David R. Beukelman
Janice C. Light

Augmentative & Alternative Communication

Supporting Children and Adults with Complex Communication Needs

FIFTH EDITION

Augmentative & Alternative Communication

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Fifth Edition

by

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Dr. Light holds the Hintz Family Endowed Chair in Children's Communicative Competence in the Department of Communication Sciences and Disorders at Pennsylvania State University. She is actively involved in research, personnel preparation, service delivery, and outreach to enhance communication and improve outcomes for children with complex communication needs (e.g., children with autism spectrum disorder, cerebral palsy, Down syndrome, traumatic brain injury, and other disabilities). Her research focuses on the development and implementation of augmentative and alternative communication (AAC) to support the communicative competence, language development, and literacy skills of children with complex communication needs. Dr. Light has been the principal investigator on more than 20 federally funded research grants to improve outcomes for individuals who rely on AAC. She is

currently the Principal Investigator of the Rehabilitation Engineering Research Center on Augmentative and Alternative Communication (The RERC on AAC), a virtual research consortium funded by the National Institute for Disability, Independent Living, and Rehabilitation Research. She is also the project director on two federally funded grants to support the training of graduate students as the next generation of clinicians, researchers, university faculty, and leaders in AAC. Dr. Light is the author of more than 125 peer-reviewed papers, book chapters, and books. She is a Fellow of the International Society for Augmentative and Alternative Communication (ISAAC) and has received numerous awards in recognition of her research and teaching contributions to the field, including the President's Award from ISAAC, Distinguished Lecturer award from ISAAC, the Dorothy Jones Barnes Outstanding Teaching Award, the Helen G. and Evan G. Patishall Outstanding Research Achievement Award, the Pauline Schmitt Russell Distinguished Research Career Award, and the Faculty Scholar Medal for Outstanding Achievement in the Social and Behavioral Sciences.

Preface

As was the case for previous editions, the fifth edition of *Augmentative & Alternative Communication: Supporting Children and Adults with Complex Communication Needs* is an introductory text written for practicing professionals, preprofessional students, and others who are interested in learning more about communication options for people who are unable to meet their daily communication needs effectively through natural speech and rely on augmentative and alternative communication (AAC). Because severe communication disorders can result from a variety of conditions, diseases, and syndromes that affect people of all ages, many individuals may be interested in these approaches. Several characteristics of the AAC field have shaped the format, content, and organization of this book.

First and foremost are the individuals with complex communication needs and their families that are the focus of this book. As we revised this book, we remained keenly aware of our dependence on those who have documented their experiences with AAC. To tell the AAC story, we expected to cite traditional academic sources—professional research papers, scholarly books, and manuals. What we found is that we also made extensive use of the perspectives of people who rely on AAC. We believe firmly in the tenet, "Nothing about us without us," and we hope that we have managed to incorporate the experiences and perspectives of individuals who rely on AAC and their families into this book.

Second, AAC is a multidisciplinary field in which individuals with complex communication needs and their families, along with computer programmers, educators, engineers, linguists, occupational therapists, physical therapists, psychologists, speech-language pathologists, and many other professionals have contributed to the knowledge and practice base. We have attempted to be sensitive to these multiple perspectives and contributions by directly citing pertinent information from a wide variety of sources and by guiding the reader to appropriate additional resources when necessary. We are grateful to the researchers and expert clinicians in the field who have advanced our knowledge and improved evidence-based practice in AAC. We also wish to thank those publishers, editors, associations, manufacturers, and institutions who supported the newsletters, bulletins, books, videos, magazines, web sites, and journals that now contain the historical record of the AAC field. Without these resources, we simply would have been unable to write this book.

Third, the AAC field has developed in many countries over the past decades to meet the needs of the more than 97 million individuals with complex communication needs worldwide. In 2019, members of the International Society for Augmentative and Alternative Communication represented 42 different countries. Although Drs. Beukelman and Light are both from North America, we have made an effort to include information about the contributions of researchers, clinicians, and people who rely on AAC from around the world. Unfortunately, within the constraints of an introductory textbook, only a limited number of these contributions can be cited specifically. Thus, we acknowledge that our primary sources of material have come from North America and hope that our AAC colleagues in other countries will tolerate our inability to represent multinational efforts more comprehensively. The key principles described in this book are relevant internationally.

Fourth, AAC interventions involve a vast array of electronic (i.e., digital) and nonelectronic systems. AAC technology changes very rapidly—products are being upgraded continually, and new products are always being introduced. Such product information presented in book form would be outdated very quickly. We have therefore decided not to include references to specific AAC products; rather we have focused on the principles that guide effective evidence-based AAC systems and interventions. We refer our readers to the numerous web sites and other resources referenced in the textbook and listed on the Brookes web site where readers can find current information.

Developing expertise in AAC requires careful consideration of five key domains: 1) first and most importantly, the people who rely on AAC to communicate, their communication partners who interact with them, and the professionals who provide AAC services; 2) unaided and aided AAC systems that provide the tools for communication; 3) interventions to enhance communication and participation for children and adults with developmental disabilities who require AAC; 4) interventions for people with complex communication needs due to medical conditions that are acquired later in life; and 5) continuing advocacy to meet the communication needs of an expanding population of people internationally with complex communication needs. In an effort to cover these areas, we have divided the book into five sections—each corresponding to one of these domains.

