FUNDAMENTALS OF AAC A Case-Based Approach to Enhancing Communication

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PREFACE

As an editorial team, we feel the ultimate goal of supporting communication and advancing language is core to Augmentative and Alternative Communication (AAC). However, this goal can only be realized if AAC is embedded in the needs of individual learners as they interact within their families and communities.

While there are strong foundational concepts that underlie the field at large, the practice of AAC (the way in which we assess, intervene, and implement it) has to be co-constructed between individuals (as members of a community or multiple communities), their communication partner(s), and the professional(s) with whom they work.

There is no single, one-size-fits-all way to "do" AAC. Instead, each assessment, treatment, and/or implementation plan is unique to the individual, and arises from their cognitive-linguistic profile, physical abilities, sense of self, their psychosocial make-up, their family, and their community.

The field of AAC has grown and evolved tremendously based on an understanding of what AAC is. Its application has become more widespread, and the AAC technology has advanced. The AAC tools are always changing, but the task of supporting an individual's ability to communicate fully and independently in a manner that is meaningful to them remains constant, irrespective of who they are and how they are supported. Each AAC system represents a product wherein language, vocabulary, and access features are shaped by the individual's unique abilities and challenges, as well as by their various community affiliations.

This text is written for preprofessional and professional clinicians interested in learning how to support individuals with complex communication needs (CCN) in need of, and benefiting from AAC, in a range of clinical settings. Each chapter is structured such that fundamental concepts and principles are presented first. Each chapter also contains a relevant case study that presents the concepts and principles "in action" so that the reader is guided through the use of clinical decision making in AAC. Every case study is designed to underscore the cultural, linguistic, and social variability inherent to the fields of AAC and communication disorders, and how each individual influences the manifestation of the AAC system, treatment, and implementation plans.

Online ancillary materials are available on a PluralPlus website that contains an Instructor's Manual, videos, and tutorials.

We invite you to explore the content herein and hope you will find it informative, thought provoking, and enjoyable to read. Further, we hope you find that the multinational and multicultural perspectives contained in chapters and essays enhance your clinical practice. Most of all, we hope it inspires you to engage with people who use AAC who are our greatest inspiration. It has been our privilege to learn from them and to aim ever higher in service provision.



ACKNOWLEDGMENTS

As an editorial team we have been fortunate to be able to bring together the perspectives and expertise of our contributors to co-construct this expansive description of AAC. Sixty-four people authored content in this text, and even more shared their research, ideas, and experiences. This text represents the synthesis of lived experiences, data, practice, and love for the field, and we are so thankful for the time and effort spent by our contributors to bring this book to life. A huge thanks to the team at Plural, especially Christina Gunning, who kept this project in motion and on track amidst a global pandemic.

To our families and friends who saw us through the authoring of *Tele-AAC: Augmentative and Alternative Communication Through Telepractice,* and then watched us take on a project of astronomically larger scope, we thank you and promise to take a little more time off before the next authoring project.



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SECTION I AAC System Fundamentals



Section I includes five chapters and one essay. The first chapter emphasizes the connection between the person using augmentative and alternative communication (AAC), their communication partners, and their community in the development of meaningful AAC systems. Chapters 2 and 3 discuss AAC system features and detail no-tech AAC systems, as well as mid-tech and high-tech tools. Chapter 4 reviews mobile technology, while Chapter 5 introduces how these AAC systems can be used by persons with different physical abilities and sensory needs through alternative access methods. The

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essay in this section introduces the combination of brain-computer interfacing and artificial intelligence, and the impact these types of technology have on the field of AAC.

While not the focus of this section, ways of supporting persons who use AAC (PWUAACs), such as aided language stimulation and AAC modeling, start to emerge within the content of the chapters and their respective case studies. These strategies and other concepts (like communicative competence) are discussed in the sections that follow.

