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*Assistive Technology for **Communication***

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Assistive Technology for Communication

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Assistive Technology Outcomes and Benefits Editorial Policy

Aim and Scope

Assistive Technology Outcomes and Benefits, published by the Assistive Technology Industry Association, is an open access, peer-reviewed journal that publishes articles specifically addressing the benefits and outcomes of assistive technology (AT) for Persons with Disabilities across the lifespan. The journal's purpose is to advance the AT industry by (a) fostering communication among stakeholders interested in the field of AT, including manufacturers, vendors, practitioners, policy makers, researchers, consumers with disabilities, and family members; (b) facilitating evidence-based demonstrations and case-based dialogue regarding effective AT devices and services; and (c) helping stakeholders advocate for effective AT devices and services.

Assistive Technology Outcomes and Benefits invites for consideration submissions of original papers, reports and manuscripts that address outcomes and benefits related to AT devices and services. These may include (a) findings of original scientific research, including group studies and single subject designs; (b) qualitative and mixed methods studies, such as focus group and structured interview findings with consumers and their families regarding AT service delivery and associated outcomes and benefits; (c) marketing research related to AT demographics or devices and services; (d) technical notes and usability studies regarding AT product development findings; (e) project/program descriptions in which AT outcomes and benefits have been documented; (f) case-based reports on successful approaches to service delivery; and (g) consumer perspectives on AT devices and services.

Submission Categories

ATOB welcomes scholarly contributions. However, many stakeholders engaged in the field of AT do not have an academic background. ATOB offers a unique opportunity for these stakeholders to contribute their expertise and experience in the context of achieving successful outcomes and beneficial impacts. ATOB understands that many potential authors may lack experience in authoring papers for peer-reviewed journal publication. Therefore, the ATOB Editorial Board is pleased to offer assistance in preparing and refining relevant submissions.

Articles may be submitted under three categories:

Voices from the Field

Articles submitted under this category should come from professionals who are involved in some aspect of AT service delivery with persons having disabilities, or from family members and/or consumers with disabilities. Submissions may include case studies, project or program descriptions, approaches to service delivery, or consumer perspective pieces. All submissions should have a clear message and be written with enough detail to allow replication of results. See ATOB Editorial Policy for more details.

Voices from Industry
Articles submitted under this category should come from professionals involved in developing and marketing specific AT devices and services. Case studies, design, marketing research, or project/program descriptions are appropriate for this category. See ATOB Editorial Policy for more details.

Voices from Academia
Articles submitted under this category should come from professionals conducting research or development in an academic setting. Submissions are likely to include applied/clinical research, case studies, and project/program descriptions. See ATOB Editorial Policy for more details.

Types of Articles

Within each of the voices categories, authors have some latitude regarding the type of manuscript submitted and content to be included. However, ATOB will only accept original material that has not been published elsewhere, and is not currently under review by other publishers. Additionally, all manuscripts should offer sufficient detail to allow for replication of the described work.

Applied/Clinical Research
This category includes original work presented with careful attention to experimental design, objective data analysis, and reference to the literature.

Case Studies
This category includes studies that involve only one or a few subjects or an informal protocol.

Design
This category includes descriptions of conceptual or physical design of new AT models, techniques, or devices.

Marketing Research
This category includes industry-based research related to specific AT devices and/or services, demographic reports, and identification of AT trends and future projections.

Project/Program Description
This category includes descriptions of grant projects, private foundation activities, institutes, and centers having specific goals and objectives related to AT outcomes and benefits.

Approaches to Service Delivery
This category includes descriptions of the application of assistive technology in any setting (educational, vocational, institutional, home-life) to improve quality of life for people with disabilities.

Consumer and Caregiver Perspectives
This category offers an opportunity for product end users, family members, and caregivers to share their experiences in achieving successful outcomes and benefits through the application or use of AT devices

and services.

Mandatory Components of All Articles

Authors must include a section titled Outcomes and Benefits containing a discussion related to outcomes and benefits of the AT devices/services addressed in the article.

Authors must include a short description of the article's target audience and indicate the article's relevance to that target audience. Authors may describe their work as it relates to more than one audience and should specify the value that each group may derive from the work.

Publishing Guidelines

Review detailed Manuscript Preparation for Authors for information on formatting requirements and submission guidelines.

For More Information

Please see ATOB's Editorial Policy at http://www.atia.org/at-resources/atob for more details regarding the submission and review process, ATOB's Copyright Policy, and ATOB's Publication Ethics and Malpractice Statement.

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Introduction to Volume 15

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Welcome to Volume 15 of *Assistive Technology Outcomes and Benefits* (ATOB). The theme of this issue is “Assistive Technology for Communication.” The ability to communicate is a fundamental aspect of human behavior. Augmentative and alternative communication (AAC) supports interactions and transmission of ideas for those with complex communication needs. Technology helps them take part in human communion. Articles in this volume showcase the use of assistive technology (AT) for improving all forms of communication through text, graphics, sounds, symbols, etc., and for creating opportunities for people with a wide range of needs in a variety of different settings. Exploring opportunities to enhance communication during academic routines, independent living, and leisure activities, and supporting both younger learners and adults with cognitive, sensory or physical disabilities, this volume offers a nice compilation of strategies and resources that can benefit many professionals.

This volume begins with a very special discussion led by our guest editor, Dr. David McNaughton, around the results of the 2019 survey conducted by the Assistive Technology Industry Association (ATIA). The online survey was designed to identify training needs of those who assist users of AAC. The respondents included more than 1,000 AT and AAC practitioners. The discussion presents the views of key stakeholders in the world of AAC, including experts, professionals, parents, and AAC users, on a selected number of key survey results: (1) Strategies for improving preservice training for AAC; (2) Methods for continuing education opportunities; (3) Key players in capacity building; and (4) Improving collaboration among professionals. The participants shared their perspectives on the most surprising findings of the AAC survey. In this piece, the ATOB readers can follow an engaging virtual roundtable discussion, and learn more about strategies and resources for person-centered AAC assessment and interventions, ways to provide culturally and linguistically responsive AAC services, and other important components of the “art” of AAC.

Articles in the *Voices from the Academia* category focus on providing evidence of AAC technology effectiveness. This category begins with an article by Lori Geist, Karen Erickson, Claire Greer, and Penelope Hatch from the Center for Literacy and Disability Studies at the University of North Carolina at Chapel Hill. Their participatory action research study explored the implementation of the Project Core Implementation Model for supporting students with significant cognitive disabilities in using aided AAC with core vocabulary. Following the open-source professional development, 15 teachers were able to implement symbolic communication instruction for their 71 students with significant cognitive disabilities and complex communication needs across all grade levels. Teacher behaviors, knowledge, and self-confidence to teach core vocabulary and use AAC improved. In turn, students also demonstrated positive changes in communication skills. The next study in Volume 15 by Ben Satterfield and colleagues from Georgia Institute of Technology explored how AT improved the quality of life for adults with intellectual and developmental disabilities, many of whom also had complex communication needs. Following a multi-disciplinary, person-centered service delivery of AT and AAC, participants reported improvements in their performance as well as satisfaction and quality of life (surveys used to collect data are available in the Appendix). Many of them felt less lonely, saw themselves as more helpful, and were more involved in self-advocacy following the intervention. A model for serving adults with intellectual and developmental disabilities (IDD) through the use of technology chosen based on the skills and goals important to each individual promoted independence and empowered the participants. The *Voices from Academia* category concludes with a case study by Corinne Walker and Jane Wegner from the University of Kansas that examined the use of eye-gaze training programs for teaching an individual with cortical visual impairment and cerebral palsy to operate an AAC device. After a series of intervention sessions, a 14-year-old male participant demonstrated the visual skills necessary to use the eye-gaze and was able to use the communication program.

Articles in the Voices from the Field category offer case studies showcasing the outcomes and benefits of communication technology. The paper by Rachel Santiago, Jessica Gormley, Tami Altschuler, Michelle Howard, Harvey Pressman, and Sarah Blackstone describes the use of AT and AAC in acute care hospitals. The paper first discusses the existing barriers to communication between patients and providers during hospital stays, and then presents recommendations and resources for using AAC interventions. The case studies used throughout the article highlight the importance of this issue, especially during the COVID-19 pandemic. Communication is also important during leisure activities. The next paper, by Lauren Tucker, shares an example of how a collaboration between a nonprofit theater in Connecticut and a pre-service special education program at the local university resulted in the improved accessibility of performances and events for PK–12 students. Examples of visual supports and communication boards as well as the description of training for staff members showcase the importance of inclusivity in community experiences. Finally, a paper by Kristin Wallock and Shana Cerny focuses on the benefits of Smart Home technology for individuals living with amyotrophic lateral sclerosis (ALS). The results of a survey are presented to demonstrate how individuals with ALS use technology to support their independence and well-being.

All these articles demonstrate the power of technology for individuals of different ages, ability levels, and areas of need. Each article offers recommendations and resources to improve a variety of outcomes for these individuals. We hope you will find these resources helpful in improving your practices and making the world more accessible and inclusive.

DECLARATIONS

This content is solely the responsibility of the authors and does not necessarily represent the official views of ATIA. Dr. Evmenova disclosed three non-financial relationships. She is the Editor-in-Chief of Assistive Technology Outcomes and Benefits, Research Strand Advisor, and a member of the Assistive Technology Industry Association Research Committee.

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ATOB Guest Editor Perspective

Training Needs in Augmentative and Alternative Communication: A Virtual Roundtable Discussion

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In 2019, the Assistive Technology Industry Association (ATIA) released the results of an online survey, designed to identify training needs in the field of augmentative and alternative communication (AAC). The results were also later presented and discussed at an ATIA conference session by ATIA CEO David Dikter in February, 2020. The full report is available at https://atia.org/ATIA2019Survey.

The 2019 ATIA survey represented a massive outreach effort, supported by many individuals and organizations, to learn about training needs in AAC. The response was outstanding, with over 1,050 participants. The present paper is an edited version of an online roundtable discussion held in February 2021 to discuss a selected number of key survey findings. The discussion also addressed related topics such as strategies for building assessment and intervention capacity in AAC, opportunities for online case study discussions, supports for preservice instruction, development of collaborative AAC teams, inclusion of people who use AAC in all aspects of the assessment and intervention process, and the provision of culturally and linguistically responsive AAC services.

DISCUSSION PARTICIPANTS

- Amy Goldman (SLP-CCC) is President-Elect of the United States Society for Augmentative and Alternative Communication (USSAAC) and an AAC Strand Advisor for ATIA, and serves on the National Joint Committee for the Communication Needs of Persons with Significant Disabilities (NJC).
- Douglene Jackson (PhD, OTR/L, LMT, ATP, BCTS) served as the Florida Occupational Therapy Association president (2019-2021), and currently serves on the American Occupational Therapy Foundation board, and as CEO/Occupational Therapist of GIFTS Institute.
- Kanakavalli Kannan is the parent of a teen daughter who uses AAC. She is also a consultant who supports data analysis for Family Resource Navigators.
- Catherine (Cat) Kanter (SLP-CCC) provides support for AAC assessment and intervention at the Waisman Center Clinic in Madison, Wisconsin. She is a co-founder of ECHO AAC and the AAC Partnership Program.
- Chris Klein has used AAC for over 40 years. He is a graduate of Hope College and has studied at Western Theological Seminary. He regularly speaks at university classes, churches, conferences, and public schools using AAC.
- Sarah Marshall (SLP-CCC) provides support for AAC assessment and intervention at the Waisman Center Clinic in Madison, Wisconsin. She is a co-founder of ECHO AAC and the AAC Partnership Program.
- David McNaughton (PhD) is a faculty member at Penn State University, and is a co-leader of training and dissemination for the RERC on AAC.
- Diane Paul (SLP-CCC) is Director of Clinical Issues in Speech-Language Pathology at the American Speech-Language-Hearing Association (ASHA). She serves as an ex officio member on the NJC.
- Tracy Rackensperger (PhD) is a lifelong user of AAC, and coordinates all outreach efforts for the Living Well Georgia Project at the University of Georgia Institute on Human Development and Disability.
- Gloria Soto (PhD) is a Professor of Special Education at San Francisco State University.
- Carole Zangari (PhD) is a Professor of Speech, Language, and Communication Disorders at Nova Southeastern University. She has served as Coordinator for ASHA's AAC Division, and is one of the founders of PrAACtical AAC.

HOW CAN WE IMPROVE PRESERVICE PREPARATION?

***David McNaughton*:** I would like to start the discussion by looking at the results related to preservice preparation. In response to a question asking about strategies for improving preservice training for AAC, the ATIA respondents (a majority of whom were speech-language pathologists) described the following activities as “very or somewhat valuable”:

- Mentoring by experienced AAC professionals (94%)
- More required courses/credits in AAC (83%)
- More elective courses/credits in AAC (78%)
- Internship elective in AAC (75%)
- Scholarships in AAC specialty (72%)
- Internship requirement in AAC (65%)

***David McNaughton*:** So, it is positive to see so much interest in so many activities; what did you find surprising about this information?

***Cat Kanter*:** I was surprised by how valuable mentorship with an experienced professional was rated; I'd love to know how this would work/look across disciplines and how we might better develop opportunities for individuals in preservice programs to engage with experienced professionals.

***David McNaughton*:** Carole, can you talk a little about your experiences providing clinical supervision as part of AAC preservice programs?

***Carole Zangari*:** I did that for several decades and found it to be both extremely challenging and rewarding. One thing that I found to be very helpful was to rotate my role with AAC clients, so that I served as the clinician periodically, instead of always being in the supervisory role. Our clinic director wasn't crazy about it, but I found that it got my clients “caught up” and it also made me a better clinical supervisor. I had to be a little sneaky about it sometimes and took my lumps for that, but it was worth it!

***Sarah Marshall*:** This type of mentoring is so valuable; AAC is a complex and dynamic practice area that tends to be less of a "see and do" and requires more of a "collaborate and trial" type of learning model.

***Amy Goldman*:** Sarah, I agree that AAC is really an "art" rather than a science in so many ways, and that doesn't necessarily "fit" with how today's pre-professionals learn, especially when there is so much content (and skills to be learned) in a preservice program!

***Sarah Marshall*:** Agreed. We face that barrier a lot in our preservice training (and some in-service training, too). Many of our learners are very focused on the technology itself, and very “black and white” in their thinking of applying one device to all clients with a particular diagnosis.

During our first two weeks of training new students at the University of Wisconsin, we have all students complete a guided observation. The first week they are asked to look at the learning preferences/needs/strengths/etc. of the individual and not pay attention at all to the device. The second week we ask them to look at the features of the device an individual is using. We then take them through our decision-making process of how we mapped a particular client strength/need to a feature on the device. Some students just "get it" pretty quickly after that, but others really struggle. I wonder why that is? How can we help all students advance their clinical skills in AAC, despite personal strengths, challenges, and preferences across the many content areas of speech-language pathology?

David McNaughton**:** Sarah, I really like your instructional activities to support a "person-centered" approach to assessment. I think this is a powerful way to make sure each person with complex communication needs is considered as an individual, with careful thought to their strengths, preferences, and challenges.

I think the issue of "novices" making the same recommendation for individuals with very different strengths/preferences/challenges has a lot to do with (a) the goal of the assessment/intervention process and (b) the level of support provided for decision making. The ASHA 2020 survey provides a good reminder of the challenges that speech-language pathologists (SLPs) face. SLPs working in schools have average caseloads of 40–50 children (American Speech-Language-Hearing Association [ASHA], 2020); it is easy to understand why they can feel overwhelmed.

I think some of the key elements to teaching and supporting individualized AAC decision making are exactly what you described: (a) present the goal as one of developing individualized communication supports for a particular person, with the focus on promoting communication during valued activities for that individual; (b) provide an organized decision-making process that considers both short-term and long-term objectives for communication and participation (Beukelman & Light, 2020; Willingham, 2007); (c) practice the decision-making process with lots of different examples. AAC is a complicated area. Communication is the most amazing thing we do as human beings, and practicing the use of a strategic approach can be helpful when there are so many factors to be considered.

Kanakavalli Kannan**:** David, I love everything you have said here. I think families benefit from hearing this too, time and again, to reaffirm and advocate.

Sarah Marshall: I am so glad you specifically highlighted the barriers (e.g., caseload size, variety, time, etc.) school SLPs face and how that can lead to difficulty learning/executing new skills. We have developed new programs to increase collaboration and provide supports for families and professionals during AAC assessment and intervention: the AAC Partnership Program, and ECHO AAC (please see the section on Continuing Education, below). One of my favorite parts of these programs is learning more about those barriers firsthand from the professionals, family members, and people who use AAC who participate (Figure 1 on following page).

Figure 1: Project ECHO Virtual Presentations

Prior to the start of these programs, never having worked in the school setting was a huge missing link in my outpatient evaluations. Although I strove to be person-centered and collaborative with the entire team, looking back, not all of my recommendations were realistic or as well-informed as they could have been. My favorite part of ECHO AAC program is the "all teach, all learn" philosophy—and that has really held true for enhancing my own clinical skills (both for patient care and clinical supervision).

My turn to recap... I really appreciate your succinct three-prong approach to supporting individualized decision making. You can never restate the goal of supporting communication, participation, and independence too much. I'm thinking we should add an intro slide at the start of each ECHO AAC case study discussion as a reminder of the real reason we're all here.

Amy Goldman**:** Sarah, when I was at Temple University I frequently lectured in an Occupational Therapy class called clinical decision making, which walked through one or more case examples with a "meta" explanation of steps in the assessment process for each client case. Challenging to prepare, but I think a good approach (similar to the individualized decision making David described), and probably more important than a lecture on "This is AAC."

Sarah Marshall**:** What a neat class! Anecdotally, our team does guest lectures to the AAC class at UW–Madison focused on feature matching and language intervention through AAC. Both lectures are heavily focused on case studies and clinical decision making; I had thought we were doing a great job. This semester, however, one of our more outspoken students doing a clinical practicum shared that although those lectures were interesting, she felt it didn't prepare her for the "real deal." She was an excellent student and really seemed to "get" the clinical decision making we've been talking about. Yet, she felt that first learning in the classroom setting still felt too theoretical, despite our best efforts, and she struggled to apply what she learned in the classroom during her practicum. Having received this feedback this semester, I'm looking forward to seeking feedback from additional students as to whether they felt similarly, and exploring how to best move forward. I'd love to hear what others who are teaching in University settings are helping with this.

***David McNaughton*:** Thank you for your honesty Sarah, and for sharing this story. I wonder if one piece of it is sharing the (good? challenging?) news with students that AAC intervention is frequently a long-term process. In teaching, I know I am most likely to share the clinical stories that end with the most positive outcomes, and when new career professionals do not see the same results quickly (or fully understand how much work went on behind the scenes), they may question their own competence, and that is an uncomfortable feeling for anyone.

Sarah, people who study instructional design would tell you that you are doing the things that are most likely to result in positive learning outcomes: providing lots of practice with a clear problem-solving framework, and gradually giving the learner more independence and responsibility for decision making (Archer & Hughes, 2010; Bereiter & Scardamallia, 1993). There is stress for the student as they take on that responsibility, but those will be the challenges they face on the job.

I think it would be very interesting to talk to the students about whether they implemented the key aspects of the assessment/intervention framework they were taught, and if not, what challenges did they encounter? Maybe there is a need for more support as they implement the framework in new and more challenging settings, probably why we see such an interest in mentorship programs in the survey, and why AAC ECHO has been so well received! It may also be that there are new issues that need to be addressed in preservice preparation. We regularly invite recent grads back to speak with current students; it helps to keep our preparation relevant to today's classrooms, and is a good reminder to faculty of the challenges of real world AAC intervention.

***Douglene Jackson*:** When working in academia, I developed and taught the assistive technology course for Occupational Therapy (OT) graduate students, provided guest lectures on AT, and hosted groups of OT Assistant students through the assistive technology centers in Florida. Students often are provided with various theories and case studies but appeared to struggle with translating this knowledge into practice. I found that students were challenged with understanding the various components of an AAC evaluation and benefited from learning about an interdisciplinary approach to assessment and intervention. As a result of working with various professionals, I developed and taught a framework to scaffold their knowledge, the OCTOPUS Framework (Jackson, 2017). It is important to reinforce the need for a client-centered approach and that recommendations for AAC needed to be conceptualized across the lifespan. Having those who actually use AAC share their lived experiences has been powerful to include in academic programs and other training.

The survey speaks to the need for additional training and mentorship expressed by many students I have encountered. Many occupational therapy programs have a range of education provided, varying from a few hours to a week or two dedicated to AAC. Specifics for AAC are not provided in the Accreditation Council for Occupational Therapy Education (ACOTE) standards. Effective programs should include didactic and experiential opportunities with AAC, including engagement with users of AAC.

***David McNaughton*:** Thank you Douglene, interesting to see that preservice preparation in OT faces some of the same challenges as SLP and education. Chris, as a person who uses AAC, what is the message you want to send when you present in preservice classes on working with people with complex communication needs?

Chris Klein: I have been at this for quite a while. I started teaching in Hope College's Exceptional Child class, and the adapted physical education class, when I was still a student, and that was 29 years ago! The most important thing I try to get across is that anybody with a disability can be a success. I believe that too often we just take a quick look at the person and we rule them out. We don't let the person show us their abilities before writing their goals.

I believe we need to make sure people with complex communication needs have a place at the table—in assessment, in setting educational goals, in training professionals—in everything. In assessment, the assessment team needs to learn that we have to allow the person to show us the abilities they have before deciding the course of action. Let the person make their own decisions, and then see if we need to adjust something. This is the problem I faced during my school years (Klein, 2017), and it is an ongoing problem. All people have different types of abilities, so before we try to make decisions about what someone's abilities are, why not investigate and let them show us what their abilities are, and what they could be. Of course, this is under the assumption that everybody understands what supports are out there to accomplish an evaluation that will give the person the opportunity to demonstrate their skills and capabilities, and that will help to identify the best path for the future.

David McNaughton: Chris, I agree, there are many benefits to the dynamic assessment approach that you have described: teach, assess, teach, assess, and only then start to set goals based on the progress observed when appropriate supports are provided.

***Tracy Rackensperger*:** At the University of Georgia, we have one AAC class offered in the Communication Disorders department and I guest lecture in their class. I think it is really important that students interact with a diverse group of speakers with a wide variety of perspectives. I think it is more engaging for the students, and there is expertise that can only be provided by a person who uses AAC.

***Amy Goldman*:** I think it is particularly powerful to have guest speakers who use AAC (and they should be PAID!).

***Tracy Rackenperger*:** I also was the faculty instructor for a class called Introduction to Disability for about 10 years (Wow! It's weird to say that). I tried to teach that people with disabilities are really diverse. Some people with disabilities are homebodies, while others are very active. Some have more health issues than others. There is a lot of diversity in the disability population.

I think having someone with lived experience is really helpful in teaching students. They get to hear about my life. Also, I use my unique situation of being not on government programs to highlight the economic inequities and privileges I see. Currently, I teach a directed study in disability. Directed study offers an individualized learning opportunity that requires the student to work closely with me to co-design a project of interest to the student using process-oriented guided inquiry. We meet as a group at the beginning of the semester and then they work one-on-one with me for the rest of the semester.

***Kanakavalli Kannan*:** Tracy, thank you so much for sharing this. As a parent and active participant in my daughter's team, diversity in disabilities is something I have to get new team members to understand. I would love for my daughter to listen to your lecture or have an opportunity to talk to you.

***David McNaughton*:** On this topic, I would like to mention the archive of webcasts, including both Consumer Perspectives and Research to Practice (some of which are co-presentations with people who use AAC), at the AAC Learning Center. We will be adding more in the coming years with the assistance of Tracy, Chris, David Chapple, Anthony Arnold, and Godfrey Nazareth, all of whom are working for the recently funded RERC on AAC. I also wanted to ask, how does the survey information "match up" with your clinical experience or research?

***Amy Goldman*:** I've heard more about mentoring as something that would be helpful on the job vs. preservice, but agree it would be helpful in increasing team member skills. Scholarships would incentivize the pursuit of AAC knowledge across disciplines. I would like to give a plug to the McLean Yoder Schiefelbusch Fund (MYS Fund), developed by the NJC in collaboration with the American Speech-Language-Hearing Foundation (ASHFoundation). Our goal is to endow this ASHFoundation fund so that student scholars who are interested in the communication needs of individuals with severe disabilities can receive scholarship support while they are establishing their research agenda.

***David McNaughton*:** Amy, that speaks to my next question about barriers and supports. On an abstract level, there is always recognition and support for more coursework, internship opportunities, mentoring, but what are some of the barriers you see? What are the supports?

***Amy Goldman*:** Barriers include: difficulty in cross-referencing coursework in multiple departments; "room" for electives in personnel prep programs; sources for scholarship dollars that emphasize AAC (or severe disabilities); and inter-professional preparation on the master's level.

Cat Kanter: Amy, I completely agree! I'd also add the following with regards to mentorship: availability (both in number and in time) of experienced AAC professionals to provide desired mentorship and comparability of mentorship relationships/experiences.

Carole Zangari: I can't say that these data were very surprising, but I do think it speaks to the fact that AAC professionals continue to recognize the need for support in this area. We also have to be sure to recognize that while being a good mentor brings many rewards to veteran AAC professionals, it is also time-consuming. I think it is important not to respond to this need by setting up systems that further burden AAC-experienced clinicians without compensation. There are MANY who do this because it is their passion, but I do not think it is helpful in the long run to build systems that perpetuate this dynamic. The time spent in mentoring should be accounted for in their paid work time, or additional compensation should be provided by the system. Otherwise, we will continue to get results like this and the slow pace of growing the pool of qualified providers will creep along. I worry a lot about burnout in our best professionals, and building systems that require them to volunteer their time (which they willingly do) is short-sighted at best, in my humble opinion.

***Amy Goldman*:** At the preservice level, I believe there have been federal grants (although they are highly competitive). For example, my colleague Jenn Seale at the University of Maine recently received an Office of Special Education Programs (OSEP) grant that addresses AAC and early intervention. Years ago at Temple, I was involved with an OSEP grant focused on individuals with significant disabilities and AAC; it was a post-graduate "certificate," taught by experienced professionals, to experienced professionals (special education teachers and SLPs). For the individuals who participated, tuition was free, and the credits they earned resulted in a pay-scale increase. We need more programs to provide support for practicing professionals!

***David McNaughton*:** Amy, the OSEP Personnel Preparation grants have been a great source of financial support for students, and the specialized AAC coursework developed for funded students is available to students in the entire program. We are currently working with both SLP and SPLED graduate students as part of the OSEP-funded AAC Collaboration Project. It has been great to have students from two disciplines participate in classes (and practicum experiences) "side-by-side."

***Cat Kanter*:** UW–Madison also recently received an OSEP grant for a similar training initiative with SLP and Special Education grad students learning and working together.

Sarah Marshall: One additional support we offer at the Waisman Clinic is 1–2 clinical fellowship positions per year exclusively in the area of AAC. We focus heavily on the Clinical Fellow/Clinical Fellow mentor relationship and provide between 30–50% clinical supervision throughout the year.

***Amy Goldman*:** The interest in additional required AAC coursework was surprising, given the fact that it would likely extend the preparation program, especially in areas like speech-language pathology (SLP). "Internship in AAC" is also hard to interpret, given the range of clients, and with varying age and disability types, it's unlikely that a "dedicated" internship could be constructed for any discipline (e.g., speech-language pathology). I would have been interested to know how respondents would have rated other choices like: AAC courses offered through multiple schools/departments so that pre-professionals from diverse disciplines learn together; embedding AAC in autism coursework; embedding AAC in other disability topics.

***David McNaughton*:** Amy, the "embedding" vs. the "stand-alone" question is a fascinating one. Clearly having AAC content presented in context (e.g., in a class on aphasia), and also having dedicated classes on AAC, is ideal at the preservice level, but some programs may not have the distributed expertise to provide this. Online resources to support evidence-based practices, like those provided by ASHA and the National Joint Committee for the Communication Needs of Persons with Severe Disabilities, have been very helpful. As part of the RERC on AAC, we have developed a series of web-based interactive modules on evidence-based practices in AAC; currently there are seven modules, with more on the way!

Our goal is that they would be used by faculty with existing AAC coursework, and we have worked to align our content with current textbooks in the field (e.g., Beukelman & Light, 2020). We have seen good uptake since we launched in 2019, with over 35 colleges and universities (as well as the AAC Partnership Program in Wisconsin) making use of the materials.

We are also starting to develop supports for in-class discussion and practice activities, so that there is a "flipped" model of instruction to develop expertise with the content. For example, Dr. Kelsey Mandak developed an online module on "active listening skills" for SLPs (Mandak et al., 2020). Faculty can now download Powerpoint and print materials to support the practice of active-listening skills with preservice clinicians in class. Over 400 preservice clinicians have completed the active listening module in the past year, and 97% would recommend it to others, so we have been excited to see this uptake.

Diane Paul: Respondents likely want to see a requirement for a course dedicated to AAC. Current ASHA accreditation standards are more general and don't specify courses on particular clinical topics. Standards indicate that the program must include "content and opportunities to learn" so that each student can demonstrate knowledge and skills in assessment and intervention across the lifespan for "disorders and effectiveness of augmentative and alternative communication needs". The information could be infused throughout a variety of courses rather than being taught during a course devoted exclusively to AAC.

Amy Goldman: I understand ASHA's rationale in its accreditation standards, but it also may inhibit the potential for course offerings in AAC. In my opinion, on the other hand, an exclusive AAC course that is nothing more than a vendor parade won't improve preparation either. Perhaps a discussion of what a "quality" program that addresses AAC looks like is where the site reviewers could get some additional guidance. I'm not familiar with how other disciplines might address preservice preparation in AAC—with a few exceptions, like Penn State!

Diane Paul: Standards can be changed too. I was just sharing what ASHA's current standards are. Regardless, I like your suggestion, Amy, to prepare a model for a high-quality program to address AAC. The ASHA SIG 12 (AAC) could be involved. I think they've already made an effort to collect course syllabi. Some components would be interprofessional training, bring in the user experience as a central component, provide mentorships—shadow and watch what AAC experts are doing. And another key component of any course would be to provide practical experiences.

Carole Zangari: I would love to hear thoughts on how to scale up some of the AAC practices taught in preservice programs and professional development so that more professionals are using them. The problem of pedagogical AAC information is the easiest to address and this is being done in many ways by many people. The harder part is to build the implementation skills for AAC strategies in both assessment and intervention. First of all, we have little to no science to guide us as to what the best practices are for translating AAC content into clinical/educational application. More real-world research on this topic is critical, but we can't always wait for that. Being successful with an AAC client in a clinical rotation is very, very different than being effective as an actual clinician or teacher. We need more implementation science research in AAC, and the support for helping student teachers/clinicians make the transition to professionals without getting beaten down by the systems in which they are employed. I hear from many of them who are gung-ho to implement AAC in their first years as professionals, but slowly give up as they get overwhelmed by other demands and unhelpful policies and practices in the workplace. We have to figure this out so that we stop losing the momentum that we've picked up by increasing preservice AAC training.

Also, why is there so little work in AAC being done for preservice special educators? We have data that students with the most significant cognitive limitations, for example, have VERY little access to SLP time (let alone with an SLP who is AAC-knowledgeable). A big implication of that is that there is a huge need for teachers to be living and breathing AAC facilitation strategies, writing IEP goals that appropriately incorporate AAC, using testing methods that are fair for AAC users, etc.

David McNaughton**:** Thank you Amy, Diane, and Carole, I think the more we do, the more we realize how much there is to be done! I agree, preservice preparation in special education, and in general education, can and should be doing more. Part of the rationale behind the AAC Learning Center Moodle is to make it "easy" for interested faculty to add AAC content to their class, even if they do not feel like they are "experts." But again, clearly, far more work is needed.

I would like to thank everyone for the resources they have been providing in this discussion. It is now easier to share online resources, but there is the added challenge of promoting evidence-based practice. Preservice preparation is a key first step, but as Carole notes, implementing these practices in real-world contexts highlights the need for supports for practicing professionals.

HOW CAN WE IMPROVE CONTINUING EDUCATION?

David McNaughton: Survey respondents were asked to identify their three most preferred methods for continuing education activities.

Continuing Education Opportunities Ranking in the Top 3

- Mentoring by experienced AAC professionals (in-person or online; 81%)
- Continuing education on job site (70%)
- Recorded online education (41%)
- Live online education (39%)
- Continuing education at state conferences/conventions (27%)
- Continuing education at national conferences/conventions (14%)

Sarah Marshall**:** I really enjoyed reading this response. It does affirm with what we've seen in Wisconsin with regards to creating a culture change in widespread AAC acceptance and implementation. Our clinic staff often presented at state conferences, yet attendance was never that high. Feedback we've received is that general practice SLPs don't want to spend "too much time" on a specialty area when they need to gain continuing education in so many areas during the short time period of a convention. For those who did attend the various presentations, it was often the side conversations after the presentation that felt most meaningful. There is something special about that 1:1 connection, or community involvement, in which you can process and then apply information.

David McNaughton: Sarah and Cat, I know that you and your colleagues at the Waismann Center have developed some fascinating initiatives in Wisconsin that make strategic use of online training, live interactions, web-based discussions, and more! Can you provide some more information about the AAC Partnership and AAC ECHO programs? Your work directly addresses the preferences identified in the survey.

***Sarah Marshall*:** Both programs grew out of needs we saw in Wisconsin, but I think the same challenges are often seen around the country. When our AAC clinic was faced with what was close to a two-year waiting list, and people were traveling five or more hours round-trip for services, we knew our treatment model had to change. Cue ... AAC Partnership Program and ECHO AAC.

The AAC Partnership Program is an AAC evaluation capacity-building program. SLPs from across Wisconsin enroll in the program. They have access to the AAC Learning Modules on the AAC Learning Center Moodle, which helps to ensure we share common terminology and an assessment framework prior to partnering. We then schedule their students/clients for an expedited feature-matching evaluation that is completed collaboratively with the entire team. Instead of adding the individuals to our caseload and extending our waiting list, we instead provide ongoing mentorship to support the partner SLP in implementing the selected AAC system. We also provide support throughout the SGD funding process (e.g., templates, proofreading for red flags, etc.). The AAC Partnership Program has not only empowered general practice SLPs to practice more confidently in the area of AAC, but it has improved the access crisis in Wisconsin by helping children get scheduled for evaluations in a far more timely manner. Our ECHO AAC program is our other capacity-building program—but I'll let Cat introduce that program!

