et al. (2010) reported that only a small percentage (8.6%) of individuals with intellectual disabilities who had complex communication needs had access to any form of aided or unaided AAC. Without these communication supports, the vast majority of people with severe and profound disabilities rarely, if ever, would have interacted with others in their community and would have had no means to contribute to decisions on where and how they would live. In a study of the experiences of 16 parents of children with autism spectrum disorder, Hines, Balandin, and Togher (2011) reported that, even though the parents were engaged with multiple service-delivery professionals, referrals to communication services "appeared to happen by chance" (p. 263). Hustad and Miles (2010) reviewed the communication skills and educational plans of 22 young children with cerebral palsy and reported that, among all children who could have benefitted from AAC, only 57% had AAC-focused speech-language goals/objectives in their educational plan. For adults with complex communication needs,

Table 1. Target groups, roles, capacity building goals, and strategies to maximize participation for people with complex communication needs.

Target group and roles	Capacity building goal and strategies
"Finders" • Help connect persons with complex communication needs with AAC services	General awareness of AAC and benefits • Support information and advocacy organizations in providing empirically supported AAC information • Infuse AAC into pre-service and in-service coursework of education, medical, and rehabilitation professionals • Raise awareness of the positive impact of AAC by supporting people who use AAC in a full range of activities
AAC service providers • Support communication and participation of persons with complex communication needs and key stakeholders	Expert knowledge, skills, and attitudes to provide effective AAC assessment and intervention • Promote understanding of a full range of individualized AAC techniques and strategies, and professional responsibilities • Develop and evaluate impact of empirically-supported clinical guidelines • Teach expert decision-making strategies, including supporting participation of person who uses AAC and key stakeholders in AAC assessment and the intervention process • Provide interprofessional education to build collaboration skills
People with complex communication needs • Develop operational, linguistic, social, and strategic skills to communicate successfully	Widely and easily accessible expert AAC assessment and intervention • Encourage person-centred approaches to assessment and intervention • Teach skills needed for communication and participation
Communication partners and advocates • Use partner strategies to support communication by people with complex communication needs	Knowledge, skills, and attitudes to provide communication partner support • Provide instructional activities and resources (e.g., web-based and blended instruction) • Develop AAC systems that are more easily learned by communication partners
Community partners and healthcare professionals • Support successful interactions with people with complex communication needs in community settings (e.g., restaurants, medical offices)	Knowledge, skills, and attitudes to support participation and communication in community activities • Develop communication access standards and provide support for adoption • Investigate new approaches (e.g., trained communication assistants)
AAC researchers • Build capacity in research	Broad network of AAC researchers • Prepare individuals to conduct and disseminate research • Emphasize collaboration with stakeholders and researchers from other fields

including ALS, aphasia, and intellectual and developmental delays, access to AAC services varies widely (Beukelman et al., 2008; Mirenda, 2014), and some individuals report significant delays in receiving services (Nordness, Ball, Fager, Beukelman, & Pattee, 2010).

In order to help people who might benefit from AAC connect with appropriate services, efforts are needed in at least three main areas. First, there is a need to raise broad awareness in society of the positive impact of AAC by supporting the participation of people who use AAC in the full range of 21st century experiences. There is increasing evidence of the benefits of AAC for meaningful participation in the community (Batorowicz, McDougall, & Shepherd, 2006; Hajjar, McCarthy, Benigno, & Chabot, 2016; O'Neill, Light, & McNaughton, 2017), post-secondary education (Chung, Behrmann, Bannan, & Thorp, 2012), employment (McNaughton, Bryen, Blackstone, Williams, & Kennedy, 2012), and medical services (Burns, Baylor, Dudgeon, Starks, & Yorkston, 2017). It is not only the right of people with complex communication needs to be full members of the community, but their participation also increases the number of people who are aware of the potential impact of AAC intervention. Michael Williams, a long-time practitioner of AAC, encouraged people who use AAC to embrace this role as communication ambassadors, noting:

> 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 (Williams et al., 2008, p. 203).

