

FAMILY MEMBER EXPERIENCES WITH AUGMENTATIVE AND ALTERNATIVE  
COMMUNICATION SYSTEMS USED BY NONSPEAKING AUTISTIC INDIVIDUALS

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A DISSERTATION

Presented to the Affiliated Faculty of  
The College of Graduate and Professional Studies  
at the University of New England

Submitted in Partial Fulfillment of Requirements  
For the Degree of Doctor of Education

It was presented on  
04/18/2023  
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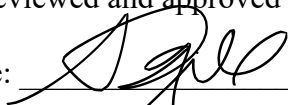
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ABSTRACT

Nonspeaking autistic individuals who have no way to communicate cannot share their thoughts, dreams, or desires. The purpose of this qualitative narrative inquiry was to explore the experiences of family members of nonspeaking autistic individuals who use augmentative and alternative communication (AAC) systems. This study documented family members' experiences of identifying, learning, and implementing two types of AAC: Rapid Prompting Method and Spelling to Communicate. Through one-on-one interviews, five participants shared their lived experiences. Three themes emerged from the data. The first theme was an increase in well-being for the entire family. All five participants described transformations and improvements in life not only for their speller, but for the entire family. There was an increase in well-being both physically and emotionally for spellers and their families. The second theme was a remarkable improvement from the past. All five families shared changes to communication and, for their nonspeaking autistic family member, shared a dramatic shift in the social aspect of their family member. They also shared major improvements in self-injurious behaviors. The third theme was that learning and implementing AAC was laborious but beneficial for the communication partner. They all described the commitment it took and that it was worth every minute. Each participant talked about sharing the benefits and changes with other families. All of the participants encouraged families who might be considering spelling as AAC.

**Keywords:** autism, nonspeaking, augmentative and alternative communication, narrative inquiry

## DEDICATION

For my partner, best friend, and love of my life, Will, I couldn't have done this without you. I promise to spend more time with YAH, you, and our gardens!

Emily, when you came into my life, you inspired me to be the best me I could be. You are a gift and I hope someday you find your inspiration and know how much I love you.

For Ryan, you have taught me love without words. Your creativity, kindness, and love of YAH moves me. Thank you for being you and for YAH for allowing me to be your mom.

To all the people out there who have not yet found their voice. I'm praying for you daily.

In memory of my dad who made me feel like I was the most important person in the world. Your smile and positive energy will be with me forever.

## ACKNOWLEDGEMENTS

Completing this dissertation helped to strengthen my belief in myself. It challenged me in every way possible. With passion, persistence, and continued support, I was able to finish.

Dr. Andrea Disque, I was blessed to have you as my lead advisor. Your dedication, attention to detail, and consistent feedback is what got me to the end. I will be forever grateful for your kindness, positive energy, and encouragement.

Dr. Chad Walls, thank you for your advice, direction, and support along the way. I appreciate the thoughtful questioning and honest feedback.

Mark, Elizabeth, Jade, Lydiann, and Marcy, thank you for sharing your stories with me. Thank you for your time, honesty, and vulnerability. Without you this research would not be possible.

For my family and friends, your support and belief in me motivated me to push forward until the end. Will, thank you for everything. I could not have done this without you.

Mom, Valerie, Susan, Michele, and Nancy I am lucky to have so many moms throughout my life to look up to. Thank you for being part of my life journey and models of strong independent women.

Ineke, my best friend, daily confidant, and biggest cheerleader, cannot wait to celebrate with you!

Shane, Olivia, Andrea, Avery, Anthony, Lydiann, Liam, and Levi, I am honored to hear you call me auntie. Find something you believe in and work hard to make it happen!

Finally, to my sister Julie for giving me the book that led us to life changes and open communication.

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## CHAPTER 1: INTRODUCTION

Kedar (2012), a 14-year-old teenager with autism, described his life before and after being able to communicate. Kedar had difficulty following instructions and exhibited odd behaviors; therefore, his teachers assumed that he was not intelligent. Kedar was taught the same information over and over. When he learned to communicate at Age 7 with a letter board, Kedar was unable to hold the board himself because of coordination and inability to hold the board still. Some rejected his new abilities and, not until Kedar could use his keyboard independently without being touched or guided, would they admit that the knowledge was his own. At Age 15, when Kedar (2012) wrote a book, he described himself living in a dual world, one with an intelligent mind and a body that reacts to impulses like “a lizard chasing a cricket” (p. 144) Many people might believe that nonspeaking autism is a cognitive and language processing disability, when it is primarily a motor disability (Bethany, 2022). This motor disability prevents the individuals from moving and doing what they actually want to do (Bethany, 2022). These individuals might tell their bodies to move, but it refuses to move (Bethany, 2022). How the external behaviors of autism are responded to by those who are working with them might make the disability exponentially worse (Bethany, 2022).

Autism was diagnosed as early as 1908 when autism was used to describe patients with schizophrenia (Sole-Smith, 2014). The autism diagnosis was separated from schizophrenia in 1943 when Dr. Leo Kanner coined the term “early infantile autism” (Al Ghazi, 2018). According to the International Association for Spelling as Communication (I-ASC), a nonprofit organization composed of individuals from the nonspeaking and neurodiverse communities, their families, trained practitioners, and informed allies, communication is universal and, if one has access, agency, and autonomy, one can hear from all. I-ASC (2022) is committed to support access to effective communication and equitable access to all aspects of education, employment,

relationships, and the community for nonspeaking people. Nonspeaking is the term that is used when a person does not speak (Holland et al., 2021). The term nonverbal is more common; however, it means “without words” (Holland et al., 2021). Someone who is nonspeaking can still communicate through other means (e.g., writing, sign language, or pictures) and can still understand what you are saying to them. (Prizant & Fields-Meyer, 2016). Seven million people in the United States have been diagnosed with autism and, of that number, 2.3 million are nonspeaking (I-ASC, 2022). The U.S. Centers for Disease Control and Prevention’s (2023) collaborative, Autism and Developmental Disabilities Monitoring Network, tracks the number and characteristics of children with autism spectrum disorder in the United States. The Autism and Developmental Disabilities Monitoring Network (USCDC, 2022) reported that, as of 2018, autism affects one out of 44 children in the United States. According to the National Autism Association (NAA; n.d.), which is a parent-run nonprofit organization whose mission is to respond to the most urgent needs of the autism community, 50% of children who are diagnosed with autism are also diagnosed as having an intellectual disability. Forty percent of children with autism do not speak (NAA, n.d.). Over the last 20 years the rate of autism has increased significantly in the United States and is the fastest growing developmental disorder (NAA, n.d.).

The 2022 Valedictorian of Rollins College, Elizabeth Bonker (2022), typed her commencement speech with one finger, she told the audience that she is one of the few lucky nonspeaking autistics who have been taught to type. Bonker (2022) told her audience, “God gave us a voice and we should use it” (line 66). Bonker is an example of what can happen when an individual learns to communicate. Bonker learned to communicate using Rapid Prompting Method (RPM) when she Age 6. At Age 15, Bonker co-authored a book, *I Am in Here: The Journey of a Child with Autism Who Cannot Speak but Finds Her Voice* (Bonker & Breen, 2011). Bonker described how learning the letterboard did not cure her autism and the challenges,

but she continues to battle courageously (Bonker & Breen, 2011). Bonker has learned to appreciate the little things and believed that lives should be used for service (Bonker & Breen, 2011).

Autism is a bio-neurological, developmental disability that appears before Age 3 and is characterized by impairments of social communication, repetitive behaviors, and restricted interests (Mahadevaswamy et al., 2021). Methods used to detect autism are drawn from behavioral analysis of the individual and are dependent on the skill of the examiner (Mahadevaswamy et al., 2021). It is important recognize that educational and medical professionals might only look at the individual with autism's deficits when trying to support, instead of considering the strengths and that needs that might evolve over time (Prizant & Fields-Meyer, 2016). When only looking at a checklist of what a nonspeaking autistic individual cannot do, taking a standard measure and comparing it to other children, the child as a whole might be missed (Prizant & Fields-Meyer, 2016). Talking to the parents, who know the child better than anyone else, and having a collaborative process, is important although most of the time a verdict of diagnosis is delivered according to the psychologist's professional observations (Prizant & Fields-Meyer, 2016). This is important for nonspeaking individuals because they are often underestimated and seen as not having high intellectual abilities. As Molko (2022) stated, "Just because someone is nonspeaking, does not mean they are nonthinking" (p. 1 ).

Only 50 nonspeaking autistic students, using Spelling to Communicate (S2C) and RPM (which are forms of augmentative and alternative communication [AAC]) are now in college, graduate school, or have already graduated using a letterboard or keyboard as their preferred method of communication (Howe, 2022). In this study, I explored the experiences of family members of autistic individuals who use an alternative approach to communication and their

interactions around education, socialization, and employment opportunities inside and outside of the home.

### **Definition of Key Terms**

**Applied behavior analysis:** ABA is the application of techniques on individuals with autism with the goal of changing their observable behaviors. Also, known as behavioral therapy, these terms will be used interchangeably in this paper (Peña, 2019a).

**Apraxia:** This medical diagnosis indicates challenges with fine and gross motor planning needed to perform tasks or execute purposeful movements (Peña, 2019a).

**Autism:** This developmental disability is characterized by difficulties with communication and socialization. Autistic individuals might have problems with sensory processing, motor planning, and repetitive behaviors (Peña, 2019a).

**Augmentative and alternative communication:** AAC includes all of the ways that a person communicates besides talking. People of all ages can use AAC if they have trouble with speech or language skills. Augmentative means to add to someone's speech. Alternative means to be used instead of speech. Some people use AAC throughout their life. Others might use AAC only for a short time (e.g., if an individual has a surgery and cannot talk; American Speech-Language-Hearing Association [ASHA], n.d.-a).

**Communication regulation partner:** A CRP holds the letter board or keyboard for nonspeaker, and assists them with sensory regulation (Vosseller, 2017).

**Facilitated communication:** This technique involves a person with a disability pointing to letters, pictures, or objects on a keyboard or on a communication board, typically with physical support from a "facilitator." This physical support usually occurs on the hand, wrist, elbow, or shoulder (ASHA, 2018).



**Letter board:** This laminated board features the alphabet, numbers, symbols, and punctuation. Used with a communication partner who holds the board as the communicator points to the letters and symbols to generate words or statements (Vosseller, 2017).

**Motor-based interventions:** A variety of motor-based intervention protocols are used to treat apraxia. Most approaches include a high amount of practice, a small set of treatment targets, homework, and the use of visual and tactile cues (Maas et al., 2014).

**Neurotypical:** These people have standard brain processing and functioning (Singer, 2017).

**Neurodivergent:** The brain functioning and processing of these people deviates from what is considered “typical” (Singer, 2017).

**Nonspeaking:** This term means the absence of speech. This term evolved from the term “nonverbal,” which infers a deficit in receptive and expressive language (Peña, 2019a).

**Nonverbal:** This term means that the person has no language or is without words (Krejcha, 2022).

**Praxis:** This term denotes imitation and gesture production, both representational or nonrepresentational, that can be performed with or without the use of tools (Kilroy et al., 2022).

**Rapid prompting method:** RPM is a method of communication that empowers a student with the means to express their learning, understanding, reasoning, and thoughts (Mukhopadhyay, n.d.).

**Spelling to Communicate:** S2C teaches individuals with motor challenges the purposeful motor skills necessary to point to letters to spell as an alternative means of communication (Vosseller, 2017).

## **Statement of the Problem**

My study was focused on the experiences of family members of nonspeaking autistic individuals who have limited ability to communicate, which might severely limit educational, social, and employment opportunities (Jaswal et al., 2020). This limited communication affects family life and interactions (Desiningrum et al., 2019). The parents of autistic individuals face many challenges on a daily basis: being unable to relax and feeling exhausted, sad, afraid, frustrated, and sometimes helpless (Goodwin et al., 2022).

According to Jaswal et al. (2020), 30% of autistic individuals have a limited ability to communicate, and most of them never gain access to an effective means of communication. However, options such as S2C and RPM can provide an alternative to communication (Peña, 2019). A few researchers documented the everyday impact of AAC interventions for individuals who use them and their family experiences (Kron, 2017). AAC is type of communication that supplements or replaces speech for individuals who have challenges speaking (ASHA, n.d.-a). This type of communication might include gestures, communication devices, boards with symbols or letters, and picture exchange communication systems (PECS; Peña, 2019a). A growing community of autistic people use letterboards and keyboards to communicate (Peña, 2019a). More research is necessary to uncover the answer to relationships among experiences and alternative communication (Peña, 2019a).

## **Purpose of the Study**

The purpose of this qualitative narrative inquiry was to explore the experiences of family members of nonspeaking autistic individuals who use AAC systems. Nonspeaking autistic individuals are those who do not communicate by speaking (Prizant & Fields-Meyer, 2016). Family members are defined as individuals who live with someone who has nonspeaking autism. AAC, as defined by ASHA (n.d.-a), includes all of the ways that a person can communicate other

than speaking, including systems that spell words by pointing to letters and that use a keyboard. I focused on two forms of alternative communication, S2C and RPM, both of which are focused on purposeful interventions with the intentional practice to increase motor outcomes to teach individuals how to point to letters to spell (United for Communication Choice, 2022). RPM is a method of teaching that can be used to teach academics, to develop motor skills, and to communicate (Mukhopadhyay, 2014). S2C teaches individuals to use purposeful motor skills to point to letters to spell (Taborga, 2022). Odeh et al. (2020) looked at 13 studies of motor interventions in which the subjects had an improvement of language, and found that, for at least 12 of the subjects, their language had increased on at least one outcome.

I describe the experiences of family members of nonspeaking autistic individuals who use AAC systems. This qualitative narrative inquiry was focused on exploring the experiences that family members have had with AAC for their nonspeaking autistic family member.

### **Research Questions and Design**

To understand better the experiences that family members have regarding AAC systems, the following research questions guided this study:

- **Research Question 1:** How do family members of nonspeaking autistic individuals describe their experience with identifying, learning, and implementing AAC?
- **Research Question 2:** How do family members of nonspeaking autistic individuals describe transformations within their families since implementing AAC?

In this study, the researcher explored the experiences of a specific group—families of nonspeaking autistic individuals—that experienced a central phenomenon—the use of two AAC systems: S2C and RPM; therefore, qualitative research was best suited for this investigation. Qualitative research promotes a deep understanding of a social setting or activity from the perspective of the research participants (Bloomberg & Volpe, 2016). It implies exploration,

discovery, and description (Bloomberg & Volpe, 2016). I employed a qualitative narrative inquiry as the research approach for this study. A narrative inquiry tells a self-narrative through living, telling, retelling, and reliving experiences (Bloomberg & Volpe, 2016). Narrative research records the lived experiences of the people who are studied and then retells the story (Bloomberg & Volpe, 2016). To gather data, I conducted semistructured interviews through Zoom. Family members of nonspeaking individuals who use AAC systems (S2C or RPM) were invited to participate in interviews to share their experiences through telling stories about their lives both in and out of their home within the areas of education, socialization, and employment opportunities. The data collected from the interviews was then rewritten into restoried narratives, after which the data was analyzed to determine the common themes that occurred across the stories.

### **Conceptual and Theoretical Framework**

Ravitch and Riggan (2017) suggested that the conceptual framework is a support and they explained why the research is important and why the theoretical framework is important. The conceptual framework is a logical sequence of supports that helps the reader understand the need for this research (Ravitch & Riggan, 2017). The components of a conceptual framework point to the significance of the topic, guide the development of research questions, support what I hoped to learn from the study, and provided evidence for how the research might influence the topic area. The conceptual framework also described my relationship to the research, and the theories that would inform the analysis (Ravitch & Carl, 2021). The conceptual framework for this study included my interest in AAC systems. This study is drawn from the following themes that were developed through the review of the literature: (a) the brain and how it affects language and communication for nonspeakers with autism; (b) assessments that are used to determine interventions for nonspeakers with autism; and (c) presuming competence, which is believing, even when a child cannot speak, that they can think, process, and know what is going on in

the world around them (Peña, 2019a). The topical research for this study is framed by how the abilities of nonspeaking autistic individuals are viewed and by the theoretical framework of experiential learning theory (ELT).

At Age 2, after losing all of his ability to speak, my son was diagnosed with autism. From that day on, our family's lives were devoted to research, advocacy, and trying to help him learn to communicate. Year after year we tried countless interventions, spent an incredible amount of time and money searching for hope, and felt completely defeated. Our family experience was not unlike those of families all over the world. Some individuals find an intervention that works, and some do not.

In March 2021, I read *Underestimated: An Autism Miracle* (Handley & Handley, 2021). Little did I know that that book would lead our family on our final quest for finding our son's ability to speak. After reading Handley and Handley's book (crying the entire time), I felt like the book was written about our son, for the family's journey had so many connections to our own, and I was filled with a new (still slightly skeptical) hope! We were put on a wait list for an appointment to see the speech–language pathologist (SLP) who had worked with Handley's son in Virginia. We are now a year and a half in with using this method and it has worked! My son is writing songs, doing algebra, and knows the periodic table. I've learned that my son is funny, filled with kindness, empathy, and love and that he can now tell us all he had not been able to for 17 years. As a family, our experience with AAC programs has completely changed our lives and the way we interact with our son. There was a big shift in our family in how we viewed autism and behavior, for we realized that our son did not need to be fixed and could not control a lot of what his body was doing. We learned about neurodiversity and presuming competence. Our son just needed a different way to show what he knew and to work on his motor skills.

Neurodiversity is a recent theory and movement that embraces variations of the human brain such as autism, dyslexia, attention deficit hyperactivity disorder, and perceptions of the world (Cook & Purkis, 2022). The AAC systems referenced in this study each embrace presuming competence in the individual. Presuming competence is a different way of looking at a disability than as a medical neurocognitive disorder; it promotes respect and inclusivity for individual difference (Giroux & Pélissier-Simard, 2021). Parents and family members can see life from a strength perspective through the lens of neurodiversity, instead of the medical model that views individuals as lacking appropriate behavior and needing treatment (Hillman, 2020). Neurodiversity can reduce the stigma that brain differences are deficits, and it encourages an inclusive mindset that values all differences and eliminates putting people into one category according to how they might act, think, or learn (Cook & Purkis, 2022).

In most countries, the medical model of a disability is used in both educational and health care to diagnose and treat the person; according to Price (2022), this is the model to which parents are introduced for help with their child:

The medical model of a disability understands disability as a condition that exists inside an individual person's body or mind. If you are disabled, you personally have a problem that must be identified, diagnosed, and then either treated or cured. (p. 2290)

Under this model, families are led to believe that they must find a way to fix their child (Price, 2022). Discounting nonspeaking autistic abilities is promoted by some leading medical institutions (Blueshift Educators, 2021). This belief might drive misguided practices and policies for schools and facilities and might make parents believe that this is what is right for their nonspeaking autistic individual (Blueshift Educators, 2021). Harmful behavioral therapies might begin during early childhood and can have major traumatic impacts on individuals (Blueshift Educators, 2021). The ability to listen and understand what is being communicated might not be

demonstrated through a person's behavior; this might create a lack of understanding of autistic people and lead to more segregation. How we educate our community and families about autism has major social ramifications (Blueshift Educators, 2021). Whitty, a 35-year-old who participated in Blueshift Educators's (2021) documentary reflects on how horribly he was treated, and he is still processing the years of trauma. Whitty's advice is to be a positive force for students, believe, presume competence, and respect all as humans. He also shared how a true connection with other people is sought by autistic individuals and that autistics are intelligent and sensitive (Blueshift Educators, 2021). Autistic individuals are speaking out; it is time to listen.

Van Schaik et al. (2022), a nonspeaking writer, described wellbeing as a moving target. He shared that bodies, senses, and emotions are changing constantly. He believed that, if one could be grounded, managing this change would be easier. Van Schaik et al. (2022) shared that, even after gaining a voice, families and professionals still miss this. There is no cookie-cutter formula for well-being for neurotypicals or nonspeakers; therefore, the first step for families and professionals is to begin listening to the individual and figuring out what they need, want, and desire for well-being. The neurodiversity framework accepts differences (Van Schaik et al., 2022). The neurodiversity movement has driven a powerful, cultural, and political force (Tougaw, 2020). The promoters of the movement advocated that researchers, physicians, and policy makers should develop methods that acknowledge the gaps (differences in people's brains) and value those differences and create a support to help people instead of trying to change them (Tougaw, 2020).

Jaswal (2017) described the path of autism as not a happy one for nonspeaking autistic individuals. For families of nonspeaking autistic individuals, life has been filled with guilt and sacrifice (Botsford et al., 2008). Autistics have been found to have been bullied, abandoned, isolated, tortured, and misunderstood (Botsford et al., 2008). Goble, a parent of an autistic

individual, wrote three pearls of wisdom to give advice and to share stories after raising a son with autism for 43 years, “1. Each day is a new day. 2. You count too. 3. Even if your child does everything he can to convince you [that] he doesn’t want limits; you must not give in; you must set them” (Botsford et al., 2008, p. 22). Jaswal (2017) reviewed Silberman (2016) who wrote about autism and the history of autism. Silberman gave the hope of a different future for those who have autism. Silberman shifted the focus from the need to change someone with autism to loving them for who they are. The goal of neurodiversity is to focus on building on someone’s strengths and finding a way to allow them to show what they do know (Jaswal, 2017). Silberman (2016) asked readers to imagine society denying wheelchair users public access to buildings by insisting that someday everyone would be able to walk. This is comparable to denying a person with autism AAC, hoping that someday they would talk.

The theoretical framework that guided this study was ELT. Kolb (2015) described ELT as “experience is transformed into learning and reliable knowledge” (p. 21). ELT is a learning by doing approach in which the learner creates new knowledge by engaging and applying new knowledge (Pandey & Vaughn, 2021). ELT (a) allows insights into nonspeaking autistic individuals’ learning, (b) enables nonspeaking autistic individuals to become self-directed, and (c) promotes learner engagement through learning by doing (Zijdemans-Boudreau et al., 2013). Family members are learners throughout the process of finding, learning, and using AAC systems, and through this study, I provided the opportunities for family members to share their stories. ELT has helped with transitioning individuals with the support of their family between the classroom and society (Zijdemans-Boudreau et al., 2013). For families, learning to use S2C or RPM takes a great deal of practice, consistency, reflection, and collaboration, which are parts of ELT. Training for family members and supporting interactions with peers throughout the



family's learning should be a focus throughout their acquisition of skills to use the AAC system (Donaldson et al., 2021).

### **Assumptions, Limitations, and Scope**

In this qualitative narrative inquiry, I explored the experiences of family members of nonspeaking autistic individuals who use AAC systems to communicate. The interactions between autistic individuals and their families are derived from data collected through semistructured interviews. I describe the experiences of family members with nonspeaking autistic family members who use AAC systems within the areas of social, academic, and employment opportunities.

#### **Assumptions**

Assumptions are beliefs in research that researchers might not actually be able to prove (Simon & Goes, 2018). In this study, I used semistructured interview questions; therefore, the data was gathered through the participant responses. An assumption that some researchers hold is that a participant will answer the interview questions and share their stories honestly. Making sure that the participants know that their information will be kept confidential and that their identity will remain de-identified through the use of pseudonyms provides a better chance that they will respond honestly (Simon & Goes, 2018).

I ensured that the findings and interpretations were accurate throughout the data collection (Creswell & Guetterman, 2019). Using qualitative data created an opportunity and a need for me to check findings to ensure the accuracy of what was reported. I accomplished this step through member checking of the participants' restoried narratives (Creswell & Guetterman, 2019). I made the best, most effective use of the chosen research methods. I used ethical guidelines, as provided in the *Belmont Report* (National Commission for the Protection of

Human Subjects of Biomedical and Behavioral Research, 1978) throughout the study and built in checks for credibility.

### **Limitations**

Limitations are influences on findings from research that are developed from the design or the methodology and that affect the transferability of the findings (Bloomberg & Volpe, 2016). The limitations' weaknesses are potential problems that I determined. They could include a lack or loss of participants or errors in measurements and are commonly related to data collection and analysis (Creswell & Guetterman, 2019). This qualitative research was limited by subjectivity and personal bias because of the involvement that I had within the study. The awareness of potential bias and a safeguard was used to reduce bias of the research. Limitations included a small sample size from a large demographic area of sampling. It was not possible to study the family members' experiences of every nonspeaking; therefore, I used a sampling of five family members from across the United States.

### **Scope**

The parameter of the study that framed the problem was the scope (Bloomberg & Volpe, 2016). This includes what the research included as part of the study, as well as what is not included. The scope of research in this study included family members of nonspeaking autistic individuals who have used AAC programs, specifically S2C or RPM. I focused on these two methods according to my own experience. In addition, I wanted to hear the experiences of family members with these two methods regarding ASHA's (2018) perception that they are a form of facilitated communication. Facilitated Communication is a technique that involves physical support to the individual to communicate using a letterboard or keyboard (ASHA, 2018). S2C and RPM do not require touching the individual for them to communicate. Delimitations are the choices about the study that the researcher makes to narrow the scope (Bloomberg & Volpe,

2016). The delimitations in this study included (a) the research questions (RQs); (b) the family members who were of nonspeaking autistic individuals, instead of all autistic individuals; (c) family members were Age 18 or older; and (d) the study included a nationwide spread.

### **Rational and Significance**

Currently only 2% of nonspeaking autistic Americans have access to using a letterboard or keyboard as their means of communication (I-ASC, 2022). Although this number is growing, research is needed to explore the experiences of family members with nonspeaking autistic family members who use AAC systems within the areas of education, socialization, and employment opportunities. In a study of AAC systems, Palazini (2019) recommended that parents be part of the decision-making process on what type of communication system they use with their family member and how communication systems are used across multiple settings for social opportunities. Employment challenges for individuals with autism who use AAC included a high percentage of unemployment, struggles with socialization, and training (Richardson et al., 2019). Currently, 7 million people in the United States have autism; of this number, 2.3 million are nonspeaking (I-ASC, 2022).

Knowing that autism is different for each person emphasizes the need to have different interventions (NAA, n.d.). Generally, the interventions that are offered to families are very similar and they often do not include using an AAC system (NAA, n.d.). ASHA (n.d.-a) does not endorse a specific type of alternate AAC program; however, ASHA does recommend the use of motor learning principles (Maas et al., 2014). Motor learning principles are processes that support gaining and retaining motor skills, including motor performance and motor learning. They require practicing skills and receiving feedback (Maas et al., 2014). Evidence to support childhood apraxia, which is a motor speech disorder that causes difficulty in speaking is limited as is treatment research in this area. Nonspeaking autistic individuals who have not found an

effective way to communicate, potentially because of the lack of research available, might have an impact on their families (Maas et al., 2014). Often the greatest barrier for AAC are the low expectations and negative social attitudes, individuals with developmental disabilities have frequently been excluded from society (Beukelman & Light, 2020).

Oti-Boadi et al. (2020) focused on the experiences of ageing parents of young adults with autism and found five themes: psychological exhaustion, future uncertainties, planning for the future, isolation and stigmatization, and social support. Psychological exhaustion was described by mothers who both compromised their own health and eliminated most social activities by having to provide continuous care for their child into adulthood. Disruption in career was prevalent, including loss of work because of not being able to handle both the care of an individual with autism and a workload (Oti-Boadi et al., 2020). The ability to determine an individual's level of independence with nonspeaking autism might be a concern of families (Cheak-Zamora et al., 2017). The concern of future uncertainties might contribute to families' worry about how their autistic family member will care for themselves if the parents "are no longer here," and how the person will defend themselves (Oti-Boadi et al., 2020, p. 62). Although parents or caregivers express their anxiety about the future, they also want to promote independence of decisions around managing health care needs (Cheak-Zamora et al., 2017). Parents reported the hope of outliving their family member because of these concerns (Oti-Boadi et al., 2020). Most of the parents in Oti-Boadi et al.'s (2020) study also reported concerns about planning for the future and the difficulties of identifying the strengths in their family member to try to support a job for them. The financial burden of a family of an individual with autism includes medications, dietary support, and care costs. Families described needing to leave more money to the individual with autism as compared to their other children (Oti-Boadi et al., 2020).

According to Oti-Boadi et al. (2020), the support of family members of nonspeaking autistic individuals (both physically and emotionally) is a challenge. The concern of isolation and stigmatization was present, as was society's negative perceptions about individuals with autism. Parents described how they stopped attending social events because of all of the challenges and negative experiences (Oti-Boadi et al., 2020). In a systematic review and metasynthesis of qualitative evidence, Samsell et al. (2022) found that families of children with autism make many life alterations and structure their lives around the person with autism. According to Samsell et al. (2022), this includes "physical modifications to homes for safety, intentional social isolation, increased financial expenses, and homeschooling" (p. 93). Parents need to educate themselves on how to manage all areas of life. Doing so helps them to become the expert on their family member with autism (Samsell, 2022). In a phenomenological study in which Oti-Boadi et al. (2020) explored the lived experiences of parents living with their young adults with autism, families recognized the need for social support; however, the challenges that coincide with providing these opportunities brought on additional stress.

In a review and meta-analyses that was focused on gross motor impairment and its relation to social skills in autism, Wang et al. (2022) found that gross motor impairment is pervasive and is related to core social impairment for autistic individuals. Wang et al. also identified treatment recommendations for motor deficits in autistic individuals. Furthermore, Wang et al. (2022) expressed the need for more research on motor interventions for autistic individuals. For autistic individuals, having social interactions opportunities in the community is vital to communication development (Spellers and Allies Advocacy Network, 2022). When motor impairments prevent communication, they might prevent progress in all areas including academics, socialization, and employment. Currently only .002% of nonspeakers with autism are in college or have graduated (Spellers and Allies Advocacy Network, 2022). Evidence-based

practices, technology solutions, and AAC services are highly needed, for without more research, individuals with complex needs have a high risk in the area of education, employment, health, and community living (Light et al., 2019). The majority of individuals are given traditional speech therapy services and are not taught an augmentative and alternative approach to communication, which is often viewed as a last resort (Donaldson et al., 2021). My study was focused on family members of nonspeaking autistic individuals who use S2C or RPM experiences that occurred both in and out of the home. My study is important to these family members and their nonspeaking autistic individual. My study might also be significant to family members of nonspeaking autistic individuals who have not yet found a way to communicate, for it might provide another option that has not been shared with them about how to communicate. Samsell et al. (2022) discussed the experiences of family members and described them as experts in the field of autism. There is a need for interventions that integrate family and community perspectives (Samsell et al., 2022).

### **Summary**

The focus of this qualitative narrative inquiry was to explore the experiences of family members of nonspeaking autistic individuals who use AAC systems. The large number of individuals without meaningful, effective communication is a problem because of the significant emotional and financial burdens placed on families (Kaur & Bhat, 2020). In this study, I looked to family member experiences to help provide the data that would provide the stories of using S2C or RMP. This study supports the use of letter board and keyboard communication.

To explore the experiences of a specific group—family members of autistic individuals who have experienced the central phenomenon—a qualitative narrative inquiry was best suited for this research. A narrative inquiry enabled me to reveal deeper understandings of perspectives of those who might not otherwise be heard or recorded elsewhere (Deakin University, 2022). I

employed a qualitative narrative inquiry study that was focused on studying families of autistic nonspeakers who have learned to communicate, using two specific AAC systems: S2C or RPM. To gather data, I administered structured interviews through the Zoom platform. This data was then restoried into narratives that provided insight into the lives of families with nonspeaking autistic individuals who have used S2C or RPM.

The conceptual framework for this study included my interest in AAC systems. The topical research for this study was framed through how nonspeaking autistic individuals' abilities are viewed, and the theoretical framework of ELT. Neurodiversity is a recent theory and movement to reclassify conditions not as mental illness or medical conditions, but instead, to natural neurological variations, and it is used in this study to support family experiences of using alternative forms of communication. Advocates see human thinking as having many variations (Cycleback, 2020). Neurodiversity is focused on sensory processing, cultural sensitivity, using a strength approach, and finding ways for accessibility (Radulski, 2022).

A gap in awareness of neurodiversity in the educational sector might leave parents and family members desperately looking for help (Hannant, 2021). Social communication for nonspeaking autistic individuals allows one to assume that they are difficult to engage (Hills, 2020). Often family members might not take into account their autistic family member's preference when planning social events (e.g., the physical or sensory environment). Autistic peers might have differences in social interactions, but they have the same desire for friendships and relationships (Crompton et al., 2020). Many barriers might exist to employment for nonspeaking autistic individuals (Kuder, 2021). For family members, this means additional familial or external support for the individual who is unable to work (Kuder, 2021). Communication can be one of the barriers (Kuder, 2021). Many comprehensive programs help to support college, transitions to careers, and embracing family support to create successful

opportunities for those with neurodiversity (Kuder, 2021). Nonspeaking autistic individuals need support from their families to gain access to interventions (Kuder, 2021).

The AAC systems S2C and RPM both have specific processes for teaching academics, motor skills, and communication. The experiential learning that families have of learning the process of using these systems will provide valuable insight into the research. The theoretical framework that guided this study was ELT, which is described as learning through one's experiences (Irby et al., 2013). In my study, I looked at the experiential learning of families of nonspeaking autistic individuals and their experience with AAC.

In Chapter 2, I expand on the concepts of ELT and the theory of neurodiversity. The literature review also presents an in-depth report of the factors that support the concept of teaching nonspeaking or unreliably speaking individuals' purposeful movement to improve motor skills that will allow them to communicate. I looked at the history of AAC and the practices that are used widely today as well as their limitations. These limitations include traditional interventions, ABA, assessments from nonspeakers, the association of social and motor skills, least dangerous assumption, presuming competence, the brain and body disconnect, and beyond behavior. I also included what life is like living with someone with autism. The purpose of this qualitative narrative inquiry was to explore the experiences of family members of nonspeaking autistic individuals who use AAC systems.



## CHAPTER 2: LITERATURE REVIEW

Losing the ability to speak or to control one's body enough to communicate wants, needs, or other thoughts affects millions of autistic people in the United States (NAA, n.d.). Half of these individuals might also be labeled intellectually disabled (NAA, n.d.). The test on which the medical experts base a diagnosis for a nonspeaking person with a motor deficit is used to look at observable behaviors (U.S. Centers for Disease Control and Prevention, 2023). This means that medical experts do not have an accurate measure for what the person is thinking, but only what they see happening on the outside of the person (Stout, 2017). The use of this diagnosis leads autistic people to be often taught lower level materials because they are not able to express the knowledge that they might actually be holding within (Stout, 2017).

The purpose of this qualitative narrative inquiry was to explore the experiences of family members of nonspeaking autistic individuals who use AAC systems. A growing movement of self-advocates, parents, and professionals claim that individuals are cognitively aware, stuck locked inside their body, without a voice, and that motor issues might prohibit them from showing what they, as nonspeaking autistic individuals, know (Tougaw, 2020). The researcher focused the narrative inquiry on the stories related to two methods of communication: S2C and RPM. S2C teaches individuals with motor challenges the purposeful motor skills necessary to point to letters to spell as an alternative means of communication (Vosseller, 2017). RPM is a method of communication that empowers a student with the means to express their learning, understanding, reasoning, and thoughts (Mukhopadhyay, n.d). Jaswal et al. (2020) suggested that 30% of autistic children and adults have limited ability to communicate and that most never find a way to have adequate communication. Not having a way to communicate limits all aspects of life for both the nonspeaking autistic individual and the family members, severely limiting educational, social, and employment opportunities (Jaswal et al., 2020).