***Cat Kanter*:** After developing our AAC Partnership Program, we received feedback that many SLPs and teams wanted one or more follow-up appointments with our clinic for ongoing AAC implementation support, and we were looking for a way to provide evidence-based practice as well as ongoing collaborative problem solving virtually to continue to support our team. Enter ECHO AAC, our online learning community.

The Extension of Community Healthcare Outcomes (ECHO) is a national capacity-building model developed at the University of New Mexico, originally targeted to meet the needs of patients requiring specialty medical care. Both the Universities of Wyoming and New Mexico have further expanded this model to include outreach into educational settings, which is what we now use (Root-Elledge et al., 2018). ECHO AAC provides a series of six sessions in the spring and fall which include 45 minutes of didactic content and 45 minutes of case-based problem solving with our whole ECHO AAC group. It's been wonderful to see the community develop, and we have enjoyed participation from SLPs, OTs, people who use AAC, parents, educators, and others.

The case-based learning is a very unique part of the ECHO model, as it encourages audience participation. ECHO follows the "all teach, all learn" philosophy in which each person's expertise is valued. We've found that ECHO AAC has become a wonderful tool to create a Community of Practice among participants, allowing for natural resource sharing and problem solving among all members of the AAC team. I think ECHO really captures what we miss in the AAC-PP, which is mentoring from other professionals. As someone who practices exclusively in the area of AAC in an outpatient setting, I am not as well equipped to mentor another SLP on AAC implementation in the school setting, yet our ECHO AAC community provides that missing link! We're excited to continue to measure the outcomes of this program!

***Carole Zangari*:** I am a big fan of the ECHO model and love how the assistive technology community has put it into action. You and Sarah are doing a terrific job with the public sessions for ECHO AAC and I can only imagine how powerful the problem-solving segments are for your whole team. Congrats to you, Sarah, and all the others who are making such a big impact with this innovative approach!

***David McNaughton*:** Cat and Sarah, I also find this approach fascinating! Can you share a little information on what you have seen with respect to participation, and where this might go next?

***Cat Kanter*:** Currently, we have three different iterations of our ECHO AAC program.

1. *ECHO AAC.* Our original ECHO AAC is an open model, where participants are encouraged to join sessions they can attend and review recorded sessions if they cannot attend. In 2020, we provided 18 hours of professional development training (for free) and had participants from 14 unique roles participate including individuals who use AAC, parents, AAC vendors, psychologists, audiologist, social workers, OT, paraprofessional, administrator, AT specialist, SLP, students, teachers, and ABA providers. As of February 2021, we had over 197 individuals participate live from 97 unique "health centers" (e.g., schools, outpatient clinics, universities, etc.) from across Wisconsin. We also have a mailing list of ~450 individuals who receive our invitations and the recordings. In the fall of 2020, ECHO AAC grew outside of the state of Wisconsin, and had individuals participate from 15 different states as well as a participant from Canada! Overall, 95% of attendees have agreed that the trainings are useful and relevant, and they would share the information they learned from ECHO with others. Over 98% also indicated they would make a change to their practice after attending ECHO.
2. *ECHO AAC Autism*. In August, 2020 we launched a 3-series pilot specifically aimed at increasing knowledge and collaboration with ABA providers around the state of Wisconsin. We had 22 providers around the state participate in our pilot; most were BCBAs, although we also had two case managers and one student participate. One hundred percent of participants said they would attend ECHO sessions again in the future. Over 95% said they would share information with colleagues, and 100% agreed that the sessions were relevant and useful.
3. *ECHO AAC Families*. This spring, we're launching an ECHO AAC Families specifically to provide support to families of children who use AAC. The goal is to provide greater ongoing support, accessible materials and research, and create a community of families.

Kanakavalli Kannan: I am very excited to read about your ECHO AAC program, especially with the involvement of families! There is a significant shortage of SLPs with AAC expertise for families to access and the costs are very high, making it unaffordable for many of our families in our area (California). Your model of capacity building sounds very interesting!

Amy Goldman: Sarah, your program sounds amazing! I am really taken by the interdisciplinary aspect. Do participants come as a team to your sessions?

Sarah Marshall: Yes, absolutely! For both AAC-PP and ECHO AAC we encourage team involvement! We don't directly investigate if team outcomes are different for those who participate together versus not, but I'd love to learn that answer. Anecdotally, the sessions flow better and reported team outcomes are improved when more team members are involved (not surprising). Some of the most influential team members in ECHO-AAC sessions have been paraprofessionals, parents, and people who use AAC. Our weekly feedback surveys have echoed (pun intended) that observation.

David McNaughton: Carole, I see the work that Sarah and Cat are doing in building communities of practice through activities like AAC ECHO as being part of the solution, as well as the work that you do through PrAACtical AAC to share intervention strategies as implemented by practicing clinicians. The ASHA SIG-12 and QIAT LISTSERVs, and Facebook sites like AAC for the SLP and Ask Me, I'm an AAC User also serve valuable roles. It is very encouraging to see these innovative approaches to supporting evidence-based practices in real-world settings (Figure 2)!

Figure 2: The PrAACtical AAC Blog

PrácticAAmente Conectados Con Links – Febrero 2021

AAC friends, we are back with another AAC Link Up in Spanish. If you have materials or videos in Spanish... [Read More...]

Welcome!

PrAACtical AAC supports a community of professionals and families who are determined to improve the communication and literacy abilities of people with significant communication difficulties. It was founded in 2011 by two SLP professors, Carole Zangari and the late Robin Parker, around a shared passion for AAC.

WHO ARE THE KEY PLAYERS IN CAPACITY BUILDING?

David McNaughton**:** The survey was one of the largest efforts of its kind, and saw a very strong response rate from the AAC field. With that said, it is important to note that it overwhelmingly reached (and was responded to) by professionals who are active in providing AAC services, so it is not surprising that SLPs were the most frequent respondents.

Survey Respondent's Role

- SLP (60%)
- Occupation Therapist (10%)
- AT Specialist (9%)
- Parent (7%)
- AT Consultant (3%)
- Researcher (3%)
- Administrator (3%)
- Educator (1%)
- AAC user (1%)

Clearly, it is important to have an understanding of the training needs of SLPs, but what other voices need to be heard in a discussion about training needs and building capacity? And how do we cast a wider net in future research efforts?

Amy Goldman**:** I believe survey results were heavily influenced by having such an overwhelming majority of respondents serving children as school-based practitioners or in early intervention. Clearly this is an important segment, but we need to find better ways to reach and include the "voices" of AAC users and family members, as well as practitioners serving adults (including those with acquired disabilities). Also, in future research, it would be wonderful to be able to tease out more information on the professional background of the "AT Specialist;" that may be a role that is carried out by someone who is credentialed in another field (OT, SLP, educator). It would be helpful to know more about their skills and needs.

Cat Kanter**:** Amy, the need to hear from clinicians serving adults also stood out to me, as I consider vision specialists, neurologists, etc. as key members of the team for many of our adults with neurodegenerative conditions, as well. Another key area is individuals working within the inpatient setting; we need to find a way to get the perspectives of people who have other primary roles, but frequently interact with people with complex communication needs, like nurses and other medical staff.

David McNaughton**:** Cat, good thing we have the hard-working team at the Patient-Provider Communication Forum working to spread the word about AAC among medical professionals!

***Gloria Soto*:** We need to find better ways to hear the voices of educators, too; they play a critical and pivotal role in the success of AAC implementation in schools.

***Douglene Jackson*:** It is evident from the survey that the demand for professional development is there, with variance in how that might occur. Mentorship and on-the-job training were the highest but that can be hard to establish within the workplace. It would be beneficial to develop local professional communities of practice that focus on building capacity of various professionals, working in partnership with AAC users. An interprofessional approach, including leveraging the virtual space where appropriate, can help provide support and use a group mentorship model to build a more competent workforce. I would also recommend reaching out to the state-funded assistive technology programs to help with training and technical assistance, although each state program varies.

***Chris Klein*:** I have to admit seeing the low level of participation by people who use AAC is very frustrating. First, I believe people who use AAC don't really have a voice at the table, and they should have a BIG say when decisions are being made. And I get that a lot of SLPs are working with school-age children, but that is when it is important to give the family and child a voice at the table. This is an industry that is run by manufacturers, professionals, and educators. In the last 20 years, I haven't seen much progress made on key issues like education and employment. This is why it is important for me to continue to push for a seat at the table. I will continue to advocate and push for people who use AAC to have their voices heard! People who use AAC should have a voice. The problem is, I don't think we do, and I believe that has to change.

I wanted to share more, and I believe I can articulate it. This is just my experience, as I have worked with a lot of families over the last 10 to 12 years. The evaluation process for an AAC device still baffles me, because not every speech language pathologist knows AAC. I understand that and I’m not sure what to do about it. However, I have seen people select a device because the speech language pathologist was comfortable with it, instead of looking at the other devices. There is no “one size fits all,” so I would like to see more comprehensive trial periods before deciding on a device. Too often, if a decision is rushed, a device is selected that doesn’t work for that individual, so it sits there on the shelf, which doesn’t do any good.

I was also in an evaluation where a speech language pathologist told a mom that if she asked her daughter if she wanted to eat a shoe, her daughter would say yes. Now, I had been interacting with her daughter, and it was obvious to me that she had receptive language. She would get excited about talking about “Little Kitty,” and other things that interested her. I knew she wanted to talk, but she didn't get a chance to do so.

That is the stuff that really frustrates me. There is a lot of work that needs to be done, from the preparation and expertise to do the evaluations, to the counseling process, to changes in the requirements for funding, and to the commitment to developing language. The best evaluations I have been involved with are the ones in which a person has an opportunity to trial every communication device that person wants to try. I just want to give the person the best chance to communicate and build on something. It isn’t about selling a certain communication device. It's about giving the person access to language, so that he or she can develop communication skills. It's about giving the person the best tools to have a successful life.

The lack of employment opportunities also is unbelievably disturbing, and it needs to be addressed. There has to be some long-term employment opportunities or internships at the university level, so that opportunities are there to build your resume. I have built a good resume, but I lack experience. I haven't had a "job" where I would go to work every day and work with a team every day. I have work experiences, but not comprehensive full-time employment, which puts you even further behind, as if a lack of communication is not enough. Again, I believe this could and should be done based on a person's interests and abilities, with supports as needed. Everybody can be employed, so let's figure out how to get that done. It takes cooperation between everybody.

Lastly, I do believe people who use AAC need to have a much bigger voice at the table. I believe we need to push for that voice, and I am willing to do that. We need to look at a person and not think about the limitations, but the possibilities. I hear too often that "not everyone can be a Chris Klein." Well, Chris Klein wouldn't exist if no one gave me the chance to show my abilities. So that is one thing, and I would love to see more cooperation between the team and the person; this is how it should be working. After watching *Crip Camp: A Disability Revolution* (Newnham & Lebrecht, 2018), I have been motivated to start a movement like that in the world of AAC. It is time for people who use AAC to become the voice of the industry, and not the other way around.

Sarah Marshall: Well said, Chris. I want to let you know that your voice, and voices of others who communicate using AAC, really matters and does make change. Through our ECHO AAC program, we have had three different individuals who use AAC share about the importance of feature matching and the detriment they have personally experienced when SLPs forced their "preferred" system onto them. We had many SLPs on those calls who have subsequently shared in feedback surveys that this information was important for them to hear, and that they will consider more systems in the future. We did not see the same amount/level of feedback when we, as SLPs, encouraged trialing multiple devices. The voices of people who use AAC can make a critical difference in changing attitudes and practices!
Gloria Soto: Chris, I agree wholeheartedly with you. I receive daily emails from professionals or family members who get caught in turf wars, or services driven by individual preferences based on false assumptions or whatever is "in" at the moment, rather than basing professional decisions on evidence and best practices. As such, children are left without robust AAC systems and without systematic interventions that are goal-driven and grounded on developmental theories and evidence. We know that professional decisions are often based on professionals' sense of self-efficacy, and whether they feel they can support the system. Professionals have too much power to steer the process; it can be in the right direction, or it can lead it to a total disaster. The voices of persons who use AAC are ESSENTIAL in this process. Parents need to "see" what is possible with appropriate supports. Thanks for continuing to advocate.

Kanakavalli Kannan**:** I absolutely agree and echo what Chris has stated so beautifully about needing AAC users and families at the table. I also share his concerns with the inappropriate use of a candidacy model that too often exists in AAC assessments and device justifications. Many families require a lot of advocacy to even get an AAC evaluation for their children, and are often stuck with children having to demonstrate various abilities to show they are "ready." As a parent and as a parent advocate, there are very high barriers for AAC evaluations, the lack of professionals serving children who have complex communication needs, and many problems with the affordability of such evaluations and devices.

I also wonder if assessments and intervention/implementations need to be seen differently. AAC implementations often fail without strong team coordination; often an SLP works with their client in a school setting, with weak or no carryover plans for the supporting members during the rest of the day. We need to find ways to better understand and respond to the experiences and the needs of families, AAC users, educators, and other support staff like paraeducators.

David McNaughton**:** Kanaka, you raise excellent issues. One way to build understanding across team members is to make use of the growing resources developed by people who use AAC (e.g., Stefanie Faso, John Draper, David Chapple) and parents (e.g., Fighting Monsters with Rubber Swords, Love That Max, and Uncommon Sense.) In addition to learning how to listen on an individual level, these resources can help us think more broadly about the goals and experiences of people who use AAC and their families.

HOW CAN WE IMPROVE COLLABORATION AMONG PROFESSIONALS?

David McNaughton: In the table below, you see the level of confidence expressed by respondents about their skills, and the skills of their peers, by setting. What do you find surprising about this information? What does this mean for service delivery, and collaboration?

Confidence in Skills (own, peer)

- Special schools/transition (93%, 37%)
- Hospital (93%, 59%)
- Rehabilitation (90%, 53%)
- Outpatient (89%, 57%)
- Schools: preK–12 (88%, 37%))

Amy Goldman**:** I was surprised that the responses regarding "peers' skill" from those in special schools was almost exactly the same low percentage as seen in other school settings! I was (pleasantly?) surprised that peers in hospital/ rehabilitation/outpatient are rated as highly as they are. What is it about those settings that accounts for that?

Sarah Marshall**:** Amy, I agree. I think it is a pretty jarring mismatch between confidence in providers' own skills versus those of their colleagues. I wonder if lack of insight into other professionals' work setting barriers might contribute to the rating of confidence of peers. As I've begun to learn more about what it entails to provide AAC services in the school (although I have much more to learn), I am willing to admit that my own confidence in my peers/colleagues has grown. I think there is hidden expertise in all practicing clinicians that needs/deserves a platform to be shared.

I think it's important to reframe the focus on AAC to more of a focus on language intervention through another modality. I question how the survey would differ if the question was assessing confidence in providing language intervention. "Generalist" or "specialist," our trust and confidence in our colleagues is where discussions, supports and resources can begin.

To your point about hospital/rehab/outpatient, I wonder if outpatient "specialty" centers account for this increased confidence? Perhaps even the availability of additional AAC resources in comparison to some school or early intervention settings?

Douglene Jackson**:** I find it striking that across the board the confidence in colleagues was low, being lowest for the school environments. I might hypothesize that this could be due to working in silos and not truly embracing interprofessional team approaches, especially when considering intervention. Team evaluations occur more frequently than intervention and those working in school environments might utilize more pull-out approaches versus push-in. Those working in more clinical settings rated their colleagues with increased confidence, although still low, which leads to questions around the quality of intervention provided for AAC users. With such questions regarding the abilities of providers arise, this further validates the need for further education and possibly the establishment of baseline competencies across these contexts.

Gloria Soto**:** I also am surprised by the high level of confidence among some professionals, and also the low levels of confidence toward their peers. It points to a perception of uneven levels of training and experience among team members. This is quite problematic but really informative.

Self-efficacy is a very elusive construct, which is context-specific. Also, often times those who we regard as experts express lower levels of confidence, as they are aware of the complexities of the task at hand.

David McNaughton**:** Gloria, I agree with you that sometimes those who have been at this the longest have a richer understanding of the complexity of the challenge than "novices," ironic in many ways! To follow up on what Chris Klein said earlier, one "tension" I see in the field today is the temptation to provide the same AAC system to all individuals with complex communication needs on a clinician's caseload, which may lead to a clinician feeling “confident” because they “understand” the AAC system they regularly recommend. Individualized AAC assessment and intervention IS challenging, and we need better instruction at the preservice and in-service level to make that a reality (and that is on me as a university faculty!).

Gloria Soto: That is so scary, David. I have seen that too, the idea that "one AAC system fits all." And of course, the system is whatever the "professional" feels more comfortable with, rather than following a process that is child-driven, and with the end goal in mind of optimal and "independent" communicative competence.

I also am disheartened by the fact that so many children with complex communication needs end up receiving ABA services alone. I regularly receive emails from SLPs who feel that they are being completely shut out of the decisions around communication intervention. There seems to be a limited awareness of the multiple benefits of including AAC (e.g., reduced frustration, supports for social interaction) and an overemphasis on verbal imitation and requesting routines. I have seen entire schools "forbidding" the use of a robust communication system in favor of "behavior compliance." There are ethical considerations that we need to address, and have no recourse to do it. As a field we need to develop a consensus of what is malpractice and unethical.

Amy Goldman: Conflicts with ABA specialists (and others) is increasing, I believe (based on a nonscientific reading of Facebook and ASHA SIG 12 posts). How can we engage ABA specialists (outside of those who are dually credentialed with SLP and ABA) in inter-professional training and other experiences to get "on the same page"?

Sarah Marshall: Amy, I agree. I think these conflicts are far too common, yet ABA and SLP collaboration has the potential to be a "dynamic duo." We recently offered an ECHO series, entitled *Collaboration between BCBAs and SLPs with AAC: Having Conversations that Matter* (Weber, 2020). Barb Weber was our presenter and she is dually certified. I think it was helpful to have a dually certified individual be the source of knowledge dissemination, as all attendees could relate. She shared some excellent tools on developing a shared vocabulary, recognizing the overlap in goals and creating a common ground, and a wide range of collaboration strategies.

Gloria Soto: Sarah, THANKS for sending these two resources. It is very helpful to see how the two approaches to communication intervention can support each other!

Diane Paul: The conflicts between ABA specialists and SLPs certainly are dramatic in the extremes. If ASHA posts anything on social media that even hints at support for ABA, we know there will be concerns expressed. The full range of perspectives was highlighted in a recent ASHA Leader article by Nancy Volkers (2020), in which she addressed the extreme positions that we sometimes see, ranging from "ABA is abusive" to "ABA should be used for everyone." ASHA recently contributed to an article by the Association for Behavior Analysis International (ABAI) entitled "Interprofessional Collaborative Practice Between Behavior Analysts and Speech-Language Pathologists," which stresses collaboration. We've received feedback from SLPs asking why we endorsed this article. We didn't endorse it (and were not asked to do so). However, ASHA supports collaboration and supports the U.S. Department of Education and the Centers for Medicare & Medicaid Services (CMS) in saying the ABA should be one treatment option for children with autism based on individual needs. And SLPs should be involved whenever there is a communication challenge. We have posted additional relevant sources of information at the AAC Learning Center.

Kanakavalli Kannan**:** My personal experience for my daughter makes me think that often the attitudes towards the AAC learners are often the biggest barriers, and that peers (which as used here seems to mean other professionals like teachers and paraeducators) play a critical role. Also, skill building for these other professionals requires regular training and oversight, and that is hardly ever planned for within an implementation/support plan. If SLPs who specialize in AAC do not spend the time to build that training and capacity among other team members, it is a disservice to the AAC learner, especially in school settings where there is significant juggling between the demands of language, literacy, and pacing of the classroom. What I find surprising about this information is, do SLPs consider themselves as key players in building peer skills in the area of AAC, and what do they consider as barriers in building the peer skills?

Sarah Marshall**:** I can speak to my own clinical practice a bit and some of the ways we've attempted to grow towards a more capacity-building approach, recognizing that 1:1 therapy can only go so far and that team training is essential for success. As an outpatient clinic, we involve parents heavily in sessions, but family/school team training outside of the caregiver who accompanied the individual has historically been minimal. I want to highlight that this is NOT because I didn't recognize the importance or that I didn't want to put in the work, but it's just not reimbursable for my employer. I am not sure if school SLPs have more flexibility (likely not), but we just don't have any insurance codes that we can bill to capture this critical time spent.

This always weighed heavily on me, as I would want to train team members, attend IEP meetings, or offer additional support outside of the therapy environment, but I also needed to uphold my productivity requirements for my position. We did, and still do, our best to overcome these barriers by videotaping sessions (with permission) to highlight teaching strategies, creating handouts for families/teams, and relying on vendors for training on operational features so we can maximize our time focused on language.

In Wisconsin, we also offer a sister program to our clinic-based services, called the "Communication Development Program," that focuses exclusively on family and team training. Prior to COVID this was done in-homes/in-schools but now we're transitioned to offering these services virtually. This program is funded through children's long-term support waiver dollars, thus allowing the flexibility of not having to go through insurance. This approach draws upon the small amount of money available to the state under the Assistive Technology Act (2004), however, and it is a somewhat complicated approach to funding support.

ECHO AAC was, in part, developed to address some of these issues. By bringing an interdisciplinary team to the table, particularly those who use AAC and their family members, we are able to provide education not only on various AAC topics, but on roles and responsibilities, highlighting who needs to be involved. As I shared with Chris earlier, the individuals on our ECHO sessions who use AAC have been the best instructors. I also think this provides an opportunity for peers to coach peers, and peers to recognize skills they didn't necessarily realize their colleagues had.

I believe that there are many SLPs who are passionate, motivated and continually striving to do their best (reflected in the "confidence of self" rating). Unfortunately, many of these same SLPs also are facing barriers outside of their control, which may impact their ability to provide the type of person-centered AAC services that they would like to deliver. I know advocacy is at the forefront of solving some of these barriers, both for reimbursable insurance codes and manageable caseloads in the schools.

***Amy Goldman*:** I am assuming the respondents to this survey consider themselves the "AAC expert" and (hopefully) their "peers" refer/defer to them when it comes to intervention/assessment for AAC for their clients/patients. However, it does raise the concern, how do we "spread" knowledge/skills regarding AAC and empower (some level) of AAC skill to the others? SHOULD we? Or should we maintain the "expert" model?

***Sarah Marshall*:** I couldn't agree more. This has been a huge push of our AAC Partnership Program in Wisconsin. The "expert" model, often in which an AAC "expert" is practicing in isolation and is the keeper of the expertise, is what we feel contributed to our AAC access crisis and 2-year waiting list in Wisconsin. Our clinic often heard from school SLPs that "they don't do AAC" or "your clinic is where you go to get a device." In my opinion, this is not a sustainable model, nor is it in the best interest of the individual and their family. We've instead shifted to a capacity-building model in which mutual trust and respect for each team member's expertise in the evaluation process is identified and valued.

I agree that the AAC "expert" remains an integral part of the team; however, they're just one key player amongst a much larger team. Empowering AAC finders, general practice SLPs, consumers, and family members has been a game changer in Wisconsin. Through our program, many general practice SLPs have since taken on the AAC expert role on the team, or referred another child to our clinic when another team member is needed for the evaluation process.

***Gloria Soto*:** I would be curious to see how the responses would have changed if the question had included culturally and linguistically responsive (CLR) AAC services. The literature is consistent that most SLPs don't feel confident in cultural and linguistic responsiveness in action. Confidence in one's own knowledge and ability to implement in practice are different constructs.

I guess one of the questions that comes up in this area is, do AAC professionals understand the scope of cultural and linguistic responsiveness? It is wonderful to see how manufacturers are addressing issues of cultural representation in pictures and voices. We still have a long way to train preservice and in-service professionals in family-centered practices which are ultimately responsive to the unique needs and strengths of a family. There are many changes that are necessary at the preservice level to address the changing needs of our classrooms, and the need to provide culturally/linguistically responsive AAC services. And change starts with reflection and recognition of the ideologies that permeate our practices.

***Diane Paul*:** Gloria, excellent points! I have posted additional resources at The AAC Learning Center.

Amy Goldman**:** Gloria, I would be surprised if AAC providers have more skill than the "average" SLP in CLR-AAC services ... I'm just hypothesizing that AAC providers make AAC their priority for CE and might not focus on (general) CLR. So specialized preservice and continuing ed that combines both would be great! I do believe there is more attention being paid now to CLR services in general, and it is great to see symbols and (soon, I understand) voices that assist in appropriate representation.

Cat Kanter**:** Gloria, this is SUCH an important distinction and I hope future research will address CLR-AAC services! In my clinical experience, I've seen a lot of what David described: many clinicians choose one AAC system for all culturally and linguistically diverse children on their caseloads. I see this especially within our bilingual English and Spanish speaking communities, where we've had entire districts who only purchase and implement one bilingual system even if they offer multiple English-only systems. While part of that speaks to systemic issues with providing CLR services, I do think a large part is also due to SLPs' lack of confidence in exploring and implementing CLR-AAC services.

David McNaughton**:** Cat, I agree; one more area in which new supports are needed to ensure that decisions are based on the needs of the individual. Gloria, I know you have done a lot of important work on this topic, I would like to recommend Solomon-Rice, Soto, and Robinson, (2018) and Tönsing and Soto (2020) to our readers.

NEW DIRECTIONS FOR ADDRESSING TRAINING NEEDS

David McNaughton**:** Throughout this discussion, a number of you have mentioned new initiatives for capacity building that you have developed. I wanted to use this final section as a place to discuss innovative strategies for the challenges we face in the field of AAC.

Tracy Rackensperger: It is important to have families and professionals understand that people using AAC are capable of doing a lot. Stories of a wide variety of people using AAC need to be shared, especially of those with intellectual disabilities. Families sometimes say to me, "But my child has XYZ and isn't going to college." Maybe or maybe not? People can still be very successful no matter what they are able to do. We need to share that message. Stories should be shared online through social media. Younger folks like Twitter and Snapchat, older folks (like me) stick with Facebook.

Cat Kanter**:** Tracy, I love that you brought this up! I'm lucky enough to work with a wonderful young woman who uses AAC whose goal is to develop an AAC Mentorship Program precisely for the reason you discussed—she grew up not knowing anyone else who communicated like she did. Creating opportunities and awareness is such a HUGE part of building capacity. She's also recently joined our ECHO AAC network, and many participants have specifically commented on how the perspective she brings to case studies completely changes their thinking.

Chris Klein**:** I also strongly believe that people who use AAC need to play a key role, and I would like to share some information about building networks among people who use AAC. I believe communication is about building relationships, and I believe language development happens best when you are in a social setting. This is true for typically developing children, and for children who need AAC. This is why I believe we need to create opportunities for people to have social interaction if we want them to have success in learning AAC, which I believe, at its heart, is learning language.

When the pandemic hit, I started a group called Device Verses. We started out with three to four people who use AAC. We have about 10 to 12 people now. It is a place where people who use AAC can feel welcomed. Yes, we are studying the scriptures. We are also supporting one another and becoming a great community for one another. This is my latest attempt to build a community where everybody feels welcomed, and to combat social isolation. I am amazed at how many people who use AAC haven't felt or been welcomed into a church or faith community. This troubles me, so I am always working with another group to help churches become more welcoming and inclusive to those that have complex communication needs.

Diane Paul**:** I am so glad to learn about this program that addresses the spiritual needs of people who use AAC. It emphasizes the need to have a broad, far-reaching, whole-person perspective.

Chris Klein**:** Thanks Diane, participation in faith communities has always been an important part of my life, and I know that is true for many people with complex communication needs (Klein & Lowe, 2010). I also believe Device Verses is making an impact on beginning users. It wasn't my plan to have such an impact on beginning users, but I have a couple of them joining the group on Wednesday nights and they are communicating better in the last six months. That peer interaction has a great effect, and I believe we need more of that going forward. Tracy is right. We need to share stories and we also need to share that everybody can be successful no matter what their abilities. I hear too often that not everybody can be a Chris Klein. Yes, I know that, because not everybody can be a Michael Jordan, either. However, everybody can be successful, and we need to share that more!

David McNaughton**:** Chris, I think you have hit the nail on the head—people have no sense of the range of positive outcomes that are possible. And we don't know what the outcome will be until we make an honest effort to provide supported opportunities for learning. I think we need to get lots and lots of different "stories" out to parents, and professionals, and the community at large, so people set ambitious goals for every individual. Too often the path forward is restricted by the limited awareness of possibilities. We need to do a better job of "spreading the word" on positive outcomes.

Tracy Rackensperger**:** Exactly!

David McNaughton**:** Kanaka, could I ask you to say a few words about your work with the Family Resource Navigators? It is a different way of thinking about “building capacity,” but often parents need support both for what is possible and in how to access/advocate for services.

Kanakavalli Kannan**:** Family Resource Navigators is a parent-led, parent-staffed agency in the San Francisco Bay area that supports families in navigating the various systems (school districts, regional center, insurance, etc.), so they can get the supports and services their children need. We work with families of children from 0–22 across various programs, and have been doing this work for over 25 years now. The biggest challenges we face are increasing awareness among professionals, increasing awareness among family members, and the small number of clinicians who have skills in providing family-centered AAC services.

Diane Paul**:** Kanakavalli, we have seen those same challenges across the country. Some other suggestions for new directions:

1. As Gloria described, CE and preservice should emphasize ways to serve individuals and families from diverse cultural and linguistic backgrounds.
2. Some people feel overwhelmed with the breadth of technology. Preservice and CE should teach strategies for including consideration of mobile technologies and apps in AAC assessment and intervention.
3. We need better knowledge translation and communication among clinicians, researchers, and vendors. There is a tendency among clinicians to rely on vendor information, which has a sales component.
4. ASHA may want to establish a Consumer Advisory Panel, particularly in the age of value-based care, to help with the development of outcome measures that use consumer input.
5. There are a number of strong organizations that address AAC, but we need to increase collaboration; for example, we need to build stronger connections between the ASHA SIG 12 (AAC) and the NJC and the NJC network.
6. We need to promote a lifespan perspective in training, and address not only the school-age years, but employment, community integration, and other key issues in adult life.

David McNaughton**:** Diane, wonderful ideas, each worthy of a full discussion on their own! I know ASHA has worked to build valuable resources and structures to support interaction across professions; the National Joint Committee network has played an especially valuable role.

Cat Kanter**:** While it was initially aimed at in-service professionals, we've found more and more preservice undergraduate and graduate students are joining our ECHO AAC sessions biweekly to learn and problem-solve along with our community. Establishing early communities as a young professional is so helpful to knowing where to turn when encountering difficulties or unknowns (as we all do) in the future.

Sarah Marshall**:** Something that has been very helpful for us since COVID-19 is the acceptance and use of telehealth. We've had greater team involvement from more rural areas of Wisconsin now that we can offer virtual participation. It also provides an opportunity for us to provide more "eyes-on" mentorship; whereas, prior to COVID-19 all of our discussions occurred via phone or email without the child present.

David McNaughton**:** I will be interested to see what happens in this area once children are back in school. When I look at the ASHA 2020 SLP survey, it says that SLPs typically spend about 20 hours a week with children in therapy rooms or classroom settings, and about two hours per week with parents/families. SLPs in schools report average caseloads of 50 children; I see a lot of time pressure on their ability to work with families via teleconference (once children are back in school). With that said, I hope that there will be a way to get home teleconferencing recognized as a valuable (perhaps key) use of SLPs' time. Hopefully, continued use of teleconference will be a positive outcome of COVID-19.

Amy Goldman: David, I agree that COVID-19 will have some permanent impact on how we "do business"; hopefully, employers/funders will continue to recognize the efficacy of videoconferencing/training and support it as a part of service delivery options. How are videoconference skills being developed on the preprofessional (or continuing education) levels? (BTW, check out some of the ATIA offerings in this regard!)

***Douglene Jackson*:** Telehealth has certainly changed the way we practice and I was happy to have been working in the space prior to COVID-19. I have been asked by various practitioners to help them figure out the landscape of telehealth and find that this has provided much insight into the challenges, barriers, and supports for everyday life. Leveraging asynchronous and synchronous means for telehealth service delivery can promote increased access to services and specialists, especially for those practitioners needing guidance and mentorship for those with more complex communication needs. AAC really takes a team approach and using the virtual space for service delivery and capacity building of providers is critical to establish a well-equipped AAC workforce to support users across the lifespan and in multiple contexts.

***David McNaughton*:** Thank you, Douglene, interesting to see the commonalities across our professions, and I support your call for more attention to using a team approach. I am sorry to bring our discussion to a close, but thanks to all of you for the content you have shared. Amy, you have provided a great transition to a resource I wanted to be sure we discussed, the ATIA Learning Catalog. It contains a rich and growing collection of content from past conferences, as well as special recordings, and is available at the ATIA Learning Catalog.

DECLARATIONS

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Voices from Academia

Initial Evaluation of the Project Core Implementation Model

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ABSTRACT

Many students with significant cognitive disabilities have difficulty expressing themselves through speech or sign language. These students could benefit from aided augmentative and alternative communication (AAC) systems and interventions aimed at teaching communication. Unfortunately, access to such communication systems and interventions is limited for this group of students. Teachers have the potential to address this persistent problem and service need if provided effective training, resources, and support. The current participatory action research study applied mixed methods to investigate changes after classroom professionals had access to the training and resources included in the Project Core implementation model. The results are encouraging with regard to the potential for teachers to develop the knowledge, skills, and dispositions required to help students with significant cognitive disabilities learn to use aided AAC that features core vocabulary. The study provides guidance and a replicable approach to the development of an implementation model aimed at teachers and classroom-based intervention practices.

Keywords: augmentative and alternative communication, aided language input, core vocabulary, significant cognitive disabilities, symbolic communication

INITIAL EVALUATION OF THE PROJECT CORE IMPLEMENTATION MODEL

Students with significant cognitive disabilities comprise approximately 1% of the K–12 population and almost 10% of students with disabilities in U.S. public schools (Thurlow & Wu, 2016). Among these students, at least 165,000 are unable to use speech, signs, or graphic symbols to meet their communication needs (Erickson & Geist, 2016; National Center for Educational Statistics, 2017) and could benefit from access to aided augmentative and alternative communication systems (AAC). Aided AAC refers to a variety of external tools, with or without voice output, that individuals can use to select letters, words or symbols to communicate. Unfortunately, students with significant cognitive disabilities and complex communication needs have little access to aided AAC (Erickson & Geist, 2016). On average, they spend less than an hour per week with specialists like speech-language pathologists (SLPs) who have training in AAC interventions (ASHA, 2018; Brandel, 2020; Brandel & Loeb, 2011). Classroom teachers spend most of the school day working directly with students and have the potential to address this persistent problem and service need. With training and support that is consistent with the needs of teachers and the structure of their classrooms and instructional activities, it is possible that teachers and their staff can deliver effective access to aided AAC and communication intervention within the context of a typical school day.