Both assessment and intervention activities should regularly target participation in typical environments, both to address AAC intervention in real world conditions and contribute to wider societal awareness of the positive impact of AAC. In addition, the AAC community should continue to work with information and advocacy organizations to provide AAC information resources for people with complex communication needs, family members, and the broader community. For example, the International Society of Augmentative and Alternative Communication (ISAAC), in conjunction with the US Society of Augmentative and Alternative Communication (USSAAC), have hosted a series of webinars on a variety of topics related to AAC (ISAAC, 2018). In addition, Communication Matters (2018), the UK chapter of ISAAC, provides a variety of information materials to provide access to services and training information, while the AAC Learning Center (2018), a joint project of the Rehabilitation Engineering Research Center on Augmentative and Alternative Communication (RERC on AAC) and Pennsylvania State University, provides structured learning experiences, links to print materials, and webcasts by both AAC researchers and people who use AAC.

Second, beyond raising general awareness of AAC, work is needed to infuse AAC into the pre-service and in-service coursework of the broad range of professionals (e.g., general education teachers, daycare workers, doctors, nurses, vocational rehabilitation staff) who may, if only occasionally, encounter a person who would benefit from AAC (Beukelman et al., 2008; Yorkston, Baylor, & Burns, 2016). These individuals play especially important roles in those situations in which a person may only temporarily require AAC

(e.g., post-surgery), but will require rapid access to AAC during an especially critical time of their lives (Happ et al., 2011). Typically, health, education, and other professionals receive only minimal training in interacting with people with complex communication needs and have only a limited understanding of the potential benefit of effective AAC strategies and technologies (Finke, Light, & Kitko, 2008; Happ et al., 2011). They should be introduced to the broad range of people with complex communication needs for whom AAC interventions could be of benefit, as well as the breadth of AAC options and services that are available. The goal is that they understand their role as a Finder and are able to help an individual access needed services.

Third, for those who have a professional role in assisting the identification process, work is needed to ensure that AAC team professionals (e.g., speech-language pathologists, special education teachers, occupational therapists, assistive technology specialists, applied behaviour analysts) have a full understanding of the potential of AAC intervention, their professional responsibilities, and the limits of their own expertise (Lund et al., 2017). An AAC intervention should not be limited by the knowledge of the service provider; sometimes Finders must play the role of finding the needed expertise for an existing AAC team or determining how to make an appropriate referral.

Ideally, the benefits of AAC would be so commonly known that a referral to an AAC professional would become as commonplace as the knowledge that someone with an injured leg can benefit from crutches or a wheelchair (Williams et al., 2008). Increased public awareness, however, creates both benefits and challenges. In the area of tablet technology, for example, increasing numbers of individuals with complex communication needs (and their family members) are seeking out and purchasing communication technologies, including AAC apps (Caron, 2015; McNaughton & Light, 2015; Meder & Wegner, 2015). Social media tools, however, have also spread the use of communication interventions for which there is no evidence of efficacy or are counter-indicated by existing research (Hemsley & Dann, 2014). The challenge is to create and raise awareness of empirically supported information resources (Schlosser & Sigafoos, 2008) that can assist self-empowered individuals (including the person with complex communication needs, families, and other key stakeholders) in making informed decisions and knowing when to act independently and when to seek professional assistance. Of course, referring for services is just the first step; it is critical that service providers are knowledgeable and skilled in delivering AAC services.

Developing the knowledge, skills, and attitudes of AAC professionals

When she was 28 years old, Tracy Rackensperger, a young woman with complex communication needs who uses AAC, described some of her life goals:

> Being able to be independent and having the freedom to control my own destiny are the most important things to me. I am a very ambitious individual with lots of goals for my life … I, and others who use augmentative communication, want good jobs, good places to live, and individuals who care about us and love us. It is important for the individuals who work with people who use augmentative communication to believe they can succeed at high levels. (Rackensperger, 2006)

Since Tracy wrote those words, she has successfully completed a doctoral programme, obtained employment in a university setting, and organized the assistance needed to live independently. These achievements make clear the importance of providing AAC assessment and intervention services that not only meet current communication needs but also anticipate and enable planning for future communication growth. This must be a team effort driven by the needs, skills, and interests of the person with complex communication needs (Beukelman & Mirenda, 2013; Williams et al., 2008), and requires that team members have the knowledge, skills, and attitudes to provide appropriate assistance.