In the literature review, I explore the brain and body connections, including the use of AAC systems that teach nonspeaking autistic individuals the purposeful motor skills necessary to point to letters to spell as an alternative means of communication. I used the literature review to examine research that shows how interventions might have failed and could potentially harm the nonspeaking autistic individuals who were being taught the same low academic level of information year after year and sometimes for decades. A divide exists in the current research, and the autism community highlights the difficulties that families face when they struggle to find a way for their family member to communicate. The heart of the problem is that no one really understands completely what autism is and experts certainly do not agree on what is the correct plan to support individuals (Singer, 2017). According to Singer (2017), even in an imperfect world, each family deserves the right to make choices according to an assessment of their own prospects.

Dysregulation of one's body can give an appearance of someone who is out of control and unable to learn (Assimakopoulos, 2018). The truth is that the person locked in a dysregulated body, yet wants to learn, wants to communicate, and wants a better life, but they are stuck by apraxia or praxis (Peña, 2019a). Apraxia is a medical diagnosis that indicates that the person has challenges with fine and gross motor planning needed to perform tasks or execute purposeful movements (Peña, 2019a). Praxis refers to imitation, and gesture production both representational or nonrepresentational, and can be with or without the use of tools (Kilroy et al., 2022). Individuals' bodies will not do what their brains are telling them to (Peña, 2019a). A nonspeaking autistic individual is a person who has autism and is unable to speak. Autism is a developmental disability that is characterized by difficulties with communication and socialization. Autistic individuals might have problems with sensory processing, motor planning, and repetitive behaviors (Peña, 2019a).

The cognitive section of a nonspeaker's brain is intact; however, the motor strip (motor cortex) and sensory system needs support (Vosseller, 2017). The motor cortex is the part of the brain that is located in the left hemisphere and from which movements are elicited. It is the only control center that can communicate with the motor control structures (Sahni et al., 2020). Sensory processing is how the world is interpreted through senses and, by learning about how to support the senses of nonspeaking autistic individuals, one can help them to navigate the world. At this time, of 2.3 million nonspeakers in the United States, only 5,000 of them have access using a letterboard or keyboard (Howe, 2022).

I focused the literature review on the broad category of communication through intentional motor planning and used it to explore the following parameters. In Research Theme 1, I used it to explore how the brain works in the areas of sensory, motor, and language. In this exploration, I included detailed information about apraxia, the brain, and the body disconnect that people with autism experience. Apraxia is a neurological condition that affects the brain and body connections (ASHA, 2015). In a 3-year study, Tierney et al. (2015) showed that two thirds of people with autism also have apraxia and that the checklist for autism spectrum disorders (ASD) does not overdiagnose autism in children with apraxia (ASHA, 2015). Looking at speech versus language (language in the brain), one must examine two separate areas of the brain: Wernicke's area that controls receptive language and one's understanding of language and Broca's area which controls expressive language and the way that one turns language into words (Vosseller, 2022). Language is 100% cognitive and exists in a different area of the brain than the motor system (Vosseller, 2022). People use the motor system for all forms of communication (Vosseller, 2022).

In Research Theme 2, I also present research in presuming competence and the theory of using the least dangerous assumption when working with a person who is nonspeaking.

Presuming competence is the belief that every individual, when given the appropriate supports, is capable of learning (Peña, 2019a). One must believe, even when an individual cannot speak, that they can think, process, and know what is going on in the world around them (Peña, 2019a).

How do assumptions limit a person's opportunities? Thinking that someone cannot communicate because of their behavior, a disability label, a test score, or a missing skill could be limiting their opportunity to succeed (Berg & Williams, 2021). Professionals and experts in the field consider that most nonspeaking autistic individuals are low functioning when most individuals with autism are uniquely intelligent (Bonker & Breen, 2011). For example, Dillon, who was considered cognitively low-functioning and whom school professionals diagnosed with autism, was given a typing device, he typed, "Get me out of special ed. I'm not retarded" (Bonker & Breen, 2011). By looking beyond behaviors, one might look at an individual's abilities not disabilities. Individuals with autism will not make progress when adults do not believe in their abilities and believe that their heads are empty and their minds are broken (Peña, 2019b).

In Research Theme 3, I looked at how nonspeaking autistic individuals are assessed to determine intelligence. This examination was important because the assessments are used not only for diagnosis, but also for recommended interventions that can potentially limit the individual's progress by keeping them at a lower level of skill or assuming that they are not intelligent because of their ability to communicate. The American Psychiatric Association's (2013) *Diagnostic and Statistical Manual (DSM-5)* provided the standard by which autism is currently diagnosed. To meet diagnostic criteria for autism spectrum disorder, according to *DSM-5* (American Psychiatric Association, 2013), a child must have persistent deficits in each of three areas of social communication and interaction and at least two of four types of restricted, repetitive behaviors. The separation of language and motor might show two skillsets and might explain why traditional assessments of nonspeakers do not show what an individual truly knows;

however, more research is needed to determine the connections between motor and language (Ramos-Sánchez et al., 2022).

Assessments, including the *DSM-5* with which individuals with autism are diagnosed, test language through motor abilities (initiations, conversations, gestures, facial expressions, sensory reactions, repetitive movements; Rice et al., 2022). Communication comes from two different areas of the brain working together, so they should be assessed separately. Broca's area coordinates the motor area of speech and Wernicke's area supports language comprehension (Turken & Dronkers, 2011). For example, to diagnose a person with apraxia, a speech language pathologist (SLP) would examine a child's mouth, tongue, sounds, and syllables that they are able to produce (ASHA, n.d.-c). Intelligence assessments look at the language produced to determine intelligence. Studies have suggested that early intelligence quotient (IQ) is the best predictor of adult independence; however, the extent of actual scores related to scores at older ages is not understood (Bishop et al., 2015). Zurcher-Long (2017), a nonspeaking autistic person, cautioned specialists about measuring intellectual ability by the symptoms of autism itself. In a research survey, Zurcher-Long showcased the importance of AAC for those who cannot produce spoken language. "Just because we cannot speak, does not mean we cannot think" (Zurcher-Long, 2017). In addition, the lack of consensus widespread regarding how to measure an adult's intelligence because of the unreliability of assessments (Bishop et al., 2015).

### **Conceptual and Theoretical Framework**

Ravitch and Riggan (2017) suggested that the conceptual framework is a support with which to argue regarding why the research is important and why the theoretical framework is important. The conceptual framework is a logical sequence of supports that helps the reader to understand the need for this research (Ravitch & Riggan, 2017). The components of a conceptual framework can be used to argue the significance of the topic, to guide the development of

research questions, to support what I hoped to learn from the study, and to show how research could influence the topic area. The conceptual framework also describes my relationship to the research, and the theories that informed the analysis (Ravitch & Carl, 2021).

### **Personal Interest**

At Age 2, after losing all his ability to speak, my son was diagnosed with autism. From that day on our family's lives were devoted to research, advocacy, and trying to help him learn to communicate. Year after year we tried countless interventions, spent an incredible amount of time and money searching for hope, and felt completely defeated. Our family experience was not unlike those of families all over the world. Some individuals find an intervention that works, and some do not. Most parents keep searching for the magical key that works to unlock the world to meeting their child. In addition to being a parent of a child with autism, I was also a special education teacher, a National-Board-certified exceptional needs specialist, a school principal, a director of instruction, and I am currently an assistant superintendent. Not only did I understand and advocate through the lens of a parent, but I did so also as an educator.

In March 2021, I read, *Underestimated: An Autism Miracle* (Handley & Handley, 2021). Little did I know how that book would lead our family on our final quest for finding our son's ability to speak. After reading Handley & Handley's (2021) book (crying the entire time), I felt that it was written about our son, for the family's journey had so many connections to our own, and I was filled with a new (still slightly skeptical) hope! We were put on a wait list for an appointment to see the SLP who had worked with Handley's son in Virginia. We were able to gain access to a 4-day, online training in learning to use RPM, a new way of teaching and a pathway to communication, reliable motor skills, and sensory tolerance. We completed the training with people from all over the world. This taught us a different way of teaching our son. Through daily work, he progressed quickly academically and in July of 2021, I drove with my

son from Maine to Virginia for four appointments with an SLP, to learn how to teach S2C (Vosseller, 2022).

We are now a year and a half in with using this method and it has worked! He is writing songs, doing algebra, and knows the periodic table. I have learned that my son is funny, filled with kindness, empathy, and love and that he can now tell us all he had not been able to say for 17 years. As a family, our experience with AAC programs has completely changed our lives and the way we interact with our son.

### **Topical Research**

This study is founded on the following themes that were developed through the review of the literature: (a) the brain and how it affects language/communication for nonspeakers with autism; (b) assessments that are used to determine interventions for nonspeakers with autism; and (c) presuming competence which is believing, even when a child cannot speak, that they can think, process, and know what is going on in the world around them (Peña, 2019a). How do assumptions limit a person's opportunities? In thinking about what someone can and cannot do because of their behavior, a disability label, a test score, or a missing skill, assumptions could be limiting their opportunity to succeed (Berg & Williams, 2021). Finally, in the study, I looked at how life changes for nonspeaking autistics who learn to communicate through the stories that their family members share. All of these factors relate to the movement of neurodiversity by offering families a different way of looking at their child through the lens of the people who have had unique experiences using AAC systems.

The theory and movement of neurodiversity provides support for this study (Singer, 2017). Neurodiversity is a recent theory and movement to reclassify conditions not as mental illness or medical conditions, but as natural neurological variations (Cycleback, 2020). Advocates of neurodiversity see human thinking as having many variations (Cycleback, 2020;

Price, 2022; Silverman, 2016). Neurodiversity views brain differences as normal rather than as deficits (Simmons et al., 2021). Neurodiversity is focused on a person's strengths rather than on their weaknesses (Simmons et al., 2021). Singer (1997) developed the concept, rejecting the idea that people with autism have a disability; Singer believed that their brains just worked differently. By changing how autism is viewed, the person's experience and how they feel about life might change. This change would include how to talk and listen to a person with autism and trying to understand their behavior rather than to change it (Delahooke, 2020). Neurodiversity is focused on three main points (Radulski, 2022). Radlusk (2022) described Point 1 as sensory processing. Neurodiverse people vary in how they process sensory information. For some people, lights might seem brighter, and sounds seem louder, but other people might experience the opposite effects. Point 2 is cultural sensitivity, which is really shifting perspectives on stigmas about people and moving beyond awareness to acceptance. Point 3 is using a strength-based approach and finding ways for accessibility (Radulski, 2022).

Neurodiversity informed the research in this study by offering a different perspective to understanding how families interact with their nonspeaking autistic family members. Often, what family members see happening with external behaviors are viewed as negative and as needing to change. Looking for the function of a behavior might give clarity to a sensory need that a person seeks to support (Delahooke, 2020). Neurodiversity (a) provides a different reason for external behaviors, (b) is focused on what the person is thinking, and (c) appreciates and values differences instead of judging the person. From the outside world, people with autism are viewed as having a lack of empathy, not having a sense of mind, having little or no ability to form friendships, and as being odd (Singer, 2017). In a biography of Temple Grandin, an autistic scientist, Wood (2016) explained autism as a deficit in the systems that causes a person to overreact to some incoming sensory information and underreact to others. Grandin (as cited in



Wood, 2016) described autism as a family disorder. Meaning the whole family is affected. Parents might feel shock, depression, anger, and sadness and other family members might experience this as well (Wood, 2016). For families, what is known today is very different from a year ago or 10 years ago (Wood, 2016).

Often family members might not take into account their autistic family member's preference when planning social events (e.g., the physical or sensory environment). Autistic peers might have differences in social interactions, although they might have the same desire for friendships and relationships (Crompton et al., 2020). Difficulties in interactions of verbal and nonverbal communication styles might require a high amount of energy and effort for nonspeaking families. Having relationships and being socially connected, for both the autistic individual and the family members, plays a role in both physical and psychological health (Crompton et al., 2020). Sometimes, unintentionally, family or friends might make offensive statements. Many neurodivergent people are lonely and isolated and will be friends with anyone, regardless of how they are treated (Cook & Purkis, 2022). Families might often have difficult relationships and some families might have a deficit approach that is focused on a person's impairments and functional deficits when trying to help their family member with autism (Pellicano & den Houting, 2022). When viewing autism through a deficit approach, the traditional medical model and interventions have a goal of altering impairments to remediate or eliminate them to enhance functioning. This approach assumes a normative standard and that anything else is unfavorable (Pellicano & den Houting, 2022). Some approaches to teaching individuals with autism seek to cure conditions and this can be very harmful (Cook & Purkis, 2022). ABA, which is focused on eliminating behaviors, might cause strain and increase depressive symptoms in families (Cook & Purkis, 2022). Most parents do not realize that ABA interventions could be harmful, for the individual is unable to communicate with them (Cook &

Purkis, 2022). Handley & Handley (2021) said that ABA is cruel and treats individuals as though they were stupid because it does not presume competence.

In the field of academia, neurodiversity might help to rethink autism and the way that people on the autism spectrum have been stigmatized with a label that focuses on barriers. The neurodiversity movement celebrates autism and the differences in people's brains (Kuder, 2021). This approach is different than the medical model of a disability that is focused on fixing the individual (Kuder, 2021). The number of students who are neurodivergent and enter college is increasing (Kuder, 2021). According to their own experiences, each family might seek a different level of support during this time. Families might experience many stressors during a college transition; therefore, it is important to have a parent partnership (Kuder, 2021). Traditional school settings can be loud and physically large and might leave autistic people in distress. This might be a barrier to the school setting; therefore, by looking through a neurodiverse lens and including autistics in the conversation, access to academics for autistics could be improved (Pellicano & den Houting, 2022). A gap in awareness of neurodiversity exists in the educational sector, which might leave parents desperately looking for help (Hannant, 2021).

Neurodiversity Rising: Eliminating Bias in Hiring, an online conference, sought to explain the importance of inclusion at work and it showcase neurodiverse hiring practices (SpArk Philadelphia, 2020). Exploring neurodiversity might contribute to supporting educational development and has the potential to support a variety of fields. The Frist Center for Autism and Innovation at Vanderbilt University (2018) has a goal of enhancing the 21st-century workforce by engaging autistic talent. This organization embraces the intellectual and neurological diversity that each person, including nonspeaking autistic individuals, brings (Vanderbilt University, 2018). There can be many barriers to employment for individuals with autism, and communication might be one of the barriers. Many examples of comprehensive programs help to

support college transitions to careers and to embrace family support to create successful opportunities for people with neurodiversity (Kuder, 2021).

### **Theoretical Framework**

The theoretical framework that guided this study was ELT. Kolb (2015) described ELT as “experience [that] is transformed into learning and reliable knowledge” (p. 21). According to Kolb, there are four modes or stages of the experiential learning cycle: concrete experience, reflective observation, abstract conceptualization, and active experimentation.

Kolb’s (2017, as cited in Kurt, 2022) learning cycle begins with concrete experience; this experience in which the learner engages can be new or reimagined. Families’ experiences with communication systems might vary. Families require training that involves the use of the system with the person learning to use AAC (Beukelman & Light, 2020). Just as dance requires two people to move together, communication requires a two-way exchange (Beukelman & Light, 2020).

Reflective observation happens when the learner reflects on an experience (Kurt, 2022). An important piece in this part of the learning cycle is communication (Kurt, 2022). When a family member learns to use an AAC system, they often become a communication partner and daily facilitator of AAC. This requires a collaboration between the individual and the person assisting with the communication process (Beukelman & Light, 2020). For families to learn, they might first observe a trained professional using the AAC with their family member. To be successful, reflection on practice and making adjustments is necessary. Working with a trained professional and using observations and feedback can help families of nonspeaking individuals to address barriers (Beukelman & Light, 2020).

Abstract conceptualization involves making sense of the experience (Kurt, 2022). This might include using prior knowledge and forming conclusions (Kurt, 2022). Families might have

much experience to build on, depending on their opportunities with communication options. Depending on a person's experiences and beliefs about AAC, this experience might help to shape their conclusions about the system (Beukelman & Light, 2020). When a family experiences a successful communication opportunity, it might help them to be motivated to continue with the practice and to gain the knowledge and skills necessary to accommodate their family member with communicating successfully (Beukelman & Light, 2020).

Active experimentation refers to the testing stage of the cycle (Kurt, 2022). The learner returns to the task, applying conceptions that they now formed to their experience. The learner is now able to make predictions, analyze, and plan (Kurt, 2022). By practicing, this helps them to retain the information that they learned (Kurt, 2022). For families using AAC, practice is a must. Two types of practice might assist families with successful AAC use: relational and participatory practice (Beukelman & Light, 2020). Relational practices involve active listening, compassion, empathy, respect, and having a good attitude. Participatory practices involve decision making and using family strengths and capabilities of being involved (Beukelman & Light, 2020).

Once family members learn to use AAC with their nonspeaking autistic family member, that step is only the beginning. AAC involves daily support, practice, and refining of skills (Ogletree, 2020). The time and commitment involved in learning an AAC system can be a frustration for families. Being focused on solutions can help them with continued success. Families can identify and prioritize challenges, collaborate, problem solve, apply, and repeat (Ogletree, 2020).

ELT allows insights into student learning, enables students to become self-directed, and promotes learner engagement through learning by doing (Zijdemans-Boudreau et al., 2013). Family members have been learners throughout the process of finding, learning, and using AAC systems, and my study provided the opportunities for family members to share their stories. ELT

has helped with transitioning individuals with the support of their family between the classroom and society (Zijdemans-Boudreau et al., 2013). For families, learning to use S2C or RPM takes a great deal of practice, consistency, reflection, and collaboration, which are parts of ELT.

Training for family members and supporting interactions with peers throughout the families learning should be a focus throughout their acquisition of skills to use the AAC system (Donaldson et al., 2021).

ELT will also support them when listening to the family members share their stories. Family member perspectives informed this study by exploring any collaboration, engagement, and knowledge of AAC, as they described their experiences. Family members of individuals with nonspeaking autism had the opportunity to describe their family life interactions (i.e., social, academic, employment) inside and outside the home since their nonspeaking autistic individual began using AAC and describe the knowledge that they have gained through their experience. The experiences that these family members shared are drawn from their collaborative learning experiences using S2C or RPM.

Family members shared their experiences, both inside and outside of the home, in relation to the social life of their family member. This included new social opportunities and how the individual was able to communicate with them or others. AAC can provide the opportunity to develop strong and rewarding relationships. Communication allows participation and involvement, and affects family relationships (Beukelman & Light, 2020). The academic experiences that families might have had provided the knowledge of their engagement and changes that might have occurred after learning to use AAC. The families shared knowledge about their family member's school experience, learning after high school, and college. The transformation of academics has been affected by using AAC programs. Using AAC across the lifespan has been found to be effective for individuals with autism (Beukelman & Light, 2020).

Lastly, families shared their experiences of using AAC to assist their family member with employment. The experience of using AAC in the workplace provides valuable knowledge that families can share. Some families have described the employment of a family member with autism as providing them a break. Others have described being proud of their family member's employment, for they felt that they had instilled a work ethic in their child (Richardson et al., 2019).

### **How the Brain Works for Nonspeaking Autistic Individuals**

Ashburn (2022) stated, "Speech is a motor skill" "Language is not." People who have motor differences might not have cognitive impairments so significant that it would preclude them from understanding and communicating language (Ashburn, 2022). One should concentrate on developing motor skills to help communicators spell out their thoughts (Ashburn, 2022). The goal for all nonspeakers is to help them as the communicator to develop the most independence and autonomy possible (Ashburn, 2022).

### **Autism**

Autism is a developmental disability that is characterized by difficulties with communication and socialization (Peña, 2019a). Autistic individuals might have problems with sensory processing, motor planning, and repetitive behaviors (Peña, 2019a). The term "nonspeaking autistic" refers to an individual with autism with the absence of speech. This term evolved from nonverbal, which infers a deficit in receptive and expressive language (Peña, 2019a). Puleo (2022), a nonspeaking autistic speller, stated, "Autism is a mind/body disconnect" (p. 11). Puleo explained that controlling his body is the hardest thing for him to do. Puleo (2022) shared that his mind understands everything, but it is difficult when people think he is not intelligent because of his body actions. Puleo's (2022) advice for parents of individuals with

autism is to forget everything that they have heard and read about autism, to invest all efforts and interventions in their child's motor function and believe that they can succeed.

### ***Brain–Body Disconnect***

A brain's home is inside of a human body. The body is the tool people use to move around the world (Kearney & Lanius, 2022). Bundles of nerve fibers connect the body to the brain and allow many different functions to occur, including emotion, cognition, actions, and sensations. When sensory input is received, it connects with the emotional and cognitive information and creates a response. Pathways might be altered and can affect cognition, social capacities, and one's sense of self (Kearney & Lanius, 2022). People have two sensory systems, vestibular and somatosensory. The vestibular system never sleeps and affects physical and social movements (Kearney & Lanius, 2022). The somatosensory system includes skin, muscles, and joints. They detect pain, temperature, and proprioceptive input and touch (Kearney & Lanius, 2022). An optimal level of muscle tonicity is required for motor actions and responses to occur. The body prepares to fight or flee when triggered by high stress or fear (Kearney & Lanius, 2022). Many individuals with autism have sensory difficulties (Weiner & Greiner, 2020). Light, sound, movement, and touch can all have an impact on the behaviors of an individual with autism. Knowing an individual and structuring the environment to support their needs can help aid in their success (Weiner & Greiner, 2020). Typically, a person filters out irrelevant sensory information and focuses on what is relevant, this helps them to maintain calm, alert presence (Middletown Centre for Autism, 2020). At least 85% of individuals with autism differ in how they perceive and respond to information that is coming through their senses (Middletown Centre for Autism, 2020). Individuals might have hypersensory or hyposensory responses to input. Hypersensory responses mean they receive a greater intensity and might have behaviors of anxiety, distractibility, aggression, escape, or shutdown senses (Middletown Centre for Autism,

2020). Hyposensory responses mean that the individual underreacts to sensory input, which might lead to two behavioral responses: (a) sensory seeking (which might look like hyperactivity, impulsive, fidgeting, or making noises), (b) low registration (where there are no responses and the person is disengaged) or lethargic (Middletown Centre for Autism, 2020). Strategies to help control the sensory environment can help support an individual in self-regulation (Middletown Centre for Autism, 2020).

Williams (n.d.), an SLP, described a term for the phenomenon—“What you see is not what you get”—which is described by many people with autism as a brain–body disconnect. This combination of a sensory system that is disorganized and having difficulty with motor planning make intentional movements difficult for individuals to achieve. Williams described behaviors of autistic individuals as trying to regulate their sensory systems.

How does one know what someone else is thinking, especially if that person is unable to tell anyone what they are thinking. Even then, how does one prove what they are thinking? Naoki Higashida (Higashida et al., 2016), an autistic 13-year-old boy in Japan, described what was in his mind and why he behaved as he did. His behaviors made others think he did not understand what they were saying, but when he was finally able to communicate, he shared his beautiful mind and supported so many others who are going through the same challenges (Krauss, 2020). People need to change the conversation around autism (Krauss, 2020).

Thirteen-year-old Higashida (Higashida et al., 2016) wrote about many of his outward actions and what they meant. One of the questions he asked was, “Do you prefer to be on your own?” He talked about how many autistics leave the room or revert to a comfortable area and their families assume they want to be on their own. Higashida (Higashida et al., 2016) shared that this was the furthest from the truth and that they go to be by themselves because things always go wrong.



## ***Behavior***

A new perspective on behavior can be helpful regarding how challenges of disruptive behavior are handled (Delahooke, 2020). Delahooke (2020) used 30 years of experience and research to offer a new option to handling discipline for challenging behaviors. Delahooke recommended that, instead of trying to change the child's behavior, one should build a relationship with school-aged, nonspeaking autistic individuals and meet them where they are. For autistic individuals, it is essential to understand their sensory responses when deciding how to support them. Once shared with families, they can use the ideas presented and include checklists to determine what might be happening for the person and what might be a trigger for them (Delahooke, 2020). A paradigm shift exists from simply classifying legitimate, functional behavior to looking at it as a range of strategies to cope, communicate, and deal with an overwhelming and frightening world, which gives families a new way to look at autism (Prizant & Fields-Meyer, 2016). By looking at the motivation behind behavior, one can look at ways to help the person. It is not helpful to dismiss behaviors (Prizant & Fields-Meyer, 2016).

Autism should not be defined as behaviors that are dysfunctional (Bervoets & Hens, 2020). The proponents of one movement suggest that the strict identification in the *DSM-5* diagnosis should be abandoned (Bervoets & Hens, 2020). The *DSM-5* is the tool that psychologists use currently to diagnose autism. This change would require a new way to diagnose autism (Bervoets & Hens, 2020). Looking at human behaviors as neurological differences rather than as behaviors that are dysfunctional could liberate autistics from the psychiatric stigma (Bervoets & Hens, 2020). It is important to have openness and understanding of lived experiences of autistics to uncover motivations of behaviors (Bervoets & Hens, 2020). Inspiration can be found in the autism community that embraces a neurodiverse approach (Bervoets & Hens, 2020). When looking at behaviors that appear on the outside of one's body,

sometimes apraxia or praxis might be the cause (Ellawadi, 2021). According to Case-Smith (2021), the terms of motor planning and praxis are sometimes used interchangeably. Impairments in motor planning have effects on daily functioning, including social and communication (Ellawadi, 2021). Some people with apraxia might appear to have a general awkwardness or clumsiness in addition to impaired vocalization (Powers, 2021). Praxis can result in awkward motor execution, and difficulty sequencing abilities (Powers, 2021).

### *Apraxia and Praxis*

Apraxia is a motor speech disorder that makes it difficult to speak (ASHA, n.d.-a). One can think of apraxia as the brain telling a person's body to do something, but their body cannot do it. Praxis is the neurological process by which cognition directs motor action (Ayres, 1985). It is the ability to execute chains of smooth motor movements (Hussman, 2015). Apraxia refers to the inability to conduct praxis movements in the absence of elementary motor, sensory, or coordination deficits that could serve as the primary cause (ASHA, 2015). In a 3-year study, ASHA (2015) showed that two thirds of children who were initially diagnosed with autism also had apraxia and found that the Checklist for Autism Spectrum Disorders (CASD) does not overdiagnose autism in children with apraxia.

In a study on the performance of motor control and different regions of the body, Lombardo (2017) discovered a group of autistic individuals who had lower motor performance with an atypical rightward shift and a left hemisphere association of motor ability. These findings suggested that direct interaction between an individual's motor skills and learning might contribute to the ability to interact precisely with and manipulate the environment (Lombardo, 2017). For autistic individuals, this discovery means that controlling their bodies to perform accurately might be a challenge. Apraxia is a neurological motor impairment that might affect voluntary movements, causing paralysis or slowness in reactions (Ellawadi, 2021). Apraxia can

impair movements of one's body, including arms, legs, and speech (Ellawadi, 2021). Some approaches to teaching individuals the skills to speak are focused on sounds and sentences, other approaches look at linguistic and motor programming. For people with significant intelligibility or for people who cannot produce any sounds the focus might be on the use of AAC (Ellawadi, 2021).

### **Nonspeaking Autistic Individuals**

Nonspeaking autism refers to individuals with complex communication challenges (Delahooke, 2020). Individuals can be completely unable to speak, minimally be able to speak, or be an unreliable speaker that says things that they do not intend to say or that they do not mean what they say. Nonspeaking individuals often have a motor sensory difference that makes speech and physical movements an obstacle (Thornton, 2020). Nonverbal is the term used most frequently, but it is both inaccurate and insensitive (Delahooke, 2020). Each person with autism is unique and respecting their individual differences is essential (Delahooke, 2020). Sensory overresponsivity has been studied and found to affect 56%–70% of people with autism. This can interfere with behaviors and sleep and can cause gastrointestinal issues and anxiety (Delahooke, 2020).

### **Assessments for Nonspeaking Autistic Individuals**

Medical assessments are often common, for pediatricians see children in their earliest stages most often and can look for developmental milestones that might be delayed (Ellis, 2018). A common screening tool for autism is the Checklist for Autism in Toddlers; the Childhood Autism Rating Scale is determined by the core symptoms of autism (Ellis, 2018). Genetic testing might also be done, but it is not clear how helpful this would be for interventions (Ellis, 2018).

School-aged, nonspeaking autistic individuals are assessed on their academic, motor, and speech abilities using a number of assessments (Christopher & Lord, 2022). In schools, it is

common to assess students from multiple angles; for example, a student with a complex profile might have an occupational therapist, an SLP, a physical therapist, a psychological teacher observation, and a classroom observation that would be reviewed at a team meeting. According to Christopher and Lord (2022), having multiple data points from different informants is helpful to support students with autism. Best practices in assessments include a detailed developmental history and observation (Christopher & Lord, 2022). Current findings highlight the importance of taking an individualized approach to identifying and characterizing motor ability in children rather than basing the analysis on diagnostic status alone (Surgent et al., 2020).

Clinical assessments can include individual case studies that create a description of a profile of a school-aged, nonspeaking autistic individual (Vidal et al., 2020). This can include a communication profile, a sensory motor profile, and a student's social interaction profile. For a nonspeaking student, this testing often includes an augmentative communication evaluation (Vidal et al., 2020). Decisions for supporting autistic students include the need to consider sensory–motor influences on social interaction and to support the flexible use of alternate communication (Vidal et al., 2020). When looking into what a student who cannot speak knows, this testing can become very complex, and the results can be overwhelming for parents and the professionals. The United States has federal regulations regarding special education and each state has its own laws governing how the decisions should be made and what services are required (Individuals with Disabilities Education Act [IDEA], 2004). The federal law for special education is the IDEA (2004), it includes 13 disabilities that qualify for special education; state laws are used to decide who qualifies for each disability category. The federal law includes a free, appropriate, public education and least restrictive environment; states decide on what instruction or services are provided (IDEA, 2004). The federal law provides procedural safeguards that states must follow. The IDEA (2004) required services to students until Age 21,

states can choose to limit or extend the end age to Age 18 and older. Finally, schools must start transition planning for after high school at Age 16; however, some states have decided to start transition planning at Age 14 (The Understood Team, n.d.).

### **Motor-Based Assessments for Nonspeaking Autistic Individuals**

The Test of Gross Motor Development-Third Edition (TGMD-3) is a standard referenced test that is used to assess gross motor deficits in children. Allen et al. (2017) demonstrated that the TGMD-3 visual support protocol is valid and reliable for measuring the motor performance of children with ASD. Children with ASD were found to have reduced motor performance compared to typically developing peers, the inclusion of visual supports was established as an effective means of improving their TGMD-3 performance scores (Allen et al., 2017).

### **Cognitive Assessments for Nonspeaking Autistic Individuals**

In cases in which people cannot speak or reliably communicate, it can be difficult to assess whether an individual is able to understand spoken language (Petit et al., 2020). In a noninvasive neural test of language comprehension for nonspeakers, Petit et al. (2020) attempted to discriminate brain signals in nonspeaking individuals. Petit et al. tested the sensitivity of two auditory paradigms, focusing on neural responses and seeking to validate electroencephalography systems. Petit et al. also assessed whether multivariate decoding methods could improve sensitivity. Their findings were variability in neural responses, suggesting variation in either the cognitive response to lexical–semantic violations or the neural substrate of that response. Language is a crucial part of everyday life and is often taken for granted (Petit et al., 2020).

According to Giofrè et al. (2019), research on the implications of the assessments used to assess children on the autism spectrum is insufficient. Giofrè et al. studied 50 autistic individuals Ages 6–16 who participated in assessments that included the Wechsler Intelligence Scale for

Children-Fourth Edition (WISC-IV), and Leiter International Performance Scale-Third Edition (Leiter-3). The WISC-IV has four main categories: verbal comprehension, perceptual reasoning, working memory, and processing speed (Giofrè et al., 2019). It also has a full-scale number. This test requires the ability to respond to a question (Giofrè et al., 2019) The Leiter-3 has four categories: figure ground, form completion, classifications and analogies, and sequential order. Giofrè et al. (2019) looked at the nonverbal section of the test that includes working memory, forward and backward nonverbal memory, and nonverbal processing speed. The study confirmed that the two tests that were highly related could produce different intelligence performance scores. Giofrè et al. found discrepancies between verbal and nonverbal scores, including higher nonverbal scores on the Leiter-3 that were two full scale higher than WISC-IV such that evaluators might underestimate the real potential of children. This finding is important to note, for the interventions and programs planned for the individual might be determined by these scores. Giofrè et al. advised practitioners who work in this area to be cautious when evaluating the participants. Families of nonspeaking autistic individuals are looking to the professionals at school for support for their child. When discrepancies in assessments arise, they open the door to questioning whether the evaluators are accurately determining what the person knows and is able to do. This problem risks that individuals might be underestimated, and that underestimation might affect what is recommended for them as communication tools (Peña, 2019a).

Camodeca (2019) reported a need for research on the psychometric properties that are used in diagnosing autism. Camodeca looked at the criterion of the Autism Spectrum Rating Scales, which was developed under the *DSM-IV* and updated for the *DSM-5*, which is known as a “gold-standard” measure. Clinicians have limited diagnostic utility for children with complex psychiatric presentations. Camodeca stated that the Criterion Validity of the Autism Spectrum

Rating Scales could be used to obtain information (e.g., the identification of strengths and weaknesses) and that further research should be conducted.

### **Challenges of Nonspeaking Autistic Individuals**

Between 50%–80% of autistic individuals have some type of movement problem (e.g., clumsiness, balance, or unusual gait; Zeliadt, 2019). This problem, combined with deficits in communication and motor skills, might create problems engaging in relationships (Cheung et al., 2022). Motor deficits can lead to difficulty imitating nonverbal cues (Cheung et al., 2022). Motor skill development can be embedded into physical activities (Cheung et al., 2022). Individuals often struggle to generalize skills that they have learned (Cheung et al., 2022). Autism might also include many neurological challenges, including anxiety, sensory issues, and language processing (Prizant & Fields-Meyer, 2016). Professionals might discourage children in their earliest forms of communication by being told to be quiet or stop certain types of talking; this correction might shut down the individual's attempts to communicate (Prizant & Fields-Meyer, 2016). Parents and educators should listen, observe, and ask why a child is communicating in a certain way (Prizant & Fields-Meyer, 2016).

Before he could communicate, Niko Boskovic shared in his autobiography that he had to do whatever others wanted and had no say in how he spent his free time. Before he could communicate using a letterboard, he was treated as unintelligent (Peña, 2019b).

Adam Morgan shared how, in middle school, teachers treated him like a baby and had low expectations of him. He hated school, until he learned how to type on an iPad. Before he learned to type, he experienced a great deal of loneliness (Peña, 2019b). A challenge faced by those who are nonspeaking might include getting people to believe they have more inside than what they are able to show that they know (Delahooke, 2020). It is a challenge to make an effort to understand behaviors before trying to eliminate them (Delahooke, 2020).

Emma Budway shared in her autobiography how, her whole life, she was excluded. She was loud and unregulated, which caused people to stare and think she was unintelligent (Peña, 2019b). During her teenage years, Emma learned to use a letterboard and began to advocate for basic human rights (Peña, 2019b). Learning to use a letterboard to communicate has assisted Emma in reaching her goal of moving out of her parents' house to live with her friends in an apartment (Peña, 2019b).

### **Supporting Nonspeaking Autistic Individuals**

Berg (2020), a practitioner with a degree in communication sciences and disorders, promoted not having to assume that someone knows everything to presume competence; it is really about presuming that individuals can and want to learn. Berg (2020) shared 10 ways to presume competence:

1. assume all individuals are aware, and able to understand,
2. talk normally in an age-appropriate way,
3. include nonspeaking people in the conversation,
4. allow time and space for nonspeakers to participate in group conversations,
5. present age-appropriate content,
6. practice communication often,
7. teach and use robust vocabulary,
8. avoid interpreting what your speller is communicating,
9. presume competence in the body of the individual, and
10. support opportunities for spellers to develop friendships.

