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Review of Communication Alternatives in Autism: Perspectives on Typing and Spelling Approaches for the Nonspeaking

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A Much-Needed Addition to the Literature on Autism and Education:

A Review of Communication Alternatives in Autism: Perspectives on Typing and Spelling Approaches for the Nonspeaking (2019)

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Abstract

This manuscript reviews Edlyn Vallejo Peña's edited volume, *Communication Alternatives in Autism: Perspectives on Typing and Spelling Approaches for the Nonspeaking (2019)*. The volume includes ten chapters by autistic authors active in the field as activists, self-advocates, artists and leaders, along with Peña's experiences as a parent and original research.

Keywords: autism, augmentative and alternative communication, inclusive education

Communication Alternatives in Autism: Perspectives on Typing and Spelling Approaches for the Nonspeaking (2019), edited by Edlyn Vallejo Peña, is comprised of ten chapters written by autistic authors, activists, bloggers, students and/or self-advocates who use letterboards and keyboards to communicate. Peña bookends these chapters with personal experiences as a parent, and findings from her research on best practices for educators supporting students on the autism spectrum who type and spell to communicate. Harnessing the disability rights mantra "Nothing about us, without us" this volume centers on the voices and experiences of contributing authors as they recount navigating educational and community spaces not designed with them in mind, in the midst of controversy around their chosen augmentative and alternative communication (AAC) methods, such as Rapid Prompting Method (RPM) and Facilitated Communication (FC). In her introduction, Peña situates the authors' stories within the debates and research surrounding teaching individuals with autism to communicate through pointing, spelling and typing. The ten chapters that follow are divided into three major sections that span three generations of social, educational and political realities for autistic people. The narratives reveal shifts to increased access and illustrate barriers to inclusion and access to communication that remain a reality for many autistic students who do not use speech as their most reliable form of communication.

In Section 1—*Escaping the Institutionalization Mindset*—Tracy Thresher (Chapter 1), Larry Bissonette (Chapter 2) and Amy Sequenzia (Chapter 3) tell stories of growing up at a time where institutionalization of autistic children was common. Key themes include consequences of low expectations, ableism, presumption of competence, and support and solidarity. All three authors detail experiences across what Sequenzia terms "non-learning

environment[s],” (p. 56) ranging from segregated special education classrooms, special schools and residential institutions. They each describe childhood and adolescence without formal access or consistent support for communication through typing, often coupled with segregation. Their narratives illustrate nuanced experiences navigating the world with bodies that do not always cooperate with their intentions. Their narratives highlight how sensory, movement and medical needs impact access to communication, educational and social opportunities in an ableist society.

Thresher, Bissonette and Sequezia are united as “survivor[s] of low expectations” (p. 41) and by their continued contributions to a paradigm shift around autism through writing, film, poetry, art and advocacy. Thresher and Bissonette share a common experience as co-stars in the documentary *Wretches and Jabberers* (Wurtzburg & Biklen, 2010); they describe the life-changing experience of filming and the continued impact of their work in countering deficit discourses of disability. Sequezia emphasizes the impact of social media on her connections, continuing education and advocacy. True throughout many chapters in the volume, each author ends with words of guidance. Thresher highlights the presumption of competence as key to breaking down barriers, while Bissonette centers the vital need for inclusion, urging others who type and spell to communicate to “make laps around the noisy field of jabberers [speaking people] with your typed words” (p. 50). In a poetic end, Sequezia emphasizes “Access/Support/Respect” as bedrocks of learning for all, including nonspeaking, students (p. 65).

In Section 2—*A movement toward full inclusion*—Ido Kedar (Chapter 4), Samuel Capozzi (Chapter 5) and Dillan Barmache (Chapter 6) detail experiences living at a time of transition: part of the generation of access to education for all, which impacted their adolescence and young adulthood. Like many of the co-authors, they describe isolating experiences of not having reliable means of communication early in life. They discuss: unmet motor needs in behavioral interventions, inaccurate assumptions based on communication, regulation, and movement differences, and the power of support for access and self-confidence. While Kedar, Capozzi and Barmache experienced a range of educational placements, their narratives converge around how learning to use letterboards and keyboards to communicate as adolescents ushered in increased educational and community inclusion. Yet they make clear that those transitions were not seamless, necessitating their own and their families’ advocacy efforts. Kedar details years of hard work to gain entry to inclusive settings, including honing his motor planning for pointing and tolerance for sitting through lengthy classes. Barmache underlines the tenuous nature of his communication and inclusion as dependent on others’ willingness to honor his typing, and on his own efforts as a self-advocate. Capozzi reflects on his experiences at the intersections of disability and privilege, particularly as it plays out in inequitable opportunities for autistic students like him to access higher education.