TARGET AUDIENCE AND RELEVANCE

The current project was inspired by K–12 students with significant cognitive disabilities and complex communication needs who often require increased access to aided AAC systems and more intensive AAC interventions. Significant cognitive disability is a term created by the Office of Special Education Programs (2005) to identify the relatively small group of students with a disability or multiple disabilities that significantly impact intellectual functioning and adaptive behavior to such an extent that they cannot achieve grade level standards even with the best instruction and appropriate accommodations. According to the U.S. Department of Education, students with significant cognitive disabilities are a diverse group of students who receive special education services under a variety of eligibility categories (e.g., autism, intellectual disability, multiple disabilities) and who require extensive, repeated, individualized instruction and support, substantially adapted materials, and targeted instruction to acquire, maintain, and transfer skills across settings (Office of Special Education Programs, 2005). Research suggests 18 (Towles-Reeves et al., 2012) to 35 percent (Browder et al., 2008) of students with significant cognitive disabilities do not use symbolic communication. Those who use AAC tend to use single symbols for an extremely restricted range of purposes (Erickson & Geist, 2016).

Guided by implementation science, the project sought to develop and ultimately provide open-source access to training and resources to support teachers in implementing early symbolic communication instruction for their students across the entire school day. This information may be of interest to school administrators, curriculum coordinators, coaches, teachers, SLPs, and assistive technology providers for the purposes of planning, professional development (PD), and preparing communication materials, intervention, and ongoing support for teachers and students. The iterative and collaborative approach described may also be of interest to program designers who are engaged in the development of solutions that seek to address related areas of need.

Implementation Science

Many communication interventions that are found to work well (i.e., those that have a strong evidence base) are slow to move from controlled studies to typical classrooms (Olswang & Prelock, 2015). The field of implementation science attempts to address this challenge by leveraging researcher and practitioner collaborations from the outset in order to increase understandings of the context, potential barriers, and necessary resources for effective delivery of practices known to lead to positive outcomes for students (Fixsen et al., 2013; Olswang & Prelock, 2015). Implementation science was first established in healthcare to respond to persistent reports that empirically supported innovations were not demonstrating the targeted outcomes when rolled out in typical settings (Kelly, 2013; Nordstrum et al., 2017). The goals of implementation science include reducing disparities in access to interventions and promoting the use of evidence-based practices and programs in common clinical, home and community-living settings (Eccles & Mittman, 2006; National Institutes of Health, Fogarty International Center, 2018). Implementation science accomplishes this by promoting the adoption, delivery and sustained use of evidence-based interventions while emphasizing external validity and often applying mixed-methods designs (University of Washington, 2020).

The Project Core Implementation Model

The primary goals of Project Core are twofold: (1) to empower teachers and classroom professionals to deliver early symbolic communication instruction during the naturally occurring academic and daily routines of the school day, and (2) to improve communication outcomes of students with significant cognitive disabilities and ultimately improve their academic performance on mandated end-of-year assessments in English language arts. The specific AAC and communication intervention practices targeted by the Project Core implementation model include: (a) attributing meaning to early forms of communication like body movements, facial expressions, gestures, and vocalizations (Rowland, 2011) to support language learning (Yoder et al., 2001); (b) personal access to aided AAC systems (e.g., Douglas et al., 2012; Ganz et al., 2012); (c) use of high-frequency words, called core vocabulary, represented by graphic symbols (e.g., Banajee et al., 2003; Cross et al., in press; Trembath et al., 2007); and (d) aided language input strategies to build receptive understanding of language and show students how to use graphic symbols to communicate (e.g., Brady et al., 2013; Romski & Sevcik, 1996; Sennott et al., 2016).

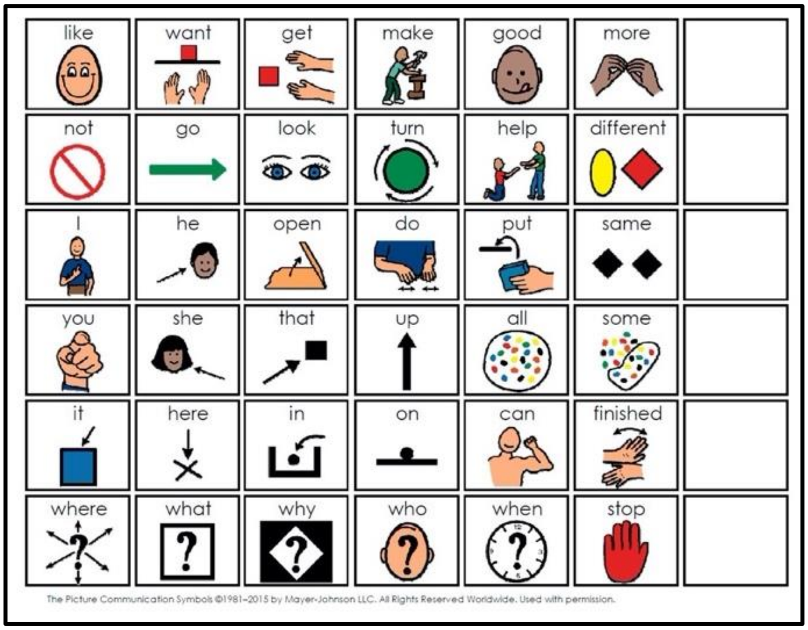
Design Requirements

Design efforts were aimed at creating a sustainable implementation model and providing a replicable approach. Design of the Project Core implementation model required careful attention to multiple factors including the need to: (a) fully consider potential funding barriers that could reduce access to the teacher and student-facing components and explore the potential of open-source options as a starting point where needed; (b) ensure the availability of all components for download, distribution, and use on an as-needed basis; and (c) apply a PD approach that allows school-level implementation teams to facilitate teachers' access to learning and practice opportunities during group sessions and/or through self-directed study.

Aided AAC Formats with Universal Core Vocabulary

Given the substantial need for aided AAC that is detailed in the current literature (Erickson & Geist, 2016; National Center for Educational Statistics, 2017) and funding barriers reported by partner sites, the research team worked to provide access to aided AAC using core vocabulary in downloadable, open-source formats. A core vocabulary list was defined based on previous research (see Cross et al., in press) that included 36 words (e.g., go, not, like) that are powerful as single-word utterances, can be combined to produce utterances with more complex syntax, and can be used across purposes and contexts. This core vocabulary was given the name *Universal Core*, and each word was paired with a graphic symbol and organized in various grid layouts (see Figures 1 and 2). Good usability (i.e., easy to learn and use) for teachers with little to no background in AAC and support for student access were design priorities. The resulting Universal Core vocabulary formats support access through (a) pointing with a finger or selecting with a whole hand, (b) looking at the intended word and symbol using an approach called eye gaze, or (c) moving through the available choices to a selection using an approach called partner-assisted scanning (e.g., partner says each word and points to the symbol, then waits for the student to indicate in some way that it is the one they want to choose or the desire to move on to the next one). Additionally, 3D symbols were designed and made available, each with a unique raised element, texture, the printed word, and Braille (see Figure 3).

Figure 1: Example of the 36 Location Universal Core Vocabulary Communication System Represented by Picture Communication Symbols© by Mayer-Johnson

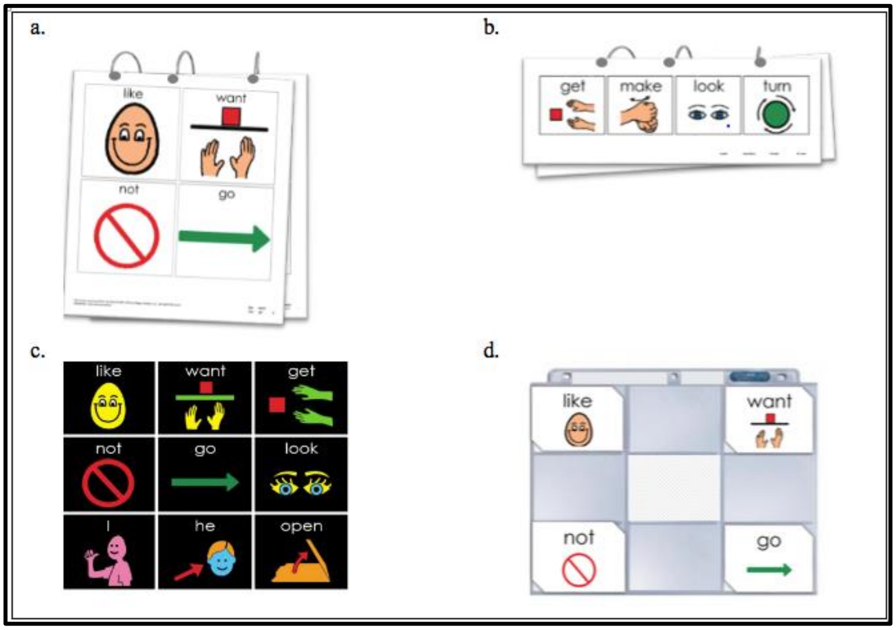


like	want	get	make	good	more	
not	go	look	turn	help	different	
I	he	open	do	put	same	
you	she	that	up	all	some	
it	here	in	on	can	finished	
where	what	why	who	when	stop	

The Picture Communication Symbols ©1981–2015 by Mayer-Johnson LLC. All Rights Reserved Worldwide. Used with permission.

Note: Used with permission.

Figure 2: Examples of Multiple Formats of the Universal Core Vocabulary Represented by Picture Communication Symbols© from Mayer-Johnson



Note: Used with permission. Example formats include: The 4 location x 9 page – Direct Selection (a) version designed for students who use direct selection given large targets. At least initially, the communication partner supports navigation from one page to the next. The 4 location x 9 page – Partner-Assisted Scanning (b) version designed for students who require partner-assisted scanning. The symbols are arranged horizontally to maximize the likelihood that partners will scan through the items in the same order each time. The 9 location x 4 page – Direct Selection/High Contrast (c) version designed for students who use direct selection given large targets and high contrast symbols. At least initially, the communication partner supports navigation from one page to the next. All layouts are available in high contrast like this example illustrates. The 4 location x 9 page – Eye-Gaze (d) version designed for students who can indicate choices using eye pointing.

Figure 3: Example of 3D Symbol

The simple layouts in the various open-source formats were aimed at increasing the teaching and learning opportunities for students who did not otherwise have access to personal AAC systems. If students have access to a more robust AAC system, or when they get access to such a desired system, the Project Core implementation model encourages use of each student's personal system to apply the targeted teaching practices. See http://www.project-core.com/app-and-sgd-product-keys/.

Professional Development

The focus of initial PD sessions was informed by the literature. As the project got underway, the focus and content of subsequent sessions were also informed by analysis of teacher self-assessments and classroom observations. All PD sessions focused on communication intervention using core vocabulary, with the specific content for each session emerging as a result of time spent in the school throughout the year as the research team observed, interacted with, and listened to the teachers and students. Table 1 offers a complete listing of topics that were covered during the PD sessions delivered to teachers participating in the current study, and the associated PD modules subsequently made available via the Project Core website after the initial modules were implemented, evaluated, revised, and implemented again in other research sites.

Table 1: Topics Covered and Associated Online Modules

Session #	Topic(s) covered	Associated online modules
1	• Overview of the development project • Overview of teaching principles: aided language input, core vocabulary, naturalistic teaching	• Project Core Overview
2	• Early forms of communication • The Communication Matrix • Importance of personal access to an AAC system with core vocabulary • Aided language input • Universal Core vocabulary formats • Examples incorporating Universal Core vocabulary into literacy instruction	• Beginning Communicators • Supporting Individual Access to the Universal Core • Aided Language Input
3	• Review of Universal Core vocabulary formats and importance of all students having personal access to an AAC system • Examples incorporating AAC and core vocabulary into common activities	• Universal Core Vocabulary
4	• Examples incorporating the Universal Core vocabulary into literacy.	• Teaching Communication During Academic Routines
5	• Review of design-based research goals • Facilitated exchange of examples of specific classroom examples	
6	• Use of core vocabulary during daily routines	• Teaching Communication During Daily Routines and Activities
7	• Attributing meaning • Encouraging versus requiring communication • Modeling communication versus managing behaviors • Ways to support communication of yes and no • Partner-assisted scanning	• Beginning Communicators • Aided Language Input • Supporting Individual Access to the Universal Core Vocabulary
8	• Incorporating the Universal Core vocabulary into literacy instruction: (a) Shared reading, (b) Predictable chart writing, (c) Independent writing	• Shared Reading • Predictable Chart Writing • Independent Writing

The approach and formats for PD were informed by researchers' reflections on their delivery of the initial content and facilitation of learning activities, observations of participant interaction during the face-to-face PD sessions, observations in the classroom after new intervention strategies had been introduced in the PD sessions, and follow-up conversations with teachers in their classrooms about questions, concerns, and perceived barriers to implementation. Teachers consistently expressed the desire for more examples and demonstration of the intervention strategies with students like those they teach, which the researchers addressed through the inclusion of scenario-based case examples. Additionally, teachers frequently had scheduling conflicts during the times the face-to-face group PD sessions were offered. This need for greater flexibility was ultimately addressed by designing the final PD in two formats: facilitated and self-directed. The facilitated format packages the materials needed to deliver the PD in a group setting, and the self-directed format provides online, on-demand access. See http://www.project-core.com/professional-development-modules/.

The aim of the current study was to evaluate and refine components of the Project Core implementation model as designed. The emphasis was on development and formative evaluation of the implementation model itself (Blasé et al., 2015). Data were gathered to evaluate the effectiveness of the professional development and adequacy of implementation supports and resources. The findings guided improvement cycles (see Blasé et al., 2015) aimed at building a final implementation model that is effective across educational settings (Anderson & Shattuck, 2012; Steketee & Bate, 2013). The data were extremely important for the intended purposes and provide preliminary evidence of the overall effectiveness of the implementation model.

METHODS

The study aimed to evaluate and refine the fit of the Project Core implementation model to the specific needs of classroom teachers and related classroom professionals working with students with significant cognitive disabilities and complex communication needs. The study took a participatory action research approach to guide the initial evaluation of the Project Core implementation model. Reflective cycles of observation and interaction, data collection, analysis, and application of findings were applied (Ozanne & Saatcioglu, 2008). The study was aimed at measuring observable changes in targeted teacher practices and student access to AAC after teachers had access to the implementation model. The participatory action research approach was critical to: (a) evaluating and refining the fit of the implementation model to the specific needs of classroom teachers, (b) evaluating changes in observable teacher practices and self-reported knowledge and skills after engaging in PD and using the materials included in the implementation model, and (c) gathering initial information on associated changes in observable student access to AAC and measurable changes in communication ability level. Mixed methods were used to investigate changes after classroom professionals had access to the training and supporting resources included in the implementation model. The study was guided by three primary questions related to teacher practices and one secondary question related to student outcomes, including: (a) did teachers increase their use of graphic symbols and aided language input strategies; (b) did teachers' self-perceptions of their ability to teach communication improve; (c) did teachers provide students with increased access to aided AAC (e.g., graphic symbols), and (d) did students achieve higher levels of communication?

Setting

The study was conducted in a public separate special education school in the southeastern US. Given that more than 90% of students with significant cognitive disabilities are educated in segregated classrooms or schools (Erickson & Geist, 2016; Kleinert et al., 2015), the site provided maximal access to a relatively large group of students with significant cognitive disabilities and complex communication needs and supported the evaluation of the model in a setting that was representative of the norm. The school serves approximately 130 students ages 3-22 with significant disabilities. The majority (> 90%) of students are eligible for free or reduced lunch. The reported race/ethnicity at the school level is White (40%), Black/African-American (33%), Hispanic (14%), and other (13%). There is a full-time principal, a curriculum coordinator, a team of full-time related service providers (3 SLPs, 2 occupational therapists, 3 physical therapists), a full-time nurse, and a team of part-time specials teachers (i.e., media, adapted physical education, art, and music). In addition, each classroom has at least one paraprofessional, as well as access to a floating paraprofessional to support personal care needs.

Participants

The participants included classroom teachers (*n* = 15) and students (*n* = 71). Initially there were 16 teachers, but one left the school in the middle of the year. On average, participating teachers were experienced special educators (*M* = 13.6 years; *SD* = 8 years). Student participants were in preschool (*n* = 32), elementary (*n* = 16), middle (*n* = 7), and high school (*n* = 16). Originally, there were 79 student participants, but 8 left the school during the year for a variety of reasons (e.g., family moved). All student participants had significant cognitive disabilities and were deemed eligible for special education services under a number of different categories including multiple disabilities (*n* = 20), autism (*n* = 17), developmental disability (*n* = 20), intellectual disability (*n* = 11), other health impairment (*n* = 1), hearing impairment (*n* = 1), and unknown (*n* = 1). Participating students represented racially and ethnically diverse groups, with the majority identifying as White (*n* = 35) or African-American (*n* = 20), and the remaining as Asian (*n* = 6), Hispanic or Latino (*n* = 4), multiracial (*n* = 4), American Indian or Alaska Native (*n* = 1), and one unknown. There were more male (*n* = 45) than female (*n* = 26) students in the study, which reflected the school overall. Baseline classroom observations and meetings with the school leadership team revealed that the majority of participating students (> 80%) did not have personal access to any form of aided AAC at the beginning of the school year.

Procedures

Delivery of Professional Development

Approximately 12 hours of PD were delivered by the research team over eight 1.5-hour face-to-face sessions. Each PD session included didactic sharing of information, videos, student examples, discussion, guided practice, and numerous activities. The research team met after each PD session to debrief on the session and gather researchers' insights on how well the content and examples provided were received by the teachers and to identify necessary revisions and additions (refer back to Table 1 for a complete listing of topics covered during the current study).

Data Collection

Classroom Observations. During the first month of the school year, researchers began conducting classroom observations. Observations applied the methodology of participant observation (Jorgensen, 1989) during 20- to 30-minute periods, with 141 observations completed across the 15 participating classrooms between the fall and spring of the school year. During the observations, researchers recorded descriptive field notes that provided a written record of what was happening in the classroom. These records included specifics about what and how teachers and students communicated and information about the environment itself. The observations were summarized later to determine the presence or absence of teacher and student behaviors including: (a) teacher attribution of meaning to students' communication attempts, (b) teacher use of graphic symbols, (c) teacher demonstration of use of core vocabulary, and (d) student access to AAC with core vocabulary. Interrater agreement was 86% when observation summaries were independently coded by research assistants and compared to initial data for 28% (*n* = 40) of the total classroom visits.

Teacher Self-Assessments. To gain insights regarding the overall impact of the PD on teacher knowledge and dispositions regarding the communication intervention, participating teachers were invited to complete a 12-question self-assessment at the beginning and end of the school year. Each question used a 5-point Likert-type scale asking teachers to report their level of agreement with each statement. Finally, all adult participants, especially the principal, team of speech-language pathologists, and a couple of teachers, interacted regularly with members of the research team. These unstructured interactions directed the focus of efforts in identifying and refining specific aspects of the communication instruction, the PD, and additional materials recommended for a complete implementation model.

Student Communication Matrix Profiles. Members of the research team completed a Communication Matrix profile (Rowland, 2004; 2011) for each student at the beginning and end of the school year. The Communication Matrix (Rowland, 2004; 2011) is a direct observational tool/behavioral inventory used to measure early communication behaviors, including those that occur before students begin to demonstrate symbolic communication understanding and use. The Communication Matrix includes a set of 24 yes/no questions that are dispersed across four major communication purposes (refuse, obtain, interact socially, and provide or seek information). Each yes response is then further defined using nine categories of communication behaviors (body movements, early sounds, facial expressions, visual behaviors, simple gestures, conventional gestures and vocalizations, concrete symbols, abstract symbols, and language) that occur at seven levels of communication complexity (pre-intentional behavior, intentional behavior, unconventional communication, conventional communication, concrete symbols, abstract symbols, and language). The use of core vocabulary is scored at level 6 for single word utterances and level 7 for word combinations. The researchers observed each student over multiple sessions and recorded all behaviors that were used independently (i.e., without teacher prompting or assistance). In an effort to reduce the risk of researcher bias, beginning- and end-of-year assessments for each student were completed by different members of the research team and the beginning-of-year assessments and scores were not reviewed prior to completing the end-of-year assessments.

Data Analyses

The study employed descriptive data analyses of frequency counts and percentages to describe changes in observable teacher behaviors, self-reported knowledge and dispositions, and provision of student access to AAC with core vocabulary. The non-parametric Wilcoxon signed-rank test was used to compare student Communication Matrix profiles at the beginning and end of the school year.

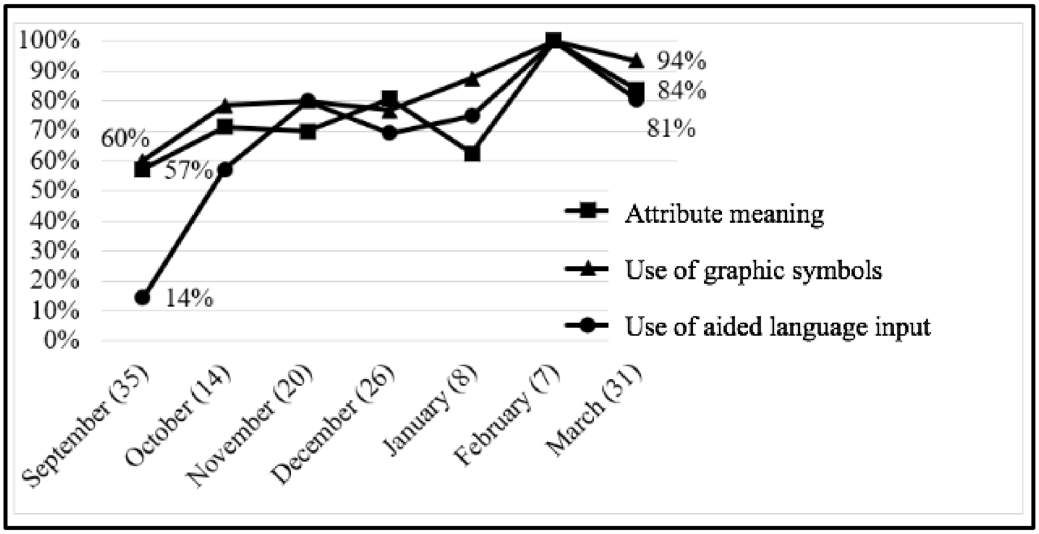
RESULTS

The results provide preliminary evidence of changes in teacher practices given access to the PD and supporting resources included in the implementation model. The results also document changes in student access to AAC and levels of communication after Project Core intervention practices were introduced.

Teachers

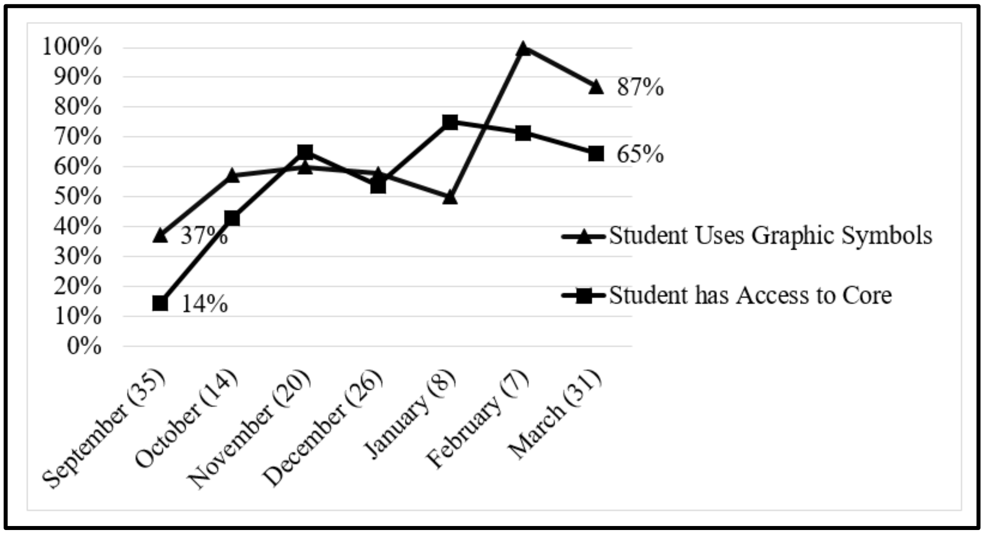
As indicated in Figure 4, frequency counts of teacher behaviors noted in the summaries of each participant observation session reveal that teachers increased their: (a) attribution of meaning to student behaviors (noted in 57% of observations in the fall and 84% in the spring); (b) use of graphic symbols (noted in 60% of observations in the fall and 94% in the spring); and (c) demonstration of core vocabulary (noted in 14% of observations in the fall and 81% in the spring). As indicated in Figure 5, teachers also increased the frequency with which they provided students with access to personal AAC systems with core vocabulary (noted in 14% of observations in the fall and 65% in the spring).

Figure 4: Classroom Observation of Teacher Behaviors



Note: Number of observations per month appear in parentheses.

Figure 5: Classroom Observation of Student Use of Symbols and Access to Core Vocabulary



Note: Number of observations per month appear in parentheses.

Teachers also reported higher levels of confidence in their skills. As reported in Table 2, teachers reported agreement or strong agreement with 71% of items at the beginning and 94% of items at the end of the school year on the self-assessment. Substantial shifts were noted for some items. For example, at the beginning of the year, only 40% stated that they agreed (20%) or strongly agreed (20%) with the statement, “I feel comfortable and confident in my ability to use AAC with my students.” By the end of the year, 90% reported agreement (50%) or strong agreement (40%). On a related survey statement, “I understand how to use a core vocabulary approach with my students who need AAC,” there were also notable changes. At the beginning of the year, teachers reported strong disagreement (11%), disagreement (33%), or uncertainty (44%), and by the end of the year, 100% reported agreement (56%) or strong agreement (44%).

Table 2: Teacher Self-Assessments

Question	***n***	**Pre**					**Post**				
		1	***2***	***3***	***4***	***5***	***1***	***2***	***3***	***4***	***5***
I have experience using symbols to support my students’ learning and communication.	11	0	0	0	4	7	0	0	0	3	8
My classroom provides a lot of opportunities for my students to communicate.	10	0	0	0	7	3	0	0	0	5	5
Academic goals are included on my students’ IEPs.	11	0	0	2	2	7	0	0	0	3	8
All my students have opportunities throughout the day to make meaningful choices.	10	0	0	0	1	9	0	0	0	3	7
I have experience using augmentative and alternative communication (AAC) with my students.	11	0	0	2	7	2	0	0	1	5	5

Question	*n*	Pre					Post				
		1	***2***	***3***	***4***	***5***	***1***	***2***	***3***	***4***	***5***
I feel comfortable and confident in my ability to use AAC with my students.	10	0	1	5	2	2	0	0	1	5	4
I understand how to use a core vocabulary approach with my students who need AAC.	9	1	3	4	0	1	0	0	0	5	4
I am able to recognize nonverbal communication behaviors in my students.	11	0	0	1	7	3	0	0	0	4	7
I know how to attribute meaning to my students' communication behaviors.	10	0	1	2	4	3	0	0	0	5	5
I regularly use symbols to model communication when interacting with my students.	10	0	2	0	6	2	0	0	0	5	5
I assess my students' communication skills regularly.	11	1	1	0	7	2	0	0	0	7	4
I have used the Communication Matrix to assess my students.	9	4	1	4	0	0	1	2	2	3	1
Percent Total Responses		5%	7%	16%	38%	33%	1%	2%	3%	43%	51%

Note: 1 = strongly disagree; 2 = disagree; 3 = unsure/neutral; 4 = agree; 5 = strongly agree.

Students

Participant observations also provided data regarding students' use of graphic symbols, which was noted in 37% of observations in the fall and 87% of observations in the spring. The Communication Matrix (Rowland, 2004; 2011) provides further evidence of positive change in student communication skills. At the beginning of the school year, participating students' highest level of communication abilities as measured on the Communication Matrix ranged from early pre-intentional communication behaviors (*n* = 7) to intentional, non-symbolic behaviors (*n* = 50) to beginning symbolic communication *(n* = 9). Behaviors required to score on the Communication Matrix were not observed for the remaining 5 students during pretesting. The mean highest communication level for the group at pretest was 4.3 (*SD* = 1.5). As reported in Table 3, there were increases in the number of students demonstrating intentional (level 3), conventional (level 4), and symbolic (levels 5, 6, and 7) communication skills from pretest to posttest. Furthermore, the mean highest communication level for the group at posttest was 4.9 (*SD* = 1.5). One-tailed Wilcoxon signed-rank tests at a significance level of 0.05 indicated that the median posttest ranks were statistically significantly higher than median pretest ranks for subscales measuring communication for the purposes of *Refusing* (Z = -1.702, *p* = .045, *r* = -.14), *Obtaining* (Z = -3.409, *p* < .001, *r* = -.29), and *Social* (Z = -3.990, *p* < .001, *r* = -.33). The differences on the subscale addressing communication for the purpose of *Information* were not statistically significant (Z = 1.155, *p* = .125, *r* = -.21); however, it is important to note that the information subscale can only be administered to students with communication behaviors at a conventional level or higher (levels 4, 5, 6, and 7) and therefore only included 24 students at pretest.

Table 3: Number of Students of Each Level on the Communication Matrix (Rowland, 2004; 2011)

	Refuse		Obtain		Social		Information	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Not Scored	5	1	1	0	8	0		
1	2	3	5	1	4	0		
2	5	2	13	6	9	6		
3	43	43	23	26	28	28		
4	7	10	6	4	16	26	0	0
5	3	3	7	13	0	3	10	17
6	6	8	13	11	6	8	14	13
7	0	1	3	10	0	0	0	3
Total	71	71	71	71	71	71	24	33

Note: Per the requirements of the Communication Matrix, the ability to communicate to provide or seek information is only measured at levels 4 and higher.

Mandated End-of-grade Tests in ELA

School performance on the state's required end-of-grade alternate assessment based on alternate achievement standards provides additional evidence of the impact of Project Core on this school. Prior to initiating the focus on communication and interaction through Project Core, there were no students in the school who achieved mastery on this required assessment. In fact, 93% of the students scored at the lowest level possible (level 1 on a 4-level scale). After one year of participation, these numbers shifted with 13% of the students achieving proficiency and 58% scoring at the lowest level.

Summary

Overall, these results are encouraging with regard to the potential for teachers to develop the knowledge, skills, and dispositions required to use AAC that features core vocabulary to teach students with significant cognitive disabilities to use symbolic communication. Increases in observable behaviors provide evidence that teachers successfully learned to use aided language input strategies, while attributing meaning to non-symbolic behaviors and providing students with access to their own AAC systems with core vocabulary. Additionally, teachers reported increased levels of confidence in their abilities to use and teach core vocabulary and AAC in the classroom. Importantly, the findings also suggest that these changes in teacher behaviors contributed to increases in student communication, including the use of graphic symbols on AAC systems.

OUTCOMES AND BENEFITS

The main outcome of the current study is a replicable implementation model aimed at addressing the persistent problem of limited access to aided AAC systems and communication intervention faced by many students with significant cognitive disabilities. The components of the implementation model were evaluated and revised and provide a replicable approach for related lines of research and development in assistive technology. The promising results provide preliminary evidence of the beneficial impact of the implementation model on teachers' perceptions of the value and relevance of the use of aided AAC and targeted communication intervention, their knowledge and skills for delivering access to aided AAC and foundational communication instruction, and observable changes in classroom practices and student access and use of aided AAC and core vocabulary to communicate.

DISCUSSION

The participatory action research study applied mixed methods to evaluate and refine an implementation model aimed at empowering classroom professionals to teach symbolic communication to their students with significant cognitive disabilities and complex communication needs. Specifically, the researchers sought to create an implementation model that increased the use of teaching practices positively associated with increased symbolic communication skills. The study supported the successful development of a sustainable implementation model (see http://project-core.com) and the mixed-methods evaluation provides important preliminary evidence that it was successful in improving teachers' knowledge and practices, as well as students' communication outcomes. Teachers with little confidence in the use of core vocabulary and AAC instruction prior to engagement in PD and the overall project made notable gains in the use of the targeted teaching practices.

These changes in teacher practices appear to have positively impacted their students' communication skills. This relatively large group of students with significant cognitive disabilities who had little to no conventional communication at the beginning of the school year made gains in their level of communication across multiple purposes: refusing, obtaining, and social interactions. Individual students may have benefited more from other communication interventions, but the universal approach described here allowed these teachers to improve the communication skills of large numbers of students in a relatively short period.

Students with significant cognitive disabilities are often faced with policies that call for them to demonstrate their ability to use an aided AAC device with voice output before they can receive one of their own (Center for Medicare and Medicaid Services, 2017). They also have limited time with professionals who can help select and teach them to use personalized vocabulary and AAC systems (ASHA, 2018). It should certainly be our collective goal to address both of these issues, but while we do, we must also work to ensure that all students have access to instruction that will help them communicate more successfully today and achieve maximal benefits when they do get access to appropriate technologies and highly qualified professionals in the future.

Ensuring that students have access to intensive and ongoing communication instruction is the long-term goal of the current series of investigations. By targeting teachers, we are maximizing the intensity and quantity of symbolic communication instruction that students will receive. The results of the current study suggest that special education teachers can develop the knowledge, skills, and dispositions required to teach communication using aided language input strategies and core vocabulary that can be integrated into naturally occurring activities throughout the day.

The core vocabulary selected for the current study was intended to provide teachers and their students with significant cognitive disabilities with access to a set of words and symbols that could be used to communicate across the school day. In general, core vocabulary can be used to communicate for a broad range of purposes in a variety of contexts. In the current study, the use of the Universal Core vocabulary empowered teachers to target communication as part of their academic (e.g., shared reading) and non-academic (e.g., mealtime) routines. Prior research with students with significant cognitive disabilities has emphasized the use of personalized vocabulary (Romski et al., 2006) and often focused on teaching single communication purposes such as requesting (Davis et al., 2000; Frost & Bondy, 2002). The current study offers a new direction for this line of research by demonstrating the potential impact of an open-source, universal set of core words as an initial lexicon for students with significant cognitive disabilities that allows their teachers to demonstrate and support symbolic communication throughout the day. More research is certainly needed to make rigorous claims of causation; however, given a history of minimal to no gains in symbolic communication after several years of school for 55% (*n* = 39) of the student participants, including 32% (*n* = 23) in middle or high school, this preliminary evidence is encouraging.

