Supporting Individuals Who Use

Augmentative and Alternative Communication

BREAKING DOWN OPPORTUNITY BARRIERS

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Contents

Preface

It is well established that a wide variety of individuals with complex communication needs can increase their ability to communicate efficiently and effectively using Augmentative and Alternative Communication (AAC). AAC includes unaided and aided modes of communication. Unaided modes do not involve the use of additional equipment or materials (e.g., facial expressions, body language, gestures, sign languages, and sign systems). Aided modes do use additional equipment/materials and include systems that do not use technology (e.g., photographs, line drawings, written words), systems that utilize technology that is relatively simple in form (e.g., simple battery-operated devices, single message voice output devices), and systems that use technology that is more complex such as speech generating devices and laptops/tablets with software that allows them to operate as AAC systems.

Although AAC can increase communicative efficiency and effectiveness, many individuals who use AAC experience barriers in their development of communication skills. The Participation Model (initially conceptualized by Rosenberg and Beukelman in 1987 and then revised by Beukelman and Mirenda in 2013) provides a comprehensive and systematic framework for AAC assessment and intervention, including an evaluation of barriers related to access (limitations in the current capabilities of the individual or in the communication systems that they use) and opportunity (limitations based upon policy, practices, knowledge/ skills of professionals or communication partners, and attitudes; Beukelman & Light, 2020). It is essential to consider both access and opportunity barriers when designing systems and supports for individuals who use AAC. However, Light and McNaughton (2015) note that, too often, the focus of research and practice has been on issues related to access barriers with far less attention to opportunity barriers.

The Purpose of This Book

This book is designed to support those who find themselves frustrated by the opportunity barriers experienced by individuals who use AAC and are searching for ways to break down those barriers. Individuals who may be in a position to break down opportunity barriers include people who rely on AAC, speech-language pathologists, occupational therapists, physical therapists, special education teachers, family members, and other professionals in school, health care, and community settings.

Section and Chapter Format

The text is divided into four sections, with each section devoted to a frequently encountered opportunity barrier (knowledge/skill, practice, attitude, policy). Within each section, readers will (a) develop a deeper understanding of the impact of the barrier through the eyes of individuals who use AAC or their families, (b) acquire knowledge based on current research and recommended practices related to addressing the barrier, and (c) learn how professionals have successfully addressed the barrier via case examples from the field.

Readers will note that both identity-first and person-first language is used in this book. This is intentional. The language used in different parts of this text (e.g., interviews, case studies) honors the preferences of the individual (or group of individuals) and reflects the language that the individual used to describe themselves (American Psychological Association, 2020; University of Kansas, Research and Training Center on Independent Living, 2020).

Section I: Knowledge/Skill Barriers and Supports

Chapters 1 to 3 are devoted to understanding and addressing knowledge and skill barriers. Knowledge barriers refer to deficits in understanding how to best address the communication needs of AAC users. In contrast, skill barriers occur when professionals do not have the skills needed to serve these individuals, despite having adequate knowledge. *Chapter 1* includes

interviews with two parents of children who use AAC. Both interviews highlight how knowledge/skill barriers and supports have impacted their child's communicative success and provide the reader with a personal perspective that underscores the need to attend to knowledge/skill barriers when supporting individuals who use AAC.

Research suggests that the experiences of the individuals interviewed in *Chapter 1* are not unique, and many professionals and communication partners report experiencing knowledge/skill barriers that prevent them from fully supporting individuals who use AAC (e.g., Assistive Technology Industry Association, 2012; Cameron et al., 2018 Norburn et al., 2016; Sanders et al., 2021). As a result, *Chapter 2* provides strategies and user-friendly tools for addressing knowledge/skill barriers, including (a) identifying AAC knowledge/skill needs, (b) accessing resources to address knowledge/skill needs, (c) using principles of instructional design, (d) engaging in instructional coaching, and (e) supporting professionals and communication partners via virtual instruction and telepractice.

