

A Parent's Autoethnography: Examining My Experiences and Identity as Parent, Educator, and
Researcher While Teaching Literacy to My Adolescent Sons Who Have Autism and Use
Augmentative and Alternative Communication

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Abstract

This autoethnography was completed from my unique perspective as a mother to two adolescent sons with autism spectrum disorder (ASD) who have complex communication needs and use augmentative and alternative communication (AAC) to communicate. Although literacy is a human right (Ontario Human Rights Commission, 2022a), it often has been overlooked in my sons' self-contained classrooms in high school. As my sons' parent and educator, I gathered my reflections, observations, descriptions, journals, lesson plans, and artifacts to examine the experiences I encountered in developing their literacy. Initially, I conducted a pilot project based on Erickson and Koppenhaver's (2007) *Children With Disabilities: Reading and Writing the Four Blocks® Way*, the results of which guided my planning in teaching literacy with an adaptation of the more recent *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* (Erickson & Koppenhaver, 2020). I coded by hand each line of the collected data to extract categories and then streamline these into the meaningful themes to respond to my two research questions: (a) What are the experiences of a parent educator who has been teaching literacy awareness and skills to her adolescent sons who both have autism and use AAC devices? (b) Does the experience shape her identity as a parent, educator, and researcher? Thematic findings pertaining to the first question revealed experiences related to *planning and questioning* and my own *transformational learning and mindshift*. Thematic findings related to the second question include: *Parental concerns*; *Educator: advocating and imposter syndrome*; *Researcher: Lesson planning and questioning*; and *Transformational learning and mindshift*. Findings are discussed in light of the literature on experiences of parents as educators of children with exceptionalities. The study also presents implications for theory, practice, and research, as well as limitations and future directions.

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CHAPTER ONE: INTRODUCTION

Learning to read and write are milestones that many neurotypical children achieve during the elementary school years. According to the Province of Ontario's Ministry of Education (2021), literacy skills are critical and are considered foundational for "all other academic achievement and for a lifetime of success" (para. 2). Unfortunately, many students with significant disabilities—including intellectual, developmental disabilities and complex communication needs—are not given the same opportunities or instructional activities and can be excluded from educational contexts where they could gain these skills (Ruppar, 2017). Furthermore, research suggests that if literacy skills are taught, the instruction often tends to focus more on functional word lists rather than on the foundational skills of literacy (Browder et al., 2009). Other literacy activities for students with significant disabilities were one-to-one instruction with comprehension questions that were unrelated to the general curriculum, using mostly worksheets and symbolized pictures (Ruppar, 2015).

Additionally, in secondary schools (i.e., Grades 9 through 12), sustained and coordinated literacy programming is difficult to implement given that the day is divided into subject periods and often with different teachers. Moreover, typical life skills programming that is offered to many students with significant disabilities, particularly those with autism spectrum disorder (ASD), tends to emphasize functional academics and independent skills, but not authentic literacy skills (Shurr & Bouck, 2013).

This thesis will focus on my perspective as a mother and educator to two sons with ASD who have complex communication needs and require the use of augmentative and alternative communication (AAC) to communicate. AAC is a method that allows the user a means to communicate not using verbal speech. According to the American Speech-Language-Hearing

Association (ASHA) (n.d.a), AAC can include but is not limited to gestures, facial expressions, drawing, pointing to pictures, pointing to words, using a speech generating device, et cetera. Accordingly, the role of AAC will be emphasized throughout this thesis as I describe how I support its use as my sons' parent and educator. As both my sons use AAC, specifically speech generating devices on their iPads with a communication app Proloquo2Go, I chronicled, self-analyzed, and interpreted my work with my two sons as they reinforced their literacy skills using a literacy instructional framework.

In this thesis, the term *literacy* encompasses all aspects of literacy, including phonological awareness, phonics, reading and writing, as well as engagement with text and other people, communication, and literate behaviour. Therefore, throughout the thesis when I refer to reading and writing, I am also taking into consideration engagement, interactions, communication, and purposes of literacy as well.

Background of Problem

Individuals who are developing language through the use of AAC need to be able to translate their internal thoughts in order to consider how they relate to the external symbols: "As they develop knowledge of the content of aided communication, they must figure out not only what their graphic symbols mean, but also what they are for and ultimately how they work together" (Smith, 2015, p. 219). However, if the person is unable to use a symbol for their thought or the word symbol is not accessible, they need to be able to utilize foundational literacy skills. For instance, the individual needs to utilize initial letter sounding strategies or spell words to convey their message; otherwise, they will need others to assist them in communication (Koppenhaver, 2000). Thus, when an individual has a thought they want to convey, if the symbol is not on their AAC device and they do not have alphabetic knowledge or have access to

supports, they are unable to express their point of view. As it is impossible to have an AAC device that is able to convey every idea a person has, learning the alphabet and literacy strategies is the only way that an individual might be able to convey their thoughts and feelings when they desire to do so.

As noted above, literacy skills (e.g., phonological awareness, letter identification, concepts of print, reading comprehension, writing) are foundational skills for all humans. However, it can be argued that for people who use AAC as a way to communicate, these skills are even more imperative. According to the ASHA (n.d.b), the ability to write and spell at even basic levels allows the person the ability to convey their thoughts. Furthermore, the ASHA (n.d.b) notes that reading and writing allow maximum participation in education and employment and allow the person to access knowledge and increase experiences.

Even though the critical importance of teaching literacy skills is evident, as noted above, many students with significant disabilities are not being taught literacy in a comprehensive way. There are many challenges to teaching students with complex communication needs due to their “inability to participate in conventional literacy activities such as reading aloud, providing spoken responses to literacy activities (e.g., producing sounds that correspond with letters, blending individual sounds into spoken words), or answering reading comprehension questions” (Fallon & Katz, 2008, p. 113). Clearly, additional time, planning, effective instructional methods, accommodations, and the use of AAC are essential to meet these needs.

After elementary school, many adolescents with disabilities who are minimally verbal or nonverbal are placed within a self-contained functional learning classroom in secondary school. Although there is a shift towards inclusive education, according to the Ontario Ministry of Education, in 2017 just over 50% of students with developmental disabilities were in regular

classrooms (Bennett et al., 2019). Unfortunately, nearly three decades ago the research regarding literacy instruction within the self-contained special education classes revealed that they were not receiving the same opportunities as typical learners in general education (Koppenhaver & Yoder, 1993). In comparison, a study by Ruppar et al. (2018) found that students in contained classes were 10 times less likely to be exposed to academic literacy activities; it seems that literacy is still not a priority for this population of students. “Typically, it has been assumed that reading is a skill beyond the intellectual capabilities of most students with ID [intellectual disability] and that at best they might be taught to recognize a limited number of sight words” (Allor et al., 2010, p. 500).

In Alberta, Canada, the Edmonton Regional Learning Consortium (ERLC, 2016) states that “in the past, the emphasis for students with significant disabilities was often on ‘life skills’ programming rather than communication supports and literacy instruction” (para. 11), which further indicates a possible pervasive problem across Canada. Moreover, in the secondary school setting, sustained literacy programming is difficult to implement given that the day is divided into subject periods and often with different teachers. Accordingly, the typical life skills programming that is offered to students in contained classes tends to emphasize functional academics and independent skills (Bouck & Joshi, 2012). As an illustration, Ruppar (2015) examined eight self-contained classes and found that written and spoken expressive communication were underemphasized, the literacy activities were not in a natural setting, nor were literacy skills taught for use in authentic settings and circumstances. Finally, a disproportionate amount of time was spent where the student passively listened to the teacher reading with no opportunity to respond (Ruppar, 2015).

Often when “students who use AAC reach transition age, key decision makers such as parents, school personnel, or even the students themselves may no longer believe that

conventional literacy is attainable” (McNaughton & Beukelman, 2010, p. 37). Therefore, “they may have low expectations for literacy achievement or may consider conventional literacy a low priority” (McNaughton & Beukelman, 2010, p. 38). According to McNaughton and Beukelman (2010), even though literacy development is on continuum from emergent to conventional, many educators insist on a

reading readiness perspective ... [such that] certain levels of linguistic and cognitive ability must be reached before students can benefit from literacy instruction. For example, only once a student begins to have some phonemic awareness skills are they able to receive further literacy instruction. If a student does not demonstrate the required skills, then they are not taught advanced literacy skills. By these standards, many students, with significant cognitive disabilities would never be considered ready for formal literacy instruction. (McNaughton & Beukelman, 2010, p. 37)

Another barrier is that phonics instruction and phonemic awareness is often not taught or observed in the secondary school setting, yet this type of instruction is crucial for someone who uses AAC, as this may increase their independence and self-expression (Rupper, 2015). Specifically, phonetic skills enable the AAC user the ability to independently write their own words. “The use of sounds to create words and words to create phrases is critical to independent communication ... [providing skills] ... to create novel messages and words, rather than relying on someone else to preprogram a device” (Ruppar, 2015, p. 242). Thus, it is imperative that foundational literacy skills are taught for users of AAC, especially those vulnerable groups with disabilities.

Today we know that everyone, regardless of disability, should be given instruction to be taught to read (OHRC, 2022a). In fact, the ERLC (2016) notes several studies that reveal “recent research shows that with high expectations, sound literacy instruction, and the support of

assistive and communication technologies, individuals with cognitive disabilities can acquire literacy skills and demonstrate intelligence beyond what would have been predicted by test results” (para. 11). However, even though research has illustrated that literacy can be taught to students with significant and complex communication needs, sadly this is often not the case.

Statement of Problem

There is a disconnect with respect to literacy learning for adolescent students with significant communication disabilities where foundational literacy skills are needed but are not being taught. As a parent with two children with ASD who have complex communication needs that require the use of an AAC device, it is disconcerting that these skills are not a major component in their education. Clearly, for adolescent students with disabilities and complex communication, there needs to be an approach that teaches foundational literacy skills during their school day. This was my personal call to action.

System-wide across Ontario there is no explicit direction within the Ministry of Education (MOE) mandating that elementary or secondary teachers instruct literacy skills for students with significant disabilities. There are three publications from the MOE on teaching literacy skills in general: *A Guide to Effective Instruction in Reading Kindergarten to Grade 3* (MOE, 2003a), *Early Reading Strategy* (MOE, 2003b), and *Supporting Early Language and Literacy* (MOE, 2011). The focus of these documents is on strategies for teaching literacy to the mainstream education student population. There is text related to struggling readers; however, there is no text or discussion on teaching literacy to children with significant disabilities, autism, or any neurological disorder.

The next set of MOE documents I examined were: *Policy/Program Memorandum 140: Incorporating Methods of Applied Behaviour Analysis (ABA) Into Programs for Students With*

Autism Spectrum Disorders (ASD) (MOE, 2007c); *Policy/Program Memorandum 156: Supporting Transitions for Students with Special Education Needs* (MOE, 2007d); *Special Education in Ontario: Kindergarten to Grade 12. Policy and Resource Guide* (MOE, 2017); *Making a Difference for Students With Autism Spectrum Disorders in Ontario Schools—From Evidence to Action* (MOE, 2007b); *Effective Educational Practices for Students With Autism Spectrum Disorders: A Resource Guide* (MOE, 2007a); *Education for All: The Report of the Expert Panel on Literacy and Numeracy Instruction for Students With Special Education Needs, Kindergarten to Grade 6* (MOE, 2005); and the Ministry of Children, Community and Social Services’ (2022) *Ontario Autism Program*. Four of these resources will be highlighted and discussed below for their inclusion of some information on literacy instruction for students with ASD.

Upon a detailed review of each of these documents and resources there are varying degrees of information on ASD and literacy, especially for students with complex communication needs. Surprisingly, some documents made no reference to this student population with respect to literacy learning while other documents provided a cursory or narrow focus on literacy instruction. In the MOE’s (2017) *Special Education in Ontario, Kindergarten to Grade 12*, there was text that recommended that the teacher when developing learning expectations, indicate that they “should take care to provide an appropriate challenge for the student. The expectations should be designed to develop the student’s literacy, numeracy, and cognitive skills. They should be achievable by the student, with reasonable effort, during the reporting period” (p. E28). Interestingly, this same document also stated that “a very small number of students who are unable to demonstrate the most basic literacy or numeracy skills may receive only an alternative report” (p. E44). These statements are conflicting as the first

statement acknowledges that all students should be provided with instruction and have literacy expectations and instruction, yet there is mention that there are still some students that don't require any instruction. This might be interpreted by teachers as teaching literacy is optional for certain students. The document does not provide examples or strategies that could be utilized to assist those students that are not attaining basic literacy skills.

Another document with some reference to literacy skills instruction is the *Making a Difference for Students With Autism Spectrum Disorders in Ontario Schools—From Evidence to Action* (MOE, 2007b), however, the text here is limited to only the following statement: “classroom teachers have the primary responsibility for a student’s literacy and numeracy development. Programming for students with autism spectrum disorders will be designed and implemented in collaboration with the classroom teacher and other individuals involved with the student” (p. 9). An important omission is that there is no direction provided to the teacher on how to implement literacy instruction to students with ASD.

The document *Effective Educational Practices for Students with Autism Spectrum Disorders: A Resource Guide* (MOE, 2007a) includes some discussion and text (approximately five pages) on teaching reading and writing to students with ASD. This document could be considered as an initial starting point or introduction, however, there is scarce detail on how to teach the fundamentals of literacy. As well, there is no mention on the importance of teaching the skills in a comprehensive way and no direction on teaching individual skills in isolation. Given that this document was written in 2007, it is disheartening that more guidance and support have not been produced or provided to teachers in this area.

Further, *Education for All: The Report of the Expert Panel on Literacy and Numeracy Instruction for Students With Special Education Needs, Kindergarten to Grade 6* (MOE, 2005),

is the most extensive and inclusive document for literacy instruction for students with special needs. Even though the document includes a section on assistive technology (i.e., predictive text software) that is extremely helpful for students, the document does not address AAC at all. Despite there being a number of evidence-based instruction ideas listed in the document, there are no suggestions or instructions on how to adapt the methods if the student is nonverbal or has other complex communication needs. Table 1 itemizes the aforementioned MOE documents along with a brief summary of the contents of the document. It should be noted that this summary only encompasses the literacy related topics in the MOE document.

Finally, the OHRC (2022a) outlines the *Right to Read: Public Inquiry Into Human Right Issues Affecting Students with Reading Disabilities*. Although this report outlines that the Supreme Court of Canada deems learning to read is a human right (Moore v British Columbia Education, 2012), a significant number of students still are unable to read within the education system. The report notes ableism and low expectations for certain groups of students. It should be noted that this report does not address the needs of students who are the focus of this present study as the focus of the inquiry was students with reading disabilities. It is noted that students with ASD, developmental disabilities, and intellectual disability were not included in the inquiry but are at even higher risk of reading failure and that the recommendations would benefit this population as well (OHRC, 2022c). Further, the OHRC (2022c) notes that some of these students are placed in contained classrooms that “focus on social and life skills with little academic instruction in reading, writing or math.... who are behind in reading may not be considered suitable candidates for reading interventions, even though these interventions would help them improve their reading” (para. 14).

Table 1*Summary of Ministry of Education Documents*

MOE publication	Summary
<ul style="list-style-type: none"> – <i>A Guide to Effective Instruction in Reading Kindergarten to Grade 3</i> (MOE, 2003a) – <i>Early Reading Strategy</i> (MOE, 2003b) – <i>Supporting Early Language and Literacy: Research Monograph #37</i> (MOE, 2011) 	<ul style="list-style-type: none"> • The focus of these documents is on strategies for teaching literacy to the mainstream education student population. • There is text related to struggling readers, however, there is no text or discussion on teaching literacy to children with significant disabilities, autism, or any neurological disorder.
<i>Policy/Program Memorandum 140: Incorporating Methods of Applied Behaviour Analysis (ABA) Into Programs for Students with Autism Spectrum Disorders (ASD)</i> (MOE, 2007c)	<ul style="list-style-type: none"> • Did not include literacy
<i>Policy/Program Memorandum 156: Supporting Transitions for Students with Special Education Needs</i> (MOE, 2007d)	<ul style="list-style-type: none"> • Did not include literacy
<i>Special Education in Ontario: Kindergarten to Grade 12. Policy and Resource Guide</i> (MOE, 2017)	<ul style="list-style-type: none"> • Quote that “a very small number of students who are unable to demonstrate the most basic literacy or numeracy skills may receive only an alternative report” (p. E44). • This might be interpreted by teachers as teaching literacy is optional for certain students. • This document does not provide examples or strategies that could be utilized to assist those students that are not attaining basic literacy skills.
<i>Making a Difference for Students with Autism Spectrum Disorders in Ontario Schools from Evidence to Action</i> (MOE, 2017)	<ul style="list-style-type: none"> • Quote that “Classroom teachers have the primary responsibility for a student’s literacy and numeracy development. Programming for students with autism spectrum disorders will be designed and implemented in collaboration with the classroom teacher and other individuals involved with the student” (p. 9) • An important omission is that there is no direction provided to the teacher on how to implement literacy instruction to students with ASD.

Table 1 (cont'd)*Summary of Ministry of Education Documents*

MOE Publication	Summary
<i>Effective Educational Practices for Students with Autism Spectrum Disorders: A Resource Guide</i> (MOE, 2007a)	<ul style="list-style-type: none"> • This document could be considered as an initial starting point or introduction, however, there is scarce detail on how to teach the fundamentals of literacy. • There is no mention on the importance of teaching the skills in a comprehensive way and no direction on teaching individual skills in isolation.
<i>Education for All: The Report of the Expert Panel on Literacy and Numeracy Instruction for Students with Special Education Needs, Kindergarten to Grade 6</i> (MOE, 2005)	<ul style="list-style-type: none"> • Is the most extensive and inclusive document for literacy instruction for students with special needs. • Includes a section on assistive technology which is extremely helpful for students (i.e., predictive text software) • The document does not address AAC • Despite there being a number of evidence-based instruction ideas listed in the document, there are no suggestions or instructions on how to adapt the methods if the student is nonverbal or has other complex communication needs.
<i>Ontario Autism Program</i> (Ministry of Children, Community and Social Services, 2022)	<ul style="list-style-type: none"> • Did not include literacy

Despite the Ontario government providing teachers with guidance and information on students with special needs, including those with ASD, the focus is mainly on behaviour and other characteristics of these students with ASD. There is little information on instructional methods, adaptations, accommodations, modifications or on practices related to how to teach literacy to students with ASD who have complex communication needs. This recognition has been the impetus for my work and study of my own experience and practice.

Autoethnography

I had originally planned to perform a series of case studies involving adolescent children with ASD for my thesis research, however due to the coronavirus disease (COVID-19) pandemic my original plans were disrupted. Given my lived experience, I turned to autoethnography as a specific category of research methodology to study my role as I pursue my research interest of improving literacy for adolescents with ASD.

Ellis and Bochner (2000) are prominent autoethnographers and they define autoethnography as “autobiographies’ that self-consciously explore the interplay of the introspective, personally engaged self with cultural descriptions mediated through language, history, and ethnographic explanation” (p. 742). They further note that “Autoethnographers vary in their emphasis on the research process (graphy), on culture (ethno), and on self (auto) [and that] different exemplars of autoethnography fall at different places along the continuum of each of these three axes” (Ellis & Bochner, 2000, p. 740). Intrigued and excited by this methodological approach, I decided I would write an autoethnography as a mother and educator of two adolescent boys who are diagnosed with autism and use AAC to communicate and learn literacy skills.

At first, I wondered if anyone would be interested in my perspective. As a parent this is all I know, but what is somewhat unique is my instructional dedication to my sons' literacy learning. It is often remarked to me how exceptional my situation is having two sons with autism who are nonverbal and minimally verbal. I have examined the statistics. In March 2018, the National Autism Spectrum Disorder Surveillance System (NASS) released the most up-to-date Canadian prevalence rate: 1 in 66 Canadian children and youth (ages 5–17) are diagnosed with ASD (NASS, 2018). Of the 1 in 66 children with ASD, there is approximately a 20% chance of having a sibling with ASD (Ozonoff et al., 2011). In terms of verbal ability, approximately 30%–50% of children with ASD do not develop functional speech and require AAC (National Research Council, 2001). And finally, according to Autism Speaks Canada (n.d.), one-third of people with ASD have an intellectual disability. Therefore, the mathematical probability of being a mother to two children with ASD who are minimally and nonverbal underscores that I have a fairly unique perspective.

Autoethnography explores different contexts and deepens the researcher's understanding, assumptions, and values of what is being examined. It further helps the reader understand more about the culture or person connected to the culture. This allows "others from both inside and outside a culture to become familiar with the characteristics that distinguish that culture ... [thus] creat[ing] a collaborative journey between the author and the reader in understanding of knowing the culture studied" (Pitard, 2017, para. 27).

One reason that I am eager to explore my parent as educator role through autoethnography is that I am often met with negative societal perspectives of my boys in all contexts of their life. For example, this occurs when they are being spoken down to by the cashier at the grocery store or a physician specialist in a medical appointment dismissing a

medical issue due to their disability and not a pathological process. I feel that I am often put in situations where I need to advocate for their right to be included, accepted, and educated, especially when it comes to literacy and communication skills. Consequently, I want to affirm that they do belong, they are teachable, and they have plenty to offer society.

“Autoethnographers speak against, or provide alternatives to, dominant, taken-for-granted, and harmful cultural scripts, stores and stereotypes. ... Autoethnographers offer accounts of person experience to complement, or fill gaps in, existing research” (Adams et al., 2017, para. 10). I contend that I have something to offer to the educational literature on parents as educators supporting learners with ASD who are using AAC to learn literacy skills.

Throughout my research I want to examine and reflect on how I instruct my children in literacy and most importantly, how this impacts my views. I further want to contemplate their instruction through different lenses. I will not just be the “mom”; I will also be the “teacher” and for matters of this study I will also be the “researcher.” To be clear, this is an autoethnography illuminating my unique position and not the efficacy of an intervention or approach.

Background Narrative

To appreciate my research purpose for this autoethnography, I believe that it is integral to present a brief personal narrative inquiry as context. “Narrative inquiry attempts to capture the ‘whole story.’ ... It requires going beyond the use of narrative as a rhetorical structure to an analytical examination of the underlying insights and assumptions that the story illustrates” (Mertova & Webster, 2020, p. 3). This narrative inquiry will offer background into my prefatory experiences as a parent and concurrently an educator of my sons.