The authors in Section 2 call for increased communication access and support for sensory and movement differences. Kedar encourages parents to resist deficit discourses and

urges people with autism not yet accessing communication to: “have hope...I am fighting for your freedom and so are others. Hang in there.” (p. 82). Capozzi, too, offers hope, along with reminders that autistic people should be leading the direction of their own lives. Barmache urges educators, families and communication partners to balance communication, sensory, motor and emotional supports for autistic students, and move away from interpreting their capabilities based solely on observable behavior.

Section 3, *Triumphs and Obstacles in Navigating the Educational Maze*, Henry Frost, Emma Zurcher Long, Philip Reyes and Rhema Russell discuss recent experiences as students across a range of educational settings. They highlight: agency, self-advocacy, relationships, and self-expression. All four authors describe struggling to access communication until learning to spell and type to communicate by early adolescence, and associated advocacy for inclusive education. They, too, offer insider views of living with sensory and movement differences. Frost, Reyes, Zurcher Long and Russell describe navigating gaps in communication access between home and school, and highlight barriers created by segregation, ableism and limited access to trained communication partners. Each author discusses significant friendships and/or mentor relationships as crucial to their journeys, made possible through reliable access to communication. Frost underscores the importance of seeing himself represented in autistic peers and mentors, arguing that AAC be used in academic *and* social inclusion. Zurcher Long emphasizes the relationship between communication and agency, noting that upon learning to type, she “...went from being told most things, to being asked” (p. 135).

Section 4 authors offer examples of how communication can, and must, serve to support individual agency, along with/through advocacy, connection, friendship, and inclusion—in every sense of the word. Frost details his viral advocacy campaign “I Stand with Henry” to attend his neighborhood school and resist segregation. Zurcher Long tells of her love and use of music, rhythm, and movement as part of her identity. Reyes describes using writing—through letters to his neurotypical peers and his blog—to foster understanding about autism as a way of being. Russell collages advocacy letters, narrative and poetry to tell her story. She ends her chapter—and the final section of the book—with a poem highlighting the beauty and urgency of connection for communication.

Peña concludes the volume by connecting themes raised across the authors’ narratives to results of her research study about best practices in education for students who use letterboards and keyboards to communicate. This is a fitting end to what seems like a resounding call from all ten co-authors for a paradigm shift and educational practice tailored to experiences of nonspeaking and unreliably speaking people. Based on interviews with 14 school and college educators, informed by themes across the authors’ chapters, Peña lays out a framework for supporting students who use letterboards and keyboards to communicate. She offers these findings grounded in the intersecting necessities of: establishing foundational beliefs in students’ competence and remaining grounded in humility, providing access to

communication and associated supports, including those to address sensory and movement needs, and constructing opportunities for inclusive participation and engagement.

This book is a much-needed addition to the literature on autism and education; it models how published work can, and should, amplify the voices of autistic people as authorities on their own experiences. As Peña notes, “The growing community of minimally speaking and nonspeaking students who demand communicative accommodations and inclusion in educational settings suggests that we are at a tipping point in history” (p. 189). *Communication Alternatives in Autism* evidences and contributes to this historical moment. Given that history grounds the volume’s structure, additional contextualization of the authors’ narratives within the history of disability rights, as well as scholarship and activism around neurodiversity, would have been helpful. Overall, I highly recommend this text for anyone whose personal or professional experiences reflect, intersect with or impact the lives of autistic people. There is a critical need for this information to get to educators, administrators, therapists and parents to change practice. There is also great value and possibility for autistic people, particularly whose communication access is emerging, to build community, forge connection and learn from autistic-led representation. In line with the authors’ guidance, I encourage you to let powerful narratives guide your actions. As Barmache reminds us:

Reading my story is not enough—it is a beginning. Take what I have said with you as you look to other people who are impacted by autism. Take lessons from each typer in this book and really believe that every autistic child can achieve this level of expression if you reach out with an open mind. (p. 111)

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Endnotes:

¹ In this review, I alternate between use of person first, identity first language and language referencing the autism spectrum to mirror and honor the varied representation preferences amongst the authors, and across the autistic community.



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