Chapter 3 illustrates the successful use of the strategies presented in *Chapter 2* through three case examples from the field. The first case demonstrates the use of instructional coaching to tackle the knowledge/skill barriers experienced by a school team. The second case shares how the knowledge/skill barriers of preservice and inservice professionals were addressed through online training. The third case illustrates the use of telepractice to attend to the knowledge/skill barriers experienced by the parents of a toddler with complex communication needs.

Section II: Practice Barriers and Supports

Chapters 4 to 6 are devoted to understanding and addressing practice barriers. Practice barriers involve common practices of organizations, schools, businesses, or communities that, although not formally written as policy, are accepted in that context (Beukelman & Light, 2020). *Chapter 4* includes interviews with an adult with cerebral palsy who relies on AAC, and a parent whose child with autism spectrum disorder relies on AAC. Together, the two interviews demonstrate how practices can serve as either barriers or facilitators to AAC implementation. The interviews also highlight the importance of individualizing AAC decisions, the benefits of interprofessional collaboration, and the need to seek family input.

Although the two interviews in Chapter 4 largely focus on barriers and facilitators experienced in school contexts, practice barriers related to time, resources, and personnel constraints exist across a variety of settings (Andzik et al., 2019; Chung & Stoner, 2016; Gormley & Light, 2019; Uthoff et al., 2021). These barriers can limit an AAC team's ability to (a) individualize AAC systems, (b) collaborate with other professionals, and (c) meet cultural and/or familial needs. *Chapter* 5 describes how common practice barriers identified in research create limitations to AAC assessment and implementation. In addition, this chapter provides freely available resources that teams can use to advocate for and support changes to practice and includes examples of evidence-based practices that can be adopted under less-than-ideal practice conditions.

Finally, *Chapter 6* provides case examples from three speech-language pathologists who work with children or adults across school, home, and medical settings. The case studies highlight common practice limitations as well as demonstrate how context and individual client and family characteristics can lead to unique barriers. Each of the cases provides concrete examples of how strategies discussed in *Chapter 5* can be applied in real-world contexts.

Section III: Attitude Barriers and Supports

Chapters 7 to 9 focus on understanding and addressing attitude barriers. Negative attitudes held by family members, professionals, and peers can present obstacles to realizing the full benefit of AAC. In *Chapter 7*, three men who use AAC recount their experiences related to negative attitude barriers and discuss potential pathways for addressing attitude barriers based on their experiences. From their respective points of view, it becomes clear how attitudinal barriers such as low expectations, misunderstandings about how individuals learn AAC, and ableism, affect these individuals.

Chapter 8 focuses on the research related to attitude barriers and strategies to address these barriers. Literature examining negative attitudes toward individuals with disabilities, including those who use AAC, is reviewed. This includes a focus on attitudes toward both children and adults who use AAC as well as tools for assessing attitudes. Further, strategies and pathways for overcoming attitude barriers such as increasing visibility of individuals

who use AAC, and increasing communication partner understanding of AAC are presented.

The final chapter of this section, *Chapter 9*, provides three case studies that further our understanding of attitudinal barriers. Specifically, we learn from an adult who uses AAC who details her experiences with attitudinal barriers and the strategies she has used to overcome them. Further, we hear from two speech-language pathologists who discuss attitudinal barriers and "real world" solutions to those barriers based on experiences in their clinical practice.

Section IV: Policy Barriers and Supports

Chapters 10 to 12 focus on understanding and addressing policy barriers. We often first think of policies as legislation or formal laws. However, policy is also enacted at the level of organizations (e.g., a school system's policies around inclusion and AAC, a vocational rehabilitation organization's policy on job coaching and personal care). Policy is also present in an individual's written home "rules." Collectively, policies can serve as powerful facilitators for access, supports, and services for individuals who use AAC.

Chapter 10 provides interviews with two people who use AAC and who are experts in the policy field. These interviewees share insights and examples of how policies effect the AAC community. Further, the interviewees discuss how law and policy need to change in order for people who use AAC to experience more equity in society.

Chapter 11 focuses on (a) major types of AAC policies, (b) policy consideration frameworks, (c) AAC policy barriers and pathways, and (d) future directions. Here, literature is reviewed that identifies the role of policy in relation to AAC service provision. In particular, barriers are identified and ways to address these barriers are detailed.