In the US, the speech-language pathologist (SLP) on the AAC team has the professional responsibility for assessing the communication skills and challenges of the individual with complex communication needs, as well as the intervention needs of communication partners (American Speech-Language-Hearing Association, 2016). There are marked differences, however, between the performance of clinicians with different levels of training and experience. Based on interviews with 25 SLPs with varying levels of experience, Dietz et al. (2012) reported that novice AAC clinicians (individuals who infrequently conducted AAC assessments) described spending considerable time collecting broad background information during assessment but had limited understanding of how this information would actually assist in the AAC intervention. In contrast, AAC specialists first gathered case history information in order to focus on specific areas of need and to identify individual interests and needs of the person with complex communication needs and other key stakeholders. The assessment activities described by specialists then included the identification and trial use of different components of an AAC system and provision of instruction for both the person with complex communication needs and key stakeholders. Notable in the comments of the AAC specialists was the importance of individualization: working with the person with complex communication needs and key communication partners to identify communication priorities; learning the unique communication needs, skills, and challenges of each individual; and identifying personally motivating vocabulary and contexts for communication.

While there has been some growth in the number of speech-language pathology programmes that include coursework in AAC, there are still concerning gaps in many programmes (Costigan & Light, 2010). An analysis of the curricula for SLP graduate programmes in the US reveals that only 68% in the US have stand-alone coursework in AAC and 20% have no AAC coursework at all (Molt, 2017).

There is a growing awareness that coursework in AAC is just the beginning. As in many fields, the challenge is to assist the communication professional in learning to transition from *novice* solutions (i.e., habitual solutions based on

the comfort and familiarity of the professional with a particular approach) to expert solutions (i.e., individualized solutions driven by the specific needs and skills of the person with complex communication needs) (Schlosser & Raghavendra, 2004). To facilitate the transition from novice to expert, AAC clinicians must learn how to make use of evidence-based practices during the assessment and intervention process to support the full participation of people who use AAC in a wide range of communication environments. Bereiter and Scardamalia (1993) have described the importance of supported problem-solving in the acquisition and generalized use of expert strategies. The use of case studies can provide students with a clinical context for new information and introduce them to the wide range of goals and strategies (e.g., enabling the participation of the person who uses AAC and family members, working with team members) that are critical elements of successful AAC assessment and intervention (Cook, 2011; McCarthy & Dietz, 2014). For practicing clinicians, the use of ongoing professional development groups to discuss clinical challenges, whether live (Williams, John, & Beatty, 2017) or through teleconference (Hardesty, Warren, Arce, & Bowser, 2017), has been recommended as effective methods for building professional competencies.

Supporting the participation of persons who use AAC and key stakeholders

Novice clinicians (including those who are beginning as well as those who have few opportunities to practice) require instruction in order to engage and sustain the participation of people who use AAC and key stakeholders from the beginning of the assessment/intervention process. While clinicians frequently believe they are providing family-centred services, family members often report that they do not experience family-centred services (Mandak & Light, 2017). As Dana Nieder (the parent of a child with complex communication needs) noted, the failure of communication professionals to fully understand and consider the views of parents, spouses, and other key communication partners can lead to misunderstanding and reduce the likelihood of successful intervention:

> Parents may not be holding back because AAC is tough to learn, or difficult to logistically manage, or cumbersome, or unfamiliar. They might be really scared of making the "wrong" choice for their child—they might worry that providing AAC to a little one may seem like an easier way to access words right now, at the cost of risking long-term speech development. It's your job (as professionals) to create a supportive, open environment in which these discussions can be had, to acknowledge these (very real) fears, to provide information and support, and to help these families connect with other AAC families (online or in person) (Nieder, 2017).

The attitude of people with complex communication needs (and other key stakeholders) will have a profound impact on acceptance and use of the AAC system, and their views and priorities must be included in every step of the assessment and intervention process (Johnson, Inglebret, Jones, & Ray, 2006).

Supporting AAC team members

There are many different ways in which AAC team members can acquire new knowledge and skills, and research is needed to identify the training techniques that are perceived as the most effective, efficient, and socially valid (Crema & Moran, 2012; Quinn, Beukelman, & Thiessen, 2011). AAC team members at all levels of experience may benefit from clinical guidelines to ensure regular consideration of evidence-based practices in AAC assessment and intervention (Beukelman, Garrett, & Yorkston, 2007; Binger et al., 2012; Dietz et al., 2012; Lund et al., 2017) and coordinate the information needed to make individualized solutions to address personal needs (Dietz et al., 2012; Lund et al., 2017). Stakeholders frequently describe the challenge of dealing with multiple team members, all with different perspectives and areas of expertise. As one parent has described:

> … A very negative experience is the lack of collaboration, each sector of professionals believes they can do it on their own … In the early years we had about 40 people involved with [Josh] from physicians to school personnel and they wouldn't talk to each other … There are lots of good skills around the table and lots of good problem-solving skills, but because of professional ideology and people not knowing how to work together, the whole process is diminished (Lund & Light, 2007, p. 328).

