

MULTIMODAL AAC

FOR INDIVIDUALS WITH
DOWN SYNDROME

Krista M. Wilkinson
Lizbeth H. Finestack

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Multimodal AAC for Individuals with Down Syndrome

edited by

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The Pennsylvania State University
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and

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BROOKES
PUBLISHING C^o®

Baltimore • London • Sydney



Paul H. Brookes Publishing Co.

Post Office Box 10624

Baltimore, Maryland 21285-0624

USA

www.brookespublishing.com

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Typeset by Progressive Publishing Services, York, Pennsylvania.

Manufactured in the United States of America by

Sheridan Books, Chelsea, Michigan.

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The extract in Chapter 7, page 168, is from Büssing, A., Broghammer-Escher, S., Baumann, K., & Surzykiewicz, J. (2017). Aspects of spirituality and life satisfaction in persons with Down syndrome. *Journal of Disability and Religion*, 21, p. 16, reprinted by permission of the publisher (Taylor & Francis Ltd, <http://www.tandfonline.com>).

Library of Congress Cataloging-in-Publication Data

Names: Wilkinson, Krista M., editor. | Finestack, Lizbeth H., editor.

Title: Multimodal AAC for individuals with down syndrome / [edited by]

Krista M. Wilkinson, Ph.D., Lizbeth H. Finestack, Ph.D.

Description: First [edition]. | Baltimore : Paul H. Brookes Publishing Co., 2020. | Series: Augmentative and alternative communication; [unnumbered series] | Includes bibliographical references and index.

Identifiers: LCCN 2020023168 (print) | LCCN 2020023169 (ebook) |

ISBN 9781681254128 (paperback) | ISBN 9781681254135 (epub) |

ISBN 9781681254142 (pdf)

Subjects: LCSH: Language disorders in children—Treatment. | Communicative disorders in children—Treatment. | Down syndrome—Patients—Language.

Classification: LCC RJ496.L35 M847 2020 (print) | LCC RJ496.L35 (ebook) |

DDC 618.92/855—dc23

LC record available at <https://lcn.loc.gov/2020023168>

LC ebook record available at <https://lcn.loc.gov/2020023169>

British Library Cataloguing in Publication data are available from the British Library.

2024 2023 2022 2021 2020

10 9 8 7 6 5 4 3 2 1

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I

Introduction to Down Syndrome and Augmentative and Alternative Communication

1

Introduction to How Augmentative and Alternative Communication Can Promote Communication, Speech, and Language in Individuals With Down Syndrome Across the Life Span

Krista M. Wilkinson

Individuals with Down syndrome (DS) have diverse personal goals, preferences, and abilities, as well as unique social, academic, and vocational aspirations (National Down Syndrome Society, n.d.). Individuals with DS are a heterogeneous and diverse group, but there are some phenotypic characteristics associated with the genotype, including certain physical, cognitive, language, and health sequelae. These phenotypic characteristics are outlined by Abbeduto and McFadd in Chapter 2 of this volume. Given the needs of individuals with DS, support services related to academic, social, health, vocational, and other valued outcomes must target strategies and skills that will enable these individuals to meet their goals and fulfill their aspirations to the maximal extent possible.

Communication is key to achieving many, if not all, of these personal goals and aspirations. In particular, communication, speech, and language skills are fundamental to promoting access to educational, vocational, social, and health care advocacy opportunities. Literacy provides an entrée into academics, jobs, and social media and is a foundation for social and professional advancement. Individuals with DS have documented difficulties in producing and comprehending spoken or written language (e.g., Kumin, 1994; Martin, Klusek, Estigarribia, & Roberts, 2009; see Chapter 3 for a detailed discussion of speech production in DS) that can present a barrier to achieving valued outcomes.

AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

The tools and techniques of augmentative and alternative communication (AAC) are one type of support that can help mitigate communication difficulties and promote optimal outcomes for individuals with DS across the life span. Laubscher and Wilkinson provide a detailed description of a variety of these tools and techniques (see Chapter 4). AAC is discussed with relation to specific topics in the other chapters in this volume. This chapter offers a brief introduction to AAC and multimodal communication for readers who are new to the approaches.