Chapter 12 offers three case examples that illustrate how people who use AAC experience barriers in policy and the strategies that they have used to address those barriers. The first case describes how a team worked through special education policy challenges to end a lack of access to AAC in the classroom for a child with an intellectual disability. The second case provides a more personal account of how policy impacts the life of a person who uses AAC in ways the general public takes for granted, such as an expectation of adequate writing instruction at school. The final case provides an international perspective on the impact of policy on AAC service provision and shares a vivid exemplar of how hard families work to navigate the complex policy environments they may encounter.

Conclusion

Chapter 13 provides readers with information on how to go "beyond the book" by actively addressing the unique opportunity barriers that they encounter in home, school, and community settings. Recognizing that barriers are uniquely influenced by the contexts in which they occur, Chapter 13 discusses the importance of considering variables related to

contextual fit and provides a framework (as well as several tools and examples) that incorporates the use of group problem-solving processes to develop strategies to address opportunity barriers.

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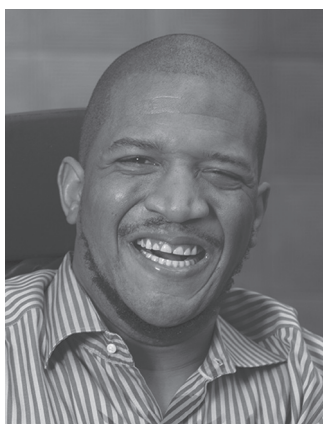
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Section I

Understanding and Addressing Knowledge/Skill Barriers

Section Overview

Knowledge barriers refer to insufficiencies in understanding how to address the communication needs of individuals who use AAC; while skill barriers occur due to lack of competency when supporting these individuals, despite having adequate knowledge. Knowledge and skill barriers are often interconnected and strategies to address these barriers are interrelated. Further, the knowledge and skills needed by different communication partners (e.g., family members, peers, teachers, speech-language pathologists, para-educators, community members, health care professionals) will vary. For example, the knowledge/skills that a peer needs to interact with an individual who uses AAC is very different from the knowledge/skills that a speech-language pathologist who is taking the lead on vocabulary selection and device programming needs for that same individual.

This section is devoted to knowledge/skill barriers with a specific focus on understanding and addressing barriers related to (a) identifying AAC knowledge/skill needs and accessing resources to address those needs, and (b) using principles of instructional design, instructional coaching, virtual instruction and telepractice to address the unique knowledge/skill needs of professionals and communication partners. Upon completion of this section, readers will be able to:

- Describe the impact of knowledge/skill barriers and facilitators on the lives of individuals who use AAC and their families.
- Summarize the research on knowledge/skill barriers.
- Identify effective strategies for addressing knowledge/skill barriers.

1 Knowledge/Skill Barriers: Learning From Individuals Who Use AAC and Their Families

Susan S. Johnston, Vanessa J. Ince*, and Cas McNamara*

Understanding the impact of knowledge/ skill barriers and facilitators on the lives of individuals who use AAC and their families can assist practitioners as they design effective and efficient interventions to address those barriers. Although the barriers and facilitators experienced by individuals who use AAC and their families will vary based upon the unique situations that they encounter, the following interviews provide the reader with insight into knowledge/skill barriers from the perspective of two parents whose children use AAC.

Vanessa J. Ince—Parent of a Child Who Uses AAC

In the first interview, Vanessa Ince, the parent of a young child with a rare chromosomal disability, shares information about the knowledge/skill barriers and facilitators that she has encountered in supporting her daughter's use of AAC. Vanessa's interview draws attention to the importance of training support staff and being knowledgeable about the unique needs of individuals who use AAC.

Will you introduce yourself including your name, age, gender, and race/ethnicity?
I'm Vanessa Ince. I am 55 years old. I'm Caucasian and I live in Hawaii.