When nonspeaking individuals struggle in certain areas, it may be difficult to assess what they know. Clear evidence of one's capabilities can be tricky when you are trying to assess someone who is unable to communicate. Professionals must make decisions without



unambiguous evidence. They should determine the least dangerous consequences to the student if that assumption was to be proven wrong. Do not assume that all students understand that all students are capable of learning. To do the opposite could prohibit learning and have traumatic consequences (Donnellan et al., 2013).

Visible Learning (n.d.) looked at thousands of studies and has put forward research on more than 300 million students around the world. Hattie told people that everything they do in the world of education has an impact on student learning (Visible Learning, n.d.). Hattie advised that people should focus on the things that have the highest impact and avoiding those with lesser impacts (Visible Learning, n.d.). Some things have a negative impact on student achievement. Teacher estimates of achievement are the judgements that teachers make about their student's ability and that have been found to be the number one positive influence (Visible Learning, n.d.). Teachers who believe in their students will drive student achievement and those who do not will inhibit growth. Teachers form their opinions of achievement through questioning, observing, written work presentations, how the student reacts to increased challenge, and assignments and tests (Visible Learning, n.d.). According to Kedar (2012), if a student is unable to write, speak, or regulate their body, the teacher's judgement on their ability to achieve will affect their learning.

Dweck (2008) explained two types of thinking about situations: first, having a fixed mindset and, second, having a growth mindset. A fixed mindset describes when people believe qualities (e.g., intelligence and talent) are fixed such that, even though one might work hard, one will never go beyond what is within their fixed qualities (Dweck, 2008). A growth mindset enforces the belief that people can grow with experiences, work, and mentorship. Yeager and Dweck (Burton, 2020) showed that people with a growth mindset are more likely to thrive when faced with challenges and that those with a fixed mindset might fail to meet their potential.

Family members who believe their nonspeaking individual has the ability to grow through experiences have the opportunity to thrive when using AAC. If a family believes their individual does not have the potential to grow their intelligence and abilities, they might not have the same opportunity for success.

### **Communication for Nonspeaking Autistic Individuals**

A variety of interventions are used to support communication for nonspeaking autistic individuals (Gitimoghaddam et al., 2022). Interventions such as ABA are commonly used to support individuals with autism (Gitimoghaddam et al., 2022). ABA has a goal of altering behaviors by choosing a behavior that is not desired and altering the environment to eliminate the behavior (Roane et al., 2015). Intentionally focusing on motor skills through physical activity and exercise is growing as an intervention in response to the needs of individuals with autism (Ruggeri et al., 2020). AAC systems include all of the ways that someone communicates besides talking (e.g., an iPad, keyboard, PECS, letterboard, or another speech device; ASHA, n.d.-a). More recently, RPM and S2C have shown evidence of success for nonspeaking autistic individuals (Peña, 2019a). ELT informs each method of communication through the family's and individual's knowledge learned and transformation from experience (Irby et al., 2022).

### **Interventions for Nonspeaking Autistic Individuals**

Interventions for nonspeaking autistic individuals are focused on language, learning, and social skills (Prelock & McCauley, 2021). Most schools in North America heavily rely on ABA as the “gold standard” for autism interventions (McPhilemy & Dillenburger, 2013). Although mostly common in North America, the social ABA interventions were reviewed in 2013 by the McPhilemy and Dillenburger conducted a study of 15 families from Europe who participated in home, self-managed support. McPhilemy and Dillenburger's results were that ABA interventions had a positive impact on social skills, challenging behavior, and communication. Occupational

therapy is a common intervention for individuals with autism because it supports individuals by helping them look at the big picture of psychological, physical, emotional, and social situations. Occupational therapists assist in supporting the individual's goals of participating in everyday life activities (Crabtree & Demchick, n.d.). Another intervention is focused on motor skills. In three studies, Ohara et al. (2020) reported that fine motor skills had a stronger relationship with social skills than had gross motor skills. SLPs play an important role in assessing and diagnosing and planning interventions for an individual with autism. They consult with family members and work to create a partnership with families to transfer what is worked on during therapy across all settings (ASHA, n.d.-a). Augmentative alternative communication (AAC) is used when traditional interventions have not worked, and a child is not beginning to speak after being provided with SLP services (ASHA, n.d.-a). RPM is an AAC intervention that focuses on four teaching objectives: cognitive, skill, tolerance, and communication (Mukhopadhyay, 2022). Through continued practice, skills, confidence, and expression grow for nonspeaking autistic individuals. S2C is a form of AAC which teaches people with motor challenges how to use purposeful motor skills to point to letters to communicate, working to achieve synchrony between the body and brain (Vosseller, 2022).

### **Applied Behavior Analysis**

ABA has been shown to be effective as an intervention for autistic individuals (Lerman, 2016). ABA uses specific techniques for individuals with the goal of changing their behaviors (Dhawan, 2021). This involves making an observation of particular behaviors, analyzing what happened before, during, and after the behavior, and creating some strategies to try to eliminate the behavior. (Dhawan, 2021). Dhawan (2021) compared behavior management for autism with ABA, Play Therapy, and Neurolinguistics Programming and found that ABA enhances communication and reduces interaction impairments (Dhawan, 2021). However, when compared

to speech therapy and occupational therapy, ABA is not focused on what the individual wants (Dhawan, 2021). Although ABA has shown multiple benefits in developed countries, the implementation of them is a challenge because of the cost of trained individuals (Dhawan, 2021). Interventions for autism cannot and should not have a one-size-fits-all approach, for what works for one student might not work for another (Dhawan, 2021). ABA is an effective intervention technique for social communication and interactions (Dhawan, 2021). More research is still required to understand which type of intervention should be used for social communication and interaction across the autistic population (Dhawan, 2021).

Nevertheless, critics of ABA argue that ABA damages patients psychologically, and self-advocates have supported this view, saying that ABA takes away the person's voice (Kirkham, 2017). Practitioners of ABA might discourage any behavior that does not fit the social norm and works to eliminate behaviors that might be the nonspeaking autistic individual's own form of communication (Kirkham, 2017). For example, if a person flaps their hands, this might be a way of calming or soothing their body, but ABA practitioners might discourage hand flapping. In schools, courtrooms, and parent groups arguments continue over the use of ABA as the standard intervention for nonspeaking autistic individuals (Kirkham, 2017). Nonspeaker Kedar described in his autobiography the weekly humiliation he experienced in the form of ABA supervision; he performed drills in front of an entire room of professionals who worked with him. Kedar shared deficits and mistakes were discussed in front of him. The professionals assumed that he did not understand the discussion, which added shame and anger to the frustration that Kedar experienced (Peña, 2019, p. 70).

Kasari et al. (2022) noted that the National Institutes of Health, a division of the U.S. Department of Health and Human Services, supported that new assessment measures are needed to share accurately the strengths and weaknesses of minimally verbal, school-aged children with

autism. According to Schwartz and Elizabeth (2021), it is time for the behavior analysts to re-examine how they interact with people with whom they work. Many changes have been made since the origination of ABA. The latest is that ensuring attention to quality of life while receiving an ABA intervention is a priority. The categories to ensure a quality of life include self-determination, emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, and a person's rights and inclusion. People who work with individuals with autism are being pushed to ensure that their civil rights are respected (Schwartz & Elizabeth, 2021).

According to Kirkham (2017), ABA affects communication options for nonspeakers by focusing on requiring certain behaviors (e.g., eye contact) for the nonspeaking autistic individual. ABA also requires that the individual acquire one skill before moving on to another. A person might be working on the same skill for many years (Kirkham, 2017). ABA is based on compliance training and some nonspeakers refuse to cooperate with the directions that they are given or they are not visual learners; therefore, it appears they do not know the information that is being asked when, in reality, they are just being noncompliant (Peña, 2019).

### **Occupational Therapy and Motor Skills**

The American Occupational Therapy Association (Crabtree & Demchick, n.d.) described occupational therapists as trained medical providers who support a variety of skills, including motor skills. Occupational therapists evaluate a person's sensory, motor, cognitive, social and communication skills and, from their evaluation, develop goals that support eliminating barriers to everyday life activities (Crabtree & Demchick, n.d.). Motor skills are used to do many daily living skills (Johnson, 2021). Activities of daily living can include getting ready for school or work, doing chores, working on hobbies, or playing sports (Johnson, 2021). These tasks can be very difficult when someone has a motor challenge (Johnson, 2021). An impairment in motor

could limit a person's ability to learn functional and social skills (Kaur, 2019). Motor impairments affect social communication development and show a need for interventions (Kaur, 2019).

Motor impairments have been found widely for individuals with autism (Günel et al., 2019). Occupational therapy has been found to be a necessity for individuals with poor motor planning because it allows for a focus on providing motor planning direct (Günel et al., 2019). Occupational therapy supports individuals by helping them to look at the big picture of psychological, physical, emotional, and social situations. Occupational therapists assist in supporting an individual's goals and in participating in everyday life activities (Crabtree & Demchick, n.d.). Within the realm of occupational therapy, Kaur (2019) conducted research on yoga for improving motor skills. Bishop et al.'s (2015) affinity approach has also been shown to support improved motor skills for nonspeaking autistic individuals.

Kaur (2019) conducted research on Creative Yoga Intervention to improve motor and imitation skills of children with autism and showed that an 8-week yoga intervention might lead to generalized and training-specific improvements in gross motor and imitation skills of children. In Kaur's study, someone who was novel to the individual in the pretest and posttest sessions administered the Bruininks-Oseretsky Test of Motor Proficiency to evaluate both fine and gross motor skills. Kaur found improvements in activities that were not practiced during the intervention (e.g., balance, motor planning, and execution during a problem-solving task). Kaur recommended using music and yoga as an essential part of care for people with autism.

According to Gasiewski et al. (2021), occupational therapy can support communication for nonspeakers by focusing on strategies that support the human body, motor planning, and body mechanics. Occupational therapists can help to explain why a person is struggling with a certain task in relation to visual, fine, and gross motor skill deficits. They can also assist with

sensory activities that will support being able to focus and attend to communication (Gasiewski et al., 2021).

### *Association of Social and Motor*

Fitzpatrick (2020) suggested that spontaneous, implicit, social motor synchronization is related to autistic traits in different ways than more explicit, intentional, social motor synchronization, although both are related to social knowledge. This approach can help with measuring social motor at an early age. By measuring social motor early, interventions could begin sooner (Ohara et al., 2020). In three studies, Ohara et al. (2020) reported that fine motor skills had a stronger relationship with social skills than had gross motor skills. Among the gross motor skills associated with social skills, object control skills seemed most closely linked to social skills. Among fine motor skills, manual dexterity seemed to be most closely related to social skills (Ohara et al., 2020). According to Ohara et al. (2020), social skills require the development of nonverbal skills (e.g., eye contact, gestures, and body awareness). Clumsiness and early motor delays might limit social opportunities and, because complex motor sequences are required to interact, individuals might have fewer opportunities to practice social and motor skills (Ohara et al., 2020).

Both object control and manual dexterity require visual–motor integration (Ohara et al., 2020). Ohara et al. (2020) described the difference in language and social skill development for individuals with autism. Ohara et al. reported that language might be prevented by the destruction of white matter in the left cerebral hemisphere. This emphasizes the importance of continuing to look at associations between motor skills, social skills, and language development (Ohara et al., 2020).

The affinity-based approach is used to look at strong interests in objects or things as a positive attribute and is used to help children with social skills (Barros et al., 2019). This

approach has the potential to be used as a therapeutic technique, for it is a much different type of intervention than current best practices such as ABA (Bishop et al., 2015). The affinity approach is part of the neurodiversity movement whose advocates look at differences in the brain (Barros et al., 2019). Affinities can be used for intentional motor practice and can be helpful to teach children with autism new skills (e.g., using exercise equipment) with the idea that the more practice they have, the more independent they will be by creating a habit of exercise (Bishop et al., 2015).

Craig et al. (2021) researched the relationship between motor skills and social communication abilities, using several multiple motor assessments to look at three main areas: motor skills, IQ, and social communication ability. Craig et al.'s findings were that preschoolers with autism had a greater impairment in motor skills than those who were developing typically. Greater motor impairment correlated with social communication abilities; therefore, Craig et al. suggested that this correlation could help identify motor difficulties for interventions. Craig et al.'s findings supported motor and social connections, leading to more productive therapeutic practices for those with autism. Their findings also gave evidence of a correlation between social communication abilities and motor skills.

### ***Speech Language Pathology***

An SLP is an expert in social communication (ASHA, n.d.-a). A common intervention for nonspeaking autistic individuals is speech language therapy (ASHA, n.d.-a). This often starts at an early age and can be used at any age to support communication (ASHA, n.d.-a). SLPs play an important role in assessing and diagnosing and planning interventions for an individual with autism. They consult with family members and work to create a partnership with families to transfer what is worked on during therapy across all settings (ASHA, n.d.-a). According to Van Volkenburg (2021), each SLP should look at the whole child to create an intervention plan that is



focused on their individual needs. No specific SLP therapy has been found to be the “gold standard” (Van Volkenburg, 2021, p. 51). No single best intervention for autism exists in the area of SLP services (Van Volkenburg, 2021). According to Van Volkenburg (2021), “Evidence-based interventions for SLPs are discrete trial training, functional communication training, video modeling, PECS, Voice Output Communication Aide, Peer Meditated Instruction and Intervention, Social Narratives and Social Stories, and Imitation and Modeling Therapy” (p. 132). In a case study, Van Volkenburg (2021) investigated therapy methods that SLPs used with children with autism and expressed the need for more research in the areas of more creative types of therapy.

### ***Augmentative or Motor-Based Approaches to Communication***

AAC are types of communication that replace speech for those who have challenges with speaking (ASHA, n.d.-a). AAC can include gestures, speech generating communication devices, communication boards with symbols or the alphabet, and PCESs (Peña, 2019). Augmentative communication is used when traditional interventions have not worked, and a child is not beginning to speak after being provided with speech language pathology services. An augmentative communication evaluation that an SLP completes can help the parents and the SLP to decide what type of intervention is appropriate to use (ASHA, n.d.-a).

There are many types of AAC, including no-tech or low-tech ACC (e.g., writing, drawing, spelling by pointing to words or letters, and facial expressions), and then there are high tech options (e.g., using an iPad, computer, or other speech generating device; Kron, 2017). AAC does have limitations for various reasons. Some of the limitations reported were difficulty of use, device repair time, need for charging, lack of independence, need for hand over hand instruction, not being waterproof, being heavy and having to lug it around all day, low volume, and limitations of vocabulary (Kron, 2017).

ASHA (n.d.-a) categorized social communication as follows: social cognition, spoken language processing (listening and speaking), pragmatics, written language processing (reading and writing), and social interaction. According to ASHA (n.d.-a), if a student is a nonspeaker, a nonwriter, and has trouble controlling their body, how these areas are assessed can have a great impact on what interventions are chosen for them. Knowing the person will help one to determining what type of AAC intervention is appropriate to use. To communicate, a child might learn sign language or might learn to use picture boards or computers that talk (ASHA, n.d.-a). These methods are one type of AAC (ASHA, n.d.-a). For individuals who present with motor planning and coordination challenges, other forms of communication have been developed, including RPM and S2C (Handley & Handley, 2021).

### ***Rapid Prompting Method and Spelling to Communicate***

Communication through intentional motor planning consists of two programs: RPM and S2C (Handley & Handley, 2021). RPM is an intervention that focuses on four teaching objectives: cognitive, skill, tolerance, and communication (Mukhopadhyay, 2022). Through continued practice, the skills, confidence, and expression of nonspeaking autistic individuals grow. S2C teaches people with motor challenges how to use purposeful motor skills to point to letters to communicate, working to achieve synchrony between the body and brain (Vosseller, 2022). These programs have been compared to facilitated communication, which is also referred to as assisted or supported typing, it involves a person pointing to letters on a letterboard or keyboard, with a physical support from a facilitator who touches the person's hand, wrist, or elbow (ASHA, n.d.-a). The main difference is that there is no physical support in either RPM or S2C.

Mukhopadhyay (2022) created RPM to help her son, who is a nonspeaking autistic individual. According to Mukhopadhyay (2022), RPM empowers a student with tools to express

learning, understanding, reasoning, and thoughts. The teacher supports learning how to access auditory, visual, tactile, and kinesthetic channels of the student (Mukhopadhyay, 2022).

Mukhopadhyay (2022) focused her work on assisting students to use what she calls “open learning channels” (p. 91). When one is working with a person who uses RPM, one should look to identify their dominant learning channel (Mukhopadhyay, 2022). When a person is able to integrate each aspect of a learning channel (e.g., the auditory channel, environmental noises, speech sound, volume, pitch, intensity), they are in auditory mode. This means they are able to learn using their auditory system (Mukhopadhyay, 2022). Mukhopadhyay (2022) has helped thousands of people learn to communicate their valuable insights. Alan Alexander is one of those individuals. Alan did not learn to communicate until he was 40 years old. The first sentence he ever expressed was how, when he turned 30 years old, he had forgiven God. Alan talked about life before RPM as a torture chamber with no escape (Peña, 2019). Alexander is extremely grateful and would like RPM to be used as an intervention for others at earlier ages (Peña, 2019).

S2C is another form of AAC. Tino et al. (2020) explained that S2C teaches individuals with motor challenges the purposeful motor skills to point to letters to spell as an AAC. Synchrony between the brain and body is the goal (Vosseller, 2022). Individuals who learn how to use S2C or RPM might learn how to type independently (Tino et al., 2020). At that point, their thoughts, dreams, and knowledge can be shared with the world, and then it is much harder to deny that it is truly them communicating. Tino et al. (2020) shared his life as a nonspeaking autistic individual. Tino did not learn to communicate until Age 23. Prior to this, Tino sat in his basement watching YouTube videos for hours on end, but now has written a book, is in a social group with friends, plays the piano, and even has a girlfriend (Tino et al., 2020).

Kedar (2012) shared thoughts about, if he had not been taught how to use a letterboard, which later became a keyboard or iPad, he would never have been able to share his own ideas,

jokes, and thoughts. He stresses that this is how it is for all those who cannot communicate (see also Peña, 2019). Kedar (2012) talked about how Mukhopadhyay saved him and helped him to strive for real communication and learning.

Bergmann, who uses a letterboard or keyboard, earned his degree from Harvard Extension School, and was one of the speakers at Harvard's 2022 commencement. He was monitored by the accessibility office during each of his exams and was the first nonspeaker to graduate from Harvard University (CBS Sunday, 2021). For years, Bergmann was classified as intellectually disabled, until he was Age 12 and learned how to communicate with a letterboard (CBS Sunday, 2021).

Handley and Handley (2021) shared their experience of finding a method of communication that showed Jamison Handley's true, brilliant self. At Age 17, Jamison was freed from his self-described prison of silence (Handley & Handley, 2021). Forty percent of those on the autism spectrum are labeled as intellectually disabled (Handley & Handley, 2021). Handley and Handley (2021) challenged experts about their belief of nonspeaker cognitive abilities. Jamison Handley described how learning to use a letter board made possible his dream of majoring in political science at the college level. He shared that, from his behavior, one might assume that he had the intellect of a toddler. Now, he can use a keyboard to express all thoughts and wants to be the first autistic person in the senate to veto a bill (Handley & Handley, 2021).

Jaswal et al. (2020) conducted a quantitative study designed to measure experienced letterboard users who worked with head mounted eye tracking to measure how quickly and accurately individuals looked and pointed at letters as they participated in a familiar activity. The individuals responded to questions about a piece of text, a common instructional practice that was used at their educational center. The results of the study showed that nine nonspeaking participants rarely made errors and visually fixated most letters about one half of a second before

pointing to them. Their response time reflected planning and production. Jaswal et al. (2020) concluded that the speed, accuracy, timing, and visual fixation patterns suggested that the participants pointed to letters that they had selected themselves, not letters that they were directed to point to by the assistant.

### **Identifying, Learning and Teaching, and Implementing Augmentative and Alternative Communication**

An individual who is unable to meet their communication needs using speech should receive AAC interventions (Beukelman & Light, 2020). Positive effects on communication, language and literacy have been documented (Beukelman & Light, 2020). Sometimes professionals erroneously believe that certain prerequisites must be met before individuals are ready to use AAC (Beukelman & Light, 2020). Every person with complex communication needs has the right to receive AAC (Beukelman & Light, 2020). This begins with an assessment to identify the individual's immediate needs. An AAC assessment should include a referral to a qualified SLP for assessment and intervention planning. The AAC assessment would help to individualize AAC by looking at needs and capabilities, matching features, trials, selection, and personalization. Throughout this process the family must work closely with the professionals to support the training and implementation (Beukelman & Light, 2020). Communication experiences by families affect relationships. Beukelman and Light (2020) shared how they were able to start sharing things that were not possible before AAC, for example, talking about the Los Angeles Dodgers and baseball, and just having father and son conversations like all families' experience on a daily basis (Beukelman & Light, 2020).

### **Identifying Augmentative and Alternative Communication**

Assessing a person's strengths and needs, matching with a possible AAC solution, and then procuring a device are the first three phases to finding an AAC (Ogletree, 2020). When

selecting an AAC device, the SLP looks at predictors, which are factors that might affect the outcome (e.g., a person's cognition level; Loncke, 2019). Another factor in selecting an AAC is a moderator, which might also affect the outcome (Loncke, 2019). An individual's ability to imitate gestures would be an example of a moderator. A final factor in selecting a device is a mediator, which is a support that is available after an intervention has been started (e.g., adult input at home; Loncke, 2019).

Selecting an appropriate AAC system requires looking at visual, auditory, and tactile presentations of messages, symbols, and codes (Beukelman & Mirenda, 2012). Many AAC devices have visual displays that show letters, symbols, or codes; for individuals with a visual impairment, auditory or tactile options are available. This method could include spoken words or braille. To determine an individual's best approach to AAC, an SLP would give a capability assessment to assess motor control, cognition, language, and literacy (Beukelman & Mirenda, 2012). Focusing on a person's strengths rather than deficits is critical, for one can match strengths to one or more AAC techniques (Beukelman & Mirenda, 2012).

Assessment of a nonspeaking autistic individual might include observation, interviews, rating scales, and a combination of methods (Ganz & Simpson, 2018). AAC assessments work to evaluate communication needs and capabilities as well as participation patterns. Family members, as part of the AAC team, might contribute to the assessment through interviews and rating scales. The AAC team usually includes the nonspeaking autistic individual, their family members, and professionals who work with the individual. The team role is to work together to make suggestions for how to support the nonspeaker on their communication goals (Beukelman & Light, 2020). The professional completing the assessment looks for gaps and barriers that might be affecting communication for the individual and builds ways to remove barriers and to fill in gaps (Ganz & Simpson, 2018). A growing number of family members are using AAC to

support communication (Ganz & Simpson, 2018). It is imperative that the family members understand the system and be able to support the use of AAC across all settings. Each AAC system should be individualized to meet the person and their family's needs (Ganz & Simpson, 2018).

Family involvement in identifying the appropriate AAC does not come without challenges. The decision-making process requires family involvement or negative consequences can occur for all involved (Mandak et al., 2017). Despite the recognition of importance for families to be involved, little guidance is available for professionals on how to establish family-centered relationships. Mandak et al. (2017) presented a framework with a goal of closing the gap between knowing family involvement is necessary and implementing family-centered services for nonspeaking autistic individuals regarding AAC services.

### **Learning and Teaching Augmentative and Alternative Communication**

For family members, learning how to use an AAC device requires training, and this training has been successful when followed by coaching from a trained professional (Snodgrass & Meadan, 2018). Using video recordings to share progress with professionals who are not able to be in the natural setting has also been used (Snodgrass & Meadan, 2018). This type of ongoing support for AAC among communication partners might include someone who supports the communication process of a nonspeaking individual with autism and is needed for continued success and growth (Snodgrass & Meadan, 2018).

According to Gevarter et al. (2021), parents might have the ability teach their children with fidelity how to use AAC. Nonspeaking autistic individuals are able to generalize or use the skills they learned to use the AAC that their parents taught to them (Gevarter et al., 2021). Gevarter et al. (2021) suggested keeping targets in the learners' zone of proximal development, which means providing an opportunity that is not too hard, not too easy, just right for advancing

skills. Modeling or showing the person how to use AAC is a commonly used instructional method for teaching AAC (Gevarter et al., 2021). This might look like using an assistive device to show a nonspeaking autistic individual the process of how to use it. Presuming competency of the nonspeaking autistic individual includes assuming that they understand verbal language; therefore, one should speak to individuals using age-appropriate instruction (Gevarter et al., 2021). Using direct instruction that might begin with physical prompting, which might look like physically moving the individual's hand to use the device and following it by reducing prompt dependency, which means that relying on the person who is moving the hand is an important part of helping some individuals learn how to use AAC (Gevarter et al., 2021).

Parents do not usually think about what words they need to teach their child. When teaching a person to use AAC, parents need to learn how to offer a vocabulary curriculum, which means they will determine what words are taught and included on the AAC device. This includes teaching specific vocabulary that is entered into the AAC device (Mandak & Light, 2018). Parents also need to learn where to get help with programming, broken devices, and what abilities and needs the family has in using AAC (Mandak & Light, 2018). A parent's attitude can have a big impact on the inclusion for an AAC user and, if a person has a positive attitude, they are more likely to have success and carry the success into another setting for their child (Mandak & Light, 2018).

### ***Implementing Augmentative and Alternative Communication***

It is critical for AAC to be used across all settings, which might include home, school, and the community (Ganz et al., 2014). Implementation across all settings with all potential communication partners will assist nonspeaking autistic individuals in meeting their goals (Ganz et al., 2014). When implementing AAC the communication partner, which includes family members, they might use prompts which are physical or verbal guidance to assist in the correct



use of the AAC device (Ganz et al., 2014). Allowing time for the nonspeaking autistic individual to attempt a correct response is an important part of implementing AAC (Ganz et al., 2014).

Family members are often the daily support person for those who rely on AAC. Eye tracking research has provided information to help make decisions about AAC practices for individuals with autism, and I believe there is a need to provide a longer wait time for processing. This could mean providing additional time for a person to respond when you ask a question (Loncke, 2019).

Once the type of AAC is chosen, the team (which is comprised of the nonspeaking autistic individual, family members, and professionals who work with the individual) works to support communicative intent, vocabulary for preferred items and activities, appropriate protesting, and conversational skills. Communication begins with a reason to communicate, family members can provide opportunities as a communication partner and work to achieve engagement of interactions in communicating (Ganz & Simpson, 2018). Once the act of communicative interaction has occurred, family members can support teaching and can expand vocabulary. It is critical that individuals who use AAC have exposure to a rich language and are introduced to new concepts (Beukelman & Light, 2020). Teaching often begins with preferred items and includes appropriate ways to meet needs (e.g., asking for help, and taking a break; Ganz & Simpson, 2018). Teaching individuals how to protest appropriately is important. Using phrases such as “No, thank you,” “I am all done,” “I want more” support an individual’s quality of life (Ganz & Simpson, 2018, p. 222). Teaching conversational skills is critical to meaningful social communication (Ganz & Simpson, 2018).

When planning for AAC interventions for nonspeaking individuals with autism three areas should be considered: promoting social interaction, providing intervention across the life span, and using effective intervention techniques (Beukelman & Light, 2020).

Social interaction should always be built into communication opportunities when implementing AAC in the real world (Beukelman & Light, 2020). Autism is a lifelong disability and, although early intervention is important, it is never too late for a person to learn. Family members play an important role in supporting adolescents and adults with autism with social opportunities. Time should not be wasted on interventions that show little or no progress or have negative effects. Monitoring interventions and checking on progress is important to be sure that negative effects do not occur (Beukelman & Light, 2020). Family members are the best advocates for making changes when something is not working. The attitudes of key stakeholders are extremely influential in the success of AAC (Mandak & Light, 2018).

Although extremely complex communication impairments might be lifelong, little is known about the families who provide for the individual (Mandak & Light, 2018). In the area of AAC, family-centered services provide families with support needed to implement AAC. Family-centered services recognize the importance of family members with the implementation and look to build relationships and support skill development (Mandak & Light, 2018). When individuals cannot communicate effectively, this adds stress to families and affects relationships (Mandak & Light, 2018). For families of individuals who use AAC, the family-centered services are a practice that views all families as interconnected; therefore, the services are delivered to the whole family. According to Mandak et al. (2017), family perspectives reveal the challenges of implementation between beliefs and practices. Many areas still require improvements in the family-centered services practice (e.g., enabling families, sharing information, respect, and providing support). The improvements in family-centered services must be made or the lack of improvements could lead to poor outcomes for both the individual and their family. When used effectively, family-centered services might lead to decreased family stress, increased satisfaction, and improved outcomes with using AAC (Mandak & Light, 2018).

Therrien (2019) conducted a study to explore the perspectives of adults who use AAC in relation to their use of aided communication. Aided communication refers to communication supports that are external to the person, including communication boards and voice output devices; all of the participants listed family members as communication partners (Therrien, 2019). A fundamental factor in supporting the implementation of the AAC is the communication partner having time to talk. The participants were asked what they liked most about using the communication, and one person said, “My family hears me” (Therrien, 2019, p. 8). The participants also found it easier to work with a family member to communicate (Therrien, 2019).

Batorowicz et al. (2014) conducted a study in which the parents mentioned the importance and lack of ongoing social experiences. Batorowicz et al. suggested that afterschool programs were needed to provide social opportunities for those who use AAC. The parents described a special understanding and relationship between siblings and said that, when watching them play, one might not know that one of their children had a communication problem (Batorowicz et al., 2014).

Implementing AAC includes use in the nonspeaking individual’s home, school, and the community (Ganz et al., 2014). Promoting social interaction, providing intervention across the life span, and using effective intervention techniques should all be considered in planning for AAC use (Beukelman & Light, 2020). Attitudes are the key to success and family members are the best advocates for ensuring that progress is being made (Mandak & Light, 2018). When time is invested to talk with a nonspeaking autistic individual, they can feel support and improve their communication skills. Friendships are desired by all people, including those who use AAC, and working to provide opportunities for peer interactions who have shared interest and commonalities in life can support friendship success and quality of life (Therrien, 2019).

## **Transformations from Augmentative and Alternative Communication**

Transformations are meant to be experiences and changes to life that family members and individuals can share. With the right supports, anything is possible (Peña, 2019). Most families and nonspeaking autistic individuals have little communication or social supports. Hearing success stories can help to educate, inspire, and bring hope to families (Peña, 2019). RPM and S2C are controversial in the world of AAC because some people and organizations claim that the letters and words that nonspeaking individuals spell do not belong to the speller (Handley & Handley, 2021). Some individuals move from using a letterboard to typing independently on a keyboard; however, when this happens, no one can deny that the autistic individual is the author of the words (Handley & Handley, 2021). From this experience, one can see an individual transformation to independent communication. The topics of transformations of family members and those of nonspeaking autistic individuals were explored.

### **Transformations for Family Members**

Autism presents a unique set of challenges for a family. On average, families experience more financial strain, time pressure, a higher divorce rate, and an overall lower well-being (Ellis, 2018). Health insurance companies might lack coverage, even for interventions that are seen as the most evidenced-based interventions (Ellis, 2018). Families might feel hopeless, isolated, and in grief (Ellis, 2018). Living with autism affects the entire family, including mothers, fathers, and siblings. The quality of life for families with autism might be lower overall (Ellis, 2018).

According to Prizant & Fields-Meyer (2016), one of the leading experts on autism, parents are the experts when it comes to living with someone with autism. Prizant & Fields-Meyer was the founding director of Bradley Hospital's Communication Disorder Department and has been a tenured faculty at two colleges, including Brown University. Prizant and Fields-Meyer are the authors of the Social, Communication, Emotional Regulation, and Transactional

Support (SCERTS) Model. The SCERTS Model is a newer type of naturalistic, developmental, behavioral intervention that collaborates with family members to use teaching strategies in everyday activities (Yi et al., 2022).

Prizant and Fields-Meyer (2016), who works regularly with parents who feel like they should do something for their child but have been advised by experts to go another way, advises parents to trust their gut when it comes to their children. Prizant and Fields-Meyer shared how parents of two teenage boys with autism discovered that they liked hiking. The parents decided to hike a 9-mile trail, which the occupational therapist advised against, but the parents trusted their instincts; not only did the boys handle the challenge, but they also thrived. Sometimes finding a hobby or passion can connect a family (Prizant & Fields-Meyer, 2016).

Peña (2019) and Peña's spouse did whatever it took for their son to access communication. They chose a controversial method of communication, RPM; without their belief in their son, their family would never be where they are today, for now they are able to know all of their son's inner thoughts (Peña, 2019). Peña (2019) described watching her son express his thoughts from being stuck in silence to taking her breath away. Prior to communicating using AAC she did not truly know her son. Before RPM, Peña hoped her son would someday find happiness. Now she wishes for him to have a purposeful life (Peña, 2017).

Handley and Handley (2021) described how their family changed. Handley and Handley shared that life before S2C was miserable, but now that Jamison Handley could communicate, he does not have self-injurious behaviors. J. B. Handley wrote about having to pick Jamison up from school when he was out of control and harming himself; he also described the phone call and the trauma for their family. J. B. Handley even shared feeling scared for his son. After learning to communicate these behaviors went away. The Handley family was convinced that their son was cognitively inside and learned not to look at the outside behaviors for what is truly

going on. J. B. Handley was preparing to file guardianship papers for his son, for he thought he would need to make all decisions for him when he turned Age 18, a situation with which most adults or family members with significant disabilities are faced. After learning to communicate by spelling, Jamison Handley no longer needed his parents to become his guardians, for he could make his own decisions. J. B. Handley also described the guilt that he felt for underestimating his son for so long (Handley & Handley, 2021).

Virginia Breen, a mother of a nonspeaking autistic individual, wrote about the ups and downs of any family, including those who live with autism. Breen shared the sacrifices that families make when dealing with autism. Breen has two children with autism and an older child for whom she made a special time each week to try to ensure quality time and support outside of the home. Elizabeth, Breen's daughter, learned to communicate using RPM. Breen shared how experts could not tell Elizabeth's intelligence, but once she was able to communicate, Elizabeth spelled "I am in here" (Bonker & Breen, 2011, p. 28). Breen shared how autism has been both a connector and a barrier. "Elizabeth has taught me, words are not needed" (Bonker & Breen, 2011, p. 30).

Assimakopoulos (2018) wrote, from her first-hand experience with a younger brother with autism, about how autism affects a family. Assimakopoulos talked about her family being turned upside down when the brother was diagnosed with autism at Age 2. At Age 10, a new world opened for the brother and family. Since then, they have developed a real bond that had been missing for many years. From Assimakopoulos' experience, she has learned that families with autism hold many experiences that can help with research. Assimakopoulos became inspired, and her family's lives have been changed forever.

Park (2020) conducted a study to examine the experiences of 12 parents with complex communication needs who received AAC interventions and found an increase in satisfaction

compared to conventional speech therapy interventions. The parents who participated in Park's (2020) study recognized the importance of AAC and started this type of communication early. AAC brought an increase in hopes of independence and realizing true potential. These parents also reported an increase in their competence as parents and reported the need for increased parent training, financial assistance, and cooperation among institutions (Park, 2020).

Families have identified many obstacles to living with autism, and those who have found communication through AAC interventions have been able to share positive life transformations. Hearing success stories can help educate, inspire, and bring hope to families. Most families and nonspeaking autistic individuals have little communication or social supports (Peña, 2019). "We've misunderstood autism the whole time. It's not a cognitive disability, it's a motor planning disability" (Handley & Handley, 2021, p. 134).