Limitations and Future Directions

The findings are limited by the lack of a comparison group, the broad range of student disability and special education eligibility categories, the restrictive setting, and the risk of observer bias, given the lack of data collectors who were blind to the targeted intervention. The design aspects of the current study required partnership between the researchers and study participants and a willingness to actively support the shared development work; thus, the risk of researcher bias could not be removed from the process (Anderson & Shattuck, 2012). However, this study provided the research team with important information needed to create PD modules, self-reflection and observation tools, and other implementation supports that will add structure and control for future research aimed at evaluating the impact, scalability, and sustainability of the Project Core implementation model while more directly controlling for researcher bias.

The findings are also limited by the way the Communication Matrix was used. It is unusual for members of the research team to complete the Communication Matrix without consulting all members of the child's team, including families and caregivers outside of school. A number of factors contributed to the decision to use the assessment in this way. First and foremost, training the school teams to conduct the Communication Matrix would have interfered with the goals of the study because it may have led teachers to believe the goal was improved performance on the Communication Matrix rather than the successful development and evaluation of an implementation model that allowed them to teach symbolic communication. Other factors that influenced the decision included the large number of students enrolled and a desire to have the Communication Matrix completed in a consistent manner across all student participants as early as possible in the school year. Per the guidance offered by the developers of the Communication Matrix (Rowland, 2012), we did not attempt to engage in any sort of interrater reliability as the tool "does not lend itself to traditional measures of interrater reliability" (p. 3). In the end, this preliminary evaluation study revealed that teachers benefited from learning more about the Communication Matrix, and training for teachers on its use is now incorporated into the Project Core implementation model.

CONCLUSION

Students with significant cognitive disabilities and complex communication needs require intensive and repeated instruction to learn. While most special education teachers do not receive pre-service training on how to meet the communication needs of students with significant cognitive disabilities, they typically spend many more hours with their students each day than SLPs. The current study provides preliminary evidence that special education teachers can develop the knowledge, skills, and dispositions required to deliver symbolic communication intervention. The study also provides preliminary evidence that students with significant cognitive disabilities who have not developed conventional or symbolic forms of communication can continue to learn and develop as communicators as a result of their teachers' efforts. While the guidance of specialists like SLPs is important to realizing the full benefits of communication interventions such as the one described here, it is encouraging to find that teachers can move students toward conventional and symbolic communication as part of their everyday instruction.

DECLARATIONS

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Voices from Academia

A Model of AT and AAC Service for Adults with Developmental Disabilities

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ABSTRACT

A group of 63 adults with intellectual and developmental disabilities, many of whom (75%) demonstrated complex communication needs, was provided with assistive technology that was selected based upon their personal goals. The aim was to discover whether assistive technology would improve quality of life for participants and allow them to do things they could not do previously. Performance gains were evident in every case that involved a performance goal. A quality of life survey indicated that many participants felt less lonely, saw themselves as more helpful, and were more inclined to be involved in self-advocacy following the intervention. While AT services were provided for 62 of the 63 adults in the project, 35 participated in the research and completed the survey. A multi-disciplinary model for service delivery of assistive technology and augmentative and alternative communication emerged from this project that focused on improving performance on skills important to each individual and enhancing quality of life.

Keywords**:** assistive technology, complex communication needs, intellectual disability, developmental disability

INTRODUCTION

Adults with intellectual and developmental disabilities are an underserved group in our society. When dismissed from the public school system at age 22, these individuals generally experience difficulty transitioning to the larger community and to the world of work. Unemployment and inactivity are often exacerbated by coexisting health issues including communication disorders (Mirenda, 2014; Taylor & Hodapp, 2012). Largely dependent upon family for support, their isolation takes a toll on their families as well. Most wait for some time to receive state funding (often Medicaid waivers) to enable their participation in a day program or for other support for their daily care (Braddock et al., 2008). Fuhrmann et al. (2018) and Young (1990) suggest that there are barriers and hindrances in the form of social conditions in the environment that obstruct and prevent individuals with developmental disabilities from full participation in the communities around them. These obstacles inhibit their full participation and the development of relationships.

The majority of individuals with intellectual and developmental disabilities also have challenges with verbal communication (Mirenda, 2014). This means that they do not have functional speech sufficient to engage in everyday communication activities (Stancliffe et al., 2010). Difficulty with communication limits individual choice and self-determination and defines educational opportunities (Brault, 2012). It also inhibits social connections with individuals in their communities and undercuts prospects for obtaining meaningful employment (Butterworth et al., 2012; Davies et al., 2002). Kozma et al. (2009) reported that, overall, the quality of life for individuals with developmental disabilities appears to be inferior to that of people in the general population.

Recognizing these factors, the Georgia Department of Behavioral Health and Developmental Disabilities (DBHDD) and Georgia Tools for Life (TFL) at Georgia Tech sought to explore how assistive technology (AT) might be applied in the lives of individuals with intellectual and developmental disabilities to foster a measure of independence and self-reliance. These two organizations embarked on a three-year effort to identify and work with individuals who might benefit from using AT. The presence of a large proportion of individuals with Complex Communication Needs (CCN) required the integration of augmentative and alternative communication (AAC) systems and strategies to meet the needs of these individuals. A multi-disciplinary team which included AT specialists, speech language pathologists (SLPs), an occupational therapist (OTs) and rehabilitation counselors met with individuals with intellectual and developmental disabilities and their families to discover what skill or goal they personally wanted to achieve. The team worked with the individuals to select AT and AAC tools and strategies that would help them progress toward their goals and provided training, modeling and support.

TARGET AUDIENCE AND RELEVANCE

The target audience for this paper includes individuals with intellectual and developmental disabilities themselves, their families and friends, and all who serve them. It also includes the teachers and administrators, transition coordinators, vocational rehabilitation counselors, and support coordinators who work with them. Those who shape or influence public policy would find this paper useful as well. The hopeful vision espoused by home and community-based care (HCBC) advocates would be reinforced by the identification of tools that foster individual independence, self-reliance, and connection to the community, and that are focused on the goals of the individual.

LITERATURE REVIEW

While progress has been made over the past three decades to move individuals with intellectual and developmental disabilities from institutional settings into the community (Mirenda, 2014), integrating these individuals into their communities remains a challenge (Chowdhury & Benson, 2011). People with developmental disabilities are often unemployed or underemployed (Hirst, 1987; Howlin, 2005; Kuh et al., 1988). A 2015–2016 survey indicated that only 19% of individuals with developmental disabilities were employed (National Core Indicators, 2019). The majority of adults with developmental disabilities are idle and live at home in the care of their parents (Braddock et al., 2008; Taylor & Hodapp, 2012). Research suggests that people with intellectual and developmental disabilities experience adverse health outcomes more frequently than typical peers (Helmsley & Balandin, 2014; Lipscomb et al., 2017). Because they generally have low incomes, most receive medical care under the state Medicaid program rather than through private insurance (Reichard et al., 2011). We observed that many of the participants in our study demonstrated a sedentary lifestyle, which may contribute to poor health conditions. The communication challenges that many in this group face complicate what is often an already daunting set of medical problems. An individual’s inability to tell caregivers what is wrong or where it hurts, or to share with medical providers the nature of the problems they experience, often results in inadequate health outcomes (Rose et al., 2005; Taylor & Hodapp, 2012).

As many as 81% of people with developmental disabilities are considered to be living below the poverty line (Butterworth et al., 2012). They are generally living at home, where family members serve as care providers. These care providers are generally unpaid. Many people with intellectual and developmental disabilities in our study were on a *planning list*; waiting for Medicaid waiver funding. Without this waiver funding they are unlikely to be able to afford any sort of independent living arrangement or participation in a day program. Many have been waiting for a decade or more.

The use of AT for persons with intellectual and developmental disabilities has been shown to promote independence and enhance the quality of performance on daily tasks (Davies et al., 2002; Gilson et al., 2017; Wehmeyer et al., 2006). Cell phones, tablets and other portable and wearable devices have been used to demonstrate that individuals with intellectual and developmental disabilities can do tasks more independently, reinforcing the autonomy of the individual and reducing the level of required supervision (Cihak et al., 2008; Ferguson et al., 2005; Furniss et al., 2002; Mechling, 2011; Riffel et al., 2005). Apps and systems have been developed that provide prompting for such tasks as taking medication, and performance of daily tasks by providing step-by-step visual and auditory support for successful task completion (Cannella-Malone et al., 2006; Davies et al., 2002; Riffel et al., 2005; Van Laarhoven, et al., 2007). Further, there is an emerging body of research supporting the use of AT to successfully support these individuals in the workplace (Morash-Macneil et al., 2017). However, care must be given to carefully considering the needs of the individual, and identifying AT approaches that will provide support for personally selected goals (Scherer, 2005).

Many individuals with developmental disabilities also have difficulty with communication (Mirenda, 2014). Only about 10% of those with CCN use AAC systems or sign language to communicate, leaving the remaining individuals with CCN with only gestures, behaviors and unintelligible utterances (Kozma et al., 2009; Lakin et al., 2011; Stancliffe et al., 2010). Many have transitioned out of the school system without the communication tools they need (Light & McNaughton, 2015).

AAC systems and supports have been found to enhance engagement and participation in learning as well as to foster social engagement with peers (Mirenda, 2014). Properly selected, implemented, and supported AAC systems can lead to significantly enhanced communication ability (Gustavsson et al., 2005; Näslund & Gardelli, 2013; Moser, 2003; Shakespeare, 2006).

There is an ever-increasing corpus of literature that suggests that AAC tools and strategies can make a difference in the lives of people with developmental disabilities (Light & McNaughton, 2015; Lund & Light, 2007; Mirenda, 2014; Roche et al., 2015; Snell et al., 2010). Selection and implementation of an AAC system is an individualized process (McNaughton et al., 2019). Successful implementation of AAC necessitates a team approach to insure an all-inclusive consideration of the individual’s needs, interests and concerns. In addition to the SLP, this includes family members and care providers, and others in the individual’s circle of care (e.g., other therapists, medical professionals, educators, etc.; Beukelman & Mirenda, 2013; DePaepe & Wood, 2001). Properly selected, implemented, and supported AAC systems can lead to significantly enhanced communication ability (Gustavsson et al., 2005; Moser, 2003; Näslund & Gardelli, 2013; Shakespeare, 2006).

There have been a number of obstacles to AT and AAC use among people with intellectual and developmental disabilities. First, many people with intellectual and developmental disabilities are not familiar with AT or AAC and are not aware that these tools could help them (Light & McNaughton, 2013). Second, the cost of systems and access to funding have been major factors that have limited acquisition of these tools. Third, a lack of support and training has resulted in the abandonment of many AT devices and AAC systems. The impact of these factors is compounded by difficulties in communication and a general lack of advocacy in making their needs known.

METHOD

Measuring AT Outcomes from a Person-Centered Approach

Georgia Tech and DBHDD approved the details of a contract in April of 2017. Shortly thereafter, a “referral portal” was launched through which the agency’s Program List Administrators (PLAs) could refer individuals to the program. The first referrals appeared in May of 2017.

The project was designed to take a person-centered approach. Once an individual was referred, the team at TFL would conduct an interview to learn more about the individual. This included a discussion with the family or care providers. On the initial visit, the team, individual, and family came together to explore the individual's personal dreams and desires, abilities, and challenges. They sought to identify some skill or goal that would be meaningful to the individual. These goals focused on independence and varied from engaging in a preferred activity in their free time, to tracking their blood pressure, to communicating regularly with family or friends. At this point, pre-intervention data was collected about performance and satisfaction. The team then met with the individual at least twice more to provide and implement AT that would address the skill or goal. The second visit focused on the provision of AT that addressed the skill or goal on which the individual wanted to focus. Examples of AT items provided are listed in Table 1. Demonstration and training were important parts of this visit. The third and final session was used to explore how the AT had addressed this goal or skill. Data were collected on performance and satisfaction. Visits with individuals were conducted in their homes to provide a natural setting that would be comfortable for the individual and instructive to the team.

Table 1: Examples of Technologies Provided by Area of Need

Area of Disability	Examples of AT Provided
Communication	• Tablet with communication app • Static display AAC devices • Communication wallets with communication symbols • Plexiglas eye-gaze board • Emergency ID bracelet
Mobility	• Adapted can opener • Modular hose for mounting devices and controls • Digital home assistant and smart plugs for voice activation of appliances • Switches and switch interfaces
Vision	• Currency reader • Voice labelling system • Picture phone with enlarged speed dial • Braille labeler • Enlarged keyboard
Hearing	• Pocket-sized sound amplifier • Doorbell that sends text message to resident • Flashing door- bell alarm • Bed-vibrating alarm clock
Activities of Daily Living	• Rocker knife Adaptive cutting board • Adaptive scissors • Weighted mug • Automatic toothpaste & soap dispensers • No-tie shoelaces • Long handle shower sponge
Cognition	• Cognitive prompting tools • Audio reminder devices • Personal schedule apps • Vibrating reminder watch • Automatic pill dispenser • Blood pressure tracker

Joe A. was one of the individuals served by this project. Joe was a 28-year-old man with partial paralysis. He wanted to gain more independence with his daily tasks and recreation. The project team provided and trained Joe with AT tools that included a soap dispenser, a toothpaste dispenser, and a long-handled bath brush, all of which he could operate with just one hand. Additionally, a cellphone mount attached to his wheelchair and a "smart speaker" enabled Joe to better access his world by using his voice. He was also able to play video games with greater independence and less frustration.

Sara L. was another individual who participated in this project. Sara lives at home and has limited mobility. Once in bed, she cannot turn lights on or off or control other appliances. The team equipped her with a smart home assistant device and smart plugs for her lighting fixtures and appliances. She was able to control her environment by herself, which she said gave her a greater sense of independence and security.

This project incorporated a research component that measured two elements: (a) the performance changes in an individual with regard to the skill or goal, and (b) the satisfaction and quality of life of the individual and the engagement of the family/support person. In order to operationalize the changes in performance, the team adapted the Student Performance Profile (SPP; see Appendix A) developed by Watson et al. (2010) for use with an adult population. In order to collect data on quality of life and satisfaction, the research team was asked to develop a survey based upon the National Core Indicators (https://www.nationalcoreindicators.org/). This survey became known as the *Foundational Measures Survey* (Satterfield, et al., 2017; see Appendix B). The paper form of the survey was available in May of 2017. An accessible iPad app version of the survey was released for use in August of 2017.

Adapted Student Performance Profile

The team adapted the SPP (Watson et al., 2010) as a protocol for collecting pre- and post-intervention performance on skills important to the individual. This instrument was selected because it permitted the collection of outcomes data on performance changes across a range of different AT devices. Progress in the use of an adapted can opener and progress using a tablet with a communication app would appear to be very different things. However, the SPP allows the researcher to identify a task-related goal and measure the degree to which the individual can perform the task independently before, and then after, the implementation of the AT. The SPP also aids the team in examining other possible influences other than AT that may have influenced the evident progress.

Individual goals involving targeted skills or tasks were identified using a user-centered approach. A baseline measurement of an individual's ability to perform a task was taken before the AT intervention was presented. The scale was a simple 5-point Likert scale where 1 represented "not able" (successful on less than 10% of attempts), 2 represented "seldom able" (successful on between 10% and 40% of attempts), 3 represented "sometimes able" (successful on between 40% and 60% of attempts), 4 meant "often able" (successful on between 60% and 90% of attempts), and 5 represented "fully able" (successful on between 90% and 100% of attempts). The team included data collection about care provider engagement as well.

Foundational Measures Survey/National Core Indicators Survey App

The research team was charged with measuring the quality of life and satisfaction of individuals and their families in the context of the National Core Indicators (NCI; https://www.nationalcoreindicators.org/). Finding no NCI-based instrument designed specifically for sampling the perceptions and responses of individuals with intellectual and developmental disabilities, the team set about to design a survey that addressed the anticipated outcomes of the project via elements of the NCI. With the help of AbleLink Technologies, an accessible iPad app was created for the participants to use. The app was designed to present questions with auditory and visual support with limited text. Each of the 35 questions provided a 5-point Likert scale, where 1 was “strongly disagree” and 5 was “strongly agree”. The measure has five sub-scales representing key theoretical constructs: Relationships, Satisfaction, Self-Determination, Community Inclusion, and Health, Wellness and Human Rights. The FMS was presented twice, once pre-intervention and once post-intervention. To differentiate this instrument from the original NCI measure, it was named the Foundational Measures Survey (FMS; see Appendix B).

The app was designed to accommodate the individual participants to the greatest degree possible. If the individual could complete the survey for themselves, the team would facilitate their use of the app. If the individual was unable to complete the survey, a paper version was provided for the care provider to complete. The survey was presented at the outset of an individual’s participation in the project and again at the end, providing a pre- and post-intervention view of the individual’s perceptions on each of the relevant foundational measures.

Participants

The original target population was that of adults with intellectual and developmental disabilities who were on the p*lanning list* in Georgia and awaiting the Medicaid waiver. Participants had to be at least 18 years old and out of school, since public education is also a source for AT devices and services. The project sought to avoid any duplication of services.

Partway into the project, a subset emerged from among the target individuals. This group of individuals was comprised largely of adults with CCN. These adults were in a particularly awkward position because of their inability to address their daily communication needs effectively by speech alone. It was unclear whether participants left high school without an effective communication strategy in their transition plan, but it was evident that each one was now without a satisfactory solution for their communication challenges. At this point in their lives, there are no longer systems of support in place to pay for AAC evaluations or devices, or to provide ongoing therapy support. It is widely known that these communication challenges negatively impact multiple domains, resulting in extremely low rates of employment (McNaughton & Nelson-Bryen, 2002; 2007) and poorer health care outcomes (Helmsley & Balandin, 2014). Most significant of all is the fact that the challenges preclude access to the foundational right to communicate their hopes, dreams, needs, and wants, as well as their ability to connect with their family, friends, and community (McEwin & Santow, 2018; McLoud, 2018).

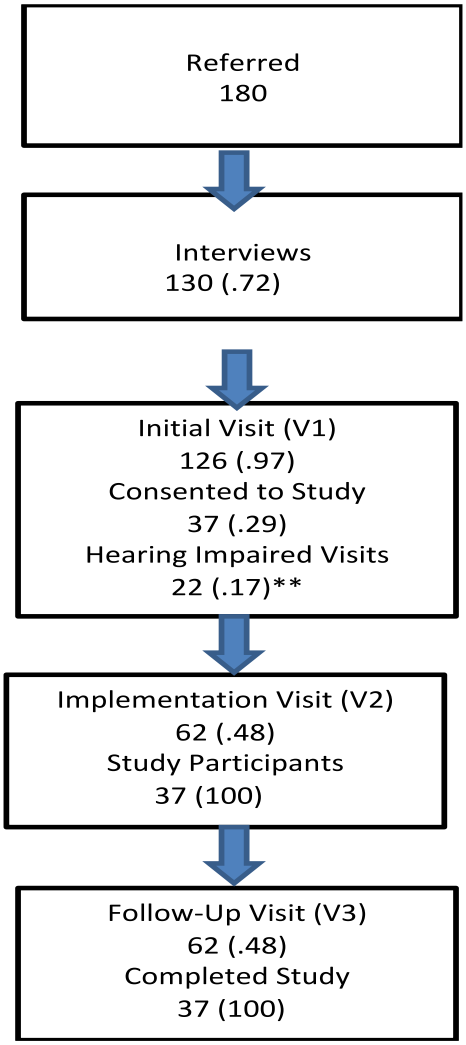
There were 180 individuals who were referred by the agency with a variety of needs (see Table 2). The team was able to reach and conduct intake interviews with 130 of the referred individuals. In all, the team made 270 face-to-face visits, each involving two team members for a total of 440 member contacts. These visits included 126 AT consults, 62 implementation of AT visits, and 83 follow-up visits and final visits to collect endpoint data. Orders for AT products were placed for 62 participants.

Table 2: Referrals by Region by Identified Area of Need*

Referred	**Communication**	**Mobility**	**Vision**	**Hearing**	**Activities of Daily Living**	**Cognition**	**None**
180	135	48	24	32	54	39	15
Percent of those referred	75.0%	26.67%	14.20%	17.77%	30.00%	21.66%	8.87%

**A number of individuals were referred as having multiple areas of need.*

Figure 1: DBHDD Study Flow – Project Visits* by Tools for Life Team



**Each visit involved two (2) members of the TFL team.*

***Consult only, AT provided by another entity.*

Of the 126 individuals the team was able to visit, there were 83 who completed the project. Of this number, 37 agreed to be research participants. Participation in the research was optional. The team provided the AT consultation, goal identification, implementation of the identified AT, and the support and training to all individuals, whether they took part in the research or not. As shown in Figure 1, 22 individuals were hearing impaired and by contract received consultations only with AT provided by another entity.

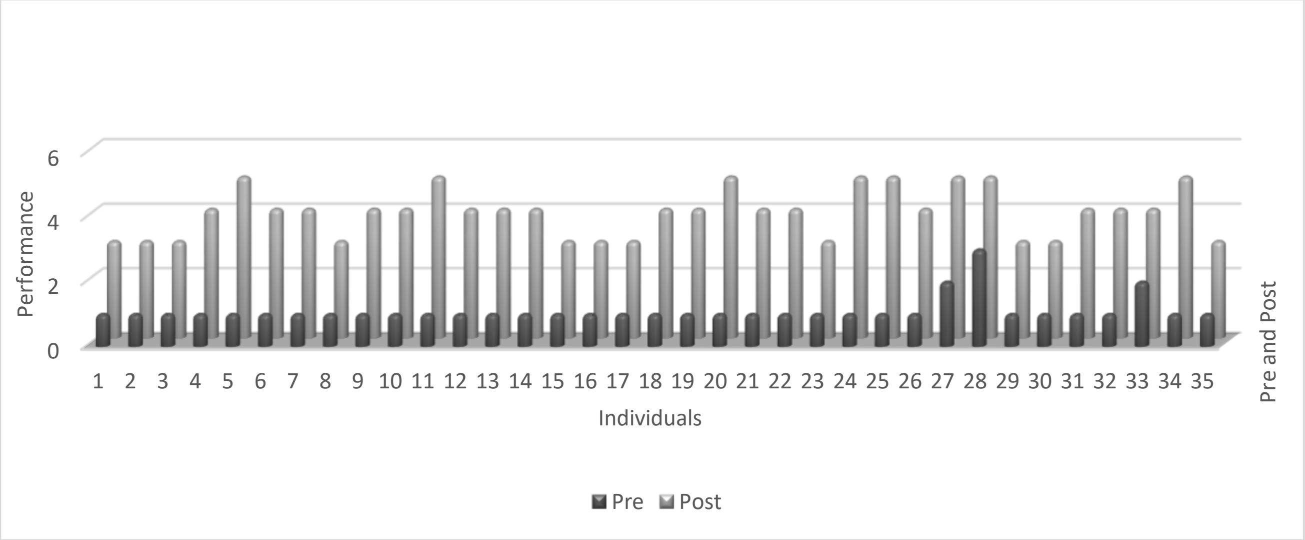
Analysis and Results

There were two research questions being explored in this project. These related to performance and satisfaction or quality of life.

Performance

The first research question asked whether the introduction of AT could help adults with developmental disabilities acquire skills or enhance the performance of tasks that were important to them. A total of 35 participants in this project had performance goals. To measure progress, the adapted SPP was administered during the initial visit and again during a follow-up visit after the AT was implemented. Every one of the 35 individuals demonstrated improved performance over the course of the project. Figure 2 presents a view of progress made by individual participants as measured by the 5-point scale provided by the SPP framework described above.

Figure 2: Performance Before and After Introduction of AT by Individual



Based upon this scale, the mean improvement for all participants was 2.83. The performance gains by disability area by the end of the project are shown in Table 3. Individuals with CCN demonstrated improved performance at slightly less than the mean (2.69) for the group.

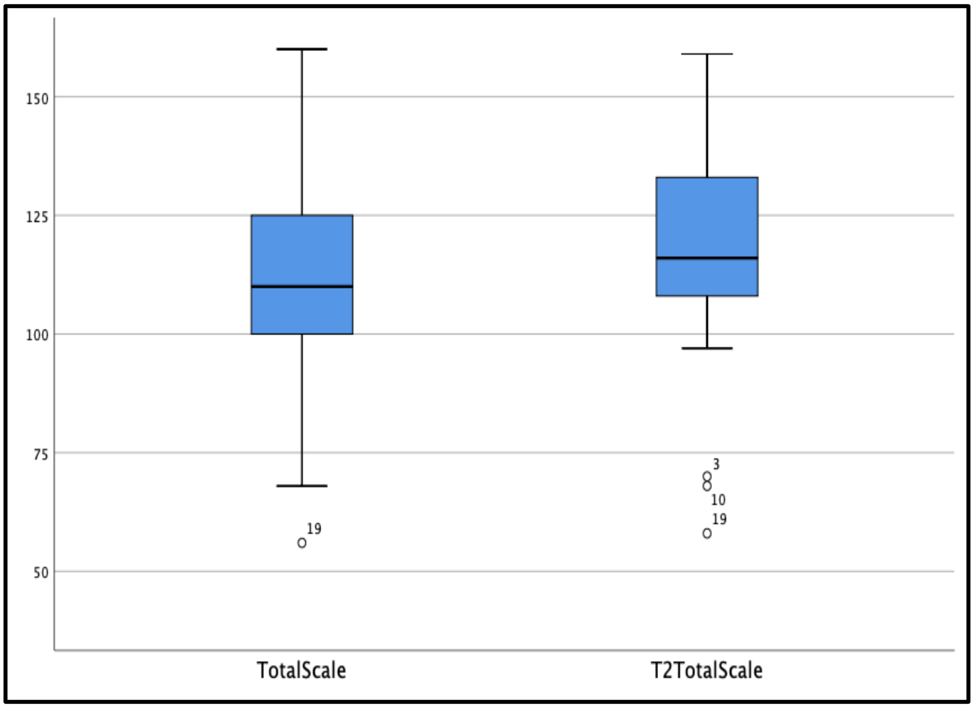
Table 3: Performance Gains by Disability Area by End of Project (scale of 1 to 5)

Area of Disability	**Communication**	**Mobility**	**Vision**	**Hearing**	**ADLs**	**Cognition**	**Not Identified**
Change from Baseline to Final	2.6897	2.7273	3.0000	3.0000	2.6364	3.0000	2.0000

Quality of Life/Satisfaction

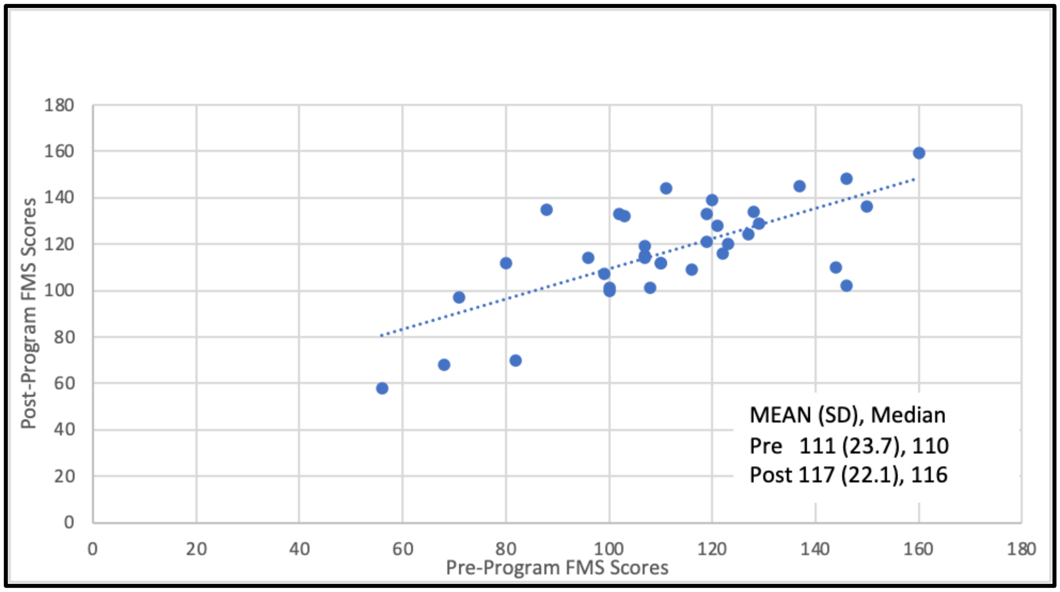
The second research question sought to discover whether the introduction of AT would make a difference in the individual (and family's) level of satisfaction and quality of life as reflected in the National Core Indicators (NCI). There were 35 individuals (or their care providers) who completed both pre- and post-surveys. Scores for the FMS total composite scale were computed, and the distributional properties examined suggesting non-normality and the subsequent use of non-parametric statistics. FMS scores ranged from a low of 56 to a high of 160 before the program and a low of 58 to a high of 159 after. The boxplots in Figure 3 highlight the change in the distributions of pre-post FMS scores.

Figure 3: Box Chart Comparing Pre and Post Responses to Foundation Measures Survey



A Wilcoxon Signed Rank Test (the NPar approximation of a paired *t*-test) revealed a statistically significant increase in total FMS scores following participation in the program, $z = 1.98$, $p < .05$, with a medium effect size ($r = .40$). The median score on the FMS scale increased from pre-program (*Mdn* =110) to post-program (*Mdn* =116). Sixty-five percent of participants increased their scores following participation in the program (see Figure 4). All data analyses were performed using IBM SPSS Statistics for Macintosh (Version 27).

Figure 4: Scatterplot of Pre and Post Program Foundational Measures Survey Scores (n = 35)



Descriptive In-Depth Analysis of Individual Survey Items

We calculated change scores to further descriptively examine some of the individual survey items that changed following the introduction of AT. As shown in Figure 3, the survey items that presented perhaps the most intriguing changes were: the drop in average response to the statement “I feel lonely” and increases in the average response to the statements about helping others, liking technology, having choices regarding social media and the community, participation in self advocacy, and feeling safe at home.

Taken together, these responses indicate an elevated sense of agency and personal empowerment. The concepts of helpfulness, self-care, and self-determination are also reflected in these responses. While the individual items do not stand on their own, they do shed light on and support the significant finding of change in the FMS composite scores.

Two Items of Note. First, there were several individuals who received AT that addressed self-care (e.g., blood pressure tracker, automatic pill dispensers, etc.) that allowed or influenced individuals to monitor health conditions and to take their medications independently and appropriately. As such, the increase in the average responses to this question tends to confirm the success and the usefulness of this intervention. They also confirm the team’s recorded observations of individuals’ successes at using these tools. As this was a subset of the full group of survey respondents, the relative impact of this intervention upon the total survey result is noteworthy.

Second, our team made notes in our data collection that some individuals had difficulty with some of the vocabulary we used in specific survey questions. Some of the individuals did not appear to understand the concept of self-advocacy. Our team took time to explain this, as it is such a fundamental concept. It is possible that the fact that we emphasized this by spending extra time on it may have influenced the result in this survey. But the relatively sizeable increase in the responses following the AT interventions is intriguing, and suggests this be studied further.

We also observed some other curious trends at the individual item level: decreases in average response to the statements regarding feeling connected with families and friends, satisfaction with the support received, and feeling respected in the day programs and at home.

The decrease in levels of satisfaction in these areas is interesting. Perhaps they are indicative of increased expectations in light of greater independence. The team came away with the sense that some individuals appeared empowered by the AT that they had been provided. We wondered if this sense of empowerment led them to recognize that something was missing in the area of self-determination. It is possible that the lower ratings on these items reflect an expression of frustration and the desire for greater autonomy. Given that care providers had now experienced the difference that the AT could make, we wonder if their eyes had been opened to greater possibilities. It is also possible that caregivers viewed the individuals in a different light, having observed their success and witnessed their expression of preferences not previously anticipated. These areas all warrant further study.

Care Provider Satisfaction and Engagement

Care providers for the individuals in this study were important stakeholders in this process. Most were family members providing unpaid support. With very few exceptions, these were very selfless and committed people. In this project, the response of the care providers was enthusiastic. Most pitched in and supported the intervention. When asked about their level of satisfaction with the AT introduced, 60% stated that they were highly satisfied, 40% reported that they were satisfied, and none reported being unsatisfied. As for the services provided by the research team, 68.57% reported being highly satisfied and 31.43% said they were satisfied. Again, none reported being unsatisfied. Results of the care provider survey are displayed in Table 4.

Table 4: Care Provider Satisfaction with Project

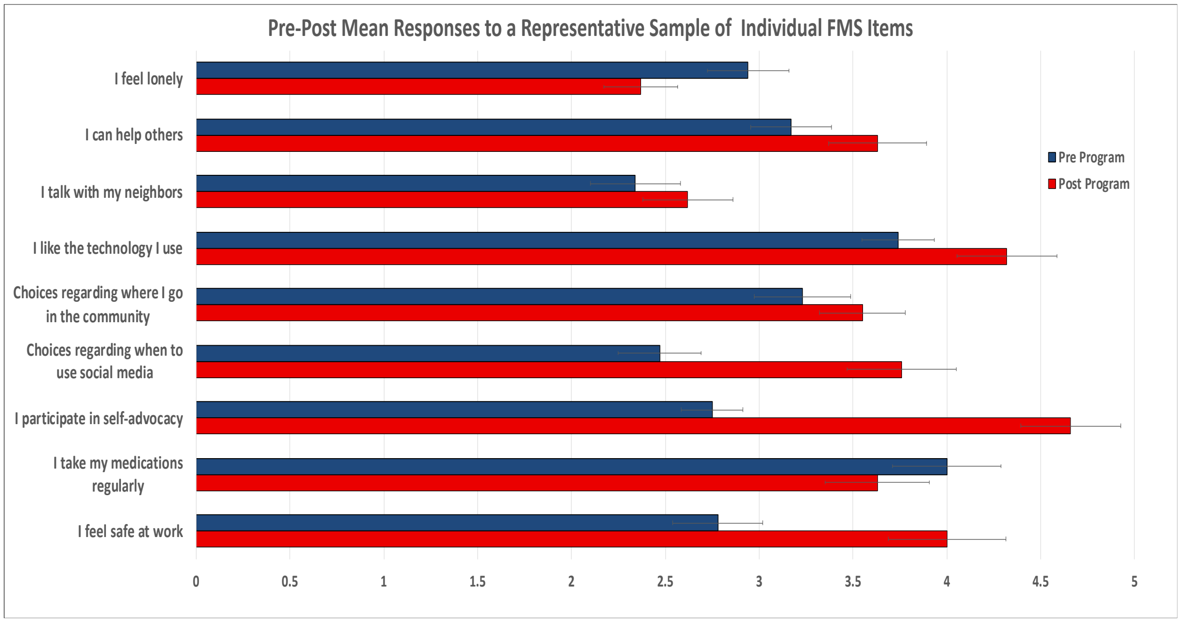
	Care Provider Device Satisfaction		**Care Provider Satisfaction with Services**	
Highly Satisfied	21	56.57%	24	64.86%
Satisfied	14	37.84%	11	29.73%
Unsatisfied	0	0.00%	0	0.00%
No Response	2	5.41%	2	5.41%

Discussion

Our study found that the individuals in our project were reflective of the profile of people with intellectual and developmental disabilities depicted in the research literature. Most were not working or attending a day program. Many were cared for by family members. Most lacked the resources to enable them to live in a more independent setting or the support to engage with their community more regularly. The majority were sitting at home and not physically active. A large proportion of them were persons with CCN who did not express their preferences and needs effectively. Because these individuals were waiting for Medicaid waiver funding to expand their options, the concept of providing AT made sense as a way to help these individuals achieve some measure of greater independence, self-determination, or connection to their community.