Clinical guidelines for AAC assessment and intervention should emphasize a trans-disciplinary team-based approach in which the person with complex communication needs (and their communication partners) play key roles (Sonnenmeier, McSheehan, & Jorgensen, 2005; Soto, 1997). Interprofessional educational activities should be provided at the pre-service and in-service level to help ensure that professionals have the knowledge and team work skills needed for working as part of an AAC team (Blackstone et al., 2015).

Although the development of clinical guidelines for the field of AAC is a new area of research (Simmons-Mackie, King, & Beukelman, 2013), early research demonstrates the benefit of organized supports for planning AAC assessment and intervention activities. For example, Karnezos (2017) reported that the provision of a checklist of key areas for AAC assessment resulted in a more thorough discussion of the skills, interests, and needs of the person with AAC during the planning of an AAC assessment by AAC team members. Both parents and professionals reported an interest in using the checklist in the future to assist team discussions and decision-making.

Much of the research to date on team decision-making has focused on service delivery models in which team members engage in face-to-face discussion (Batorowicz & Shepherd, 2011); a team-based approach may be especially challenging in areas in which participants are geographically dispersed (Binger et al., 2012). New communication technologies may assist innovative solutions. For example, the Wyoming Institute for Disabilities makes use of video conferencing technology to provide weekly professional development, peer-coaching, and case co-management assistance to educators, administrators, and service providers throughout the state of Wyoming (Hardesty et al., 2017). During video conferences, service providers participate in de-identified

case discussions and can receive follow-up assistance for implementation in their local schools. Such approaches not only share important information for the team members for a particular case, but also help build capacity for delivery of future AAC services.

Supporting learning for the person who uses AAC

The identification and development of an AAC system is only the beginning; equally important is the support for the person who uses AAC and his or her communication partners in learning how to use AAC to address a variety of needs in a variety of environments. At age 39, Randy Horton, an adult with cerebral palsy, obtained his first AAC device. He received 96 hours of instruction that addressed not only device operation but also linguistic, strategic, and pragmatic competence. As Horton, Horton, and Meyers (2001) noted,

> 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 (p. 49).

Individuals with both developmental and acquired disabilities have described the initial challenge of learning to make effective use of AAC technology. Rackensperger, Krezman, McNaughton, Williams, and D'Silva (2005) reported the experiences of seven adults with cerebral palsy who learned to use speech-generating devices. The participants described in positive terms instructional activities such as practice in functional opportunities in the community and learning from peers who use AAC. The importance of ensuring initial positive experiences in the introduction of a new AAC device was memorably summarized by one participant who wrote that, when first confronted with the challenge of reading device manuals in order to learn the AAC device, "My mom and I wanted to throw it off a cliff … " (Rackensperger et al., 2005, p. 173).

Current AAC systems often require significant effort and time to learn (Light & McNaughton, 2013). There is not only a need for technical development that can help reduce the learning demands of AAC systems and be used to teach functional use in a wide variety of contexts (Klein, 2017; Light & McNaughton, 2014). Individuals who use AAC need learning opportunities for basic device operation or vocabulary retrieval under controlled conditions as well as functional use in key communication environments. To date, much of the intervention research in the field of AAC has targeted simple requests for objects and activities (McNaughton & Light, 2015) and focused on decontextualized settings, with the researcher as the communication partner (Snell et al., 2010). Future research must address the impact of interventions targeting a wide range of communicative functions, skills, and psychosocial factors (Light & McNaughton, 2014) in the natural environment, with typical communication partners. As Chris Klein, an adult with cerebral palsy and a proficient user of AAC technology commented:

> … teaching people how to communicate socially has been overlooked. We don't know how to teach this and thus we work on the things that we know how to do best. However, by doing that, we are limiting the person. The goal of AAC should be to say anything that you want to say. It isn't about telling a person what you need and/or want. It's about becoming an effective communicator, so you can build relationships (Klein, 2017, p. 63).

In order to promote the development of relationships, it will be necessary to consider the learning needs not only of the person who uses AAC but also their communication partners (Beukelman & Mirenda, 2013; Chung & Carter, 2013; Light & McNaughton, 2015).