### **Transformations for the Nonspeaking Autistic Individual**

Individuals tell of a time when their lives changed because they learned a new way to communicate (Peña, 2019). Individuals explain how they were treated prior to being able to show their knowledge, and they advocate for us to change how autism is viewed. Peyton Goddard, a nonspeaking autistic individual from California "lives to teach" (Peña, 2019, p. 65). Peyton started interventions at an early age and, despite trying everything possible, she was abused, neglected, and labeled as a "severely mentally retarded, low functioning autistic"; however, at Age 44, she said, "With no way to tell I'm competent, I'm treated as throw away trash and deemed unfit for public schools" (Peña, 2019, p. 65). Peyton progressed from years in segregated schools to becoming the valedictorian of her community college (Peña, 2019).

Kripke-Ludwig (2020) described Rachel, a nonspeaking autistic, who went from having no hope and no words to attending college; the unconscious biases of special education teachers were discussed. Rachel shared that the teachers did not believe she could learn, so she was not

allowed to progress in her grade level work. The school and her family did not know that Rachel knew everything her peers knew (Kripke-Ludwig, 2020). Once Rachel was able to communicate through the use of AAC and a letterboard, her life path changed. Rachel shared how her expectations of herself and of others have changed. Rachel shared that she was saved from boredom and failure (Kripke-Ludwig, 2020).

The transformations for nonspeaking autistic individuals who learned to use AAC included those who were social, academic, and personal (Peña, 2019). In her 2022 valedictorian commencement speech at Rollins College, Bonker (2022) shared that she is one of the lucky nonspeaking autistics that was taught to type. Bonker credits this intervention for unlocking her silence. Bonker went from no communication, to using a letterboard, learning to type, and graduating from college. She is dedicating her life to supporting others who have not yet learned to communicate.

Kedar (2012) wrote about his experience of learning to communicate using a letterboard (now keyboard) and how it has transformed his life. Until he was Age 7, Kedar had no way to show anyone what he knew. Kedar wrote about his behaviors that were misinterpreted and how he was stuck in silence. Kedar credits Mukhopadhyay (2022), who is the creator of RPM, and her teachings of RPM for saving him. Kedar (2012) can now type independently and hopes that someday everyone will understand that not speaking is not the same as not understanding.

Before learning to use a letterboard Jamison Handley described trying to talk, but nothing would come out. Jamison said that school “sucked” for years, and that he was treated like he was stupid (Handley & Handley, 2021, p. 121). Jamison Handley wrote about his first experience learning to use S2C at Age 17 and how Elizabeth, an SLP and the creator of S2C, told him that he was smart. He attributes getting his life back to Elizabeth and says that she saved his life



(Handley & Handley, 2021). Jamison Handley graduated in 2022 and plans on attending college to study neuroscience (Handley & Handley, 2021).

Ian, a nonspeaking autistic individual who spells to communicate, said, “Unintelligent, unresponsive, incapable, low functioning,” are all labels that may have been used to describe a nonspeaking autistic individual (Assimakopoulos, 2018, p. 39). Ian wrote about autism and how easy it is for neurotypicals to make assumptions according to what they see from a person with autism (Assimakopoulos, 2018). Prior to learning how to spell, Ian shared that no one listened to him, and he was very angry. Finding the ability to spell changed Ian’s life. Now Ian has friends, his life has meaning, and he is able to advocate for others who have not yet found their voice (Assimakopoulos, 2018).

One of the hardest parts of life for nonspeaking autistic individuals is making friends (Assimakopoulos, 2018). A group that was established at Growing Kids Therapy Center in Herndon, Virginia, meets weekly to socialize, advocate, and write a magazine called *The Tribe*. The Tribe is a group of young adults who use letterboards to communicate. Assimakopoulos (2018) learned about this group when her brother became a member of the Tribe. Assimakopoulos wrote about observing the Tribe, that these seven young adults would meet together to socialize, advocate, and support new spellers. A nonspeaking autistic individual Tribe member spelled, “Tribe is my family, my friends, and my confidantes . . . They understand me like no one does” (Assimakopoulos, 2018, p. 83). Communicating using AAC has allowed these nonspeakers to come together and find friendship (Assimakopoulos, 2018).

Peña (2017) discussed life as a nonspeaking autistic individual. Peña shared that it is his right to have communication. Peña shared that his experience of his inability to speak could be confused for his intelligence. Peña also shared that he uses his iPad to communicate and

advocate for others to use AAC for communication. Peña learned to communicate using RPM and says that technology has saved him from silence.

David Temple, a nonspeaking autistic individual, learned to type at Age 5. He followed the same curriculum as other children his age. His mother believed in his abilities. Temple was the first nonspeaking autistic individual to be accepted to the University of California, Berkley. Temple is passionate about changing how people view autism. Temple typed letters for donations for autism awareness and raised over \$250,000. Temple has been part of a group of typers who have met monthly for the last 16 years. They call themselves Loud Talking Fingers (Peña, 2019).

Alan Alexander learned how to communicate through RPM at Age 40. Alexander shared that, before RPM, he was in a deep darkness and an abyss of silence. Over the years, he learned patience and wisdom. Alexander thought he would never find a way to communicate. When Alexander turned 30, he forgave God, but still could not communicate it. Alexander has a goal to surround himself with people who are positive and to be kind to others (Peña, 2019).

Coming from a life of silence into a world where a nonspeaking autistic individual can share their thoughts, desires, feelings, and ambitions reveals many life transformations for those who have learned to communicate via AAC. Common challenges of nonspeaking autistic individuals include educational segregation, motor and sensory difficulty, presumed incompetence, and lack of access to communication (Peña, 2019). Nonspeaking autistic individuals who have been provided supports and resources have found resilience, accomplishments, and achievements (Peña, 2019). There is hope for a life of friendship and learning, and anything is possible (Peña, 2019).

## Summary

There are many ways to attempt to support communication for nonspeaking individuals, each having an impact and each person involved transforming through knowledge learned. The brain affects language/communication for nonspeakers with autism (Williams, n.d.). By learning about how brains function, behaviors may be seen in a different light. A term for the phenomenon “What you see is not what you get” is described as a brain–body disconnect (Williams, n.d.). This disconnect is a combination of a sensory system that is disorganized and difficulty with motor planning, which make intentional movements hard for individuals to achieve (Williams, n.d.).

ELT is the framework used in my research; however, when learning new ways to support communication, family members experience with communication systems might vary. Family members require training to learn how to use and support their nonspeaking family member for each type of AAC they will use (Beukelman & Light, 2020). Just as a dance requires two people to move, communication requires a two-way exchange (Beukelman & Light, 2020). Kolb’s (2017, as cited in Kurt, 2022) learning cycle begins with concrete experience; this can be a new experience or a reimagined experience in which the learner engages. A growing number of families are using AAC to support communication. It is imperative that the family understands the system and is able to support the use of AAC across all settings (Ganz & Simpson, 2018). For family members, learning how to use an AAC device requires training that has been successful when followed by coaching from a trained professional (Snodgrass & Meadan, 2018). Implementation across all settings with all potential communication partners will assist nonspeaking autistic individuals in meeting their goals (Ganz et al., 2014).

The purpose of this qualitative narrative inquiry was to explore the experiences of family members of nonspeaking autistic individuals who use AAC systems. Through my research on the

family member experiences, I hoped to strengthen the research that supports providing ACC to individuals who have not yet found their voice. Learning ways to support autistic individuals through family member experiences will be one more piece of research to support some of them in their quest to communicate.

### CHAPTER 3: METHODOLOGY

The purpose of this qualitative narrative inquiry was to explore the experiences of family members of nonspeaking autistic individuals who use AAC systems. Nonspeaking autistic individuals are people who do not communicate by speaking (Prizant & Fields-Meyer, 2016). Family members are defined as individuals who live with someone who has nonspeaking autism. AAC, as defined by ASHA (n.d.-a), includes all the ways a person can communicate other than speaking, including systems that spell words by pointing to letters and using a keyboard. I focused on two forms of alternative communication: S2C and RPM; both of these forms of communication focus on purposeful interventions with the intentional practice to increase motor outcomes to teach individuals how to point to letters to spell (United for Communication Choice, 2022). RPM is a method of teaching, it can be used to teach academics, develop motor skills, and communicate (Mukhopadhyay, n.d.). S2C teaches individuals to use purposeful motor skills to point to letters to spell (Taborga, 2022).

The qualities of life are marked by living, telling, retelling, and reliving experiences (Clandinin & Connelly, 2000). There are many types of narrative inquiry, but all of them begin with a look into lived experiences. The relationship between the research and sacredness of what is being shared along with trust is paramount (Bloomberg & Volpe, 2016). Communication is to “achieve synchrony between cognition and motor to express thoughts, emotions, and desires” (I-ASC, 2022). I looked into the lived family experiences of those who use S2C or RPM and retold them to share them with others. Interviews capture the perspectives of family members who have experienced AAC through two specific programs.

To understand better the experiences family members have regarding AAC systems, the following research questions were used to guide my study:

- **Research Question 1:** How do family members of nonspeaking autistic individuals describe their experience with identifying, learning, and implementing AAC?
- **Research Question 2:** How do family members of nonspeaking autistic individuals describe transformations within their families since implementing AAC?

Qualitative research involves the study of things and people when they are in a natural setting (Clandinin & Connelly, 2000). Qualitative researchers attempt to make meaning of the findings from the perspective of the participants. Qualitative research was the best fit for this study as the qualitative researcher seeks to examine experiences by allowing the researcher into the world of others to understand their stories through a holistic approach (Clandinin & Connelly, 2000).

According to Clandinin and Connelly (2000), narrative inquiry brings experience and storytelling together in qualitative research. Narrative inquiry is one way to understand someone else's experience. It involves collaboration between a researcher and research participant, and forming a story lived and told (Clandinin & Connelly, 2000). The knowledge learned in the collaboration from the individual's story is retold by the researcher to provide some meaning of the experiences (Clandinin & Connelly, 2000). Narrative research does not look for or lead to conclusions but seeks to share the lived experience of others (Clandinin & Connelly, 2000). Narrative inquiry supports this study through the analysis and resharing of family's experiences of nonspeaking autistic individuals with AAC as each individual with autism is unique and each family story is unique, too. I did not seek conclusive findings, but to share the stories of the families.

### **Site Information and Demographics**

There was no specific site for this study. The participants were recruited from all states across the United States. According to the NAA (n.d.), 1 in 44 children who live in the United

States are affected by autism and 40% of these children do not speak. This is a large number of individuals and their family members who might be affected by not being able to communicate. Recruitment for this study began by posting a recruitment flyer on parent networking group sites that are focused on two main types of motor-based communication: S2C and RPM. I had access to these groups because I am a parent of an autistic individual who uses a motor-based form of communication. Through these parent sites, I sought family members of nonspeaking autistic individuals who were willing to talk about their lived experience.

### **Participants and Sampling Method**

The target population for this study included individuals who were 18 years of age and older and are family members of nonspeaking autistic individuals. Family members of the nonspeaking autistic individuals could be any family member who had had experience in identifying, learning, and implementing S2C or RPM. The individual had to be willing to share their experiences and have their stories retold.

I used purposeful sampling to seek participants who had a family member who was a nonspeaking autistic individual so that I could explore their experience using AAC specifically S2C or RPM. Purposeful sampling involves the investigator selecting a sample from which they can learn the most. The sampling began by selecting the criteria from which my sample was recruited. This ensured that the participants would have information rich knowledge (Merriam & Tisdell, 2016). Snowball sampling was also used. I asked the participants whether they knew of other participants whom they could recommend (Creswell & Guetterman, 2019). According to Creswell and Guetterman (2019), no specific number of participants should be included in a qualitative design. Five participants were invited to participate in a semistructured interview and to share their story about their experience in identifying, implementing, and using two forms of AAC—S2C or RPM—with a nonspeaking autistic family member. Recruitment was left open

until five participants were interviewed. The participants, beyond the five who expressed interested, were thanked for their interest.

The participants were recruited through a recruitment flyer that was posted on social media that included my name, statement of the research project, stating that participation is voluntary, and a brief list of procedures involved. The Participant Information Sheet (Appendix B) was included in this post. The recruitment materials were posted on FaceBook groups, including: The Nest! Growing Kids Therapy Center Client Community, RPM Connections, NeuroClastic, Letterboard Learning, and S2C Home Education Support. The recruitment materials were posted weekly until five participants were interviewed. These social media groups focus on S2C and RPM. Interested participants who self-identified as meeting the study criteria were asked to reach out to me, using my UNE email to schedule an interview at a mutually agreeable time. I gathered contact information (names and emails) during the recruiting process and kept them on a Master list that was stored separately and securely from the study data. I was the only person who had access to the master list. The master list was destroyed after all the transcripts were verified for accuracy.

### **Instrumentation and Data Collection**

Individual, semistructured, one-on-one interviews were conducted and were audio recorded on the Zoom platform. An individual Zoom link was sent to each participant to maintain confidentiality. One-on-one interviews were used for interviewing participants who were excited to share their ideas and did not hesitate to speak with me (Creswell & Guetterman, 2019). I used a guided set of interview questions to prompt participants to share their stories. The interview questions were developed by me according to information found in the literature review, and conceptual and theoretical framework. At the start of each interview, I reviewed the Participant Information Sheet with each participant and gained verbal consent. Interviews were



conducted in a private setting to ensure that others could not hear our conversation. I informed the participants that they could leave the camera on or off, skip questions, and stop the interview at any time. I recorded the audio of Zoom interviews. The interviews lasted about an hour. The audio recordings were then transcribed using the auto transcription feature in Zoom. The audio transcriptions and all data were stored on a password protected computer to which only I have access.

### **Data Analysis**

The narrative inquiry process began with the interview; participants and I engaged in conversations about the participants' experiences. I began by developing a relationship with the participant which is important in the narrative inquiry process (Clandinin, 2016). This began with sharing my own personal justification for the research (Clandinin, 2016). The inquiry is framed around research questions that you explore as you experience the participants lived experience (Clandinin, 2016). From that point, I imagined myself as the participant, trying to view their experience and begin to make connections to how they described their lived experiences. This was important because there are multiple ways to retell a story; therefore, building a relationship with the participant helped to ensure that I was accurately able to describe their experience (Clandinin, 2016). I began reading and rereading the transcripts and attempted to immerse myself in the data. I replaced identifying information with pseudonyms (Clandinin, 2016). I worked to write restoried narratives, by gathering the stories, analyzing them for key elements (e.g., the time, plot, place and scene) and then rewrote the story in a chronological sequence. Understanding information from the participant's past, present, and future helped me to form casual links between ideas (Creswell & Guetterman, 2019). To easily identify elements of setting, character, actions, problem, resolution from the stories, I put the stories into a table to assist me in sequencing them and in coding for them themes (Creswell & Guetterman, 2019).

From the stories, I then coded for themes according to the type of interaction, personal or social, timeline past, present, future, and where the situation took place. The themes assisted in narrowing how the results were presented. I sought to achieve familiarity with the data through open-minded reading, which is the narrative inquiry process. I searched for meanings and themes and organized them into meaningful wholeness (Sundler et al., 2019). The restorying began with the place, characters, and events. I reworked the transcription into a logical sequence to retell the story (Creswell & Guetterman, 2019). These restoried narratives were then sent to the participants, and they were provided with 5 calendar days to review and respond with any feedback. If I did not hear back from the participant in 5 calendar days, the restoried narratives were considered accurate.

### **Limitations, Delimitations, and Ethical Issues**

In this research, I used a qualitative narrative inquiry study. Ethical issues were narrated throughout the entire research process. The distinction of fact and fiction can at times be muddled when reading narrative inquiry (Clandinin & Connelly, 2000). Ethical issues shift as research moves through its processes, but I kept a close eye on limitations, delimitations, and ethical issues (Clandinin & Connelly, 2000).

#### **Limitations**

Limitations are features in a study that might affect the results or my ability to generalize findings (Roberts & Hyatt, 2019). Qualitative research methods are limited by subjectivity and personal bias because of the involvement that I had within the study (Merriam & Tisdell, 2016). A limitation in my study was the small and spread-out population of individuals who used S2C or RPM; I could not restrict the study to a single state. Limitations to this study included the time it would take to conduct and analyze data. I attempted to mitigate this limitation by limiting the study to five participants. The patterns and themes found during the interviews might have been

difficult to pinpoint (Christiansen, 2021). In the study of family member experiences with AAC systems used by nonspeaking autistic individuals, limitations included a small sample size from a large demographic area of sampling. It was not possible to study every nonspeaker's family member's experiences; therefore, I used a sampling of five family members from across the United States. A limitation in the study was focusing only on two forms of AAC. By limiting the study to two forms, it gave me experiences that were focused on the AAC on which I intended to focus.

### **Delimitations**

Delimitations clarify the boundaries of the study and indicate how the study's scope has been narrowed (Roberts & Hyatt, 2019). Delimitations often include the time, location, and sample size for the study and include aspects of a problem and criteria that would be included in the study (Roberts & Hyatt, 2019). By reviewing the choices made in the design of the research, what I intended to focus on and what I did not intend to cover in the research would assist me in focusing the participants on during the interviews (Bloomberg & Volpe, 2016).

In the study of family member experiences with AAC systems used by nonspeaking autistic individuals, a delimitation in the study included only interviewing family members who were over Age 18. A second delimitation, which is determined by the sample selected, was sampling only individuals who live in the United States. These delimitations support having a wide range in the sampling size and ensuring the protection of youth.

### **Ethical Issues**

Ethical issues are present in all types of research (Roberts & Hyatt, 2019). There are clear ethical standards regarding the rights of humans. This includes the right to confidentiality and consent (Roberts & Hyatt, 2019). I followed the basic ethical principles of having respect for persons, beneficence, and justice that are found in the *Belmont Report* (U.S. Department of

Health and Human Services, Office for Human Research Protections [OHRP], 2021). The basic principles are the judgements that are used to evaluate human actions (OHRP, 2021).

Respect for persons focuses on two convictions, that one should treat individuals as self-ruling and that persons with limited self-ruling have protection (OHRP, 2021). I respected persons by making sure that each participant was capable of self-determination and that all of the participants entering the study were there voluntarily. Participants verbally acknowledged that they entered into the study voluntarily.

Beneficence focuses on ensuring that people are treated in an ethical manner through showing respect for their decisions, protecting them and securing their well-being. This includes doing no harm, maximizing benefits, and minimizing harm (OHRP, 2021). In this study, I ensured confidentiality by using pseudonyms and tried to limit any harm that could unintentionally occur.

In this study, I ensured that the basic principles for ethical practice were used throughout the research process. Ethical issues could arise if the participants were to disclose sensitive information during the interview (Creswell & Guetterman, 2019). I was also aware of disclosure of any personal information during the interview. Confidentiality is most important when conducting research (Creswell & Guetterman, 2019). Having clear expectations, boundaries and process for the interviews was extremely important in this research to not have any biased influence on the interview process because of my own experiences as a parent and an educator.

### **Trustworthiness**

In qualitative research the need to clarify how one has accounted for trustworthiness is important. This includes the credibility of the research, dependability of the methods used, and transferability of research context (Roberts & Hyatt, 2019). The trustworthiness of the data is

directly related to the trust built between myself I and the participants (Merriam & Tisdell, 2016).

### **Credibility**

The credibility refers to whether the participant's perception matches my description of the information that they shared with me (Bloomberg & Volpe, 2016). To ensure that I had a close match, I sent a draft of restoried narratives to the participants, and they were provided with 5 calendar days to review and respond with any feedback and to let me know if anything did not match. The credibility of the study relied on the quality of my ability to connect, listen, and restate the stories shared with me. Following the same procedures for all interviews also assisted with credibility of the research by allowing the same opportunities for each participant and allowing them each the same amount of time.

### **Transferability**

Transferability is how well the study has been planned and followed through to determine whether similar processes would work for other researchers in their own settings and communities (Bloomberg & Volpe, 2016). Lessons learned through one study might be transferrable to other studies. By providing more detailed information about background and shared experiences, I was able to share a clear understanding of the study. Although it was not possible to generalize the findings to all settings, it will be of use for others who might conduct further research (Bloomberg & Volpe, 2016). In the study of family member experiences with AAC systems used by nonspeaking autistic individuals, readers are able to learn more about the two types of AAC used by families and are able determine whether the experiences shared might transfer to their own lives.

## **Dependability**

Dependability refers to the tracking of processes and procedures that are used when collecting and interpreting data (Bloomberg & Volpe, 2016). Providing detailed explanations of how the data were collected, transcriptions of the interviews, and checking for consistency assisted in providing dependability of data (Bloomberg & Volpe, 2016). According to Bloomberg and Volpe (2016), dependability is important when determining whether a study is trustworthy. I validated the findings by asking the participants to check their restored narratives and to provide feedback to me within 5 calendar days.

## **Confirmability**

Confirmability relates to objectivity in the research (Bloomberg & Volpe, 2016). This implies that the findings reported were a result of the research completed, not of my biases (Bloomberg & Volpe, 2016). Staying objective and keeping a focus on the research questions and not adding personal input during the interview and analysis aided with the study's confirmability. The findings are the result rather than outcome of my biases (Bloomberg & Volpe, 2016). I kept a solid trail of data and field notes which served as support in assessing findings (Bloomberg & Volpe, 2016).

## **Summary**

In this qualitative narrative inquiry, I explored the experiences of family members of nonspeaking autistic individuals who use AAC systems. More research is necessary to uncover answers to relationships among experiences and AAC (Peña, 2019). I looked at the lived family experiences of those who use S2C or RPM to retell their stories and to share them with others. Limited research has been found to support the use of S2C and RPM, two AAC systems. This is important because parents seek out alternate forms of communication (e.g., a letterboard or keyboard) when their children are unable to communicate through traditional methods, despite

many years of traditional speech therapy (Jaswal et al., 2020). There was no site for this study, for the semistructured interviews took place through Zoom with participants across several states in the United States.

Beginning with a recruitment flyer that was posted on FaceBook groups—The Nest!, GKTC Client Community, RPM Connections, NeuroClastic, Letterboard Learning, and S2C Home Education Support—weekly until five participants were interviewed. Semistructured one-on-one interviews were conducted and audio-recorded on the Zoom platform. I validated findings by sharing a draft of the restoried narratives with each participant.

The narrative inquiry process began with the interview; I and the participants engaged in conversations about the participants' experiences. I began by developing a relationship with the participant, which is important in the narrative inquiry process (Clandinin, 2016). I read and reread the transcripts and attempted to immerse myself in the data. I then worked to write restoried narratives. From the stories, I then spent time coding, and looking for themes.

Confidentiality is most important when conducting research (Creswell & Guetterman, 2019, p. 23). I followed the basic ethical principles of having respect for persons, beneficence, and justice as found in the *Belmont Report* (OHRP, 2021). Limitations to this study included the time it took to conduct and analyze data. A limitation of the study was that the research could not be measured and that all of the questions asked were not quality checked. A delimitation in the study included only interviewing family members who were older than Age 18. A second delimitation was the large demographic area of sampling from an entire country. To avoid issues of trustworthiness, I focused on credibility, dependability, confirmability, and transferability through each step of the review process (Bloomberg & Volpe, 2016).

## CHAPTER 4: RESULTS

The purpose of this qualitative narrative inquiry was to explore the experiences of family members of nonspeaking autistic individuals who use AAC systems. Nonspeaking autistic individuals are people who do not communicate by speaking (Prizant & Fields-Meyer, 2016). Family members were defined as individuals who live with someone who has nonspeaking autism. As ASHA (n.d.-b) defined it, AAC includes all the ways that a person can communicate other than speaking, including systems that spell words by pointing to letters and using a keyboard. I focused on two forms of alternative communication: S2C and RPM, both of which are focused on purposeful interventions with the intentional practice to increase motor outcomes to teach individuals how to point to letters to spell (United for Communication Choice, 2022). RPM is a method of teaching, it can be used to teach academics, to develop motor skills, and to communicate (Mukhopadhyay, 2014). S2C teaches individuals to use purposeful motor skills to point to letters to spell (Taborga, 2022). Odeh et al. (2020) conducted a study to look at 13 studies of motor interventions that had an improvement on language; at least 12 studies showed that language increased on at least one outcome.

In my research, I describe the experiences of family members of nonspeaking autistic individuals who use AAC systems. I focused this qualitative narrative inquiry on exploring the experiences that family members have had with AAC for their nonspeaking autistic family members. To understand better the experiences that family members have had regarding AAC systems, the following research questions were used to guide this study:

- **Research Question 1:** How do family members of nonspeaking autistic individuals describe their experience with identifying, learning, and implementing AAC?
- **Research Question 2:** How do family members of nonspeaking autistic individuals describe transformations within their families since implementing AAC?



In this study, I explored experiences of a specific group, family members of nonspeaking autistic individuals, with a central phenomenon, the use of two AAC systems: S2C and RPM; thus, qualitative research was best suited for this investigation. Qualitative research promotes a deep understanding of a social setting or activity from the perspective of the research participants (Bloomberg & Volpe, 2016). It implies exploration, discovery, and description (Bloomberg & Volpe, 2016). I employed a qualitative narrative inquiry as the research approach for this study. A narrative inquiry tells a self-narrative through living, telling, retelling and reliving experiences (Bloomberg & Volpe, 2016). Narrative research records the lived experiences of the people being studied and then retells their story (Bloomberg & Volpe, 2016). To gather data, I conducted semistructured interviews through Zoom. Family members of nonspeaking individuals, who use the AAC systems of S2C or RPM, were invited to participate in interviews to share their experiences through telling stories about their lives both in and out of their home within the areas of education, socialization, and employment opportunities. I then rewrote the data collected from the interviews into restored narratives, after which I analyzed the data to determine the common themes that occurred across the stories.

### **Analysis Method**

I posted a recruitment flyer (Appendix A) on S2C Home Education Support, and The Nest Facebook Pages. I also sent the administrators for RPM Connections the flyer and requested them to post it on their Facebook pages. The flyer invited people to be participants if they were family members of nonspeaking autistic individuals who lived in the United States and had experience using S2C or RPM and, if so, to email me if they were interested in participating. The Participant Information Sheet was included as an attachment in the recruitment post. I planned to send the flyer to GKTC Client Community, NeuroClastic, Letterboard Learning Facebook pages to request that the recruitment flyer be posted; however, within the first day of recruitment, I had

eight people reach out to me and only needed five for my study; therefore, I did not post the flyer on those additional sites.

The Interviews were scheduled through email by individuals who reached out to me expressing interest in participating. The first five people were scheduled for a 60-minute interview. The Participant Information Sheet was reviewed at the start of each interview. After reading through the Participant Information Sheet, the participants were asked whether they wish to continue. The participants had an opportunity to discuss any questions or concerns before the interview began. The participants then acknowledged verbally whether they would like to proceed with the interview. All of the participants acknowledged that they had read the Participant Information Sheet and that they would like to participate voluntarily in the study. Each participant was asked 32 questions during their 60-minute interview (Appendix C).

After the recorded interviews were transcribed using Zoom's auto-transcription feature, I reviewed them for accuracy. I restored the narratives, then I sent them to each participant to review for accuracy. I sent the drafts of the restored narratives to each participant via email and gave them 5 calendar days to review, retract, or withdraw information. After 5 calendar days, if the participants did not suggest any revisions, I considered the transcripts accurate. Four people emailed me with minor revisions, and one emailed me with satisfaction of accuracy of the restored narrative.

The data collected for this study came from the participant responses in the semistructured interviews. The narrative inquiry process began with the interview; the participants and I engaged in conversations about the participant's experiences. I focused on reading and rereading the transcripts to immerse myself in the data. I then wrote restored narratives, by gathering the stories, analyzing them for key elements (e.g., time, plot, place, and scene), and then I rewrote the story in a chronological sequence. Understanding information

from the participant's past, present, and future helped me to form causal links between ideas (Creswell & Guetterman, 2019). To identify easily elements of setting, character, actions, problem, resolution from the stories, I put the stories into a table which assisted me in sequencing and coding for themes (Creswell & Guetterman, 2019). From the stories, I then coded for themes according to the type of interaction (whether personal or social), timeline (i.e., past, present, or future) and where the situation took place. The themes assisted me in narrowing how the results should be presented.

### **Presentation of Results and Findings**

I created the restoried narratives for this qualitative narrative inquiry from five, 1-hour-long, one-on-one, semistructured interviews that I recorded via Zoom. Each participant self-identified as being a family member of a nonspeaking autistic individual who had experience with RPM or S2C as an AAC system they used with their family member. The transcribed interviews were about experiences of family members with identifying, learning, and implementing S2C or RPM. I wrote the participant stories as narratives, and the participants reviewed them for accuracy.

#### **Mark**

Mark is a brother of a 30-year-old nonspeaking autistic individual, Rick. Rick uses an AAC system to communicate. Mark and Rick live in Pennsylvania. Rick uses AAC in the form of a letterboard with the process of S2C. Rick began using RPM 6 years ago. Since then, Mark learned how to work with Rick as his communication partner and became a S2C practitioner who works with about 25 nonspeaking autistic individuals a week.

#### ***Identifying, Learning, and Implementing Augmentative and Alternative Communication***

Mark shared that his family learned about this type of communication from an acquaintance who had called his mother to share her experience learning about RPM with a

nonspeaking autistic individual for whom she cared. The friend shared that it had been very helpful for her, and she thought that it might work for Rick as well. Mark shared that his mother was always willing to try anything to help his brother. To learn how to use RPM, Mark and Rick's mother signed up for a 3-day workshop, after which he was doing so well with the process that she signed up for a second set of workshops. Mark remembered that his mother and father took Rick down to Virginia to see a practitioner to support him in S2C. Once his mother was communicating with Rick, Mark also learned to communicate with him as well by attending an Introductory workshop. Mark shared that Rick had a solid foundation for using S2C, having worked with a practitioner, and that, when he began spelling with him, that experience made it much easier. Mark decided to become trained through a 6-month course to become a practitioner and to leave behind his career in radio. A family friend of many years also became a practitioner to work with Rick. Together, Rick and the family friend opened a center that now focuses on teaching S2C to nonspeaking autistic individuals. Families can bring their nonspeaking autistic individual to the center where Rick and his co-owner work with them on lessons, groups, or training the family how to use S2C. Currently, the center hosts two book clubs in-house.

### ***Supports***

Before Rick learned how to use a letterboard to communicate, he used PECS and some other types of communication; however, according to Mark, it was basic and did not include very much communication: "I don't have a memory without Rick in my childhood, most of what I remember includes him trying something that my mom wanted to try to support him." Mark shared that Rick went to occupational therapy. Mark shared one intervention that stood out that worked on building pathways in the brain; it started out very simple, having a real pencil, a picture of a pencil, and the word pencil: "We helped Mark to make the connections between the object, picture, and word." Looking back, Mark realized that the occupational therapist used

much purposeful motor planning in interventions that Rick received. Purposeful motor planning wasn't necessarily the intention at the time, but Mark can now see how the interventions helped to feed Rick's brain and engage his body and brain, which might have helped with the skills he has now that allow him to communicate.

Mark shared that many children whom they knew were nonspeaking autistic individuals who received ABA therapy and that Rick had not received it. Rick participated in the Son-Rise program when he was younger. According to Mark, Son-Rise does not focus on putting limits on people; it focuses on relationships and making friends. Rick has now told Mark, from his memories of working in the Son-Rise program, that it "was one of the first times that someone outside of his family treated me like I was smart, and aware." Rick told Mark that he has very fond memories of one of his Son-Rise teachers working with him because "they didn't treat me like he was unaware of what was going on."

### *Neurodiversity and Presuming Competence*

Mark shared that neurodiversity is a broad umbrella term for people and how they interact with the world. He described that, when he works with autistic individuals, he does not ask them something he would not ask a person without autism. Mark talked about how presuming competence can be applied to anyone with whom one is interacting; he stated,

In the setting of what we're talking about with nonspeakers, it's understanding that they understand everything that's going on around them, and [that] they want to be able to share what's going on in their head. It's just their brain and their body [that] are disconnected.

Mark shared that he learned in a training that it was like when one teaches someone how to hit a baseball; one gives them a bat and throws a ball and they miss. Mark asked,

Would you go and teach the person what a bat and a ball are? No, you would assume they know what a bat and a ball are. You would teach the fundamentals of how to even hold the bat and swing it before even beginning to toss the ball.

Mark felt the term “presuming competence” went hand in hand with the term “least dangerous assumption.” Mark believes, no matter who is in front of you, that believing in their abilities and having high expectations is always the right choice.

### ***Transformations on the Family***

Rick has a large family who, according to Mark, have all noticed a big difference in him since he learned how to communicate. His family has always treated him with respect, and they talk to him no differently than they do to any other family member. Mark shared that one uncle calls Rick “Letterman.” Mark said the impact on his family “has been massive.” His family always treated Rick as a respected family member, but none of them realized the depth and perception that he was holding within. Mark said, “I learned my brother was just as big of a smart ass as me, if not bigger!” Mark shared that Rick is “quick on his board and will have a smirk on his face when throwing a zinger back at me.” Mark said, “No one realized what was stuck inside of him.”

From Mark’s perspective, there have been no negative impacts from learning how to use a letterboard as AAC. It has drastically improved Rick’s life and his brother’s relationship:

It comes down to a sibling relationship which is phenomenal, our relationship is just like anybody else. The two of us are brothers and while he does have a quick wit, he’s incredibly perceptive . . . [if] you think about it, his entire life, all he’s done is observe.

Challenges still exist for Rick regarding emotional regulation. Being autistic, Rick’s emotions come outward and that can lead to frustration on his end. According to Mark, Rick has to try to sort through emotion and communicate that to somebody. Mark described, “Rick is

having to think, okay, how can I craft this in a way that they're going to be able to follow it, while managing my already heightened emotions?"

Mark shared a proud experience when his brother was given a parasailing experience as a gift. They were able to ask Rick if he wanted to go and he told them he wanted to give it a shot. Mark shared a picture of Rick parasailing, and he was smiling ear to ear. Mark said he absolutely loved it, and when they used the letterboard after the experience to see what Rick thought, he said, "That was so much fun. I really enjoyed it." When a practitioner with whom Rick works asked him about parasailing, Rick said, "I was a little nervous at first, because I was afraid that my body would let go of the harness, once we went up, I felt like my body went weightless, and I just really enjoyed it."

Mark shared that Rick wants to be a consultant for businesses and wants to help to support making businesses a little more autism friendly. According to Mark, Rick feels that there are a lot of people who still do not know how to interact with people with autism. Rick wants to consult with businesses to educate them by having a conversation about autism and how to treat people, specifically nonspeaking autistic individuals because it is not necessarily their fault they do not know. Rick wants to go into business and show them how to interact with autistic individuals. Mark shared that he has seen the difference it makes when someone is treated as an equal. In his own experiences, when Rick and his friends are treated just like everybody else, they are happier and calmer. Whereas, if someone acts afraid of them, that makes them afraid, too, and it makes them tense, and then it becomes a cycle that just continues to perpetuate itself. Rick talked much about this idea.

Mark shared a few months ago that a close family member had died at a young age. He shared that Rick was having a very hard time working through his emotions. Using the letterboard, his family was able to talk to Rick about how he was feeling. Without the letterboard

his feelings would have been bottled up with no outlet. Another family member who was extremely close to Rick died a few years ago. Rick was able to write an entire screenplay about his relationship with him. Mark shared that he wrote it in a Ferris Bueller sort of way in which the main character is the nonspeaker. Mark stated,

It's him, but he breaks the fourth wall to talk to the audience, but when he's not talking to the audience, his character is a nonspeaker. It was a unique concept that he had to be able to explain. Like "This is what my daily life is like, and this is what it's like this: what it was like for me to go through the passing of someone who was really important to me."