Specifically, the four chapters in Section I are organized to introduce readers to people with complex communication needs and AAC services. Chapter 1 introduces the reader to AAC in general and to people with complex communication needs in particular. Often using these individuals' own words, we attempt to convey what it means to communicate using AAC. Chapter 2 introduces the Participation Model that provides a framework for AAC assessment and intervention and discusses AAC assessment to determine participation patterns and unmet communication needs; environmental supports and opportunity barriers; and individual skills and capabilities. Chapter 3 introduces the reader to AAC intervention, including planning, implementation, evaluation, and follow up to enhance the communication and participation of individuals with complex communication needs. Chapter 4 discusses strategies and techniques for collaborating with family members and other communication partners, including intervention to reduce barriers and support the participation of individuals who rely on AAC.

Section II contains four chapters that describe the components of AAC systems. Chapter 5 reviews vocabulary selection and message management in AAC systems

for people who rely on AAC. Chapter 6 is a detailed presentation of the most common approaches to unaided and aided vocabulary and message representation, organization, and layout of AAC systems. Chapter 7 discusses a range of access techniques that are designed to accommodate a variety of motor, language, and cognitive impairments. Chapter 8 focuses on the processes involved in the selection and personalization of AAC systems to meet the communication needs of children and adults with complex communication needs.

Section III contains five chapters that review AAC interventions for children and adults with developmental disabilities. Specifically, Chapter 9 introduces key considerations that are unique to people with cerebral palsy, Down syndrome, intellectual developmental disabilities, autism spectrum disorder, and childhood apraxia of speech. Chapter 10 introduces AAC interventions to enhance the communication and participation of beginning communicators, including those who are preintentional, those who are presymbolic, those who are learning to use and combine symbols, and those with challenging behaviors. Chapter 11 summarizes what we know about building more advanced linguistic, operational, social, and strategic skills to enhance communicative competence. Chapter 12, written by Janice C. Light and David B. McNaughton, focuses on the factors that affect literacy learning for people with complex communication needs, strategies for fostering emergent literacy, and the key components of interventions for teaching conventional and advanced literacy skills. Finally, Chapter 13, written by David B. McNaughton, provides guidelines for thinking about and planning interventions to enhance participation in education, employment and volunteer activities, assisted and independent living, health care, and community activities.

Section IV, composed of five chapters, focuses on individuals with acquired communication disorders. Chapter 14, written by Laura J. Ball, Amy Nordness, and David R. Beukelman, reviews AAC interventions for adults with acquired physical disabilities, including amyotrophic lateral sclerosis, multiple sclerosis, Parkinson's disease, and brainstem stroke. Chapter 15, written by Kathryn L. Garrett, Joanne P. Lasker, and Julia King Fischer describes a functional classification scheme for people with severe aphasia and contains related intervention strategies and techniques. Chapter 16, written by Elizabeth K. Hanson and David R. Beukelman, introduces AAC strategies for people with degenerative language and cognitive disorders, including primary progressive aphasia and dementia. Chapter 17, written by Susan Koch Fager and David R. Beukelman, addresses AAC assessment and intervention techniques that are organized according to the cognitive levels of people with traumatic brain injury. Finally, Chapter 18 reviews a wide range of AAC interventions to support patient-provider communication for patients in medical settings. Particular attention is focused on the development and maintenance of patient-provider communication programs to support people who are communication vulnerable.

We end with Chapter 19 that focuses on advocacy. Many individuals who require AAC face substantial policy, practice, attitude, knowledge, skill, and service delivery barriers that preclude their access to communication. Concerted advocacy is required to overcome these barriers to ensure access to AAC and meaningful opportunities for communication.

It is our belief that all people who rely on AAC have the fundamental right to an effective "voice" to communicate. We hope that this book will serve to advance knowledge and practice so that individuals with complex communication needs receive the evidence-based AAC services that they require for their voices to be heard.

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First and foremost, we gratefully acknowledge Pat Mirenda's significant role in co-authoring the first four editions of this textbook. Although she was not an author for the fifth edition, she graciously allowed the use of her previous writing to be integrated into this edition. Special appreciation is also due to a number of individuals with whom we have been fortunate to work before and during the production of this book. These include the staff and administrators of public school districts and other community agencies in Nebraska and Pennsylvania; the Research Institute for Rehabilitation Science and Engineering at Madonna Rehabilitation Hospital; Quality Living, Inc.; Services for Students with Disabilities at the University of Nebraska–Lincoln, and the Munroe-Meyer Institute at the University of Nebraska Medical Center. These individuals have collaborated with us extensively over the years and have thus greatly contributed to our AAC experiences and knowledge. As university faculty, we are well aware of the tremendous contributions made by our students to the AAC knowledge and practice base during their involvement in our graduate programs and as alumni of our universities. Finally, and most importantly, we thank the many people who rely on AAC with whom we have collaborated, and their families—they have taught us about the AAC field and have allowed us to share their stories. May their voices grow ever stronger.

We also want to acknowledge the role of the Barkley Trust in supporting AAC efforts at the University of Nebraska–Lincoln through the years, as well as the Hintz Family Endowed Chair that supports the AAC program at The Pennsylvania State University. While we were preparing the fifth edition, Janice C. Light was the Principal Investigator and David R. Beukelman served as researcher for the Rehabilitation Engineering Research Center on Augmentative and Alternative Communication (The RERC on AAC), funded through the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) of the United States Department of Health and Human Services (Grant #90RE5017). We appreciate the funding support provided by NIDILRR to advance knowledge, improve technology solutions, and build capacity in the AAC field. In addition, we appreciate the support, encouragement, and assistance that we have received from Liz Gildea, Tess Hoffman, MaryBeth Winkler, Astrid Zuckerman, and the rest of the team of the Paul H. Brookes Publishing Co.