What Is AAC?

AAC refers to methods for supplementing communication and language when speech is not meeting an individual's full communication needs (Beukelman & Light, 2020). AAC includes the methods of communication and the interventions that help to optimize the effectiveness of these methods.

Methods of AAC are typically classified as either aided or unaided. Aided forms of AAC include external devices such as low-technology books containing letters or symbols or high-technology aids that produce written or spoken output upon activation. The physicist Stephen Hawking is one well-known individual who used aided AAC; he used a switch to gain access to letters and phrases on a high-technology aided AAC device that then translated his input into speech and written output. Unaided forms of AAC include any form of communication that involves the body, from facial expressions and body posture to gestures, pointing, or signed languages such as American Sign Language. AAC is an evidence-based means to support optimal communication in individuals with developmental disabilities (including DS) and in individuals with acquired disabilities (Beukelman & Light, 2020).

In addition to teaching individuals to use these methods of communication, instruction for communication partners in interacting with a person who is communicating via AAC helps to optimize the effectiveness of the intervention (Kent-Walsh & McNaughton, 2005). Partner instruction has been reported by speech-language pathologists in a survey to be one of the top contributors to successful adoption of AAC systems (Johnson, Inglebret, Jones, & Ray, 2006). Studies have demonstrated that brief teaching sessions, including ones that are conducted online, positively affect how communication partners interact with individuals who use AAC (Binger, Kent-Walsh, Berens, Del Campo, & Rivera, 2010; Binger, Kent-Walsh, Ewing, & Taylor, 2010; Douglas, Light, & McNaughton, 2013; Douglas, McNaughton, & Light, 2014). A meta-analysis of the effectiveness of communication partner instruction has underscored the importance of this element of AAC intervention (Kent-Walsh, Murza, Malani, & Binger, 2015).

What Is Multimodal Communication?

Multimodal communication refers to the fact that everyone communicates via a diverse range of methods. Even individuals who use natural speech as their primary mode of expression do not typically rely solely on speech; they use inflection and prosody to emphasize or even change meaning (turning a statement such as “the car is blue” into a question by altering the prosody—“the car is blue?”), they

use gestures and facial expressions for similar purposes (an eye roll can reverse the meaning of a statement such as “sure”), and they use written prompts and alarms on their smartphones to make lists, remind them of appointments, and so forth. Even for individuals who use speech, the act of communication incorporates a diverse set of behaviors that enrich the meaning and nuance of the messages being expressed and understood.

The importance of diverse forms of communication is also true for individuals who might rely on AAC as a primary or supplementary form of communication. An individual who uses a high-technology form of AAC will also have a rich set of unaided communication behaviors that can supplement or even provide different communication functions for that individual. For instance, idiosyncratic communication forms (e.g., signs, facial expressions) may not be well understood by unfamiliar communication partners. Aided AAC systems are often critical in these situations because the feature of voice output offers an important conventional means of expression to promote understanding by the unfamiliar partner. Aided AAC, however, is often slow in terms of the rate of message preparation (Beukelman & Light, 2020). Individuals might therefore prefer to rely on idiosyncratic or unaided modes of communication with highly familiar communication partners, such as close family and friends. Thus, a main takeaway in any discussion of AAC is recognizing that there are diverse forms of communication that can supplement one another and, in some cases, serve different functions for an individual.

Multimodal Communication Across the Life Span

Related to this discussion is the important point that the communication needs and challenges of individuals change across the life span. A young child who is at the outset of linguistic development and is communicating primarily with familiar partners (a small group of family, friends, and perhaps child care) has different communication needs and challenges than an older child who is making the transition into kindergarten where he or she will be interacting with a larger group of unfamiliar partners and experiencing formal academic content. New demands on expression and comprehension occur when children begin to be exposed to literacy instruction as well as when they enter into the more informal uses of literacy on social media. The demands of self-advocacy grow and are indeed incorporated into academic planning as individuals reach adolescence, and new challenges emerge for communication around the social, vocational, or educational endeavors of adulthood. Thus, it is important to consider the applications of AAC throughout the life span, understanding that the types of communication challenges will vary across ages and contexts.