Key Terms Reviewed in This Section ■ Aided Communication ■ Mid-tech AAC ■ Alternative Communication Synthesized Speech ■ Voice Output ■ Augmentative Communication Unaided Communication Functional communication ■ Generative language ■ Display representation (schematic, semantic-syntactic, taxonomic, alphabetical, ■ Language intervention chronological, and Pragmatic Organization Mobile technology Dynamic Display)¹ ■ Software design ■ Speech-generating devices ■ Iconity ■ No-tech AAC ■ Acquisition of Learning Process (ALP) for ■ Picture Exchange Communication System access (PECS) Calibration ■ Visual Scene Displays ■ Direct access Dwell ■ Indirect access Digitized Speech Infrared ■ High-tech AAC ■ Scanning patterns ■ Language System

¹http://podd.dk/eu-wp/?page_id=33



Chapter 1 A CO-CONSTRUCTED DESCRIPTION OF AAC

Nerissa Hall, Hillary K. Jellison, Maria Burke, William Burke, Craig Burke, and Julia Serra

Introduction

William Burke is 17 years old. He has used augmentative and alternative communication (AAC) in various ways since he was 5 years old. His parents, Maria and Craig Burke (as pictured alongside Will in Figure 1–1), along with speech pathologists/AAC consultants, Hillary Jellison and Nerissa Hall, and speech-language pathology assistant/graduate student, Julia Serra, authored this chapter collaboratively. AAC ensures that an individual has a voice and can be understood. It also serves to connect people with one another, and within their communities. Through synthesis of the perspectives of various stakeholders, one can better understand the power of AAC.

Fundamentals

AAC refers to ways of supporting existing speech and communicating using means other than verbal speech. AAC includes intrinsic, unaided forms of communication (such as facial expressions, gestures, body posturing, and sign language), as well as extrinsic, aided methods (like use of objects, pictures, writing, and typing). AAC is symbolic in that the form or method of AAC represents a letter,



Figure 1–1. Will and his family at the time of authoring this chapter.

word, phrase, or sentence that could otherwise be verbalized.

While AAC is often considered a system involving a carefully organized set of words, icons, letters, and/or phrases, it is important to note that AAC is far more than just a system. AAC establishes a way to communicate and share information between two or more individuals. AAC serves to make meaning. It serves to supplement and augment an individual's existing speech or as an alternative for someone who is nonverbal, aphonic, or hard to understand. AAC creates a connection and allows for meaningful engagement and participation.

For AAC to be efficient, it needs to be relevant and accessible to the individual, with the ability to change and evolve over time, as does the PWUAAC. Adjustable features mean that practitioners and consumers can customize the vocabulary, language, and visual and auditory presentation of the systems (as detailed in the chapters of the first section of this text) to accommodate an individual and personalize the tool that represents their voice. Technological advancements mean that most anyone can use AAC tools through access to manipulative objects or icons, capacitive screens that are responsive to the electrical properties of human touch, the extensive array of switches to account for limited movement, eye-gaze access options, brain-computer interfaces (BCIs) that detect neural signals (Brumberg et al., 2018), or artificial intelligence (Cognixion, 2021), for example. These programming and technological features help ensure the efficiency of the AAC system.

For AAC to be effective, it needs to empower an individual to express themself in an authentic way that is understood and serves to connect them with their communication partner(s). Both the partner and the community need to be taken into consideration for this connection to be genuine. AAC represents an intersection between an individual with complex communication needs (CCNs), the people with whom the individual communicates, and their environment(s). The AAC system arises from the interplay between these elements, evolving as these elements change over an individual's life span.

While there are strong foundational concepts that guide the field, the practice of AAC (the way in which we assess, intervene, and implement it) has to be co-constructed between individuals, their communication partner(s), and their respective communities. The professional(s) with whom they work add to and facilitate this co-constructed communication, rather than dictate it. The role of the speech-language pathologist (SLP) is to establish a foundation for collaborative and transdisciplinary work where the individual and their communication partners are involved in truly meaningful ways. There is no single, one-size-fits-all way to "do" AAC. Instead, each assessment, treatment, and implementation plan must be unique to the individual, and arises from their cognitivelinguistic profile, physical abilities, sense of self, their psychosocial makeup, their family, and their community.

A Change in Focus

"Doing" AAC work means embracing a mindset of discovery, where one is open to and seeking to understand what is important to the individual far beyond the confines of the clinical environment. This involves careful integration of what one knows about the field of AAC with the unique information presented by the individual themself. It means to establish a space and time for genuine involvement of the individual and their family members, caregivers, and important communication partners. For SLPs, this means orchestrating the involvement of various stakeholders and empowering the influence of their input in the ways in which an AAC system is established and subsequently implemented. This is meaningful work that changes lives.