I wish to thank my wife, Helen, and our extended family, who have been generous with their understanding and support over the years and five editions of this textbook.

—David R. Beukelman

I am grateful to my family—my husband, David B. McNaughton, and my children, Christopher, Kathryn, and Matthew. They believed in me, inspired me, encouraged me, and provided their unconditional love throughout my work. They remind me always of what is truly important in life.

—Janice C. Light

We dedicate the book to children and adults who rely on AAC and their families.

—David R. Beukelman and Janice C. Light

I

People Who Require Augmentative and Alternative Communication

1

Augmentative and Alternative Communication Processes for Children and Adults with Complex Communication Needs

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

Bob Williams has relied on augmentative and alternative communication (AAC) throughout his life. He is the former Deputy Commissioner of the Administration on Disabilities and former Director of the Independent Living Administration of the United States Department of Health and Human Services.

For most of you who read this book, daily communication is so effortless and efficient that you hardly think about it when you interact with others face to face, over the phone, through e-mail, by texting, or through other digital communication media. You probably do not remember the effort that you initially expended as an infant and toddler to learn to speak because now these processes are largely automatic. Usually, you just talk, formulating your messages and executing speech movements as you express yourself. However, effortless communication is not an option for all people (Beukelman & Ray, 2010) because some are unable to meet their daily communication needs through oral speech. Yet, effective communication is essential for self-determination, learning and development, education, personal care, social engagement, and employment. It is also essential for medical care, as noted in a statement from the Joint Commission titled *Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care: A Roadmap for Hospitals:*

> No longer considered to be simply a patient's right, effective communication is now accepted as an essential component of quality care and patient safety . . . Effective

> communication [is] the successful joint establishment of meaning wherein patients and health care providers exchange information, enabling patients to participate actively in their care from admission through discharge, and ensuring that the responsibilities of both patients and providers are understood. (2010, p. 1)

The purpose of this book is to introduce you to people with complex communication needs who rely on AAC, to those who assist them, and to the AAC supports and technologies that they use to communicate effectively. The American Speech-Language-Hearing Association (ASHA) defines *augmentative and alternative communication* (AAC) as an area of clinical practice that addresses the needs of individuals with significant and complex communication disabilities characterized by impairments in speech-language production and/or comprehension, including spoken and written modes of communication.

Without understandable speech, people with complex communication needs face severe restrictions in their communication, participation, and inclusion and in all aspects of life—education, medical care, employment, family, and community involvement—unless they are provided with other communication supports. The development of AAC offers great potential to enhance the communication effectiveness of people with complex communication needs. However, for many, this potential has not been fully realized. There is an urgent need for people to assist those who rely on AAC. In addition to supporting those who rely on AAC and their families and caregivers, there is a continuing need to develop a range of competent AAC stakeholders, such as educators, speech-language pathologists, physical therapists, occupational therapists, those who design new technologies, rehabilitation engineers and technicians who provide AAC intervention services, people who shape public policy and funding, and researchers who document AAC use and acceptance patterns as well as investigate communication processes when AAC is used.

WHAT IS AUGMENTATIVE AND ALTERNATIVE COMMUNICATION?

The American Speech-Language-Hearing Association Special Interest Division 12: Augmentative and Alternative Communication (AAC) defined AAC as follows:

> Augmentative and alternative communication (AAC) refers to an area of research, as well as clinical and educational practice. AAC involves attempts to study and when necessary compensate for temporary or permanent impairments, activity limitations, and participation restrictions of individuals with severe disorders of speech-language production and/or comprehension, including spoken and written modes of communication. (2005, p. 1)

AAC intervention services and technologies are part of habilitation and rehabilitation services. *Rehabilitation* refers to intervention strategies and technologies that help people with acquired disabilities to regain competence, whereas *habilitation* refers to intervention strategies and technologies that assist people with developmental disabilities to develop competence for the first time.

There are a wide range of AAC systems designed to meet the needs of individuals with complex communication needs. These systems include both unaided and aided options. Unaided AAC does not require any external equipment or technology, whereas aided AAC does require some form of equipment or technology. Examples of unaided AAC include vocalizations and speech approximations, gestures, signs, and eye blink codes (e.g., raising eyes to indicate "yes" or closing eyes to indicate "no"). Aided AAC includes low-technology options, such as communication boards or picture exchange systems, and high-technology options, such as computer-based speech-generating

technologies, including mobile technologies (tablets and phones) with a wide range of AAC applications and digital communication media. These aided AAC options may utilize various representations for vocabulary concepts (e.g., photographs, picture symbols, written words, letters of the alphabet). These representations may be organized and displayed in many different ways. They may be accessed via a wide range of techniques including, for example, directly selecting items with a finger, toe, or eyes, or selecting items that are scanned or offered individually or in groups. Chapter 5 provides more details about the selection of vocabulary for AAC systems to meet the needs of individuals with complex communication needs; Chapter 6 provides more discussion of the representations, layouts, and organizations of AAC systems; and Chapter 7 provides more details about access to aided AAC as well as feedback and output.