Supporting learning for communication partners and advocates

The importance of providing appropriate instructional assistance for the communication partners of people who use AAC has been well documented (Kent-Walsh et al., 2015; Simmons-Mackie, Raymer, & Cherney, 2016). Family members, education professionals, and other key stakeholders need knowledge not only in the operation and upkeep of the components of the AAC system (e.g., learning signs, updating vocabulary, and stored messages in AAC devices) but also in techniques to develop the functional use of the AAC system over time (Johnson et al., 2006). As a parent of a young adult with autism in a study by Hamm and Mirenda (2006) commented: "Receiving technology is only half the battle—receiving expertise and services so that the technology can be used in day-to-day, functional contexts is the other half" (p. 143).

Effective support for the use of AAC will require educational activities for not only key stakeholders and advocates, but also the many individuals who interact with the person who uses AAC. Adults with complex communication needs who reside in medical or residential care settings, for example, may receive services from as many as 15 personal care attendants in a week (Blackstone, 2005). Although interactions involving AAC depend upon both the skills of the person with complex communication needs and their partners (Beukelman & Mirenda, 2013), communication partner training has received limited research attention. A review of 30 years of research published in the AAC journal, for example, provided evidence that 85% of intervention research focused solely on the person with complex communication needs, while only 15% addressed intervention with the communication partner (McNaughton & Light, 2015).

Recent reviews of research in communication partner training in AAC document the positive impact of instruction in interaction strategies (e.g., providing an expectant delay, modelling the use of multiple modes of communication) for a range of individuals (Kent-Walsh et al., 2015; Simmons-Mackie et al., 2016). For children with complex communication needs, training for parents, educational staff, and peers in school settings has received special attention (Brock &

Carter, 2013; Chung, Carter, & Sisco, 2012; Douglas, 2012; Therrien, Light, & Pope, 2016). In terms of adults, medical and other healthcare professionals (Happ et al., 2011), as well as caregivers (spouses, children, close friends), are the most frequently studied (Simmons-Mackie et al., 2016).

Of special interest are those communication partners for whom instruction must be specifically modified. For example, peer training in preschool and school environments has often received special attention (Mirenda, 2014), perhaps because these are the environments in which children spend a significant period of time at the ages at which communication and social skills are learned. At the same time, training activities must be adjusted to the developmental needs of the partner, and to establish and maintain "typical" peer-to-peer communication exchange. For example, Thiemann-Bourque, McGuff, and Goldstein (2017) described the benefit of teaching peer partners without disabilities to stay, play, and talk with preschoolers with severe ASD who made use of speech-generating devices. The intervention for the peer without disabilities included both training in how to be a responsive communicator as well as coaching during play activities with the preschooler with ASD, and produced positive changes in both peer partner behaviours and the communication by the preschoolers with ASD. Trottier, Kamp, and Mirenda (2011) reported similarly positive findings in teaching six peers without disabilities to play with two 11-year old children with ASD who used a speech-generating device. The peers were provided with instruction and scaffolded prompting from a trainer to engage the participation of the two children with ASD in a board game. Again, the use of the targeted peer behaviours resulted in an increase in appropriate communication by the children with ASD.

One novel approach may be to reduce the need for partner training by making use of AAC system components that are more easily learned and are embedded in the activity itself. Therrien and Light (2018) examined the impact of providing an iPad© [1] with a communication app on the communicative interactions of five pairs of children (i.e., a child without disabilities and a child with ASD and complex communication needs). The communication app used visual scene displays to create digital texts on the iPads so that the books contained pages with relevant vocabulary programmed as hotspots to support communication. Joint engagement in the book activity increased for all dyads, and four of the five children with ASD demonstrated increases in communicative turn-taking with peers. The use of AAC as a universal environmental support (Therrien & Light, 2018), a shared means of communication that can be easily used by all participants, may be an important strategy to provide access to a quickly learned communication technology, as well as to assist in the development of communication skills across communication partners and communication contexts. Similar results have been observed for adults as well. Brock, Koul, Corwin, and Schlosser (2017) reported that, for adults with aphasia, the use of a visual scene display (in comparison with a traditional grid display) resulted in a greater number of conversational turns with a communication partner, longer utterances, and less frustration.

New strategies are needed to assist people with complex communication needs who face the challenge of transitioning across environments—moving from contexts in which skilled partners are available to settings in which partners may be unfamiliar with AAC (Beukelman, 1991). These transitions are often especially problematic for beginning communicators who benefit from knowledgeable partners (Hamm & Mirenda, 2006). Insufficient opportunities to use AAC, failure to provide vocabulary that meets the needs of the individual, and limited numbers of trained communication partners are frequently identified sources of abandonment for AAC systems (Johnson et al., 2006).