Every so often Rick stays overnight with Mark. Sometimes they watch movies. Mark can now ask Rick, "What are you in the mood for?" He is able to say, "Let's watch something that's funny." It's the things that are simple that he now can take part in. He has a say in his daily life now, and has told Mark, "It's nice to be part of the conversation instead of the subject of it." Mark thinks that that says it all, that Rick is finally a participant in this life, instead of just watching from the sideline. Mark shared that, because Rick is able to use a letterboard to communicate, that ability has brought him and his brother much closer. He shared that Rick's personality definitely comes from the household in which they grew up! There are very few things that the brothers will not joke about. Mark laughed, "and in typical sibling fashion he'll rip me, and I'll fire one right back at him." Rick has no problem throwing a couple of barbs in Mark's direction.

Mark shared that some teachers with whom Rick has worked in the past and who see him communicating now have apologized for treating him like a little child. They have felt horrible and have said that saying sorry was not enough. Mark shared that Rick tells them

There's no bitterness for me, you were all working off of the information that you knew at the time, and I can't be bitter about that. I can't expect you guys to have known what



we know now. Because, if you knew 20 years ago back then what we know now, you would have jumped right on board. I'm not going to hold any resentment toward you now.

### ***Behaviors***

Mark shared that Rick had a few instances of behavior that was concerning prior to learning to communicate. One time, Rick eloped and was lost in the neighborhood and after a few hours the family found him. When Rick was younger, the biggest challenge was that he would scream for hours. Rick does not scream anymore, but Mark remembers it happening throughout his childhood. Mark now describes Rick as "pretty chill." "It was one of his mentors at a day program, who made it her mission to work with him, and to get him into a better place. My mom and dad can't speak more glowingly of this woman," Mark remembered. Mark said this woman built a relationship and worked until she found a way to connect with Rick and eventually, he stopped screaming. Mark shared that. When people see Rick who worked with him when he was little, they are amazed by how much he has changed and how much he can communicate, and they cannot believe that he is the same child they knew. A former staff member told Mark, "I'm amazed at how far he's come. He's come so far, and I'm so proud of the work that that you guys have put in, and that he's put in to get to where he is today." Mark said, "It has taken a lot of work to get to where we are, but it has been worth every minute."

### ***Advice for families considering Augmentative and Alternative Communication***

Mark shared that he is not a parent, so he would not understand what parents go through until he is one. Regarding the experience as a sibling, watching his brother learn to communicate using a letterboard, Mark said that, at first, "[I was] skeptical of my own brother." Mark remembered looking at his brother's spelling, and thought, "What are you talking about? What do you mean? It's that simple? There's no way it's this simple. It's right under our nose. This is

the way out!” Mark was skeptical for a while, but the turning point for him was when he saw Rick spell open-ended for the first time. Mark said, “My mouth was wide open, and I probably looked like a codfish.” Mark thought to himself, “I have to learn how to do this.” Mark encourages families to be open minded to seeing their nonspeaking autistic individuals in a different way. Mark encourages others to try to be as open-minded as possible, because there were several things that he thought about his own brother that were completely and totally wrong.

For siblings who are growing up with a brother or sister with autism who have not learned to communicate, Mark advised,

Just try to be that person that they can come to and be that person that can support them, even without words. Try to be patient with your sibling and put yourself in in their shoes and to try to support them as best as you can.

Mark encouraged treating nonspeaking autistics as one would anyone else, “If they’re 23 treat them like they are 23.” Aside from going about things in age-appropriate ways, Mark recommended coaching a nonspeaker’s body first. Sometimes, with spellers, their bodies get stuck, and it is not because they do not want to do something. “They just they have lost awareness of where their body is in space,” Mark explained. Mark shared an example:

If Rick grabbed my arm, instead of saying, “Hey, let go,” you can coach the body by saying, “Let’s open up the fingers, open up the fingers on, uncurl the fingers,” and you might have to even coach them to do that. Just gently. Bring your fingers up and go.

“Okay, open those fingers, open them up. Good. Keep that open, keep it open.”

Mark encouraged families to keep a calm demeanor. If one’s demeanor rises up, then their demeanor will rise up. So, if one stays nice and calm, one can help them. By coaching the body part and voicing what one wants to see, one can yield much positive results for

nonspeaking autistic individuals. Sometimes, their bodies just get stuck, and they just need that little extra coaching to get them to where they need to go. Mark closed our interview sharing, “It is not lost on me on how, how fortunate I am!”

### **Jade**

Jade is the mother of Cedric, a 22-year-old, nonspeaking autistic individual. Jade is also Cedric’s teacher for homeschool and his CRP. Cedric uses the AAC system in the form of a letterboard and the process of S2C. Cedric is also learning to use a keyboard with an iPad for feedback, but this is an emerging skill, and Jade described it as “very challenging for his motor system.” Cedric began learning the RPM 7 years ago. Since then, Jade has become an S2C practitioner, and Cedric has recruited another S2C practitioner with whom he works once or twice a week.

### ***Identifying, Learning, and Implementing Augmentative and Alternative Communication***

Jade first learned about RPM from a woman whom she met whose son was using a 26 stencil letterboard. The woman lived in Atlanta, and Jade met with her over Skype so that Jade could watch her son spell. Jade asked the young man who was spelling whether this was something she should try with Cedric and the young man spelled, “Absolutely!” A practitioner that the woman recommended happened to be doing a workshop the following month 3 hours away from where Jade lived. The workshop for spellers was full, but Jade and her daughter were allowed to go and observe. For 3 days they sat and watched, via closed circuit television, the practitioner worked multiple times with seven or eight families. Jade said, “[I] took reams of notes and could hear the practitioners voice in her head prompting.” Jade saw enough to know that she was going to invite Cedric to use RPM and S2C. She bought the stencil letterboard and lessons and started working with Cedric for 15 minutes a day. Each day Jade and Cedric would sit down, and Jade said, “[I] would do my best to prompt his body to get to the letters.” Once a

month, they would send a video of them working together to the practitioner and then would do a Skype session for feedback. Sometimes Jade would talk to the practitioner on the phone or on Skype and Jade would be given “marching orders” for the ways to improve her skills as a CRP. They started in July and, in September, Jade, her husband Matt, and Cedric went to Virginia for a week to work on spelling. Cedric had two sessions a day with practitioners, and Jade and Matt watched and were given training to work with Cedric. The practitioner told Jade that, if she organized a group of families in her area who were interested in learning to spell, she would come there to do an outreach training. The practitioner they worked with began teaching RPM but transitioned to teaching S2C early in Cedric’s journey.

Jade organized a parent S2C group at her local library which met every other month. In 2017, 2018, and 2019, the mentor S2C practitioner traveled to their area and offered training to Jade, Cedric, and 10–15 other interested families. Jade said, “Each outreach was 3 days that were very helpful because they were very intense.” Jade said that having two sessions a day helped “my skills get a lot better.” Jade had the opportunity to watch other families and to help them get started on their journey.

### ***Supports***

According to Jade, Cedric has no words that can be spoken and understood. The family was told first to use PECS. Jade described this as printing, laminating, and cutting out small pictures on which she would put Velcro and keep in a book. Jade made hundreds of pictures and, for 4 years, the family had wall to wall carpet on their walls because the little Velcro pictures could stick on the walls. Jade said, “The only person who ever used them was me. So, that didn’t work.” No training was provided on PECS for the family.

Cedric also was introduced to ABA in preschool. The challenge with ABA was, as Jade described, “Cedric never played the reinforcement game.” The ABA therapist would say,

“Here’s a skittle, here’s a skittle, look, look, look! Look!” Cedric would take one, and then he would not want anymore. Jade explained, “If you don’t have a reinforcer, ABA doesn’t work. Cedric was not a very welcomed candidate for any ABA programs.”

The next trial for Cedric was sign language. Jade took sign language classes that she found on her own and she tried to work with Cedric on learning this skill. Jade said, “Sign language didn’t take off.” Next, the family was introduced to Touch Talk, but it required motor skills with which Cedric did not respond. Then Cedric tried Proloquo2Go at school on the iPad. Then the family tried the Language Acquisition through Motor Planning (LAMP) program, which Jade said, “Is so hard, and the thing about all these programs is the SLP teachers have the best of intentions, but they would just throw them on us with no training.” Jade said, “I was just handed the device with a new program and no training.” At that time, Jade said,

I didn’t know about coaching the body. Perhaps all of those methods would have worked better or had more possibility of working if I had known to coach his body . . . those are all the ones that we tried, and none of them ever worked for us.

Jade shared her and Cedric’s experience using the Social Communication Emotional Regulation Transactional Support (SCERTS) model. SCERTS had very precise elements that were used in Grades 1–3. Jade talked about going to meetings at school and having a whole assessment done, with reports written up, but “Nothing would change.” Jade found that the SCERTS model had “lovely ideas, but the implementation is a little weak.” As a parent, Jade observed that no one at the school had training in the model, so Jade was running the meetings, but it was not producing results.

Prior to Cedric learning how to use a letterboard to communicate, Jade shared that they had done the Son-Rise program prior to S2C. Jade and Matt decided that, when Cedric was in fourth grade, to homeschool him and to use the Son-Rise program, which is offered through the

Autism Institute of America. According to Jade, Son-Rise used to be in person, but with COVID-19, it became an online program. Son-Rise trains parents how to work with their own autistic children. Jade shared, “That’s what I loved about Son-Rise, I was in charge. I got to hire the people I wanted to and train them the way I wanted to and give them the feedback that I wanted to.” This worked for Jade, Cedric, and their family. Being at home also reduced all the distractions at school. With Son-Rise, Jade said, “The training is specific to parents, and it gives you a really clear Boom! Boom! Boom! This is how you can do it for your child.” Jade shared that she trained, over the course of their experience with the Son-Rise program, 60–70 different volunteers. Some volunteers would just come for 15 minutes, but decide it was not for them, while other people volunteered weekly for years. Jade said,

Son-Rise is really great, because it helped me look at my beliefs about my child. And what beliefs would be useful for him. It was based on where I . . . where we want to go, and I think that experience really helped me. Then I was able to say, “Hey, you know, speech isn’t going to work” . . . it was really hard to give up that dream of speech and go for S2C. I think one thing that parents don’t really, and I didn’t realize is that going for augmented communication doesn’t mean you give up on speech. You can do both, often when we go for augmented of communication, or we go for a spelling, the child starts to communicate using speech, not always. It’s kind of like learning two languages. You can learn Japanese, and you can learn English, and there’s not going to be a conflict.

Starting out spelling, Jade used three letterboard stencils (Appendix E) with Cedric and would use the lessons that their practitioner sells. She gave Cedric two choices of lessons (e.g., a lesson about the gym and a lesson about potato chips), and then asked him which one he wanted to do. Jade would try to start with two that would be on the same letter stencil. Then she would prompt him verbally by saying, “Okay, which one?” Jade would give him a pencil that he would

use to poke the letter on the stencil. Jade would prompt, saying, “Go, go, go, get it, get it, because I have no idea where you’re going. Go, go, go, go!” Jade would give him lots of prompts and at first, she didn’t realize that she needed to prompt his eyes to look to the letters to which he wanted to point. That was one piece of feedback she received during one of her Skype meetings with the practitioner. At first, Jade said that Cedric “would sit in the chair. He would come, he was very cooperative.” After a while, Cedric started moving to the floor and Jade shared, “Because I was so excited about him spelling, I went to the floor with him. Now, I know that it would probably [have] served him better if I had stayed in the chair with him.” Cedric now spells a lot while sitting on the floor.

Jade was cautious about pushing Cedric to spell outside of the home because the practitioner shared that it could increase anxiety and then the motor could be harder to perform. Jade said, “I know that from learning foreign languages, I could do it in class fine, and then I go out in the community, and it’s much harder to speak.” Jade thought it was about 2 years before they were able to communicate anywhere.

To Jade’s surprise, when speaking about Cedric, she shared, “He’s not shy!” Jade said, “It really depends on each person’s personality and their confidence level. I think it helped that we had worked with so many volunteers. I would always say to him, Cedric, you’re training these volunteers to be with someone who has autism. You’re changing the world because these people that come to our home have never met a nonspeaking individual. You’re training them how to be with someone with autism.”

Jade shared that they had two volunteers who became competent working on spelling with Cedric. However, the two volunteers were “young people who didn’t stick around. Not because they didn’t want to work with us anymore, but because they [had] other aspirations.”

### *Neurodiversity/Presuming Competence*

Jade shared that she had read *NeuroTribes* (Silberman, 2016) and most recently *May Tomorrow Be Awake* (Martin, 2022), both of which were focused on neurodiversity. Jade shared, “I love that neurodiversity is an avenue to every for everyone to be accepted for how they are, and the unique ways that we each think.” Jade said that this was Martin’s (2022) idea. Jade said, “One of his arguments was that we are all a bit neurodiverse, and that the more we can accept our differences, then the more we can see our similarities, too.”

Jade said, “Presuming competence is the least dangerous assumption we can make about anyone’s intelligence. Cedric reminds me regularly that intelligence is invisible. When I presume competence, I’m believing in the individual I am with.” Jade explained that presuming competence is believing that the individual completely understands what is being said and is able to reason fully within their head. Jade said, “I know that listening does not have a look. If it did, no one would be able to be a spy! Listening Is learning.”

### *Assessments*

Cedric completed the Vineland Adaptive Behavior Scales (Sparrow et al., 2021) and other assessments when he was evaluated at Age 6. The Vineland Adaptive Behavior Scales is the leading instrument for the diagnosis of intellectual and developmental disabilities. The school psychologist, who had previously never met Cedric or Jade, evaluated Cedric. The psychologist wrote a report, but Jade contested it and chose to have an independent evaluation conducted. Cedric was evaluated again that same year, using an independent evaluator. The school district that Cedric attended evaluated students every 3 years; therefore, at Age 9, he had a second school evaluation. Jade said, “That school psychologist told us he no longer had autism.” Again, the family did an independent evaluation because they disagreed with the conclusion. Jade shared that Cedric again had “the whole slew of tests, battery of tests and we got this huge report, and



they told us that his intelligence was that of a 2-year-old. They told us he couldn't talk." The assessments shared no strengths, they only focused on deficits.

Jade said that they had a speech evaluation completed at the Children's Hospital because she wanted to find an alternative way for Cedric to communicate. They went to review the speech evaluation, but the SLP "basically told us that he wasn't ready for AAC," Jade said. They told Jade, "He couldn't do anything because we hadn't started with object identification first." The family was told to start with a board that had objects on it like a shoe, cup, or spoon, and Cedric had to point to the object. Jade was then to take the object. Until Cedric could do that the SLP would not recommend any augmented communication. Jade felt that she was "less than competent." She said, "None of these evaluations back then showed his potential that you see today in writing songs, doing high school or beyond math, his advocacy work, and making friends. None of them." Jade shared that that was why her family chose to leave the school system. She also shared that, since leaving the public school system, each year she would write a letter saying that they were home schooling. No one ever checked on them. Jade said, "I had reams of documentation of what we were doing. But no one ever called us, no one ever came, no one ever checked to see if we needed anything."

### ***Transformations on the Family***

Prior to spelling, Jade knew her son was intelligent, but Cedric could only communicate food requests. Cedric's family recognized how intelligent he was and validated that they kept believing that there was intelligence inside of him. Jade always said to his teachers, "He's got to be understanding more, or he'd be more frustrated, and he [is]!" Jade discussed how intuitive Cedric is and how, when he was in first and second grade, he had an all-female team of staff that worked with him. Jade would know when the women were menstruating by the attitude that Cedric would show when he came home. Jade said she could tell the staff members were having

their periods because of the major change in what she saw from Cedric once a month! Jade said, “Cedric is intuitive and very sensitive to smell. So, he may have smelled the sanitary napkins or felt the difference in attitude of staff.” Therefore, Jade “knew he was smart, what I love about spelling is his ability now to communicate and can demonstrate his intelligence.”

The first time Jade had the courage to ask Cedric a question that was not in a lesson was an open-ended question on Memorial Day, 2018. The family was trying to plan something to do and did not know where they wanted to go. Jade said, “Hey, Cedric, where do you want to go?” Cedric spelled “ice caves.” Jade and Matt looked at each other questioning whether there were ice caves! They looked it up and found that, 2 hours away from where they lived, there were ice caves. They had no idea! The family packed up the car and went. It was a beautiful day. They went to the ice caves and hiked 3 miles to get there. Jade said, “It was absolutely magnificent, such beautiful ice caves.” When they came back, Jade asked Cedric how he knew about the ice caves. Cedric spelled, “I heard about it on the radio in 2015!” Jade looked online and found reports that had been on the radio in 2015 where there had been a tragedy at the ice caves in which they collapsed. There had been a great deal of media coverage about the ice caves. The family would never have gone there if Cedric could not have spelled.

The opportunities that are now available for Cedric on Zoom are “just fantastic,” Jade shared. She said, “For Cedric, being in a Zoom classroom is more useful because he gets really loud. So, he doesn’t disturb other individuals because you can mute.” Jade talked about Cedric’s weekly schedule, which is now full of classes, social groups, writing songs, and getting together with friends, and how he also is now meeting weekly with a friend in person with a new practitioner who has a practice near where they live. Jade said, “When these spellers get together, they have a unique way of being with each other. First meeting, there was some tension, but yesterday’s meeting was like butter.” Cedric is now able to express his support for others. Jade

shared an example: the other young man leaves the room a lot and when he only left twice during the hour session, Cedric spelled “It’s so great that you stayed in the room.”

Cedric’s week is filled with activities; he has several group meetings with peers, and Jade and Cedric usually do some outdoor activity daily. Cedric takes part weekly in a book club and I-ASC meetings and works with an occupational therapist on purposeful motor actions. Jade said, “[This] has really helped me work on purposeful motor, and I recognize how to coach better.” Cedric has a class with an S2C practitioner and another speller. He is also in a sensory group, and a song writing class with a musician and songwriter. He rides horses, and he has a writing class. Cedric works at a local barn, and he usually teaches a dance class. This week was special, Cedric was presenting at an online concert for spellers a song that he wrote with two friends. Cedric visits his grandparents often who are now in their eighties. Cedric’s grandparents are both educators, and so they are always so excited to see Cedric spell!

### ***Behaviors***

Cedric had a lot of self-injurious behaviors before spelling. This also contributed to one of the reasons that his family decided to homeschool. At that time, the behaviors were getting worse. Jade shared, “We just thought, ‘Hey, this isn’t working. We’ve got to do something different.’” Since then, Cedric has been able to spell,

We’ve really seen a drop in those self-injurious impulses. I really do like to call them impulses, because it reminds me that there’s no intention behind them. When he has these self-injurious impulses, it’s his body taking over and it’s his body that’s in control. It’s not his brain telling him to do it.

Jade talked about her experiences prior to being an open communicator on the boards. She said that the biggest challenge was that Cedric would attack them in the car. Cedric is more than 6 feet tall. He would scratch and have episodes where the family would have to pull off the

road and just get out of the car and wait for him to calm down because it was not safe to drive. Jade said since becoming open and fluent on the boards this had not happened. She said, “I think we’ve gotten better at listening to what he’s saying, because we’re really trusting that it’s an impulse, not a behavior.” Now that the family can talk with Cedric, and he can spell to them what’s happening, they have not seen the attacks occur.

At times, Cedric would hit his head with an open palm and, sometimes, he would make his head bleed. “When he does it now, it’s usually because he’s not feeling well or there’s some other environmental stimulus. It’s too hot. It’s too cold.” Jade shared, “There’s maybe a tree being cut around in the neighborhood, or some sound that’s triggering it.” Now, Jade can tell him, I hear that, too. Jade really wants teachers to understand this because it took her so long to get it. She said,

I’ve been doing this since 2016, and it’s really this year that I understand that these self-injurious actions are an impulse, like blinking, for Cedric when he is feeling those intense sensations those impulses are like what blinking is for neurotypical folks.

Jade believes part of it is changing the language. She feels it would be helpful for parents and staff to realize that it is not defiance. Jade described it as “a neurological glitch.”

Jade believes that, for Cedric, it comes down to his impulsive body, “He’s never refusing to do something. He just can’t get his body to do it.” The word refuse is challenging for Jade. Jade described Cedric spelling that he wanted to make a smoothie. “He is able to come over, unscrew the milk, pour some milk in the blender, and then sits down the milk, and then he leaves the area without finishing making the smoothie.” Jade shared that she would say, “Hey, wait! There’s more.” Cedric spelled, “I can’t, my body. I can’t do it.” Jade honors that because she is so excited [that] he got the milk, and then next time, he will be able to do more.

One time, the family was on an airplane and had to get off because Cedric's body was so out of control and his family could not help Cedric get his body under control. Jade was really happy with herself because she was able to stay calm and not become upset herself. Jade shared that Cedric had communicated with her, "When he's having an episode like that, if we're calm, it's more useful. I kind of relate it to having a seizure. When he's hitting his head, screaming, there is no way to bring him out of it." They had to get out of the airplane. Luckily, the airplane was still on the ground, so they could get off the plane. Jade said,

The whole issue was [that] the plane had been delayed. The airline kept saying, "In 15 minutes we're going to go." Fifteen minutes would go by, and Cedric felt that they were lying. Cedric really doesn't appreciate it when people lie.

Jade said, "There was a woman who was sitting near us, who was very judgmental, and was having a hard time being near him. Cedric, he was feeling that, too." Jade said, "That was then, and now he's a different person. Let's do it again and see, you know, because we want to learn and grow!" Cedric recently has completed two cross-country trips on airplanes. Jade shared,

Not only did it go well, but we had a baby who screamed for 2 hours at the beginning of the flight on the way back. Cedric did well with that, he probably did better than I did!

Then he slept!

### ***Advice for Families Considering Augmentative and Alternative Communication***

Jade shared that she and Cedric recently talked to a family with a 7-year-old, nonspeaking autistic individual. Jade would advise anyone who was considering spelling to talk to a speller. She said, "Ask your questions to a speller because they are the experts." Cedric spelled to the family, "Do it!" Jade explained learning to spell is a journey it, it does not have to be rushed. For the 7-year-old, she recommended to get outside. "Do all the activities and support

all interests and introduce all kinds of materials.” Jade said, “If they don’t want to spell one day, just be easy about it and let them know you’ll be there when they are ready.” The more fun someone can have with introducing spelling, especially with a young person, the experience will be better for all. Jade recommended, “Just experiment and do it because, there is nothing better than having a robust system of communication.” She mentioned, “Proloquo2go is great, but somebody else has to program it.” Proloquo2go is an app that can be used for AAC on an iPad. It uses pictures that, when touched on the screen, produce a voice output (AssistiveWare, 2009). Jade asks parents, “How would you feel if someone else was programming what you’re going to say when you have all the words in your head?” Jade said,

Consider the idea that your child is impulsive, and that purposeful motor is really, really hard. I can put three objects down on a table that are not preferred objects, but just three objects like a pencil, a cup, and a coaster. Then I’ll ask Cedric, “Okay, which one would you like to pick up?” And he’ll spell and tell me, “I want to pick up the coaster.” I will then say, “Okay, great, pick it up.” Then, I literally have to wait 5 to 10 minutes until he gets his body over to it and picks it up. It’s so hard and so much work for him to do.

Despite this difficulty, Jade would tell families “Go for it. Find a practitioner you can work with.” She also tells families,

You be the CRP, you’re the one on the carousel. A SLP told me, you’re on a carousel and SLPs, occupational therapists, teachers, they get to hop on and off, but you’re the operator and as the operator, being able to communicate with your child is . really is life-saving.

The only negative thing Jade could think of about spelling is that other people will think that they can just pick up a board and spell with Cedric. When he broke his finger, they went to an occupational therapist and the therapist wanted to just pick up the board and use it. As a CRP,

one has to be very present to where the speller is pointing, and to hold those letters in their head, so that then they can help form the words. Unless one practices that, it doesn't just happen naturally. "Or at least it didn't come naturally to me, I had to really practice," Jade shared. For families who are considering using a letterboard to spell as AAC, Jade said, "There's no side effect. It's not like taking medicine with a risk of a side effect. You'll strengthen the skills you and your child have. It's not going to hurt speech; it'll help that center in the brain develop."

### **Lydiann**

Lydiann is the mother of Martin, a 16-year-old, nonspeaking, autistic individual who uses AAC systems. Martin communicates using a letterboard through the method of S2C. Martin began using RPM 8 years ago and, since then, has transitioned to working with practitioners using S2C.

### ***Identifying, Learning, and Implementing Augmentative and Alternative Communication***

Lydiann first learned about RPM from another mother. Lydiann and Martin used to receive services through the Son-Rise which is a very child-centered, play-based, therapy intervention. Lydiann described Son-Rise as "another like outside the box type of thing." Lydiann said, "I made a lot of connections with other parents that way, and one of the other Son-Rise moms I knew was doing actually RPM at the time." Lydiann spoke for an hour or more on the phone with this mother who told her what a difference it was making for her son the things that she was learning about him. Lydiann had heard of it before in conferences, but just did not really fully understand what it was until she heard a parent perspective. Lydiann said, "When the parent told me everything that her son was like starting to communicate to her, I was like, well, what do we have to lose?"

Martin's first session was with a practitioner who used RPM, but who transitioned to teaching the S2C method by the second time Martin had seen her. The very first thing Lydiann

did was to go to an outreach presentation that a practitioner offered a few hours away. The practitioner gave an overview of what RPM is and the science behind RPM, and then explained technical information on what she was doing in a workshop with spellers. Lydiann did not sign up early enough to get Martin in for a session but was able to observe other kids' sessions. Lydiann still remembers the first person she ever saw spell. The practitioner asked the audience, "What are some of the words that you've heard used to describe your kids?" There was a speller in the audience, and the practitioner asked the speller, "What have you heard people use to describe you? She spelled, "stupid." Lydiann said, "It was the first time I had ever seen anyone actually spell, I was hooked right away, because it was amazing to see it in action." The first time Martin actually used a letterboard was with the same practitioner when she came back to the area for a second time. Lydiann spent the next year, between her first and second visits, working on the things that the practitioner taught them and doing vision therapy. Vision therapy teaches a child how their brain controls the eyes to improve visual skills and how to use the skills to improve learning, reading, and attention (Lazarus, 2020). The family started with using three stencil letterboards, doing academic lessons at home, and practiced, practiced, practiced. Lydiann shared, "It's hard to remember back because he's been spelling for 8 years, and he's been open for 7 [years]. It took us like a year to get to open." Being open means Martin can be asked and can answer open-ended questions.

Lydiann mentioned vision therapy, which she felt really worked on gaining control of Martin's eyes to help support his visual motor. When the family first started using S2C, they were still working with the Son-Rise program, so they spent a lot of time working on isolating one finger for him to be able to point because he had a hard time using a pencil to poke letters on the stencil letterboard. Lydiann said,



I feel like I could give you like 1,000 examples of different things that that we've worked on. Right now, he's really focused on trying new foods and working through the sensory aspect of eating. There's motor involved in that, too. We work on coaching his body, to even just open his mouth for something that that he's not used to, or to keep his hands down because his reaction is to shield himself from something that that is not a preferred food.

Lydiann shared that they work on specific exercises to assist with coaching motor. He has been working on helping to put the silverware away. Lydiann said, "We're constantly working on breaking down motor steps. Sitting in a chair is one of his big goals. He really wants to, so we are trying to coach his body to stay sitting in a chair." Lydiann said, "[We] tend to do a lot of rotating between stuff."

Lydiann started by doing lessons on interesting topics and, in the beginning, only asked questions she to which knew the answer so that she could assist with coaching his motor. When Martin would point to letters, he would be off to the right or the left of a letter Lydiann would coach him by saying "to the right" to help him refine the practice of aiming at the letter to which he intended to aim. The alphabet was divided up between three separate boards to give Martin a nice big target to focus on. Initially, they practiced at home, and then they would have a session with one of the practitioners. Martin spelled more fluently with the practitioners than he did with Lydiann. Therefore, his first open-ended communication was after they had practiced for a year in between sessions with practitioners. When recollecting Martin's first open-ended question response, Lydiann shared,

I still remember what he said. The practitioner was doing a lesson on the Wellenda brothers, [who] were daredevil high wire walkers who had gone across Niagara Falls without a safety net. They had broken a world record, and the practitioner asked Martin

to imagine that you've just broken a world record. What is it? Martin spelled, "The practitioners name smartest student."

Lydiann said, "What I love so much about this is it's classic, Martin! It's hilarious to me that's the first thing he's spelled wide open!"

Initially, there was a cost to receive the interventions. As a family, Lydiann said that they "figured it out." They did some fundraising and figured out how to pay for S2C services because there was no local practitioner at the time, and they had to travel to access services. In the beginning, the biggest challenge was being patient. Watching Martin work with practitioners who had so much more experience than Lydiann did, she wanted to be as good as they were right away. Lydiann described, "Sometimes I would get frustrated or hard on myself when things weren't happening as quickly as I wanted them to." Over time, things started flowing better. It was just a matter of practice, practice, practice. Lydiann stayed the course and overcame the challenges presented because she felt that this was going somewhere that was going to be meaningful for him. Lydiann described this change

like having a light turned on in a dark room that you could feel your way around, if you think about literally being in a dark room, especially if you're kind of familiar with the room you're probably not going to fall flat on your face, tripping over anything. Then you flip the light on, and it's like, "Okay, there's all these details that you're missing underneath." That's what it's like, having a light turned on to let me actually see my kid for the first time.

### ***Supports***

Lydiann shared they tried traditional speech therapy; Martin began early intervention at 18 months old as he was diagnosed very young. In the early days, there were many picture cards

and picture schedules with which they had minimal success except for a few preferred activities.

Lydiann said,

Honestly, a lot of times, those picture cards we had laminated picture cards all over our house, and more often than that, most of them just ended up becoming something that he would stim with more so than a communication tool.

The picture worked enough they could see him making connections. This was one of the things that that helped Lydiann early on to recognize he was understanding more than he was able to communicate. Lydiann shared that Martin also briefly did ABA. Lydiann said they did it regularly for few months before he was school age. They also worked with a speech therapist, who was a board-certified behavior analyst. Sometimes in sessions, she would incorporate ABA. Lydiann did not find this effective and described the sessions as “match, this red ball to that red ball, match this green cup to that green cup.” Martin was a child who, if he did not see the point in an activity, he would not want to put in the effort. According to Lydiann, ABA never did anything for Martin. It did not feel right to Lydiann because she has always been drawn to relationship-based interventions, which ABA is not.

Lydiann shared that they tried a couple of different applications that were also picture-based. “I mean the vast majority of anything that anyone ever tried with him prior to RPM/S2C was picture-based,” Lydiann said. Martin tried the Proloquo2go application on an iPad. Martin would practice making requests and have some success; however, each time a new picture icon was added, all the other pictures shifted position on the screen. Martin would still be pointing to the same spot where the former picture appeared. His body had memorized the previous motor plan. It was not effective for Martin.

Then they tried LAMP. Unlike Proloquo where the icons shifted when you added a new one, in LAMP the pictures always stay in the same spot. The LAMP core vocabulary includes

about 80 little picture icons on one screen. Lydiann shared that they did have more success with LAMP than with Proloquo2go because, again, everything stayed in the same place. Even though Lydiann considered Martin's progress successful, Martin only ever got to basic requests, so he could request a drive, food, and two or three preferred activities.

Lydiann also tried something with Martin called Prompts for Restructuring Oral Muscular Phonetic Targets (PROMPT). PROMPT was focused on physical aspects of speech production such as movements of lips, tongue, and jaw. An SLP uses tactile cues (e.g., gentle pressure on the face and neck) to correct movements for producing speech sounds (Vollmer, 2023). Lydiann believes, "It's the only thing we ever did that actually seemed to make a bit of a difference." Although Martin had minimal success, Lydiann could tell that it was doing something for sound production. Martin's apraxia is very severe, so it was a challenge to get very far. Lydiann said, "I think we could have kept doing that for years, and we wouldn't be anywhere near the level of communication that we are at now."

As mentioned previously, Lydiann loved the Son-Rise program. They learned about how perspectives and attitudes for one's child are important and still use many of the techniques that they learned. There are certain things that Lydiann still draws upon. Lydiann said, "I'm grateful for that experience, because it was a very positive experience overall."

When Martin first started S2C, he was still using Son-Rise as well as LAMP and, once he became open, they continued using these for a while. When Lydiann asked him whether he wanted to continue using LAMP, Martin spelled, "I don't really see the point when I can say whatever I want with my letterboard." Spelling was and is Martin's preference.

### ***Neurodiversity and Presuming Competence***

In Lydiann's family neurodiversity means, "An acceptance of who Martin is and knowing there's nothing wrong with him just because he's different . . . [It is] a celebration of

those things that make him the unique individual that he is.” Lydiann finds Martin fascinating in the way he looks at things and how he sees the world because he has synesthesia. Synesthesia is when you experience one sense through another such as is seeing things or people as colors (Nelson, & Melinosky, 2023). Lydiann wishes she could crawl inside his head for a day. Lydiann said, “We are trained as human beings to interpret body, language, or facial expressions in certain ways and it took some practice to get past the assumption that, because his body was doing something, that was his true motivation.” For Lydiann, believing in his desire to do things, his ability to do things, and certainly his cognitive abilities made it easy for her to presume competence of Martin’s mind. It was harder for her to get to a place of presuming competence of his body.

### ***Assessments***

Martin was homeschooled from Age 5. Prior to that, he was in early intervention and preschool at their county board of developmental disabilities, but he never went to public school. He had an Individual Education Plan (IEP) because the family was receiving funding for therapy services, but he was never schooled in a traditional setting. Lydiann refused the IQ testing because “early on, I was scared of what it would say.” As Martin has gotten older, she refused it because she does not care what his IQ score says. She is confident that IQ testing would probably show that he has an intellectual disability because of the way that testing of an IQ is measured, but she has “seen plenty to know that he does not have an intellectual disability.” Lydiann described assessments as “heartbreaking for me, even though they weren’t necessarily focused on intelligence, it was just everything focused on what he cannot do, very little on the strengths. So, they were always pretty depressing for me.” Now, Lydiann “takes them with the grain of salt.”

### *Transformations on the Family*

Lydiann said, “I cannot say enough about the doors that S2C has opened for him and his connections with other people.” Lydiann shared the changes seen within their own home, being able to communicate, and being able to have family game night. Before, the family had no idea what Martin wanted to do or how to support him better to participate in the motor side of certain games. Lydiann shared, “I am in awe constantly of the relationships he has with his peers.” Even though Lydiann homeschools Martin, he has an IEP because the family receive funding from the state to help pay for therapy services. For years, when they asked Martin what he wanted for a goal in his IEP, he would say that he wanted friends, repeatedly. Even though he was communicating, she was still struggling to figure out how to make that happen for him because he did not really have peers. Ironically, the COVID-19 pandemic and everything going virtual helped Martin make connections with peers. Lydiann said, “This has been life changing, I mean for him and for me because as a parent to watch his friendships is the most satisfying things in my world.” Now Martin has an amazing peer group. They support one another without judging and can agree to disagree. Lydiann said, “If only the rest of the world could operate like you guys do.”

The social aspect is probably the biggest transformation as Martin has had multiple opportunities to meet friends in person. A couple of years ago, the family went to Florida and met the friends that he had met in an online group. They also traveled to Utah to meet another friend and family and had the opportunity to meet Martin’s songwriting teacher and mentor in person. Many of the songs that Martin writes are about his friendships and other relationships. He has written songs for his brother, his grandmother, and even one for his music teacher. “There’s just not adequate words to describe how incredibly life-changing that has been for him,” Lydiann said.