WHO RELIES ON AUGMENTATIVE AND ALTERNATIVE COMMUNICATION?

There is no typical person who relies on AAC. They come from all age groups and socioeconomic, ethnic, and racial backgrounds. They have a wide range of communication needs and capabilities. Their only unifying characteristic is the fact that they require adaptive supports to communicate effectively because their spoken, and/or written, communication is temporarily or permanently inadequate to meet all of their communication needs. Some of these individuals may be able to produce a limited amount of speech, but it is inadequate to meet their communication needs with communication partners who are not familiar with them or in communication situations that are challenging for them, such as speaking in groups, in noisy environments, and about content that is unfamiliar to their communication partners.

A variety of developmental or acquired conditions can result in significant difficulties speaking or writing without adaptive supports. Common developmental causes of such severe communication disorders include severe intellectual developmental disability, cerebral palsy, Down syndrome, autism spectrum disorder (ASD), and developmental apraxia of speech. Acquired medical conditions that result in the need for AAC supports include amyotrophic lateral sclerosis (ALS), multiple sclerosis, traumatic brain injury, stroke, high-level spinal cord injury, and a range of degenerative cognitive and linguistic disorders. (See Sections III and IV of this book for further discussion of AAC interventions related to each of these groups of people.)

It is difficult to determine precisely the prevalence of individuals with complex communication needs who would benefit from AAC. Although reports provide some sense of the prevalence of individuals with severe speech and/or writing limitations, it is important to note that most of these studies are more than 15 years old. Since that time, the demographics of the population have changed significantly (Light & McNaughton, 2012). There are increased incidences of some disability groups that experience severe communication disabilities (e.g., individuals with ASD). People are living longer than in past generations and are experiencing communication disabilities that come with longevity (e.g., Alzheimer's disease). Medical advances have resulted in increased survival rates and longevity for children born with developmental disabilities and individuals with acquired conditions. There is a growing body of research evidence documenting the many positive benefits of AAC—to enhance communication, support language development, increase participation, support comprehension, and decrease frustration and problem behaviors. Furthermore, there is convincing evidence that AAC intervention does not inhibit speech development or recovery.

As a result, it is now understood that AAC interventions benefit a much larger group. This group includes not just those with severe speech and writing impairments, but also infants and toddlers who are at risk for speech development, individuals who use natural speech but require AAC to supplement or clarify their speech, individuals who require AAC to support comprehension (e.g., those with degenerative cognitive and linguistic disorders such as Alzheimer's disease), and those with temporary conditions resulting, for example, from intubation following surgery. Light and McNaughton (2012) concluded:

> There are increased numbers of individuals with complex communication needs: They represent a wide range of ages, both younger and older, than ever before; they experience a wide array of disabilities (both developmental and acquired), resulting in an extensive range of motor, sensory perceptual, cognitive, and language skills; they come from diverse cultural and linguistic backgrounds; they participate in a wide range of environments (home, school, work, and community); and they require services over a longer life span, as their needs and skills change over time. (p. 199)

Given these changes, recent estimates have suggested that approximately 5 million Americans and 97 million persons worldwide may benefit from AAC to enhance their communication and increase their participation in their communities.

WHAT IS IT LIKE TO RELY ON AUGMENTATIVE AND ALTERNATIVE COMMUNICATION?

Perhaps more relevant (certainly, more interesting) than demographic figures are the stories and experiences of people who rely on AAC. In the following section, we provide first-person accounts in the writings and presentations of people who rely on AAC. From these and other accounts, we can glean some small sense of what it is like to be unable to communicate through traditional speech or writing and to rely on AAC. Rick Creech, a young man with cerebral palsy, provided a stark description of being unable to speak:

> If you want to know what it is like to be unable to speak, there is a way. Go to a party and don't talk. Play mute. Use your hands if you wish but don't use paper and pencil. Paper and pencil are not always handy for a mute person. Here is what you will find: people talking; talking behind, beside, around, over, under, through, and even for you. But never with you. You are ignored until finally you feel like a piece of furniture. (Musselwhite & St. Louis, 1988, p. 104)

Jim Prentice, who has relied on AAC for years, wrote:

> Augmentative and alternative communication can provide a person with the ability to have and develop strong and rewarding relationships with others. Deny a person the ability to articulate intelligibly and that person is sentenced to live in social, intellectual and emotional isolation. (Prentice, 2000, p. 213)

Tracy Rackenspurger recently shared the following insights:

> I happen to be a person with cerebral palsy . . . I am a public service faculty member at the University of Georgia . . . In addition to my natural speech, I use an augmentative and alternative communication device . . . I use augmentative communication to communicate with people who have difficulty understanding my own natural speech. People who have known me for a while can understand my natural speech almost all of the time. Strangers usually have no clue what I am saying unless I use augmentative communication. (Rackensperger, 2018; see a webcast of the presentation at the AAC Learning Center).

In an early account of AAC, Christy Brown, who first communicated by writing with chalk held in his left foot, recounted the day when he printed his first letter:

> I drew it—the letter "A." There it was on the floor before me. . . . I looked up. I saw my mother's face for a moment, tears on her cheeks. . . . I had done it! It had started—the thing that was to give my mind its chance of expressing itself . . . That one letter, scrawled on the floor with a broken bit of yellow chalk gripped between my toes, was my road to a new world, my key to mental freedom. (Brown, 1954, p. 17)

Communication allows participation in activities that are valued and inclusion in groups within society. Gus Estrella and Janice Staehely provided insight into how their ability to rely on AAC affected their family relationships.