One promising approach is the development of AAC systems that are more intuitive for both the person with complex communication needs and the communication partner (Light, McNaughton et al., 2019; O'Neill et al., 2017). Caron, Light, and Drager (2016) provide evidence that changes in the AAC device can make it easier to add vocabulary and, thereby, assist the development of communication systems that are more responsive to vocabulary needs in a particular context. The goal is that both the person with complex communication needs and his or her partner view the AAC system as appropriate to the individual and an important support to positive interaction (Hines et al., 2011; Johnson et al., 2006).

Developing communication supports in society

Although some communication environments can be anticipated for an individual and preparations can be made to provide training for communication partners, people with complex communication needs will also participate in situations in which partners have limited opportunity/capacity for traditional partner training activities. David Chapple, an adult with cerebral palsy and a proficient user of AAC technology, described his reflections on a visit to the emergency room at a local hospital:

> I wasn't very surprised that none of the nurses and doctors had ever seen an AAC system. They had a lot of questions. Sometimes I felt like they were more interested in my ECO (a speech-generating device) rather than my health … It was a little overwhelming because I was in a lot of pain and I didn't feel like giving a lecture about how to use the ECO. I know that seems sarcastic since the nurses needed to know everything, but that was my mind at the time. Once I had a little rest and been given something for the pain, I realized I needed to make people understand me so they could give me the best care (McNaughton et al., 2012, p. 49).

The increased participation of people who use AAC in society has raised new awareness of the wide range of environments in which communication supports may be needed (King & Simmons-Mackie, 2017). There are two key communication partner groups of special interest: (a) community partners who may infrequently interact with people who use AAC (e.g., restaurant workers, shop keepers), and (b) healthcare professionals who may have multiple brief interactions

[1] The iPad is a registered trademark of Apple Inc., Cupertino, CA. www.apple.com.

with a wide range of people with complex communication needs (e.g., nurses in an intensive care unit).

Supporting community partners

As people with complex communication needs expand their participation in societal activities, they will increasingly encounter individuals (e.g., store employees, café workers) who have had limited, if any, interactions with people who make use of AAC. The use of an introduction strategy on the AAC system (i.e., appropriate information about the individual's means of communication, instructions on how the new partner can best communicate with the individual who uses AAC) is a common clinical recommendation (Light & Binger, 1998). Light, McNaughton, et al. (2019) advocate for new approaches to this challenge and for research and development in techniques to provide just-in-time training (e.g., the playing of brief videos demonstrating the use of preferred partner strategies) for new communication partners in the community.

Solarsh and Johnson (2017) have documented an innovative approach to the challenge of building supports for community participation, and describe the process of engaging with people with complex communication needs, speech-language pathologists, and community members to create communication access standards. Businesses and organizations are audited for their use of recommended communication practices and those that meet the standards earn the right to describe themselves as communication accessible. As of 2017, some 160 businesses and organizations in Victoria, Australia, have been awarded a communication access license.

In another approach, Collier, McGhie-Richmond, and Self (2010) investigated the use of trained communication assistants: persons who had been taught to assist in but not influence communication exchanges between people with complex communication needs and partners who may have limited interaction with people with severe disabilities. The assistants accompanied people with complex communication needs within community settings. All nine persons with complex communication needs reported a high degree of satisfaction with the project. As one participant (who used partner-assisted scanning with a communication board) noted, the communication assistant programme extended benefits to people with complex communication needs that are often provided to other people with disabilities:

> Participant: I NOT HEAR I GET HELP COMMUNICATION. I NOT SPEAK I GET NO HELP …
>
> Project manager: Do you mean: If you were deaf, you could get help from a sign language interpreter to help you communicate. But you can't speak and you get no services like that?
>
> Participant: 'yes' (nods head and lifts eyes) (Collier et al., 2010, p. 53).