One of the sources of data for an autoethnography is chronicling one’s memories (Chang, 2008). Pseudonyms have been used for both of my sons. The story begins with both my sons

being diagnosed with ASD at ages 3.3 years (for my son, Alvin) and 17 months (for my son, Charles). The diagnosis for my first son was much harder to receive as a parent as early diagnosis wasn't emphasized as much then and many of my concerns were brushed off as an anxious first-time mom. Concerns raised by parents are noted in the literature and can assist in leading to an earlier diagnosis if physicians pay attention and appropriately refer swiftly (Becerra-Culqui et al., 2018). Early diagnosis is important as this can lead to an improvement in social outcomes related to autism (Gabbay-Dizdar et al., 2022). After multiple visits to the doctor with concerns of autism and being told by doctors, "I don't know what to say, he doesn't have autism," referrals were made and ultimately a diagnosis was given. The diagnosis for my second son was much easier to obtain. Within 9 months of each other, both boys were diagnosed with ASD.

When I think back, I remember feeling overwhelmed learning about the diagnoses and the "laundry list" of therapies, strategies, and interventions proposed, and also learning about the high costs of therapies and the waitlist for every professional service. The other obstacle that kept me worried was that service delivery models, as well as criteria for entry into programs, were constantly being revised. In the short time between the children's diagnoses, changes were being made and I found myself often telling the health-care providers about the changes when resources were suggested as their information was already outdated.

There was a constant barrage of professionals weighing in on everything from their sleeping, eating, speaking, intelligence, et cetera. I often felt like we were on a treadmill, constantly trying to meet milestones with the time ticking away. When I would proudly attend an appointment to show off a new skill one of them learned, we were quickly told that now that they were that much older, they should be doing so much more. The finish line just kept moving.

Not only were service delivery models and service criteria changing, so too were the professionals' attitudes towards what expectations I should have for my boys. At first, I was told if they weren't talking by 6 years of age, they will never talk. That changed to an age deadline of 9 years and then again to 12 years of age. The reason it kept changing was that parents of children with ASD continued to support and advocate for speech therapy and the critical age for skill development just kept getting older and older.

There were other examples of speech and language pathology (SLP) service delivery models changing at this time too. In the school where one of the boys was attending, he was going to be discharged from the school board offered speech services because his pronunciation was so unintelligible. The school board stated that he needed more intensive speech therapy which was through a different branch of SLPs within the school board that worked on the language aspect. After I provided the appropriate paperwork and medical notes and filled out all the forms and waited another waitlist, he was finally picked up for this alternative service. After the initial assessment, the SLP determined that my son couldn't access their speech services as he was indeed able to talk enough to have the basic language foundations. This was such an exasperating circular argument. His school's Special Education Resource Teacher (SERT) supported me and rallied for my son to access to language supports, and we finally received a few extra sessions.

Although I was never actively discouraged by the school system, I have been discouraged by other professionals who have provided consultations. I began to conclude that certain professionals seemed to lower their expectations and their perceived potential for my sons' ability to speak. As soon as any professional heard that my sons were nonverbal, the boys were put in the derogatory "low functioning" and "lacking potential" categories. In order

to receive the Ontario government provincial payment therapy program, the boys had to be “just autistic enough”—meaning not “too severe” that they were “unteachable” and not “high functioning” that they didn’t require any therapy. As soon as the “nonverbal” label was considered there was then additional worry that in every single assessment the boys might be deemed not “teachable.”

Assessments were needed to access many programs and interventions. After one assessment, I was given an appointment with a psychologist and psychometrist. I was told that Alvin didn’t know his alphabet. I knew this wasn’t the case as I had seen him on many occasions identify letters and letter sounds. Also, in his Intensive Behaviour Therapy (IBI) he had demonstrated letter knowledge as well. However, during their assessment when requested to answer a myriad of uninteresting questions, my son refused. Thus, the assumption became that he didn’t know his letters and sounds. I wouldn’t have faulted the assessors for drawing that conclusion, however, I was bewildered by the fact that they used this as the basis for the conclusion that he should no longer be in any academic programming. I was told “not to waste my time” on my son learning letters and sounds. After I disagreed, I was told that if I was insistent on him learning to read, I should focus on a few functional words that he might be capable of reading, like “stop” and “exit.” I was also encouraged to move him out of any academics and into life skills programming, even though his age was in still in the single digits; this was such drastic advice for a child who refused to participate in an assessment.

We sought the services of other educational professionals such as a SLP therapist who specialized in reading. After one session she deemed that Charles would not see the importance of reading or ever read for the enjoyment of reading, and she believed that reading was not a required life skill for him. I was also told I could return and try speech therapy, but she thought it

was a waste of money. I didn't return. I knew I wasn't going to listen to her advice and my resolve to figure out a way to teach the boys to read wasn't diminished but I was disheartened to think of other parents whom she might discourage. What if I listened to the "professionals" and gave up trying to teach them to read and write? I steadfastly maintained that literacy skills are life skills; who was I to take this potential away from my sons?

In the early grades of elementary school, teachers attempted to teach them literacy through skill-based reductionist methods; for instance, worksheets, drill based, isolated skills, and sight word reading (Coyne et al., 2012). When my sons couldn't demonstrate their knowledge of the basics, they were not taught anything else. One example I recall, Alvin was repeatedly given the same worksheet to circle a specific letter. Regardless of him being able to circle the correct letter or not, he was given the same worksheet over and over again. I asked the teacher about this and was told that when he circled the correct letter it was assumed it was a lucky guess and when he circled the incorrect letter it was proof that he didn't know his letters. This caused huge behaviour issues within the classroom as no matter what he did, he was not given any new worksheets (or engaging activities).

I brought this issue to the attention of the educational staff about my boys' lack of moving forward on their literacy skills, but it was often met with a resignation that they were not demonstrating literacy knowledge so there could be no movement. There was never any concrete strategy offered to remediate for these shortcomings.

We then left public school and both boys attended a private school. While the private school was willing to try different programs for reading, none of them worked. The various reading programs were all siloed in that they only looked at one aspect of literacy skills at a time, for instance, letter naming, letter sounds, sight words, et cetera. Thus their reading skills were either nonexistent or they couldn't see how letters and sounds work together to form words, and

then sentences. As they started to learn some concepts and skills separately, they kept them all discrete or separate and they couldn't see how it all fit together. It was clear that both boys could see no purpose to learning letter sound to read. I often likened their behaviours of rhyming off their letters, phonics skills, and sight words as no more important than stacking blocks or completing a puzzle; to them it was a made-up, meaningless task.

Through the autoethnography process that I engaged in, I found myself often reflecting back on the early childhoods of my sons and the pervasive dogma of some professionals labelling the boys being "low functioning" and having "low expectations" because of their ASD and them being nonverbal and minimally verbal. Although I challenged and argued these labels, in some instances, I didn't know any better. Yet, I perceived that there was a contradiction in the advice that I was receiving. For example, when typically developing toddlers learn literacy skills, they will ask for their favourite book to be read repeatedly, perhaps hundreds of times. It has been noted by Trivette et al. (2012) that research since the 1980s demonstrates the benefits of literacy skill acquisition of repeated readings of a loved story. However, when both my children kept repeatedly going back to the same book, I was told by therapists to discourage this as it was said to be a perseveration and deemed as a negative behaviour that should be stopped. It saddens me to know that I might have squashed their love of a story because of their diagnosis and perceived negative behaviours regarding perseveration.

All these situations have fueled me to find an approach to teaching literacy to students like my sons. I have always kept literacy at the forefront of the boys' education. I have continually pushed for literacy skills every chance I had, at Individual Education Plan (IEP) meetings, parent-teacher meetings, at speech consultations, and psychological consultations. Some professionals agreed on the importance of developing literacy skills, but others brushed off

my persistent emphasis on literacy learning. Although I made it a priority to be immersed in literacy learning, the boys still were not able to read as none of the teaching strategies worked for them. It makes me angry that since they were not able to read, that when they began high school, literacy instruction was not a focus of their course work. After a certain age, everyone seemed to consider them as lifelong non-readers. If not for me being passionate about this pursuit, they would never have learned some of the basic skills that they now have. Therefore, my autoethnography needed to be explored.

The importance of literacy skills for my sons was always evident to me. As they both struggle with speech, I was desperate to know what they were thinking. Their AAC devices, while limited, offered a great deal of insight on this. However, even the process of using these devices has been fraught with challenges. There has been a huge evolution in AAC awareness, utility, and research since my boys were first suggested to pursue a device. It has been widely espoused (however, not always practiced) for years that there are no prerequisite skills prior to starting AAC (Cress & Marvin, 2003). Unfortunately, when Alvin was first assigned an AAC device by his SLP there were several prerequisites set out for him. Once again, based on a single assessment, his performance was not what was expected so he was declined any AAC device services. I asked what he could do to demonstrate his ability to benefit from such accommodations. I was given a few suggestions and one was to purchase our own “practice” device (this was prior to tablets and iPads) that would be less technical. We could then attempt to get another assessment prior to being discharged if my son demonstrated some skills. As we were lucky enough to be able to afford the less technical device and afford to have my SLP work with him privately, I was able to advocate for another assessment prior to discharge. I also asked if I could offer suggestions on things that he might be interested in communicating about. For instance, the first assessment was asking him to use a device to talk about Mr. Potato Head and

puzzles as these seemed to be the “go-to” toys to talk about in any early assessment we had done. Since both my boys have absolute disdain for these toys, the assessor was receptive to my suggestions of squishy and stretchy toys, slime, candy, and cupcakes. Now, these were topics that were worth talking about! Alvin was ultimately successful in gaining access to the program. However, I often have commented that had it not been for our privileged situation of being able to afford the low technology device, the private therapy, English being our first language, and knowledge of the systemic process, we would have to take our discharge and would not have had access to any AAC programming.

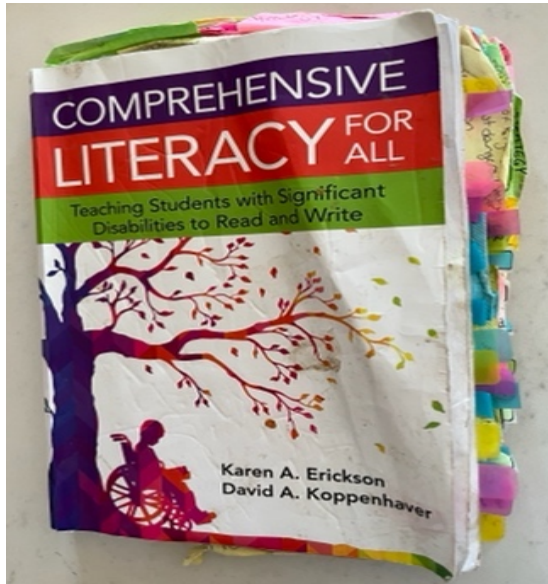
Although I am a huge supporter, advocate, and promoter of AAC to help aid communication, and I am amazed at the technological advances, there are some limitations. I have said countless times in meetings when referring to the necessity of teaching the boys to read and write that the device although transformational to their lives, is restricted to what is programmed in their device. For example, when they have worries or nightmares, I have no idea what it is about as they don’t have the words or know where to find something reflective on their device. I often think, if they could phonetically spell, they could write out a few words to communicate their thoughts and emotions.

I have constantly sought knowledge to support their learning by scouring the literature, databases, and attended webinars for ideas to help teach students with similar profiles of my children to read and write. Although we have tried numerous programs and strategies, through my own searching, I found a resource that held promise: Erickson and Koppenhaver’s (2007) *Children With Disabilities: Reading and Writing the Four Blocks® Way*. I engaged with some of the strategies in an adaptation and modification from the Four Blocks® Framework in a pilot project that I describe in Chapter 3. Then Erickson and Koppenhaver (2020) wrote a different resource with further updated research and more evidence-based strategies and interventions in

Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write. I devoured this resource. I agreed with their pedagogy, and I could relate to many of their stories. I learned many literacy instructional strategies that I tried with my sons (see Figure 1, which shows my well-worn copy with all the sticky notes).

Figure 1

My Copy of Comprehensive Literacy for All: Teaching Students with Significant Disabilities to Read and Write



I do not see myself as a “teacher”; however, I do see myself as a strong advocate for my sons’ education and a partner with their teachers and educational assistants (EAs). During March 2020, the first of many COVID-19 pandemic lockdowns, I had my chance to attempt some of the interventions in the *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* (Erickson & Koppenhaver, 2020). While I was home with my sons full-time for 7 months, I didn’t follow the book systematically, but I handpicked some of the strategies and tried them. I started to see less aversion to literacy activities in my sons and more derived enjoyment during some of these literacy lessons.

Prior to COVID-19 lockdowns my sons were heavily programmed after school with city run programs, community outings with a mentor, Special Olympics, powerlifting, et cetera. Then in March 2020 with program and store closures, and camp cancellations, there was a stark change to our family life, which was stressful for us all. Parents in general of adolescents on the autism spectrum “appear to experience elevated levels of stress and caregiving demands compared to parents of adolescents and adults with a variety of other developmental disorders. This is likely due, in part, to the unique impairments and behavioral challenges associated with autism” (Seltzer et al., 2004, p. 244).

I worked daily with my children on their literacy skills and continued with their school curriculum that was assigned to them. Their teacher and program offered a great deal of support and learn-at-home suggestions. The boys and I found a way to divide our days into a balance of time for academics, activities, fun/free time, and daily living skills. Although we did have continual, remote support from their teachers and EAs, ultimately, their education was on me for the 7 months that they were out of school. Relatively quickly we fell into a nice routine, and I

adapted to my new role as primary educator and since I have always been doing academic work with them, they both accepted this role for me willingly.

This gave rise to the opportunity to work on an autoethnography of my own experience through the lens not only as a parent, but also as an educator and a beginning researcher while working with my sons since June 1, 2021 through to January 2, 2022. However, I must acknowledge that in doing this autoethnography and heavily using the resource *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* (Erickson & Koppenhaver, 2020), I have a confirmation bias. I wholeheartedly believe all students regardless of their identification or diagnosis can learn to be literate to some extent; all students will not necessarily be reading and writing paragraphs, but they can acquire some literacy skills that are relevant within their own lives. I have attempted many programs and resources prior to using the *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* (Erickson & Koppenhaver, 2020) and they all have not made any significant difference. While working with the boys during the pandemic, I noticed the difference with this resource, thus I must declare my confirmation bias at the beginning of this study.

This thesis is an exemplification of my reflection on my teaching and what I have learned in the process about literacy acquisition. This research study is a dream come true. The passion to teach my sons to read and write is pervasive in me. I am driven to help them be limitless as well as help change the insidious prejudice that exists against people with autism who are nonverbal. I am also driven to tell my story through autoethnography.

Purpose of Study

The purpose of this research will be to examine my role as a parent educator attempting to support my sons' ability to read and write. Specifically, I adopted Erickson and Koppenhaver's (2020) *Comprehensive Literacy for All: Teaching Students With Significant*

Disabilities to Read and Write and I will provide an examination of my perspective as an untrained teacher to use this resource and my experience as an educator. Ultimately, the goal of this research is to advocate that literacy is a life skill and change the pervasive perception that people with ASD who use AAC cannot learn literacy skills.

Research Questions

My research questions are:

1. What are the experiences of a parent educator teaching literacy awareness and skills to her adolescent sons who both have ASD and use AAC devices?
2. Does the experience shape her identity as a parent, educator, and researcher?

Overview of Document

Now that the foundation has been laid for the background and purpose of this research, the balance of this thesis will provide details on the literature and methodology that guided the research. Chapter 2 will also examine the theoretical and conceptual frameworks of teaching literacy to students with ASD who use AAC devices for communicating. Chapter 3 outlines the autoethnography methodology and details the research design. Chapter 4 will discuss the results of the autoethnography. Chapter 5 comprises the overall discussion and offers implications for theory, practice, and research.

CHAPTER TWO: REVIEW OF THE LITERATURE

This chapter begins with the theoretical framework and conceptual model followed by a review of the literature on ASD and adolescence. There will be a summary of the literature related to AAC, reading, vocabulary, and strategies for teaching literacy, including *The Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* (Erickson & Koppenhaver, 2020).

Theoretical Framework

The study's theoretical framework is grounded in Vygotsky's sociocultural theory of development (Vygotsky, 1978). Most pertinent to this thesis is the reality that as students with complex communication needs are learning literacy skills, they need added support in terms of learning strategies and application. According to Vygotsky (1978), the role of the teacher is one that supports the student in development through what he terms as "the zone of proximal development which is the distance between the actual developmental level as determined by independent problem solving and the level of potential development as determined through problem solving under adult guidance or in collaboration with more capable peers" (p. 86). Therefore, the teacher's role is essential in the learning and in the development of the student. The teacher assists the child in the difference between what he/she already knows and what they are trying to teach him/her. Vygotsky (1978) further explains that the "first level can be called the *actual developmental level*, that is, the level of development of a child's mental functions that has been established as a result of certain already *completed* developmental cycles" (p. 85). Vygotsky (1978) notes that if the teacher can demonstrate how to solve problems or collaborate in finding a solution, then the student can work toward developing new skills and knowledge.

The term "scaffolding" was coined by Bruner (1978) and "refers to the steps taken to reduce the degrees of freedom in carrying out some tasks so that the child can concentrate on the

difficult skill [the student] is in the process of acquiring” (p. 19). The teacher’s scaffolding helps the student to reach this potential development.

One instructional strategy or scaffold that the teacher can utilize is the “think aloud.” Teachers can articulate out loud to the student their own thought process while reading (Davey, 1983). Students need to have processes broken down and explicitly taught (Archer & Hughes, 2011). Accordingly, the teacher works with the student to help explicitly develop “their inner voice” as according to Vygotsky, “egocentric speech was used for self-guidance and self-direction” (Prior & Welling, 2001, p. 13). Vygotsky distinguishes between private speech called egocentric speech and inner speech. In his view, speech develops in the schema “first social, then egocentric then inner speech ... the true direction of the development of thinking is ... from the social to the individual” (Vygotsky, 1934/1962, pp. 19–20).

To apply these theoretical constructs to the learners that are the focus of the present study, it is necessary for the teacher to articulate to the nonverbal student their egocentric thinking and what they are thinking to themselves, so the student can learn from this. This is a very important step as Vygotsky emphasizes the importance of speech and action in children stating that it is not just about narrating what they are doing but “their speech and action are part of *one and the same complex psychological function* (Vygotsky, 1978, pp. 25–26). For a person who has complex communication needs, there is no speaking out loud. The student needs to be taught how to use his/her inner speech. According to Erickson (2003), inner speech is needed to process words in sentences and longer texts. Erickson (2003) further notes that AAC users reportedly know about inner voice; however, unless AAC users have been directly taught the inner speech, this does not develop until later. Therefore, explicit cognizance of inner voice and direct intervention is imperative when teaching AAC users to read and encouraging silent

reading comprehension (Erickson, 2003). When the teacher directs the student to “think in their head” or “read in their head” while demonstrating what they are thinking by “thinking aloud,” this assists the student in what they should be doing while reading. By thinking out loud the teacher is taking their inner self-dialogue for comprehension and revealing the process in an observable way (Walker, 2005).

Further, in terms of inner speech, Vygotsky (1934/1962) stated that “in the beginning, egocentric speech is identical in structure with social speech, but in the process of its transformation into inner speech it gradually becomes less complete and coherent as it becomes governed by an almost entirely predicative syntax” (p. 145). Therefore, he argued that inner speech was more about semantics and not about phonetics (Vygotsky, 1934/1962). Thus, when asking readers with complex communication needs and who are minimally verbal to respond, you are requiring their focus and cognitive load to be on sounding out the words and the physical mechanics involved in this skill and not on comprehending what they are reading. Thus, the cognitive load of phonetics over comprehension might lead to further frustration and poor understanding (Prior & Welling, 2001). Consequently, the emphasis and intervention need to be on focusing on thinking out loud, about both decoding and comprehending.

Conceptual Framework

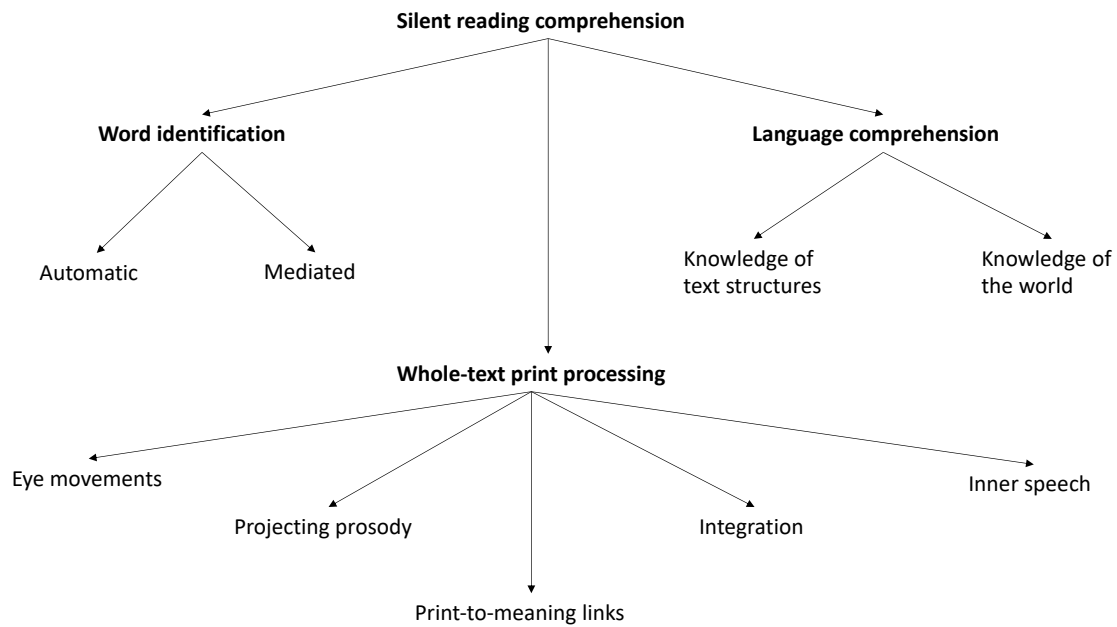
Independent, silent reading is a lifelong skill. It is fundamental in that “the ability to read silently with comprehension, changes lives by opening rich opportunities for lifelong learning. Therefore, the primary goal of literacy instruction is to teach student to read silently, not orally, and to do so with understanding, or comprehension” (Erickson & Koppenhaver, 2020, p. 91). When silent reading with students who use AAC, it is important to consider different instructional frameworks. The Whole-to-Part (WTP) model is the underlying theoretical

foundation that Erickson and Koppenhaver (2020) use for their *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write*. Its foundations are in the work of Cunningham (1993) and Erickson et al. (2017).