So how important is augmentative communication technology to a person who has a severe speech disability? And when does the importance of augmentative communication technology become more evident to the person and to their family and friends? This may vary from person to person, and it could occur during different stages in a person's life. In my personal life, the importance became more evident at different points in my life. One was definitely when my father and I started talking and sharing things that we couldn't before. We would talk about baseball, the Los Angeles Dodgers in particular. And who can forget basketball and the Arizona Wildcats? We were finally having father and son conversations, just like the other fathers and sons were having since the beginning of time. (Estrella, 2000, p. 40)

With my new voice, my world began to open up. Cautiously at first, I went to work learning the [AAC device]. . . . Soon even my family's skepticism toward [my AAC device] vanished as they saw my communication with people increase. I will never forget the time when my sister was so pleased that she could keep a conversation with me going while tending her garden. (Staehely, 2000, p. 3)

AAC technology also allows people to develop social, employment, and care networks beyond their immediate families and those who are in face-to-face relationships with them. Two individuals described how they used AAC to expand their social networks and social roles.

When I got my new computer, I also got hooked up to the Internet and to e-mail. My world changed overnight! At the time, I was very much involved with the local Disability Services Advisory Council. With my speech problem, they had a very hard time understanding me. When I got e-mail, I had no problems. When there were questions that the council wanted my input on, all they had to do was send an e-mail, and they would get an answer right back from me. (Price, 2000, p. 114)

Currently, I use my [AAC device] to communicate at work, in meetings, and on the phone. At home, I usually communicate by facial expressions, letter signing, and typing notes on my computer. Usually when people get to know me and my communication methods, they have no trouble understanding me. Of course, some people learn faster than others. Also, e-mail plays a heavy role in my communication methods. There are many people to whom I only e-mail instead of picking up the phone and calling them. I feel e-mail is the most effective way for me to communicate. (Cardona, 2000, p. 244)

Family members have also talked about the impact of AAC on their loved ones.

Wendy recalled the difference AAC made for her husband Leon (who was unable to speak because of ALS) when they had visitors. "It is very hard for some people to go visit a person who can't talk to them . . . but Leon communicated until the very end (of his life) by using his device. His friends came regularly because he could communicate with them." (McKelvey, Evans, Kawai, & Beukelman, 2012)

Although employment has been an elusive goal for many with complex communication needs, AAC supports efforts to enter or to maintain involvement in the employment arena. Godfrey Nazareth requires AAC technology because of an acquired disability (ALS), as did the late Stephen Hawking; both provided some insights.

. . . I am using my (smart) phone as my speech generating device . . . For over a decade now I have been battling painful symptoms of ALS including the loss of my own natural voice. I am an entrepreneur and a research scientist . . . I use my portable digital voice to communicate in all professional settings. I also make extensive use of my voice in social settings, whether it is hanging out with friends, giving talks at church, or just using it to lecture my daughter. My story today is living, standing proof, and powerful testimony on the impact and amazing possibilities that portable speech generative technology can open up for individuals who have no voice. (Nazareth, 2018; see a webcast of the presentation at the AAC Learning Center web site)

Without my computer, I cannot communicate . . . [It] has provided me with the means to continue working and researching . . . [It] also allows me to keep in touch with my family and friends; I can e-mail and make phone calls at any time using the mobile technology. . . . It is vital for my security and safety that I can make calls for myself should the need arise. (Hawking, 2003)

AAC was initially considered essential to support social interactions among people; however, DeRuyter, McNaughton, Caves, Bryen, and Williams (2007) described the future as they wrote:

> Full access to e-mail, cell phones, digital music stores, e-commerce, digital photo albums, and e-books are all activities that require digital independence. These are fundamental communication activities in the twenty-first century and are necessary for full participation in schools, the workplace, and the community-at-large. We must ensure that AAC technology . . . support[s] greater participation in today's Information Society. (p. 268)

Olinda Olson, a woman with ALS who used mechanical ventilation for respiratory support, illustrated the multiple uses of eye-tracking AAC technology (AAC technologies that are operated by tracking an individual's eye gaze to locations on the display). She used it to communicate face-to-face with her family and residence staff, access the Internet, and send and receive e-mail, which she used to manage her personal and medical care and to communicate with her children who live at a distance. In a webcast, she said:

> This is an eye gaze computer [AAC technology]. I use it to communicate with family and friends. . . . I also use it to read books and my Bible. [She then demonstrated using the AAC system to turn on her nurse call light.] . . . I love the eye gaze [to access my AAC technology]. It allows me to keep in contact with my children. (Fager & Beukelman, 2009; AAC Learning Center—https://aac-learning-center.psu.edu)

At one point, she sent her AAC team an e-mail explaining that her daughter-in-law was pregnant. Her son and daughter-in-law lived a thousand miles from her and she had recently made her first use of Skype, a video-calling application integrated into her AAC technology, so that she would be ready to meet her first grandchild within a few hours of the child's birth (S. Fager, personal communication, October 2010).

PURPOSES OF AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

The ultimate goal of AAC intervention is not to find a technological solution to communication problems but to enable individuals to efficiently and effectively engage in a variety of interactions and participate in activities of their choice. Light (1988) identified four purposes that communicative interactions fulfill: 1) communication of needs/wants, 2) information transfer, 3) social closeness, and 4) social etiquette (see Table 1.1). To Light's original list, we would add a fifth purpose—to communicate with oneself or conduct an internal dialogue.