As they were traveling, he was able to let them know what things he did or did not want to stop and see along the way. Lydiann said, “The whole trip was just amazing, more than I could have ever hoped for.” Being able to communicate on the trips was very beneficial as Lydiann said, “I don’t know exactly what I would have assumed in the past, but I never would have assumed what he told me.” For example, Martin had the complete opposite reaction than Lydiann expected him to have from seeing the homeless man on the street. Martin spelled, “I really want to help him.” Martin became very dysregulated because he wanted to do something for the homeless man. Lydiann said, “Without the letterboard, I would have no idea, absolutely no idea that that is what was causing him to be upset.”

Martin is part of a group called Forging Friendships that conducted advocacy work for nonspeaking autistic individuals. They planned a trip to Washington, D.C., and the group of spellers met with legislators. Martin met with both his state representatives and aids from our senators’ offices to discuss communication access for nonspeaking autistic individuals. During this same trip, he got to see all of his friends again, and meet some other friends for the first time, which, for the family, was amazing. The Motormorphosis Conference, which Martin also attended on this trip, was an incredible experience, coming together with hundreds of other nonspeakers. This opportunity created a connection with people who “experience the same world.” It was meaningful not only for Martin, but also for Lydiann as a parent. Lydiann said, “There is nothing like connecting with another parent who understands your experience as a parent.”

Therefore, Lydiann learned from Son-Rise about attitude, she felt like they were already in a place of somewhat presuming competence as they were already embracing that there are things that autism brings to their lives that they would not have otherwise, but Martin’s use of S2C showed them what Martin was thinking. Lisa [Lydiann] said, “It’s just so hard to put into

words because how can you put into words what it means to have a relationship with your child, to really know your child and his sense of humor.” Martin cracks Lisa [Lydiann] up [makes her laugh] on a daily basis, and she never knew how humorous he really was. Before S2C Martin would giggle at certain things so they could kind of tell, but now he can communicate his humor. Lydiann also thought he was a sweet kid, but she said, “He’s the sweetest. Most 16-year-olds do not have that depth of thought or compassion for other people, they’re much more self-centered.” Lydiann has thought about where she would be if it were not for S2C, and she spoke:

I just . I don’t even like to think about it because I have no idea where we would be, but we would not be living this life. The gift of truly knowing him and for him having real meaningful relationships and connections with other people is priceless.

Martin was 9 years old when he started S2C, and his brother Anthony was Age 6.

Anthony does not remember a time when he could not talk to his brother. Lydiann thinks siblings in general are an underserved and underrepresented, and she would love to see more support offered for them.

A surprise that Lydiann has learned about Martin was his love of Stonehenge. Martin told Lydiann that he was bored, so she asked him if there was something he wanted to learn about. Martin spelled, “[I want] to go to Stonehenge.” Lydiann had no idea the degree to which he was paying attention to everything around him. The family did take him to Foamhenge, which is a full-sized replica of Stonehenge made out of big giant blocks of foam. Martin’s friend, whom he met online, went to Stonehenge, and zoomed with him from the real Stonehenge and brought him a T-shirt.

The transformations that have happened over the last 8 years for Lydiann, Martin, and their family have been “priceless.” Between social connections, travel, and educational



opportunities, Martin's life is now full. He has met his goal of making friends and is able to share whatever he wants whenever he wants.

### ***Behaviors***

Lydiann has seen a drastic reduction in self-injurious behavior for Martin, but she thinks that it is because she is able to understand more of where that behavior actually comes from. She said, "I've definitely seen less self-injurious stuff which I attribute to a reduced anxiety and frustration." Lydiann talked about Martin's impulse control and how the more they practiced working on his motor skills, the better the outcome. Lydiann has focused for the last year and a half more on Martin's whole body motor goals and she is seeing less eloping (leaving the area). Martin still does a decent amount of running back and forth and, especially in a new environment, he explores the space moves, but Lydiann no longer worries that he is going to take off down the sidewalk or run out into the street. She still has an eye on him, but it is no longer a panic situation. In new environments Lydiann is still concerned.

Martin's rigidity has decreased, and he is much more flexible than he used to be. He used to be so tied to routine that, if Lydiann did the wrong thing at the wrong time, there would be a huge meltdown. Now, according to Lydiann, he is so mellow,

I can't really even think of like one thing anymore that he is like that has to be a certain way for him to manage himself. We no longer have to have things be so structured or predictable, it's a big change.

### ***Advice for Families Considering Augmentative and Alternative Communication***

Lydiann would tell families considering spelling to "Go for it, literally, that's the first thing that comes to my mind, but I would tell people to believe in your kid and believe in yourself." Lydiann talked about not just the ability to presume competence in your child, but in yourself, too. When speaking about AAC, Lydiann said, "It's life changing, it will open so many

doors for your child and for you.” Lydiann thinks that it is important for people to know that learning to spell is a process. She said that she was a little impatient at the beginning because she so desperately wanted to communicate with her son. Overall, it took Martin a year to become open-ended in communication. Lydiann shared that, sometimes, if one hears success stories of children learning the S2C or you see a video of a child who is fluently communicating, she wants others to know that “Nobody starts there, and everybody is different.” Lydiann’s advice is “Not [to] compare your kid to others, your kid is capable too!”

### **Marcy**

Marcy is the mother of Levi, a 29-year-old, nonspeaking autistic individual who uses AAC. Levi uses a letterboard and the S2C method. Levi’s journey using S2C began 5 years ago at Age 24. Marcy said, “It’s just amazing; it’s been such a ride, I can’t even express.”

### ***Identifying, Learning, and Implementing Augmentative and Alternative Communication***

Marcy learned about S2C from a friend whose son is also autistic. The friend had been taking her son to Virginia to see a practitioner and shared their experience with the method. Marcy had also heard about spelling when she saw a “60 Minutes” television segment on RPM. Marcy always had that in the back of her mind and thought she would love to do that with her son. Marcy’s friend scheduled an intensive training during a Mother’s Day weekend. Marcy was busy and was unsure whether she really wanted to attend; she shared, “I really didn’t think a lot was going to come of it,” but she decided to go anyway.

Marcy and Levi went to their first session during this time and Marcy said, “My son was able to do some open communication on the first session.” It made her cry, and she shared that even thinking about it makes her cry. Marcy said, “It was the best Mother’s Day gift I could ever get.” Marcy said part of that initial session with the practitioner was put on Levi’s YouTube channel, and it has almost 4,000 views. Marcy always looks back at that moment and how

incredible it was. Marcy could not believe he was able to show her that he could spell the first time.

Initially, when Levi was learning, he only worked with a practitioner; eventually a local center was opened that Levi attends now. At first, the practitioners wanted him to learn with only them; however, after a while, when Levi became very good at spelling, Marcy was told it was time for her to learn. Marcy trained during some coaching sessions, and then she practiced at home with Levi. The sessions were in person and the practitioner would take 15–20 minutes of every session in which Marcy would be using the letterboard with Levi, and they would give her tips and advice for practice.

Marcy said that, when they started doing it at home, he initially resisted working with her. Sometimes, she could only get him to sit down for 15 minutes. A couple of times, he got very frustrated, and he smacked Marcy. She said, “We just worked through it all.” It took a year of consistent and hard practice, and now they are fluently communicating together. All of Levi’s writing for his books, his videos, and his blog are all done with Marcy as his communication partner. She said,

He writes a blog, and he is obsessed! Sometimes I don’t even have time to sit down.

There was one day I just didn’t have time to sit down with him to write. I, said, “Levi, I just can’t do it today.” And he spelled, “Oh, okay, I guess I’ll be a nonspeaker today! Guilt?”

When Marcy and Levi started S2C, they used the three-letter letterboards and, once he became more proficient, they were able to move on to the 26-letter stencil board. He then advanced to using the laminated letterboard and pointing to the letters with his index finger. Marcy said the laminated board “is the way that he does all of his writing, because he’s much quicker on that.” Levi is now able to use a keyboard. He’s also very good using a handheld

keyboard and the next step will be to put the keyboard on the slant board. A slant board is a stand that holds the keyboard and can sit on top of a table. Marcy said,

When you start there, it kind of takes you back to the beginning. It's super hard and very slow. There are some we work on it, and he's really good at it. And then other days I don't know if he's ever going to be able to do this, it's rocky.

Marcy recalled that one challenge to SC2 was Levi being resistant. Marcy had heard of other families in which the child would spell willingly with the practitioner, but then when they tried to do it at home, the child gave the mother a hard time. This proved to be true for Marcy and Levi. She often wondered whether Levi thought, "I work hard enough outside of the home. I don't want to be working in the home, but you know we worked through that." Marcy shared that another challenge is that she is the only one in the family currently who can spell with Levi.

### ***Supports***

Levi participated in speech therapy, physical therapy, and occupational therapy. Marcy said, "I did everything that you're supposed to do. We did, ABA, which now [that] Levi has spelled, he despised." Knowing that now, Marcy said, "Things were different back then. They weren't so proactive as they are now like." She shared, "All those years of speech therapy, I feel were totally wasted. They did nothing for him."

### ***Neurodiversity and Presuming Competence***

Marcy believes neurodiversity is a whole spectrum where everyone's different and no two people are the same. Marcy thinks of presuming competence as "Never judge a book by its cover." She talks to Levi like you would talk to anyone else. Marcy said she used to talk to her son like a baby, but now she talks to him like she would talk to any of her kids. Marcy said, "He'll be wandering around, not looking at you, but believe me, he listens to every single thing."

### *Assessments*

Growing up, the results of assessments always showed that Levi was mentally retarded. Marcy said, “When he first diagnosed, they painted such a bleak picture.” Marcy would never have thought they would be where they are today. When Levi was diagnosed, Marcy remembered, “It was one in 10,000 kids had autism, and now it’s like one in 60 something, or even worse.” They did not have many supports when Levi was diagnosed. Marcy said, “They would never have mainstreamed him in school back then, and I wouldn’t have felt comfortable with that.” The family opted to send him to a private school for autistic children where they felt he was safe because she thought they understood him better. In his early school years, it worked well; however, as Levi got older, Marcy realized that the school was lacking in academics for Levi. Levi told Marcy that most of what he has now learned he has taught himself. Marcy said, “His teachers were lovely, but they underestimated him, as did I.”

### *Transformations on the Family*

According to Marcy, S2C changes everything. Marcy said, “It changes the way you look at your kid.” Sometimes she tries to figure out if he is different now because he can communicate, or because they treat him differently.” Marcy considered, “It’s a little bit of both, you know, he understands now.” Marcy includes him in things that she never would have done before because before she thought he would not be interested in sitting down to watch a documentary. Marcy took Levi to watch a movie about Mr. Rogers and shared that, “He loved it, and wrote a blog about it afterwards, it was just amazing.” Marcy and Levi play games together, and he told his family that he wanted to learn to ride a two-wheel bike, and he did! Recently, Levi spelled, “I want to go to London,” and now the family is talking about going to London this summer.

Levi can now tell Marcy if he is nervous about something, and she can reassure him. Marcy said, “It changes everything. I can’t even begin to tell you in every way.” Levi is also now able to share important medical information. For example, Marci and Levi attended a sporting event where Levi looked over at her and gave her a weird look. Marcy asked, “What’s wrong?” She could tell there was something he needed to tell her. Marcy put the letterboard up, and he spelled, “I think I’m about to have a seizure. I’m seeing auras.” Marcy shared that’s what Levi said he sees before he has a seizure. She said it was some kind of visual disturbance. Marcy said, “The place was bustling, and there were flashing lights, and he was able to tell me that at the basketball game.” Marcy was able to quickly give him his medicine to prevent the seizure.

According to Marcy, Levi’s siblings adore him, and being able to spell has improved their relationship greatly. Levi writes beautiful poetry about their family, and sometimes Marcy feels like saying to him, “We’re not worthy. He writes in such glowing terms and sees us in such a light that I’m like. ‘Gosh! Are we really like that?’” Marcy said, “It’s just improved everything. The whole family dynamic is better in a good way.” Levi will sit at the dinner table and go back and forth with his brother. Marcy said, “They even F bomb each other! Just typical sibling, teasing. I never thought I would see.”

Marcy would never have known that Levi loves World War II, and “He’s a good poet.” Marcy would never have known that Levi has synesthesia. This means that he sees colors with certain musical tones. Levi likes being autistic and has told Marcy, aside from seizures and apraxia, he would not want to change anything, which surprised her. For Marcy, that brings neurodiversity in mind: “We don’t need to change people and it must feel terrible when people are always trying to change you into something that you’re not.”

Levi has written a few books, and he currently writes a blog. He is planning on doing a whole series about different aspects of autism for children. He has more than 300 posts on his

blog, and every day he comes downstairs and checks to see how many people have read his blog and what comments they leave. If his numbers are low, he immediately wants to start writing. Levi also has a large number of followers on his YouTube channel and is up to around 10 videos that Marcy and her sister helped him to produce.

Marcy said, “I personally enjoy my time with him so much. His likes are very much my likes. He loves going thrift shopping.” Marcy remembers, a few years ago, being in a rut with him because he would come home from school and get on the computer in the basement, where he would be watching and “stimming” on videos, watching credits for literally hours on end, and she could not get him to stop. Stimming is a repetitive self-stimulatory behavior, it can include spinning in circles, body rocking, vocalizations (e.g., grunting and muttering), and other habits (Kapp, 2023). Marcy would try to get him to come upstairs and go for a walk or do something. He would resist all the time, and she remembers being sad and thinking to herself, “Is this what life is going to be like for the rest of our life?” Marcy felt an incredible guilt that Levi would be down in the basement being nonproductive, then S2C came and “just changed everything.” Now, Marcy said they can read an article together and discuss it or watch a podcast and talk about it. Marcy shared, “Stuff that I never thought he would even understand.”

Marcy now has a whole new group of friends that are all parents of nonspeakers who met through their S2C center, and they are all committed to making their children’s lives as fun as they can be. They are constantly planning different activities to include sports games, social activities, even group walks. None of these activities occurred before S2C. Levi works at a bakery at the local supermarket baking cookies, and he tells Marcy how much he loves it. Levi previously had a retail job, but he was able to tell her that the job was not for him. Levi has also shared that he wants to go back to school some day and go to college.

### ***Behaviors***

Marcy used to think that Levi was being defiant when they were working together, and she did not realize that he could not stop himself. She now thinks about the struggle with his body and that she had no idea he could not control what his body was doing. When he would become “really revved up and dysregulated, I would start getting dysregulated, and my reaction fed into his and made things 100 times worse.” Now when Levi gets like that, she becomes “emotionless,” and it helps the situation. Sometimes, Levi will be doing something or looping (doing it over and over again) and he would spell on the letterboard, “Please ignore me and just don’t listen, don’t respond to what I’m saying.” Marcy would have never thought to do that before. She would have just tried to keep fixing it, or still see him as being aggressive.

The use of this communication method does not erase the fact that at the end of the day Levi still has autism, and he still has challenges, “But it does make everything much better in my mind,” Marcy said. Levi was not self-injurious; he would be physical and hit his family. The most significant improvement since spelling has been a reduction in his aggression towards his family and an increase in his all-around happiness. Marcy said, “He is such a happy guy. You can just tell he’s in a good place. He’s just always happy, and I see a big change from before.”

### ***Advice for Families Considering Augmentative and Alternative Communication***

For Marcy, Levi communicating was an abrupt change, and it was easy for her as a parent to see it working; therefore, it was easy for her to continue using S2C. Marcy knows of a couple of people in their group who took months of practice before they started seeing any progress. Marcy said, “I give them a lot of credit that they didn’t give up, and they just kept doing it with the hopes that someday they will see it.” Marcy would tell people to “Just give it some time, at least months, to see and to believe it once you start seeing it.” Initially, when Levi first started spelling with practitioners, Marcy and her husband videotaped everything. They would go back



and look and try to see if they were moving the board even just a little bit. After a while, “There are so many things that happen that you can’t ignore it anymore. You have to believe it.” Marcy is not sure whether S2C will work with every single person. Marcy said,

I can’t sit here and say it’s going to help 100%, every single person, but in the people that I’ve seen, that have started, we’re all in the same boat. All of our lives have been affected in such a positive way that I think, for the majority of people. It’s a very helpful intervention and a low-risk intervention. I am amazed that there are some parents out there who don’t even want to try. I don’t understand that. It’s not like you’re giving your kid a medication. You’re just sitting down and reading them a story, a lesson, and seeing if they can understand it! I don’t understand why you wouldn’t try.”

Marcy thinks because S2C is not promoted by schools or the speech–language community parents do not think that they should try it or that it could be bad. She feels that this has contributed to a big divide in the autism community. Marcy supports people trying this method. Very recently, a friend, whose son is a speller, shared, “Why did I listen to you? My son told me my hair looks like shit today!” Marcy said, for her and her family, their lives have totally changed: “When you’re their communication partner, your relationship becomes so deep. I’m so connected to him in such a special way. I love everyone in my family, but he and I share this very special bond.”

### **Elizabeth**

Elizabeth is the mother of 26-year-old Lucy who is an unreliably speaking autistic individual who uses AAC. Lucy uses a letterboard, a wireless keyboard, and an iPad to communicate. Her goal is to be independently typing on a keyboard with a speech generating device. Originally, Lucy was taught with RPM and then S2C to spell and type to communicate.

### *Identifying, Learning, and Implementing Augmentative and Alternative Communication*

Lucy has been spelling for 10 years and started focusing on typing about 6 years ago. According to Elizabeth, Lucy's goal is to be as independent as she can be. Elizabeth said, "People respond differently to the wireless keyboard with output; there is something about them seeing the person independently typing each word on a screen."

The family learned about spelling through a therapist that they worked with for years. According to Elizabeth, one of the popular early therapies for people with autism outside of ABA was Floortime, and Lucy was an early patient in the clinical practices with the developers of the technique, as they were based nearby. Floortime meets children where they are in language, motor, visual, and intellectual abilities and works to build strengths and abilities through building relationships and interacting (Davis et al., 2014). It looks to develop who they are and challenges them to be creative, curious, and spontaneous to support moving the individual intellectually and emotionally (Davis et al., 2014). Floortime was one of the first therapies that Lucy attended, and the sessions, although arduous, seemed to help. Lucy did not speak until she was Age 12. Elizabeth said, "She was really late, she spoke, and then she lost all of her speech." The Floortime therapist told Elizabeth about a medical conference that included a young man who spelled to communicate. He did it independently, and he got up on a stage with 500 people in the audience. Elizabeth said, "It was game changing." Elizabeth had already seen the "60 Minutes" piece on RPM with Mukhopadhyay (2022) and Tito and was immediately interested, but it took some time to access. Elizabeth never doubted the science supporting RPM, they just needed to find a way to gain access. Elizabeth said, "We just were kind of overwhelmed living in the world of autism."

Soma Mukhopadhyay (n.d.), who developed RPM, came to the area and Lucy worked with her later traveled out of state to work with the provider. Soon after, a local speech therapist

with whom they worked was trained in the communication method of RPM and it became an easy decision for the family, and she began coming weekly to Lucy's home and working with her. Elizabeth said, "It was kind of mind blowing." Elizabeth and one of Lucy's brothers were also trained; Elizabeth was completely committed to it and was fluent with Lucy by the end of the year. Elizabeth said, "Now, I'm fluent with all of her closest friends, too." Elizabeth said they practiced every day for at least an hour without missing a single day.

When they began spelling, there were three families that lived in the same town, so the practitioner did a big loop to meet with them. After this there was a surge in people learning to spell and their speech therapist opened a practice. The three families started carpooling and they did groups out there. The three families are still very close, and the adult spellers now live together in the same apartment.

Elizabeth would go to sessions, watch videos, and practice to help herself learn how to support Lucy. Elizabeth said,

I remind people [that] it was very intense. I remember one of the early sessions. I literally put my head down on the table and started crying. The therapist is telling you what you're doing wrong, that this is the most important thing you're ever going to master in your life. When you're not doing it, and your child is screaming, and you're crying, I mean it's intense. I wouldn't want to go to it again. But you know, after you get it, you got it!

Lucy always had a very intense schedule of activities to meet her motor needs: ice skating, walking, and swimming. Their family has always been very active. They also did much reading out loud to help with Lucy's regulation and for enjoyment. They read materials in which Lucy and Elizabeth were both interested.

When they began spelling with Lucy, they asked her closed questions. This meant there was only one answer to the question. Then they went from simple facts to three-word questions, and then to open questions such as, “How do you feel about the Holocaust?” Elizabeth still spends much time reading to Lucy every day. She started out reading Lucy historical fiction, and then they went straight from historical fiction at a sixth-grade level to a book about slavery and the Revolutionary War. Then they read *Night* by Elie Wiesel, a story about the Holocaust that a young man wrote when he was 17 years old. Elizabeth said, “We made this huge jump, initially for years I wrote down everything because it was blowing my mind!” When Elizabeth would read to her, she thought Lucy didn’t know about World War II, slavery, or that there was a revolution and, once she became open, she learned Lucy had a much broader understanding than she could have ever imagined. Elizabeth said, “I was just writing down everything because I wanted to share it with her father and her siblings, and I was like, how do you know this every day in every lesson?” Elizabeth reflected on one scene in a book about the Holocaust and she asked Lucy, what was happening Lucy spelled, “You know there is no God.” Elizabeth said, “It was so profound, I didn’t tell her about God. Lucy spelled, “God left these faithful people on the highest holiday of the year and has left them empty.” Lucy understood exactly what the author was saying, which was dark. Elizabeth said, “It was just incredible, and there were all these concepts that I never understood, she understood.”

“The most important thing that happened for all of us is that when someone can communicate it becomes easier,” Elizabeth said. They never believed that Lucy had an intellectual disability, but everybody else thought she did. It was what the professionals were telling them, and that is what the IQ test would demonstrate. The family recognized that if Lucy could understand the meaning of life, the Holocaust, and the cruelty of slavery, she obviously understood many things.

When they were able to start presuming competence it changed everything socially. Elizabeth said, “We understood that she understood.” Lucy said to her family, “I’ve been listening all my life.” Elizabeth has thought about all these things they said in front of her—conversations that they should not have had in front of her—they talked about whatever they wanted like “she was the wallpaper.” When the family recognized that Lucy loved to socialize and had a way to communicate, they started including her in everything. Her social world grew, as everyone was able to presume competence, and then start engaging with her in a different way. Everybody started to see her as a capable, intellectually curious person who needed social opportunities. Elizabeth said, “The most important thing wasn’t so much that she could talk to other people, it was that everyone changed the way they interacted with her, and that made her life just grow exponentially.”

The hardest thing about learning to spell was that Lucy could not just start using the letterboard with anyone, they required training. She said, “We couldn’t get the educators, we couldn’t get the schools. We couldn’t get them to let her do any of this in an academic setting.” At one point, when Lucy was in high school in the ninth grade, the school had determined they would not accept the way she communicated, and they purported that her intelligence was at the fourth-grade level. The teachers would not give her any schoolwork above a fourth-grade skill level. A small breakthrough happened when Lucy had a new teacher and he actually started reading out loud for his whole class at lunch, which Elizabeth had recommended. The teacher said “Oh, my gosh! The whole room is quiet. It helped the entire class!” Elizabeth has always said to Lucy’s teachers, “It’ll make your lives more interesting, instead of asking her colors or her numbers, that’s boring. it’s boring to her, it’s boring to you.” Elizabeth read books in which both she and Lucy really want to engage, and then they were both motivated. Even with small

successes, the school could never figure it out, so they eventually pulled Lucy out of school.

Elizabeth said,

Quite frankly, the people with the best outcomes are the people that kind of go in on their own, and that's pretty horrific, because that means that this then becomes an opportunity only for individuals of privilege for families that they can afford for one parent to leave the workforce and spend their entire career just focusing on this. We should have home schooled and just gone through the whole curriculum ourselves.

The family's biggest frustration was that the schools would not support Lucy's AAC method, would not presume competence, and would not support a speller. They live in one of the highest funded, well-regarded school districts in the country. Elizabeth said, "We could no longer send her somewhere where they didn't recognize her potential."

There are many therapies that families continue attending for many years spending an immense amount of money and not seeing progress. For S2C and RPM, once families have fluency, they can go back and get help for routine maintenance, but they are not tied to a weekly session. This removes the ongoing financial commitment for families, which is helpful for families and might be one of the reasons that some providers are opposed to it.

### ***Supports***

Lucy started in an inclusive preschool but was expelled when she was Age 2. Elizabeth said that, since then, "It was kind of just a bunch of broken starts and stops." She never had an inclusive opportunity past preschool, and schools would consider her time in the cafeteria time around nondisabled peers as inclusion. Although, at lunch, all of the kids who had disabilities sat together. Elizabeth said, "It wasn't like the captain of the football team is sitting next with them, that was not inclusion."

Elizabeth shared, “Lucy never did ABA, she had Floortime which is the exact opposite of ABA.” Elizabeth said, “Now everyone can get ABA paid for by insurance. But back then you couldn’t, and we were spending \$40,000 to \$50,000 a year.” They did everything they could with nutrition, supplements, Floortime, speech therapy, occupational therapy, physical therapy, and cranial–sacral therapy. Elizabeth said, “If there was a therapy, we did it.” They did everything that there was at the time, but never did ABA. Elizabeth shared,

The way Lucy presents she doesn’t have a lot of [the] skills of her peers that did a lot of ABA. But I’d also say she’s free of a lot of the neurosis that they have. Lucy seems to have no anxiety. She has no obsessive compulsions. Lucy’s happy and she presents more autistic than a lot of people that have done a lot of ABA. But with our new lens, and approach to neurodiversity and what they should look like. You know you don’t ask someone with cerebral palsy to walk faster. So, why do we do it with autism? Lucy’s just kind of wild in her space, but she’s a happy wild in her space.

### ***Neurodiversity and Presuming Competence***

Elizabeth and Lucy read *Neurotribes* (Silverman, 2016) and met the author. To Elizabeth, Neurodiversity means celebrating everybody where they are and recognizing autism is a motor issue. They believe that autistics are social, care deeply, and cannot make their body do what their brain wants it to do. Elizabeth and Lucy embrace the thought of neurodiversity. Elizabeth talked to the father of a child with a new diagnosis, and they were talking about how the family was really working hard to get him to stop flapping his hands. This seemed like much work that maybe was not necessary. Elizabeth said,

If we had inclusive schools, if we always had autistic people living amongst us, if they were able to go to school, if they were able to be working, and if they were able to be our neighbors, then we wouldn’t become undone by someone who occasionally screamed, or

someone who flaps their hands. We should celebrate if we can get comfortable around anyone who's different than us, whether they have black or brown skin, a different faith, or they are queer or trans. I mean just being able to embrace everybody.

Elizabeth feels quite responsible, and quite sad for the amount of time that Lucy had to hear her parents talking about and desperately searching for a cure. Elizabeth said, "And not telling our friends and neighbors that she was autistic because maybe we could get her so she was less autistic or could pass for neurotypical."

Lucy would never ask for someone to use person-first language when they are talking about her and say she is a person with autism. According to Elizabeth, Lucy says, "I'm autistic." Presuming competence is probably the singularly most important thing a parent can do for a child with a disability. Elizabeth thinks that, if one can presume competence, then it will help one as a parent. The two most important things that families need to do, are to work on autonomy, and presuming competence. They might start with what their child is able to do, and what they will need support with. From there, one needs to figure out how to let each person live their most self-determined life and help individuals find their purpose. If one can presume competence, then one can presume that everyone should and does need to have a purpose. "If you can see the potential, it helps her to see her potential, and it helps other people see the potential for a really amazing group of individuals that need support, and deserve to live their fullest life," Elizabeth said.

### *Assessments*

According to Elizabeth, all of Lucy's assessments were very limiting. They told Elizabeth that Lucy probably had an IQ of 50. Lucy completed a nonspeaking IQ test. This test was focused on assessments that were done through the lens of behavior and communication. The one thing that the assessments did was to qualify her for adult services. Adult services are



opportunities for support in homes and in the community to promote independence. Adult services might include career planning, home support, assistive technology, work support, and community support (Taylor et al., 2017). According to Elizabeth, Lucy has a better quality of life, but she is going to need support all of life. “I guess that’s the bright side of the rest of the world not presuming competence,” Elizabeth said, “at least she qualifies for lifelong supports.”

### ***Transformations on the Family***

Lucy can spell, so the family can look to the future. Elizabeth talked about the movie, “Life Animated,” a film about an autistic person derived from the book, *Life Animated: A Story of Sidekicks, Heroes, and Autism* (Suskind, 2016). Suskind (2016) wrote this book about his son Owen, and the documentary film was a derivative of the book. Elizabeth took Lucy and the family to see the film at a local film festival. In the film, Owen has a job and a girlfriend, and then he moves into his own house. Elizabeth said,

It was a beautiful film, and I didn’t think that much of it. When we [got] home, we used the letterboard to do an unpacking of the day. I asked Lucy if she [saw] herself ever being in a relationship or falling in love? Lucy told me she does! I’m like, Oh, my God! I asked a couple of other questions. Do you want to work? Lucy answered, “Yes, I want to work.” Then the most unbelievable thing she said to me was that she could see herself living alone like Owen.

Up to that point, Elizabeth had no perception of the future. She just assumed that Lucy would live with them for the rest of their lives. Elizabeth then had to try to figure out something else. When someone starts communicating, Elizabeth said, “You’ve got to listen!” Once Lucy had told them that she wants this independent life, they had to make it happen. This was a pivotal moment; they would never have known of Lucy’s desires if she was not able to communicate.

Elizabeth says spelling, “Makes her an equal. Her quality of life has improved dramatically, and so has ours!” Elizabeth (and Lucy) still become frustrated, but “the future’s bright, and you know, as a parent of a pretty significantly affected adult child, with a very significant disability, she can spend the night by herself.” Lucy can do all these things that nobody ever thought she could do. Lucy is happy, she has friends. Elizabeth can go to sleep at night and her greatest fear has been relieved. Elizabeth knows that Lucy can live without her, and she did not know that before, a discovery that she described as “profound.” Elizabeth pointed out,

Her future is bright, and we just have to keep advocating. We need to keep a very keen eye on the inequities that are involved here because it cannot just be people of privilege that have access to a technique that changes lives so profoundly. We feel there’s huge social justice issues surrounding this, and I know Lucy thinks that it’ll be her life’s work to advocate for those without communication.

Lucy’s relationship with her siblings has changed since she began spelling. Now that she is able to say something sweet, or they can laugh at the same thing, and understand what Lucy is thinking. It has changed everything. Before spelling, she was screaming, and they were all miserable. Elizabeth described it being like “Everybody, hit the deck!” Now Lucy travels with them and the family takes her everywhere. Elizabeth said,

I feel lucky and I wonder if my other children are who they are because they were part of this profound experience. It’s made us all close. I think there’s a resiliency about my kids, a compassion, and the capacity for understanding people unlike them. Sadly, I don’t know if you would get it another way. I’m really proud of what we have.

The most surprising thing the family learned about Lucy was when they were trying to figure out the next steps for her. The family talked to her about going back to get her high school

diploma, going to college, getting a good job. Lucy wants to advocate, and her goal is to try to make it better for the for the next generation of nonspeakers and to be able to live a life of purpose. Lucy thinks that it is important to demonstrate that there are people with positive outcomes with this diagnosis. Elizabeth said, "I also think it doesn't mean we have to do everything like society tells us." If what Lucy does with her life is to advocate, to do question-and-answer, to do interviews, talk to her legislatures, and continue to fight with the school district about the next generation of children that should be included, that is a valuable life. Elizabeth said, "That is just as valuable as having a job and getting a paycheck." Her value in life is to demonstrate that there is a quality of life with kind of a set of individuals that have historically been segregated out of society.

Once Elizabeth learned this was her daughter's goal, she became involved with a new nonprofit organization that focuses on inclusive housing for people with disabilities. The nonprofit, Our Stomping Ground, has housed 52 people with disabilities to include nonspeaking autistic individuals that would historically have been institutionalized or put in group homes. Since Elizabeth began working with this housing project she said, "Individuals are moving out of group homes to move into these apartments." The nonprofit has expanded this organization into six properties near her area. All this has happened because of communication. Elizabeth said, "Lucy lives in her own apartment with a roommate Monday through Friday, and we have her come home on the weekends." Lucy goes to a day program, she is part of a social justice group, she is in a book club, and they walk two and a half hours a day. Lucy is also taking a class right now at the University and participates in yoga and other clubs. According to Elizabeth, she just goes, goes, goes, with, her friends!" Lucy's two closest friends live in the same apartment building on her hall. Elizabeth does not know whether Lucy will always live there. Elizabeth said, "It's been a really important part of her transition into adulthood and having that

independence.” Lucy can spend the night alone in the apartment. She is very social, but she can be alone for 5 or 6 hours a day, which Elizabeth previously had not thought was possible.

### ***Behaviors***

Lucy had pretty, significant self, abusive behavior before learning how to spell to communicate, and now all of those behaviors are gone. Elizabeth said, “She’s actually way better regulated, but she’s still loud.” Lucy’s loud outbursts typically come out of nowhere and she just explodes. After these explosions, Lucy expresses, she is very sorry, and she does not want to be embarrassed in public. Since learning to spell, Elizabeth said,

It’s all better, everything is better. It’s not like she’s not autistic. It’s not like she can do everything she wants with her body, but everything is better. We have absolutely had no more self-injurious behavior. The scars of the past have all faded and it’s just better.

Elizabeth thinks of when she observes some of the worst cases of self-injurious behaviors, they are almost always people that do not have a way to communicate; they are isolated, and they do not have friends. Elizabeth asks, “Why would you not explode?” According to Elizabeth, people have better quality of life if they are able to access those very basic needs, communication is a human right. Elizabeth said, “Lucy seems pretty happy with her friends. She seems very, very happy. They really care for each other. They love each other, and I think it’s good.”

### ***Advice for Families Considering Augmentative and Alternative Communication***

Elizabeth has conversations all the time with families considering AAC. She tells them, “It’s the single, most important thing that you can do.” Elizabeth says, “I’ll change everything. A lot of times when you have a family where the individual is talking some families should know it’s not everything they want to say. We encourage everybody to get started.” Elizabeth thinks

everyone can benefit from fuller communication. Parents should find a way to presume competence and help their child experience the world. Here is the advice Elizabeth gives:

Help your child to figure out their autonomy and purposes. You've got to find community, and you've got to find a way to communicate, and after that I think you can do anything. Autism can be a very isolating diagnosis and not being able to communicate is unsustainable. Keep reading, keep working at it and find people that can take this journey with you. The exciting thing is [that] everybody gets better. I get better as a parent, Lucy's better regulated, and we have community. Everyone needs community, It's not just our adult children or our younger children, it's the parents, and it's the siblings.

### **Themes**

After I restoried the narratives and member checked them, I manually coded them for themes. Three themes emerged from the data. Theme 1 was an increase in well-being for the entire family. All five participants described improvement in life not only for their speller, but also for the entire family. There was an increase in well-being both physically and emotionally for spellers and their families. Theme 2 was a remarkable improvement from the past. All five families shared amazing changes to communication for their nonspeaking autistic family member. Family members also shared a dramatic shift in the social aspect of their family member. They also shared major improvements in self-injurious behaviors. Theme 3 was that learning to implement AAC was laborious but beneficial for the communication partner. They all described the commitment it took and that it was worth every minute. Each participant talked about sharing the benefits and changes with other families. They all encouraged families who were considering spelling as AAC to give it a try.