According to Erickson and Koppenhaver (2020), the WTP model maintains that three abilities are necessary to achieve silent reading comprehension (see Figure 2). The three abilities are word identification, language comprehension, and whole-text print processing (e.g., sentences, paragraphs, pages). Next, these abilities are described in detail.

Figure 2

Model of the Constructs Underlying the Whole-To-Part Model of Silent Reading Comprehension



Note. Obtained from *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* (Erickson & Koppenhaver, 2020, p. 89)

Word Identification

In the WTP model within the ability of Word Identification, AAC users have two components to consider: automatic and mediated word identification. According to Samuels et al. (2005), automatic word identification is when the reader is able to effortlessly know the word from memory without consciously having to expel cognitive resources to phonetically decode. Increased automaticity increases word identification and thus, the better the comprehension, as the reader is able to use their working memory for comprehension and not decoding.

The second emphasis is on mediated word identification which is conscious decoding of words, using letter recognition, phonics, and spelling patterns (Erickson & Koppenhaver, 2020). There is a positive relationship between a reader's decoding skills and over time their automaticity (Cunningham, 1993; Share, 1999).

Both automatic and mediated word identification are required for AAC users for successful silent reading comprehension and must be both taught equally. Comprehension is negatively affected if instruction is emphasized for only one component. For example, if a reader is not taught how to decode unfamiliar words and only taught a bank of sight words, "they are forced to skip or guess words. When readers are taught to stop and sound out or consciously think about every word they encounter, they are expending cognitive resources that would otherwise be devoted to comprehension" (Erickson, 2003, p. 6). Therefore, it must be emphasized to teach both components of word identification.

Language Comprehension

In the WTP model, language comprehension is divided into two components: knowledge of text structures and knowledge of the world. Language comprehension could be in reading text as well as listening orally to text being read (Erickson & Koppenhaver, 2020). The knowledge of

text structures including syntax and “the use of pronouns, features of different text types (e.g., narrative vs. expository), and relationships across sentences. ... Without experience and familiarity with a variety of text structures, readers and listeners ... will experience difficulty comprehending written language” (Erickson, 2003, p. 7).

Knowledge of the world is the AAC reader’s life experiences or “background knowledge ... related to the topics and situations assumed by a text’s author. Readers must have this knowledge and be able to access it when needed in order for successful language comprehension to occur, either while listening or reading” (Erickson et al., 2016, p. 280). It is important to emphasize world knowledge as well as expose students to as many experiences as possible to develop and expand their world knowledge. Therefore, both experiences with knowledge of text as well as knowledge of the world are necessary in reading and language comprehension. If there is a lack in either of the two components, it will lead to challenges in silent reading comprehension for the AAC user.

Whole-Text Print Processing

It is important to note that many AAC users have strong oral comprehension skills and language reception, and other AAC users can read single words in isolation but do not comprehend when reading independently (Erickson et al., 2006). Therefore, other factors are necessary in learning to read for AAC users other than word identification and language comprehension in the WTP model. The third and final element in the WTP model is the whole-text print processing. This element has five components: eye movements, projecting prosody, making print-to-meaning links, inner speech, and integration. Each component will be explained next.

Eye movements are very important to read with ease. According to Erickson and Koppenhaver (2020), “the eye movements required for processing and connecting text consist of

rapid, intermittent movement (i.e., saccades) accompanied by splint-second fixations” (p. 91). They further note research that states that eye movements are not simply behaviour of visual tracking but are “distinct and involved in word identification” (p. 91)

Projecting prosody or reading with expression (rhythm) is also important for AAC. When reading silently, the AAC user requires prosody skills even when the reader is silently focusing on syntax and grammatical markers (Erickson et al., 2006). Specifically, “the use of inner voice in projecting prosody is particularly important in achieving successful silent reading comprehension for persons who use AAC” (Erickson, 2003, p. 6)

Print-to-meaning links are important for AAC users when developing silent reading comprehension. The AAC reader develops direct print-to-meaning for instance, in “word spellings, morphemes spellings, capital letters, and punctuations. This occurs prior to, or in tandem with, making print-to-sound associations during oral and silent reading” (Erickson & Koppenhaver, 2020, p. 91). The direct print-to-meaning links further assist the AAC reader as this link “helps the reader to hold words, phrases and clauses in working memory while the sentence being read can be interpreted and eventually integrated into the understanding of the rest of the text” (Erickson & Koppenhaver, 2020, p. 91).

Inner speech, as previously mentioned, is imperative to teach students using AAC to further develop their silent reading comprehension skills. Erickson and Koppenhaver (2020) cite the work of Acheson and MacDonald (2011) in that “inner speech use facilitates decoding words, interpreting sentences, and monitoring comprehension. It allows the reader to hold ideas in memory and integrate them across connected text” (p. 91).

Integration is the skill to combine and integrate the above four components (eye movements, projecting prosody, making print-to-meaning links, inner speech). Whole-text print

processing is developed skilfully through the AAC user reading copious amounts of texts that are relatively easy for the reader (Erickson & Koppenhaver, 2020). Silent reading comprehension will not be successful if the four components are not taught and used when reading texts, if these skills are taught separately they will not transfer. As well, the skills need to be taught with texts that are meaningful to the AAC reader (Erickson, 2003).

Combining Word Identification, Language Comprehension, and Whole-Text Print

Processing

All three elements are necessary in supporting AAC users to become readers. Erickson and Koppenhaver (2020) developed the *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* resource using the WTP as the basis for the conceptual framework. Therefore, in using this conceptual framework, a comprehensive approach is necessary. Thus, the approach “simultaneously must be comprehensive (i.e., focus on word identification, oral language, and silent reading fluency), encourage the use of inner speech, and provide instruction and practice in the use of the chosen mode of AAC to communicate about the reading process as well as the content of passages read” (Erickson et al., 2016, p. 282).

Combining word identification, language comprehension, and whole-text print processing simultaneously provides the context and skills to learn literacy as each literacy skill is not taught individually with no connection making. The skills are taught in a literacy rich environment with connections to the AAC user.

This model is encouraging in that it provides several essential components to successful silent reading comprehension and therefore, it does not isolate a single issue as to why a reader might be struggling. This offers a potential conceptual foundation for reading intervention for AAC users (Erickson et al., 2016).

Autism Spectrum Disorder

Autism spectrum disorder (ASD) is a developmental disorder that is “characterized by severe impairment in several areas of development and functioning, including reciprocal social interaction, verbal and nonverbal communication, and the normal range of behaviors, interests, and activities” (Shatkin, 2015, p. 114). Additionally, the *Diagnostic and Statistical Manual of Mental Disorders* (DSM–5; American Psychiatric Association [APA], 2013) diagnoses ASD based on three levels of severity and differentiates if there is an intellectual impairment and or a language impairment. Approximately 50% of children diagnosed with ASD also have an intellectual disability (Shatkin, 2015).

In terms of verbal ability, approximately 30%–50% of children with ASD do not develop functional speech and require AAC (National Research Council, 2001). Thus, it is important to note, that not every individual with autism has difficulty with speech, nor does everyone with ASD require AAC. However, those who do require AAC need additional supports for developing their communication skills as well as literacy instruction due to their lack of ability to speak. Researchers and clinicians are beginning to stop “viewing language as being equivalent to speech ... suggest[ing] that interventionists are focusing on enhancing skills that individuals with disabilities have, rather than centering on what this population is incapable of doing (Nunes, 2008, p. 22). My interest has always been on the population of learners with autism who are nonverbal or are minimally verbal in that they speak in few word utterances and often that speech is unintelligible.

According to Autism Ontario (n.d.), ASD is a “lifelong neurological disorder that affects the way a person communicates and relates to the people and world around them. ... [It] can affect behaviour, social interactions, and one’s ability to communicate. ASD crosses all cultural,

ethnic, geographic, and socioeconomic boundaries” (para. 1). In March 2018, the National Autism Spectrum Disorder Surveillance System (NASS) released the most up-to-date Canadian prevalence rate: 1 in 66 Canadian children and youth (ages 5–17) are diagnosed with ASD (NASS, 2018). Furthermore, according to the DSM–5, there is a difference in male and female prevalence of ASD of 4:1 (APA, 2013).

ASD and Adolescence

The period of adolescence is often characterized as a period of bodily change, tumultuous emotions, and uncertainty. However, for an individual with a developmental disability and a communication disorder, the effects during this period are often heightened (Cridland et al., 2015). As previously noted, autism is a lifelong neurological disability, therefore the diagnosis of ASD will continue to exist throughout adolescence and into adulthood. As ASD is a spectrum and all individuals are impacted differently, it is important to note that some individuals with ASD do not see any change in their characteristics. For instance, some individuals who are more severe on the spectrum or have lower IQs can experience a loss of skills (McGovern & Sigman, 2005; Seltzer et al., 2004). Some research indicates 30% of adolescents with ASD can have a reduction in their adaptive functioning skills (Picci & Scher, 2015). It is noted that “adolescence may be an especially vulnerable period of development in autism that makes the transition into adult social roles and adult levels of adaptive functioning overwhelmingly difficult” (Picci & Scherf, 2015, p. 105).

However, interestingly, Bal et al. (2019) have noted that during adolescence, for many individuals with ASD, there have been some improvements in some of their ASD-related challenges. For example, Bal et al. (2019) noted that

social-communicative symptoms improve across childhood and adolescence. ... Timing and amount of change varied for different symptom categories and participants with

different language abilities. ... Some older adolescents and adults with ASD may not exhibit the same difficulties observed in young children with ASD. (p. 89)

However, improvements are varied and most often continued impairment persists into adulthood (Schall & McDonough, 2010).

Furthermore, as often observed with neurotypical adolescents, a positive relationship between the parent and teen is related to improved psychological and behavior outcomes as the adolescent with ASD enters adulthood (Smith et al., 2008). However, there is no uniform developmental milestone that all individuals on the spectrum progress to. Therefore, it is important to continue to work towards individual goals and support the development and maturity of each individual person with ASD as they continue through adolescence and enter into adulthood.

ASD and Reading

Reading is a complex process and is challenging for many children to learn. In particular, some individuals with ASD may struggle with reading due to factors attributed to their diagnosis. For instance, some children with ASD find reading (both decoding and comprehension) particularly difficult (Norbury & Nation, 2011). This difficulty is more pronounced when language impairments are present as, “in general decoding and comprehension skills develop in concert, but in developmental disorders of reading, they may become dissociated” (Norbury & Nation, 2011, p. 192). Just as ASD is a spectrum disorder, students and their learning preferences and abilities vary greatly. Understandably there is variability amongst reading ability as well. For example, some students with ASD can read fluently but have difficulty with comprehension, which is referred to as hyperlexia; others on the spectrum are poor decoders and are not able to decode words (Nation et al., 2006). As the task of learning reading can be quite onerous for some learners, keeping intrinsic motivation high can be difficult.

It is important to reiterate that according to the DSM–5, the defining characteristics of ASD include impairments and deficits in social-communication and social interaction, yet, these impairments that people with autism have may also affect their ability to read (APA, 2013). For instance, Fleury and Hugh (2018) reviewed literature and noted that individuals with ASD often exhibit lower levels of joint attention, which “has implications for the overall quality of engagement during activities that rely heavily on social interactions” (p. 3597). Thus, if the student finds it challenging to have divided attention on the teacher and also to attend to a book, it will make learning to read and engaging in reading activities more difficult. Moreover, it was found that some “children with ASD spend less time passively engaged in book reading (e.g., listening to the reader and looking at books) compared to typically developing children and more time engaging in either disruptive or unengaged behaviours during shared reading activities” (Fleury & Hugh, 2018, p. 3603). This challenge related to divided attention is especially true for AAC users (Strum et al., 2006).

Further, “reading comprehension is conditioned by pragmatic characteristics and language comprehension, such as understanding metaphors, jokes, and ironies, making inferences, understanding idioms, or understanding meanings whose interpretation depends on the context” (Tarraga-Minguez et al., 2021, p. 3). This makes it difficult for some students on the spectrum due to some of the challenges some people with ASD have in making these types of inferences (Tarraga-Minguez et al., 2021).

Another challenge that many individuals with ASD have difficulty with is the theory of mind, which is the “ability to understand the thoughts, feelings, and beliefs of others” (Finnegan & Accardo, 2018, p. 72). Theory of mind is important regarding emotions and learning as “the distinction of self and other constitutes an important element of both empathy and Theory of

Mind, as it enables the differentiation between one's own emotional or mental states and the states shared with others" (Preckel et al., 2018, p. 3). The theory of mind is "vital in social interactions and ... could affect reading comprehension. Reading fiction requires students to understand characters' perspectives, which drive characters' actions, which in turn drives the plot" (Finnegan & Accardo, 2018, p. 72). Furthermore, many students with ASD will find it difficult in more advanced grade levels as reading requires "understanding the purpose of a text, the author's stance, and ... the recognition of literacy devices such as irony, satire, and hyperbole" (Finnegan & Accardo, 2018, p. 72). Thus, as reading fluency and reading comprehension expectations get more difficult, the further behind students with ASD might fall.

When working with adolescent students with ASD, age-appropriate reading materials are very important. This can be challenging as many of the books for students learning to read and beginner readers are targeted to younger children and not adolescents (Smith et al., 2009). To be age respectful, it is important to offer books that are age appropriate for an adolescent beginning reader. Adolescent students with autism need exposure to rich language and literature by exposing them to texts that capture their interests and expand their language learning potential (Smith et al., 2009).

One way to expand exposure to age-appropriate texts is through digital literacies. Digital literacies "include the ability to read and interpret media (text, sound, images), to reproduce data and images through digital manipulation, and to evaluate and apply new knowledge gained from digital environments" (Jones-Kavalier & Falnigan, 2006, p. 9). By expanding what are considered literacy skills and incorporating what are considered essential, everyday texts (e.g., emails, text messages, voice chats, etc.), there is a purpose and function for individuals with ASD to be literate and participate in our digital literacy infused environment (Cihak et al., 2015).

Finally, it is also important to offer age respectful themes or narratives for adolescents with ASD. Many students with ASD have difficulty understanding emotions when reading age-appropriate books that include themes of the people working through emotions and facing day-to-day problems. Students with ASD need scaffolding to see how the characters work through their feelings and problems (Smith et al., 2009, p. 21). Further, in “addition to building language, age-appropriate literature provides an opportunity for students to compare the lives of others with their own” (Smith et al., 2009, p. 20).

Augmentative Alternative Communication

People who have complex communication needs may require the use of augmentative and alternative communication (AAC) to communicate. According to the ASHA (n.d.a), AAC encompasses “a variety of techniques and tools, including picture communication boards, line drawings, speech-generating devices (SGDs), tangible objects, manual signs, gestures, and finger spelling, to help the individual express thoughts, wants and needs, feelings, and ideas” (para. 2). Furthermore, the ASHA (n.d.a) breaks down the explanation further and defines the term *augmentative* as in “supplementing existing speech, and *alternative* when used in place of speech that is absent or not functional” (para. 2). Thus, any tool or technique that helps a person express their thoughts, requests, ideas, feelings is considered AAC. Specifically in this study, AAC is a speech generating device, specifically an Apple iPad with a robust vocabulary system app.

AAC and Vocabulary

When people communicate through the use of AAC they need to be able to take their internal thoughts and think of them in terms of how they relate to the external symbols (Smith, 2015). “As they develop knowledge of the content of aided communication, they must figure out

not only what their graphic symbols mean, but also what they are for and ultimately how they work together” (Smith, 2015, p. 219).

Selecting vocabulary that is included on AAC is challenging. Beukelman and Mirenda (2013) cite Musselwhite and St. Louis (1988) who several decades ago suggested that when choosing vocabulary, it needs to be “of high interest to the individual, have potential for frequent use, denote a range of semantic notions and pragmatic functions, reflect the ‘here and now’ for ease of learning, have potential for ... multiword use, and provide ease of production or interpretation” (p. 34). Further to this point, vocabulary can be divided into core and fringe words (Beukelman & Mirenda, 2013). “Core vocabulary refers to words and messages that are commonly used by a variety of individuals and occur very frequently” (Beukelman & Mirenda, 2013, p. 31). Core words make up approximately 80% of everyday words people use and contain mostly “pronouns, verbs, auxiliary verbs, prepositions, adjectives, and determiners” (Witkowski & Baker, 2012, p. 75). Alternatively, fringe vocabulary refers to “words and messages that are specific or unique to the individual. ... Such words serve to personalize the vocabulary included in an AAC system and to allow expression of ideas and messages that do not appear in core vocabulary lists” (Beukelman & Mirenda, 2013, p. 33). Fringe words make up the remaining 20% of vocabulary and are most often nouns (Witkowski & Baker, 2012).

Witkowski and Baker (2012) note the importance of core vocabulary in terms of a crucial component in teaching reading. They observe that many of the frequently benchmarked 220 Dolch (1948) words are core words. It is vital that these high frequency words are taught so that students with AAC might be able to “participate more fully in automatic word recognition activities, as well as phonological and phonemic activities that lead to decoding” (Witkowski & Baker, 2012, p. 79).

The Center for Literacy and Disability Studies (2013) at the University of North Carolina (United States) has worked on a project called the Dynamic Learning Map which developed a list of the first 40 words a AAC user who have complex communication needs should start with (see Table 2). The intent is that after these initial 40 core words are learned, then the AAC user should continue to add more core words as they develop their language. As mentioned above, these words are part of the Dolch words that are recommended for all literacy learners.

Table 2*Dynamic Learning Map Universal Core Vocabulary (Dennis et al., 2013)*

I	like	not	want
help	it	more	different
who	she	you	he
where	up	on	in
me	make	get	look
what	need	are	is
some	put	all	this
don't	that	go	do
when	finished	can	here
open	turn	stop	over

Language Modeling With AAC

Language is typically learned through children being spoken to by their parents and hearing other people speaking to each other. According to Vygotsky (1978), “children learn speech from adults ... [and] through imitating adults and through being instructed about how to act, children develop an entire repository of skills? Learning and development are interrelated from the child's very first day of life” (p. 84). Unfortunately, for AAC users their environment does not typically consist of others using the modes of communication they need to learn (e.g., graphic symbols, manual signs or speech generating devices); consequently, they have no natural models to observe and imitate. Showing, encouraging, and supporting, not “telling,” is the way to encourage these children to communicate using AAC (Blackstone, 2006, p. 3). Furthermore, not all family members, teachers, and clinicians know how to use the AAC user’s mode of communication and thus do not know how to model using it for the learner (Blackstone, 2006).

Modeling becomes an essential if not a key instructional strategy in AAC (Blackstone, 2006). In this regard, scaffolding becomes an important tool during modeling as well. “Scaffolding is often used with modeling to extend or expand language use. It means providing a structural connection between a child’s early attempts at communicating (pointing to a symbol) and more advanced use of an AAC system” (Blackstone, 2006, p. 3). An example of scaffolding and modeling occurs when expanding the AAC utterance of a student, the facilitator would point to the multiple symbols while also providing the verbal model for it and offering it as well in the context of a spoken sentence (Blackstone, 2006). Modeling and scaffolding can be implemented both explicitly in a direct teaching environment as well as incidentally throughout various activities within the day (Blackstone, 2006).

Although there are various modeling techniques to teach AAC language instruction, three prominent ones include Goossens et al.'s (1992) aided language stimulation, Ronski and Sevcik's (1996) system for augmenting language, and Drager et al.'s (2006) aided language modeling (Beukelman & Mirenda, 2013). All three techniques are based on the assumption that, by observing a facilitator during a preferred and motivating activity, an individual can make a "mental template" of how to recreate and recombine the symbols and generate communication while performing the activity (Beukelman & Mirenda, 2013, p. 273).

This is done by the communication partner speaking and at the same time using key words on the AAC. For instance, if you wanted to say "I want to go to the park" the partner would verbally say that out loud but at the same time press "I" "want" "go" on the AAC. You can start with only one word and gradually increase the number of buttons pushed as the AAC user develops their language. The words highlighted allow the user to convey the message. By seeing and hearing the sentence modeled, the user sees where the buttons are as well as how the language sentence is developed. "Because these techniques mimic the way natural speakers learn to comprehend language, they are intended to teach language in a very natural way that reduces the need for more explicit instruction" (Beukelman & Mirenda, 2013, p. 273). Thus, it is imperative that people with complex communication needs are in environments where AAC modeling and scaffolding are present and encouraged (Blackstone, 2006). Sadly, this often is not the case. Blackstone (2006) notes many examples of research that demonstrates that even when there are trained speaking parents, teachers, and other children rarely used the AAC users' mode of communication when they communicated with the AAC user. Moreover, they "never use AAC with one another. [Therefore, AAC users] often have very restricted input (speaking and

AAC modes) and have fewer communicative experiences ... than children who develop speech” (Blackstone, 2006, p. 4).

AAC Strategies for Teaching AAC and Literacy

As noted above, modeling or aided language stimulation is a key strategy in teaching as well as interacting with an AAC user. As the user sees more and more people using AAC to communicate, than they will use it as well. According to AssistiveWare (n.d.), the idea should be to simply “use AAC to teach AAC.” There are several other strategies that are identified to teach and support AAC users to learn literacy, and many such AAC strategies for literacy will be used during this autoethnography. A brief description of each additional strategy is included in Table 3, along with examples. The strategies that will be discussed are: attributing meaning; comment, ask, respond (CAR); completion, recall, open-ended, wh-, distancing (CROWD); descriptive teaching; recasting; repetition with variety; scaffolding/gradual release of responsibility; think alouds; explicit teaching; and waiting time. It is important to note when words are written in all capitals and bolded that it indicates that these are the buttons pressed on a AAC device.

Attributing meaning is when an adult attributes meaning and responds meaningfully to a child’s behaviour, communication, or body language in an attempt to help shape future interactions (Yoder et al., 2001). For instance, when a student accidentally presses the wrong button on their device, the adult responds as if that was what they had intended to say. Attributing meaning is also important when the student is behaving and communicating in other ways not just using AAC. For instance, when the student is crying, the adult could use their device and point to **FEELINGS** and say “Crying, I think you are **SAD**.”

Comment, ask, respond (CAR) is a strategy to use when interacting with an AAC user. It means following the user’s lead and then to comment and wait, ask questions, and wait, and

respond by adding a little more elaboration (Cole et al., 2002). The “A” in CAR has been revised to “ask for participation” as the goal and it is not to “test” the AAC user but rather to encourage participation (Erickson & Koppenhaver, 2020).