Table 1.1. Characteristics of interactions intended to meet various social purposes

	Social purpose of the interaction			
Characteristics	Expression of needs/wants	Information transfer	Social closeness	Social etiquette
Goal of the interaction	To regulate the behavior of another as a means to fulfill needs/wants	To share information	To establish, maintain, and/or develop personal relationships	To conform to social conventions of politeness
Focus of interaction	Desired object or action	Information	Interpersonal relationship	Social convention
Duration of the interaction	Limited—emphasis is on initiating interaction	May be lengthy—emphasis is on developing interaction	May be lengthy—emphasis is on maintaining interaction	Limited—emphasis is on fulfilling designated turns
Content of communication	Important	Important	Not important	Not important
Predictability of communication	Highly predictable	Not predictable	May be somewhat predictable	Highly predictable
Scope of communication	Limited scope	Wide scope	Wide scope	Very limited scope
Rate of communication	Important	Important	May not be important	Important
Tolerance for communication breakdown	Little tolerance	Little tolerance	Some tolerance	Little tolerance
Number of participants	Usually dyadic	Dyadic, small or large group	Usually dyadic or small group	Dyadic, small or large group

(continued)

Table 1.1. *(continued)*

Characteristics	Social purpose of the interaction			
	Expression of needs/wants	Information transfer	Social closeness	Social etiquette
Independence of the communicator	Important	Important	Not important	Important
Partner	Familiar or unfamiliar	Familiar or unfamiliar	Usually familiar	Familiar or unfamiliar

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Communication of Needs and Wants

As shown in Table 1.1, the goal of expressing one's needs and wants is to regulate the behavior of one's communication partner toward an action-oriented response. Examples include asking for help, requesting a favorite activity, or ordering food in a restaurant. Here, the content of the message is important, the vocabulary is relatively predictable, and the accuracy and rate of message production are critical. The high degree of predictability and concreteness inherent in these messages likely explains why needs/wants vocabulary often predominates in many communication systems. In fact, it is not unusual to see AAC systems that consist almost entirely of such vocabulary, regardless of how motivating or relevant the person using the AAC system finds the messages. However, this limited focus on the expression of needs and wants is very problematic. People who use AAC need to be able to communicate for a wide range of communication purposes—not just expressing needs and wants, but also exchanging information and developing social closeness.

Information Transfer

The second area of interaction, information transfer, involves messages that are more complex and difficult to convey because the goal is to share information rather than to regulate behavior. Information transfer is critical in education, employment, and health care. Examples of people engaging in this kind of interaction include a child telling her teacher what she did over the weekend, an adolescent talking with friends about the upcoming senior prom, an adult answering questions during a job interview, and a person with a medical condition communicating face to face or over the Internet with health care providers. As is the case with needs and wants, the content of the message is important. Information transfer messages, however, are likely to be composed of novel (rather than predictable) words and sentences that communicate a wide variety of topics. Accuracy of message production again remains paramount; however, the importance of communication rate varies depending on the person relying on AAC and on the communication situation.

Social Closeness

Communication related to social closeness greatly differs from the expression of needs and wants or the transfer of information. The goal of this type of interaction is establishing, maintaining, or developing social engagement to build friendships and

other interpersonal relationships. Thus, the content of the message is often less important than the interaction itself. Examples of people interacting in this way include a child greeting classmates, a group of teenagers cheering for their team at a basketball game, and an adult expressing feelings of sympathy to a friend whose mother recently died. In such interactions, the rate, accuracy, and content of the message, as well as the independence of the person communicating, are secondary to the feelings of connectedness, closeness, and intimacy achieved through the interaction.

Social Etiquette

The goal of the fourth type of interaction, social etiquette, is to conform to social conventions of politeness through interactions that are often brief and contain predictable vocabulary. Examples of people practicing social etiquette include a child saying "please" and "thank you" to his or her grandmother, an adult expressing appreciation to a caregiver, or an adult telling the cashier at the grocery store to "Have a good day." These messages resemble those that express needs and wants because accuracy and communicative independence are important factors for success.

Internal Dialogue

The fifth type of interaction is to communicate with oneself or to conduct an internal dialogue. To remain organized on a day-to-day basis, individuals often make lists, enter information into calendars, and prepare daily activity schedules. Diaries, journals of personal insights, lists of future plans, and records of personal reflections also fit into this category.

AUGMENTATIVE AND ALTERNATIVE COMMUNICATION IS ONLY PART OF THE ANSWER

The personal accounts of the lived experiences of people who rely on AAC are encouraging. These individuals rely on a range of different AAC supports to communicate effectively with a variety of different people in different situations to meet a wide range of goals (i.e., expression of needs and wants, information exchange, social closeness, social etiquette, and internal dialogue).

Certainly, assistive communication technology can change people's lives. However, AAC technology is not magic. A piano alone doesn't make a pianist, nor does a basketball make an athlete. Likewise, AAC alone doesn't make one a competent, proficient communicator (Beukelman, 1991). Those who rely on AAC begin as AAC novices and evolve in competence to become AAC experts with appropriate support, instruction, practice, and encouragement. Therefore, AAC options must be provided to them in a timely manner so that they can become competent and proficient communicators.