### *Increase in Well-Being for the Entire Family*

Mark, Jade, Lydiann, Marcy, and Elizabeth all reported an increase in well-being for their family. The ability to know their family member on a deeper level has been life changing for all of the participants. Mark described, “Without the letterboard, Rick would have had his feelings bottled up with no outlet.” Now that Jade’s family can talk with Cedric and he can spell to them what is happening and what he needs, they have not had any physical attacks. Jade said, “I think we’ve gotten better at listening to what he’s saying because we are really trusting that it’s an impulse, not a behavior.” Lydiann found what she learned about Martin to be fascinating, she has learned he has synesthesia and sees things or people as colors. She also talked about the connections he has made with peers and “as a parent to watch his friendships is the most satisfying thing in my world . . . if only the rest of the world could operate like you guys do!” Jade shared that she “always knew her son was smart. What I love about spelling is his ability to now communicate and can demonstrate his intelligence.” Marcy shared how Levi can now tell her whether he is nervous about something, that he wanted to learn how to ride a bike, and recently that he wants to go to London. Elizabeth learned her daughter’s deepest desires about housing, work, and her future. “Lucy seems very, very happy with her friends. They really care for each other. They love each other, and I think it’s good,” Elizabeth said. The participants shared that life went from answering basic questions to the creation of life goals, friendships, and value of inclusion. Mark said, “It is not lost on me how fortunate I am!” This sentiment shines through each interview. Lydiann talked about now having family game night. Jade shared the first time Cedric was able to decide what their family did as “Magnificent!” Lydiann discussed the family taking their first ever family vacation and being able to know what Martin wanted to do and see along the way. She shared, “It’s just so hard to put into words what it means to have a relationship with your child.”

For the nonspeaking autistic individuals to have their family members see their intelligence provided an increase in their well-being as was described by the participants in this study. Marcy described seeing her son spell for the first time as, “The best Mother’s Day fit I could ever get!” From Mark’s perspective there has been no negative impact, it has drastically improved the brother’s relationship.

It comes down to a sibling relationship which is phenomenal, our relationship is just like anybody else. The two of us are brothers and while he does have a quick wit, he’s incredibly perceptive . . . if you think about it, his entire life, all he’s done is observe.

All of the participants described the increase in socialization for the nonspeaking autistic family members. The weeks are now filled with either virtual or in person opportunities to socialize, advocate, and be together with others. Jade and Lydiann described how the virtual world has made such a difference to make connections with peers. Mark, Marcy, and Elizabeth all described the amount of in-person social opportunities to which their family members now have access in their area. All of the participants shared that traveling to be with other spellers and the beautiful friendships that have grown from learning to communicate has been life changing. Jade shared that Cedric is now able to express his support of others and that, when a young man who typically leaves the room often during a session only left twice, Cedric spelled, “It’s so great that you stayed in the room.”

In addition to the autistic individuals gaining new friends, Jade, Lydiann, Marcy, and Elizabeth all described the connections they have made to other family members and how impactful that was to them. Lydiann said, “There is nothing like connecting with another parent who understands your experience as a parent.” Four participants learned about spelling as a form of AAC through another parent reaching out to share their child’s success. The participants talked about how it felt to meet others who were walking a similar path. Marcy now has a whole

new group of friends that met through their S2C center and are committed to making their children's lives as fun as can be. She said they are constantly planning different activities, which did not occur before they used S2C.

All of the participants shared experiences that they include their family member in activities now that learned to communicate. From parasailing to thrift shopping, the ability to ask their nonspeaking autistic individual if they want to participate has brought a higher quality of life to all five participants and their families. The participants also described enjoying their time with their family member. Marcy said, "He still has autism, and still has challenges, but it does make everything better in my mind." Elizabeth said, "If you can see the potential, it helps her to see her potential, and it helps other people see the potential for a really amazing group of individuals that need support and deserve to live their fullest life."

All five of the participants described their family member as being happy. Life has become easier for the entire family. Elizabeth said, "Everything is better." It was clear in my interviews that the relationship, which has been built through the process of learning to spell and communicate together, has improved the quality of life for both speller and family members. Lydiann shared the transformations that have happened over the last 8 years for their family have been "priceless." Between social connections, travel and educational opportunities, Martin's life is now full.

### ***Remarkable Improvement From the Past***

Each participant described communication before RPM or S2C as minimal. Mark, Jade, and Lydiann shared that their family member had used PECS on an iPad prior to spelling. They shared that it did not include communication but was pictured based and included primarily food or a few activities. All of the nonspeaking autistic individuals, as Mark described, "Were stuck inside." Now all of the nonspeakers are able to be "part of the conversation instead of the subject



of it.” Mark said, “Rick is now able to be a participant in his life, instead of just watching from the sideline.” All of the participants gave a very similar description. Jade described Cedric’s communication prior to spelling by using an iPad that had pictures on a screen. She asked, “How would you feel if someone else was programming what you’re going to say when you have all the words in your head?” Lydiann shared a series of augmentative attempts prior to spelling, but Martin only ever got to basic requests, so he could request a drive, food, and two or three preferred activities. Even with a method called PROMPT that “seemed to make a bit of a difference” Lydiann said, “I think we could have kept going for years, and we wouldn’t be anywhere near the level of communication that we are at now.” Marcy talked about interventions prior to S2C including speech therapy, physical therapy, occupational therapy, ABA, she said, “I did everything that you’re supposed to do.” Levi spelled he despised ABA. Marcy said, “All those years of speech therapy, I feel were totally wasted. They did nothing for him.” Elizabeth shared that they were spending \$40,000 to \$50,000 a year on therapies for Elizabeth, they did everything they could for her. When spelling came along, “it was kind of mind blowing,” Elizabeth said.

Drastic improvements in family and friend relationships were presented in detail by all five participants. Mark, Jade, Lydiann, Marcy, and Elizabeth described the layout of their family member’s week with many activities that involved friends, learning, and a life that was very different than before spelling. Marcy shared that Levi writes beautiful poetry about their family and shared, “We’re not worthy, he writes in such glowing terms and sees us in such a light that I’m like, gosh! Are we really like that!” Marcy said, “It’s just improved everything, the whole family dynamic is better in a good way.” Jade shared that he is a different person and has completed two cross-country trips with their family on airplanes. Cedric is now able to visit his grandparents who are in their eighties and have a conversation with them. Martin has traveled

several times to meet friends out of state. He was able to meet his songwriting teacher; many of Martin's songs are about his family and friendships. "There's just not adequate words to describe how incredibly life-changing this has been for him," Lydiann said. Mark said the impact on his family "has been massive" and his nickname from an uncle is "Letterman". Mark said, "I learned my brother was just as big of a smart ass as me, if not bigger!" Elizabeth shared when the family recognized Lucy was a social person and she was paying attention and could now communicate, they started including her in everything. Her social world grew, and everyone started seeing her as a capable, intellectually curious person who needed social opportunities.

Mark, Marcy, Lydiann, and Elizabeth described an improved relationship with siblings and the humor that has been seen in their conversations. Mark shared that Rick's personality definitely comes from the household that they grew up in. There are very few things the brothers will not joke about; Mark laughed and shared, "In typical sibling fashion he'll rip me, and I'll fire one right back at him." Marcy shared that Levi's siblings adore him and he will sit at the table with his brother and go back and forth, Marcy said, "They even F-bomb each other! Just typical sibling teasing [that] I never thought I would see." Lydiann shared that Martin has written a song for his brother Anthony and they are able to have family game nights. Anthony was 6 years old when Martin started spelling, and he does not remember a time that he could not communicate with his brother. Elizabeth shared that Lucy's relationship with her siblings has changed since she began to spell. Now she is able to say something sweet, or they can laugh at the same thing, and understand what Lucy is thinking.

Mark, Jade, Lydiann, Marcy, and Elizabeth all noted a reduction in unwanted behaviors. Mark and Lydiann discussed the improvement in eloping. Mark shared that when Rick was younger, he was in the neighborhood for a few hours; that is not a concern anymore. Lydiann shared that she is no longer worried about whether Martin might take off down the sidewalk or

run out into the street. She still keeps an eye on him, but it's no longer a panic situation. Jade, Lydiann, and Lucy all reported major decreases in self-injurious behaviors. Jade said, "Cedric had a lot of self-injurious behaviors before spelling." Jade shared they have seen a drop in those behaviors that she likes to call impulses. Lydiann has seen a drastic reduction in self-injurious behavior for Martin which she attributes to a reduced anxiety and frustration. Elizabeth said Lucy had significant self-abusive behavior, and now that she can spell, it is completely gone. Lucy said, "We have absolutely had no more self-injurious behavior. The scars of her past have all faded and it's just better." Marcy and Jade reported an elimination of aggressive behavior. Jade shared that she views behaviors as impulse because there is no intention behind them. Jade talked about prior to communication their biggest challenge was that Cedric would attack them in the car. Being over 6 feet tall, they would have to pull off the road and get out because it was not safe to drive. Since her son learned how to spell, she has not seen any physical attacks. Marcy said that Levi would be physical and hit his family. The most significant improvement since spelling has been a reduction in his aggression toward family and an increase in his all-around happiness. Marcy said, "He's such a happy guy. You can just tell he's in a good place. He's justly happy, and I see a big change from before."

According to the participants, the learning opportunities that the five nonspeaking autistic individuals currently have are remarkably different than what they were exposed to prior to spelling. Jade and Elizabeth pulled their child from the public school because of concerns they had about the education they were being offered. Jade shared that when Cedric was in public school, "I was just handed the device with a new program and no training." She said no training was provided with PECS and using the iPad with multiple programs. Jade said she would go to meetings at school, a whole assessment would be done, reports would be written up, and "nothing would change." She also shared his behaviors were increasing and she thought "this

isn't working, we've got to do something different." Jade decided to begin homeschooling when Cedric was in fourth grade. Since learning to spell, Cedric's week is filled with activities, he has several group meetings with peers, and Jade and Cedric usually do some outdoor activity daily. Cedric has a book club, Spellers and Allies Advocacy Network (2022) meetings, and sometimes he has a session with an occupational therapist online who helps him work on purposeful motor actions. He is also in a sensory group, a song writing class with a musician and songwriter. He rides horses, and he has a writing class. Cedric works at a local barn, and he usually teaches a dance class. Elizabeth shared that when Lucy was in high school, in the ninth grade, the teachers would not give her anything past fourth grade skill level. A small breakthrough happened when Lucy had a new teacher and he actually started reading out loud for his whole class at lunch, which Elizabeth had recommended. The teacher said "Oh, my gosh! The whole room is quiet. It helped the entire class!" Even with small successes such as this, the school could never figure out how to offer her an age-appropriate education, so they eventually pulled Lucy out of school. Elizabeth said,

Quite frankly, the people with the best outcomes are the people that kind of go in on their own, and that's pretty horrific, because that means that this then becomes an opportunity only for individuals of privilege for families that they can afford for one parent to leave the workforce and spend their entire career just focusing on this. We should have home schooled and just gone through the whole curriculum ourselves.

Because of Lucy's ability to communicate, "Lucy lives in her own apartment with a roommate Monday through Friday and we have her come home on the weekends," Elizabeth shares, Lucy goes to a day program, she's part of a social justice group, she's in a book club, and they walk two and a half hours a day, Lucy is also taking a class right now at the university, participates in yoga, different clubs, and according to Elizabeth, "She just goes, goes, goes, with,

her friends!” Lucy’s two closest friends live in the same apartment building in her hall. Sh’s very social, and she can be alone for five or six hours a day, which previously, Elizabeth did not think was possible.

Mark, Jade, Marcy, and Lydiann all described accomplishments in writing, from songs, to screenplays, books, and blogs by their family members. Mark shared when a close family member passed away a few years ago, Rick was able to write an entire screenplay about his relationship with him. Mark stated in the screenplay, “He breaks the fourth wall to talk to the audience, but when he’s not talking to the audience, his character is a nonspeaker.” Jade talked about the opportunities that are now available for Cedric on Zoom and how they are “just fantastic.” She said, “For Cedric being in a Zoom classroom is more useful because he gets really loud. He does not disturb other individuals because you can mute.” Jade also shared that Cedric was presenting a song at an online concert for spellers that he wrote with two friends.

Lydiann shared that many of the songs that Martin writes are about his friendships and other relationships. He has written songs for his brother, his grandma, and even one for his music teacher. Lydiann described, “There’s just not adequate words to describe how incredibly life-changing that has been for him.” Marcy shared that Levi has written a few books, and he also currently writes a blog. He is planning on doing a whole series about different aspects of autism for children. He has more than 300 posts on his blog and, every day, he comes downstairs and checks to see how many people have read his blog and what comments they leave. If his numbers are low, he immediately wants to start writing. Levi also has a large number of followers on his YouTube Channel and is up to around 10 videos that Marcy and her sister helped him produce.

Mark, Jade, Lydiann, and Elizabeth described the advocacy work their nonspeaking autistic family member has participated in. Mark shared Rick has a business idea and wants to be

a consultant for businesses and support making businesses a little more autism friendly.

According to Mark, Rick feels that many people still do not know how to interact with people with autism. Rick wants to consult with businesses and educate them by having a conversation about autism and how to treat people, specifically nonspeaking autistic individuals, because it is not necessarily their fault they do not know. Rick wants to go into businesses and to show them how to interact with somebody, even if it is not the traditional way. Mark shared that he has seen the difference it makes when someone is treated as an equal. In his own experiences, when Rick and his friends are treated like everybody else, they are calm and happy. Whereas, if someone acts afraid of them, they become afraid, too, and it makes them tense, and then it becomes a perpetual cycle. Rick talks much about this idea. Jade shared that Cedric meets weekly with Spellers and Allies Advocacy Network (2022). Lydiann shared that Martin is part of a group called Forging Friendships that conducted advocacy work for nonspeaking autistic individuals. This group planned a trip to Washington, D.C., where the spellers met with legislators. Martin met with both his state representatives and aids from our senators' offices to discuss communication access for nonspeaking autistic individuals. Elizabeth shared that Lucy wants to be an advocate and her goal is to try to make it better for the for the next generation of nonspeakers and to be able to live a life of purpose. Lucy thinks that it is important to demonstrate that there are people with positive outcomes with this diagnosis. Elizabeth said, "I also think it doesn't mean we have to do everything like society tells us." If what Lucy does with her life is to advocate, to do question-and-answers, to do interviews, to talk to her legislatures, and to continues to fight with the school district about the next generation of children that should be included, that is a valuable life. Elizabeth said, "That is just as valuable as having a job and getting a paycheck." Her value in life is to demonstrate that there is a quality of life with kind of a set of individuals that have historically been segregated out of society.

Before being able to communicate, the participants described their family member being treated as being younger or with less ability than they actually are and not having someone in their life who believes in them. Marcy shared when Levi was growing up, the results of assessments always relayed that Levi was mentally retarded. The family opted to send him to a private school for autistic children where they felt he was safe because she thought they understood him better. In his early school years, it worked well, but as Levi got older, Marcy realized that the school was not teaching Levi appropriate academics. Levi told Marcy that most of what he has learned he has taught himself Marcy said, “His teachers were lovely, but they underestimated him, as did I.” Now, Marcy said they can read an article together and discuss it or watch a podcast and talk about it. “Stuff that I never thought he would even understand.” Elizabeth shared that all of Lucy’s assessments were pretty limiting. Elizabeth was told that she probably had an IQ of 50. After RPM/SC2, the family recognized that if Lucy could understand the meaning of life, the Holocaust, and the cruelty of slavery, she obviously understood many things. When they were able to start presuming competence, it changed everything socially. Elizabeth said, “We understood that she understood.” Lucy said to her family, “I’ve been listening all my life.” When the family recognized that she was a social person and she was paying attention and she had a way to communicate, they started including her in everything. Her social world grew, as everyone was able to presume competence, and then began engaging with her in a different way. Everybody started to see her as a capable, intellectually curious person who needed social opportunities. Elizabeth said, “The most important thing wasn’t so much that she could talk to other people, it was that everyone changed the way they interacted with her, and that made her life just grow exponentially.”

Each participant discussed believing in their family member and assuming they could do anything has made a major impact on their life. Mark shared,

In the in the setting of what we're talking about with nonspeakers, understanding that they understand everything that's going on around them, and they want to be able to share what's going on in their head. It's just their brain and their body are disconnected.

Mark believes that, no matter who is in front of you, using the assumption that the nonspeaker has high expectations is always the right choice. Mark shared that some teachers, with whom Rick had worked in the past and who have now seen him communicating, have apologized for treating him like a little child. They felt horrible and that saying sorry was not enough. Mark shared that Rick told them,

There's no bitterness for me, you were all working off of the information that you knew at the time, and I can't be bitter about that. I can't expect you guys to have known what we know now. Because if you knew 20 years ago back then what we know now, you would have jumped right on board. I'm not going to hold any resentment toward you now.

Jade said, "Presuming competence is the least dangerous assumption we can make about anyone's intelligence. Cedric reminds me regularly that intelligence is invisible. When I presume competence, I'm believing in the individual I am with." Jade explained that presuming competence is believing that the individual completely understands what is being said and is able to reason fully within their head. Jade said "I know that listening does not have a look. If it did, no one would be able to be a spy! Listening is learning." For Lydiann believing in Martin's desire to do things, his ability to do things, and certainly his cognitive abilities made it easy for her to presume competence of Martin's mind. It was harder for her to get to a place of presuming competence of his body. Marcy said she talks to Levi like you would talk to anyone else. Marcy said, "He'll be wandering around, not looking at you, but believe me, he listens to every single thing." According to Marcy, S2C changes everything. Marcy said, "It changes the way you look



at your kid.” Sometimes she tries to figure out if he is different now because he can communicate, or because they treat him differently. Marcy thinks, “It’s a little bit of both, you know he understands now.” Marcy includes him in things that she never would have done before, because before, she thought he would not be interested in sitting down to watch a documentary, for example. Lucy talked about how, when they were able to start presuming competence, it changed everything socially. Lucy said, “We understood that she understood.”

***Learning and Implementing Augmentative and Alternative Communication was Laborious but Beneficial for the Communication Partner***

All of the participants described trying many different types of interventions to help their family member learn how to communicate. Mark said, “I don’t have a memory without Rick in my childhood, most of what I remember includes him trying something that my mom wanted to try to support him.” Lydiann said she could give 10,000 examples of different things they’ve worked on. Marcy discussed Levi initially being resistant to S2C and working through learning to spell with him as his communication partner.

The participants whom I interviewed described not getting support from the school system. Elizabeth said, “Schools not supporting this method of AAC and not presuming competence” was her family’s biggest frustration. Jade shared that none of the evaluations that were completed showed Cedric’s potential; therefore, they chose to leave the public school. Marcy said her family chose to send Levi to a private school for autistic children where they felt he was safe because she thought they understood him better. In his early school years, it worked well; however, as Levi got older, Marcy realized that the school was lacking in academics for Levi. Levi told Marcy that most of what he has learned he has taught himself. Marcy said, “His teachers were lovely, but they underestimated him, as did I.” Lydiann described assessments

from the school as “heartbreaking for me, even though they weren’t necessarily focused on intelligence, it was just everything focused on what he cannot do, very little on the strengths.”

Mark, Jade, Lydiann, and Marcy all heard about RPM and S2C from another parent. Elizabeth heard about RPM from a Floortime therapist with whom they were working. All five participants described the process of identifying, learning, and implementing AAC as much work. Mark shared his experience learning to use RPM. He and his mom went to several workshops. Rick’s parents took him to Virginia to see a practitioner to support in S2C. Mark trained in a 6-month course to become a practitioner and left his career in radio.

For 3 days, Jade sat at a workshop and watched, and “took reams of notes.” Jade began working with Cedric daily. Once a month, Jade would send a video to a practitioner for feedback. Jade would be given “marching orders” for the ways to improve her skills as a CRP. Jade took Cedric to Virginia for two sessions a day with practitioners and Jade and for additional training for her and her husband to work with Cedric. The mentor S2C practitioner traveled to their area and offered training to Jade, Cedric and 10–15 other interested families. Jade said, “Each outreach was 3 days that were very helpful because they were very intense.” Jade said having two sessions a day helped “my skills get a lot better.”

The very first thing Lydiann did was to go to an outreach presentation offered by a practitioner a few hours away. Lydiann was able to observe other children’s sessions. Lydiann spent the next year between her first and second visits working on the skills that the practitioner taught them. Initially, they practiced at home and then would have a session with one of the practitioners. Martin’s first open-ended communication was after they had practiced for a year in between sessions with practitioners. Lydiann said in the beginning, the biggest challenge was being patient. Lydiann described, “Sometimes, I would get frustrated or hard on myself when

things weren't happening as quickly as I wanted them to." Over time, things started flowing better. It was just a matter of practice, practice, practice.

Marcy's first experience learning S2C was intensive training over a weekend. Marcy said that, initially, when Levi was learning, he only worked with a practitioner. Marcy trained during some coaching sessions, and then she practiced at home with Levi. Marcy said when they started doing it at home, he initially resisted working with her. There were times when she could only get him to sit down for 15 minutes. There were also a couple of times when he got very frustrated, and he smacked Marcy. She said, "We just worked through it all." It took a year of consistent and hard practice and now they are fluent communicating together. Levi is now able to use a keyboard. Marcy said, "When you start there, it kind of takes you back to the beginning. It's super hard and very slow." There are some days when they work on it, and he was very good at it. However, other days, she said, "I don't know if he's ever going to be able to do this. It's rocky."

A practitioner trained Elizabeth in how to use RPM; Elizabeth was completely committed to it and was fluent with Lucy by the end of the year. Elizabeth said they practiced every day for at least an hour without missing a single day. Elizabeth would go to sessions, watch videos, and practice to help herself learn how to support Lucy. Elizabeth said,

I remind people it was very intense. I remember one of the early sessions. I literally put my head down on the table and started crying. The therapist is telling you what you're doing wrong, that this is the most important thing you're ever going to master in your life. When you're not doing it, and your child is screaming, and you're crying, I mean it's intense. I wouldn't want to go to it again. But you know, after you get it, you got it!

Despite all the hard work, all participants shared it was worth the time. From Mark's perspective, there have been no negative impacts from learning how to use a letterboard as AAC. It has

drastically improved Rick's life and the brother's relationship. Marcy said, "It's just amazing, it's been such a ride, I can't even express." Jade said, "Just experiment and do it because, there is nothing better than having a robust system of communication." Lydiann said, "I cannot say enough about the doors that S2C has opened for him and his connections with other people."

Elizabeth shared,

You've got to find community, and you've got to find a way to communicate, and after that I think you can do anything. Autism can be a very isolating diagnosis and not being able to communicate. Keep reading, keep working at it, and find people that can do this journey with you. The exciting thing is [that] everybody gets better. I get better as a parent, Lucy's better regulated, and we have community. Everyone needs community, it's not just our adult children or our younger children, it's the parents, and it's the siblings.

### ***Important Finding***

Mark remembers seeing his brother spelling and said, "What are you talking about? What do you mean? It's that simple? There's no way it's this simple. It's right under our nose. This is the way out!" Mark said, "My mouth was wide open, and I probably looked like a codfish."

Mark thought to himself, "I have to learn how to do this." He encourages families to keep an open mind to seeing their nonspeaking autistic individual in a different way. Mark advised,

Just try to be that person that they can come to and be that person that can support them, even without words. Try to be patient with your sibling and put yourself in their shoes and to try to support them as best as you can.

Mark encouraged treating nonspeaking autistics like you would anyone else. "If they're 23 treat them like they are 23." Jade encourages families who are considering spelling to

talk to a speller, they are the experts. Go for it! You be the CRP, you're the one on the carousel. A SLP told me, you're on a carousel and SLPs, occupational therapists, teachers, they get to hop on and off, but you're the operator and, as the operator, being able to communicate with your child is . . . really is life-saving.

Lydiann encourages others to believe in their child "and believe in yourself." She said, "It's life changing and will open so many doors for you and your child." Lydiann thinks it is important for people to know that learning to spell is a process. She said that she was a little impatient at the beginning because she wanted so desperately to communicate with her son. Overall, it took Martin a year to become open-ended in communication Lydiann shared, "Sometimes, if you hear success stories of kids learning the spell to communicate, or you see a video of a child who's fluently communicating," she wants others to know that, "Nobody starts there, and everybody is different." Lydiann's advice is to "not compare your kid to others, your kid is capable too!"

Marcy does not understand why people would not want to try, "It's not like you're giving your kid a medication, you're just sitting down and reading them a story, a lesson, and seeing if they can understand it." Marcy supports people trying this method. Just the other day, a friend whose son is a speller shared, "Why did I listen to you? My son told me my hair looks like shit today!" Marcy said, for her and her family, their lives have totally changed. "When you're their communication partner, your relationship becomes so deep. I'm so connected to him in such a special way. I love everyone in my family, but he and I share this very special bond." Elizabeth said,

It's the single, most important thing that you can do. It will change everything! A lot of times when you have a family where the individual is talking some, families should know it's not everything they want to say. We encourage everybody to get started.

Lucy thinks everyone can benefit from fuller communication. Parents should find a way to presume competence and help their child experience the world collaboratively. All of the participants agree that families should try spelling as a form of AAC.

### **Summary**

The purpose of this qualitative narrative inquiry was to explore the experiences of family members of nonspeaking autistic individuals who use AAC systems. After the University of New England's (UNE) Institutional Review Board (IRB) approved the study (Appendix D), I shared the recruitment post on several Facebook pages that were focused on S2C or RPM. I asked interested participants, who self-identified as meeting the study criteria, to reach out to me. I had eight immediate responses from family members who wanted to participate in this study. Zoom interviews were scheduled and completed. The first five participants who reached out for this study were able to share their experiences with identifying, learning, and implementing S2C or RPM with their nonspeaking autistic family member.

I worked on gathering the stories, analyzing them for key elements (e.g., time, plot, place and scene) and then on rewriting the story in a chronological sequence. From the stories, I then coded for themes according to type of interaction (personal or social), timeline (past, present, or future) and where the event took place. The themes assisted in narrowing how the results were presented.

Three themes emerged from the data. Theme 1 was an increase in well-being for the entire family. All five participants described improvement in life not only for their speller, but also for the entire family. The well-being both physically and emotionally for spellers and their families increased.

Theme 2 was a remarkable improvement from the past. All five families shared significant changes in communication for their nonspeaking autistic family member. Family

members also shared a dramatic shift in the social aspect of their family member. Furthermore, they shared major improvements in self-injurious behaviors.

Theme 3 was that learning and implementing AAC was laborious but beneficial for the communication partner. They all described the commitment that it took and that it was worth every minute. Each participant talked about sharing the benefits and changes with other families. They all encouraged families who might be considering spelling as AAC to give it a try.

## CHAPTER 5: CONCLUSION

In this qualitative narrative inquiry, I explored the experiences of family members of nonspeaking autistic individuals who use AAC systems S2C or RPM. My desire to study this topic stemmed from my personal experience as a parent, navigating 16 years of interventions with my son and finding that AAC changed our lives. My goal was to capture other families' experiences and to share them to support other families who might be exploring this option.

To understand better the experiences that family members have regarding AAC systems, I used two research questions to guide this study:

- **Research Question 1:** How do family members of nonspeaking autistic individuals describe their experience with identifying, learning, and implementing AAC?
- **Research Question 2:** How do family members of nonspeaking autistic individuals describe transformations within their families since implementing AAC?

Five participants shared their experiences with identifying, learning, and implementing S2C or RPM with their nonspeaking autistic family member through interviews. Three themes emerged from the data. Theme 1 was an increase in well-being for the entire family. All five participants described improvement in life not only for their speller, but also for the entire family. The families had an increase in well-being both physically and emotionally for both the spellers and their family members.

Theme 2 was a remarkable improvement from the past. All five family members shared changes to communication and a dramatic shift in the social opportunities for their nonspeaking autistic family member. They also shared major improvements in self-injurious behaviors.

Theme 3 was that the experience of learning and implementing AAC was laborious but beneficial for the communication partner. All of the participants described the commitment it took and that it was worth every minute of their time. Each participant talked about sharing the



benefits and changes with other families. All of the participants encouraged families that were considering spelling as AAC to give it a try.

### **Interpretation and Importance of Findings**

Qualitative research promotes a deep understanding of a social setting or activity from the perspective of the research participants (Bloomberg & Volpe, 2016). It implies exploration, discovery, and description (Bloomberg & Volpe, 2016). According to Jaswal et al. (2020), 30% of autistic individuals have limited ability to communicate and most never gain access to an effective means of communication. Few researchers have documented the everyday impact of AAC interventions for individuals who use them and their family experiences (Kron, 2017).

#### **Research Question 1**

Research Question 1, “How do family members of nonspeaking autistic individuals describe their experience with identifying, learning, and implementing AAC?” was created to understand better the experiences that family members have with identifying, learning, and implementing AAC systems. The family members described their experience as a journey that required a great deal of determination and dedication and that ended with positive results. Overall, the participants described the identification process as being time-consuming. The learning process was intense but exciting, and the implementation process required practice and consistency. Overall, all of the participants described the process of identifying, learning, and implementing AAC as life changing.

All of the participants described trying many different types of interventions to help their family member to learn how to communicate. Mark said, “I don’t have a memory without Rick in my childhood, most of what I remember includes him trying something that my mom wanted to try to support him.” Lydiann said she could give a thousand examples of different things they had worked on. Interventions for nonspeaking autistic individuals were focused on language,

learning, and social skills (Prelock & McCauley, 2021). Most schools in North America rely heavily on ABA as the gold standard for autism interventions (McPhilemy & Dillenburger, 2013).

Cedric was introduced to ABA in preschool. The challenge with ABA, as Jade described it, was that “Cedric never played the reinforcement game.” The ABA therapist would say, “Here’s a skittle, here’s a skittle, look, look, look! Look!” Cedric would take one, and then he would not want one anymore. Jade explained, “If you don’t have a reinforcer, ABA doesn’t work. Cedric was not a very welcomed candidate for any ABA programs.” Lydiann shared that Martin also briefly had ABA interventions. Lydiann said they did it regularly for few months before he was school age. They also worked with a speech therapist, who was a board-certified behavior analyst. Sometimes, in sessions, she would incorporate ABA. Lydiann did not find this effective and described the sessions as “match this red ball to that red ball, match this green cup to that green cup.” Martin was a child who, if he did not see the point in an activity, would not want to put in the effort. According to Lydiann, ABA never did anything for Martin. It did not feel right to Lydiann because she had always been drawn to relationship-based interventions, which ABA is not. Marcy said, “I did everything that you’re supposed to do. We did, ABA, which now Levi has spelled [that] he despised.” Knowing that now, Marcy said, “Things were different back then. They weren’t so proactive as they are now.”

The participants who were interviewed described not receiving enough support from the school system. Lucy said, “Schools not supporting this method of AAC and not presuming competence” was her family’s biggest frustration. Implementing AAC includes its use in the nonspeaking individual’s home, school, and the community (Ganz et al., 2014). Each AAC system should be individualized to meet the person and their family’s needs (Ganz & Simpson, 2018). Jade shared that the evaluations that were completed did not show Cedric’s potential, and

that was one reason why they left the public school system. In cases where people cannot speak or reliably communicate, it can be difficult to assess whether an individual is able to understand spoken language (Petit et al., 2020). According to Giofrè et al. (2019), there is an insufficient amount of research on the implications of the assessments used to assess children on the autism spectrum. Marcy realized that the school was lacking in age-appropriate academic opportunities for Levi. Levi told Marcy that most of what he had learned he had taught himself. Marcy said, “His teachers were lovely, but they underestimated him, as did I.” Families of nonspeaking autistic individuals shared that they looked for support from the professionals at school in how to help their child. When there are discrepancies in assessments, it brings into question the accuracy of what a person knows and is able to do (Peña, 2019). This could risk individuals being underestimated in their abilities and might limit what is recommended for AAC (Peña, 2019). Lydiann described assessments from the school as “heartbreaking for me, even though they weren’t necessarily focused on intelligence; it was just everything focused on what he cannot do, very little on the strengths.”

Augmentative communication is used when traditional interventions have not worked, and a child is not beginning to speak after being provided with speech language pathology services (ASHA, n.d.-a). An augmentative communication evaluation, which an SLP can complete, can help families decide what type of intervention is appropriate to use (ASHA, n.d.-a). Mark, Jade, Lydiann, and Marcy all heard about RPM and S2C from another parent. Lucy heard about RPM from a Floortime therapist with whom they were working. All of the participants were working with speech pathologists at this time, yet none of the speech pathologists recommended RPM or S2C.

For family members, learning how to use an AAC device requires training, and this training is most often successful when followed by coaching from a trained professional

(Snodgrass & Meadan, 2018). For 3 days, Jade attended a workshop as a viewer and “took reams of notes.” After that, Jade began working with Cedric daily. Once a month, Jade would send a video to a practitioner for feedback. Jade would be given “marching orders” for the ways to improve her skills as a CRP. Using video recordings to share progress with professionals who are not able to be in the natural setting is one way that families can receive coaching (Snodgrass & Meadan, 2018). Lydiann also attended an outreach presentation that a practitioner offered a few hours away where she was able to observe other S2C sessions. Modeling or showing how to use the AAC is a commonly used instructional method for teaching AAC (Gevarter et al., 2021). Lydiann spent the next year, between her first and second visits to the S2C practitioner, working on the techniques that the practitioner taught them. Initially, she and Martin practiced at home, and then would have a session with one of the practitioners. However, a practitioner trained Lucy in how to use RPM; Elizabeth was completely committed to learning how to use RPM with her and was fluent with Lucy by the end of the year. Elizabeth said they practiced every day for at least an hour without missing a single day. Elizabeth would go to sessions, watch videos, and practice to help herself learn how to support Lucy. Elizabeth said,

I remind people it was very intense. I remember one of the early sessions. I literally put my head down on the table and started crying. The therapist is telling you what you're doing wrong, that this is the most important thing you're ever going to master in your life. When you're not doing it, and your child is screaming, and you're crying, I mean it's intense. I wouldn't want to go [through] it again. But you know, after you get it, you got it!

Attitudes are the key to success, and family members are the best advocates for ensuring that progress is being made (Mandak & Light, 2018). Despite all the hard work, all of the participants shared that it was worth the time.

Families require training that involves the use of the system with the person learning to use AAC (Beukelman & Light, 2020). Marcy said that, when they started doing S2C at home, he resisted working with her initially. There were times when she could only get him to sit down for 15 minutes. There were also a couple of times when he got very frustrated, and he smacked Marcy. She said, “We just worked through it all.” It took a year of consistent and hard practice, and now they are fluent communicating together. All of Levi’s writing for his books, his videos, and his blog are done with Marcy as his communication partner. She said,

He writes a blog, and he is obsessed! Sometimes I don’t even have time to sit down.

There was one day I just didn’t have time to sit down with him to write. I told him, I just can’t do it today. And he spelled, “Oh, okay, I guess I’ll be a nonspeaker today!” Guilt?

Lydiann described, “Sometimes I would get frustrated or hard on myself when things weren’t happening as quickly as I wanted them to.” Over time, things started flowing better. It was just a matter of practice, practice, practice. Just as a dance requires two people to move, communication requires a two-way exchange (Beukelman & Light, 2020). Lydiann stayed the course and overcame the challenges presented because she felt that the program was going somewhere and that it was going to be meaningful for him. Lydiann described this change:

Like having a light turned on in a dark room that you could feel your way around, if you think about literally being in a dark room, especially if you’re kind of familiar with the room you’re probably not going to fall flat on your face, tripping over anything. Then you flip the light on, and it’s like, okay, there’s all these details that you’re missing underneath. That’s what it’s like, having a light turned on to let me actually see my kid for the first time.