Completion, recall, open-ended, wh-, distancing (CROWD) is a component of dialogic reading which is a structured shared reading approach (Lonigan & Whitehurst, 1998). CROWD is used only after students are successfully interacting with the CAR strategy. Then CROWD is used in the “A” (Ask for participation step in CAR) (Erickson & Koppenhaver, 2020).

Completion of sentence, recall what has already happened, open-ended question, wh-questions, and distancing are all questions relating to the reader’s experiences (Erickson & Koppenhaver, 2020)

Descriptive teaching is a strategy developed by Van Tatenhove (2009) that uses core words to describe more difficult fringe vocabulary and concepts. By using core words, it reduces the need to program rarely used fringe and academic vocabulary words (e.g., the word “evaporation”). Instead, for the word “evaporation,” the student could use words such as **“WATER GO UP.”**

Recasting is defined as “an adult reformulation of an immediately preceding child utterance in which the adult models more complex and/or accurate linguistic structures, while employing elements of the child’s prior turn and maintaining its intended meaning (Soto et al., 2020, p. 250). For example, if the child says with his device **“TWO DOG”** then the parent can model the linguistically correct statement, “That’s right, there are **TWO DOGS.**” It is important to emphasize that this is a positive strategy in which the AAC user is not degraded by saying that they did it wrong, but rather affirmed by what they said while seeing the modeling of the grammatically correct structure.

Repetition with variety is a strategy that “sustains beginning reader’s interest while providing the rereading practice (i.e., repetition) necessary to increase interaction, vocabulary knowledge, sight word automaticity, reading fluency and text comprehension” (Erickson & Koppenhaver, 2020, p. 18). This variation “keeps learning interesting and prevents learning opportunities from being reduced to rote repetition” (Erickson & Koppenhaver, 2020, p. 18).

Gradual release of responsibility is a concept first cited by Pearson and Gallagher (1983) as a process of scaffolding where the teacher starts out fully supporting the student and then gradually reduces the amount of support until the student is working independently.

Think alouds (Davey, 1983), as noted above, are commonly employed. Teachers can express their thoughts out loud so the student can learn and internalize similar strategies. For instance, while writing, the teacher can “think aloud” about how capital letters are used at the beginning of the sentence, or when reading, the teacher can share how he/she is thinking and comprehending by using strategies. In terms of AAC use, the teacher can “think aloud” to find where various vocabulary is actually located in the AAC device.

Explicit instruction (Archer & Hughes, 2011) is appropriate when some concepts need to be broken down and taught in a systematic way. For instance, when teaching negative words like “not,” the concept could be taught by making two categories of things the student “likes” and does “not like.” Then the student classifies examples of which one is “not” a food.

Wait time is the time waiting for the AAC user to respond. When commenting or asking an AAC user a question, approximately 10–30 seconds of wait time is needed to not only process the words articulated, but then to also formulate what the response will be and then to find where it is on the device, and motor plan to press the correct buttons (Koppenhaver et al., 2001).

In reviewing the aforementioned literature on AAC strategies for teaching AAC and for literacy learning, it is evident that successful execution of ACC involves vocabulary and language modeling and use of several strategies to build foundational literacy skills for students with complex communication needs. Table 3 depicts some of the AAC strategies that are recommended along with some examples.

Table 3*AAC Strategies*

Name of strategy	Examples
Attributing meaning	Try to think of what the student might be trying to say; for instance, “You laughed at that part of the book. ... I think you find that part “FUNNY.” ”
CAR: Comment, ask, respond	<ul style="list-style-type: none"> – Comment: “The CAR is BLUE” [wait] – Ask for participation: “Tell me about your mom’s CAR” (if the child says TRUCK) – Respond (adding a little more): “Oh yes, that’s right; your mom drives a TRUCK and it is red.”
CROWD: Complete, recall, open-ended, wh-, distancing	<p>If the student was reading E.B. White’s (1952) <i>Charlotte’s Web</i>:</p> <ul style="list-style-type: none"> – Complete: Charlotte said Wilbur was “_____ pig.” – Recall: “What happened to Templeton the rat at the fair?” – Open-ended: “Tell me what you see in this picture.” – Wh: Where did Wilbur go to live after he left Fern?” – Distancing: “Your aunt lives on a farm. She doesn’t have any pigs but she has cows right?”
Descriptive teaching	Example: When teaching the word “setting,” look up words they would have readily on their AAC and use “WHERE.”
Recasting	When student says “GO SWIM” the adult would recast and say, “That’s right we are going to GO SWIMMING ”
Repetition with variety	Read the same book through shared reading daily but with a different purpose each day. For instance, Monday look at all the pictures and make a prediction what the book will be about. Tuesday, create a new title for the book, etc.
Gradual release of responsibility	Monday the teacher reads the text to the student and each day gradually encourages and teaches the student to read more and more without support until on Friday the student is reading the text independently.
Think alouds	The dog looks very sad. I am going to look in the FEELINGS folder and there I see the word SAD .
Explicit teaching	Put foods in different categories on what you “like” and what you “not” “like” to help teach the concept of “not.”
Wait time	Wait 10 to 30 seconds for response from AAC user.

Foundational Literacy Skills

The focus of this research is on an autoethnography of a parent educator working to improve foundational literacy skills with her sons. As part of her educator learning journey, she developed her background knowledge related to the following foundational literacy skills: letter identification, phonemic awareness, phonics awareness, fluency, vocabulary, and reading comprehension.

Letter Identification

According to the National Early Literacy Panel (2008), alphabetic knowledge encompassing letter names and sounds is the single biggest predictor of later literacy achievement. Letter identification is a component of Erickson and Koppenhaver's (2020) *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write*.

Phonemic Awareness

Phonemic awareness is the second strongest predictor of later literacy achievement (National Early Literacy Panel, 2008). Phonemic awareness is defined as “the ability to notice, think about, and work with the individual sounds in spoken words. Before children learn to read, print, they need to become aware of how the sounds in words work” (Armbruster et al., 2003 p. 2). Further, students must “understand that words are made up of speech sounds, or phonemes. Phonemes are the smallest parts of sound in a spoken word that make a difference in the word's meaning” (Armbruster et al., 2003, p. 2). An example, changing /s/ in sit to a /h/ will change the word and meaning to hit. Teaching students that if you can change a letter, it will change the meaning of the word is an important skill.

Phonics Awareness

Phonics awareness includes the knowledge that letters “systematically represent the component sounds of the language. Understanding the basic alphabetic principle requires an awareness that spoken language can be analyzed into strings of separable words, and words, in turn, into sequences of syllables and phonemes within syllables” (Snow et al., 1998, p. 51).

Further “phonics instruction teaches children the relationships between the letters (graphemes) of written language and the individual sounds (phonemes) of spoken language. It teaches children to use these relationships to read and write words” (Armbruster et al., 2003, p. 13). Finally, research has demonstrated that systematic and explicit phonics instruction makes a more significant contribution to children’s growth in reading than instruction that provides non-systematic or no phonics instruction (Armbruster et al., 2003).

Fluency

According to the National Early Literacy Panel (2008), fluency is a prevalent component of reading ability. “Reading fluency refers to efficient, effective word recognition skills that permit a reader to construct the meaning of text. Oral fluency is manifested in accurate, rapid, expressive oral reading and is applied during, and makes possible, silent reading comprehension” (Pikulski & Chard, 2005 p. 510). Readers tend to struggle with fluency if they are struggling with decoding and reading comprehension as well (Pilulski & Chard, 2005).

Vocabulary

Vocabulary is essential in learning to read. “Vocabulary refers to the words we must know to communicate effectively. ... Oral vocabulary refers to words that we use in speaking or recognize in listening. Reading vocabulary refers to words we recognize or use in print” (Armbruster et al., 2003, p. 34).

When a person is beginning to read and write they use the words they know and have heard to make sense of the printed word they are reading or hearing (Armbruster et al., 2003). New vocabulary can be taught indirectly or directly through instruction (Armbruster et al., 2003).

Reading Comprehension

Reading comprehension is the ultimate goal of reading. “To achieve comprehension in reading, an effective reader should be able to successfully implement such practices as relating the text with his or her own background knowledge, summarizing information, drawing conclusions, and posing questions at the text” (Kirmizi, 2010, p. 4752). Therefore, instruction needs to be given to assist students to be able to relate real world knowledge to what they are reading. Knowledge of these foundational literacy skills is helpful in understanding and applying the *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* (Erickson & Koppenhaver, 2020) framework and the instructional strategies.

Emergent and Conventional Literacy Instruction

The concept of emergent literacy was first introduced by Marie Clay (1979). Clay described the behaviours that children exhibited when they interacted with books, before they had the ability to read and write. In the *Comprehensive Literacy for All: Teaching Students with Significant Disabilities to Read and Write* framework, emergent literacy is defined as “all of the reading and writing behaviours and understandings that precede and develop into conventional reading and writing” (Erickson & Koppenhaver, 2020, p. 4)

The concept of emergent literacy is integral for students with significant communication disabilities. Unfortunately, for many years, instruction for students with disabilities was based solely on developmental theory (Smith et al., 2009) and not on supporting emergent literacy. It was commonly assumed that students with significant communication disabilities “were not

psychologically mature enough for certain tasks and should prolong their studies at the lower levels until developmentally ready” (Smith et al., 2009, p. 20). This was exclusionary and had detrimental effects as sadly, “this theory prevented many individuals from being taught with materials that were fitting or proper for their age and has present us with a significant void in the availability of appropriate resources” (Smith et al., 2009, p. 20). Seemingly, emergent literacy instruction was not always offered as its utility might have been overlooked.

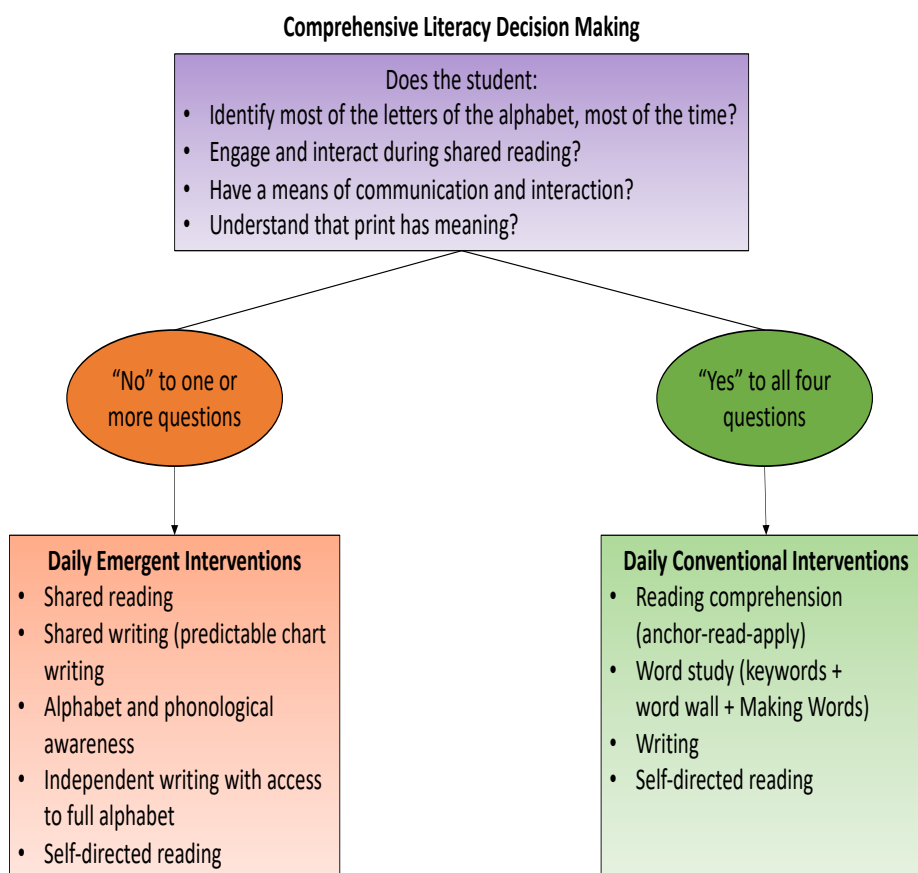
Students who have successfully developed their emergent literacy skills continue to develop their conventional literacy skills. Conventional literacy is defined as “reading and writing that adhere to accepted conventions of form, content, and use” (Koppenhaver, 2000, p. 271). This includes syntax, spelling, comprehension, and writing (Koppenhaver, 2000).

In a more inclusive fashion, Erickson and Koppenhaver’s (2020) *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* framework offers suggestions to determine which how students might be offered appropriate literacy instruction. They suggest the following four questions be asked of the student with significant communication disabilities as an entry point for literacy instruction; does the student:

1. Identify most of the letters of the alphabet, most of the time?
2. Have interest and engagement during shared reading?
3. Have a means of communication and interaction?
4. Understand that print has meaning? (p. 8)

If a teacher is reviewing the student’s profile, and there are any “no” answers to any of the four above questions, then the student should receive emergent literacy instruction. Emergent literacy instruction includes shared reading, shared writing, alphabet and phonological awareness, independent writing with access to full alphabet, and self-directed reading. If all the

answers are “yes” then the student should receive conventional literacy instruction. Conventional literacy instruction includes reading comprehension, word study, writing, and self-directed reading. Figure 3 presents a flowchart depicting this educator decision-making process.

Figure 3*Comprehensive Literacy Decision-Making*

Note. Obtained from *Comprehensive Literacy for All: Teaching Students with Significant Disabilities to Read and Write* (Erickson & Koppenhaver, 2020, p. 201)

The Connection Between Literacy and Language Development

Learning to read is often regarded as an achievable skill for many students in the education system. The advantages of learning how to read are numerous. According to the OHRC's (2022a) *Right to Read Inquiry*, when students do not learn how to read it can affect confidence, self-esteem, and lead to mental health issues. The Inquiry notes it affects people continuing their education, employment, and income to list a few (OHRC, 2022a). Furthermore, with the advent of information and communication technology (especially in first world countries), literacy has become a way of staying socially connected via texting, emailing, and social media.

It is evident that literacy instruction is imperative for everyone, including users of AAC. Research has established the link between literacy and language acquisition (Snow et al., 1999). In fact, "some students with severe disabilities begin demonstrating literacy skills and understanding before developing other consistent means of symbolic communication" (Koppenhaver & Erickson, 2003, as cited in Erickson, 2017, p. 193). The ability to convey thoughts on their AAC device affords users "the opportunity to initiate topics, to develop ideas, to provide clarification, to communicate independently, to interact with a diverse audience, and to express ideas, thoughts, and feelings" (Light & Kelford Smith, 1993, p. 10). Consequently, literacy is imperative to the independence and self-determination of students who use AAC (Ruppar et al., 2011).

It is imperative to include the AAC population when examining reading. However, if the person is unable to use a symbol for their thoughts or the word symbol is not there, they need to be able to utilize foundational literacy skills. For instance, the individual needs to utilize initial letter strategies or spell words to convey their message, otherwise they will need others to assist them in communication (Koppenhaver, 2000). As noted above, literacy skills (e.g., phonological

awareness, letter identification, concepts of print, reading comprehension, and writing) are foundational skills for all people, and are imperative for people who use AAC as a way to communicate. According to the ASHA (n.d.b), the ability to spell at even a basic level allows the person the ability to convey their thoughts. Furthermore, the ASHA (n.d.b) notes that reading and writing for AAC users allows maximum participation in education and employment and allows the person to access knowledge and increase experiences. Unfortunately, this does not always occur for AAC users.

According to Light and Kent-Walsh (2003), people with complex communication needs often are not given the same quantitative or qualitative experiences, nor provided the instruction to learn literacy skills. Additionally, Strum et al. (2006) add that amongst the AAC literacy learners “a common thread within this heterogeneous group is limited access to authentic literacy learning opportunities that foster ongoing literacy development” (p. 21). In addition, phonics instruction and phonemic awareness are often not taught or observed in this setting and yet this type of instruction is crucial for someone who uses AAC, as this may increase their independence and self-expression (Ruppar, 2015). Specifically, phonetic skills enable the AAC user the ability to independently write their own words. “The use of sounds to create words and words to create phrases is critical to independent communication [providing skills] to create novel messages and words, rather than relying on someone else to preprogram a device” (Ruppar, 2015, p. 242). Thus, it is important that foundational literacy skills are taught for users of AAC, especially those vulnerable groups with disabilities.

According to the OHRC (2018), people have “the right to equal treatment in education, without discrimination on the ground of disability, as part of the protection for equal treatment in services” (p. 4). Further, the OHRC’s (2022b) *Right to Read Inquiry* noted “The *Moore v British Columbia (Education)* decision (*Moore*) confirmed that human rights laws in Canada protect the

right of all students to an equal opportunity to learn to read; this decision was lauded as a significant victory for students with disabilities” (p. 2). Notwithstanding this being a human right issue, many people with disabilities are not being taught how to read and write, thus excluding them not only from the aforementioned benefits but also from the basics of everyday living.

Literacy for people with complex communication needs who use AAC are provided with a way to communicate and enables learning, educational assessment, an increased opportunity for employment, and facilitates independent living (Light & Kent-Walsh, 2003). One could reasonably conclude that literacy may be integral for AAC users as it affords them autonomy and “enhanced face-to-face communication and the added ability to participate in asynchronous communication” (Erickson, 2003, p. 6)

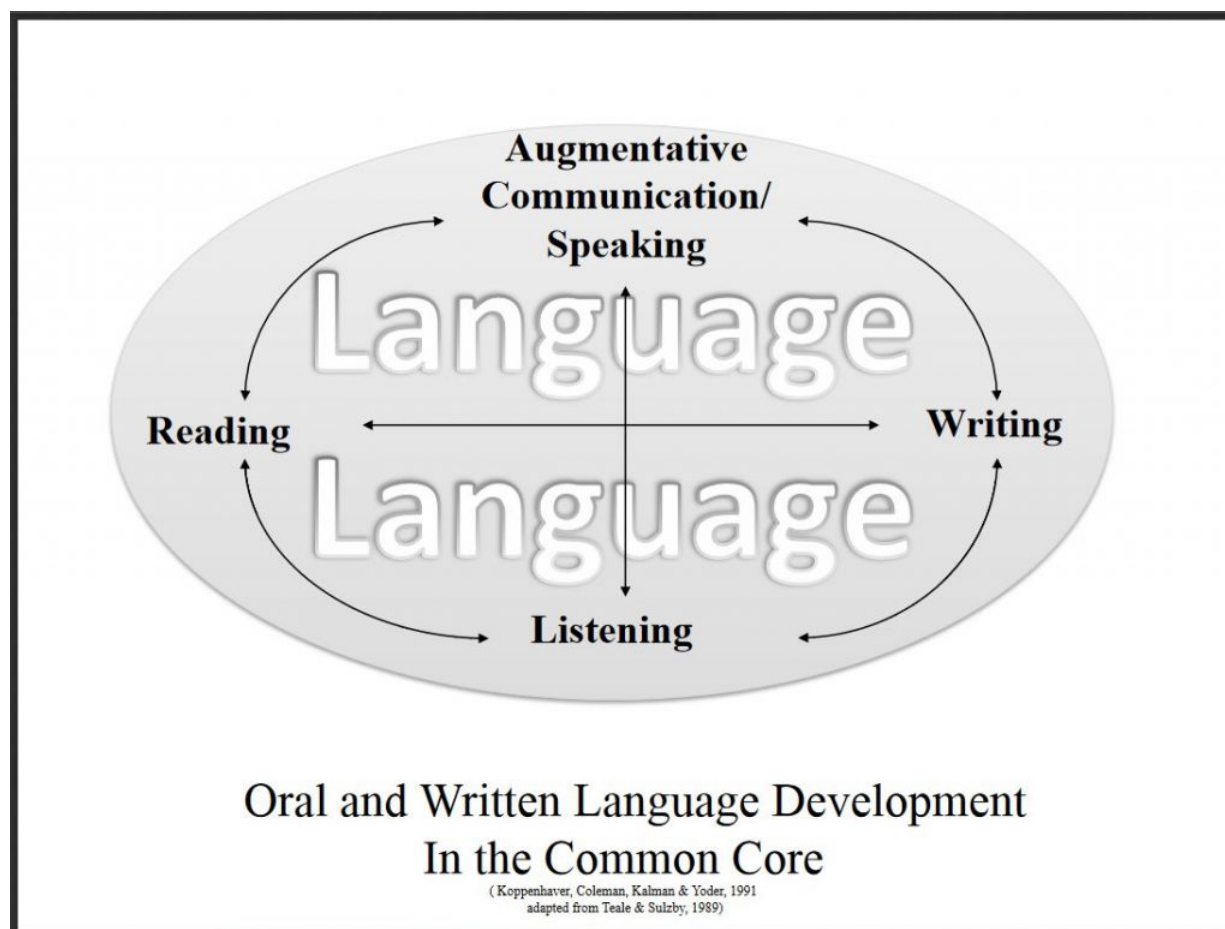
The fact that communication allows people the ability to express their own thoughts and ideas cannot be overemphasized. It allows people the opportunity to comment, reject ideas and situations, and express what is on their mind. These are fundamental skills that society assumes all individuals possess. Communication also allows socialization. Teaching AAC users how to communicate affords them these basic rights that others often take for granted. Obviously, there are many essential benefits in teaching literacy to people with complex communication needs, extending from independence to employment and beyond. As noted above, a goal of AAC communication is for the user to be able to express their own wants, needs, thoughts, desires, and concerns.

Through the use of AAC language and emergent literacy strategies, independent communication skills will develop. Moreover, it is important to develop reading, writing, and language at the same time. For decades the interconnectedness has been known between these three concepts. The ERLC (2016) cites an important study from Sulzby and Teale (1991) that states, “from an emergent literacy perspective, reading and writing develop concurrently and

interrelatedly in young children, fostered by experiences that permit and promote meaningful interaction with oral and written language” (para. 10). This interconnectedness and interrelatedness have been adapted to include AAC language development and not just oral language (Koppenhaver et al., 1991). Figure 4 depicts this interrelated association. Furthermore, a study by Goh et al. (2013) examined students with autism who struggled with communication and the benefits of reading and writing; Goh et al. noted that “the ability to read and write ... provides an alternative mode of communication with the potential to support a fully functional language system” (p. 105).