From the perspective of the individual who relies on AAC, communicative competence involves the ability to efficiently and effectively transmit messages in all of the interaction categories based on individual interests, circumstances, and abilities. Communicative competence depends on knowledge, judgment, and skills in four interrelated domains: linguistic, operational, social, and strategic (Light, 1989; Light & McNaughton, 2014). The *linguistic* domain refers to receptive and expressive skills in the native language(s) of the family and broader community as well as skills in the language code of the AAC system (e.g., signs, aided symbols). The *operational* domain

refers to the technical skills needed to operate aided AAC systems or to produce unaided modes. *Social* competence refers to both sociolinguistic (i.e., pragmatic) skills as well as sociorelational skills. *Strategic* competence refers to compensatory strategies that may be used to overcome environmental barriers or limitations in linguistic, operational, and/or social skills.

AAC teams should be aware of the fact that different types of communication partners might perceive the importance of various strategies related to communicative competence differently. Clearly, part of every AAC intervention should involve 1) identification of critical skills for communicative competence from the perspective of relevant communication partners and 2) instruction to support the highest level of communicative competence possible. Intervention to support communicative competence is described in more detail in Chapter 3.

In Chapters 2 and 3, we describe assessment and intervention to develop the competencies necessary to become effective communicators. In the following section of this chapter, we introduce readers to the roles of the personnel needed to provide and support effective AAC services. As you read this section, we encourage you to consider the roles that might be of interest to you.

WHO SUPPORTS THOSE WHO RELY ON AUGMENTATIVE AND ALTERNATIVE COMMUNICATION?

Of course, individuals with complex communication needs are essential participants in the development and maintenance of communication effectiveness using AAC. Person-centered AAC services allow individuals with complex communication needs to participate in ways that meet their unique needs and goals. Depending upon the situation, a team of people provide support and assistance to the individual who relies on AAC. Teams might include any of the following: AAC intervention specialists, daily AAC facilitators, communication partners, AAC finders, and AAC experts. Their individual roles are summarized below.

AAC Intervention Specialists

AAC intervention specialists lead and coordinate intervention efforts for children and/or adults with complex communication needs. Those specialists that work in educational settings tend to focus primarily on meeting the communication needs of children and youth with developmental disabilities. Those employed in medical or rehabilitation settings focus on the age levels their center serves—primarily children, primarily adults with medical conditions, or both. Finally, some AAC intervention specialists have private practices in which AAC services are provided across the age span.

AAC specialists implement a range of low-technology and high-technology AAC options, obtain the necessary materials and technologies, coordinate the team of professionals involved in AAC services, instruct and train those who rely on AAC and their important communication partners, monitor the effectiveness of AAC interventions, and recommend intervention changes, as needed.

Patty, an AAC intervention specialist, became interested in children with complex communication needs during her master's degree program. After completing the AAC course, she requested a clinical internship involving AAC and eventually completed

externship experiences with children and adults who relied on AAC. Her directed research project focused on AAC for children. Ten years after working as a speech-language pathologist (SLP) in a large urban school district, she is now one of three AAC specialists employed by the district.

Daily AAC Facilitators

Daily AAC facilitators provide ongoing daily support for the person who relies on AAC. This support includes maintaining (charging and cleaning) AAC technology, programming new messages or words in low-technology or high-technology systems, instructing unfamiliar communication partners, and serving as a liaison with other AAC personnel and AAC companies. Family members and friends often serve as AAC facilitators for people who rely on AAC who live in their homes or near their families. For those who live at a distance or in long-term care facilities, a staff member usually serves as a daily communication facilitator.

Beth is employed as a certified nursing assistant in a long-term residential care (nursing home) setting, a role that involves serving as a daily communication facilitator. Early in her career, Beth was assigned to care for an elderly woman with aphasia. Together, Beth and the woman's daughter realized that, with appropriate communication support, including written choices and photographs, this elderly woman could interact well enough to communicate her wants and needs and to interact socially. After this rewarding experience, Beth became a regular AAC facilitator for residents with complex communication needs.

Communication Partners

Communication partners are those listeners who interact with people who rely on AAC. They are referred to as *partners* because effective communication often requires the co-construction of messages; those who rely on AAC and their partners collaborate for the successful joint establishment (co-construction) of meaning. Some communication partners are very familiar with the individual who relies on AAC and their communication supports; others may not be.

AAC Finders

AAC finders are those professionals, including school and medical personnel, who identify persons with complex communication needs, are aware of AAC services and resources and where they can be located, and can make referrals for individuals and their families to appropriate AAC service providers. When appropriate, physicians may also certify AAC prescription for the funding of AAC technologies and AAC intervention services.

Dr. Gary Pattee is a neurologist who serves a relatively large number of patients with ALS. Through the years, he has become very knowledgeable about AAC options and services in the region he serves. He effectively communicates this information to his patients and their families to prepare them for the time when he will refer them for an AAC assessment with sufficient time to schedule and complete the assessment, complete the trial with AAC options, obtain the technology and learn how to effectively communicate with it. We have collaborated with Dr. Pattee for many years, clinically and on research projects. He is an ultimate AAC finder.