Supporting healthcare professionals

There are many healthcare professionals (e.g., nurses in an intensive care unit) who can be reliably predicted to have at least a small number of interactions with people with complex communication needs, but will generally have only brief interactions with people with a wide variety of communication skills and needs. These circumstances create special challenges, as these healthcare professionals will need to learn general strategies and techniques that can be used to assist many different people who require AAC rather than customized strategies that have been demonstrated to be successful with a specific individual. Simmons-Mackie (2018) suggested the use of communication partner instruction based on communication accommodation theory: helping communication partners learn how to support the generalized use of AAC strategies such as writing, drawing, and photographs to supplement residual spoken communication for those who experience aphasia. In a series of studies, Happ and colleagues demonstrated both the positive impact of generalized training on nurse-patient communication (Happ et al., 2014), as well as the challenges of meeting the educational needs of large groups of professionals with many learning demands and limited time for training activities (Happ et al., 2015).

Traditionally, communication partner instruction has been delivered by a trained professional in one-on-one or small group training (Kent-Walsh et al., 2015). As such, it is often dependent upon the availability of both the professional and the communication partners, and access to these opportunities can be limited by both scheduling and funding challenges. Web-based instruction may provide one technique to quickly provide targeted instruction; however, future research should investigate the impact of blended instruction, that is, combining web-based instruction and live feedback on the use of targeted skills (Douglas, McNaughton, & Light, 2013; Quinn et al., 2011).

Building capacity in research to improve practice, policy, and technology solutions

Many factors have contributed to the growth in the use of AAC over the past 35 years: consumer advocacy, research, technical development, and policy development have all contributed to improved access to AAC services for people with complex communication needs. Many stakeholders have played important roles in directing this progress. For example, the involvement of people with complex communication needs (and other advocates) has led to important changes in policy and outcomes in education (e.g., Individuals with Disabilities Education Act (IDEA), 2004), funding for AAC technology (e.g., Steve Gleason Act, 2015; Technology-Related Assistance for Individuals with Disabilities Act, 1998), employment accommodations (e.g., Americans With Disabilities Act, 1990), and participation in society (e.g., United Nations, 2006).

AAC research has also played a role in many of these changes and has grown dramatically in recent years (McNaughton & Light, 2015). A search for journal papers using the terms "augmentative communication" or "augmentative and alternative communication" produced only eight articles for the 10-year period between 1975 and

1984; a search of the years 2005 to 2014 yielded 762 journal papers on the topic of AAC (McNaughton & Light, 2015). Clearly, however, not all change in the field of AAC follows a sequence of scientific discovery, dissemination in scholarly journals, uptake by professionals, and use by stakeholders (Mirenda, 2017). With both positive and problematic results, some of the most dramatic changes in the field have been carried out with no or limited research evidence (Hemsley & Dann, 2014; Mirenda, 2014, 2017). At the same time, sustained research has resulted in a richer understanding and improved clinical practice in areas such as access technologies (Fager, Fried-Oken, Beukelman, & Jakobs, 2019); the development of more effective AAC displays (Light, Wilkinson, Thiessen, Beukelman, & Fager, 2019); and AAC technology for communication and participation in school, employment, and independent living (Light, McNaughton, et al., 2019).

Such research is critical to provide evidence-based instruction for pre-service and in-service professionals; guide clinical practice; and give direction to technical development, policy, and legislative changes. To ensure the continued growth of the evidence base, there is a need to increase the number of individuals with the expertise to not only develop and conduct research, but also encourage application of knowledge in clinical and technical development activities; integrate knowledge and information from multiple fields; and assist dissemination through teaching, presenting, and writing (Beukelman, 2017). Although there are increasing numbers of individuals who conduct research in the area of AAC, there are only a small number who specialize in the area. For example, a recent search of Web of Science[2] research addressing intervention for adults who require AAC found only five researchers that had published five or more research papers in the past 15 years.

Because of the dramatic growth of the field of AAC, there are now new challenges and opportunities for the research community. The inclusion of people with complex communication needs in general education classrooms, post-secondary education, work settings, and the community, and the growing awareness of communication needs in a variety of settings across a person's lifetime (e.g., medical settings, legal settings), have sparked a new series of questions that require future research. To address these questions, AAC researchers will need to collaborate with key stakeholders, other AAC researchers, and with researchers from other fields, including those who offer multiple theoretical or disciplinary perspectives. For example, researchers and clinicians with an interest in aphasia have a rich history of investigating and documenting the impact of *communication supports*, defined as "any intervention programme, technique, strategy, training, material, or modification that supplements speech and language skills resulting in improved communication interactions between people with aphasia and their communication partners" (King & Simmons-Mackie, 2017, p. 349). Researchers with experience in AAC have much to learn from (and share with) those who approach the provision of communication supports from their experiences with different populations and different theoretical perspectives.