PURPOSE AND FRAMEWORK OF THIS BOOK

The goal of this book is to present an interdisciplinary approach to maximizing speech, language, communication, and literacy success for individuals with DS over their life span and across social, family, academic, health care, and adult/vocational contexts. The chapters in this book focus on how multimodal AAC can help support the expressive and receptive speech, language, and literacy skills of individuals with DS. The book is intended to offer useful information to readers with diverse forms of contact with individuals with DS, from family members to professionals

with whom the individual will interact (e.g., educators, occupational or physical therapists, speech-language pathologists, employers, health care professionals).

This book emphasizes how AAC can support participation in meaningful and valued activities as the primary outcome measure of interest. This approach is in keeping with the World Health Organization's (2001) *International Classification of Functioning, Disability and Health*, which has been applied broadly across health-related fields (e.g., Pless & Granlund, 2012; Simeonsson, Björck-Åkesson, & Lollar, 2012). This framework underscores the importance of considering an individual's functioning within the larger context of the personal and social (community) supports available to that individual. The framework also emphasizes that the desired outcome of intervention is to promote participation in activities that are meaningful and relevant to the individual and his or her interests. The different ways in which participation can be supported via AAC are infused throughout the chapters, including participation in meaningful social, academic, and vocational activities and in important roles such as self-advocacy for health care participation and transition planning.

RATIONALE FOR PROVIDING AAC SUPPORTS FOR INDIVIDUALS WITH DOWN SYNDROME

A detailed discussion of how to supplement expressive and receptive speech and language skills in individuals with DS is urgently needed for several reasons. These include issues related to 1) the early developmental trajectory and outcomes in speech and language in individuals with DS, 2) difficulties of articulation and intelligibility in individuals with DS even after speech has emerged, 3) the presence of intellectual disability and its implications not only for expression but also for comprehension of spoken or AAC input, 4) the changing communication demands that occur over the life span, 5) the increased risk for cognitive decline (Alzheimer's disease) at earlier ages in individuals with DS, and 6) the changing role of the individual within and outside the family unit as the individual becomes independent.

Early Developmental Trajectory in Individuals With Down Syndrome

Although individuals with DS may follow a typical sequence of communication and speech development, the age at which speech begins to emerge is typically later than their peers. It is critical to provide children with DS tools for language development via AAC, even before speech emerges, to support their overall development. Moreover, AAC can provide a means to jumpstart language and related cognitive development in order that young children with DS do not fall further behind their peers with typical development. As Ronski and colleagues (see Chapter 5) clearly demonstrate, provision of AAC early in life does not in any way interfere with speech development, but rather AAC can offer important communication opportunities and experiences.

Difficulties With Speech Intelligibility

Once speech emerges, it may not meet all of the communication needs of individuals with DS, particularly in settings with unfamiliar communication partners. For instance, Kumin (1994) noted that 95% of parents reported that their child's

speech is not fully intelligible to unfamiliar communication partners, causing Martin and colleagues (2009) to conclude that “nearly all individuals with DS may be difficult to understand at least some of the time” (p. 115). The reasons for this difficulty relate to physical, motoric, and potentially cognitive impairments, and these are outlined by Kent and Vorperian (Chapter 3). Because of this continued difficulty with speech intelligibility, AAC could be beneficial to promote optimal communication outcomes in individuals with DS, which is explored in all of the chapters of this volume.

Presence of Intellectual Disability and Implications for Comprehension

The presence of intellectual disability as well as vision and/or hearing loss can mean that comprehension of spoken language input may also be compromised. Promoting comprehension of input is critical to virtually all valued outcomes, from engaging with family, friends, and colleagues to self-advocacy within vocational and health care settings. Limitations in comprehension can lead to restrictions in the ability to engage maximally within school or vocational settings and can lead to unconventional or challenging behaviors and the onset of negative social consequences (withdrawal or isolation).