Figure 4

Oral and Written Language Development (Koppenhaver et al., 1991)



The Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write Framework

The intervention used for this thesis is based on an adaptation of Erickson and Koppenhaver's (2020) *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write*. The framework includes both emergent and conventional learning instruction as it is noted that "emergent literacy was necessary but not sufficient to address the literacy needs of individuals with significant disabilities" (Erickson & Koppenhaver, 2020, p. 88). Emergent and conventional learning will be discussed in depth below.

The framework is referred to as "comprehensive" as it "addresses each of the element that is required for each student to learn to read with comprehension and to write to convey thinking" (Erickson & Koppenhaver, 2020, p. xviii). This framework diverges from the reductionist and functional literacy approaches that can be found pervasive in special education programs. Instruction is also "comprehensive" as it not only addresses key foundational literacy skills, for instance, phonics, vocabulary, and comprehension but it also attends to "motivation, social and cultural aspect of reading and writing during self-directed reading and writing. This prepares students for real-world reading, writing, and communicating" (Erickson & Koppenhaver, 2020, p. 98). The vital outcome enables students to read and write to communicate wherever, whatever, and with whomever they want to. Erickson and Koppenhaver (2020) claim that based on the *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* framework, and with experience, students "will gradually gain understanding and skill...and ultimately communicate conventionally face to face and in writing. They may or may not choose to write poems, autobiographies, or journals, but they will experience increased autonomy, self-advocacy, and human connection" (p. 14).

Necessary Factors That Contribute to Success

Erickson and Koppenhaver (2020) list 10 factors that are likely to contribute to students with significant disabilities being able to learn to read and write:

Knowledgeable Others

Teachers are key to teaching literacy to students who may be challenging to teach but are capable of learning. Knowledgeable others or educators do not have to be certified teachers; anyone who enriches the literary lives of students is teaching them literacy. Educators need to understand that there is no single best method to teach literacy and students learn differently and at different rates. “All children should regularly hear that they are smart, capable, and important. Every child should feel loved and valued” (Erickson & Koppenhaver, 2020, p. 16).

Means of Communication and Interaction

Every learner needs a means to communicate and in the case of learners who have challenges communicating, this might include an AAC device. These students also need access to the alphabet along with their device.

Repetition With Variety

Rereading and rewriting for different purposes “coaches new learning in familiar experience, increases the quantity and quality of learning opportunities in the classroom or community, and enables students to grow as readers and writers” (Erickson & Koppenhaver, 2020, p. 19). It is important for students with significant disabilities to have repetition (to reinforce skills) with variety as they learn literacy skills.

Cognitive Engagement

During literacy instruction, it is essential to place an emphasis on cognitive processes including reasoning, thinking, and judgment on different types of texts, comprehension, and writing exercises. These cognitive processes are generally not engaged during instructional

methods such as filling in the blanks and worksheet completion. When teachers teach to the interests of the student, the student becomes more engaged and therefore is more likely to experience success in learning to read and write.

Cognitive Clarity

Students need to know the purpose of the instructional activity, and ultimately the student needs to know “what is in it for me” (Erickson & Koppenhaver, 2020, p. 20). When there is no apparent purpose to learning, this can lead to confusion and disinterest. Students learn better and will put in more effort if they can see the purpose.

Personal Connection to the Curriculum

Teachers should note that “it is not our job to make students do anything. It is our job to make them want to” (Erickson & Koppenhaver, 2020, p. 21). Teachers need to provide students with personal connections to the curriculum so that feel a sense of belonging, feel included, and feel some attachment to what is being taught. “Personal connection invites students into learning by building their trust in their own abilities and their confidence that they can rely on the people surrounding them at home and in the classroom to help as needed” (Erickson & Koppenhaver, 2020, p. 22).

Encouragement of Risk Taking

It is essential to remember that students who struggle with literacy might be apprehensive to try to learn. When something is difficult, and there is a history of struggling, there might be risk aversion for fear of getting your answer wrong. “Publishing all students’ work ... thinking aloud and modeling potential ways of communicating ideas, and helping students find interesting materials they can read successfully all encourage risk taking” (Erickson & Koppenhaver, 2020, p. 23).

Comprehensive Instruction

Comprehensive instruction includes equal time and attention in reading comprehension instruction, self-directed reading, writing, and word study. It is important that each is given instruction daily; further, each component will be discussed in more detail below.

Significant Time Allocation

Students with significant disabilities are often not given a great deal of time for literacy instruction. It is important to offer as much instruction as possible and make literacy learning a priority.

High Expectations

Students can learn to read and write and if they have a significant disability or a complex communication need; however, this might take longer, and they might need more supports. Regardless, it is important that they believe that they can learn. It is important to hold high expectations for all students. Ann Donnellan (1984) has written about high expectations and the importance of presuming competence; she defines the criterion of the *least dangerous assumption* as “that in the absence of conclusive data educational decisions ought to be based on assumptions which, if incorrect, will have the least dangerous effect on the likelihood that students will be able to function independently as adults” (p. 141). Thus, it is important to have high expectations so the student can reach for them and not low expectations that underestimate their potential.

Components of Comprehensive Literacy for All Framework

The resource *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* (Erickson & Koppenhaver, 2020) describes the following strategic instructional elements: shared reading, predictable chart writing, alphabet and phonological awareness, writing, self-directed reading, reading comprehension, and word study. Each of these is briefly described next.

Shared Reading

Shared reading is about the instrumental shared interaction between the adult and student. Recall from above that there are many strategies for interaction using the AAC device, such as the CAR and CROWD. Erickson and Koppenhaver (2020) further note how language and literacy skills can be developed during shared reading. For example, four key actions an adult can engage in are: “labeling objects in the illustrations, talking about what is going on in the book, referring to real-life connection to the story and referencing print” (Justice et al., 2009, as cited in Erickson & Koppenhaver, 2020, p. 51). Shared reading is fundamental in emergent literacy and was a part of the present intervention.

Predictable Chart Writing

Predictable chart writing (Cunningham, 1979) is a systematic and structured instruction method to assist emergent students in learning print conventions. Typically, the teacher starts writing sentences and the students fill in the end of the sentence with personal information. This encourages engagement and interest. The predictable chart is broken down throughout the week in a sequence where each day a different part of the sequence is focused on. The sequence has five steps: “write the chart, reread the chart, work with sentence strips, be the sentence and make and publish the book” (Cunningham, 1979, p. 79). The variation keeps the students interested as the steps are predictable so they can gain confidence, yet the steps vary daily to keep them engaged.

Alphabetical and Phonological Awareness

It is essential to teach alphabet and phonological awareness. As noted above, phonological awareness is the knowledge of and ability to manipulate individual sounds in units and words. The focus of phonological awareness instruction, therefore, is on “phonemes, or individual speech sounds, not on associated graphemes (letters). ... Students learn to isolate initial and final sounds of words, break words into onset and rime, and blend and segment

words” (Mesmer & Kambach, 2022, p. 1). Mesmer and Kambach (2022) further define phonics as “learning the connection between phonemes and their written representation” (p. 1).

In the *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* (Erickson & Koppenhaver, 2020) framework, a six-cycle method (see Appendix A) “emphasizes identifying the letter name and sound, recognizing the letter in text, and producing the letter form, through flexible, distributed cycles of review based on factors that influence acquisition of alphabet knowledge” (Jones et al., 2013, p. 81).

The six cycles are: own name, alphabetical order, letter name-letter sound relationship, consonant phoneme acquisition order, and distinctive visual features letter writing. Erickson and Koppenhaver (2020) adapted this model to include AAC users and other students with significant disabilities. The adaptation includes saying the letters (using their device) and saying the letter sounds in their head. Another adaptation might be when the student is directed to produce the letter form if not able to print, then the student is directed to whatever method they use to write with.

Phonological awareness requires explicit instruction along with repetition with variety as well (Erickson & Koppenhaver, 2020). Concepts that need to be taught are segmenting words into syllables, teaching rhyme awareness, and teaching alliteration (Erickson & Koppenhaver, 2020). These concepts can be difficult to learn, and there is an added challenge for teachers to find and adapt activities to teach the skills that do not require speech production (Erickson & Koppenhaver, 2020).

Writing

According to Erickson and Koppenhaver (2020), students with significant disabilities often need different writing tools than the typical pencil and paper. These tools can take various forms such as keyboards, stamps, label makers, and letter tiles, et cetera.

Erickson and Koppenhaver (2020), further note that writing is an extremely important component for communication for someone with complex communication needs. “Writing often can aid students in learning to read. Writing enables the student to look within and across words as they compose their thoughts” (Erickson & Koppenhaver, 2020, p. 96). Specifically, comprehensive writing instruction can include mini-lessons on the facets of writing, daily writing without teacher corrections, and shared writing.

Self-Directed Reading

According to Erickson and Koppenhaver (2020), this is often not included in programming; however, “reading for comprehension for self-determined purposes is the point of learning to read” (Erickson & Koppenhaver, 2020, p. 95). Self-directed reading encourages a variety of different genres of literature. “The intent is to make students more aware of the breadth of possible reading topics, types, and authors so they can determine over time what reading has to offer them personally” (Erickson & Koppenhaver, 2020, p. 96). The students are exposed to various texts through read alouds and also through independent reading.

Reading Comprehension

According to Erickson and Koppenhaver (2020), comprehension strategies begin in emergent literacy and are carried over to conventional reading. It is essential to teach students that text has meaning and purpose. The main strategy they use is termed *anchor-read-apply*. There is an anchor by making a connection to world knowledge and setting a purpose to read, reading to achieve the purpose set out and applying what they have read to accomplish the purpose that was set.

Word Study

According to Erickson and Koppenhaver (2020), students with significant disabilities often struggle with both receptive and expressive communication skills. Therefore, explicit

teaching of reading and spelling of word patterns, high-frequency words help them read and decode words that they aren't familiar with.

Time Estimates of Components

The amount of instructional time dedicated to each component is an important aspect of Erickson and Koppenhaver's (2020 *Comprehensive Literacy for All*. Erickson and Koppenhaver (2020) suggest estimates of instructional time that should be spent in a school setting (see Table 4). For emergent literacy instruction, the approximate time during the class day is 90–135 minutes and approximately 120 minutes for conventional instruction. Nevertheless, they do identify that in some classrooms it might be hard to find 90–120 minutes a day of instruction as the students might not have the physical supports that they need, or are withdrawn to work with Occupational Therapists, Speech Language Pathologists, or other paraprofessionals. If possible, teachers should strive to complete at least two full cycles a week of comprehensive literacy instruction.

Furthermore, Erickson and Koppenhaver (2020) note that parents are able to supplement what is offered at school and they can “take the lead in helping their child learn to read and write while sitting around the kitchen table, sharing stories at bedtime, and interacting with the print they encounter throughout their lives” (p. 205). As a part of this present research study, the intervention was carried out during our typical “homework time” as often as time permitted.

Summary of Chapter Two

As a function of reviewing the literature in Chapter 2, it becomes evident how complex and multifaceted it is to teach literacy to students who have ASD and/or complex communication needs, and who may require AAC for communication. This chapter began with a summary of Vygotsky's (1978) sociocultural theory of development as the theoretical framework for the present study, followed by Whole-To-Part Model of Silent Reading Comprehension (Erickson &

Koppenhaver, 2020) as the conceptual framework. These frameworks are overarching to Erickson and Koppenhaver's (2020) evidence-based *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* that offers guidelines to teach the basic literacy components. Figure 5 presents a graphic depiction of the theoretical, conceptual, and *Comprehensive Literacy for All* (Erickson & Koppenhaver, 2020) framework. The next chapter will outline the methodology of the current study proposed.

Table 4

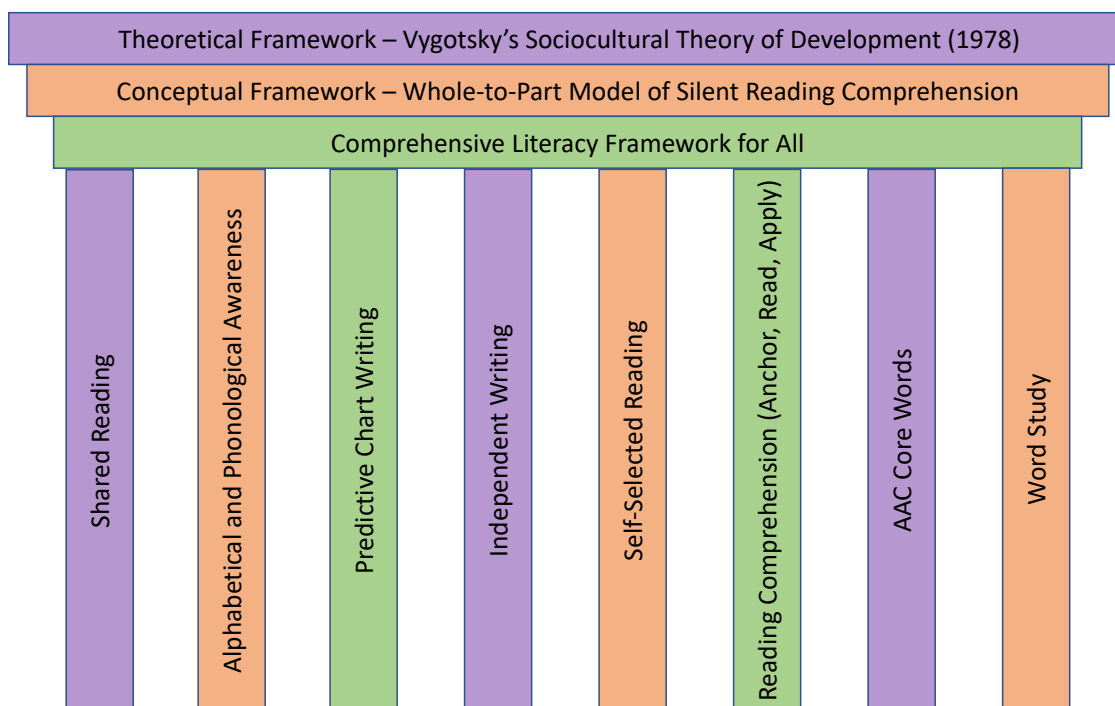
Time Estimates for Components of Emergent, Conventional, and Combined Literacy Instruction

(Erickson & Koppenhaver, 2020, p. 205)

Intervention	Emergent	Conventional	Combined
Shared reading	Two times for 10-15 minutes		10-15 minutes combined + (10-15 minutes emergent only)
Predictable chart writing	20-30 minutes		10-15 minutes combined to create the chart + (20-30 minutes emergent only for remaining steps)
Alphabet and phonological awareness	20-30 minutes		20-30 minutes emergent only (during word study)
Writing	20-30 minutes	30 minutes	30 minutes
Self-directed reading	10-15 minutes	30 minutes	30 minutes
Reading comprehension (anchor-read-apply)		30 minutes	30 minutes (conventional only)
Word study (keywords, word wall, Making Words)		30 minutes	30 minutes
Total	90-135 minutes	120 minutes	130 minutes + 10-15 minutes once per week for creating predictable chart

Figure 5

Graphic Depiction of the Theoretical, Conceptual and Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write (Erickson & Koppenhaver, 2020)



CHAPTER THREE: METHODOLOGY AND PROCEDURES

This chapter will describe the methodological and ethical considerations that were adhered to in this research study. This study was designed to address the following questions:

1. What are the experiences of a parent educator teaching literacy awareness and skills to her adolescent sons who both have ASD and use AAC devices?
2. Does the experience shape her identity as a parent, educator, and researcher?

Chapter 3 will provide a summary of the pilot study, research method, and the rationale, research design, data collection, participants, data analyses, and ethical considerations.

Pilot Study

A single case study was conducted as a pilot study from January 2020 to March 2020 at a private school in the Greater Toronto Area (GTA). The participant inclusion criteria of the study included a student between the ages of 13–17, with a diagnosis of ASD and using an AAC to communicate. The pilot study was intended to garner information about the appropriateness of these resources to extrapolate into a more in-depth future thesis study. The pilot study research questions that were examined were:

1. For adolescent students with ASD, does an adaptation of the Four Blocks® framework increase their foundational literacy skills such as:
 - a. letter identification
 - b. phonemic awareness
 - c. sight word reading of high frequency words
 - d. reading comprehension (e.g., read aloud, shared reading, or guided reading)
 - e. reading engagement (e.g., spontaneously pick up book, attend to book while reading and being read to)

- f. writing or expression (either on an AAC device or using other manipulatives like letter or word tiles)
2. Do the parents/guardians and teachers of adolescent students with ASD report any change in their child/student's literacy skills and engagement as function of participation in an adaptation of the Four Blocks® framework.
 3. What are the implementation challenges of an adapted Four Blocks® model? What are the potential solutions to overcome these challenges?

A few schools in the GTA for adolescent students with ASD were contacted and it was a private school for students with autism that agreed to participate. Based on the criteria of the study a classroom teacher who taught adolescent aged students was selected from the administrator as this teacher taught the targeted age cohort. The participant was selected by the school and teacher as a good fit for the study based on the study's inclusion criteria as the student was nonverbal and used an AAC to communicate.

The focus of the study centred on building literacy skills using an adaptation and modification of Cunningham et al.'s (1991) Four-Blocks® Literacy Framework along with modification and adaptation suggestions from *Children With Disabilities: Reading and Writing the Four-Blocks® Way* (Erickson & Koppenhaver, 2007) and *The Teacher's Guide to the Four Blocks®* (Cunningham et al., 1999).

The pilot study was divided into three phases. Phase 1 was the pre-intervention phase, Phase 2 was the intervention phase, and Phase 3 was the post-intervention phase.

Phase 1 of the pilot study started with interviews (30–60 minutes) with both the parent and teacher of the student participant. Questions were asked in a semi-structured interview regarding the student's learning preferences and motivation, the types of books chosen to read during read alouds and in shared, guided, and independent reading. Also, questions were asked

about the student's behaviours observed regarding literacy at home and at school, including the student's interest in looking at books, pointing to pictures, attending while being read to. Further, general interest in reading and writing as well as questions related to the perceived importance of reading and writing were asked. Finally, questions regarding behaviour plans and reinforcement schedules were asked of the teacher to ensure that I would be consistently implementing the behaviour plans when working with the student.

The student completed literacy assessments to garner a baseline for letter and sound recognition, sound awareness, rhyming awareness, blending, phoneme segmentation, sight words, and receptive vocabulary. The literacy assessments took over one and half weeks to complete due to breaking up the sessions into small assessment sections with additional reading activities. This helped the student stay engaged and kept the sessions fun and motivating.

Phase 2 of the study was the intervention which was an adaptation and modification of the Four Blocks® framework (Cunningham et al., 1999). I worked with the student three times a week for 30 minutes. During and after the sessions, observational notes and researcher reflections were recorded. Unfortunately, the study was cut short after 7 weeks due to COVID-19 school closures; therefore, the student only received 5 weeks of intervention. Figure 6 presents examples of some of the activities completed using the coloured framework of the Four Blocks® model.

Phase 3 of the pilot study could not be completed due to COVID 19. However, I was able to include a parent interview with questions similar to those that were initially asked; in this phase there was a focus on asking about any potential changes in the student's literacy skills noted since the intervention. Due to the COVID-19 pandemic and the school closure, I was not able to complete the followup interview with the teacher nor the followup literacy assessments with the student.

Figure 6

Examples of Activities in Four Blocks® Model

<p style="text-align: center;">Shared Reading</p> <ul style="list-style-type: none"> ○ Using his AAC we looked and read many books following the student's interest – constellations, animals, weather, science experiments, poetry, listened to songs while reading along with the lyrics in a book 	<p style="text-align: center;">Self-Selected Reading</p> <ul style="list-style-type: none"> ○ Looked at different types of genres of books for instance magazines, non-fiction, recipes, science books ○ Offered variety of types of books, graphic novels, chapter books, poetry
<p style="text-align: center;">Writing</p> <ul style="list-style-type: none"> ○ Used graphic organizers ○ Predictable chart writing ○ Different type of methods for writing for instance keyboarding, stamps, letter tiles, and label maker ○ Made squishy books ○ Think alouds 	<p style="text-align: center;">Working with Words</p> <ul style="list-style-type: none"> ○ Letter identification ○ Phonetic identification ○ Worked on Dolch Words ○ Focused on letters in name and spelling name

The research questions could not be answered; however, I was able to garner a general sense of parental observations from the parent interview. There were findings that related to the student's enhanced abilities and literacy behaviours. For example, the student was observed expressing a desire to be read to and spontaneous perusal of his "READING" folder on his AAC. The student's parent noted that they were interested in more text genres, including graphic novels. Overall, the student demonstrated an understanding of the importance of text (e.g., texting, searching on Google) and increased communications such as more frequent commenting. The student exhibited trying to print their name more often and responded to the use of graphic organizers to help formulate writing. The student was also involved in more writing opportunities to communicate about their interests at home. Finally, it was observed that the student exhibited a more positive attitude in writing and a greater interest in reading and writing in general.

There were several limitations of this pilot study. First, additional time to complete the intervention would have been useful, due to the short duration of only 5 weeks because of the COVID-19 interruptions. A second limitation was that as an intervention, it focused only on a single case study so it was hard to draw conclusions about its efficacy. Third, because the pilot study had to be stopped early, important post-intervention metrics were not obtained.

Despite some limitations, there were also several recommendations obtained from this pilot study. An important finding obtained during this pilot study was how integral it is to follow a student's interests during the sessions to maintain their engagement. Furthermore, I found that literacy is nuanced and there are many opportunities to work on literacy engendered conversations about things that interested the student, generating more reciprocal literacy-rich interactions which prompted even more communication. It was key to these interactions that we

had access to age-appropriate texts and instructional resources, which is also challenging for educators to find.

Another recommendation from this pilot study was to allow ample designated assessment and instructional time. The initial assessments were prolonged to include important rapport-building activities. The instructional sessions also ended up being compressed as sometimes behaviour issues or logistical issues took up more time during a session. Although the allotted 30 minutes represents the typical length of time available for instruction, it was difficult to get more than one or two of the Four Blocks® model areas covered. A positive recommendation for future intervention implementation is that it was advantageous to have different modes for the student to express ideas and respond through independent writing (e.g., apps, tiles, stamps, label maker, pictures, AAC). Finally, it must be emphasized that the facilitator's AAC knowledge of the device and AAC strategies are imperative. Effective AAC strategies (such as those mentioned in Chapter 2) are only useful in any instructional framework if the educator has a command of them and the AAC device. All of these realizations from the pilot study were formative in my development as an educator and informative in the design of the present thesis study.