Unfortunately, not all medical and educational personnel are well informed about AAC. Dana Nieder, the mother of a 10-year-old girl who relies on AAC, presented at the 2018 State of the Science in AAC Conference and said

> Another goal for the AAC field would be to increase AAC awareness of pediatric medical and therapy providers, particularly those who practice subspecialties that serve children with disabilities . . . From age one to two and a half, we saw at least 12 doctors, 7 therapists (4 of whom were SLPs), had 4 outpatient hospital surgeries and procedures (with associated doctors and nurses, one of which was a swallow study and also involved an SLP), and had a multidisciplinary meeting to evaluate Maya's service plan (with associated officials, case manager, etc.). The doctors included two pediatricians, two geneticists, two neurologists, one developmental pediatrician, two audiologists, an otolaryngologist [ENT], an allergist, a cardiologist, and a dermatologist. At six of those offices we also met with nurses prior to seeing the doctors at each appointment, and at the geneticists' offices we also met with genetic counselors (two). None of these doctors, therapists, or other professionals ever mentioned AAC—and Maya, who had a visible genetic syndrome, severe oral–motor difficulties, and no discernible speech, should have been a very clear potential candidate for AAC. (Nieder, 2018; see a webcast of the presentation at the AAC Learning Center)

This is a huge gap in provider awareness. Parents of children with complex medical needs or who have developmental delays are often overwhelmed, and often see a huge number of professionals. It is a reasonable assumption that one of these professionals would introduce AAC. Pediatric medical professionals are an essential category of potential "finders."

AAC Experts

Finally, AAC experts include those who prepare preprofessional students, provide continuing education to AAC finders and intervention specialists, prepare AAC-related policies, execute AAC research, and provide expert testimony for legal and policy proceedings. We began our AAC journeys in clinical intervention settings as AAC beginners: Janice Light in a children's rehabilitation center in Toronto, Canada, and David Beukelman in an adult acute care/rehabilitation hospital in Seattle, Washington. In time, our roles increased to AAC intervention specialists and eventually to AAC experts.

PREPARING FOR THE FUTURE

Several years ago, I attended an AAC research planning meeting in which Michael Williams also was a participant. Michael relies on AAC because he has cerebral palsy and his speech is very difficult to understand. One morning, I observed Michael and his wife at breakfast in the hotel where we were staying. Michael was seated at a table located close to the area where guests lined up for the breakfast buffet. On that weekend morning, we shared the hotel with a crowd of middle-school–age youth (and their families) who were participating in dance, swimming, and soccer competitions in the area. I watched Michael visit with them as they waited in line for breakfast. From a distance, I could see that Michael and the young people were having a great time—there was a lot of talking and laughing. For nearly an hour he interacted with different young people until it was their turn to move on and order breakfast. I also observed these young people as they sat down to eat with their families and friends. The prominent topic of conversation that morning was this guy who

had talked to them using his "computer." Only later did I realize that a few months earlier, Michael had written the following to others who rely on AAC: "Every time you step out of your home, cruise down the street, catch the eye of a stranger, make a purchase, attend a ball game, or say 'hello' to a child, you are making a significant change in the expectations the world has of augmented communicators" (Williams, Krezman, & McNaughton, 2008, p. 203). To learn more about Michael and his communication supports, access his webcast, *How Far We've Come, How Far We've Got to Go: Tales from the Trenches* (Williams, 2006; see a webcast of his presentation at the AAC Learning Center).

In addition to the efforts of people who rely on AAC themselves, the future success of the AAC effort depends on the preparation and development of competent AAC stakeholders (McNaughton et al., 2019). Beukelman, Ball, and Fager (2008) provided a personnel framework that clarifies various stakeholders' roles. In 2012, Binger and colleagues adapted this framework to focus AAC assessment processes. The capability of universities to prepare graduates with competence in AAC is expanding. However, some universities still prepare professionals to assist people with disabilities but provide little or no systematic preparation or clinical experience in AAC. This book is written in the hope that university programs that educate speech-language pathologists, special educators, physical therapists, occupational therapists, and rehabilitation engineers will provide training in assistive technology and AAC to their students.

There is also an urgent need to provide continuing education to other AAC stakeholders so that they remain competent technology developers, researchers, interventionists, and public policy advocates. Because people who rely on AAC are not limited to an age category, etiology, location, or situation, and because they need ongoing support at least at some level, the need for competent AAC personnel remains urgent. This text initiates the reader on a path toward competence and expertise in AAC to serve individuals with complex communication needs.

OVERVIEW OF CHAPTERS

The organization of this book reflects our experiences while teaching AAC classes. We realize that individuals from a wide range of disciplines will be introduced to AAC through this text; therefore, the chapters in Section I provide an overview of AAC assessment and intervention, and those in Section II provide specific information about the AAC supports and techniques that are unique to the field. In Section III, we shift our focus to the AAC needs of people with developmental disabilities by emphasizing interventions for beginning communicators, language learning, literacy, and participation in education, employment, and community activities. In Section IV, we deal with individuals who were at one time able to speak and write but now require AAC systems because of an acquired injury, disease, or condition. Section V reviews major concepts addressed throughout the book and examines future directions in the field of AAC.

QUESTIONS

1.1. What types of individuals should be considered for AAC support?

1.2. How do the roles of an AAC specialist and an AAC daily facilitator differ?

1.3. What is the role of an AAC finder, and who might fill this role?

1.4. Why are those who interact with people who rely on AAC referred to as "communication partners" rather than "listeners"?

1.5. How does the communication of needs and wants differ from information transfer?

1.6. How does social closeness communication differ from social etiquette communication?

1.7. What content from the quotes of people who rely on AAC impressed you the most?

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