[2]This search was conducted using the topic fields for 2003–2017 (Web of Science, 2018).

Directions for future research

Much of the research in the field of AAC has focused on the development and evaluation of new intervention approaches (McNaughton & Light, 2015), with only limited research (e.g., Collier et al., 2010; Karnezos, 2017; Mandak, Light, & McNaughton, 2018; Solarsh & Johnson, 2017) on evaluating the impact of capacity building activities. Clearly there is an ongoing need to investigate the impact of new intervention approaches (Beukelman, 1991; Mirenda, 2014) and broaden the areas in which intervention is provided (Iacono, Trembath, & Erickson, 2016). We have reached a state of knowledge, however, in which it is equally critical to build capacity in our use of currently known evidence-based practices. As Strain (2018) commented:

> We desperately need practice-based evidence, as exemplified by systematic inquiry to understand the conditions under which individuals and organizations are attracted to evidence-based practices in the first place, how we might assist practitioners in getting to a necessary level of implementation fidelity in the second place, and, finally, how we can prevent individuals and organizations from being successfully lured by the next new intervention fad and abandoning the high fidelity use of evidence-based practices (Strain, 2018, p. 2).

Successful implementation of AAC intervention requires that all key participants have the knowledge, skills, and attitudes to contribute to a team-based, person-centred approach. Research is needed to better understand how people with different learning needs (e.g., people with complex communication needs, family members, professionals) and different levels of access to information resources can best be provided with individually appropriate instructional activities. The growth of the Internet has made it easier to make information on AAC available; however, the simple provision of information does not guarantee uptake and use. The field is also faced with the challenge of providing direction for distinguishing between empirically supported information and uncorroborated (or counter-indicated) intervention practices (Hemsley & Dann, 2014).

The field also faces the challenge of adding content on AAC to existing pre-service programmes, especially those that provide no or limited coursework in AAC (Molt, 2017). Research is needed to identify (a) the mix of coursework and activities, including academic content on research, theory, and evidence-based practice; (b) presentations by people with complex communication needs; and (c) clinical experiences that are most likely to lead to the acquisition of needed knowledge, skills, and attitudes for beginning professionals (Balandin & Hines, 2011; Meder, 2017; Yorkston et al., 2016). Awareness of an intervention is just a first step in the functional use of a new approach; additional assistance is needed to adapt the approach for individual needs.

The challenge is to identify a combination of strategies that will provide effective, efficient, and socially valid support for implementation of empirically supported AAC assessment and intervention practices.

Conclusion

There is increasing evidence that the "magic" of AAC can be achieved for all, and that appropriate intervention can lead to improved education, employment, community participation, and independent living outcomes (Hajjar et al., 2016; McNaughton & Arnold, 2010; Mirenda, 2014; Trottier et al., 2011). There is also clear evidence that many people with complex communication needs do not receive appropriate AAC services, whether in the area of initial assessment or ongoing intervention. Edmond's (1979, p. 23) comments on education can be appropriately paraphrased for the field of AAC: We can, whenever and wherever we choose, successfully support communication for all people; we already know more than we need in order to do this. Whether we do it must finally depend on how we feel about the fact that we have not done it so far.

Improving access, services, and outcomes will require (a) increased attention to spreading awareness of AAC and assisting people with complex communication needs in obtaining needed services; (b) enhancing the knowledge, skills, and attitudes of professionals; (c) providing appropriate instruction for people with complex communication needs and their communication partners; (d) developing communication supports in society; and (e) building the research base to help drive continued improvement in AAC practice. Coordinated and intensive efforts are required to develop the widespread and integrated knowledge of AAC needed to support person-centred approaches to enhancing communication. As noted by Light and McNaughton (2013), "In order to truly harness the power of technology, rehabilitation and educational professionals must ensure that AAC intervention is driven, not by the devices, but rather by the communication needs of the individual" (p. 299).

AAC can be like magic, providing access to communication and participation for individuals who might otherwise be unable to interact with others. Unlike magic, however, the full success of AAC intervention is best evaluated not by a single performance under controlled conditions, but rather by the extent to which it improves access and participation in valued activities and experiences of everyday life. By building capacity to deliver and support AAC intervention and raising society's expectation for the participation of people with complex communication needs, we can ensure that the "magic" of AAC is not an exceptional event of wonder for some but rather an everyday common experience for all.

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