Since the start of this pilot project, Erickson and Koppenhaver wrote a new book, *Comprehensive Literacy for All: Teaching Students with Significant Disabilities to Read and Write* (2020). This new resource was used for the current study as an instructional framework while I reflected on my roles as parent, educator, and researcher for this thesis.

Research Methodology

A qualitative research approach was used within the constructivist (Neimeyer & Levitt, 2001) narrative (Moen, 2006) worldview and interpretivist underlying epistemological assumption (Alharahsheh & Pius, 2020). Collectively, this stance maintains that the world is socially constructed and the researcher is subjective. The following quote describes my positioning:

The constructivist, interpretivist believes that to understand this world of meaning one must interpret it. The inquirer must elucidate the process of meaning construction and clarify what and how meanings are embodied in the language and actions of social actors. (Schwandt, 1998, p. 222)

Furthermore, this research is an autoethnography as this approach is often associated with a narrative worldview (Bochner, 2012). This method was chosen as autoethnography “uses personal experience (‘auto’) to describe and interpret (‘graphy’) cultural texts, experiences, beliefs, and practices (‘ethno’)” (Adams et al., 2017, para. 1). Furthermore, “autoethnographers believe that personal experience is infused with political/cultural norms and expectations, and they engage in rigorous self-reflection—typically referred to as ‘reflexivity’—in order to identify and interrogate the intersections between the self and social life” (Adams et al., 2017, para. 1). According to the Salkind (2010) in the *Encyclopedia of Research Design*, this research approach “aim[s] for an in-depth exploration of the meanings people assign to their experiences, narrative researchers work with small samples of participants to obtain rich and free-ranging discourse. The emphasis is on storied experience” (para. 1). In particular, in an autoethnography, the researcher is a participant and has a reciprocal relationship with the other participants. My

reflections and values are focused on understanding and describing the research on my experience and role as a mother, educator, and researcher.

Current Study

In most of 2020 through 2021, COVID-19 pandemic restrictions in schools and within the province of Ontario prohibited human participant research so my original research design of compiling multiple case studies of students with ASD developing their literacy skills was no longer feasible. Therefore, I was inspired to change methods and through discussions with my supervisor and after a Research Ethics Board (REB) hearing, I chose to engage in an autoethnographic research method. REB clearance was granted file # 20-308. The focus has been on me, as I chronicled, analyzed, and interpreted working with my two sons on their literacy skills. Both of my sons have ASD, and both use AAC devices to communicate as one is nonverbal and the other minimally verbal. The literacy intervention that I used with them was adapted from Erickson and Koppenhaver's (2020) *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* and included shared reading, guided reading, predictable chart writing, alphabet and phonological awareness, writing, self-directed reading, and making words. Although the framework is meant for a full day of instruction, my sons and I worked on literacy lessons during "homework" time conforming to our home schedule which was important during the first wave of COVID-19 when all students in the province of Ontario were learning from home.

Below I will elaborate on my observations of my teaching practices and reflect on my roles as educator, parent, and researcher. I also reflect on how I taught my sons using the resource, the effectiveness of the activities, and their skill transfer from the lessons to other literacy rich activities. As I am a strong proponent of building home and school cohesiveness, I

was very interested in describing how my role of parent educator may provide potential benefit to my children and others. It became markedly evident to our family during the COVID-19 pandemic waves that structured home education is indispensable.

Rationale

Learning to read and write is a focus of the elementary school system. However, foundational literacy skills such as phonetics, letter identification, or meaningful literacy activities, are often not taught to adolescent students with significant disabilities in the secondary school setting (Ruppar et al., 2018). As noted above, students with significant disabilities and complex communication needs often have challenges learning to read and write. When these students reach secondary school usually literacy is not a focus and if implemented, literacy instruction tends to be focused on functional word lists rather than on the foundational skills of literacy (Browder et al., 2009). This struggle with literacy is evident in my two adolescent sons who use AAC and have ASD. Alvin knows his letters, letter sounds, and many of functional sight words; however, he did not have any engagement with reading or writing. In my opinion, he did not perceive to understand the purpose of print and nor that it could be meaningful. He looked at identifying letters, sounds, and words as a task much like completing a puzzle. For instance, he could read a sentence “Alvin can have a Smartie.” Then he would be able to answer questions such as, “Who can have a Smartie?” and “What can Alvin have?” However, even if he read the sentence and you told him what he was reading was true, he would not have expectation of receiving a Smartie. He would not understand that the sentence had any purposeful meaning. Charles did not know any letters or letter sounds. He was just starting to enjoy some books, but in general he was not engaged in reading and did not understand the concept of print.

During the first COVID-19 pandemic lockdown in Ontario (Spring through Summer 2020), a great deal of their education was facilitated by me; this was an optimal time to explore my experiences. The focus of this study has been on me as the researcher and my other dual roles of mother and educator to my adolescent sons with ASD.

Research Design

As a parent of two adolescents with ASD and who use AAC, I believe I have a unique perspective in teaching literacy using a resource such as Erickson and Koppenhaver's (2020) *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write*. This instructional framework includes evidence-based research such as balanced literacy (Cunningham et. al., 1999) and enhanced alphabet knowledge cycles (Jones et. al., 2013) to support literacy intervention practices. There are no standardized scripts or materials; instead, the espoused instructional practices are individualized, and asset based. The expressed core value is one of inclusion such that "people or not too anything – not too [intellectually disabled]..., not too physically impaired, not too emotionally challenged – to learn to acquire communicative competence or to learn to read and write" (Yoder, 2001, p.5).

For seven months (June 2021 to January 2022), I worked with my children (one-on-one) on lessons from *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* (Erickson & Koppenhaver, 2020). Lesson activities that were used included the following nine examples: shared reading (using AAC to focus on interactions between them and me while reading; exposure to a wide range of literature); guided reading (using AAC to Anchor-Read-Apply, predictable chart writing, structured, systematic writing); alphabet and phonological awareness; independent writing (write words independently without dictation or overt correction, model spelling informally); self-directed reading (encourage them to pick books

they want to read or look at, read alouds); reading comprehension (scaffolding [Bruner, 1978], gradual release of responsibility [Pearson & Gallagher, 1983]); AAC core words (encouraging comments, identifying sight words); word study (making words, reading and spelling high-frequency words, word families).

Even though I have been engaging in these activities for some time with my sons, I am bracketing my experience for the purposes of this autoethnography study from June 1, 2021 to January 2, 2022. During this 7-month period I have been rigorous in my lesson documentation and in the collection of data for the purposes of this ethnographic research on my roles.

Data Collection

Lesson planning and reflections on the lessons with recommendations for the next session were tracked. These data were referred to as my lesson plans and were written in an agenda calendar. The lesson plans included activities following the framework including the nine activities noted above in Research Design from the *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* (Erickson & Koppenhaver, 2020).

Different activities from the lessons were archived as photo images or videos of my sons' work. These artifacts were retained as examples of my instructional facilitation activities. For instance, I took screenshots of my son's AAC device to see what he expressed, or I would take a video of our shared and guided reading activities. This demonstrated the different accommodations that I facilitated and the various ways that I encouraged my sons to explore literacy. There were no descriptors linking the artifacts to anyone in particular and no images with my children's faces nor any identifiable information to protect their privacy. Videos were recorded with their faces showing however these will remain private and image captures have been pixelated. Occasionally, there were email and texts that were sent from the boys and these were also archived as artifacts.

I made field notes after each session about my own teaching practices within a journal as well. The nature of these field notes related to how I taught my sons using the resource; questions about what else I could try, the effect of the activities; and the skill transfer from the lessons to other literacy-rich activities such as reading aloud together. These notes were made in the week-by-week journal format and were written after each session or recorded on my cell phone for transcription if time did not allow me to write my notes.

Finally, I reflected on how I felt in this role as a parent educator of adolescents with emergent literacy skills. Lesson reflections directly followed each session (either written or audio recorded on my cell phone for later transcription) in a journal format that was written in a week-by-week journal format. Occasionally, I would add a personal memory making a connection to my sons' prior experiences. Further, I also added reflections on other events that took place, for instance, reflections that would come to me after attending a webinar or online professional development workshops, conferences, and self-paced online learning courses.

From June 1, 2021 to January 2, 2022, there were 31 weeks of these lesson plans, artifacts collected, and open-ended fieldnotes and lesson reflections. If time permitted, I typed out the fieldnotes and lesson reflections immediately following each session. When time did not, I made voice memos to myself and transcribed them at a later date. The voice memos were deleted once transcribed. All data was stored on a password-protected computer. All data collected are summarized in Table 5.

Table 5*Summary of Data Collection*

Week	Date	Data collection method					
		Lesson plans	Reflections	Field notes	Personal memory	Photos	Email/Text
1	June 1–6, 2021	√	√	√	√	√	√
2	June 7–13	√	√	√		√	√
3	June 14–20	√	√	√	√	√	
4	June 21–27	√	√	√			
5	June 28–July 4	√	√	√		√	
6	July 5–11	√	√	√		√	
7	July 12–18	√	√	√		√	
8	July 19–25	√	√	√		√	√
9	July 26–August 1	√	√	√		√	
10	August 2–8	√	√	√			√
11	August 9–15	√	√	√		√	√
12	August 16–22	√	√	√		√	√
13	August 23–29	√	√	√		√	
14	August 30–September 5	√	√	√			
15	September 6–12	√	√	√			
16	September 13–19	√	√	√			√
17	September 20–26	√	√	√		√	√
18	September 27–October 3	√	√	√			
19	October 4–10	√	√	√		√	√
20	October 11–17	√	√	√		√	√
21	October 18–24	√	√	√		√	
22	October 25–31	√	√	√			
23	November 1–7	√	√	√	√	√	√
24	November 8–14	√	√	√		√	√
25	November 15–21	√	√	√	√	√	
26	November 22–28	√	√	√		√	
27	November 29–December 5	√	√			√	
28	December 6–12	√	√	√		√	
29	December 13–19	√	√	√		√	
30	December 20–26	√	√	√	√	√	
31	December 27–January 2, 2022	√	√	√		√	√

Participant

As the study is an autoethnography, I, the researcher, am the primary participant. I reflected on working with my two children however, they were only discussed in relation to how I work with them and my skills as a parent educator. The abilities of my two adolescent sons are not the focus of this study. Pseudonyms have been used for the children, without listing any specific age, only that they are both adolescents.

Data Analysis

Once the data were collected, I organized the data files for analyzing and interpreting. The first step was to summarize all the data collected (see Table 6) and then itemize all the lessons and data collected week-by-week (see Appendix B for a detailed description of the weekly lessons and data). A preliminary exploratory analysis was conducted by the researcher getting a “general sense of the data, recording initial ideas, [and] thinking about the organization of the data” (Plano Clark & Creswell, 2014, p. 358). This general sense was discussed in consultation with my supervisor. Then I went through the lesson plans, lesson reflections, field notes, and artifacts line-by-line and began to code them for common ideas.

The analysis model I used is based on Braun and Clarke’s (2006) six phases of thematic analysis. The first phase is “familiarizing yourself with the data” (p. 87). I read through each of the entries and was able to get an overall sense of the general ideas. The second phase is “generating initial codes” (p. 88). I then started at the first entry and read every sentence. I highlighted each sentence with a different colour to represent each of the different ideas. The third phase is “searching for themes” (p.89). I made a list of all the general ideas and themes with their corresponding colours. This procedure is referred to as open coding (Plano Clark & Creswell, 2014) where I did not have pre-determined themes that I was trying to fit into. Instead,

I developed the labels or codes based on the reoccurring ideas that came up in the data (Plano Clark & Creswell, 2014). I read all the different coloured coded themes to see if there were any that could get grouped together and label with a common but different heading.

The fourth phase of Braun and Clarke's (2006) six phases of thematic analysis is "reviewing the themes" (p. 91). After the data were coded, I wrote descriptions of these major ideas and then grouped them into meaningful categories that could be ultimately articulated as thematic findings (Plano Clark & Creswell, 2014). A total of nine themes were created including: immersive, meaningful/connection making, relevant/purposeful intervention, observable changes/growth, mindshift, advocacy/imposter syndrome, parent concerns, personal memories, and planning/questioning/missed opportunities.

The fifth phase of Braun and Clarke's (2006) thematic analysis is "defining and naming themes" (p. 92). With the headings and the colour-coded sentences, I went back through each line and summarized the data in bullet points. I then met with my thesis supervisor, and we reviewed and discussed all nine themes and the bullet summaries. We agreed that the themes: immersive, meaningful/connection making, relevant/purposeful intervention, and observable changes/growth were about my sons and were not the focus of this thesis. I reminded myself that the thesis was an autoethnography about me and my reflections on my roles, not about the boys' learning.

Therefore, the nine themes were narrowed down to five themes: mindshift, advocacy/imposter syndrome, parent concerns, personal memories, and planning/questioning/missed opportunities. I then organized the data into the five thematic findings and then went through line-by-line and copied and pasted all cataloged and coloured sentences together. For instance, I wrote the heading "Mindshift" and went through all the data collected and everywhere the colour

that coordinated with “Mindshift” I copied and pasted onto a separate document. Finally, all five themes and every sentence that coordinated with its respective theme were listed in one document. When reviewing the data again I decided to combine the data derived from personal memories into the parent concerns as they aligned together better.

The final step was examining the themes and mapping them out on to each of the research questions to ensure adequate coverage. The final four themes are: transformational learning and mindshift, advocacy with teacher imposter syndrome, parent concerns, and planning and questioning. Subheadings within each theme were developed to subdivide the large themes in meaningful sections. The sixth and final phase of the Braun and Clarke’s (2006) six phases of thematic analysis is “producing the report” (p. 93). This phase will be revealed in the findings section in Chapter 4.

Ethical Considerations

This research was given clearance from the Brock University Research Ethics Board (REB) file # 20-308. A number of ethical considerations were vetted through the REB process. There is a lack of both privacy and confidentiality as this study is an autoethnography and is written in a narrative form as a first-person account of the researcher. The fact that I am writing about my children precludes any anonymity for anyone in the study. My husband, the father of our sons, granted consent for this research to take place. We contend that as parents, the potential benefit of communicating my experience as a parent, educator, and researcher while my sons are gaining literacy skills is weighed more heavily than the risks of privacy and confidentiality. Additionally, the potential to change a pervasive negative stigma for nonverbal children with ASD regarding their ability to learn how to read further outweighs the risks.

I also asked both of my sons if they wanted to participate in my study and they both agreed. However, how much they understood about what the study entails, what my schooling is about and what this means to them is uncertain. As the study was similar to our day-to-day routine of “homework”, the actual time spent working with them on their literacy development would be perceived as typical to them. As with ethnography, I made certain that I focused this study on me and my reflections, not analyzing my sons, but reflecting on my experiences and my identity.

Summary of Chapter Three

Based on what I had learned as recommendations from my previous pilot study, I utilized the autoethnography research method to chronicle, analyze and interpret my experiences as a parent and educator engaging in literacy learning with my two sons with ASD. To document this experience I used lesson plans, lesson reflections, artifacts, and field notes as data to document my role as a parent and educator of literacy skills and literacy engagement of my children. Lesson plans were written each week including activities, shared reading, guided reading, predictable chart writing, alphabet and phonological awareness, independent writing, self-directed reading, reading comprehension, AAC core words and word study. I observed my own teaching practices and reflected on how I felt in this role as a parent educator of adolescents with emergent literacy skills. I also included artifacts of photos, images, and videos. Each week the data were collected and logged. The reflections and field notes were recorded in a journal.

All the data were then open coded for major ideas and categorized. Using Braun and Clarke’s (2006) thematic analysis I followed the phases of familiarizing yourself with data by getting a general sense of the data; generating initial codes by going through the data line by line and highlighting with different colours for different ideas; searching for themes based on the

reoccurring ideas that came up in the data and grouped together any common themes; reviewing themes I wrote descriptions of these major ideas and then grouped them into meaningful categories that could be ultimately articulated as thematic findings; defining and naming themes with the headings and the colour-coded sentences, I summarized the data in bullet points and discussed with my thesis supervisor, and we narrowed down all nine themes and the bullet summaries into a final four themes.

The four themes were transformational learning and mindshift, advocacy with imposter syndrome, parent concerns, and planning and questioning. Finally, I mapped the themes on the research questions. These findings are presented in Chapter 4.

CHAPTER FOUR: RESULTS

The purpose of this study was to examine my role as a parent and educator while I was supporting my sons' abilities to read and write. The instructional framework that I used was an adaption of Erickson and Koppenhaver's (2020) *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write*, which addresses instruction of foundational literacy skills. I engaged in this research study to share my experience as a parent and educator with the personal goal to change the pervasive perception that people with ASD who use AAC cannot learn literacy skills and to advocate that literacy is a life skill.

As noted in Chapter 3, the qualitative research method used was an autoethnography. Chapter 3 provided a summary of the pilot study, research approach, current study, rationale, research design, data collection, participant, data analysis, and ethical considerations. Specifically, the data collected included lesson plans, lesson reflections, field notes, and artifacts including images, videos, and email/texts. All the data were coded for major ideas and then categorized into themes (Plano Clark & Creswell, 2014). This chapter will present the findings from the themes established in relation to answering the two research questions: (a) What are the experiences of a parent educator teaching literacy awareness and skills to her adolescent sons who both have ASD and use AAC devices? and (b) Does the experience shape her identity as a parent, educator, and researcher?

Findings

The findings will be presented sequentially in the order of the two research questions. This first section begins with the theme, "Experiences of a Parent Educator Teaching Literacy Awareness," where I describe my endeavours and reflections on teaching an adaptation of the *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and*

Write (Erickson & Koppenhaver, 2020) to both my sons with autism using their AAC. The second section, “Shaping My Identity,” describes how these experiences impacted my roles as parent, educator, and researcher.

Experiences of a Parent Educator Teaching Literacy Awareness

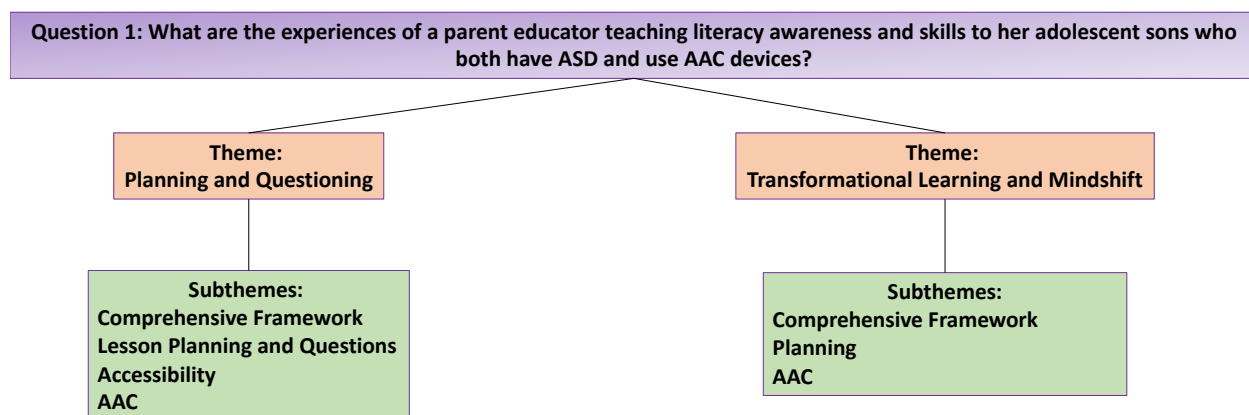
In response to the first research question, this first major section will describe my experiences as a parent educator who has been teaching literacy awareness and skills to her adolescent sons. Based on the data analyses, I distilled two themes to address the first research question and these include respective subthemes that summarize my experiences. The first theme describes my process of Planning and Questioning, and this is divided into four subthemes: Comprehensive Framework; Lesson Planning and Questions; Accessibility; and AAC. The second theme elucidates my Transformational Learning and Mindshift and was divided into three subthemes: Comprehensive Framework; Planning; and AAC.

Planning and Questioning

Figure 7 shows the themes and subthemes for Research Question 1 in graphic form.

Figure 7

Research Question 1: Themes and Subthemes



Throughout the study I completed weekly lesson plans that were general guides as to what I wanted to complete during my time with the boys. I then wrote more detailed field notes in my weekly journal entries that discussed the plans and also prompted self-questions about what worked using the resource while teaching my sons, what didn't work, what else I could try, what worked about certain activities and what didn't, et cetera. These self-questions prompted my Lesson Reflections and documentation of my experience during this autoethnography.

Comprehensive Framework

The basis of the *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* (Erickson & Koppenhaver, 2020) is the division between emergent and conventional learning interventions. Erickson and Koppenhaver (2020) recommend that four questions should be asked of the student with significant disabilities: "Does the learner identify most of the letters of the alphabet, most of the time? Are they interested and engaged during shared reading? Do they have a means of communication and interaction? Do they understand that print has meaning?" (p. 8). If there are any "no" answers for the questions, then the learner receives the emergent literacy instruction. If all "yes" then the learner receives the conventional learning instruction.

Based on where I perceived the boys' literacy skills were when I began instruction on June 1, 2021, I had anticipated that they were both in the emergent literacy category for different reasons. As we had always worked on academics and homework within our daily home schedule prior to this research study, I knew that Alvin did know his letters and letter sounds, he had trouble with rhyming and word families. He struggled with being engaged when reading as he was not interested or engaged with anything I was reading. He was just starting to understand that print had meaning. Charles did not know his letters or letter sounds, was just starting to

become engaged in books during shared reading but the engagement was not every time, and he did not understand that print had meaning as even he did not seem to understand any connections among written words and his interests.

Throughout the study I started to realize I could answer yes to all four questions for Alvin. I began to doubt myself, so I posted to the *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* (Erickson & Koppenhaver, 2020) Facebook book club and asked for the input of the members who are parents, teachers, speech language pathologists (SLP), et cetera. Although I thought he was ready to start with early conventional instruction, I wanted the added reassurance from what I regarded as a *real teacher* or SLP. The professionals reaffirmed my stance for Alvin to move to early conventional instruction. I was able to transfer this knowledge several months later when toward the end of the study, I could answer “yes” for all questions for Charles, and I was more confident and self-assured that he was in early conventional phase without asking the group’s opinion.

Initially, though, this meant I had to immerse myself in learning about both emergent strategies and early conventional strategies. The strategies included, shared writing, alphabet and phonological awareness, independent writing with access to the full alphabet, self-directed reading, reading comprehension, anchor-read-apply, word study, writing, and self-directed reading.