The project was conducted on a person-centered basis. The focus of the AT provided and the research data collected was based upon skills and goals important to each participant. The team sought to collect data that could be gathered in such a way as to measure individual progress in terms of performance as well as to measure satisfaction and quality of life. The results from the performance data collected indicate a high degree of initial success. Every individual who had a performance goal demonstrated progress. There were several items from the Foundational Measures Survey that were found to be worthy of notice (see Figure 5). These findings indicate that participants: 1) felt less lonely, 2) felt that they were more helpful, 3) liked the technology they were using, 4) were making choices with their technology (use of social media), and 5) felt they were advocating for themselves. Other results of the Foundational Measures Survey suggest that participants felt a greater sense of independence and empowerment as well as an emerging desire to experience independence and express preferences in new areas.

Figure 5: Comparison of Pre and Post Responses to FMS for Selected Questions



CONCLUSIONS AND FUTURE STUDY

The Emergence of a Model for Serving Adults with DD

What has emerged from this project is a model for addressing the needs of adults with intellectual and developmental disabilities through the use of AT. First, the model is person-centered, in that it is built around an intervention that supports a goal of importance to the individual. Second, the model is interdisciplinary, in that it involved a team of experts across multiple domains. The TFL team consisted of SLPs, OTs, AT practitioners, and rehabilitation counselors. The ability of the Tools for Life team to call upon experts from these different disciplines to shape a team around the needs of each individual proved invaluable and contributed to the progress observed in the individuals served.

The model suggests that an expert team working over the course of several visits to fashion and implement a customized solution and train the individual and the team to support the implementation can be effective. Such an approach can result in enhanced quality of life for the individual and their care providers. The length of the study provides no insight into long-term impacts, however. This should be examined in future studies of this model.

This study did not delve into the reasons why, out of the original 126 individuals, only 83 completed the project, or why only 37 agreed to take part in the research. Questions about what was common among those who participated, and among those who did not, could be explored and discussed as a direction for future research.

The fact that the team included speech-language pathologists was vital to the success experienced with individuals with CCN. That their communication difficulties were a central barrier to achieving their personal goals required skilled and experienced support. Some of these participants required additional visits beyond the three that were contemplated. Nevertheless, these individuals experienced similarly successful performance outcomes.

This article describes one model for delivering services to individuals with intellectual and developmental disabilities. There may be other methods of service for this group emerging. Future studies might look at what other approaches to support for this group might exist. Perhaps a hybrid method could be developed.

Limitations of This Study

This research was constrained by the resources of the sponsoring agency. The project was halted in response to mandated statewide budget cuts. As such, there was no provision for long-term follow up to see how participants' lives had evolved following the introduction of AT. It would be valuable to determine whether there was a need for follow-up support and training, whether there was continued use of the AT, and to what degree the indicators of satisfaction and quality of life in the Foundational Measures Survey were impacted.

The results of this project appear very positive. This study explored performance gains and customer satisfaction/quality of life. Gains were evident in both areas. However, the size of the sample was limited for such a diverse set of represented disabilities. A larger study, which included larger numbers of participants in each of the disability groups, or a focused study on individual disability groups, might produce more targeted insights.

The Foundational Measures Survey was developed by the research team in response to a requirement of the sponsoring agency. As the development of a tool for sampling of quality of life for people with intellectual and developmental disabilities is an involved process (Claes et al., 2010), the use of a survey created specifically for this study should be noted as a limitation. The Foundational Measures Survey was used by many, but not all, of the participants in this study. The team suggested that a review of the survey language, looking for even more simple phrases, might be helpful in engaging more individuals in the survey app.

The research framework for this study was laid out at the start of the project before the proportion of participants with CCN was evident. The study had set out to examine the impact of AT upon the lives of the participants. While AAC is a subset of AT, there were missed opportunities to gather data regarding the specific impact of the tools provided upon the communication capabilities of these participants. Future studies might seek to gather more specific relevant impacts of AT and AAC systems provided.

It would also be valuable to do a more definitive analysis of return on investment (ROI) from this project. The cost of providing AT services and devices under this model averaged $3464 per individual (which included travel, staff time for the interview and three visits, time for researching and costs associated with ordering the AT devices, and the AT itself—capped at $3000 per individual). However, if future studies can explore how the individual gains impact an individual’s independence and the support systems around them in the longer-term, then perhaps a means of ascribing a financial benefit can be derived. In this way, benefits can be analyzed from a financial perspective as well.

OUTCOMES AND BENEFITS

There are several outcomes and benefits from this study. This article describes a model for service delivery for adults with intellectual and developmental disabilities. These individuals have not been well served in the past. This study suggests that AT may provide a path to some measure of greater independence and self-determination.

This study points to measurable outcomes of use of AT and AAC systems with adults with intellectual and developmental disabilities that indicate improvements in individual performance and personal satisfaction. These findings should encourage families and providers to seek AT solutions that could enhance self-determination and encourage independence in the individuals they serve. These results should lead to opportunities for individuals with intellectual and developmental disabilities for growth and self-actualization.

This study revealed the significant involvement of communication in the challenges people with intellectual and developmental disabilities face. While more remains to be discovered, these results indicate that people with intellectual and developmental disabilities and CCN were able to accomplish goals that were important to them with the AT and AAC tools they received. The facilitation of generative speech and enhanced engagement with family and community are concrete first steps toward the ideal of successful and fulfilling community-based living. These outcomes should encourage the exploration of policy implications regarding broader access to AAC solutions for these adults with CCN.

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APPENDIX A. ADAPTED STUDENT PERFORMANCE PROFILE

First Visit Outcomes Questionnaire

During the initial home visit, individual goals will be explored.

Foundational Measures (FMS) Indicators

CIRCLE FMS AREA:

Relationships
Self-Determination
Community/Inclusion
Privacy
Health, Welfare, & Rights
Satisfaction
Work
Family
Safety

FMS – specific indicator/area in which individual would like to make progress

____

AT Objective or Goal (which addresses core indicator above):

Goal:				
Current (baseline) ability level (%)				
Not able	Seldom able	Sometimes able	Often able	Fully able
1	2	3	4	5

Legend:
1 **Not able** (successful on less than 10% of attempts)
2 **Seldom able** (successful on between 10% and 40% of attempts)
3 **Sometimes able** (successful on between 40% and 60% of attempts)
4 **Often able** (successful on between 60% and 90% of attempts)
5 **Fully able** (successful on between 90% and 100% of attempts)

Final Visit Outcomes Questionnaire

During the final home visit, individual goals will be evaluated.

Performance (with AT)

Goal:				
Current ability level (%)				
Not able	Seldom able	Sometimes able	Often able	Fully able
1	2	3	4	5

Legend:
1 **Not able** (successful on less than 10% of attempts)
2 **Seldom able** (successful on between 10% and 40% of attempts)
3 **Sometimes able** (successful on between 40% and 60% of attempts)
4 **Often able** (successful on between 60% and 90% of attempts)
5 **Fully able** (successful on between 90% and 100% of attempts)

If you feel your individual has made progress in this objective, please indicate (circle) the contribution each of these possible influences/intervention strategies may have made to that progress:

1. Assistive Technology (AT) provided by the AT team
   No contribution Some contribution Great contribution
   1 2 3 4 5 6 7 8 9 10

2. AT other than that provided by the AT team
   No contribution Some contribution Great contribution
   1 2 3 4 5 6 7 8 9 10

3. Personal assistance (e.g. aide, helper, interpreter, family member)
   No contribution Some contribution Great contribution
   1 2 3 4 5 6 7 8 9 10

4. Related and support services (e.g. OT, PT, SLP, etc.)
   No contribution Some contribution Great contribution
   1 2 3 4 5 6 7 8 9 10

5. Performance expectations changed (e.g. greater expectations to obtain success)
No contribution Some contribution Great contribution
1 2 3 4 5 6 7 8 9 10

6. Natural development
No contribution Some contribution Great contribution
1 2 3 4 5 6 7 8 9 10

7. Compensation for impairment by the student (e.g. use other hand if one hand is impaired)
No contribution Some contribution Great contribution
1 2 3 4 5 6 7 8 9 10

8. Other: ______________________________
No contribution Some contribution Great contribution
1 2 3 4 5 6 7 8 9 10

9. Other: ______________________________
No contribution Some contribution Great contribution
1 2 3 4 5 6 7 8 9 10

Level of care provider/family member support:				
Current ability level (%)				
None	Hesitant	Willing	Engaged	Effective
1	2	3	4	5

APPENDIX B. FOUNDATIONAL MEASURES SURVEY

Relationships	**Strongly Disagree**	**Somewhat Disagree**	**Sometimes**	**Somewhat Agree**	**Strongly Agree**
I can visit or talk with my family and friends when I want.	1	2	3	4	5
I feel lonely.	1	2	3	4	5
I have friends.	1	2	3	4	5
I can help others.	1	2	3	4	5
I talk with my neighbors.	1	2	3	4	5

Satisfaction	**Strongly Disagree**	**Somewhat Disagree**	**Sometimes**	**Somewhat Agree**	**Strongly Agree**
I like my daily program/activities I do each day.	1	2	3	4	5
I like the technology I use.	1	2	3	4	5
I like where I live.	1	2	3	4	5
I am satisfied with the support I have received.	1	2	3	4	5
The technology I use helps make my life better.	1	2	3	4	5

Self-Determination	**Strongly Disagree**	**Somewhat Disagree**	**Sometimes**	**Somewhat Agree**	**Strongly Agree**
I make (have made) choices regarding					
• My daily schedule	1	2	3	4	5
• How I spend my free time	1	2	3	4	5
• What to buy with my money	1	2	3	4	5
• The technology I use	1	2	3	4	5
• Where I go in the community	1	2	3	4	5
• When to use the internet	1	2	3	4	5
• When to use social media	1	2	3	4	5

Community/Inclusion	**Strongly Disagree**	**Somewhat Disagree**	**Sometimes**	**Somewhat Agree**	**Strongly Agree**
I go out for entertainment (movies, concerts, theatre).	1	2	3	4	5
I go out for exercise or recreation.	1	2	3	4	5
I go out to dinner/for coffee.	1	2	3	4	5
I go shopping.	1	2	3	4	5

Community/Inclusion	**Strongly Disagree**	**Somewhat Disagree**	**Sometimes**	**Somewhat Agree**	**Strongly Agree**
I am connected to/involved as much as I want it:					
• Family	1	2	3	4	5
• Friends	1	2	3	4	5
• Neighborhood	1	2	3	4	5
• Church	1	2	3	4	5
• Recreational services	1	2	3	4	5

Health, Welfare, & Rights	**Strongly Disagree**	**Somewhat Disagree**	**Sometimes**	**Somewhat Agree**	**Strongly Agree**
Health					
• I engage in activity/exercise regularly.	1	2	3	4	5
• I take my medications regularly.	1	2	3	4	5
I am treated with respect					
• Day program	1	2	3	4	5
• Home	1	2	3	4	5
• In the community	1	2	3	4	5
I participate in self-advocacy	1	2	3	4	5
I feel safe:					
• At home	1	2	3	4	5
• At work	1	2	3	4	5
• At my day program/activity	1	2	3	4	5

APPENDIX C. FOUNDATIONAL MEASURES SURVEY RESULTS

Item #	Survey Item	Pre	Post	Change
1	I can visit or talk to my family and friends when I want	3.67	3.89	0.23
2	I feel lonely	2.97	2.46	-0.51
3	I have friends	3.24	3.59	0.36
4	I can help others	3.14	3.59	0.46
5	I talk with my neighbors	2.31	2.62	0.32
6	I like my daily program and the activities I do each day	4.38	4.11	-0.27
7	I like the technology I use	3.85	4.19	0.34
8	I like where I live	4.40	4.19	-0.21
9	I am satisfied with the support I have received	4.62	4.32	-0.30
10	The technology I use helps make my life better	3.94	4.14	0.20
11	I make or have made choices regarding my daily schedule	3.61	3.68	0.06
12	I make or have made choices regarding how I spend my free time	4.00	3.81	-0.19
13	I make or have made choices regarding what to buy with my money	3.20	3.24	0.04
14	I make or have made choices regarding the technology I use	3.69	3.70	0.01
15	I make or have made choices regarding where I go in the community	3.22	3.49	0.26
16	I make or have made choices regarding when to use the internet	3.36	3.59	0.23
17	I make or have made choices regarding when to use social media	2.45	3.06	0.61
18	I go out for Entertainment (movies, concerts, theatre)	3.53	3.54	0.01
19	I go out for exercise or recreation	3.86	3.68	-0.19
20	I go out to dinner or for coffee	3.63	3.92	0.29
21	I go shopping	4.00	3.78	-0.22
22	I am connected to my family	4.67	4.38	-0.29
23	I am connected to my friends	3.80	3.70	-0.10
24	I am involved as much as I want in my neighborhood	2.97	3.08	0.11
25	I am involved as much as I want in my church, synagogue or mosque	3.19	3.47	0.28
26	I am involved as much as I want in recreational services	3.26	3.32	0.07
27	I engage in activity/exercise regularly	3.46	3.68	0.22
28	I take my medications regularly	4.00	4.29	0.29
29	I am treated with respect at my Day Program	3.58	3.52	-0.07
30	I am treated with respect at my Home	4.72	4.57	-0.15
31	I am treated with respect in the community	4.23	4.42	0.19
32	I participate in self-advocacy	2.79	3.29	0.51
33	I feel safe at home	4.65	4.73	0.08
34	I feel safe at work	2.71	3.04	0.32
35	I feel safe at my day program/activity	3.84	3.73	-0.12

N=37; two (2) failed to complete second survey.

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Voices from Academia

Eye-Gaze Access and Cortical Visual Impairment: A Case Study

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ABSTRACT

A feasibility case study was conducted to determine if eye-gaze training programs could be used to teach an individual with cortical visual impairment and cerebral palsy the visual skills necessary to operate an augmentative and alternative communication device using eye-gaze access. The individual was taught visual skills during phase 1 of the intervention through eye-gaze training programs, and communication was taught during phase 2. The individual acquired the necessary visual skills to operate the AAC device and demonstrated functional communication using the device.

Keywords**:** eye gaze, cortical visual impairment, intervention

INTRODUCTION

Augmentative and alternative communication (AAC) can provide the necessary means of communication to individuals with complex communication needs. However, if an individual has multiple disabilities that affect their motor skills, hearing, and/or vision, it can be difficult to find an AAC system that best fits their needs. In addition to determining the best device, display type, and vocabulary set for the individual, the most reliable access method must be determined. Individuals with impacted motor skills who cannot direct-select through touch often require either an adaptive switch or eye-gaze access for their devices. An individual with a severe visual impairment may use auditory scanning with an adaptive switch to access their device. Adaptive switches come in a variety of forms but do require reliable motor control over one or more parts of the body in order to activate it. For an individual without reliable motor control, direct access through eye gaze may be the only feasible access option.

Eye-gaze access has advanced greatly and can now be used with a variety of individuals who require it. Most eye-gaze AAC systems contain an infrared light source that reflects off the eye of the user. The built-in camera then detects the reflection and calculates where the eye is looking on the screen (Mohamed et al., 2007). These calculations are made after calibrating the system to the user's eyes. To calibrate the system, the individual must fixate on specific points on the screen until calibration is successful. In order to use eye-gaze access for AAC the user must have the visual control to both scan the screen for the desired word and intentionally fixate on the word for a set time to select it. Therefore, eye-gaze access functions best when an individual has intact visual skills so they can view the screen and make selections through controlled visual behaviors.

CVI

Not all individuals who require eye-gaze access for AAC have intact visual abilities. One visual impairment that can co-occur with neurologic-based motor impairments is cortical visual impairment (CVI). CVI is a type of visual impairment of neurological origin resulting from bilateral dysfunction of the visual cortex and/or the optic radiations often caused by perinatal brain damage or trauma (Matsuba & Jan, 2006). Recent neuroimaging studies have demonstrated that many key neural pathways of the visual system may be affected in individuals with CVI (Martin et al., 2016). CVI affects 30–40% of the population that is visually impaired and is the leading cause of visual impairment in children in developed countries (Huo et al., 1999; Matsuba & Jan, 2006; Roman et al., 2010). In a review of infants 0–24 months with severe visual impairment with varying origins, CVI was the most frequent diagnosis, with 24% of infants in the study affected (Ozen Tunay et al., 2020). Individuals with CVI also tend to have concomitant disorders with reports of up to 90% (Ozen Tunay et al., 2020). One chart review study found that 75% of patients with CVI had at least one associated neurological deficit, with the most common being seizures (53%) and cerebral palsy (CP; 26%; Huo et al., 1999). Co-occurring ophthalmological deficits were also commonly found, including ocular motor deficits and refractive errors (Huo et al., 1999). It is unknown how many individuals who require AAC have CVI. However, with the majority of individuals with CVI having additional neurological deficits, there is likely overlap.

The visual deficits in individuals with CVI differ greatly from individuals with visual impairments due to refractive deficits. Although the presentation of CVI varies, there are common visual characteristics seen in this disorder, including oculomotor abnormalities, abnormal visual behavioral characteristics, and visual field deficits. A number of oculomotor abnormalities, varying in prevalence, have been found in patients with CVI, including limited fixations, deficits in smooth pursuit (tracking of an object), delayed fixations, impairment in ocular motility, strabismus, and nystagmus (Chang & Borchert, 2020; Fazzi et al., 2007). Additionally, abnormal visual behaviors are commonly observed in individuals with CVI that do not occur in other visual impairments (Chang & Borchert, 2020; Good et al. 2001; Jan et al., 1987; Jan et al., 1993). Individuals with CVI have impaired visual attention (Groenveld et al.,1990; Whiting et al., 1985) and attention tends to be better when viewing objects in motion than with static objects (Jan & Groenveld, 1993; Merabet et al., 2017). Individuals with CVI tend to supplement visual information with touch; however, they often look away from their target when reaching (Good et al., 1994). They often view objects closely, which may be a coping skill for the crowding effect they experience. The crowding effect occurs when multiple objects or pictures are displayed at once and the individual is unable to process the individual images (Groenveld et al., 1990). An attraction to colored objects has been documented (Baker-Nobles & Rutherford, 1995) as well as decreased contrast sensitivity (Fazzi et al., 2007). A sensitivity to light is common in CVI, with some individuals gazing at lights (Jan et al., 1990) and others experiencing photophobia (Jan et al., 1993). Lastly, individuals with CVI may experience visual field deficits that are often in the lower hemifield (Good et al., 2001; Kozeis, 2010).

There are a limited number of intervention studies conducted with children with low levels of vision, including children with CVI, and those that do exist have low levels of evidence (Chang & Borchert, 2020; Chavda et al., 2014). Improvements in visual skills have been observed in patients with CVI, but are often associated with age of diagnosis (Matsuba & Jan, 2006) and area of injury (Hoyt, 2003). Most often, improvements are seen when the child is diagnosed prior to age 3. This is thought to be the result of the plasticity in the young brain that can form new compensatory visual pathways (Huo et al., 1999; Lambert et al., 1987; Martin et al., 2016). However, many of the existing studies report improvements in visual acuity and few studies report changes in functional vision (Chang & Borchert, 2020).

Interventions for individuals with CVI include visual stimulation and modification of environment and stimuli to capitalize on visual strengths and compensate for specific deficits (Groenveld et al., 1990; Waddington & Hodgson, 2017). Visual stimulation typically involves exposing the child to a high-contrast image or light source to stimulate their visual system (Alimović et al., 2014; Alimovic et al., 2013; Tsai et al., 2016; Waddington & Hodgson, 2017). The programs usually consist of many successive trials. The stimuli used and length of trial is often individualized to the child's strengths and deficits (Alimović et al., 2014; Tsai et al., 2016). Depending on the visual stimulation used, improvements can be made in visual acuity (Tsai et al., 2016), functional vision, and visual behaviors (Alimović et al., 2014). Greater improvements in visual functioning are seen when visual stimulation begins in the first 8 months of life compared to a start of treatment at 8–30 months of age (Alimovic et al., 2013). It is also unclear as to how long these improvements are maintained without continual use of the visual stimulation program (Waddington & Hodgson, 2017).

The literature has given suggestions on modifications to the environment and stimuli for individuals with

CVI as compensatory strategies with the goal of maximizing the use of the individual's functional residual vision (Good et al., 2001; Groenveld et al., 1990). Simplifying the visual environment focuses the individual's visual attention and reduces overload of the visual system (Groenveld et al., 1990). Visual information can be reinforced with tactile and verbal information, and rituals help to maintain consistency in the environment. When presenting stimuli to individuals with CVI, bright colors with high contrast and motion should be incorporated to utilize the strengths of detecting color and motion (Good et al., 2001).

Eye tracking is a new, innovative measurement vehicle to analyze visual behaviors in CVI (Kooiker et al., 2016; Pel et al., 2010). During these eye-tracking tasks, several visual behaviors can be measured through the presentation of different stimuli and activities. Fixations and saccades are measured to images in different areas on the monitor. Smooth pursuit of slow-moving stimuli can be measured along with optokinetic nystagmus reflexes (Kooiker et al., 2016).

Eye Gaze and CVI

Multiple aspects of CVI make eye-gaze access for AAC difficult, including apraxic eye movements, limited fixations, short visual attention, visual field deficits, and the crowding effect. Modifications and individualizing the eye-gaze device to the participant can address some of these deficits; however, the effectiveness of the system may be impacted. Modifications such as programming the system to track only the more reliable eye and increasing or decreasing dwell time can be made (Tobii Dynavox, 2015). The vocabulary set can also be modified by increasing background contrast and use of color and moving icons to adapt to visual field deficits. Finally, an individual's attraction to light can be utilized by lowering the lighting in the room and increasing screen brightness to attract attention to the screen.

AAC Teaching Strategies

When an individual learns to communicate with an AAC device, instruction on multiple levels must occur to begin to develop communicative competence. Light (1989) proposed four areas of communicative competence in AAC: operational, linguistic, social, and strategic. To gain operational competence, the individual must learn how to operate the device through their access method. Linguistic competence must also be taught so the individual understands the linguistic properties of the system (the symbols and organization of vocabulary) and can use the symbols expressively. The individual must also learn how to communicate for a variety of different functions by developing social competence. Finally, strategic competence must be developed so the individual has the necessary coping strategies to communicate using AAC. Communication competence can be achieved when these competency areas are gained and integrated into communication. Therefore, instruction in these areas should be taught together when possible so the individual learns to integrate these areas of communication (Light, 1989).

There are multiple methods for instructing individuals to use AAC to communicate. Some effective methods include incidental teaching and language modeling, which model the way that infants learn language through their environment (Beukelman & Mirenda, 2013; Hart & Risley, 1982). During incidental teaching, the communication partner sets up the environment to elicit communication from the individual who uses AAC. Some incidental teaching strategies include expectant time delay (waiting for the individual to respond while looking at him/her; Kozleski, 1991) and interrupted behavior chain (unexpectedly stopping an activity or action to elicit a response; Carter & Grunsell, 2001). A series of prompts are often used, along with incidental teaching strategies, and presented in a least-to-most hierarchy where the least amount of support is given first, followed by progressively more support, until the desired behavior is achieved. Presenting prompts in a least-to-most support order allows the communication partner to determine the necessary amount of assistance the individual needs to demonstrate the communicative behavior (Ault & Griffen, 2013). The partner also provides contingent responses to any communication from the individual who uses AAC. The communication partners of the individual learning AAC are also encouraged to provide many models on the device using aided AAC input. During aided AAC input the communication partner models their utterances on the device while also speaking them aloud. Aided AAC input has been found to be effective in teaching expressive language in AAC (Allen et al., 2017; O'Neill et al., 2018).

These instructional methods paired together can provide instruction in linguistic and social competence. Instruction in social competence should teach a variety of communicative functions through modeling, incidental teaching, and aided AAC input. Some initial communicative functions that are often taught in AAC are choice making, requesting, rejecting, and social interactions. Social interactions include introducing a topic, providing contingent responses, and asking partner-focused questions (Beukelman & Mirenda, 2013).

For many children who access their AAC devices through direct access, the modeling provided by the communication partner during aided AAC input teaches operational competence. However, for those who require switch or eye-gaze access, additional instruction is needed to ensure operational competence. There is limited evidence on best practices for teaching operational competence of eye-gaze access. This study provides a feasibility case study into a systematic method for teaching eye-gaze access and subsequent instruction in the areas of linguistic and social competence.

Despite the limitations of eye-gaze access for individuals with CVI, it was determined to be the best option in AAC access methods to pursue for the participant in this study, Jacob. Therefore, a two-part intervention was designed and implemented. The first phase was designed to teach the operational skills necessary for eye-gaze access of communication software through two eye-gaze training programs. Jacob would need to gain the visual skills of accessing the majority of the screen, visually scanning the screen for a target, and fixating on a target for a sufficient duration of time. Once these visual skills were obtained, the second phase provided instruction on operation of the communication software, the linguistic properties of the device, and the social context of communication. This investigation sought to answer two research questions. (1) Can two eye-gaze training programs be used to train an individual with CVI and CP to obtain the visual skills necessary to access an AAC system through eye gaze? (2) Once the necessary visual skills are obtained, can an individual with CVI and CP learn to communicate using communication software on a Tobii I-12 system?

TARGET AUDIENCE AND RELEVANCE

This work is relevant for practitioners and families who support individuals with complex communication needs and CVI and those that support other individuals who use eye-gaze access for AAC. The intervention discussed targeted both visual behaviors and communication and is pertinent for a variety of providers. Some individuals with complex communication needs are left with little to no method of formalized communication due to the limited access methods for AAC that fit their needs. This article demonstrates the promise of currently available eye-gaze training programs in teaching the visual skills necessary for eye-gaze access for an individual with CVI. The importance of presuming competence when working with individuals with complex communication needs is also demonstrated by Jacob's progress and quick acquisition of communication through the device. This article provides a framework for approaching the introduction of eye-gaze access with individuals who display symptoms of CVI.

METHODS

Participant

Jacob was a 14-year-old male with diagnoses of a chromosome 13 q subtelomeric deletion, encephalopathy (static) with microcephaly, CP, quadriplegic, developmental delays, seizure disorder, CVI, esotropia (a turning-in of the eye), and astigmatism. At the time of intervention, he had no reliable systematic means of communication and communicated through laughing, crying, vocalizations, facial expressions, and body language (i.e., turning his head away for dislike and waving his arms for excitement). Jacob presented with athetiod movements, spontaneous slow and involuntary movements that may be writhing and sudden (Victorio, 2020), leading to minimal voluntary control of his limbs. He presented with general low tone and his posture varied day to day, sometimes requiring a chest support for his wheelchair. It was not clear what Jacob's cognitive abilities were, as his physical and sensory deficits inhibited accurate assessment.

In addition to his motor and speech impairments, Jacob had multiple disorders impacting his vision, including CVI, alternating estropia, and astigmatism. The severity of Jacob's estropia was reduced through surgery, and he wore glasses to correct his astigmatism. A functional vision evaluation was completed a year prior at an outside location. Jacob's level of CVI was not rated in the evaluation report, but the report did provide a description of his performance on functional vision tasks. Results indicated that his nearsighted visual acuity was best within 6–12 inches, and he could perceive people up to 2 to 3 feet away. Fixations were observed to brightly colored, 4-inch pictures when presented within 12 inches of his face and when he was given auditory cues. Visual field deficits were noted in the upper, lower, and right visual fields when tracking a light source. Jacob was observed to reach for objects while looking away, which affected his accuracy. The recommendations from the assessment included decreasing background noise in his environment, using auditory cues to augment his visual input, and using motion to capture his visual attention. Jacob's auditory skills had been previously screened through auditory brainstem response testing and tympanometry. These measures indicated no abnormalities. Concerns regarding his functional hearing have been noted, but his auditory response is difficult to assess due to his limited ability to respond.

Jacob received a variety of services through the school, including speech and language intervention, occupational therapy, and indirect vision services, and he was included in general education for half of each day. His Individualized Education Program focused on increasing Jacob's ability to communicate through visual fixation, touching an object, and imitating movements; and on increasing his knowledge of cause-and-effect relationships. His vision-related goals were visually fixating on a book or iPad after a pause to indicate engagement, and combining visual fixation and touch on an iPad. Visual adaptations made at school included simplifying visual input, enforcing routines, and pairing visual information with auditory cues.

A comprehensive AAC assessment was completed by the authors with Jacob over the course of three separate days. Jacob had a previous AAC assessment 5 years prior with the second author in which a BIGmack switch and an Ultimate switch were trialed. Jacob activated a toy with both adaptive switches and used the BIGmack switch to indicate color. He had more difficulty when using the switches with auditory scanning for purposeful communication. During the most recent 3-day assessment, both switch and eye-gaze access were assessed. Four devices were trialed with eye-gaze access and two devices were trialed with auditory scanning, including a high-tech and a mid-tech device. During the eye-gaze trials and high-tech switch access trials, a board of 4 brightly colored symbols that displayed highly preferred activities was used. The Ultimate switch was used during the auditory scanning trials and was trialed in several positions. Jacob attempted to activate the switch several times, and the best location was determined to be 18 inches from the torso just left of midline. He successfully communicated "more" during a music activity and identified colors. Each purposeful communication act required multiple cycles through the options, and mishits occurred frequently. Activating the switch required great physical effort from Jacob, and he expressed frustration.

During trials with eye-gaze access, he directed his eyes toward the screen and attempted fixations to icons. He had difficulty maintaining his fixation long enough to make the selection. Due to the length of time and amount of physical effort required for auditory scanning, it was decided to first try eye-gaze training to determine if he could gain the skills to use eye-gaze access for AAC. The Tobii I-12 device was selected for the intervention as it was the largest screen available at the clinic and was compatible with multiple eye-gaze training programs.

The Intervention

The intervention consisted of 58 half-hour sessions over the course of 7 months. Sessions ranged from one to four times a week with a median frequency of twice weekly. The study consisted of two phases. Jacob was first taught the visual skills necessary to access the AAC device for communication in phase 1 through eye-gaze training programs across 31 sessions. Once Jacob demonstrated the visual skills of gaze to the majority of the screen, dwell to select, and smooth pursuit through the mastery of set levels in the eye-gaze training programs, phase 2 began. The purpose of phase 2 was to teach Jacob to communicate using the Tobii Communicator 4 software and lasted 27 sessions. The progression of the sessions was tailored to Jacob's needs and rate of learning.

Environment and Positioning

All sessions were completed in a windowless therapy room at The Schiefelbusch Speech-Language-Hearing Clinic at The University of Kansas. Visual distractors were removed from the walls, and the only room lighting was a lamp behind Jacob that provided the level of lighting necessary for the eye tracker. His wheelchair was placed at a 10-degree angle with a headrest and vest for support. The Tobii I-12 was placed on a hospital rolling mount 19 inches from Jacob's eyes and approximately 5 degrees left of center. This position was determined by using the track status function of the device to provide feedback on the placement. This position provided the best reading and utilized Jacob's unaffected left visual field. It should be noted that the ideal positioning of the Tobii I12 is 23.5 inches from and parallel to the user's eyes (Tobii Dynavox, 2015). The closer distance and slight angle could affect the gaze readings and heat maps collected during this study, but this positioning remained the same throughout the study. Room and positioning consistency was maintained for all but three sessions to improve visual attention. The clinician used her position in the room to direct Jacob's attention. During phase 1 she sat on his left side, and switched to the right in phase 2 to attract his visual attention to his right visual field. The clinician also stood behind the eye tracker on days when Jacob portrayed low visual attention to direct his visual attention back to the screen.

AAC Device and Programs

Calibration was attempted multiple times throughout the study using multiple different stimuli. Sufficient data for calibration was never achieved, so the clinician calibrated the device to herself sitting in the same position as Jacob. This is not best practice, but it was the only option for the participant. After Jacob demonstrated the skill of dwell to select in phase 1, several dwell times were trialed in the beginning of phase 2. A 300-millisecond dwell time was the most successful and was used for all of phase 2.

Eye-Gaze Training Programs. The eye-gaze training programs used in phase 1 of the intervention were Look to Learn (Sensory Software International Ltd., n.d.) and Sensory Eye-FX (Sensory Guru, 2012). These programs were chosen as they were the only commercially available programs that targeted eye-gaze skills in a progressive way at the time this study was conducted. Both programs are designed to progress the user through multiple levels of activities through which eye-gaze skills are acquired and improved. It was determined to trial both programs, as they offered different benefits. Sensory Eye-FX contained more activities with high contrast (colored objects on black backgrounds), while Look to Learn contained activities with more auditory stimulus and complex, colorful images. Look to Learn had 40 activities across five skill areas (8 activities per level; Sensory Software International Ltd., n.d.) while Sensory Eye-FX had 30 activities across five levels (6 activities per level; Sensory Guru, 2012).

The programs teach similar skills, although the order of progression differs. Table 1 provides descriptions of the 5 levels of each program, the skills targeted in those levels, and the corresponding activities. Both programs continue to target the accuracy of the user's fixations throughout the 5 levels and improve upon their eye-gaze skills. However, it was determined that once the user had mastered level 2 of Look to Learn and level 3 of Sensory Eye-FX, he had demonstrated the eye-gaze skills necessary to operate the AAC device for communication. Those skills include accessing the majority of the screen, scanning the screen through smooth pursuit and fixating on an item to select it. It was decided that Jacob did not need to demonstrate mastery over the additional levels before the communication system was introduced because the icons on the device were big enough for him to target and he did not need to learn to drag and drop to operate the communication software. The eye-gaze programs continued to be used as a warm-up activity in phase 2 to continue to progress Jacob's eye-gaze skills.