Authentic, family-centered work, by its very nature, ensures generalization into an individual's everyday life and is therefore effective and "supportive of change" (Luterman, 2021). This clinical direction is particularly important when considering AAC, as the burden of responsibility most often falls on familiar communication partners to make sure an individual can communicate effec-

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tively and have their needs met, especially in the absence of AAC. Additionally, AAC has the potential to enhance the connection between an individual and their most important partners through shared understanding and meaning. Luterman suggests that by involving the parent or family member, we, in turn, improve the outcomes for the individual (2021); intervening at the level of the caregiver can help to reduce caregiver distress (Maresca et al., 2019; Ncube et al., 2018), which can also lead to improved outcomes and quality of life (QoL). Our pull-out, outpatient, and school-based models of care do not necessarily make space for authentic intervention that emphasizes the family and communication partners (but they can!).

Further highlighting the connection between the individual and their most important communication partners within various environments is the development of friendships. AAC can positively impact QoL by supporting an individual's ability to participate more independently in social exchanges and activities. This also serves as a connection to one's community and "circles" of family, friends, colleagues, professionals, and even unfamiliar partners (Blackstone, 1999). One's community influences our way of thinking, is closely tied to an individual's identity, and is interwoven with the words used and the ways in which people engage, interact, and communicate. To know about one's community means to better understand what is consequential and pertinent for the individual and their social position. This informs the vocabulary and language adjustments necessary to make the AAC system meaningful.

AAC offers access to language, which is an "instrument of communication . . . [and constitutes] a means of asserting one's identity or one's distinctiveness from others" (Jaspal, 2009, p. 17), and is more than words programmed to support participation and overcome barriers. To afford this, AAC must be designed and individually tailored to meet and exceed the needs of the individual; to try to best reflect their uniqueness while creating space for novelty and spontaneity, as well as syntactic, semantic, and pragmatic advancement, selfexpression, and the development of their character. Digitized (voice recorded) and synthesized (computer generated) voices need to match the individual as best possible, and the individual should be involved in making this selection. Collectively, these factors allow AAC to serve as an individual's voice.

A Co-Constructed Understanding of AAC

AAC can be and can mean something different to different stakeholders. By listening to the stakeholders and letting their input carry weight and meaning, the SLP facilitates this process of collaboration and co-development of meaningful AAC.

For the individual with CCNs, AAC means having a voice, being heard, and being understood. However, it also means hard work, where the purpose and reward of the effort may not be easily discernible. While regular practice using a specific set of target vocabulary or word combinations in a prescribed context will help build upon a skill, for an individual this might need to be balanced with AAC "downtime" where using the prescribed system is not always expected. With the ultimate goal being to engage in a manner that is understood, it is important to "hear" from the individual how this can be done most effectively. With the mindset of discovery, and through the use of active listening strategies, AAC practitioners can adjust the AAC system and clinical approach to ensure meaningful connection and authentic representation of the individual.

For parents and caregivers, AAC can mean less guessing and less frustration. It can provide a shared medium for problem-solving and can foster a trusting relationship based on the premise that "we will figure this out." When well-designed and available, and tailored with linguistic and conceptual growth in mind, AAC can pave the way for opportunities and interactions not yet imagined. "Just give me some words" can set in motion a process of co-construction between a caregiver and their child that creates new conversations, new ideas, and new connections. Maria reflects on a moment with Will and writes:

So, Will's adopted as you know. When the talker (AAC system) was still exciting to him, and finally attached to his chair so he could access it at all times, we were driving together, and he asked me, "what's my Mom's name?" I answered, "Maria," but he then said "no, my other Mom." I totally didn't expect that comment but shared her name with him, and he immediately created a button for her and asked me what she looked like so he could select the best icon for her. I'd never have known he was thinking about her if not for the talker and without the talker he may have been really hesitant to talk with me about what some might think are difficult issues.

AAC can offer the opportunity to establish a real relationship with others. It can empower an individual to explore and express thoughts and feelings they may otherwise not be able to, and creates space for laughter, love, and a more enriched connection. It can also influence the communication of the caregiver and communication partner. Using AAC is significantly slower than using verbal speech (although this is constantly changing with advancing technology). Meaningful incorporation of AAC means making the time for novelty and creating the opportunities for spontaneity. It means exploring the system together or when the individual is asleep or not using it to get a sense of the potential offered within the system. It also means ensuring there is access to vocabulary and linguistic concepts that allow for the actualization of what is not yet realized.

For the individual and their caregivers as a unit, AAC can represent safety in having access to a method of communication that can be understood by people outside of their small and intimate network. AAC can mean less guessing for caregivers (the people who know the individual best and are most equipped to anticipate unmet needs and wants) as well as for less familiar communication partners. AAC can mean improved self-advocacy. By "giving some words," an interplay between the individual and their partner is established, and the PWUAAC can better advocate for themselves.