The role of AAC in supporting understanding is a theme in most of the chapters of this book. For instance, implementation of AAC is explored with regard to how it can support language comprehension in early development (Ronski et al., Chapter 5), in the school years (Finestack & Rohwer, Chapter 6), and in health care settings (Santoro, Chapter 10) as well as with regard to the specific issues individuals with DS may have in signaling difficulty understanding when communication breakdown occurs (Abbeduto & McFadd, Chapter 2; Channell & Loveall, Chapter 8). Providing AAC as a means to support understanding and coping with new situations is a theme that emerges when considering transitions (McNaughton, Babb, & Holyfield, Chapter 7) and health care provision (Santoro, Chapter 10). Targeting literacy as a means to support both comprehension and self-expression across these contexts is a key outcome, and it is discussed in detail by Barton-Hulsey and Sevcik (Chapter 11).

Changing Communication Demands Across the Life Span

Difficulty with speech production will affect communication effectiveness across a wide range of contexts and partners across the life span. Each context presents different demands on individuals, so speech might meet their needs in some contexts but not in others. Ronski and colleagues (Chapter 5) illustrate how implementing AAC supports for children with DS from the youngest ages, in ways that are consistent with family preferences and abilities, provides a foundation for development of language (including both speech and AAC). Promoting expression via a combination of AAC and speech continues to be of utmost importance as children enter school, where they interact with many unfamiliar students and teachers and begin to focus on important academic and literacy outcomes. These issues are explored in detail by Finestack and Rohwer (Chapter 6) and Barton-Hulsey and Sevcik (Chapter 11). When individuals make the transition into adolescence, adulthood, and work, they must interact with co-workers, supervisors, and potentially

customers in service industries; these topics are discussed by Channell and Loveall (Chapter 8) and McNaughton et al. (Chapter 7). As individuals experience a greater range of environments and interact with a larger number of unfamiliar partners, AAC is of critical importance for effective communication within those environments and also as a means to protect against potential discrimination, bullying, or abuse by allowing the individual an effective method of self-expression about these possible experiences.

Increased Risk for Cognitive Decline at Earlier Ages

As discussed by Channell and Loveall (Chapter 8), individuals with DS are at greater risk for cognitive decline associated with dementia or Alzheimer's disease than people in the general population, and the onset of cognitive decline appears to be earlier in individuals with DS, emerging as early as 40 years (Ballard, Mobley, Hardy, Williams, & Corbett, 2016; Zigman & Lott, 2007). Approximately 70%–80% of older adults with DS will develop clinical symptoms of Alzheimer's disease (Zigman, 2013). It is critical to have AAC supports in place for several reasons. AAC systems will be necessary to promote maintenance of comprehension and expressive skills, to the extent possible, particularly if the individual moves to a residential facility for care (with many unfamiliar communication partners). These systems may also play an important role in ongoing assessment of functioning and decline.

Changing Role of the Individual Within and Outside the Family Unit

The role of an individual within a family evolves from childhood through adolescence and adulthood, and, thus, AAC supports need to be responsive to both the family system and to the changing relationships within it, a topic explored by O'Neill, Mandak, and Fosco (Chapter 9). Throughout life, individuals with DS will need to gain access to health care, where they must be able to communicate effectively with health care providers, understand what to expect during medical appointments and procedures, and self-advocate during the process, a topic explored by Santoro (Chapter 10).

CONCLUSION

AAC supports can offer critical benefits to individuals with DS across their life span for situations in which their speech is not meeting their daily communication needs. AAC allows individuals to communicate for multiple functions, including making basic requests, transferring information, establishing social closeness, and promoting linguistic development. Some individuals with DS may require AAC across many or most settings; for others, AAC may supplement existing speech in certain situations. Both unaided and aided AAC can be incorporated for a given individual, and these will support the full range of multimodal communication that includes speech and nonverbal forms of communication. It is of particular importance to ensure that AAC is integrated within the family unit because the family remains a key context for development throughout the life span. AAC can promote early language development; support academic, literacy, and other skills during elementary school years as well as adolescence; foster transitions to

adulthood; support comprehension and expression as individuals with DS age and experience Alzheimer's disease; promote engagement in health care; and enhance participation in valued roles in society.

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“Contains a wealth of information that will be relevant to faculty who teach AAC courses and to clinicians who support families...The life span approach reminds us that it is never too early or too late to support communication development using multiple modalities.”

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