Table 1: ***Eye Gaze Training Program Level Descriptions***

		Level Description	Example Activity
Level 1	*LtL	**Sensory:** Teaches cause and effect through a visual and auditory change when a fixation occurs. Some activities require fixating on a large target while others activate wherever the user looks. *Target Skills: Visual attention, fixations, smooth pursuit*	***Cannon***: When the user looks at an area of the brick wall paint is fired from a cannon on the wall. ***Egg***: When the user looks at the large egg it cracks open to show the animal inside.
	*SE	**Blank Screen Engagement**: Teaches the user to engage with the screen through a visual and auditory change when a fixation occurs. No activities require fixation on a target. *Target Skills: Visual attention, smooth pursuit*	***Sensory circles***: When the user looks at an area of the black screen a cluster of colorful circles appears and a chime plays. When the user looks away the image and sound fade.
Level 2	LtL	**Explore**: Teaches the user to fixate on all the areas of the screen. Some activities require fixation on a target fixation and targets are smaller and in more areas of the screen. *Target skills: fixation accuracy, engagement with all areas of the screen*	***Bottles***: When the user looks at one of the glass bottles lined on a shelf it smashes into pieces ***Scratch card***: When the user looks at an area of the screen the color is removed revealing another image. All color is removed to reveal the whole image.
	SE	**Object Displacement**: Teaches the user to fixate for a reaction on the screen. All activities are colorful images on a black background and some require fixating on a specific target. *Target skills: fixation accuracy*	***Dwell bomb***: When the user looks at an area of the screen for one second, multicolored circles grow and then fly all over the screen. ***Splat***: Multicolored smiley faces float on a black screen. When the user fixates on one face it squishes out and makes a fun sound.
Level 3	LtL	**Target**: Improves the user's eye gaze accuracy. The user must fixate on individual images in various areas of the screen for the effect on the object to occur. These activities get progressively harder as the user participates. *Target skills: fixation accuracy, increase visual attention*	***Shoot***: The user fixates on traditional targets in different areas of the screen to shoot it and receive points. ***Video wall***: When the user fixates on an image it plays a video. The images progress from a display of 2 then 4 then 6. on the display.
	SE	**Zoned Focusing:** Improves the user's ability to fixate on specific targets in different areas of the screen. *Target skills: fixation accuracy, engagement with all areas of the screen*	***Lights***: The user fixates on a dim light bulb to turn it on and play a musical note. The lights are spread throughout the screen.
Level 4	LtL	**Choose**: Improves the user's choice making skills. These activities show an image and at least 3 smaller images on the side of the screen (left or right depending on the activity). The user can change the look of the larger image by choosing a small image through fixation. *Target skills: fixation accuracy, choice making*	***Drummer***: The user chooses the set of drumsticks for the drummer to use by fixating on them. The man then plays the drums with the chosen sticks. ***Dinner time***: The user chooses what the man will eat for dinner by fixating on a food item.

		Level Description	Example Activity
	SE	**Active Exploration:** Encourages the user's exploration and engagement with the screen. Some focus on making music or painting while others practice targeting. *Target skills: fixation accuracy, engagement with all areas of the screen*	***Archery***: The user fixates on traditional targets displayed in several rows and it is shot down with an arrow. ***Piano***: The user plays a song by fixating on different keys on a piano keyboard.
Level 5	LtL	**Control**: Improves the detailed eye gaze skills of the user and their drag and drop skills. Some activities work on precise fixations to an image and others teach the user to fixate on an image and move it with their gaze. *Target skills: drag and drop, fixation accuracy*	***Penalty***: The user shoots the soccer ball into specific areas of the goal by fixating on it. The user can also be the goalkeeper and chooser where to dive through fixation. ***Jungle***: The user chooses an animal to add to the picture and drags it on the screen and puts it on one of the preset stars.
	SE	**Controlled Targeting**: Increases the accuracy of the user's gaze and dwell functions. Several different skills are targeted depending on the activity. *Target skills: smooth pursuit, fixation accuracy*	***Object control*:** The user fixates on the balloon and drags it around. If fixation is not maintained the balloon falls to the bottom of the screen and pops. ***Killer bee***: A bee flies around the screen and the user must fixate on the moving bee to squash it.

Communication Software. Tobii Communicator 4 was used during phase 2 of the study (Tobii Technology AB, 2015a). The first four sessions of phase 2 used a custom designed display to determine if Jacob had acquired the necessary visual behaviors to communicate with the device. The custom display contained 6 icons with brightly colored backgrounds with contrast and the vocabulary related to high-interest activities. Jacob demonstrated the visual behaviors necessary to activate the icons on the custom board for purposeful communication. It was decided to begin to trial the Sono Flex common vocabulary user during the fourth phase 2 session because of the preset vocabulary available on the user and ability to grow as his language increased. He demonstrated the ability to use the Sono Flex user from the first session despite its lack of high-contrast, colored backgrounds. The Sono Flex common vocabulary user contained 800 commonly used words with the home screen having direct access to core vocabulary and 4 context buttons. The user had 4 rows and 6 columns for a total of 24 icons that were one inch by one inch in size. The right column on the home screen contained context pages that could be interchanged. The reading and television context pages were used during structured activities. These context pages contained words specific to that activity. Icons were on white backgrounds with a colored border coded with the Fitzgerald key to indicate word type (Tobii Technology AB, 2015a). In the video and reading context pages, only the relevant words for the activity were displayed and the rest were hidden in the initial sessions. The relevant words included action words (play, stop, go, read) and the book or video options for him to choose from. As he demonstrated use of these words over multiple sessions, the other words on the page were unhidden at a rate of several per session.

Tobii Gaze Viewer. The Tobii Gaze Viewer program was used to record eye-tracking data during each session (Tobii Technology AB, 2015b). The software collected all fixations made during a session and displayed them through heat maps and gaze plots superimposed over the activity. The heat map demonstrated the areas Jacob fixated on the most and the areas he did not look at. The gaze plot showed the number and order of fixations that occurred in the session (Tobii Technology AB, 2015b). These measurements were used to assess Jacob's visual attention and functional access to different areas of the screen.

Phase 1

Phase 1 consisted of 31 half-hour sessions focused on teaching Jacob the visual skills necessary to access an AAC device through eye gaze. Sessions began with 15 minutes of activities from Look to Learn followed by Sensory Eye-FX activities for 15 minutes. The intervention began with level 1 in each program.

Jacob remained in a level of each eye-gaze training program until he *mastered* five of the activities in the level. Jacob's performance was evaluated through a worksheet modified from the Look to Learn software. The worksheet ranked Jacob's demonstration of the targeted eye-gaze skills for the activity as either not demonstrated, developed, or achieved. His motivation, enjoyment, overall success, and level of facilitation needed were all rated on a scale of 1 (low) to 5 (high). The goal was for Jacob to demonstrate the targeted eye-gaze skills with limited assistance from the clinician. An activity was considered *mastered* when Jacob received a score of *achieved* on the targeted eye-gaze skills for the activity, a 4 or above on the levels of motivation, enjoyment, and overall success, and a score of 3 or below on the level of facilitation. The activities were repeated until Jacob mastered five activities in the level and could move to the next level in the program. This criterion of five mastered activities was modified to four activities in level 2 and three activities for level 3 of Sensory Eye-FX as Jacob was demonstrating refusal for the remaining unmastered activities by turning his head away. These activities were less visually and auditorily stimulating than other activities, which may have decreased his motivation. The next level was trialed with the option to move back to the previous level if he was unable to master the activities. He did demonstrate mastery over some of the activities in the following level in both occasions.

Intervention Strategies. The teaching strategies used during phase 1 of the study were modeling and visual and verbal cues. The clinician modeled a new activity by activating the screen with her finger and completing the task. General verbal cues were used to direct Jacob's visual attention to the screen (e.g., look at the screen to make the picture show up). Specific verbal cues were used to direct his gaze to specific areas of the screen to complete the task (e.g., look at the man with the silly face in the corner) and provide auditory information to supplement the visual. Finally, visual cues were used to attract Jacob's vision to specific parts of the screen by the clinician waving her fingers or an object in front of the target area of the screen.

Fidelity. Phase 1 sessions were administered by two different clinicians, the first author and a doctoral student who was a speech-language pathologist with AAC experience and was trained in the intervention protocol. Fidelity of the room configuration, device positioning, and administration of the eye-gaze programs were judged by an independent rater for 20% of phase 1 sessions for an average reliability of 93%. Reliability of scoring of activities was attempted from video recordings; however, due to the low lighting in the room, the recording of the screen was not sufficient to conduct offline scoring.

Phase 2

As mentioned previously, Jacob began phase 2 after mastering level 2 of Look to Learn and level 3 of Sensory Eye-FX, with reduced mastery criteria of 3 mastered activities. Phase 2 consisted of 27 half-hour sessions with a focus on teaching Jacob to use the Tobii Communicator 4 software to communicate. Each phase 2 session consisted of a five-minute warm-up activity on the eye-gaze training programs, conversational instruction, and a requesting/choice making activity. The conversational instruction used the full vocabulary set available on Sono Flex. The clinician used aided input and least-to-most prompting to teach Jacob different pragmatic functions and the linguistic properties of the device. The requesting/choice making activity used books and videos that were highly preferred as determined by parent report and Jacob's expression of excitement through body movement. During this activity, appropriate context pages of the device were used. Jacob could choose which book or video he wanted from programmed vocabulary in his device.

Jacob's utterances were transcribed by the clinician, and the pragmatic function of each utterance was coded. The transcripts were then analyzed using the Systematic Analysis of Language Transcripts (Miller & Iglesias, 2015). The pragmatic functions coded were initiations, comments, answering questions, choices, asking questions, and requests. Initiations and comments were both independently made and differed based on context with comments relating to the activity or topic of discussion and initiations were unrelated to the current discussion. Answering questions and choices were both in response to the clinician's prompt. Asking questions was defined as using the question words on the device. Finally, requests were made independently and demonstrated a want or need. Frequency counts were gathered for all of the pragmatic functions.

Intervention Strategies. The primary teaching strategies used in phase 2 of the study were aided AAC input, incidental teaching, expectant wait time, verbal prompts, and verbal and visual cueing. Table 2 shows the instructional steps of each activity during phase 2. Each time a new page was introduced, the clinician would model the new vocabulary by pointing and labeling each of the icons on the page to teach Jacob the vocabulary and cue him to the location of each word. During the conversational instruction, the clinician used aided AAC input by saying a sentence or question aloud while activating 1–3 key words of the sentence on the device through touch. This was used to demonstrate a variety of pragmatic functions (questions, initiations, etc.) and multi-symbol utterances. After the clinician asked a question or made a comment, she would provide 5–7 minutes of expectant wait time for Jacob to respond. If Jacob did not respond, a least-to-most prompting hierarchy began. The hierarchy starts with providing the least amount of support and gradually adds more support if the child does not respond to the previous prompting level. The first level was opening the relevant page of vocabulary for Jacob and providing wait time. In the next level, the clinician labeled several icons as possible responses for Jacob, followed by wait time. Finally, if no response was made, the most support was given by modeling a response and then a new topic was introduced. When Jacob did provide a response or initiation at any point in this prompting hierarchy, the clinician would prompt him to expand on his utterance and provide suggestions on how to elaborate. (view Table 2 on following page)

Table 2: Prompting Hierarchy of Teaching Strategies Used in Phase 2

Description of Prompt	Example for Conversation Interaction	Example for Choice Making Activity
General prompt or specific question using aided AAC input + wait time		
The clinician asks a general or specific question to Jacob and models the key words on the device while speaking the sentence aloud (noted in bold). Then the clinician waits for several minutes for Jacob to respond while the device is on the home page.	“**What** do you want to **talk** about” “**What** did you **do** today?	“Do you want to **read** a book or **watch** a video?”
Open relevant page of vocabulary + wait time		
The clinician opens the relevant page of vocabulary Jacob could use to answer the question and waits for several minutes.	Clinician opens the actions page. “These are actions that you might have done today”	Clinician opens the video page “These are videos you might want to watch. What do you want to watch today?”
Label several icons as possible responses + wait time		
The clinician labels several icons on the relevant vocabulary page as possible responses for Jacob to communicate.	“Maybe today you worked (points to work) at school or played (points to play) in the park or watched (points to watch) a movie. What did you do today?”	“Do you want to watch the Lion King, a truck video, or the Lego Movie?” Points to each as she says them.
Model a possible response + introduce a new topic/ starts the activity		
The clinician models a response to the question using aided AAC input. In conversation practice a new topic is then introduced and the hierarchy starts from the beginning. In choice making the activity the clinician chose is started.	“Today I **work**ed on a paper” “How are you feeling today?”	“Let’s watch **the Lion King**”.
If at any point during the hierarchy Jacob responds his utterance is repeated. During conversation he is prompted to elaborate and during choice making his choice in activity is started.		
The clinician repeats the word Jacob says and puts it in an utterance and prompts for more information.	J: work C: “Oh you worked today. What did you work on?”	J: truck video. C: “Okay let’s watch the truck video”

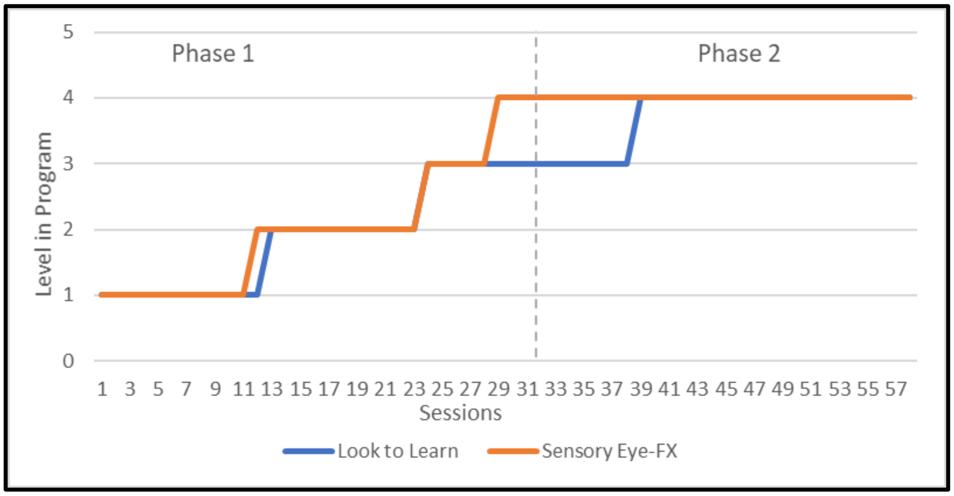
During the requesting/choice making activity, Jacob was presented with several options to choose from. A similar least-to-most prompting hierarchy was provided. First, the context page was opened with relevant vocabulary; next, the possible choices were labeled; and finally, the clinician modeled a choice and began that activity. During the reading of the book or playing of the video, the activity would stop after several minutes to provide an incidental teaching opportunity. Suddenly stopping the activity allowed Jacob the natural opportunity to ask for more or choose another option.

Visual and verbal cues were also used to teach Jacob the length of fixation needed to activate an icon. The visual cue used was a setting on the device in which a red circle that fills in a clockwise motion indicates the length of fixation needed for selection. Jacob had to fixate until the circle was completed for the word to be selected. If Jacob was not able to maintain his fixation for the set 300ms, the clinician provided verbal cues and encouragement to teach Jacob how long his fixation needed to be maintained.

RESULTS

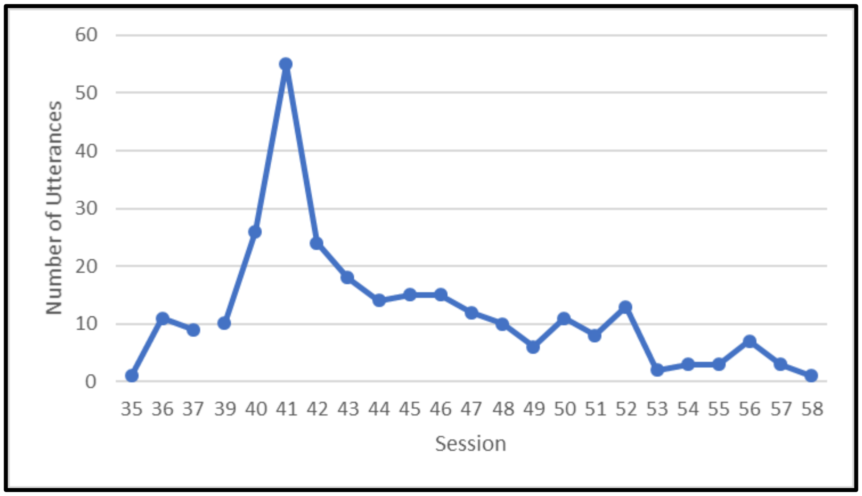
To answer the first research question, the activities and levels mastered on the eye-gaze training programs were assessed. At the end of phase 1, Jacob had mastered the first three levels on the Sensory Eye-FX eye-gaze training program and the first two levels of Look to Learn. By mastering these levels of the eye-gaze training programs, Jacob had demonstrated the visual skills necessary to access an AAC system through eye gaze. Figure 1 shows the rate of level mastery for each program. During the 5-minute warm-up activities in phase 2, Jacob continued his progress on the programs and mastered level 3 of both programs. He also mastered 4 activities in level 4 of Look to Learn and 3 activities in level 4 of Sensory Eye-FX.

Figure 1. Level mastery in eye gaze training programs.



Jacob's number and type of utterances were used to analyze the second research question. Figure 2 presents Jacob's number of utterances produced per session after the Sono Flex user was introduced during session 35. Using Sono Flex, he produced an average of 12 utterances per session for an overall total of 345 words and 152 different words.

Figure 2. Number of utterances per session using Sono Flex.



The majority of Jacob's utterances were 1 word in length. He also generated 11 two-word combinations and 1 three-word combination. An excerpt of the transcript from session 43 is presented in Table 3 that demonstrates Jacob's functional communication using the device.

Table 3: Sample Transcripts from Phase 2 Sessions

C = Clinician **J = Jacob**
Session 41- Initiations and word combinations
J: Start. C: Okay I will start reading. (Started reading the book) J: Read. C: Yes I am reading the book. J: I turn_page. C: You want to turn the page? Ok let's see (guided his hand to turn the page). J: You listen. C: Okay you want me to stop and listen to you.
Session 43- Expression of feelings and navigation
C: What else did you do today? J: Drink. C: You had something to drink? Or do you want a drink? J: Drink. C: You want a drink. J: (navigated to feelings page) Frustrated (child tears up). C: You're frustrated because you can't drink. C: I'm sorry buddy I can't give you something to drink right now (child cannot intake anything by mouth due to aspiration of liquids).
Session 52- Example of choice making
C: What do you want to watch? J: Lego_Movie. J: Show. (Clinician plays LEGO movie for several minutes and then stops it) C: Do you want to play (points to play) more of the movie or go to the next (points to next) movie? J: Truck_Video. C: Okay let's watch the truck video.
Session 54- Examples of Answering Questions
C: How are you today? J: Tired. C: What did you do for Thanksgiving? J: Feel. C: Who did you see on Thanksgiving? J: Uncle.

Jacob communicated for a variety of social functions as seen in Table 4. The most frequent pragmatic functions used were comments and initiations. His comments were often a statement of feeling or an observation of the environment.

Table 4: Frequency of Pragmatic Functions

Pragmatic Function	**Total Number Used in Phase 2**
Initiation	55
Comment	51
Answering Questions	45
Making Choices	45
Asking Questions	14
Requesting	4

The number of gaze points recorded during the entire 30-minute session is used to determine if a pattern is seen in Jacob's number of fixations and visual attention during the intervention. Jacob averaged 166.8 gaze plots per session over the course of the study. Figure 3 depicts the number of gaze points recorded at each session. [Insert Figure 3]. High levels of variability are seen in Figure 3, so to better understand general trends, the average number of gaze points every three sessions is also reported in Figure 4. Despite the variability, a trend emerged that Jacob had fewer sessions with gaze point frequencies below 50 in phase 2 (*n* = 2) than in phase 1 (*n* = 11).

Figure 3: Number of gaze points per session.

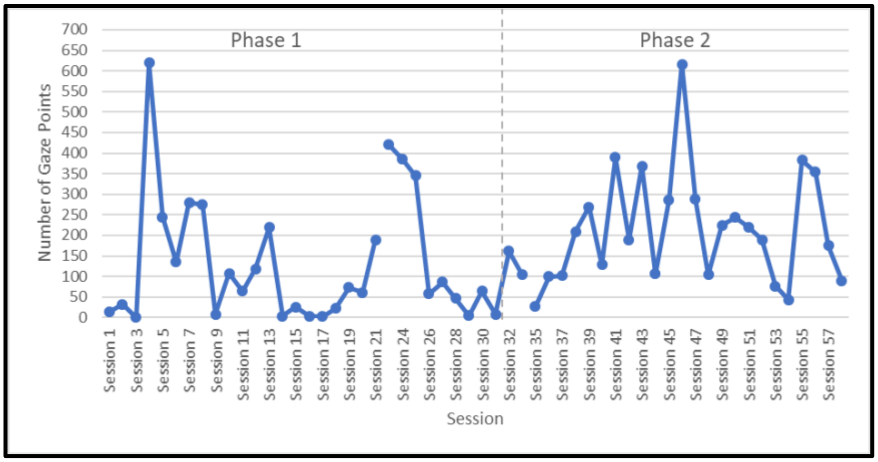
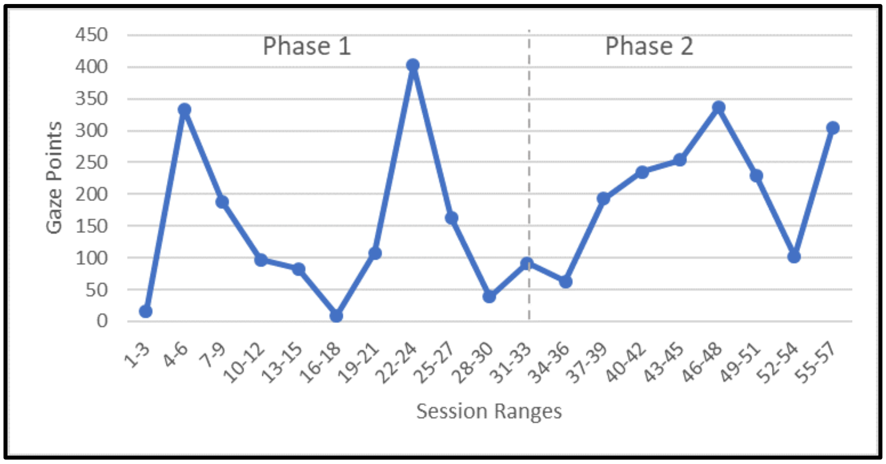


Figure 4: Average number of gaze points per every three sessions.



The other trend that is visible in these graphs is an increase in gaze points for several sessions, starting at session 4, followed by low gaze-point frequencies for another several sessions. This pattern is demonstrated throughout the intervention.

DISCUSSION

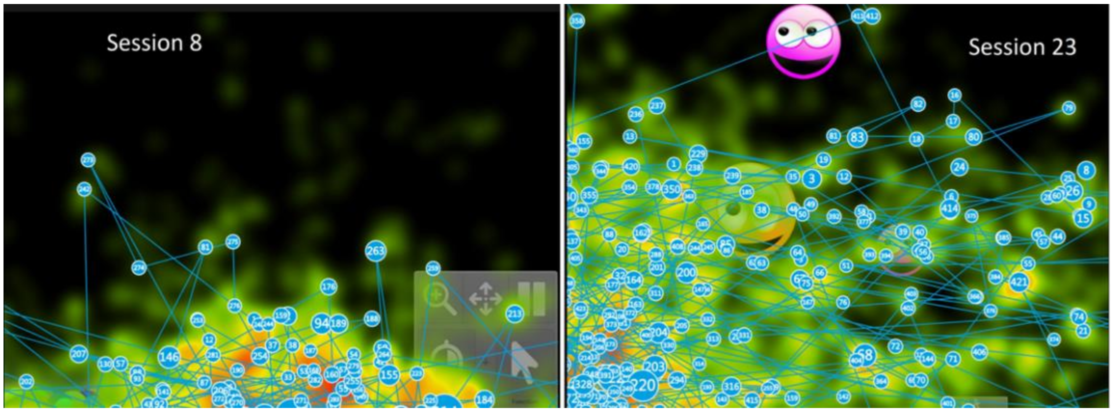
This feasibility case study answered the two research questions posed: (1) The two eye-gaze training programs trained Jacob in the visual skills necessary to access an AAC system through eye gaze; (2) He also learned to communicate using communication software on a Tobii I-12 after the necessary visual skills were obtained. Due to the nature of Jacob's disability, his level of alertness, attention, and motivation varied, and that variability is seen in the data. However, Jacob demonstrated the necessary visual skills to progress to level 4 of both eye-gaze software programs and communicate on the Tobii I12.

Functional Gains in Eye-Gaze Skills

Throughout this intervention, Jacob improved in his ability to use his vision to access the Tobii I-12 through eye gaze. Improvements were seen in his visual attention, length of fixation, access to a greater visual field, and demonstration of smooth pursuit. Improvements and variability in Jacob's visual attention and fixations were demonstrated by the number of gaze points on the screen. Although no baseline sessions were gathered, a marked increase in gaze points is seen at session 4 compared to the first 3 sessions. A pattern of several sessions of high gaze points followed by several sessions of low gaze points is then seen. This fluctuation was due to multiple factors, including attention, alertness, and interest in the activities on the programs. However, in phase 2 there is an overall improvement in visual attention, demonstrated by the drop in the number of sessions containing less than 50 gaze points. Functionally, this was demonstrated by Jacob's ability to dwell to select vocabulary to communicate in phase 2.

Improvement in Jacob's visual field was demonstrated through heat maps and fixations to various icon locations. Initial session heat maps revealed gaze primarily in the bottom and left side of the screen. As treatment progressed, he accessed the middle and right side of the screen during activities as seen in Figure 5, and by the end of phase 1, he accessed the top of the screen.

Figure 5: Heat Maps of Session 8 (left) and Session 23 (right)



Although these two images depict different activities with different skill targets (screen exploration versus fixating on an image), they were chosen because both contained colorful images on a black background. This progression in visual field was seen in phase 2 by Jacob's activation of vocabulary in many different areas of the screen to communicate. Finally, improvements in smooth pursuit were measured through his performance on activities that required the tracking of an object across the screen. Jacob progressed from only activating the screen in isolated areas to moving his eyes across the screen in a more continuous motion for longer periods. This functionally allowed him to scan more of the screen during more complex activities and to scan the vocabulary set for the word he desired.

Functional Gains in Communication

Prior to the intervention, Jacob communicated via facial expressions and some body movements. In the AAC evaluation conducted, Jacob directed his attention to a screen, but did not fixate long enough to activate an icon. During phase 2 of the intervention, Jacob functionally communicated with the clinician on the first day. Jacob progressed in his operation of the device, dwelling to select words and demonstrating some independent navigation of the dynamic display. Linguistically, Jacob communicated with an average of 12 utterances in 25 minutes per session. He accessed a variety of vocabulary with 152 different words used during the 24 sessions with Sono Flex. He also began combining words into phrases, with a total of 11 two-word phrases and one three-word phrase produced. These combinations often required several minutes of pause time between words. Finally, in the area of social gains, Jacob communicated for a variety of purposes during the phase 2 sessions, including: commenting, stating his feelings, initiating, answering questions, making choices, asking questions, and requesting.

Clinical Implications and Future Work

When working with individuals with multiple disabilities who require AAC, all avenues should be explored to ensure that their communication needs are met. This may involve training the foundational skills to use a particular access method. This study demonstrates a first step in developing an evidence-based program for teaching the skills necessary for eye-gaze access in individuals who use AAC. Further work is needed to develop a more systematic approach to teaching these skills and to evaluate the use of eye-gaze training programs with multiple populations. Future research and clinical work should use other methods of data documentation to capture functional changes in skills throughout the intervention. This could be done with using a specific assessment activity that elicits the visual skills necessary for eye-gaze access that is administered at regular intervals during the intervention and at baseline. This study lacked a baseline phase, so it was difficult to determine if the gains were a result of the intervention. Future research should administer baseline activities to better understand the individual's skills prior to intervention. Reliability scoring should also be conducted on participant performance; this was lacking in the current study.

When designing, implementing, and modifying a similar intervention, the individual's preferences, along with their visual strengths and weaknesses, should be considered. Jacob's preferences were considered in this study by altering the mastery criteria for levels 2 and 3 of Sensory Eye-FX, as he demonstrated nonverbal signs of refusal for the activities. These activities contained less visual and auditory stimuli and had a lack of color contrast. His preferences and skill acquisition were both considered by trialing the next level with the opportunity to go back to the lower level if activities were not mastered. It is important to consider the individual's preferences in order to keep them motivated and progressing.

In working with individuals with CVI, it is essential to obtain a detailed and recent functional vision report, and to work with a multidisciplinary team (Lueck et al., 2019) when designing and implementing your intervention. A detailed vision report will give you crucial information regarding the visual behaviors of your client, which are important to consider for device setup and intervention planning. Regular assessment of the individual's functional vision is also crucial, as changes may occur due to the neuroplasticity of the brain (Martin et al., 2016). In this study, the lack of a more detailed and recent functional vision assessment was a weakness and led to the need of more trial-and-error with the types of stimuli used.

There are multiple AAC systems on the market. This study used devices and programs that were current at the time but have since been updated. Providers should evaluate the devices and programs currently available in relation to their clients' strengths and needs to determine the best fit. They should also keep in mind the individual's color preferences, contrast sensitivity, perception of movement (Good et al., 2001), visual attention, perception of complex visual images, and visual field when evaluating and trialing devices and programs.

Adaptations can be made to the AAC system to capitalize on the individual's visual strengths and accommodate for weaknesses. The length of fixation necessary to select a word can be adjusted through the dwell-time setting. The individual's visual field on the device can be assessed through heat maps, and then icons outside the visual field can be moved. Many communication programs contain options for customizing the display and/or icons to increase contrast and utilize color. Finally, the teaching strategies used should also be determined through the individual's visual profile, such as using motion as a prompt or to attract visual attention, and supplementing the visual information with narration and verbal prompts. This study accommodated for visual field deficits by moving the screen, and by reducing the number of icons on the screen to reduce image complexity. Edits were not made to the system to accommodate for contrast sensitivity and color preferences. Future work should consider all of these areas when setting up the device.

When teaching communication in AAC, it is important to consider the instruction in the areas of device operation, language, and social communication. Instruction should occur on all three of these areas to allow for integration and successful communication (Light 1989). Evidence-based teaching strategies should be applied to all three areas and allow for opportunities for independent communication, and support should be increased as needed. This includes providing sufficient wait time between prompts (Kozleski, 1991), as the individual may need longer to process the visual information and make a selection than a user with typical vision. It is also important to consider that operational instruction must continue to occur once the communication system is introduced, in order to transfer the skills learned from the eye-gaze training programs to the communication system.

The result of the instruction on the individual's language and social communication outside of the therapy sessions should also be documented through parent surveys. A weakness of this study was the lack of data collection of the prompting levels needed to elicit visual behaviors and communication. Future work should document the level of support needed for communication in order to determine if the individual is becoming more independent. The number and location of icons hidden on each page should also be documented in detail along with when the icons were unhidden and the effect of the additional vocabulary on the participant's communication. Furthermore, instructional fidelity should be documented by collecting high-quality recordings of sessions and scoring fidelity with blinded coders.

OUTCOMES AND BENEFITS

This feasibility case study provides a first step in developing an evidence-based intervention to teach the eye-gaze skills necessary to access an AAC device for individuals with CVI. The intervention incorporated strategies from the CVI literature and Jacob's individual visual strengths and deficits. Jacob gained the visual skills necessary to access the AAC device and learned to communicate for a variety of functions. The eye-gaze training programs used show promise in teaching eye-gaze skills, but activities should be evaluated with the individual's preferences and visual strengths and deficits in mind. Jacob learned to communicate on a user that contained one-by-one-inch icons and lacked visual contrast. This work demonstrates the importance of presumed competence. Individuals with limited access options for AAC should be taught the necessary skills for access. Further research on eye-gaze training programs and interventions to teach eye-gaze access for those with CVI is needed.

DECLARATIONS

This content is solely the responsibility of the author(s) and does not necessarily represent the official views of ATIA. No financial disclosures and no non-financial disclosures were reported by the author(s) of this paper.

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Voices from the Field

Promoting System Change for Communication Access in Acute Care Hospitals

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ABSTRACT

Improving communication access for patients is a vital step toward improving healthcare in the United States and worldwide. A growing body of research supports the use of communication strategies, including augmentative and alternative communication and assistive technology tools, as a fundamental aspect of quality patient care and recovery. Unfortunately, a number of barriers prevent the consistent implementation of these tools in acute care hospitals, and these barriers have been amplified since the advent of the COVID-19 pandemic. This paper documents existing barriers to patient-provider communication within hospitals and presents recommendations, resources, and case studies to highlight the benefits and positive outcomes of communication interventions to guide clinical practice in this setting.

Specifically, recommendations are presented across a number of systems that impact healthcare delivery including: (a) healthcare policies and regulations, (b) healthcare providers, (c) hospital units and departments, and (d) patients and families.

Keywords: Patient-provider communication, augmentative and alternative communication, hospitals, healthcare

INTRODUCTION

A 20-year-old man with cerebral palsy and severe dysarthria tested positive for COVID-19 and was admitted to the intensive care unit (ICU) of a large hospital. He used a speech-generating device (SGD) at baseline, but due to the emergent nature of his admission, he only had a low-tech communication board at his bedside. Due to complex social circumstances, he was alone in a negative-pressure room for the duration of his hospitalization, with face-to-face visitors restricted to nurses and physicians wearing full personal protective equipment (PPE).

Thankfully, supports were in place at his hospital to ensure that he could successfully interact with staff and his family using a variety of tools and techniques. First, the medical team placed a consult order to the speech-language pathology department to assess his communication needs and provide recommendations. Through a virtual visit with the patient and his nurse (with the speech-language pathologist [SLP] calling from outside the room), and subsequent discussions with outpatient providers who treated the patient prior to his admission, the patient was given a loaner SGD with his personal page sets and settings, a rolling floor mount so he could easily touch the screen while in his hospital bed, a hospital-issued tablet for virtual consultation provided by unit leadership, and an additional tablet mount for optimal visualization. The SLP set up all the equipment outside the patient's room, demonstrated to the nurse how to use the equipment, and educated the nurse on strategies to promote carryover at the bedside. Signage was posted in his room to inform nurses at change of shift how to set up all the equipment to ensure accessibility throughout the patient's admission.