For the practitioner and communication partner more familiar with AAC systems, AAC means a medium for shared engagement. By pointing to letters, words, or icons on an individual's AAC system or comparable AAC system (strategies known as aided language stimulation [Goossens', 1989] and AAC modeling [Binger & Light, 2007], which are discussed in subsequent chapters), the practitioner can support language development and meaningful communicative exchanges by using AAC as they communicate themselves. This demonstration of multimodal communication involving AAC establishes an environment of respect and acceptance where AAC is available, visible, and incorporated into one's own communicative exchanges. These actions empower the practitioner to set the tone for success. By striving for meaningful and motivating connection, the "hard work" inherent to learning and using AAC in a verbal world can be "good work," and fun as well. The seasoned AAC practitioner can take what is almost second nature to them (creating opportunities for modeling and using AAC and multimodal communication) and extend this comfort to others, empowering more widespread acceptance and understanding of AAC leading to immersion of AAC into a way of being.

In Conclusion

The field of AAC is one that has grown and evolved tremendously as our understanding of AAC has broadened, the application of AAC has become more widespread, and AAC technology has advanced. The AAC tools are always changing, but the task of facilitating an individual's ability to communicate fully and independently in a manner that is meaningful to them remains constant, irrespective of who they are and how they are supported. Each AAC system represents a product where language, vocabulary, and access features are shaped by the uniqueness of the individual. This is consistent with the International Classification of Functioning, Disability, and Health (ICF) model developed by the World Health Organization that emphasizes collaborative practice with a focus on an individual's functioning in contexts and environments that are relevant to them (American Speech-Language-Hearing Association [ASHA], 2021). With a mindset of discovery, SLPs working in the field of AAC serve as catalysts for improved communication, meaningful connections, and truly authentic self-expression, where the AAC systems used may change and evolve based on this ongoing interplay between the individual, their partners, and their community.

Case Study: WB

As a group of authors, we use the story of Will, Maria, and Craig to bring to life "the big picture" of AAC. In truth, it is our story and a story of a shared journey influenced by Will, his parents, the communication partners, and environments experienced along the way.

Clinical Profile and Communication Needs

The Individual

At the time of writing this, Will is 17 years old and in 11th grade at a community high school. Will presents with complex communication needs due to his diagnosis of schizencephaly (a rare congenital malformation of the brain that results in a range of cognitive and motor deficits) and has been involved in intensive speech-language, occupational, and physical therapy from a very young age. Will uses a motorized wheelchair and is skilled in accessing technology via direct selection using his dominant hand. Will is a good student and has a small circle of close friends who, like most teenagers, engage with one another via texting. Proloquo4Text® on an iPhone is a backup tool to repair communication breakdowns when his verbal speech is not fully understood. "I can talk like

normal now and I love it," Will adds, but we are all aware that early access to AAC has a lot to do with why we are all here sharing what we know of AAC.

Their Communication Partners

Maria and Craig, Will's parents, along with Uncle Owen are Will's closest communication partners. Will, Maria, and Craig have worked together with Hillary and Nerissa since Will was 5 years old in outpatient, school-based, and recreational environments. In the 12 years of this partnership, there have been very many communication partners that have also been part of this journey. Maria and Craig are strong advocates for Will, sometimes in agreement and disagreement with Will (as parents can be). They push Will to be his best self, both as a person and within school. This has facilitated Will's current successes and has also fostered and developed his determination and inner perseverance.

Will has a large extended family, has friends at school, as well as many friends met through online gaming platforms. Additionally, Will and his family connect with a number of professionals in academic and medical settings. Will is active in his interactions with these communication partners.

Their Environment

As a family, the Burkes are social and have family and friendship circles that are broad, loving, and accepting. At home, Will's family has made many renovations to their house to make it accessible for Will and to support his independence in maneuvering within his home. The Burkes often entertain family and guests (and host fantastic, themed events). Communication, connection, and laughter are extremely important to this family and their circles.

Additionally, Will is an active member of his school community. He attends grade-level and honors classes, with one being English. This is something he and his team are quite proud of. Will recently took a computer-aided design (CAD) class and enjoys art classes when they fit in his schedule. Will is more of an active participant in class within small-group or project-based tasks. However, since being in school remotely (due to the COVID-19