As I planned, I tried social media and common educator platforms like Pinterest, Teachers Pay Teachers, and Instagram to come up with fun and exciting ideas to engage the boys. One popular game we played for both alphabet and rhyming skills was memory. However, it became challenging with rhymes as usually, for previous memory games we matched picture to picture. In one of our games, the goal was to match pictures that rhyme. It was very

challenging to match two pictures that rhymed as Alvin did not understand that he wasn't supposed to match pictures but rather the words that they represented. When he couldn't understand the goal, he disengaged right away as demonstrated by him not paying attention and not looking only at the pictures. For example, he was flipping the same pictures over that were closest to him. You could tell he was going through the mechanics of turning over the pictures and waiting to be told if he was right or not and then be done with the task. When I reflect on this, I realize that this must be how many well intended lessons or fun games become aversive. He had asked to play memory, but soon was disinterested when he was not able to perform. This made me realize the importance of not only explaining the tasks but also being cognizant of understanding and enjoyment, versus just task compliance. The point became flipping the cards over for Alvin which was not important to me. The goal was to practice rhyming, but it wasn't obvious to him what the task was, so I needed to re-evaluate the intervention. This was an important realization for myself as an educator.

For Charles, I focused a great deal time to teaching his letters and letter sounds. By following the *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* (Erickson & Koppenhaver, 2020) recommendations, and Jones et al.'s (2013) six cycles, I believe that I found some effective ways to teach the alphabet. We created different alphabet books that focused on items that Charles likes (e.g., baking). I believed that this was personally relevant, motivating and created a purpose for him. For example, I realized that he could pick out letters in recipe texts easier than other general texts as he related to the importance of the recipe. His focus was continually being drawn to the recipe for an authentic reason: we needed to learn the next step, or next ingredient. This was a significant learning for me as an educator.

Employing different teaching approaches such as the alphabet cycles also helped me think of him writing to communicate in different ways. I remember that as a parent, I used to encourage printing and even went to different parent printing workshops and tried different programs. I was dissuaded not to continue teaching my sons to print by an occupational therapist and to only encourage keyboarding. So I started spending our evenings working on keyboard lessons. Frustratingly, years later, another occupational therapist chastised me for not continuing to work with my boys on their printing and limiting them to keyboarding. Within the *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* (Erickson & Koppenhaver, 2020), multiple mediums for writing and expression are encouraged. This allowed them to express their new ideas and they enjoyed communicating through different modalities. For example, we used keyboarding, stickers, stamping, painting, and label making for writing.

A great deal of my time was spent trying to think of and looking for ways to appreciate the purpose of print and get Alvin engaged in reading and writing. He was not interested in me reading to him, or him reading to me. Yet, I knew that engagement would not be impossible as years ago when we read at night, he really enjoyed Judy Blume books, especially her Fudge series (1972–2002); we read them all. I think it was because he liked hearing stories about an older brother's challenges with his younger brother who loved attention; he related on a personal level. However, that was the last time I can remember him liking and being interested in what I read aloud to him. I tried similar books, other Judy Blume books, other books that I heard kids his age were reading, yet nothing was of any interest.

Throughout the COVID-19 pandemic we worked on engagement with reading and writing through exposing him to unique genres and different types of activities; this was

challenging for me to plan for as an educator. A breakthrough in his realization of the importance of print happened when I encouraged Alvin to stop asking me if his aunt or uncle were coming to our cottage and for him to text them himself and ask them. I did not think they would come as they live two hours away, and we had no plans for them to meet us. When they agreed to come, I was pleasantly surprised, and the impact of that decision was monumental in terms of Alvin making a connection. Alvin began to recognize the purpose of text and the power of communication. This is expressed in my reflection:

This was HUGE; a meaningful connection making, purposeful text. ... I almost saw the lightbulb come on when I read that they were going to come. Alvin was all smiles and when they arrived, they reinforced that they came because he texted them and asked them. I could tell he really understood how important the texting is—not just for food at the grocery store but it worked for a visit that wasn’t planned and then they came because he texted!!!! (Reflection, Week 8, July 19–25)

I posted about this breakthrough on a Facebook page book club for the *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* (Erickson & Koppenhaver, 2020) the following week. It was nice to have the affirmations and support of the members of this group. Further, it was reassuring that an SLP agreed with me in that the importance of engagement in literacy means different things to different people. One SLP wrote, “You have found something engaging for him!! This is an awesome reminder to us all that engagement doesn’t have to mean books, magazines, or similar print materials. It means enjoying an interaction over text with someone else. So exciting!” (Reflection, Week 9, July 26–August 1).

The biggest instructional challenge that I had was facilitating the intervention of activities related to “Making Words” (Cunningham et al., 1994). This strategy generally teaches spelling

patterns and assists in spelling words by manipulating letters and seeing how removing a letter and adding another makes a different word. Making words activities can often coincide with using a space to post words (called a “Word Wall”). I had tried this strategy a couple of years ago without effect as it left the boys disinterested, confused, and irritated. I now recognize that I was trying to get them to do something that they weren’t ready for or interested in.

This time, I approached this instructional strategy differently. I wanted to start positively and to ensure that they were ready for this. I looked back to my reflections, and I made 15 entries about “Making Words” and “Word Wall Words.” Two examples are:

I am really struggling with the word wall. Should I be “making words.” I have tried several times in the past and it never worked. Alvin would just mechanically move the letters and it was a task, but the words were meaningless. Charles didn’t know his alphabet and didn’t really make the connection between letters and sounds and words. (Reflection, Week 25, November 15–21)

Changed the making words again. I am having such a hard time with this. I am going to go with the original Patricia Cunningham (2000) *Systematic Sequential Phonics They Use: For Beginning Readers of All Ages*. I like the idea of having different words and not just as, at, an etc. I think they will really get a better idea with ant/and/tan etc. It’s not good to keep changing and going back and forth but I want to make the right choice. I think this is a good choice moving forward. (Reflection, Week 29, December 13–19)

I kept oscillating between, where the words that I should use in the lessons would come from, whether they would be ready to learn them, should I work with them separately or would working together help each other out? I was constantly second-guessing myself as an educator and wondering if they were simply being task compliant or did they understand the point of the

intervention? I also questioned what commercially available books I should use for guidance or should I follow different SLPs who offered different examples of “Word Wall Words.” I struggled with these instructional decisions each week as an educator.

At the end of the 31 weeks, my sons were able to follow the purpose of making new words from existing bases (e.g., b + at and m + at) and they understood that moving the letters changed the word. After accomplishing this skill, the educator in me wondered if my constant oscillating on how to teach the strategy made a negative impact on them? I was beginning to realize that much of what works and doesn’t work is trial and error in education. But I was struggling with my role as a parent wanting to be a good teacher, I didn’t want my inexperience and lack of confidence to make things more challenging or frustrating for them. I often felt like I was fumbling around with this strategy.

The types of books that interested the boys was also something that I constantly analyzed and reflected on. At the beginning, Charles’s favourite books were about bums and farts and other gross stuff. Occasionally, I tried to introduce different books, but his favourite topics remained the predominate subjects of interest to Charles. Towards the end of our 31 weeks, he started to be less interested in these books. I introduced numerous other books, but it was hard to get the same engagement out of him that he once had. I recalled that in the past with his other hobbies and interests, he has made dramatic changes where he is focused on one for a period of time and then doesn’t return back to it. I thought that maybe this would apply to his interests in text topics.

Then I recalled that years ago, Charles briefly stopped baking because I turned his love for baking into a “learning opportunity” and this demotivated him to bake. Ignorantly, I would interrupt his baking and try to teach him a lesson instead of incorporating the literacy into the

baking. Because of this experience, I continue to worry that maybe he won't be interested in reading or maybe he will become disengaged with all books and become averse to reading again. Now, I reflect on these memories as an educator and not just his parent.

I try to reassure myself and reconcile that maybe he doesn't find farts as amusing, or maybe he was simply not in the mood for these books, or maybe he will reacquaint himself with them at a later date. As an educator, I don't need to worry that he lacks desire to do an activity just because he changes his interests in what he is reading. As I continue to focus on the activities that are well-received by Charles, I have noticed that he still loves it when I act out books and am very animated. Reflecting on this, I now think that it is the interaction with me that he is engaged with. The act of shared reading is the interaction that he enjoys, so I am happy that he does interact with me for almost every book we read. I am able to use think alouds in shared reading with the AAC device commenting and interacting on the shared stories. I now am focusing on this take away and I am trying not to worry that he will potentially stop reading again as he is immersed in a positive shared literacy experience.

Alvin's interest in reading started when we tried a suggested strategy, Anchor-Read-Apply (Erickson & Koppenhaver, 2020). I tried other types of reading comprehension strategies, but they didn't seem to solidify the meaning of the story for Alvin as much as the Anchor-Read-Apply intervention. As an educator, the learning curve for me was steep, and I needed to read, and watch videos on how to do this strategy correctly.

We had been working on guided reading. I find it hard to come up with the purposes and then the anchoring activities. I wish I knew more about this. I am going to look more into it. I wish I had more "reading" background knowledge. I am trying to learn as much as I can, but it is hard to remember everything. (Reflection, Week 17, September 20–26)

It took some time for me to prepare as well as plan for this intervention, however I believe that both Alvin and I learned a lot from using this strategy. I video recorded one of our sessions as the teachers at his school were interested in how I implemented Anchor-Read-Apply. I observed that Alvin demonstrated deep comprehension when stories were connected to his life in an explicit way. This allowed me to consider different types of books for him and was able to find a publisher that made age-appropriate books at his early reading level. I also suggested the name of this publisher to Alvin's teachers at school and other parents in my book club group as these texts were highly motivating for Alvin as an adolescent reader.

Lesson Planning and Questioning

I devoted a great deal of time to questioning what impact I was having and then subsequent planning for the boys' lessons. I had to decide when they could work together and when it was best to have them separated. As they were different learners and were working on different aspects of the framework, I found it hard to differentiate activities to match both of their needs. I almost always worked with them individually as I felt like I wasn't a good enough teacher to know how to work with them together. As an example, I had to work on different instructional approaches as one of my boys needed shared reading and the another was reading for guided reading. I recognized that I wasn't skilled enough to know how to meet both of their instructional needs at the same time. I also worried about not spending the same amount of instructional time with each child.

One child is shared reading the other child is guided. I am trying to be cognizant to divide my time equally but sometimes I feel like I am doing more with one son and then will have to make sure I spend equal time with the other. (Reflection, Week 26, November 22–28)

I came to recognize that these are the questions that many teachers contemplate on a regular basis and accordingly, this must impact their lesson planning. Moving forward as a parent educator, I would like to learn more about how to be able to provide different instructional approaches while differentiating in the same lesson.

The instructional time when we always were together as a group of three was while reading stories aloud before sleep. Even during this time there were issues as they were both interested in different types of stories and genres. I tried to find books that they both liked or would alternate choices between the two boys; however, at times if one wasn't interested in the book choice, he was disruptive. Reading aloud separately was not an option as they both require supervision. I wanted this read aloud time to be pleasurable, relaxing and time to wind down after the day, not an aversive task. So, I am constantly tweaking the book choices for our evening bedtime routine in anticipation of what I think they might both enjoy. The boys aren't phased when the choice is not their preference, however, it leaves me feeling a little deflated as I want to keep their interest in reading high.

Another consideration that I began to question was the logistics and timing of the educational activities during our evenings. We started to engage in activities and book projects. We loved these projects, however, sometimes the activities would take a while to do so I could only work with one son for the evening, so the other son didn't get instructional time that day. In my reflections, I wrote, "It is important to always keep that in mind and not get bogged down with the task of teaching and you don't see the forest through the trees so to speak" (Reflection, Week 7, July 12–18). I had to also remind myself of a quote that was in the text:

...regardless of which activities you choose, the goal is to help students begin to attend to and think about the print in their environment as a means of helping them apply the

alphabet knowledge they are gaining through your explicit efforts to teach them.

(Erickson & Koppenhaver, 2020, p. 47)

Other times, family logistics such as sickness or disruptive behaviours would pre-empt what I had planned to do. At times, this made me anxious as I felt like I was letting everyone down when my instructional planning time was not being accomplished. I began to realize that this is what flexible educators have to do: let things go and focus on the things that can be controlled and not on the things that cannot. I tried to include literacy in everyday events so on the days that we couldn't do any formal instructional activities the boys still received some authentic literacy exposure. I found this to be an affirming practice as both boys seemed to see literacy learning as siloed. I believed that it was beneficial for them to recognize that literacy happens all day long, every day, and not just during school and homework time. These are the lessons that I now recognize need to be explicitly emphasized with my boys on a daily basis.

Accessibility

One major change that took place within home learning environment was how accessible we made books. Prior to this study, there were plenty of books in our house and I also have a “homework” room where all their books, supplies, and games are housed. However, I took a critical look at how accessible and inviting this space was for my boys and realized that the books piled together in stacks were inaccessible and probably not appealing to them. Throughout the study I kept re-evaluating, re-arranging, and re-organizing to make books more accessible. I divided up all the books by genre and topic in different bins with descriptive labels. I was hopeful that this would encourage the boys to self-determine what they might choose to browse and read.

After speaking with my advisor and telling her that they still were not motivated to read them, she suggested putting representative images of the genres as well as the key topic words on

the bins. I couldn't believe I didn't think of this accommodation. How could a person who doesn't know how to read, know what each bin included if they couldn't read the label? After some thought, I made the images with their buttons from their AAC devices so they could see what was in each bin and they could talk about it or request to read about a topic as well. Figure 8 presents a picture of the book bins with image labels.

Figure 8

Bins in Categories With AAC Button Labels



Another way that I made reading more inviting was I left books all over the house, such as on windowsills, counters, magazine racks, book racks, and tables. This made access to texts convenient especially when reading was relevant to their everyday activities. For example, Charles' favourite activity is baking so I left cookbooks around the house and made his favourite ones more accessible on the counters so he could flip through them and choose recipes that he wanted to make.

AAC

As previously mentioned, there has been an evolution in AAC that learners and their families have experienced related to the service model and in the way AAC has been utilized and taught. When we as a family were first introduced to AAC, it was prior to the era of iPads, so the AAC device was clunky and needed to be connected through a hardwire connection to download any pictures, and there were limited buttons. As AAC devices evolved, so too did AAC instruction. At first, the boys were only taught nouns for requests that they had which was extremely limiting when they had anything to say other than what they wanted or needed.

Another shortcoming of the AAC software was that every concept was in a folder of categories. There was a school folder and within this category were words related to school. For instance, years ago Charles had a folder on snowy owls from a school project. On his AAC device, within the school folder he had pages to assist him to answer questions posed in worksheets, however there were no words to talk about snowy owls in real life or to engage in authentic conversations about them. Once I remember Charles having a meltdown at home as he wanted a toy that had to do with the snowy owl, yet he couldn't find the word on his iPad as it was archived in his school folder. I couldn't figure out what he wanted, and he was beside himself with frustration. From an educational perspective, I now reflect on this event and

attribute it to the fact that at school he was only given words to insert into his fill-in-the-blank worksheets and they were buried in his AAC school folder. Consequently, he was left with no access to meaningful day-to-day communication tools. He lacked a command over his own communication, and I felt helpless. Luckily the AAC technology has evolved, and the buttons are not set up in vague categories anymore but in a system that is flexible and more aligned with typical vocabulary needs. Even though the AAC vocabulary bank is more robust and organized, I still reflect on the prospect of how if Charles could have spelled the first few letters of a word that he is looking for, I would have been able to help him find the words with him. He wouldn't have been limited to such a basic vocabulary system.

It is well established (Beukelman & Mirenda, 2013; Goossens et al., 1992; Ronski & Sevcik, 1996) that AAC modeling techniques are the best way to support language expression as this helps students understand the purpose of language and also teaches them where on their device the words are located. Words should be laid out with a dynamic screen and with robust, useful vocabulary representation. Also, as previously noted, core words (e.g., go, not, I, in, off) making up 80% of everyday words should be included (Witkowski & Baker, 2012). It is important to consider that there are many reasons to communicate that have nothing to do with requests for instance commenting, rejecting, and questioning. I believe that word buttons should reflect these options. I was able to use think alouds many times with the AAC as I was able to describe what I was thinking while I was modeling and using their devices. For example, if we were baking and I needed to whisk or mix or pour, I was able to think out loud that the buttons on his device would be located in the folders **“FOOD-BAKING-ACTIONS.”** They would see me pushing the buttons and verbally saying the words as well as hearing my thought process.

I now contend that it is very important for me and all educators to know students' AAC devices well. The AAC device is not only to aid in facilitating general communication, but it also becomes the means to talk about interests, books, how stories relate to life, and to ask questions, et cetera. This requires dedicated time to plan and program core words. I found that I needed to plan prior to each activity so that I knew where the words were on the AAC device related to the things that I wanted to talk about in a lesson. I noted that I had sometimes only seconds before my sons' attention would be gone if I was fumbling with their AAC to find the buttons. I pondered how teachers using AAC devices in schools have the time to do this type of planning?

Another AAC planning consideration was to actively use descriptive teaching techniques (Van Tatenhove, 2009) that use core words to describe difficult vocabulary and complex concepts. For instance, I see a need for this when working on comprehension question prompts that require responses such as "true/false," I used **"YES/NO."** Using these more familiar core words focuses on the objective of the intervention which is to determine a student's comprehension and not their understanding of words such as "false." Another example of descriptive teaching is when discussing a book on precipitation and evaporation we could discuss and demonstrate comprehension with core words for instance **"WATER," "GO," "DOWN," "SUN," "WATER," "GO," "UP."** He is then able to discuss these broad concepts with words that he is using every day when for example, he might see precipitation outside.

It is critical that to learn a language, one must be immersed in an environment where the language is being meaningfully used (Tedick & Lyster, 2020). I recognize this both as a parent and educator, yet I find there are times when I am not always modeling techniques of language learning. I can think of many missed opportunities where I should have been modeling and encouraging use of the AAC device, but I was preoccupied by my dual roles as parent and

educator. At times, I realize that I am focusing on one element (e.g., behaviours) to the exclusion of others (e.g., language expression), “I find that whatever I am focusing on it is at the detriment of something else. For instance, when I focus on AAC and core words I often overlook some of the literacy and vice versa” (Reflection, Week 17, September 20–26). Consequently, I spent a great deal of time trying to figure out new ways to include AAC and literacy in our everyday lives. I didn’t always succeed, but I kept reflecting on this tension and trying to engender meaningful expressive communication whenever I can.

The second major theme, Transformational Learning and Mindshift, will next be examined in relation to my first research question relating to the experiences of a parent educator teaching literacy awareness and skills to her adolescent sons who both have autism and use AAC devices.

Transformational Learning and Mindshift

Throughout this autoethnographic study, I have experienced some changes with respect to my perspective on teaching my sons. For this second theme, there are three subsections related to how my mind shifted and how I experienced learning related to: Comprehensive Framework, Planning, and AAC.

Comprehensive Framework

Given the fact that numerous literacy programs, suggestions, recommendations, and interventions had been ineffectual at supporting my sons to read or write, I was becoming less than hopeful that any approach would contribute to a significant change. I now believe that I had to open my mind and embrace an alternative conception of what it meant to be literate. This was truly a transformational mindshift for me. Surreptitiously, this was when the instructional approaches in the *Comprehensive Literacy for All: Teaching Students With Significant*

Disabilities to Read and Write (Erickson & Koppenhaver, 2020) began to resonate with me: there is not just one element of literacy, it is everywhere and almost in everything we do and this purpose is what needs to be taught and learned.

The other major shift in my conception of literacy that transformed my learning was that literacy instruction and learning needs to be person-centred. If an educator can't reach the learner based on their individual interests, there is no engagement, and any resultant learning may be passive and disconnected to the learner. The biggest shift in teaching both my sons was that I now tried to make each lesson relevant, meaningful, and fun. If it wasn't fun, I would try to make it purposeful. Once they were willing to see what I had planned, they were then engaged and I could see progress in both my planning, teaching, and interrelatedly, an improvement in their skills.

As I have noted, Charles is passionate about baking. To help him learn the alphabet and letter sounds we created his own alphabet book of desserts he made. Each letter was discussed, written, typed on his iPad keyboard, and identified within a recipe. The pages of the book matched these letters and the representative recipe. His book was printed, and he enjoys looking through it often. For years we have tried to teach letters and sounds to Charles. Charles has tried to memorize them however, much like memorizing symbols and sounds from another language; this was not relevant to him and not retained. By relating the alphabet to his passion of baking and demonstrating the purpose of letters in words in a recipe, he was not attempting to memorize, but learning the letters and sounds that were meaningfully connected to the texts (i.e., recipes) what he wanted to engage with. This reflection describes his reaction:

Charles is loving looking through cookbooks and we keep working on his baking through the alphabet. He loves it so much. We worked on j is for jelly roll with his virtual Mentor

from Community Living Ontario. Although he does like some shared reading his preference seems to be in seeing the purpose in recipes. (Reflection, Week 30, December 20–26)

Another aspect of the *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* (Erickson & Koppenhaver, 2020) that was transformational in my understanding of literacy education is the importance of encouraging independent writing. Much of the writing that my sons have done has been copying pre-made sentences and my constant editing of their work. The *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* (Erickson & Koppenhaver, 2020) encourages literacy development through knowing what a learner wants to talk about through their AAC and allowing them the freedom to write (type) it. Such emergent writing often looks like gibberish, much like a pre-school child scribbling. As I began to encourage the boys to write what they wanted, when I looked closely, I could see the formation of words with other letters surrounding some letter sound correspondence. This was revolutionary for me. I still get goosebumps when I look at their writing samples from the beginning of the study as compared to their written expression towards the end of the study. The teachers at their school have also been encouraging them to independently write. I sent an email to the teachers and EAs at their school on November 2, 2021 (see Figure 9) showing them the changes that I had seen in the boys' writing. They thanked me for showing them this growth.

I contend that the growth in their writing skills is evident. I credit this to the premise of allowing them to develop their writing skills similar to how a typically developing emergent learner would write (Erickson & Koppenhaver, 2020). This has transformed my learning and teaching of writing.

Planning

A huge revelation that has come out of my reflections as parent educator is my absolute love of lesson planning. The whole process speaks to my task orientated, love-to “check things off-my- list” personality. I enjoyed thinking about possible lesson topics, researching different ideas, and trying to think of fun, engaging activities we could do. Interestingly, I would sometimes get lost in the fun activities when they were so engaging for the boys and I would lose sight that another purpose of the activity or intervention was supposed to be reading and writing. This was truly an “ah-ha” moment for me as a parent educator: When teaching and learning are fun, it is fun for educators and learners.