Once optimally set up, this patient was in full control of conversations with staff and his family. He was able to express his needs, communicate his desires, and socialize freely. Conversations, both face-to-face and via virtual technologies, quickly turned from staff only asking "How are you feeling?" or "What do you need?" to the patient directing his music therapists on which artists to cover during virtual therapy. He readily connected with his medical providers and asked questions about their interests.

In this case, hospital policies were in place to purchase and stock communication equipment on the unit; leadership was committed to training staff how to implement techniques to support communication using a variety of technology; staff specializing in communication technology were consulted; and the patient and his nursing staff were able to communicate successfully throughout his admission. Practices, policies, and staff, each a component of the larger hospital system, worked together to unlock a world of communication beyond this patient's basic wants and needs.

The need for patients and providers to communicate effectively throughout the entirety of a hospital stay is paramount to medical recovery and social-emotional well-being. A growing body of literature supports the use of augmentative and alternative communication (AAC) and assistive technology (AT) interventions to enhance patient-provider communication. These strategies, which encompass a wide range of solutions (e.g., communication boards, speech-generating devices) for people with communication difficulties and disorders, have long been used to solve everyday communication challenges; however, there is often little infrastructure for service provision in hospital settings. In the United States, policies and regulations must be in place within the hospital system to address patient rights to access appropriate communication supports (e.g., The Joint Commission, 2010), but providing nonspeaking patients with the necessary means to communicate effectively with providers is not often consistently addressed (Beukelman & Light, 2020). System change across hospital enterprises is urgently warranted to ensure that all patients' communicative needs are met during what might be the most vulnerable time in a person's life.

Hospital systems are comprised of several layers of organizational structure, each of which must recognize and support communication needs as a vital aspect of patient care to collectively address patient needs at the bedside. Unfortunately, many hospital leaders and providers are unfamiliar with the patient-provider communication literature, implementation of best practice in AAC/AT, and current regulations that mandate communication access for patients with limited speech. Though some institutions in the United States are implementing best practices (e.g., Blackstone et al., 2015; Santiago & Costello, 2013), barriers exist that may prevent the advocacy, creation, and implementation of new protocols and services to improve patient-provider communication. Despite a growing body of research that demonstrates the benefits of AAC/AT interventions to support patient-provider communication and existing policies mandating use of these interventions as a standard component of patient care (e.g., The Joint Commission, 2010), individuals within all levels of hospital systems are not fully aware of the importance of these interventions nor how to effectively implement them. This paper aims to describe barriers, responses, and solutions to promote hospital-wide system change to enhance patient-provider communication, access to AAC/AT in acute care settings, and ultimately, to reform patient care.

TARGET AUDIENCE AND RELEVANCE

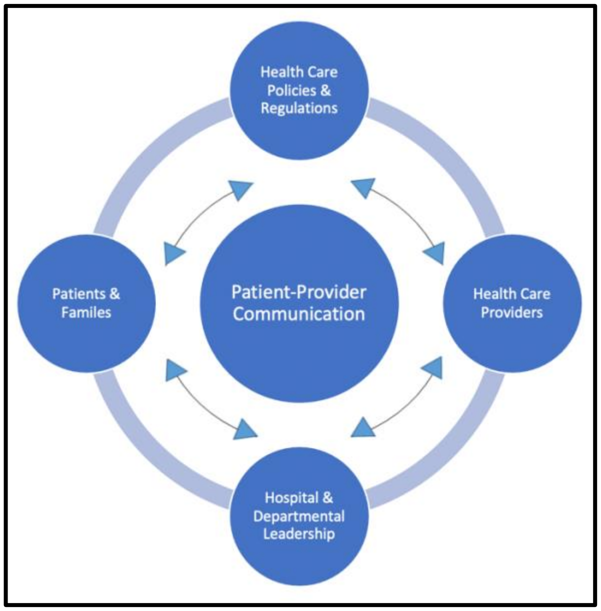
This paper is intended for healthcare providers including but not limited to speech-language pathologists, occupational therapists, physical therapists, nurses, physicians, mental health professionals, and hospital leadership. Information presented will inform these stakeholders how to promote effective and meaningful patient-provider communication and to advocate for changes within hospital systems to ensure access to appropriate communication tools, strategies, and trained staff during an acute care hospitalization. This manuscript represents the perspectives of the authors and was not subject to IRB insight.

THE CASE FOR "COMMUNICATION ACCESS" IN HOSPITALS

In a study by Bartlett et al. (2008), patients identified as having communication disorders were three times more likely to experience a preventable adverse event (e.g., medication errors, falls) compared to patients without communication disorders. These researchers also found that one-third of patients who experienced adverse events required hospital readmission. Adverse events have been linked to poorer patient outcomes, increased patient suffering and dissatisfaction, and longer hospital stays (Bartlett et al., 2008; Cohen et al., 2005; Joint Commission, 2010). Reducing communication barriers with this population could also lead to an estimated reduction of 671,440 preventable adverse event cases and a cost savings of 6.8 billion dollars (Hurtig et al., 2018). These high associated costs may be avoided when patient problems are understood, diagnosed, and treated in a timely manner.

In addition to an increased risk of adverse events, research has shown that when patients are unable to communicate and participate in their care, they are more likely to report dissatisfaction following a hospital admission. For instance, in a study of intubated patients with chronic obstructive pulmonary disease, researchers found that patients with access to AAC strategies while intubated reported higher satisfaction with care and spent less time ventilated in ICUs (El-Soussi et al., 2015). Emotionally, patients who experienced communication barriers have reported feelings of anxiety, fear, frustration, pain, and an overall loss of control (Baumgarten & Poulson, 2015). Patients who have had access to supportive communication strategies while unable to speak, whether temporarily or for extended time periods, experience reduced medical errors, increased positive patient outcomes, increased patient satisfaction, and reduced medical costs (Blackstone et al., 2015; El-Soussi et al., 2015; Hosseini et al., 2018; Rodriguez et al., 2016). They additionally receive less sedation, are transitioned faster to less intensive levels of care, report less pain, and report feeling more in control (Balas et al., 2014; Happ, et al., 2004; Patak et al., 2009; Wieczorek et al., 2015).

Figure 1: Healthcare and Hospital Systems Organization: A Radical Cycle



Ultimately, stakeholders at all levels of healthcare systems (as shown in Figure 1) must be committed to providing effective communication access to each patient; however, the route to achieving this goal is unique to each healthcare organization. Promoting and implementing effective patient-provider communication practices does not necessarily have to start from the top (i.e., healthcare policy, laws, regulations); it can also begin with a patient, family member, or practitioner who is committed to promoting patient-provider communication. Regardless of the starting point, these practices can later expand to impact other internal and external systems.

OUTCOMES AND BENEFITS

AAC & AT Strategies to Promote Effective Patient-Provider Communication

Modifying providers' interactions at the bedside to support patient participation does not always require specialized training; however, various tools and strategies are particularly effective to promote a *mutual* exchange of information. A range of communication strategies and tools exist to support healthcare interactions and should be used to prevent communication breakdowns at the patient's bedside. Providers must be equipped with basic skills like identifying patient communication signals (e.g., facial expressions, gestures), responding to these signals, and checking for understanding, which can help ensure that patients comprehend the situation and are prepared for future events and actions (Blackstone et al., 2015). Prior to defining how stakeholders within a hospital system can modify their practices, protocols, or policies to promote change, it is helpful to understand how communication can be enhanced so both providers and patients comprehend, express, and exchange meaningful messages.

AAC strategies range from *no technology* (e.g., gestures, eye movements, facial expressions, manual signs) to *low-technology* (e.g., communication boards and static visuals) to *high-technology* (e.g., speech-generating devices on various technology platforms). Inexpensive strategies like paper, pencil, dry-erase boards, and magnifying glasses can be made available in the absence of AAC specialists (e.g., speech-language pathologists, occupational therapists) for patients who have trouble speaking, seeing, understanding, and/or hearing. Patients may use written communication or simple letter boards to convey concerns and questions to providers and vice versa. Picture-communication boards and other inexpensive, low-tech tools (e.g., like materials available on www.patientprovidercommunication.org) can further support expressive and receptive communication across a variety of topics based on individual patient needs and experiences (e.g., patients who are not literate).

Some patients benefit from the use of speech-generating applications, which may be downloaded to personal or hospital-issued devices, while others may benefit from high-tech speech-generating devices to communicate broader and more diverse messages using a variety of alternative access strategies (e.g., eye-tracking, switch-scanning, mouse controls) across a variety of media platforms. Importantly, patients who cannot activate the standard nurse-call system due to muscle weakness or motor impairments need adapted nurse-call switches or systems to ensure a reliable line of communication to providers outside the room (Zubow & Hurtig, 2013).

Patients without communication impairments may also benefit from the use of communication strategies during hospital interactions including AAC/AT tools (Blackstone et al., 2015). For instance, patients who do not speak the same language as hospital providers are also at risk for communication breakdowns.

Access to interpreters, through virtual or live means, and use of low-tech and high-tech strategies that promote mutual exchange of information are essential to effective patient-provider interactions.

A *feature-matched AAC assessment* remains the gold standard for evaluating a patient's unique needs and skills to ensure that the most appropriate strategies are provided to promote effective communication (Beukelman & Light, 2020). For example, assessment of vision and hearing may support the need for large print, amplifiers, or other assistive devices. If a patient experiences difficulty with mobility, strength, and coordination, adjustable mounts for communication devices, alternative writing tools, adapted nurse-call switches, and other assistive technology solutions may be warranted. If patients have difficulty pointing to pictures, letters, and other targets to access messages, they may benefit from partner-assisted scanning of messages or speech-generating systems that incorporate eye-tracking technology or switch-scanning. In some hospital settings, emerging evidence supports the more frequent recommendation for low-tech strategies; however, a range of no-tech, low-tech, and high-tech tools should be available to support the wide spectrum of patient needs (Santiago et al., 2017).

BARRIERS TO CHANGE, RESPONSES, AND SOLUTIONS

Unfortunately, AAC/AT techniques are often underutilized in healthcare settings due to practitioners' lack of knowledge, limited access to AAC tools, and/or limited referral to speech-language pathologists and other professionals with AAC/AT skills. While there is no one-size-fits-all solution to communication access in hospitals, themes and trends from current literature highlight potential barriers and offer solutions to support service provision. As previously mentioned, healthcare decision-makers and providers at different levels of institutional organization may face a myriad of barriers that affect these efforts. Identifying barriers faced in hospitals is a first step in responding to problems and identifying solutions (Beukelman & Light, 2020). Next we discuss the different systems that impact patient-provider communication within acute care hospitals: (1) healthcare policies and regulations, (2) healthcare providers, (3) hospital and departmental leadership, and (4) patients and families. Each system is dynamic and intricately interrelated with the other systems when influencing patient care. Table 1 summarizes major barriers and potential responses and solutions based upon existing research, policy, and the clinical experiences of the authors.

Table 1: Barriers, Responses, and Solutions to Enhance Patient-Provider Communication

Opportunity Barriers in Hospitals	**Potential Responses and Solutions**
Attitudes: *Communication access is not prioritized in hospitals*	- Encourage providers to embrace change. - Participate in trainings to foster empathy when providing care to patients with communication disabilities (e.g., Baron et al., 2018). - Employ inter-professional practice and collaboration in patient care. - Recognize that providing communication access is within all health care providers' scope of practice. - Review policy and hospital regulations that address patients' rights to communication access. Advocate for integration of practices that adhere to hospital regulations and standard policy.

Opportunity Barriers in Hospitals	Potential Responses and Solutions
Knowledge & Skills: *Staff do not know about communication supports, how to use them, or effective communication strategies.*	- Review literature on outcomes of communication access including cost savings, cost benefits, patient and provider satisfaction, quality and safety (e.g. Hurtig et al., 2018; The Joint Commission, 2010). - Review literature related to best practice in AAC in acute care settings (e.g., Blackstone et al., 2015; Beukelman et al., 2007). - Include patient-provider communication and practices into pre-service staff training and routine in-service training (e.g., orientation, annual competencies) with all members of the health care team (e.g., medical students, SLPs). - Participate in professional development focused on best practices in AAC in acute care.
Resources: *Hospitals/units do not have access to communication supports or are not staffed with AAC/AT professionals that can help meet the needs of patients with limited motor, speech, cognitive, or diverse linguistic needs.*	- Allocate funds for staff, materials, and equipment to enhance patient-provider communication efficacy. - Explore alternative funding options (e.g., hospital foundations, community grants) to support the purchase of communication equipment. - Set aside time for materials preparation, delivery, and modification within productivity demands. Prepare ahead when possible (e.g., build communication symbol banks). - Create communication toolkits to support communication access at all phases of recovery (e.g., Happ et al., 2014). These toolkits should not replace the skilled evaluation and treatment by an AAC/AT professional, rather it should supplement and support the screening, assessment, and treatment process. This should include face-to-face communication, mobile communications, and nurse-call access. Decision trees and disclaimers to inform use of tool kits should be included. - Consider the needs of patients who do not speak the language of the hospital environment and integrate that into resource development. - Create a plan to prevent lost or stolen equipment, abide by infection control practices, and have practical storage solutions for tangible resources.

Practice:
Staff do not know when or how to use the communication supports; tools are available on units but are not used; AAC referrals are not routinely made
	- Adopt the mindset that providing communication access does not end with “the tool,” but instead should span *tools and strategies* that may evolve across the recovery continuum (Beukelman et al., 2007; Blackstone et al., 2015; Santiago and Costello, 2013).
	- Perform a feature-matched AAC/AT assessment at bedside and conduct diagnostic reevaluation as the patient recovers.
	- Include patient-provider communication and practices into routine staff training (e.g., orientation, annual competencies) with all members of the health care team (e.g., medical students, SLPs). Education should target:
	    - Strategies to support provider-to-patient communication and patient-to-provider communication for patients with baseline or acute communication impairments.
	    - General communication trainings (e.g., Happ et al., 2014) and personalized trainings based on the patient’s unique skills and needs.

Opportunity Barriers in Hospitals	Potential Responses and Solutions
Environment: *Strict infection control policies, patients are interacting with many people and in [potentially] different units; dense presence of medical equipment at bedside*	- Keep recommended equipment at the bedside and ensure that the patient can access the equipment during all cares, procedures, and interactions. - Provide signage regarding the patient's communication strategies, equipment operation/troubleshooting, and AAC/AT provider's contact information. - Ensure that the patient can access communication tools and strategies upon transfer within hospital (e.g., between units). - Ensure mutual exchange of medical information and AAC/AT recommendations prior to discharge as the patient transfers to inpatient rehabilitation hospital, home, etc. - Label communication devices and create a system for equipment storage - Follow hospital infection control protocols at all times to reduce the spread of communicable diseases (e.g., COVID-19). - Have a low-tech backup at all times in case of AAC/AT equipment malfunction, low battery, etc.

Healthcare Policies, Laws, and Regulations

In 2020, the COVID-19 pandemic revealed how existing laws and policies, intended to support patients with disabilities and communication impairments during hospitalizations, were not sufficiently integrated into the culture of daily practice. Laws, outlined in the Appendix, have been in place for decades to support a person's right to equal care, yet healthcare disparities continue to exist for people with communication disabilities. The Joint Commission, the accreditation body for the majority of healthcare organizations in the United States, has mandates and scoring standards that specifically address identification and provision of communication tools and strategies. Unfortunately, hospitals often do not have protocols in place that address the daily delivery of services needed by patients with communication disabilities.

Despite these known accreditation regulations and the urgent need to address communication access issues, healthcare decision makers may be unaware of communication intervention practices and potential communication tools that are readily available (Beukelman & Light, 2020). This gap in knowledge at the administrative level puts institutions at risk regarding their bottom lines, the effectiveness of their outcomes, and most importantly, the health and well-being of their patients (Hurtig et al., 2018).

Hospitals that adhere to policies and regulations designed to protect patients' communication access are likely the exception to the rule (Blackstone et al., 2015). However, these institutions, along with organizations that advocate for policy change, are setting the stage for hospital-wide change. For example, CommunicationFirst, a nonprofit organization advancing civil rights of people with communication disabilities or conditions, advocated for states and hospitals to adhere to their obligations for communication access under federal civil rights laws. In response to collective efforts from CommunicationFirst and other groups, the Office for Civil Rights at the U.S. Department of Health and Human Services announced a resolution that requires hospitals to ensure patients with disabilities can access in-person support personnel during the COVID-19 pandemic (U.S. Department of Health and

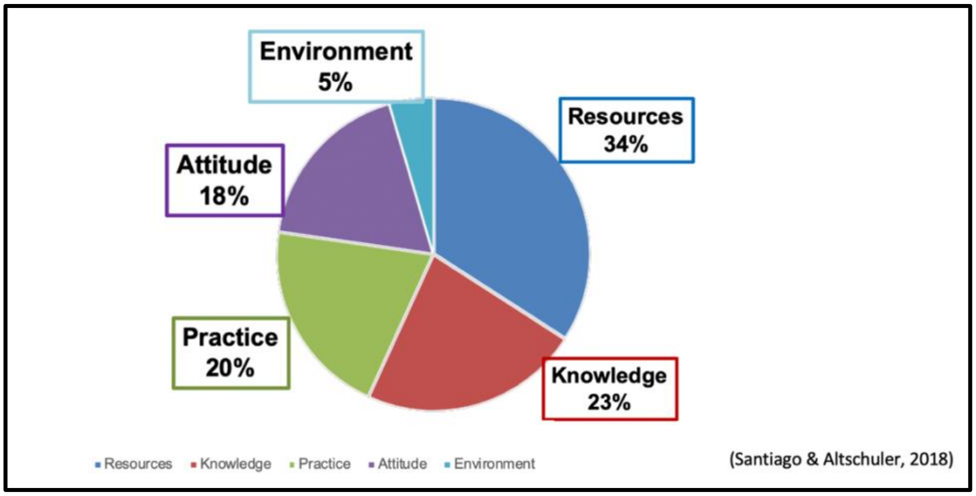
Human Services, 2020).

Department and Unit Specific Providers

To promote enhanced patient-provider communication, providers can take the following actions to integrate strategies into routine practice: (a) evaluate current barriers to successful patient-provider communication; (b) identify and participate in existing initiatives that incorporate communication access and AAC services; (c) collaborate with existing teams to broaden the reach of provider consultation to patients in need, including participation in unit rounds; and (d) promote, provide, and attend staff training focused on patient-provider communication and communication access. In the following sections, we discuss each of these actions and provide potential solutions for providers to take to engage in effective patient-provider communication with patients who benefit from communication strategies and tools.

Evaluate Barriers. The first step to understanding how to improve patient-provider communication and intervention is to understand existing barriers. Common barriers reported by patients and providers include: (a) time constraints for providers to interact with patients, (b) limited staff knowledge and skills in implementing communication interventions, and (c) limited access to AAC/AT resources and equipment (e.g., Blackstone et al., 2015; Gormley & Light, 2019; Hemsley & Balandin, 2014; Santiago et al., 2018). Although these barriers are frequently cited in the literature and should be considered when addressing AAC/AT interventions in healthcare settings, every hospital, unit, and team experience a unique mixture of challenges that should be investigated. For example, to identify the state of AAC bedside service delivery in acute care, Santiago and colleagues (2018) distributed a 35-question survey to SLPs in the United States. Many respondents indicated that there are multiple barriers to bedside AAC practice related to the available resources (e.g., limited funding, time, and equipment), staff knowledge (e.g., limited pre-service learning experiences), healthcare practices (e.g., clinical priorities do not align with communication access), staff attitudes (e.g., care provision is easier without devoting significant time to communication access), and the hospital environment (e.g., difficulties related to equipment storage, infection control precautions). Only 10% of 116 respondents reported feeling "well supported" by a hospital culture that embraces communication enhancement efforts (Figure 2).

Figure 2: Barriers to AAC Implementation



(Santiago & Altschuler, 2018)

Identify and Participate in Existing Initiatives. There are many initiatives occurring in hospitals to implement organizational change for optimal patient care. For instance, early mobility programs have received considerable attention over the past several years and numerous studies demonstrate that rehabilitation services provided to critically ill patients improve function, enhance quality of life after discharge, are cost-efficient, and are safe (e.g., Corcoran et al, 2017; Wieczorek et al., 2015). Including interventions to support communication within early mobility treatment enables patients to participate in their care early in their recovery process with a variety of professionals (e.g., nurses, physical therapists). An interprofessional treatment model involving the collaboration between the physical therapist, occupational therapist, and speech-language pathologist facilitates mobility, access, and cognitive-linguistic expertise for optimization of AAC evaluation and treatment (Altschuler et al., 2018).

Communication enhancement may be part of other hospital initiatives that providers can champion. These may include program development committees that target areas such as developmental care for pediatric patients receiving lengthy hospitalizations, promoting an autism-friendly hospital environment, intensive care unit delirium prevention and treatment, programs for patient safety and quality, and multidisciplinary tracheostomy care.

Collaborate with Existing Teams. Providers invested in enhancing patient-provider communication practices should partner and collaborate with multidisciplinary teams across the hospital setting. For example, the speech-language pathologist or AAC practitioner has a vital role as a core member of the Palliative Care team to provide early communication intervention before a condition worsens. Given access to appropriate strategies, patients can participate in decision-making for life-sustaining treatment or end-of-life care, which empowers patient autonomy and may reduce the burden of responsibility shifted to a healthcare proxy serving as a decisional surrogate. Additional examples of teams that can partner and champion patient-provider communication efforts might include tracheostomy care teams, complex care services, rehabilitation teams, neurology and oral surgery departments, and ventilation support teams. The ability to partner with social workers, child-life specialists, psychologists, chaplains, and other mental health professionals can ensure access to the appropriate communication strategies to bolster their important conversations with patients. Discussing patient feelings, concerns, perspectives, social supports, coping needs, spiritual preferences and more can effectively promote continued recovery, participation, and healing.

The Case for Staff Training. Communication skill training is part of pre-service education for many healthcare providers; however, the ability to support a patient's expressive communication during an acute hospitalization is much more nuanced. Integration of communication strategies into bedside interactions involves an understanding of the patient's baseline and current communication needs and skills, a mutual exchange of information using developmentally appropriate language, the potential use of materials that support this exchange, and the implementation of strategies to promote the patient's access to such materials.

In the case example highlighted above, communication access did not come to fruition by chance. Rather, years of staff education for hospital leadership, bedside providers, and referring physicians ensured that healthcare providers were empowered with the knowledge to recognize the patient’s needs and provide the appropriate resources. Only then could the SLP provide just-in-time training to the bedside nurse, who in turn helped inform her fellow nurses across shifts.

All healthcare professionals must learn how to use strategies and tools to effectively communicate with patients from diverse cultural and linguistic backgrounds, as well as patients who have difficulty speaking, hearing, understanding, remembering, and thinking. The knowledge and skills of providers impact the effectiveness of their service delivery and patient outcomes; therefore, pre-service and in-service training must be completed to equip healthcare workers to provide high-quality communication practices. Invested stakeholders may champion in-service education. Champions can then inform frontline care providers of best practices and provide training in implementation of potential tools and strategies.

Several education modules exist to support institutions that may not have such stakeholders available for in-service education. For example, the SPEACS-2 Communication Skills Training Program (Happ, 2014) is a research-based course for nurses aimed to teach them how to provide bedside assessment of nonvocal and ventilated patients and to select appropriately matched low-technology communication aids. Alternatively, AAC professionals may provide direct instruction and training to unit or departmental champions, who then disseminate that information to their respective colleagues. Collaboration between speech-language pathologists and nurses is key for developing a successful culture of communication (Altschuler & Happ, 2019).

Investing time and energy into evidence-based staff training on patient-provider communication practices yields positive outcomes (e.g., Baylor et al., 2019; Happ et al., 2014). For example, Boissy and colleagues (2016) found that patients reported higher satisfaction scores with physicians who completed communication skills training courses than with physicians who did not. Furthermore, Noguchi and colleagues (2019) demonstrated that staff training and interventions can promote increased awareness of patient communication needs among nurses and result in better identification of a patient’s intent to communicate, even when the patient is mechanically ventilated and sedated. In this study, patient satisfaction in nursing care and self-dignity also increased when nurses enhanced their bedside communication practices.

Hospital and Departmental Leadership

Providing quality healthcare and ensuring patient safety are top priorities for hospitals. Including communication as a quality and safety concern can begin from the patient’s first contact with healthcare providers (e.g., emergency department interactions, upon admission). For instance, a screening tool for baseline communication skills and needs can be utilized in the emergency department or in pre-operative testing. Clinical pathways or order sets for patients with diagnoses or surgeries that result in difficulty speaking (e.g. planned prolonged intubation, tumor resection, diagnosis of stroke, post-operative tracheostomy, etc.) can also be developed in electronic medical record systems to ensure that all providers are aware of the patient’s communication needs and to ensure that supports are available at all levels of care.

While some institutions have developed formal services to address patient-provider communication, others may have services driven by individual providers, and therefore, practices may vary across units and wards. These inconsistencies may result in staff confusion, reduced referral to appropriate consulting services, varied care delivery, and decreased staff training. Hospitals may also be at increased risk for program disintegration when dedicated staff members or patient-provider communication advocates transition jobs or settings. Nordness and Beukelman (2017) describe several ways hospital institutions can promote regulatory practices, guidelines, and policies to promote enhanced communication. These include: (a) establishing a formal process to order referrals to appropriate consulting services in order to assess communication needs at the bedside; (b) create streamlined daily documentation formats across disciplines that integrates communication access needs and updates; (c) incorporate communication support needs into patient rounds (e.g., daily medical rounds, rehabilitation rounds, multi-disciplinary unit rounds); and (d) establish clinical pathways or care plans to guide referral to multidisciplinary providers, for necessary accommodations and for needed services. These may also include order sets, or a series of orders that are intended to capture multiple needed consults for a specific diagnosis or medical condition.

Hospital leadership should also develop or incorporate communication access needs into regular staff training and in-services for new hires as well as seasoned employees across disciplines. Enhancing patient-provider communication hospital-wide requires commitment to hiring knowledgeable staff with experience in AAC practices and AT solutions. For hospital and departmental leadership, this also means investing in the procurement of materials and equipment, ranging from low-tech to high-tech tools, to support a wide range of patient needs. The cost of these investments may pose a barrier to departments that are not currently budgeting for these needs, despite evidence that addressing communication barriers can have quality, safety, and cost-saving benefits (Hurtig et al., 2018). As previously mentioned, the potential cost-savings and improvements in patient care suggest that it would behoove hospitals to invest the time and money in addressing patient-provider communication as effectively and supportively as possible in addition to supporting staff training and expansion.

The Patient and Family

Patients in hospitals may have baseline or acute communication impairments. Although many patients with baseline communication disabilities and their families may be aware of their rights and needs outside the hospital walls, patients must understand their rights within the healthcare system (see “Patients’ Bill of Rights” in Appendix). Patients with communication impairments may be unaware of available resources ranging from supportive staff with expertise in AAC, tangible materials on ICU or acute care floors to facilitate improved communication, and/or tools to support access to needed materials and technologies. Patients and families should partner with hospital leadership and providers to ensure communication needs are identified, respected, and supported through appropriate interventions.

When a hospital admission is planned for elective surgeries or procedures, patients and families can take collaborative action during a less stressful time prior to admission to yield more positive outcomes, experiences, and interactions. Patients with an anticipated loss of speech may also benefit from advanced planning in the context of more acute nonspeaking conditions, like emergent tracheostomy

(Santiago et al., 2019). Table 2 highlights ways patients and families can prepare ahead of a hospitalization.

Table 2: Communication Planning Ahead of a Hospital Admission

Patients with Preexisting Communication Challenges	Patients Who Anticipate a Loss of Speech
- Program medical page sets and relevant vocabulary into AAC systems - Bring communication tools and devices to the hospital along with any other needed equipment (e.g. mounts, switches, Bluetooth interfaces, etc.) - Learn about hospital policies regarding loss and theft prevention - Become familiar with the hospital's "Patient Bill of Rights" as well as state and federal laws to advocate for needs while inpatient. - Prepare signage depicting communication preferences - Complete a "Medical/Communication Passport" (Blackstone et al., 2015) with information related to medical needs and preferences, preferred communication methods, physical needs, and social information. - If over 18, identify a health care proxy and outline advanced care directives	- Learn about the anticipated impact of surgery or procedure on speech production, respiration, and physical skills - Work with a speech-language pathologist or independently create custom communication tools - Practice communicating with these tools using a variety of strategies (e.g. direct selection or pointing, eye gaze, partner-assisted scanning, etc.) - Participate in Message Banking™ if able by recording chosen messages to be programmed into a speech-generating device (Costello, 2000) - Complete a "Medical/Communication Passport" with information related to medical needs and preferences, preferred communication methods, physical needs, and social information. - If over 18, identify a health care proxy and outline advanced care directives

CASE EXAMPLE

In March 2020, as the COVID-19 pandemic swiftly spread in the United States, a no-visitor policy was immediately enforced for all patients and families at a hospital in New York City regardless of their COVID-19 status. A 25-year-old male in the Neurological Intensive Care Unit underwent a tracheostomy, was ventilator-dependent and unable to speak, and had bilateral upper-extremity weakness. Following SLP evaluation, he was trained on the use of an alphabet board to spell messages and, over the course of several therapy sessions, he learned to efficiently and effectively use partner-assisted scanning. The communication partners at his bedside were trained in implementation of this strategy and nurses provided education and demonstration to the incoming nurse during shift changes. Patient-provider communication was successful across partners, shifts, and contexts, but due to the visitor restriction, he still expressed feelings of social isolation. He wished to communicate with his wife, especially given that she was pregnant and due in several weeks. Communication access went beyond the confines of the bedside, and the SLP began conducting therapy sessions via teleconference using his cell phone so the patient could interact with his wife. His wife printed the alphabet board at home and was able to communicate with her husband during scheduled video-chat calls. He even participated in the decision making for selecting a baby name through partner-assisted scanning using virtual technology. As he regained fine motor control and strength, he was able to independently access the alphabet board and initiate the video calls to his wife and other family members. The patient was eventually able to write on a dry-erase board and use his own phone to download a text-to-speech app. During such a time of anxiety for all, he was able to ask his family questions regarding their own safety and well-being. When he was *discharged from the hospital, he expressed having had feelings of satisfaction, empowerment, and a sense of control as a caregiver himself, even while physically apart from his family.*

CONCLUSION

Improving communication access for at-risk patients is a vital step toward improving healthcare in the United States and worldwide. Patient-provider communication and use of communication strategies in hospitals has been identified as a fundamental aspect of quality patient care and recovery. Yet without efforts to recognize communication and associated interventions, hospitals cannot effectively respond to known barriers and integrate AAC/AT and services into daily practice. Shifting hospital culture takes time, commitment, and the concerted efforts of stakeholders at each level of institutional structure. Ensuring communication access through a range of no-tech, low-tech, and high-tech AAC/AT strategies, *will* yield more positive outcomes for patients, families, providers, and hospital leadership. This paper documented existing barriers to patient-provider communication within hospitals and provided recommendations, resources, and case studies that highlight the benefits and positive outcomes that stem from provision of appropriate interventions. Change can begin at the top by recognizing and responding to barriers and gaps in care at the policy and leadership levels. Change can also begin from individual patients, families, providers, and teams through action and improvements within hospitals. Regardless of how system change is launched, support must be in place at all levels of organization within a hospital system.

DECLARATIONS

This content is solely the responsibility of the author(s) and does not necessarily represent the official views of ATIA. No financial disclosures and no non-financial disclosures were reported by the author(s) of this paper.

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APPENDIX

Convention on the Rights of Persons with Disabilities

In 2006, the United Nations General Assembly adopted the treaty, the *Convention on the Rights of Persons with Disabilities* to ensure that people with disabilities have access to the same rights and opportunities as everybody else. The treaty defines communication with the inclusion of augmentative and alternative communication modes which validates AAC as a mainstream approach to meeting communication needs. Furthermore, the *Convention* sets out legally binding obligations on all countries to ensure the rights of all people with disabilities to achieve equality in society.

For more information visit: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

The Joint Commission

The Joint Commission on the Accreditation of Healthcare Organizations (JCAHO, now The Joint Commission) in the United States strongly emphasizes (Standard of Care RI.2.100) that patient have the right to effective communication and health care organizations need to provide support to achieve effective patient-provider communication of all patients. Specifically, the Elements of Performance for RI.2.100, No. 4 state, "The organization addresses the needs of those with vision, speech, hearing, language, and cognitive impairments." Additionally, the 2007 National Patient Safety goals include (2007 National Patient Safety goals- Goal 13) encouraging “patients’ active involvement in their own care,” which requires overcoming communication barriers.

For more information visit:
http://www.jointcommission.org/PatientSafety/NationalPatientSafetyGoals/07_bhc_npsgs.htm

Americans with Disabilities Act (ADA)

The Americans with Disabilities Act (ADA) of 1990 is a civil rights law that prohibits discrimination against individuals with disabilities and to ensure that these individuals have the same rights and opportunities as everyone else. The ADA requires that Title II (state and local government services) and Title III (businesses and non-profit organizations that serve the public) communicate with people with disabilities as equally effective as their communication with people without disabilities.

For more information visit: https://www.ada.gov

Rehabilitation Act of 1973

Section 504 of the Rehabilitation Act of 1973 states that “no qualified individual with a disability in the United States shall be excluded from, denied the benefits of, or be subjected to discrimination under” any program or activity that receives Federal financial assistance. As all hospitals in the United States receive reimbursement and funding from Centers for Medicare and Medicaid Services (CMS), they are required to provide effective communication supports for patients.

For more information visit: https://www.dol.gov/agencies/oasam/centers-offices/civil-rights-center/statutes/section-504-rehabilitation-act-of-1973

Affordable Care Act (ACA)

Section 1557 of the Affordable Care Act (ACA) in the United States prohibits discrimination on the basis of disability and provides that no individual shall be barred from participation in or be denied the benefits of any health program that receives Federal financial assistance. This works in conjunction with other Federal anti-discrimination and civil rights legislation.