Reflective observation happens when the learner reflects on an experience (Kurt, 2022). Family members of nonspeaking autistic individuals describe their experience with identifying,

learning, and implementing AAC as intensive, requiring determination and dedication and ending with exceptionally positive results. The learning process was intense but exciting, and the implementation process required practice and consistency. Overall, all of the participants described the process of identifying, learning, and implementing AAC as life changing.

### **Research Question 2**

I created Research Question 2, “How do family members of nonspeaking autistic individuals describe transformations within their families since implementing AAC?” to understand better the experiences of family members and any changes, for the participants in this study described transformations as emotional, real, and hard to put into words. The changes described affected the entire family. Social connections that were made for both the nonspeaker and the participants had a significant impact on their quality of life. The participants described the ability to do things that they had thought would never be possible. Being able to unlock what was inside of their family member has allowed remarkable growth. The changes with previous unwanted challenging behaviors dramatically improved. The self-injurious or aggressive behaviors of the past are gone. Being able to include their family member in activities and to ask their input on what they want to do is now possible. Sibling relationships have improved, and the participants feel closer as part of their families.

The ability to know their family member on a deeper level has been life changing for all of the participants. Now that Jade’s family can talk with Cedric and he can spell to them what is happening and what he needs, they have not had any physical attacks. Jade said, “I think we’ve gotten better at listening to what he’s saying because we are really trusting that it’s an impulse, not a behavior.” Williams (n.d.), an SLP, wrote about brain–body disconnect. Williams described a term for the phenomenon “what you see is not what you get,” an experience that many people have described with autism, for the person’s body does not do what they are telling it to with

their brain, which is known as a brain–body disconnect (p.1). This is a combination of a sensory system that is disorganized and a difficulty with motor planning that makes intentional movements hard for individuals to achieve. Williams described behaviors of autistic individuals as trying to regulate their sensory systems.

The participants shared that communication with their family member went from answering basic questions to the creation of life goals, friendships, and value of inclusion. Mark said, “It is not lost on me how fortunate I am!” The participants in this study described that, when the family members of the nonspeaking autistic individuals realized their intelligence, that realization provided an increase in their well-being. From Mark’s perspective, it has drastically improved the brothers’ relationship. Mark said,

It comes down to a sibling relationship Iih is phenomenal, our relationIhip is just like anybody else. The two of us are brothers and while he does have a quick wit, he’s incredibly perceptive . . . if you think about it, his entire life, all he’s done is observe.

When nonspeaking individuals struggle in certain areas, it might be difficult to assess what they know (Donnellan et al., 2013). According to Donnellan et al. (2013), clear evidence of one’s capabilities can be difficult when one is trying to assess someone who is unable to communicate. Professionals must make decisions without clear evidence (Donnellan, 2013). They should determine the least dangerous consequences to the student if that assumption is to be proven wrong (Donnellan et al., 2013). For this study, this means that one should not assume that students do not understand what is being spoken to them simply because they cannot speak or do not look like they are listening. To do the opposite could prohibit learning and have traumatic consequences (Donnellan et al., 2013).

One of the hardest parts of life for nonspeaking autistic individuals is making friends (Assimakopoulos, 2018). All of the participants described the increase in socialization for the

nonspeaking autistic family members. Autistic peers might have differences in social interactions, but they have the same desire for friendships and relationships (Crompton et al., 2020). The participants described the connections that they have made to other family members and how impactful that was to them. Living with autism affects the entire family, including mothers, fathers, and siblings (Ellis, 2018). The overall reported quality of life for families living with someone with autism is less than those without an autistic family member (Ellis, 2018). Lydiann said, “There is nothing like connecting with another parent who understands your experience as a parent.” Marcy now has a whole new group of friends that she met through their S2C center, and they are committed to making their children’s lives as fun as can be. She said they are constantly planning different activities, which did not occur before S2C. Families have identified many obstacles while living with autism, and those who have found communication through AAC interventions have been able to share positive life transformations (Peña, 2019). Hearing success stories can help educate, inspire, and bring hope to families (Peña, 2019). Most families and nonspeaking autistic individuals have little communication or social supports (Peña, 2019). The participants described their family member as being happy. Life has become easier for the entire family. Lucy said, “Everything is better.”

Prior to AAC, nonspeaking autistic individuals, as Mark described, “Were stuck inside.” Now all of the nonspeakers are able to be “part of the conversation instead of the subject of it.” As Mark described, “Rick is now able to be a participant in his life, instead of just watching from the sideline.” Having relationships and being socially connected, for both the autistic individual and the family members, plays a role in both physical and psychological health (Crompton et al., 2020). Martin has traveled several times to meet friends out of state. He was able to meet his songwriting teacher; many of Martin’s songs are about his family and friendships. “There’s just not adequate words to describe how incredibly life-changing this has been for him,” Lydiann



said. Communicating using AAC has allowed nonspeakers to come together and find friendships (Assimakopoulos, 2018).

Transformations also included reduction of self-injurious behaviors. Jade said, “Cedric had a lot of self-injurious behaviors before spelling.” Jade shared that they have seen a drop in those behaviors that she likes to call impulses. Elizabeth said, “We have absolutely had no more self-injurious behavior. The scars of her past have all faded and it’s just better.” Marcy and Jade also reported the elimination of aggressive behavior. Jade shared that she views behaviors as impulse, for there is no intention behind them. Neurodiversity provides a different reason for external behaviors of neurodiverse individuals, for it is focused on what the person is thinking, and those who practice the view of neurodiversity appreciate and value differences instead of judging them (Singer, 2017). From the outside world, people with autism are viewed as having a lack of empathy, not having a sense of mind, having little or no ability to form friendships, and being odd (Singer, 2017). Jade talked about prior to AAC their biggest challenge was that Cedric would attack them in the car. Being more than 6 feet tall, they would have to pull off the road and get out, for it was not safe to drive. Since her son learned how to spell, Jade has not seen any physical attacks. Kedar (2012), a nonspeaking autistic individual who learned to use RPM to communicate, wrote about his behaviors that were misinterpreted and how he was stuck in silence. Kedar can now type independently and hopes that someday everyone will understand that not speaking is not the same as not understanding.

Now that Lucy has the ability to communicate, Elizabeth said, “Lucy lives in her own apartment with a roommate Monday through Friday, and we have her come home on the weekends.” She is very social, but she can be alone for 5–6 hours a day, which previously, Elizabeth did not think was possible. This has transformed how Elizabeth and Lucy spend their days.

Puleo's (2022) advice for parents of individuals with autism was to forget everything they have heard and read about autism and to invest all of their efforts and interventions in their child's motor function and believe that they can succeed. Transformations also included their nonspeaking family members having an increase in creativity, which included writing songs, screenplays, books, and blogs. Marcy shared that Levi has written a few books, and he also currently writes a blog. He's planning on doing a whole series about different aspects of autism for children.

Before being able to communicate, the participants described their family member as being treated as though they were much younger than their actual age and as though they had a lower ability. Zurcher-Long (2017), a nonspeaking autistic, cautioned about measuring intellectual ability by the symptoms of autism. Zurcher-Long showcased the importance of AAC for those who cannot produce spoken language: "Just because we cannot speak, does not mean we cannot think" (Zurcher-Long, 2017). Marcy shared that, when Levi was growing up, the results of assessments always showed that Levi was mentally retarded. The separation of language and motor might show two skillsets and might explain why traditional assessments of nonspeakers do not show what the individual truly knows; however, more research is needed to determine the connections between motor abilities and language (Ramos-Sánchez et al., 2022). Lucy was told that she probably had an IQ of 50. After RPM and SC2, the family recognized that, if Lucy could understand the meaning of life, the Holocaust, and the cruelty of slavery, she obviously understood many things.

Presuming competency of the nonspeaking autistic individual includes assuming the understanding of verbal language and speaking to individuals with age-appropriate instruction (Gevarter et al., 2021). When they were able to start presuming competence it changed everything socially. Elizabeth said, "We understood that she understood." Lucy said to her

family, “I’ve been listening all my life.” When the family recognized that she was a social person, that she was paying attention, and that she had a way to communicate, they started including her in everything. Her social world grew, for everyone was able to presume competence, and then start engaging with her in a different way. Everybody started to see her as a capable, intellectually curious person who needed social opportunities. Elizabeth said, “The most important thing wasn’t so much that she could talk to other people; it was that everyone changed the way they interacted with her, and that made her life just grow exponentially.”

Each participant discussed that believing in their family member and assuming that they could do anything has made a major impact on their lives. Mark shared,

In the in the setting of what we’re talking about with nonspeakers, understanding that they understand everything that’s going on around them, and they want to be able to share what’s going on in their head. It’s just their brain and their body are disconnected.

Mark believes that, no matter who is in front of you, assuming that the nonspeaker has high expectations is always the right choice. Parents and family members can see life from a strength-based perspective through the lens of neurodiversity instead of the medical model that views individuals as lacking appropriate behavior and needing treatment (Hillman, 2020). Jade said, “Presuming competence is the least dangerous assumption we can make about anyone’s intelligence. Cedric reminds me regularly that intelligence is invisible. When I presume competence, I’m believing in the individual I am with.” Jade explained that presuming competence is believing that the individual completely understands what is being said and is able to reason fully within their head. Professionals and experts in the field consider most nonspeaking autistic individuals to be low functioning, when most individuals with autism are uniquely intelligent (Bonker & Breen, 2011). For Lydiann, believing in Martin’s desire to do things, his ability to do things, and certainly his cognitive abilities made it easy for her to

presume the competence of Martin's mind. It was harder for her to get to a place of presuming competence of his body. Marcy said she talks to Levi like you would talk to anyone else. Marcy said, "He'll be wandering around, not looking at you, but believe me, he listens to every single thing." According to Marcy, S2C changes everything. Marcy said, "It changes the way you look at your kid." Sometimes, she tries to figure out if he is different now because he can communicate or because they treat him differently. Marcy thinks, "It's a little bit of both, you know he understands now." By changing the way autism is viewed, a person's experience and how they feel about life might change. This includes how to talk with and listen to a person with autism and how to understand their behavior rather than change it (Delahooke, 2020). Elizabeth talked about the time when they were able to start presuming competence, how it changed everything socially. Elizabeth said, "We understood that she understood." Presuming competence is the belief that every individual, when given the appropriate supports, is capable of learning (Peña, 2019).

### **Implications**

Through my research, I have contributed to the body of research in the field of autism and AAC, specifically focusing on the experiences of family members of nonspeaking autistic individuals. Currently only 2% of nonspeaking autistic Americans have access to using a letter board or keyboard as their means of communication (I-ASC, 2022). The participants shared that their family members tried many other types of intervention before being introduced to RPM and S2C. Levi's journey to successful communication did not begin until Age 24, Mark began spelling at Age 24, Lucy began at Age 16, Cedric began at Age 15, and Martin, the youngest, began at Age 8. Currently, 7 million people in the United States have autism; of this number, 2.3 million are nonspeaking (I-ASC, 2022). In a study on AAC systems, Palazini (2019) recommended that parents be part of the decision-making process regarding what type of

communication system they choose to use with their family member and how communication systems are used across multiple settings for social opportunities. My research supports sharing how family member decision making has helped communication occur. None of the participants knew about the option of spelling until years of interventions had been provided.

The data gathered from the Interviews with the participants supports the literature presented in Chapter 2. Autism is different for each person and there is a need to have different interventions available (NAA, n.d.). Nonspeaking autistic individuals who have not found an effective way to communicate, potentially, because of the lack of research available, might have an impact on their families (Maas et al., 2014). My research has restored the experiences of families and I have confirmed how life has been transformed when communication has developed. Often, the greatest barrier for AAC users is low expectations and negative social attitudes, for individuals with developmental disabilities have frequently been excluded from society (Beukelman & Light, 2020). All five participants presented in detail the drastic improvements in family and friend relationships. Mark, Jade, Lydiann, Marcy, and Elizabeth described the layout of their family member's week with many activities that involved friends, learning, and a life that was very different than before spelling.

The parents described how they stopped attending social events because of all of the challenges and negative experiences (Oti-Boadi et al., 2020). Implications from this study might bring hope to families who have been isolated, for Marcy remembers a few years ago being in a rut with Levi because he would come home from school and would go down into the basement and get on the computer and he would watch and "stim" on videos, watching the credits for hours on end, and she could not get him to stop. Marcy would try to get him to come upstairs and go for a walk or do something else. However, Levi would always resist, and she remembers being sad and thinking to herself, "Is this what life is going to be like for the rest of our life?"

Marcy felt an incredible guilt that Levi would be down in the basement being nonproductive, then S2C came and “just changed everything.”

For autistic individuals, having social interactional opportunities in the community is vital to communication development (Spellers and Allies Advocacy Network, 2022). When motor impairments prevent communication, it might also prevent progress in all areas, including academics, socialization, and employment. Currently only .002% of nonspeakers with autism are in college or have graduated (Spellers and Allies Advocacy Network, 2022). When Lucy could communicate, her family talked to her about going back to get her high school diploma, going to college, and getting a good job. Lucy wants to advocate, and her goal is to try to make it better for the for the next generation of nonspeakers, and to be able to live a life of purpose. Elizabeth said, “That is just as valuable as having a job and getting a paycheck.” Her value in life is to demonstrate that there is a quality of life with a set of individuals who have historically been segregated out of society.

There is a high need for evidence-based practices, technology solutions, and AAC services; and, without more research, individuals with complex needs have a high risk in the area of education, employment, health, and community living (Light et al., 2019). The majority of individuals are given traditional speech therapy services and are not taught an ACC approach to communication, which often might be viewed as a last resort (Donaldson et al., 2021). Marcy shared, “All those years of speech therapy, I feel were totally wasted. They did nothing for him.” Elizabeth shared that they were spending \$40,000 to \$50,000 a year on therapies for Lucy, they did everything they could for her. When spelling came along, “it was kind of mind blowing,” Elizabeth said.

I focused this study on family members of nonspeaking autistic individuals who use S2C or RPM and their experiences that occurred both in and out of the home. This study is important

to these family members and their nonspeaking autistic individuals because they want others to have access to this type of communication. Elizabeth said,

Quite frankly, the people with the best outcomes are the people that kind of go in on their own, and that's pretty horrific, because that means that this then becomes an opportunity only for individuals of privilege for families that they can afford for one parent to leave the workforce and spend their entire career just focusing on this. We should have home schooled and just gone through the whole curriculum ourselves.

This study might also be significant to family members of nonspeaking autistic individuals who have not yet found a way to communicate, for it might provide perspectives of options that have not been shared with them on how to communicate. Samsell et al. (2022) discussed the experiences of family members and described them as experts in the field of autism. Interventions that integrate family and community perspectives are needed (Samsell et al., 2022).

### **Recommendations for Action**

After reviewing the participants' experiences with AAC, I have three recommendations for further action. The participants in this study explained that they primarily learned about this method of communication from another parent only after many years of interventions were tried. The participants also shared that the school system did not support them in this method of communication. Recommendation 1 is that options such as S2C and RPM should be provided to families beginning at an earlier age and that the public schools should support them. During the school identification process, the AAC team usually includes the nonspeaking autistic individual, family members, and professionals who work with the individual. The team role is to work together to make suggestions on how to support the nonspeaker on their communication goals (Beukelman & Light, 2020). Training should be provided to all staff who provide support for

nonspeaking autistic individuals and, if the AAC team (including the family) chooses S2C or RPM as their form of AAC, they should be provided ongoing training. There are many options for training, including in person modeling, online training, and recording work for feedback. Families should feel that they have a team from which they can get support, and all support should be focused on supporting the nonspeaking autistic individual with their AAC goals. Implementing AAC includes its use in the nonspeaking individual's home, school, and community (Ganz et al., 2014). Promoting social interaction, providing intervention across the life span, and using effective intervention techniques should all be considered in planning for AAC use (Beukelman & Light, 2020). The social desire for nonspeaking individuals is there, even if it does not appear that way; therefore, providing opportunities to socialize using AAC should be part of the implementation.

I focused Recommendation 2 also on public schools that should provide professional development in the concepts of presuming competence and neurodiversity for the people who support nonspeaking autistic individuals. Exploring neurodiversity might contribute to supporting educational development (Vanderbilt University, 2018). The Frist Center for Autism and Innovation at Vanderbilt University (2018) has a goal of enhancing the 21st-century workforce by engaging autistic talent (Vanderbilt University, 2018). This organization embraces the intellectual and neurological diversity that each person, including nonspeaking autistic individuals, brings (Vanderbilt University, 2018). All people need to start presuming competence; Elizabeth said, "We understood that she understood." Lucy said to her family, "I've been listening all my life." Elizabeth has thought about all the things they said in front of her daughter. She shared that they would have conversations about things they should not have discussed in front of her as though "she was the wallpaper." When the family recognized that she was a social person and she was paying attention and she had a way to communicate, they started



to include her in everything. Presuming competency of the nonspeaking autistic individual includes assuming the understanding of verbal language and speaking to individuals with age-appropriate instruction (Gevarter et al., 2021). For families and educators to know and understand that, just because an individual cannot speak, does not mean that they can think—and this is crucial for their quality of life.

My Recommendation 3 for action is to promote interventions, including the intentional focus on motor skills through physical activity and exercise for nonspeaking autistic individuals. Puleo's (2022) advice for parents of individuals with autism is to forget everything they have heard and to read about autism and invest all of their efforts and interventions in their child's motor function and believe that they can succeed (Puleo, 2022). In this study, I found that coaching the motor system has been effective for regulation and achievement of things formerly thought to be impossible. Mark shared that he has seen many positive results for nonspeaking autistic individuals when he used his words to coach their body to do activities that were broken down into small steps. Sometimes their bodies just get stuck, and they just need that little extra coaching to get them to where they need to go. Intentional motor practice and helpful to teach children with autism new skills (e.g., using exercise equipment) such that, the more practice, the more independent they become, creating a habit of exercise (Bishop et al., 2015). Lucy always had a very intense schedule of activities to meet her motor needs, including ice skating, walking, and swimming. She currently walks 2.5 hours a day to regulate her body. This exercise helps her to have success in all other aspects of life. Throughout this study, I heard about the practice of learning to spell and the focus on motor skills. The participants described the impulse control of their nonspeaking autistic family member. They also described that, the more they practiced working on intentional motor skills by breaking down specific steps to a task and providing verbal body coaching to their family member, the better the outcome. The ability to control and

regulate their body also improved. The participants used the practice of S2C or RPM, both of which were focus on intentional motor practice to learn to communicate. Synchrony between the brain and body is the goal (Vosseller, 2022).

### **Recommendations for Further Study**

From my findings in this narrative inquiry, I have three recommendations for further study. My Recommendation 1 is to replicate my study, but to include a larger sample size of participants. Having five families' experiences restoried helped to share a small sample of experiences, but having a larger sample size would allow a researcher to share a larger sample and to provide additional experiences and perspectives on AAC options for nonspeaking autistic individuals. It would be an excellent idea to have the perspectives of additional family members (e.g., fathers, grandparents, aunts, and uncles) on AAC for their nonspeaking autistic family members.

My Recommendation 2 is to conduct a study with siblings of nonspeaking autistic individuals who have used AAC and to focus on their relationships before and after AAC, as well as on their perspective on mental health. Siblings of nonspeaking autistic individuals have very different lives than those who do not have siblings with autism. The participants shared the challenges and gains that they had as siblings after communication; however, I only had one sibling's direct perspective in this study. Lydiann thinks siblings in general are an underserved and underrepresented group and she would love to see more support offered for them. Elizabeth shared that Lucy's relationship with her siblings has changed since she began spelling. Now, she's able to say something sweet, or they can laugh at the same thing and understand what Lucy is thinking. It's changed everything. Before spelling, she was screaming, and they were all miserable. Elizabeth described it as being like "Everybody, hit the deck!" Now, Lucy travels with them and the family takes her everywhere. Elizabeth said,

I feel lucky and I wonder if my other children are who they are because they were part of this profound experience. It's made us all close. I think there's a resiliency about my kids, a compassion, and the capacity for understanding people unlike them. Sadly, I don't know if you would get it another way. I'm really proud of what we have.

More research could support siblings of nonspeaking autistic individuals in how others have found ways to get through life. A quantitative longitudinal study could show life for siblings before their family member learned how to spell, their quality of life, emotional needs, and ability to cope, and then show the changes after they learned how to use AAC.

My Recommendation 3 for further study is to expand research beyond the United States. I-ASC (2022) claimed that they “currently [have] trained S2C Practitioners in, Canada, South Africa, New Zealand, South America, Dubai, Germany, France, Venezuela, Chile, and the United Kingdom.” Observing practices in other countries might help with practices in the United States. By studying how S2C and RPM are used in other countries, researchers could examine the family experiences of identification, learning and implementation of AAC, and transformations that might have occurred. Researchers could explore how the findings of those studies compare to family experiences in the United States.

### **Conclusion**

In this study, I focused on the experiences of family members of nonspeaking autistic individuals who had a limited ability to communicate and, through family identification, learning, and implementation of AAC, how the family members' lives have been transformed. Limited communication affects family life and interactions (Desiningrum et al., 2019). Parents of autistic individuals face many challenges daily, including being unable to relax, exhaustion, sadness, fear, frustration, and sometimes helplessness (Goodwin et al., 2022). The restoried

narratives of five family members whose nonspeaking autistic individuals can now use AAC to share challenges provide hope for other families who have not yet found a way to communicate.

According to Jaswal et al. (2020), 30% of autistic individuals have limited ability to communicate, and most of them never gain access to an effective means of communication. Options such as S2C and RPM can provide an alternative to communication (Peña, 2019). The participants in this study shared the transformations and remarkable improvements from the past since beginning their journey using S2C or RPM. Limited research has been documented regarding the everyday impact of AAC interventions for individuals who use them and their family experiences (Kron, 2017). Nevertheless, a growing community of autistic people are using letterboards and keyboards to communicate (Peña, 2019).

Three themes emerged from the data. Theme 1 was an increase in well-being for the entire family. All five participants described improvement in life not only for their speller, but also for the entire family. Spellers and their families experienced an increase in well-being both physically and emotionally.

Theme 2 was a remarkable improvement from the past. All five families shared amazing changes to their communication with their nonspeaking autistic family member. Family members also shared a dramatic shift in the social aspect of their family member. They also shared major improvements in self-injurious behaviors.

Theme 3 was that learning and implementing AAC was laborious but beneficial for the communication partner. They all described the commitment it took and that it was worth every minute. Each participant talked about sharing the benefits and changes with other families. They all encouraged families when considering spelling as AAC and to give it a try.

Family members of nonspeaking autistic individuals described their experience with identifying, learning, and implementing AAC as a journey of determination and dedication that

ended with life changing positive results. The identification process was time consuming. The learning process was intense and exciting, and the implementation process required practice and consistency. Transformations within their families since implementing AAC were described as emotional, real, and hard to put into words. The positive changes described affected the entire family. Social connections that were made for both the nonspeaker and the participants had a significant impact on their quality of life. The participants described the ability to do things that they never thought could be possible. Being able to unlock what was stuck inside of their family member has allowed a remarkable growth. The ability to know their family member on a deeper level has been life changing for all of the participants. Elizabeth shared,

You've got to find community, and you've got to find a way to communicate, and after that I think you can do anything. Autism can be a very isolating diagnosis and not being able to communicate. Keep reading, keep working at it and find people that can do this journey with you. The exciting thing is [that] everybody gets better. I get better as a parent, Lucy's better regulated, and we have community. Everyone needs community, it's not just our adult children or our younger children, it's the parents, and it's the siblings.

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APPENDIX A  
RECRUITMENT POST

Dear Family Members of Nonspeaking Autistic Individuals,

I am currently a doctoral student at the University of New England. I am conducting a study titled FAMILY MEMBER EXPERIENCES WITH AUGMENTATIVE AND ALTERNATIVE COMMUNICATION SYSTEMS USED BY NONSPEAKING AUTISTIC INDIVIDUALS for my dissertation. The purpose of this research study is to explore the experiences with identifying, learning, and implementing Spelling2Communcate and/or Rapid Prompting Method of family members of nonspeaking autistic individuals. I am seeking five volunteers to participate in my doctoral research study.

You are eligible to participate in this study if you are:

- Over 18 years old
- Live in the United States
- Have experience using Spelling2Communcate and/or Rapid Prompting Method with a nonspeaking autistic family member

Participation in this research is voluntary. Participation will consist of one interview of approximately 60 minutes. The interview will be conducted on Zoom at a time of your convenience. If there are more than five people who express interest, only the first five will be selected for an interview. All data will be kept confidential, and pseudonyms will be used to protect the identities of respondents. All identifying information, including names and locations, will be deidentified.

Please review the attached Participant Information Sheet which outlines the specific details of this study including confidentiality and privacy measures.

If you are interested in sharing your experience with me, please contact me via email at [cwotton@une.edu](mailto:cwotton@une.edu) and we can set up a time for an interview over Zoom.

If you would like additional information or have any questions, please reach out to me at the above listed email.

Thank you for your consideration of participation in this study.

Sincerely,

Christina M. Wotton  
Doctoral Student  
University of New England

## APPENDIX B

## PARTICIPANT INFORMATION SHEET

Version Date:	<i>February 22, 2023</i>
IRB Project #:	<i>0223-15</i>
Title of Project:	FAMILY MEMBER EXPERIENCES WITH AUGMENTATIVE AND ALTERNATIVE COMMUNICATION SYSTEMS USED BY NONSPEAKING AUTISTIC INDIVIDUALS
Principal Investigator (PI):	<i>Christina M. Wotton</i>
PI Contact Information:	<i><a href="mailto:cwotton@une.edu">cwotton@une.edu</a>, (207)-701-7131</i>

**INTRODUCTION**

- This is a project being conducted for research purposes. Your participation is completely voluntary.
- The intent of the Participant Information Sheet is to provide you with important details about this research project.
- You are encouraged to ask any questions about this research project, now, during or after the project is complete.
- The use of the word ‘we’ in the Information Sheet refers to the Principal Investigator and/or other research staff.

**WHAT IS THE PURPOSE OF THIS PROJECT?**

The general purpose of this research project is to explore the experiences of family members of nonspeaking autistic individuals who use augmentative and alternative communication systems.

This research is being conducted as part of the Principal Investigator’s doctoral dissertation.

**WHY ARE YOU BEING ASKED TO PARTICIPATE IN THIS PROJECT?**

You are being asked to participate in this research project because you are 18 years of age or older and have experience identifying, learning, and implementing Spelling2Communicate and/or Rapid Prompting Method with a nonspeaking autistic family member. The target population for this study will include individuals who are family members of nonspeaking or unreliably speaking autistic individuals and live in the United States.

**WHAT IS INVOLVED IN THIS PROJECT?**

- · You will be asked to participate in one semistructured interview with the principal investigator that will last approximately 60 minutes over Zoom.
- · You can choose a pseudonym to be used in place of your name for the study.

- · You will be given the opportunity to leave your camera on or off during the interview, and your interview will be recorded using Zoom.
- · You will be emailed a copy of your restored narrative to review for accuracy. You will have 5 calendar days to respond or after 5 calendar days the PI will assume that you have no comments and the restored narrative will be assumed to be accurate.

### **WHAT ARE THE POSSIBLE RISKS OR DISCOMFORTS INVOLVED FROM BEING IN THIS PROJECT?**

The risks involved with participation in this research project are minimal and may include an invasion of privacy or breach of confidentiality. This risk will be minimized by using a pseudonym for each of the participants' names and by eliminating any identifying information from the study. Participants will have the opportunity to review their restored narratives for accuracy and will be given the choice to have their cameras off during the interview. Participants have the right to skip or not answer any questions, for any reason.

Please see the 'WHAT ABOUT PRIVACY & CONFIDENTIALITY?' section below for additional steps we will take to minimize an invasion of privacy or breach of confidentiality from occurring.

### **WHAT ARE THE POSSIBLE BENEFITS FROM BEING IN THIS PROJECT?**

There are no likely benefits to you by being in this research project; however, the information we collect may help us understand the experiences of doctoral committee members when advising doctoral candidates.

### **WILL YOU BE COMPENSATED FOR BEING IN THIS PROJECT?**

You will not be compensated for being in this research project.

### **WHAT ABOUT PRIVACY AND CONFIDENTIALITY?**

We will do our best to keep your personal information private and confidential. However, we cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law. Additionally, your information in this research project could be reviewed by representatives of the University such as the Office of Research Integrity and/or the Institutional Review Board.

The results of this research project may be shown at meetings or published in journals to inform other professionals. If any papers or talks are given about this research, your name will not be used. We may use data from this research project that has been permanently stripped of personal identifiers in future research without obtaining your consent.

- Data will only be collected during one-on-one participant interviews using Zoom, no information will be taken without participant consent, and restored narratives will be checked by participants for accuracy before they are added to the study.
- Pseudonyms will be used for all participants and any personally identifying information will be stripped from the interview transcript.
- All names and e-mails gathered during recruitment will be recorded and linked to a uniquely assigned pseudonym within a master list.

- The master list will be kept securely and separately from the study data and accessible only to the principal investigator.
- The interview will be conducted in a private setting to ensure others cannot hear your conversation.
- Participants are given the option to turn off their camera during Zoom interview.
- Once member checking of the restoried narratives is complete the recorded Zoom interview will be destroyed. Once all restoried narratives have been verified by the participants, the master list of personal information will be destroyed.
- All other study data will be retained on record for 3 years after the completion of the project and then destroyed. The study data may be accessed upon request by representatives of the University (e.g., faculty advisors, Office of Research Integrity, etc.) when necessary.
- All data collected will be stored on a password protected personal laptop computer accessible only by the principal investigator.

#### **WHAT IF YOU WANT TO WITHDRAW FROM THIS PROJECT?**

You have the right to choose not to participate, or to withdraw your participation at any time until the Master List is destroyed without penalty or loss of benefits. You will not be treated differently if you decide to stop taking part in this project.

If you request to withdraw from this project, the data collected about you will be deleted when the master list is in existence, but I may not be able to do so after the master list is destroyed.

#### **WHAT IF YOU HAVE QUESTIONS ABOUT THIS PROJECT?**

You have the right to ask, and have answered, any questions you may have about this research project. If you have questions about this project, complaints or concerns, you should contact the Principal Investigator listed on the first page of this document.

#### **WHAT IF YOU HAVE QUESTIONS ABOUT YOUR RIGHTS AS A RESEARCH PARTICIPANT?**

If you have questions or concerns about your rights as a research participant, or if you would like to obtain information or offer input, you may contact the Office of Research Integrity at (207) 602-2244 or via e-mail at [irb@une.edu](mailto:irb@une.edu).



APPENDIX C  
INTERVIEW QUESTIONS

1. Describe your relationship to the nonspeaking autistic individual who uses an augmentative and alternative communication system?
2. How old is (your child, your sibling, etc.)?
3. What type of augmentative and alternative communication system does (your child, your sibling, etc.) use?
4. How long has (your child, your sibling, etc.) been using the type of communication you selected?
5. Describe in details how you identified this method? What led you to this method?
6. Describe in details the steps and processes **you** took to learn this method? Please describe any classes, appointments, etc.?
7. How have (your child, your sibling) worked on specific motor tasks to learn to spell?
8. When you began implementing S2C or RPM what did that look like?
9. How quickly were you able to implement S2C or RPM across settings (home, community, school, etc.)?
10. How did your family implement S2C or RPM to promote social experiences for your family member?
11. What support did you receive to implement augmentative and alternative communication?
12. What challenges did you face during implementing augmentative and alternative communication with your family?
13. What experiences have occurred for your family since implementing augmentative and alternative communication with your nonspeaking autistic family member?

14. What interventions did you try prior to S2C or RPM?
15. Have you heard of neurodiversity? If so, what does it mean to you regarding your nonspeaking autistic family member and their abilities?
16. Have you heard of the term presuming competence? If yes – what does it mean to you?
17. Prior to Spelling2Ccommunicator and/or Rapid Prompting Method what assessments did your nonspeaking autistic family member complete?
18. What did those assessments tell you about their abilities?
19. In your perspective, what has been the impact on your family since (you, your child, your sibling) has learned to communicate using Spelling2Communcate and/or Rapid Prompting Method?
20. How has learning how to communicate this way positively impacted your family? Have you identified any challenges or negative impacts?
21. What is something your family has learned about (your child, your sibling) that may have been surprising? What did you do with this new information?
22. Please describe your family dynamic. Have this changed within your family since starting augmentative and alternative communication specifically Spelling2Ccommunicator and/or Rapid Prompting Method?
23. What negative or unwanted behaviors have been reduced that have impacted your family?
24. Has your family seen a reduction in the following behaviors when doing activities as a family since learning to use an augmentative and alternative communication system?
  - a. Self-Injurious Behaviors
  - b. Eloping
  - c. Stereotypy/Loud Noises

- d. Work/task refusal
  - e. Aggressiveness towards others
25. What has been the most significant improvement in behavior that has directly impacted your family?
  26. In thinking about before you learned how to spell, what behavior got in your way the most in life and prevented your family from doing something you wanted to?
  27. What behavior has now been eliminated or nearly eliminated since you learned how to spell? How has that changed your family life?
  28. How would you describe any changes in educational opportunities for (your child/your sibling) and how has that changed your family life?
  29. How would you describe any changes in social opportunities for family after Spelling2Ccommunicator and/or Rapid Prompting Method?
  30. How would you describe any changes in employment opportunities for (your child/your sibling) and how has that changed your family dynamic?
  31. What would you tell families or individuals who are thinking about learning how to point, type or spell to communicate?

Please provide any other comments or feedback you would like to share with I on the impact you have had since learning.

## APPENDIX D

## INSTITUTIONAL REVIEW BOARD APPROVAL LETTER



INNOVATION FOR A HEALTHIER PLANET

Office of Research Integrity  
Institutional Review Board

Biddeford Campus  
11 Hills Beach Road  
Biddeford, ME 04005  
(207) 602-2244 T  
(207) 602-5905 F

Portland Campus  
716 Stevens Avenue  
Portland, ME 04103

**DATE OF LETTER:** February 23, 2023

**PRINCIPAL INVESTIGATOR:** Christina Wotton  
**FACULTY ADVISOR:** Andrea Disque, Ed.D

**PROJECT NUMBER:** 0223-15  
**RECORD NUMBER:** 0223-15-01

**PROJECT TITLE:** Family Member Experiences with Augmentative and Alternative Communication Systems Used by Nonspeaking Autistic Individuals

**SUBMISSION TYPE:** New Project  
**SUBMISSION DATE:** February 22, 2023

**ACTION:** Determination of Exempt Status  
**DECISION DATE:** February 23, 2023

**REVIEW CATEGORY:** Exemption Category # 2ii

The Office of Research Integrity has reviewed the materials submitted in connection with the above-referenced project and has determined that the proposed work is exempt from IRB review and oversight as defined by 45 CFR 46.104.

You are responsible for conducting this project in accordance with the approved study documents, and all applicable UNE policies and procedures.

**If any changes to the design of the study are contemplated (e.g., revision to the research proposal summary, data collection instruments, interview/survey questions, recruitment materials, participant information sheet, and/or other approved study documents), the Principal Investigator must submit an amendment for review to ensure the requested change(s) will not alter the exempt status of the project.**

If you have any questions, please send an e-mail to [irb@une.edu](mailto:irb@une.edu) and reference the project number as specified above within the correspondence.

Best Regards,

A handwritten signature in black ink that reads "Bob Kennedy".

Bob Kennedy, MS  
Director of Research Integrity

## APPENDIX E

## THE THREE LETTERBOARDS

Figure 1



*Note.* This figure shows the three letterboards that spellers begin working with as they are learning the process of spelling, a 26-letter stencil board that is the next phase when learning spelling, and a laminated letterboard that is the next phase in spelling before spellers may learn to use a keyboard to communicate.