Can you share a little bit about who you are as a person, what you are doing in your life, and what you enjoy doing?
I'm a licensed clinical psychologist and I have a private practice. I'm married to Scott, who does ultrasounds in a local clinic. I personally enjoy doing triathlons because it's a big stress reliever for me. My husband is a fisherman, and we have a boat. We enjoy swimming and spending time together outdoors as a family. We really enjoy life in Maui, and we try to be outside whenever we can.

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*These authors have contributed equally to this work and share senior authorship.

As a parent of an AAC user, can you also tell us a little bit about your daughter who uses AAC, who they are as a person, and what they enjoy doing?

Alexis is 11½ years old and is very small and spunky (Figure 1–1). She's a happy little girl, even when things are not great. She really enjoys music and things that light up. She has two dogs and likes swimming. She loves her peers at school and interacts well with them. She just loves interacting with people in general. Even though she can't verbalize anything, she has a very unique sense of humor. She likes being a little devious and playing mischievous games. As she is approaching her teenage years, she's getting a bit more active in her defiance, which is good because she's expressing her opinions and her desires. And while she used to be very slow in her movements, now she's very quick. She's always on the go even though her coordination isn't great.

As a parent of an AAC user, can you tell me a little bit about your daughter's use of AAC over the years, and her current AAC system?

Alexis was born with a rare chromosomal disability. She's missing a piece of chromosome one. It's called chromosome one deletion q24.1 q25.3, which is the piece that's missing. She's hearing impaired and vision impaired. She also has developmental delays, epilepsy, really small hands, and is nonverbal. We started her with Snap Core Software from Tobii Dynavox on

Figure 1–1. Alexis, Vanessa, and Scott Ince.

an iPad about four years ago and she still uses it today. The iPad is quite heavy but she needed to have a fairly sizable display that she could both see and also touch with some degree of accuracy. When she started using it, she had a paraprofessional that served as her communication aide. The communication aide's job was to help her navigate the AAC device. They taught the communication aide how to use the program and work collaboratively with the speech therapist. That went well, initially, and she made good progress. We started with only two or three symbols and then, over the course of maybe the first two and half years, she gradually was able to select from a field of nine. But then staff changed, and, over the years, the new communication aides haven't gotten any training and they don't seem to know how to use the AAC device.

> "But then staff changed and, over the years, the new communication aides haven't gotten any training and they don't seem to know how to use the AAC device."

In previous years, we tried to have some consistency between how the AAC device was used at home and how it was used at school. But, because of staff changes and lack of communication, that fell by the wayside. The way we're using it at home seems to be different now than the way they're using it at school. What they have her doing at school is kind of back to where she was in the beginning with only two or three symbols. At home, we have it set up for things like greetings,

making choices, and body parts (so that she can tell us if something doesn't feel good). And we have it set up so it navigates automatically. For example, she selects "greetings," and then she selects "hi mama," and then it automatically navigates back to the main page.

Can you tell me about any challenges that you have experienced related to different communication partners/professionals having the necessary content knowledge in AAC?

There have been some speech therapists who have been really good. The way they instructed us to set up the device seemed to make sense and they collaborated with us on the use of the AAC device. But I think part of the problem is that everybody quits and then we get a brand new speech therapist and they know nothing about AAC or the AAC system. They're unable to create meaningful learning experiences to help Alexis develop her communication skills, and they're unable to train the communication aide. We end up with very isolated parts on her IEP and none of it comes together in a meaningful way to promote learning. We've had about five different speech therapists in the last two years alone. And most of them haven't known enough about AAC to facilitate meaningful communication for Alexis.

I think it's also important to recognize that many individuals who are nonverbal and need AAC have numerous other disabilities as well. For example, Alexis has cognitive, visual, hearing, and physical impairments. Teaching the use of AAC for Alexis is far more complicated than teaching a child who doesn't have multiple disabilities. Because of that, professionals

need to have a deeper, and more nuanced, knowledge of AAC.