For more information visit: https://www.hhs.gov/civil-rights/for-individuals/section-1557/index.html

A Patient's Bill of Rights

"A Patient's Bill of Rights" was the name of a document that the American Hospital Association (AHA) introduced in 1973 and revised in 1992 with the expectation that observance of these rights will contribute to the delivery of effective care. The AHA encouraged each healthcare facility in the United States to adapt 12 rights to fit the needs of their patient community. In 2003, the AHA replaced its original Patient's Bill of Rights with the Patient Care Partnership, which is a brochure written in plain language and offered in multiple languages for the patient to understand their rightful expectations for their hospital stay. Each hospital may have their own Bill of Rights, however effective communication between patients and providers is most often included.

For more information visit: https://www.aha.org/other-resources/patient-care-partnership

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Voices from the Field

Partnering to Create a Core Communication Board to Improve Theater Experiences

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ABSTRACT

This article outlines a partnership between a nonprofit theater in Connecticut and pre-service special education teachers at a local university. The goal of the collaboration was to increase the accessibility of the sensory-friendly performances and events designed for students in PK-12. The process of creating visual supports and a core communication board is shared, in addition to the designing of training and implementation phases. The project not only resulted in improved supports for the school-aged sensory-friendly events for the next season, but also in a demonstrable perspective shift on the importance of inclusivity and community communication supports among pre-service teachers and community members.

Keywords: accessibility, teacher education, community-based experiences, communication

INTRODUCTION

Participation in community experiences is essential for an individual's development. Many students with disabilities are missing out on socially meaningful community participation (King et al., 2003). Communication challenges may be one obstacle for students' inclusion in their community (Batorowicz et al., 2006; Shepherd & McDougall, 2008). The increased presence of augmentative and alternative communication (AAC) devices in schools hasn't directly correlated to an increase in socially-interactive moments within the classroom (Alant, 2017) and beyond. To increase meaningful moments, AAC should be artfully integrated into an individual's environment (Alant, 2017), creating a fully inclusive space. Community spaces may have additional environmental factors—availability, supports, attitudes—impacting the meaningful moments for students to utilize AAC (Raghavendra et al., 2007). Although the research on communication supports in community spaces is growing (Derse, 2008; Naidoo & Singh, 2020; Shepherd & McDougall, 2008) there is a need to continue spreading communication supports into non-school-based environments.

Shepherd and McDougal (2008) reported on the implementation of the program Libraries for All which had the goal of increasing access to communication in Canadian libraries for everyone. This program included four different communication boards (two letter boards, a word board, and a symbol board), training for staff, and a promotion of the program. Although specific results and user testimonies weren't provided, the access to communication in a community environment was accomplished (Shepherd & McDougall, 2008). Unlike Libraries for All, the current project has a target population of PK-12 students attending sensory-friendly events at a theater with their families; however, the goals are similar.

A recent study by Naidoo and Singh (2020) outlined the integration of a low-tech, color-coded, symbol-supported visual communication board at a dental office. The research identified that visual supports increased client comfort and also highlighted the importance of continuous review of vocabulary and implementation (Naidoo & Singh, 2020). The current project describes a partnership between a private university and a nonprofit theater to add visual supports and a communication board with the goal of increasing universal communication access to school-age patrons and their families attending sensory-friendly events.

PERSONAL STATEMENT

One professor and three students from the university's special education program developed this community outreach project after identifying the need to increase community involvement and inclusivity. The special education program at the university is passionate around increasing access for individuals through universal design, AAC, and assistive technology. The professor is also a practicing assistive technology specialist with a background in theater and a family connection at the nonprofit theater. The family connection facilitated the partnership with the front-of-house staff and accessibility committee. The committee at the theater had already integrated consistent sign language supports for live events and was interested in continuing to expand accessibility. The three senior capstone students completed student teaching and were in the final semester of their undergraduate program, eager to continue their involvement in the field. The university was dedicated to producing passionate special education teachers who advocate in their school and local community for inclusion, and this project aimed to demonstrate the importance of advocacy and community partnerships.

TARGET AUDIENCE AND RELEVANCE

School, community, and university members are the main audience for this project. Special education teachers can apply this example and partner with local theaters to increase the availability of field trips and supplemental experiences for all students. As noted within this project, once the personal connection was made with the organization, the theater staff was eager to improve its offerings and take initiatives to support inclusive practices. Fostering relationships and personal connections will help build these experiences and encourage accessibility awareness within the community.

Community members can utilize this article as an example of strategies and tools to improve universally accessible experiences. The work outlined demonstrates the steps and tools that can be implemented to support universal participation for a PK-12 audience. In the initial meetings with the theater, the staff was extremely eager to hear ways to improve access. Hopefully, this project report will provide options and spark new partnerships in communities to improve accessibility.

Finally, university members can appreciate the value of community partnerships and community clinical experiences for pre-service teachers. The emphasis on school clinical experiences is essential for pre-service teachers; however, dedicating coursework to community collaborations establishes invaluable perspectives to take into a future career. University professors can design similar experiences to bridge the school/community divide and to promote communication supports in and outside of the classroom.

PROJECT OUTLINE

Partnership

A local nonprofit theater in Connecticut dedicated itself to sensory-friendly experiences for patrons beginning in 2015, primarily targeting the 18-and-under population. They began the endeavor with a large holiday sensory-friendly performance and worked in collaboration with a committee of experts in the state to design the experience for patrons with sensory needs, specifically those with autism spectrum disorder. After the initial show, the theater staff continued the sensory-friendly experiences internally. They planned sensory-friendly performances, small workshops, and social events, including drumming circles, a paint night, yoga, and Lego projects. The organization wanted to improve the theater experience for patrons attending these events and began the collaboration with the special education department at the university in 2019 to continually enhance the sensory-friendly events.

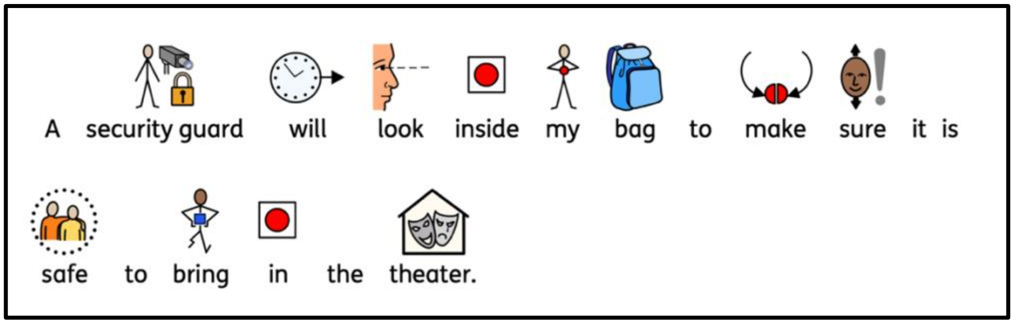
The first year of the partnership with the university focused on pre-service teachers attending sensory-friendly offerings and surveying patrons regarding their experiences. Patrons expressed the continued need for accessible community experiences. The theater staff and pre-service teachers met the next year to brainstorm ideas for increasing the accessible options. To guide this work, the pre-service teachers created an informal poll distributed via Facebook and parent networking groups throughout the state. With almost 50 responses from parents, caregivers, and special education teachers, respondents expressed that in addition to reduction in crowds, physical accessibility, and no loud noises, possible patrons would be interested in visual stories of the events, visual schedules, and low-tech communication boards to improve the theater experience.

For the 2020 season, the theater had a series of two workshops and one children's musical event. The supports were created to trial for the following sensory-friendly events in 2020: a Lego workshop for up to 20 students, a sensory-friendly performance of a kids' musical folk group (seating capacity up to 900), and a yoga session for up to 20 attendees. The team's goal was to meet after each event, process the success and feedback, and revise or adjust as needed for the next offering.

Visual Supports

The first step in the project was creating visual supports for potential patrons. Visual supports can be utilized across settings (Rao & Gagie, 2006) to improve the processing of information (Grandin, 1995) and to provide predictable environments (Fittipaldi-Wert & Mowling, 2009) and independence (Pierce et al., 2013). Types of visual supports include but are not limited to: visual schedules, visuals to structure the environment, visual scripts, rule reminder cards, and visual task analysis (Meadan et al., 2011). For the initial 2015 performance, the staff created a visual story on the live-theater experience. The story was reviewed by the pre-service teachers and updated to be generalized for any performance with symbol supports. The pre-service teachers also outlined additional scenarios such as: going to the bathroom, taking a break, getting a refreshment, and visiting the merchandise table. The pre-service teachers consulted family members of individuals with autism and other professionals to confirm the language use and appropriateness. Figure 1 displays an example from a symbol-supported visual story.

Figure 1: Sample Sentence from Main Visual Story



A security guard will look inside my bag to make sure it is safe to bring in the theater.

The website Widgit Online (https://widgitonline.com) was utilized to create symbol-supported text for the visual stories. This platform allows for symbol customization to ensure that the visuals reflect the diversity of the patron population. After the text was symbol-supported, the PDF versions were exported and sent to the theater for review. The theater media department approved the material and posted them on the public website for potential patrons to download and access. In addition to the text-based symbol supports, the pre-service teachers planned and recorded a movie to demonstrate the experience of attending a live performance directly corresponding to the written story.

Core Communication Board

The next phase of the project involved designing and implementing a communication board for the lobby of the theater during sensory-friendly performances. In preparation of creating a low-tech communication board, the pre-service teachers conducted a background of AAC, core and fringe vocabulary, and implementation strategies. Core communication boards for community locations, specifically playgrounds, have increased in recent popularity in PK-12 environments, as made evident by a search of “playground communication board” on Google revealing 2,610 options. These results include Pinterest links to the best AAC/Core boards, GoFundMe pages for boards, and articles from local schools sharing their installments.

However, the research base on these community boards is not plentiful. Early on, Derse (2008) shared the process behind her project to install a playground communication board and emphasized the importance of planning and stakeholder buy-in. In a medical setting, Naidoo and Singh (2020) found that a low-tech symbol-based communication board increased comfort during a dental appointment experience. To identify the board vocabulary, the researchers gathered dental-specific terminology and received input from dental professionals. Since the purpose of the board was also to share oral care information, the majority of the words chosen were dental-specific. Naidoo and Singh provided training to the dental hygienists using an adaptation to the Language Acquisition through Motor Planning (LAMP) approach pairing the verbalization of the word and pointing to the symbol (2020). Based on the results of the small scale study, they also recommended more training and continued vocabulary review to improve the accuracy of the board (Naidoo & Singh, 2020). Looking at visual art experiences for students with communication needs, Coleman and Cramer (2015) suggested the use of a low-tech communication board for increased participation and control in the art space. This project took those recommendations from these previous studies, especially acknowledging the need to educate the theater staff and volunteers on the purpose and implementation of the communication board.

Vocabulary. After establishing the foundational understanding of AAC, the pre-service teachers then worked to design the board for the theater. A major component of this project was choosing the core and fringe vocabulary to include on the board for the target population. Core vocabulary refers to common language that is used most often across most environments, contexts, and conversations (Banajee et al., 2003). This language includes question words such as “what” and “where,” personal identification words such as “me” and “his,” general nouns, verbs, feelings, and smaller words, such as prepositions and articles. Fringe vocabulary refers to the context-specific vocabulary that changes with the environment or conversation (Banajee et al., 2003).

Integral to the vocabulary choices was the expected user population, PK-12 students and their families. The theater shared the workshops generally to attract children ages 3–15 and the musical event had a target age of under 12. Unlike Shepherd and McDougall (2008), there was no assumption that school-age children and their families would come with their own AAC devices for general communicative functions. Choosing vocabulary was not taken lightly by the team. Input was provided from a school based AAC/AT Specialist and Speech and Language Pathologist to ensure the appropriateness of the vocabulary selection. The team decided on a majority of core vocabulary to increase the availability of general language for users across multiple opportunities. For example: “balcony” can be substituted for “up”; and to indicate that the patron has to wait for a break in the show, “close, stop” can be modeled. If a patron is looking for “refreshments,” “eat” and/or “drink” would indicate to the staff what the patron needs.

For the main board, focusing primarily on fringe vocabulary—balcony, soda, candy, merchandise—might limit the number of communication exchanges that could be initiated and communicated on the board. Although core vocabulary is rooted in conversation samples of typically-developing children, based on the article review by van Tilborg and Deckers, “core vocabulary is thus of high importance of all AAC users, regardless of physical or intellectual disabilities” (2016, p. 135). However, there remains a variety of viewpoints in research regarding vocabulary use and personally relevant AAC systems that are vital to consider when designing a communication board (Boenisch & Soto, 2015; Laubscher & Light, 2020). The team also discussed the option of creating fringe-specific word boards for additional areas of the theater during large events—for example, the concession stand, the merchandise table, and the bathroom—and utilizing photos of the items in the environment. However, the team decided to gather patron feedback from the initial implementation before adding additional layers of support.

The core communication board created for this project also includes interchangeable fringe vocabulary referencing the show or program that is being presented. If the performers were a musical band, the fringe vocabulary might include “guitar” and “drums” as well as titles of some of the songs and each of the band members’ names with actual pictures of the performance or activity. Photographs will be used to increase the personal connection to the vocabulary displayed on the board to promote communication attempts (McKelvey et al., 2010). These final two columns will be developed by the university team to ensure appropriateness of vocabulary for continued use. Updating vocabulary based on an individual’s needs is vital to continued success of the AAC use (Johnson et al., 2006); therefore, this continued revision is integrated into the implementation. The partnership agreed to review vocabulary after each event and will review and update as needed.

To assist in the development and ensure appropriateness, the pre-service teachers and professor consulted with a practicing speech and language pathologist and AAC/AT Specialist. She provided specific consultation on the language to include and made additional suggestions. For example, she emphasized the importance of including “Something else” for an individual to express that their message isn’t included on the board, which is vital when designing communication boards (Derse, 2008). Once the core communication board was finalized, the layout was sent to the theater administration for review and approval.

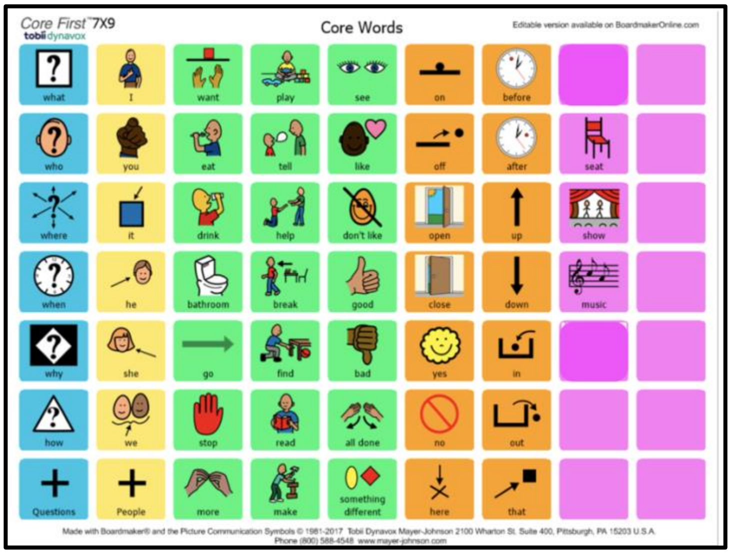
Targeting the initial population of school-aged students with communication needs attending performances was the basis for the majority of the core vocabulary. In contrast, when developing the boards for the general population, Shepherd and McDougall (2008) utilized library-specific vocabulary, based on the assumption that patrons would bring their personal devices for general communication. Hopefully, this initial project with a target population will result in the development of a communication board for general admission events, which will require additional trainings and vocabulary revision.

Designing. Boardmaker Online® was utilized to design the core communication board. This platform was chosen based on the popularity of the Picture Communication Symbols (PCS) in schools. The pre-service teachers learned about the technical components of the website, explored the templates, and began the design process. The 63 word core board template was agreed upon to not overwhelm users, but also to provide enough access to core and fringe vocabulary. The board was organized into five different color-coded sections. The first blue column was broken down into question words (what, where, when, why, and how). The yellow column was dedicated to people, such as I, we, she, he, and you. The green columns had core words (help, more, feeling, bathroom). The orange columns had small words (yes, no, up, down, before, after). The final pink columns had the fringe/content-specific vocabulary that could be changed to match the particular event occurring at the theater.

Once the pre-service teachers identified the appropriate vocabulary for the core communication board, they then had to learn how to edit cells and symbols using Boardmaker®. They were required to delete existing visuals and vocabulary, input new vocabulary and visuals, and adjust the colors of the visuals chosen. The professor discussed the importance of ensuring that the visuals were culturally representative; editing the symbols allowed the team to do so.

The final board included 63 cells, 78% (49) core vocabulary with 22% (14) available for rotating fringe words. Individual fringe word symbols based on the individual performances would be created and Velcroed to the final two columns. With input from the expert, the final board was sent to the theater for another round of feedback. The front-of-house manager printed the communication board file and laminated it on a poster. The final core communication board image is pictured below with some starter fringe vocabulary included as Figure 2:

Figure 2: Core Communication Board Created for Sensory Friendly Events



Core First™ 7X9
tobii dynavox

Core Words

Editable version available on BoardmakerOnline.com

what	I	want	play	see	on	before		
who	you	eat	tell	like	off	after	seat	
where	it	drink	help	don't like	open	up	show	
when	he	bathroom	break	good	close	down	music	
why	she	go	find	bad	yes	in		
how	we	stop	read	all done	no	out		
Questions	People	more	make	something different	here	that		

Made with Boardmaker® and the Picture Communication Symbols © 1981-2017 Tobii Dynavox Mayer-Johnson 2100 Wharton St. Suite 400, Pittsburgh, PA 15203 U.S.A.
Phone (800) 588-4548 www.mayer-johnson.com

Training. After developing the core board, the professor and pre-service teachers focused on training and implementation. The university team participated in significant research and practice when preparing to train the staff and volunteers at the theater to utilize the board. The expert advisor shared key strategies on building capacity, training, and implementation of AAC. She emphasized the importance of building an understanding of the purpose and function of AAC, in addition to effectively modeling language. Opportunities to utilize communication with a communication partner demonstrate value in the support and can contribute to its effective use (Johnson et al., 2006). The pre-service teachers collaborated and practiced the physical actions of modeling core language in combination with spoken language. After researching strategies, each pre-service teacher recorded a read-aloud while modeling communication on a low-tech communication board. The purpose of this activity was to increase their comfort with modeling before presenting to the theater staff and volunteers.

Research has shown that modeling the use of AAC systems not only increases the proficiency of use across multiple language domains, but also increases the complexity of language being expressed through these devices (Binger & Light, 2007; Sennott et al., 2016). When implementing a core communication board within a theater environment, modeling the board supports its functionality in the space and allows individuals who use AAC to see how communication supports can be integrated within the community. Modeling language on the core communication board at the theater will hopefully encourage other family and community members to participate in modeling.

A training session was scheduled for the front-of-house staff and approximately 200 usher volunteers. The professor and pre-service teachers designed a 15-minute mini-workshop providing a background on the core communication board and its purpose, as well as a demonstration of modeling. Unfortunately, three weeks before the training, the COVID-19 pandemic shut down the theater. To continue the project, the university team recorded the training to be delivered virtually to the volunteers.

NEXT STEPS

Once the theater reopens after the pandemic, the sensory-friendly programming will be rescheduled. The visual stories and video preview will be used in pre-show marketing and onsite support. The training video will be sent to the volunteers and the professor will conduct live language modeling sessions for the volunteers and staff. The professor will attend the sensory-friendly workshops and performances to model the use of the core communication board for patrons and volunteers. Observational data will be kept on patrons' interactions with the core communication board and informal feedback on its effectiveness. The theater front-of-house staff and professor will meet to review the implementation to revise the vocabulary or approach as needed based on feedback from patrons and use.

After the initial implementation during the sensory-friendly performances geared towards PK-12 students and their families, the collaboration will then discuss the creation of a communication board for general admission performances. The next phase of the project will have a targeted audience of all attendees; therefore, the vocabulary and presentation will need to be revised and updated to match. For example, when developing for an adult audience, more fringe vocabulary will be needed to reflect the unique community experience of attending a theater. This fringe vocabulary and access will need to be developed with the consideration of a variety of users, similar to the work of Shepherd and McDougall (2008). Training, review, and revision will include the theater and university team as the collaboration has continued to grow over the first two years.

OUTCOMES AND BENEFITS

When presenting their experiences to the theater staff, department chair, and other community partners—including a universal participation theater consultant—the pre-service teachers emphasized the perspective shift in their roles and purpose as future special education teachers and members of their communities. They expressed that a key benefit of the core communication board is that it increases accessibility of the theater experience, not only for individuals with disabilities, but also all patrons. They expanded that although the current project focuses on families and students with disabilities during sensory-friendly performances, the theater was open to adding a communication board for other general events. Adding a communication support to a general-admission event has the potential to increase patron awareness to communicative differences. Other groups of audience members may also benefit from its availability, for example, patrons with physical disabilities, hearing loss, or limited English proficiency. The pre-service teachers also reflected on the interest and desire to learn from the theater staff. The staff wanted to create an inclusive experience but didn’t have the knowledge background to identify what would be implemented. Providing more accommodations, increasing awareness, and establishing multiple means of access publicly in our community will provide opportunities for society to be accepting of diversity.

The pre-service teachers shared their feelings of responsibility to increase engagement with their home communities to support inclusive communication practices beyond this collaboration. One student explained that she is interested in contacting her local theater to initiate a similar program. Another reflected on her student teaching experiences and the frequent behavioral challenges on community field trips. She elaborated that in the future, if she were planning for a community outing with students, she would have a communication board ready for utilization in community settings. Although this project was one step in one community to increase communicative inclusivity, the perspective shift for all the team members was a huge benefit to the initiative and future projects.

Through the collaboration between the university and the theater, the importance of bringing the community into the classroom quickly emerged as a benefit throughout the process. Field experiences of teacher preparation programs almost always consist of being in the classroom and getting hands-on experience with real students and teachers. However, as important as this component is, that leaves little opportunity for pre-service teachers to engage with the community and make that connection between inside and out of the classroom. Especially in the field of special education, the community becomes a huge obstacle for individuals with disabilities when they reach the end of their school career. Although transition planning begins years in advance for individuals receiving special education, this often does not fully prepare them to integrate seamlessly into the community (Hoover, 2016). Through this current experience, the university team learned the importance of remembering that support and guidance does not, and should not, end in the classroom. The community should be just as accessible and important of an environment for individuals, and therefore special educators should work early on to integrate as many aspects of the community into the classroom as possible.

When reflecting on their experiences during the partnership, pre-service teachers shared how their perspectives on universal design and communication support had shifted. They expressed the idea of including an AAC board in their future classrooms, implementing communication supports in lessons, and promoting a more communication-inclusive environment. Although these concepts are reviewed and taught in the higher education classroom, this partnership allowed pre-service teachers to experience the benefits and potential impact of community engagement. As Alant (2017) posits, teachers need to not only support students' functional interactions with AAC, they also need to support the experiential process of interaction during communication. The pre-service teachers expressed the increased value of meaningful communicative interactions that will hopefully result in positive outcomes for their future students.

DISCUSSION AND CONCLUSION

Providing access to communication supports in the community is the first component in accessible community experiences for individuals with communication needs (Raghavendra et al., 2007). This article reflected the beginning stage of a collaboration between a nonprofit theater and a university with pre-service special education teachers. The goals of the partnership were twofold: increase accessibility at sensory-friendly offerings and expose pre-service special education teachers to developing supports for community settings. The project revealed two important areas for additional exploration: community acceptance of inclusive communication supports and pre-service teachers' engagement in authentic AAC and AT experiences.

Promoting an increased presence of communication supports—high tech or low tech —creates an environment where communicative differences are accepted. During some of the planning meetings with the theater, the team mentioned that the use of the core communication board might be increased to general performances beyond just sensory-friendly offerings targeted at school age audiences and families. The theater staff was excited for this prospect and agreed that other patrons could also benefit from the support. The theater staff shared that they hadn't previously considered the variety of patrons who could benefit from visual communication supports. They already offer sign language interpreters and sound amplification devices for patrons. Increasing their awareness of this support provided more opportunities to increase access at all of their events. Taking this next step toward accessibility would require a full redesign and vocabulary revision. However, this willingness demonstrates how awareness is a vital step in accessibility.

Finally, incorporating authentic experiences to apply and to implement AAC and AT for pre-service teachers is imperative to impact its use in future classrooms. The pre-service teachers within this project expressed that they had previously learned about universal design for learning, AAC, and AT, but it wasn't until this experience that they became true advocates. They shared future plans for class field trips and new analysis of previous experiences. This perspective shift is crucial for future educators to consistently and meaningfully implement communication supports and design meaningful learning environments for students to succeed.

Demonstrating the importance of school and community partnerships allows for the sharing of strategies and information. Continually increasing the public presence of communication supports and involving pre-service teachers in these projects will hopefully result in community accessibility and inclusion.

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DECLARATIONS

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Voices from the Field

Benefits of Smart Home Technology for Individuals Living with Amyotrophic Lateral Sclerosis

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ABSTRACT

In this information age, smart home technology has become a familiar tool to enhance communication and control home-based electronic devices. For those living with disabilities, however, smart home devices fall into the broader category of assistive technology. Smart home devices provide end-users multiple methods with which they can interact with others inside and outside of the home environment. The emergence of this technology has been of widespread interest to the disability community. Recent efforts have been made to introduce smart home technology to the Amyotrophic Lateral Sclerosis (ALS) community by a local chapter of the ALS Association to enable communication and alternative access to electronics within the home environment. A pilot program was implemented and outcome data was collected in an attempt to establish a nexus between smart home technology use and the impact of that use on occupational performance.

Keywords: assistive technology, occupational performance

TARGET AUDIENCE

Amyotrophic Lateral Sclerosis (ALS), commonly referred to as Lou Gehrig's Disease or Motor Neuron Disease (MND), is a progressive and fatal neurodegenerative disease affecting motor neurons in the brain and spinal cord (ALS Association, 2017a). The deterioration of motor neurons eventually leads to neuronal death, and thus inhibits the brain's ability to control muscle movement (ALS Association, 2017a). Symptom onset and rate of disease progression varies (ALS Association, 2017b). ALS adversely impacts voluntary muscle control, taking away one's ability to move, communicate, and eventually, breathe (ALS Association, 2017b). The lifespan from the time of diagnosis until death is typically between two and five years (ALS Association, 2017b).

Due to the progressive nature of ALS, frequent and ongoing adaptations are required to enhance an individual's ability to manage the disease and to enable function (Soofi et al., 2017). With ALS, there is no cure, muscle deterioration is inevitable, and complete physical independence, once lost, cannot be restored. Through this progression, assistive technology devices may be introduced as a way to compensate for functional deficits. By educating and training individuals about the benefits of assistive technology, therapists can help individuals explore and adapt to a new and different way.

RELEVANCE

The Assistive Technology Act of 2004 defines assistive technology as "any item, piece of equipment, or product system, whether acquired commercially off-the-shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities" (29 U.S.C. § 2202). The intended use of assistive technology is to optimize performance and enable individuals living with disabilities to reclaim life roles (American Occupational Therapy Association, 1998). Lahm and Sizemore (2001) suggest that assistive technology can bridge the gap between environmental demands and an individual's capacity. Smart home devices can be used widely as a form of assistive technology, given their potential to remove barriers and enhance performance (Gentry, 2009).

Due to their degree of sociability, ease of integration, affordability, and reliability, smart home products have grown in popularity and adoption continues to accelerate (Purington et al., 2018). By default, many smart home devices are universally designed and can work with people of all abilities to help maximize participation. These devices follow several principles of universal design including: equitable use; flexibility; and minimal deployment effort (Center for Universal Design at the University of North Carolina, 2008). Commensurate with the principals of universal design, smart home technology provides individuals with disabilities greater access to mainstream technology and new ways to communicate and maintain autonomy and control (Pradhan et al., 2018; Schulz et al., 2014).

Smart home devices are connected to an in-home network and enable remote control of select electronics based upon end-user preference (Wilson et al., 2016). Smart speakers, from Amazon, Google, or Apple, are among the most popular mainstream devices in this category and can serve as voice-activated environmental controls. Embedded speech recognition software, otherwise known as a digital assistant, allows for a high degree of customization (Purington et al., 2018). Personalized skills can be created by setting up voice profiles and developing routines, reminders, or blueprints. Collectively, smart speaker devices are readily paired with other smart devices to allow for greater connectivity and functionality in the home environment. In this regard, they provide alternative methods for controlling small appliances, lights, or even a television.

The ALS Association of Minnesota, North Dakota, and South Dakota manages a communication and assistive technology program. This multifaceted program provides complementary adaptive equipment and select technical support services to those living with ALS. In an attempt to embrace innovation and potentially enhance quality of life, the chapter elected to start a smart home pilot program. To optimize integration, the program included: provision of equipment, training and education, and technical support. Referrals for program participation came directly from speech or occupational therapists following individual quarterly multidisciplinary clinic visits. Subsequent screening to assess access, technological comfort level, and user preference, and to provide education about device functionality, was completed by the ALS Association staff occupational therapist. Prerequisites for participation were minimal, and included possession of an existing smartphone or tablet device along with Wi-Fi/internet within the home. Those with documented cognitive impairments, such as frontotemporal dementia (FTD), were excluded. Devices supplied by the ALS Association included: one smart speaker (Amazon Echo Plus); two remote smart speakers (Amazon Echo Dot); two smart plugs (TP Link); three light bulbs (Phillips Hue); and one optional smart home entertainment unit (Harmony Hub or Amazon Fire Cube). These smart home devices were selected for program integration because they were perceived to have the greatest potential to enhance one’s ability to complete practical and meaningful activities within the home environment, and to enhance occupational performance (American Occupational Therapy Association, 2016).

In addition to receiving the aforementioned suite of smart home devices, all participants were provided technical assistance from the Best Buy Geek Squad for installation and training. Funding and third-party referrals were managed by the ALS Association. Despite variation in training procedures, collaboration with a national electronics retailer with a large geographical footprint provided a mechanism to reach smart home program participants in the tristate area. While installation of commercially available smart home technology, such as the smart speaker, is relatively simple, it was recognized that installation of a smart home entertainment unit requires greater technical expertise. Technical support and training was offered by the retailer in an effort to reduce or eliminate barriers to usage.

After one year, the smart home pilot acquired a total of 36 users. This group represented individuals with a probable or confirmed diagnosis of ALS, willing to try a novel tool with potential to improve autonomy. Subsequently, in an attempt to determine impact, a survey was developed and IRB approval obtained. Surveys were then distributed initially via email with follow up via standard mail; participation was entirely voluntary. Of the 36 individuals originally identified for participation, 19 individuals (12 males and 7 females) completed the survey. The survey collected information on participant demographics, usage, access methods, and overall impact on occupational performance. Questions on socioeconomic status and education level were not included.

According to results, 47% of participants had been living with ALS for 2–3 years, 21% of participants had been living with ALS for 1–2 years, 16% less than one year, and 16% more than three years. Ages ranged from 28 to 86 and were fairly evenly distributed. Two participants were between ages 18–36, five participants were between 36–50, six were between 51–65, and six participants were over the age of 65. All individuals included in this particular sample had spinal or limb-onset ALS. In total, eligible participants represented those living with ALS in three different states, attending eight unique multidisciplinary clinics. Despite the relatively small response, participants were representative of a large geographic area.

OUTCOMES AND BENEFITS

Survey results revealed that all participants used their smart home technology devices daily. Majority (58%) of respondents accessed devices via voice versus 37% respondents using touch as a method of direct selection. Only a single participant reported using mixed access methods of both touch and voice. Of the 19 participants, 18 reported that the use of smart home technology gave them greater control of electronics in their home environment. A majority of participants (89%) reported that the use of smart home technology allowed them to regain some functional independence in their home environment. One respondent commented, “now I don’t have to struggle with things like switches or dials.” With respect to functional independence, over half of the participants (63%) felt that smart home technology had given them ability to complete tasks that they had lost the ability to complete. A program participant reported, “I don’t have to depend on someone else to do another thing for me. I feel that I can do some things for myself. It is very important to feel like you’re not being a burden.” Another participant reported, “nothing is so frustrating as to not be able to do something that you’ve spent your entire life doing and not even thinking about it, or have to ask someone else to do these simple things for you (i.e., turning on and off lights). Smart home technology makes this possible, thus ending a lot of problems for me and my caretaker.”

Findings revealed that participants used smart home devices for a wide range of tasks including: recreation and leisure (e.g., games and music); gathering information; communicating with others, both inside and outside the home; and completing home management activities (e.g., shopping, setting up routines, and calendar management). This technology allowed individuals to circumvent physical and environmental barriers, to embrace ability rather than disability, and to become more engaged in daily occupation (American Occupational Therapy Association, 2016). A participant reported “using this technology makes it possible for me to do things without having to struggle to do them and it makes a very big difference in my life.” Users recognized that integration of this technology into daily routines provided a mechanism or tool to aid in participation of meaningful activities. Another participant reported, “any bit of independence that is restored is greatly appreciated as I become more and more unable to do things for myself. It has helped me feel less depressed.” Participant input suggested that this technology might also support well-being, as evidenced by reported improved sense of safety, work simplification, and energy conservation. These users reported, “it makes things much easier, safer, and saves my energy” and “makes for more efficient living.” Of the 19 participants, 18 reported having a positive experience with the integration of smart home technology into their daily routines (one neutral experience was noted). Users’ acceptance of this technology implies that benefits outweighed potential risks (e.g., security and privacy; Wilson et al., 2016). Participant feedback on usefulness and satisfaction suggests that the suite of smart home devices provided, in combination with training and support, struck the right balance of device complexity and user capability, providing an experience that was empowering (Wilson et al., 2015).

CONCLUSION

According to this survey, findings revealed that both males and females living with ALS readily embraced smart home technology as a form of assistive technology to support occupational performance in the home environment. Participants found smart home technology useful at different ages and stages of disease progression. It is believed that multiple access methods allow for adaptability and prolonged usefulness of smart home devices. Intermittent assessment and adaptation is recommended to accommodate for gradual loss of function (including speech) over time. In this program evaluation, individuals living with ALS used several smart home devices to complete tasks with modified independence that perhaps they would not have been able to control due to their decreased level of function. Smart home devices removed barriers, enabling individuals to become actively involved in daily activities.

The smart home devices provided to this group offer a cost-effective method to support individuals with ALS in their home environment. This technology can enhance functional communication and offers opportunities to foster independence and control of the home environment (despite disease progression) and may also be used similarly for those living with other mobility or communication impairments. While more research is needed to determine the impact of smart home technology on one’s emotional and physical well-being, there is indication of value. In a society in which technology is embedded in nearly all aspects of human occupation, it is critical that mainstream technology is explored and appropriately integrated.

DECLARATIONS

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