Can you tell me about any challenges that you have experienced related to teaching communication partners/professionals how to effectively support and interact with AAC users?
In the beginning, we had team meetings so that everybody was familiar with the use of the AAC system and the different purposes of communication. And, at that time, the communication aide was really well trained on how to use AAC and how to help Alexis to communicate. We also had someone once who taught Alexis to use the AAC device with peers. They would show the device to Alexis and a peer, and Alexis could select the peer and choose a task to do with a peer, like read a book. That was very, very good. She had these little peer learning partners who were all familiar with Alexis' AAC system, and that was very successful. When things were going well, I think it was because the speech therapist was educated in the theory of communication and how that can be translated into an AAC system. And she taught others what to do. But now I don't think anyone is doing that anymore, and things have really fallen apart.

Can you tell me about any challenges that you have experienced related to ensuring communication partners/professionals have access to deeper/individualized/ongoing knowledge to support AAC users?
This has been a big issue for us. One of the initial barriers was that the school district didn't have anybody who knew how to do an AAC assessment. It took two years of asking and asking and asking. And then they finally found a person. But that person never showed up. And then they found another person. And that person never showed up either. Ultimately, we had to file a lawsuit in order to receive the proper assessment that she should have had years before. And when we've asked for a follow-up reevaluation it's just been denied. Flat out denied. When we've asked for training, it's kind of dismissed. Sometimes they have referred us to the Tobii Dynavox representative and said that he can help program. But he doesn't know our child's unique special needs, and he's not an educator. He can tell us how to program a system, but he can't tell us how to make it work with our child. And I think part of the problem is that the people who don't know, don't know what they don't know.

> "And I think part of the problem is that the people who don't know, don't know what they don't know."

What do you see as the role of technology for improving outcomes related to knowledge/skill barriers?
Because of COVID, I think we've learned that we can do so much online. It's such a perfect opportunity to be able to provide online training in AAC to anyone, no matter where they live. It's no longer the case where people have to travel somewhere to get appropriate training. And it wouldn't have to be this big financial burden for somebody to go to a training because they could access it from wherever they live.

What equity issues do you want to bring up connected to knowledge/skill barriers?

Scott and I have the benefit of being highly educated. We know what to fight for. We did our research, we did our homework, and we know what our rights are and we fight for them. But I think a lot of people don't even realize what their rights are for their children, let alone being able to fight for them. And I think the other problem is lack of access to attorneys. In Hawaii there are very few attorneys. In previous years, we were able to access attorneys through Hawaii Disability Rights so that we didn't have to pay a fortune to get what we needed for Alexis. But now they're no longer a functioning entity and there's not really a lot of attorneys in this field. Some families may be bogged down with working two or three jobs and they don't have the time or energy to fight for this. And the whole idea of getting a device and learning technology themselves to be able to teach that to their child may be just unobtainable.

What do you think people need to know or do to overcome knowledge/ skill barriers?
I think there has to be some recognition, and some understanding, of what it must be like to be nonverbal. I think it has to start with understanding what it must be like for a four- or five-year-old to be trapped inside a body and not be able to communicate what they want. You need to start with realizing this person has something to communicate and then you need to make sure they have a voice. And so that's starting from the bottom. And then from the top end, I would say that it all comes down to IDEA law and having proper policies that recognize that children have a right to communicate. I mean it sounds so basic, but it should be on par

with math and English and social studies and history. Giving children a voice through AAC should be part of a curriculum that professionals are expected to know and to implement.

How do you see knowledge/skill barriers being overcome? What do you envision for the future?
I think it's a combination of people's attitudes being different, having a basic expectation for people to be treated with respect, and having the tools to be able to do so. New technology is also probably important. I think technology could be improved quite a bit. AAC should be easy to use and easy to have around all the time so that the device is used in an interactive manner. You know, if a person is blind and uses a cane, you don't send them out into the world without the cane. And you shouldn't send a child that is nonverbal out into the world and expect them to function without their device, without their voice.

I also think that there needs to be a resource where parents and professionals can get answers to questions. Questions like what icon size do we use, and how can we teach our child to use the device in a meaningful way instead of just swiping at it. Maybe even like a Center where parents and professionals can tap into the knowledge of experts. Connecting the experts to individuals who use AAC, professionals, and parents would really help.

Key Points From Vanessa's Interview

Vanessa's interview highlights the positive impact of facilitators as well as the