Figure 9

Email Regarding Independent Writing

From: H K <hkavsak@gmail.com>
Subject: XXX independent writing
Date: November 2, 2021 at 9:15:57 PM EDT
To: [Teachers and EAs]

Hi Everyone,

I have added so many of you on this email as I HAVE TO BRAG about how well XXX is doing in his independent writing. I have tried to describe how he has been doing this so everyone who isn't working with XXXX knows how incredible his growth in this area has been.

Check out these 2 recent emails to me. The red is me writing what he was trying to write himself.

Bihg rtdygg

Cdirfd [edited for pseudonym]

(Bike riding XXX)

Makihg la dakes

Chofles [edited for pseudonym]

(Making pancakes XXX)

XXX and XXX take pictures throughout the day and then Charles picks his favourite. He discusses with XXX about the picture on his AAC and then independently writes (**no help sounding out the words**) an email to me. XXX does comment afterward on the letters. For instance "I see you have an "m".... you are right there is an m in swim". She then sends what he actually wrote to me separately. We don't want this to be about correcting him and telling him what he did wrong. We focus on what he got correct. Alternatively, I have also written him back so he can see how I write it (model the correct way) for example..."I like to swim too" and reading to him how I spelled it.

These ones are amazing!!!! I didn't need her to send me what he was writing. I could actually READ it myself. Look how much of the words he spelled. He is doing so well.

Compare below for the first one we started in the summer with XXX, XXX, XXX and I



Ertyip
 (Bronte Creek)

I wrote under the picture for XXX to see
 "I loved it when we went with a XXX and XXX to Bronte Creek Provincial Park"
 (Artifact, Week 23, November 2, 2021)

One of the main reasons why planning was challenging is that it is essential when you plan to maintain engagement, as if the boys don't like what they are doing, then behaviours come out. In November 2021, I virtually attended a #TalkingAAC workshop, hosted by #Talking AAC in Michigan. This conference focuses on topics related to AAC. Attendees are a group of professionals who work with and for people with complex communication needs. The workshop that I attended was divided into four learning streams, and I attended the literacy stream. This talk was on shared reading building literacy and language. I wrote the following reflection about the speaker (Poss, 2021):

She reaffirmed and expressed my feelings when she said that it IS hard if you are given no feedback or negative feedback when doing shared reading. It is hard to continue to offer reading and keep trying—it made me feel better as I would often give up for a bit when the boys were younger and either seemed indifferent or worse became aversive or behavioural when I read. (Reflection, Week 24, November 8–14)

Other attendees at this conference discussed their difficulties when working with someone who doesn't want to learn what you have planned as an educator. Hearing their stories made me feel supported as this feeling has been ongoing since my boys were young. I had been given many behaviour therapy and literacy approaches that they didn't respond to, and I felt like a constant failure. I used to believe that if I was a real therapist or teacher, I could facilitate interventions better and it was because of my lack of training that my boys weren't interested. I reflected on this:

Organizing and building lesson prep is where I am happiest. I have noticed that I really liked the lesson and material prep but then the execution and follow through is where I lack. When I try to figure out why that is I think it's because I like the creative and

making aspect but also because I don't have any pushback. Before I do anything it is still a good idea. However, often when I try to do stuff with the boys it turns out to be met with challenging behaviour, or compliance but no understanding or worse no enjoyment. I feel like I fail them when I try something and it doesn't work. They don't "get it" or don't like doing it then I give up. I always feel worse when I give up. I feel like I failed them. (Reflection, Week 4, June 21–27)

Through reflecting on my work over the past years, I have been able to see that the reason why so many things didn't work wasn't related to me, or the planning, or the execution, or the boys; it was likely that the activity was not a good fit, or the boys were not feeling well or simply they wanted to be jumping on the trampoline at that time. I now recognize their need to be self-determined as learners. I had to appreciate that I wasn't the cause of them not understanding, or not completing a task. I now keep reminding myself that mastery is not the goal. It is learning, enjoyment, interaction, communication, and having fun!

AAC

As previously mentioned, we have been on a learning journey with respect to using AAC devices. However, through reflection on these years of experience, I have shifted my perspective on AAC. During this ethnographic study, I listened to a *Talking With Tech* podcast (Bugaji & Madel, 2021) and the host made a comment that resonated deeply with me:

I listened to a *Talking with Tech* podcast with Chris Bugaj which made me realize. ...

The importance of parents being part of the team and also knowing how to do everything as they are the one constant in the student's life. Since their diagnoses, there have been huge service delivery model changes within both the government speech as well as in the Autism program. The major change in the preschool speech and language program. This

was only met with several changes in the delivery model changes for the SLP services within the school. My boys have had countless different SLPs and Communication Disorder Assistants (CDA) in the school. The requirements for service have changed several times, as well as the type of service has changed. It is also incredibly difficult to find SLPs with AAC expertise and I have not had any SLPs who specialize in AAC within the school. I have also been told by an SLP they weren't comfortable with the devices and requested repeatedly that I go back to PECS even after several other private SLPs had been consulted and recommended the Speech Generating Device. (Reflection, Week 16, September 13–19)

This really affected me as I am often the one advocating for AAC use however, there are not a lot of professional, private practice SLPs who can support this. I have found in my experience that educators in schools are not experts on AAC. I am grateful that the iPad can be leveraged as a communication device as it also has a keyboard when the AAC application is open. Without constantly using the AAC for communication, I have found that my boys are consistently left out of conversations and denied opportunities to share their thoughts and are not engaged in learning. The AAC is their only consistent communication tool and it needs to be used to guide all interactions in the school for not only communication but literacy as well.

Finally, although I do always see room for improvement for me to teach literacy and use AAC, I am emboldened to continue to learn how to most effectively use ACC as I have seen the boys' growth when using their AAC. I know much of the pressure I feel regarding AAC use is self-imposed so when I am able to see progression in their AAC use, it helps reduce the tension I feel. It inspires me to keep trying and encouraging both the boys and others to use their AAC.

I have described my experiences teaching literacy using the *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* (Erickson &

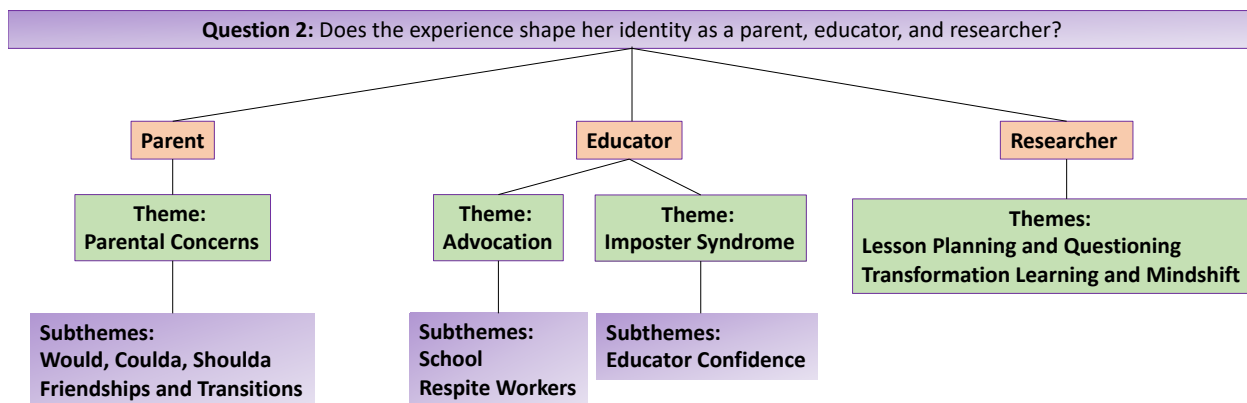
Koppenhaver, 2020) with both of my sons who have autism and use AAC. I will now subsequently examine the second research question that explores whether the experience shapes my identity as a parent, educator, and researcher. Next, I present the thematic response to this research question.

Shaping My Identity

When analyzing the data, I was able to categorize concepts that were grouped into themes aligning within three identities (Parent, Educator, Researcher). The first identity, Parent, has the theme of Parental Concerns which includes the subthemes Woulda, Coulda, Shoulda; and Friendships and Transitions. My second identity, Educator, has a theme that describes Advocacy, and subthemes for both School and Respite Workers, and a theme that describes my Imposter Syndrome with the subtheme, Educator Confidence. The final identity analyzed was Researcher and this identity included the themes of Lesson Planning and Questioning as well as Transformational Learning and Mindshift. Figure 10 shows the themes and subthemes for Research Question 2 in graphic form.

Figure 10

Research Question 2: Themes and Subthemes



Parent

Being a parent of children with complex disabilities I have been stretched in many different directions that go beyond being “just a mom.” Depending on the situation, I have been called on to be a therapist, a teacher, an advocate, an interpreter, a defender, and a friend. Nevertheless, when I reflected on the collected data, it was unsurprising to see the theme of parental concern weaved throughout my reflections.

Parental Concerns

Parenting topics were often at the forefront of my reflections. Expectedly, I wrote about my pride for the boys when they tried hard, as well as me wanting to make sure I was doing everything I could to support them to learn. These are typical parental concerns and parents are always wondering and guessing what would happen if, or what could go wrong, or should I do this? These apprehensions are described in the first sub-theme.

Woulda, Coulda, Shoulda. Like many parents, I have never turned down an opportunity to brag about my children; I can’t help it. The pride I have when I tell stories of them is palpable. For instance, we went treetop trekking for Alvin’s most recent birthday and had an amazing time. I used it as an educational opportunity, and we made a graphic organizer using think alouds and words from the AAC. We then wrote a predictable chart and ultimately wrote a book about this experience (see Figure 11).

I sent the book to families and friends. I was so proud of their literacy experience and importantly they were proud of themselves: “They sent their Tree Top Trekking book to the school. They were proud to show it off to their teachers, EAs and their classmates” (Reflections, Week 20, October 11–17).

Even though I have much pride and joy, I also have pangs of guilt and concern as I often feel like I should be doing more to support my boys. During the week of Alvin's birthday, I was walking our dog in the evening, and it suddenly hit me: I was struck with this feeling that it is only me that is going to ensure my boys get the opportunity to do reading and writing everyday like everyone else does. When the boys are not doing academic work at school, or I have not provided an opportunity for them read or write, they do not have independent access to literacy experiences. This was expressed in my reflection below:

I can't get out of my mind that they only have access to letters, reading and writing or any type of literacy is what they get from me. Only me. When I try to be mindful of all the reading that I do during a day (texting, emailing, googling, searching, reading directions on my phone etc.). I was listening to a podcast while walking my dog and it suddenly hit me. I literally stopped walking. I felt sad as I don't want their life to be so dependent and limited but also it made me feel a weight. It all comes down to me. I am the one who is going to advocate for them to be taught literacy in the schools, but I am also the one who has to do it or it won't get done. (Reflection, Week 9, July 26–August 1)

Prior to this study, I was not always ensuring that they were immersed in literacy daily. Literacy was very important; however, it was not made explicitly apparent in all aspects of our day. I began to recognize that I had to make literacy comprehensive and a part of their lives. I realized that if I don't suggest writing a text message, leave different types of books out, point out road signs, read recipes, do projects, or read before bed, there is a good chance that my sons will not be exposed to authentic literacy. I was very aware of this revelation, and I felt ... sad, and weighted. I was taking literacy for granted as I personally did not remember ever not

knowing how to read or write. Literacy is an advantage my sons don't have, and I realized that it was up to me to try to change that.

This goal for me to teach my boys the basics of reading and writing drives me to keep motivated and ruminating about how to keep moving forward. I reflect on what I perceive are missed opportunities. One example of a missed opportunity is when Charles wanted to make peanut butter and butterscotch marshmallow squares. He typically buys these pre-made at a local farmers' market. We were talking about them last Easter when we made peanut butter butterscotch bird nests with Easter mini eggs. However, there was no recipe in a cookbook or picture for him to show me. He started to get upset because he could not communicate his message. After many minutes of frustration, he brilliantly scoured my phone for a picture of the nests we made last Easter. I asked if he wanted to make those, and he said, "**NO**" and kept pointing at the nest. I asked him if it was the butterscotch flavour that he wanted to communicate about and he said, "**YES**". I then Googled a picture of the butterscotch marshmallow squares and asked if this was what he wanted. Relief came over him and I apologized for me taking so long to figure out what he wanted to communicate. We planned to go to the grocery store and buy the ingredients. Although I was happy that I figured it out, I was also sad. I wondered how many hundreds of meltdowns he has had related to me not understanding him and him not being able to make his thoughts known. I continue to reflect on this example and the multimodal literacy learning opportunities. After I finally figured out the word he wanted, it became a huge, missed opportunity for literacy. I realized that I didn't use it as an opportunity to show him how to Google search, I didn't show him how to search his iPad for an image of butterscotch chips, I did not use think alouds to help him use the search feature on his AAC device, I didn't show him how to attempt to spell and spell check the word butterscotch. At the very least I could have

reinforced that the word, “butterscotch” starts with “b.” But, I did focus on how communication was instrumental in enacting what he wanted to do: go to the store and make the squares. I now see that it is important to use literacy to help him prepare for the next time he is thinking of something he wants to communicate, and I don’t immediately understand.

I am learning how to continue to reflect on ways to improve our literacy learning experiences without the negative cycle of my worry, stress, and rumination. I am learning that when I plan for lessons and projects, they sometimes get derailed as life happens, so changes are needed and that is okay. I try to naturally include literacy in everything we do as a family as literacy is found everywhere and not just in scheduled and planned lessons.

Friendships and Transitions. Although the boys have developed meaningful relationships between each other and with most of their teachers and EAs throughout the years, they don’t have any authentic peer friendships, where a common interest is shared, equal contributions are made, and time is spent together. I have tried many strategies to help them develop friendships. They have attended countless hours of Applied Behaviour Analysis programming, as well as social skills classes and facilitated events. I have advocated for “interaction with peers” to be on their IEPs. They were in (prior to COVID) many Special Olympics sports, as well as other sports and activities. Throughout their years I have organized numerous playdates (when they were children), facilitated socialization at parties and tried peer adolescent “hanging outs.” Although they do not mind being around others, they do not seem motivated to develop relationships and they seem to prefer interactions with adults. This is a constant worry as both boys are getting older and will be out of school soon. Not only will the relationships they have developed with the staff at the school end, a pool of peers and potential friends will not be present. I wrote about this concern:

For Alvin's birthday I asked who he wanted to celebrate it with, and he said his teacher. Although it is very sweet it just emphasized to me that he has no friends. He adores his teacher, but he is done school at 21 and then who will he have outside of family? I am starting to really focus on what is going to happen after school for Alvin. (Reflection, Week 18, September 27–October 3)

One reason that likely contributes to their lack of friends is their immense struggle with communication. Adults, as compared to peers, tend to be more forgiving with inappropriate behaviours, they wait longer for them to use their AAC, and will attempt to decipher what it is they are saying. I am reminded of their interactions in a teen social group that the boys attended. As usual, they were the only ones who used AAC devices. I had reviewed the devices with the facilitator and volunteers. I was permitted to stay, so I did to observe. Both boys were ecstatic to be part of this group and they knew all the other peer participants. However, I quickly noticed that they weren't being spoken to. They were within the group, but not included in the group. I then assisted them with their AAC so they could contribute to conversation. I brought up a discussion topic related to a song by the band, "One Direction" knowing that everyone was familiar with that song and my boys liked it. A very lively conversation ensued, but again they were left behind and excluded because of the time needed to communicate through their AAC. Then the group facilitator put the song on, and they all danced. My boys were grinning from ear to ear. I reflect on this event and note that if I was not there assisting with that interaction, it would not have taken place. The band "One Direction" is not on the device as the song came up organically in conversation. Neither of my boys can spell "One Direction" so they wouldn't have been able to start the conversation. This is an ongoing challenge as school staff as well as respite workers I privately pay are continually trying to improve their own AAC skills however, these

adults are not fluent. I feel such angst about the loneliness of my boys when school is over for them when they are 21.

Alvin's recent birthday ignited worries and concerns in me again, not only related to his lack of friendships, but also related to his pending transition into life after school. "Again, I am reminded that I (and my husband) are the only consistent aspect of his life. If not for me, who would he have to push literacy, job development, social skills, academics etc." (Reflection, Week 18, September 27–October 3). I am worried about society's general lack of knowledge of people who are nonverbal and the perceived low expectations of them. I will try to help educate and advocate for AAC use as well as literacy support in day programs, future volunteer positions, and potential employment. My determination is fueled by my belief that they can learn literacy skills as well as continue to develop AAC conversation skills.

Educator

One pursuit I feel passionate about is advocating for both of my children both as a parent and educator. I feel confident in my lived expertise as a parent and feel I am empowered to ask for what's best for them. Although I have always advocated for them to receive literacy education, as a Master of Education student with a focus on literacy education, I am able to consider their specific aspects of literacy learning and am more knowledgeable of what to advocate for. This is where my identities begin to coalesce. As a function of engaging in this autoethnography and analyzing the collected data that relates to my burgeoning identity of educator, I have uncovered the themes of both Advocacy and Imposter Syndrome. The Advocacy theme is divided into the subthemes School and Respite Workers. The theme of Imposter Syndrome is divided into the subtheme of Educator Confidence.

Advocacy

When analyzing the categories of the data, I recognized that in my role as an educator for

my children, that I had to act as an advocate too. This theme of advocacy is divided into subsections of School and Respite Workers.

School. We have been blessed with an amazing team of teachers, EAs, and administrative staff at my sons' school. They are receptive and instill open dialogue between home and school. I have always felt that a collaborative relationship between home and school leads to the best outcomes for my children. When I began to code and analyze the data collected, I encountered many examples of me sharing with teachers what I was doing at home in terms of literacy showing what they are capable of doing in terms of literacy that aligned with their interests. In terms of engagement, I showed them how I introduce new subjects or build on old subjects. I also ask them what they are doing so we can collaborate and work together. I sent pictures and videos of examples that the boys were doing to school. This was very impactful not only because the teachers and EAs knew what we were working on at home, but because they could praise the boys for their work. In particular, this also allowed both boys to present their home-based projects to their classes. This also gave a sense of pride to the boys as they were able to share their work with their peers. This is advocacy as it is constantly reinforcing that literacy is everywhere and that if my sons are not engaged in their academic work at school, it showcases that they are capable of learning in other environments.

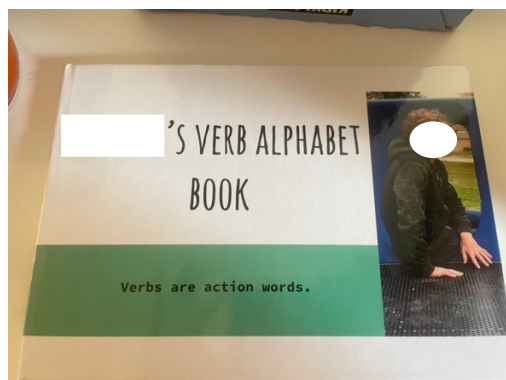
One such presentation was on worms that Alvin completed. In the first semester of the 2021 school year, he enjoyed his horticulture course. His teacher was passionate about environmentalism and gardening. I attribute his new love of worms to the teacher's enthusiasm. He brought his project into his class and presented it. His teacher was very supportive and tasked him the job to help feed and give water to the large school composter. He loved this job and the responsibility as he saw relevance and had genuine interest in it. For Christmas we bought him his own worm composter. I recognized that as a parent educator that this kind of a bridge

between home and school is essential.

The school was also very receptive to engaging the boys in independent writing. Both teachers met with me and agreed to follow the same *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* (Erickson & Koppenhaver, 2020) suggestions on emergent independent writing that I worked on at home. I was appreciative of the continued collaboration with them. One of the projects Charles worked on both at school and home that started after the pandemic, was the age-appropriate alphabet verb book (see Figure 12). This idea emerged out of a need to find respectful, relevant, levelled texts for adolescents to read. The school was also supportive during the process of authoring the book. I sent the book to a professional printer and book binder and gave copies to the teacher and the EAs who assisted Charles with the making of the book. They were so thankful and loved the gesture. This is advocacy as I heard a few times that the home projects gave the teachers ideas to use as they work with other students who have similar learning profiles.

Figure 12

Verb Alphabet Book in Hard Copy



The teacher has also been following the same recommendations from Jones et al. (2013) that I have been doing at home, regarding an alphabet enhanced letter routine that I suggested. This resource was recommended in the *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* (Erickson & Koppenhaver, 2020). The teachers and EAs at Charles's school have noticed great improvement with Charles's alphabet and letter sound knowledge. I attribute this to the consistency in instruction between home and school.

There have been other examples of how I have advocated for my boys' programming through collaboration with the school. I have requested that the school encourage "signing up" for different activities and privileges. For example, when signing up for certain gym equipment in the weight room it is important to authentically do so after practice writing their names. I have provided the school with authentic literacy-based resources such as our grocery lists and flyers, a label maker, and books and magazines the boys were interested in to read during breaks. In an attempt to make AAC use relevant, I have sent in words to focus on for modeling AAC words along with their daily conversational AAC modeling. I have also shared instructional resources and videos on shared and guided reading and word family activities. I have recognized that there is a balance between advocating and making unreasonable requests of the school and teachers. I believe that I am intentional and invitational when I send information and comments to the school.

I am appreciative of the collaboration that we have with the school and attempt to express this gratitude by thanking them for being supportive of the boys. For AAC Awareness Month, I had 13 mugs created for the teachers and EAs who are involved with both boys. I sent an email from my husband and myself thanking them for their support and also offered some AAC awareness resources. I feel indebted to them all as "not all schools are so eager and embrace AAC. We do feel lucky that not only are they open to the idea but also they want to learn as much as they can" (Reflection, Week 20, October 11–17).

As I have mentioned previously, I put a great amount of pressure on myself to advocate for literacy exposure for both Alvin and Charles every day. Some of that stress is alleviated by the coherence in providing literacy supports at home and in the school that are consistent with comprehensive literacy approaches. I wrote, “the one thing that makes me feel a little relief is that there are literacy aspects added into their school day so that means that they are getting literacy every day” (Reflection, Week 22, October 25–31). I know that we are working together to provide literacy endeavours and that between both home and school, they are getting the most access that they can to literacy every day.

Respite Workers. In the Summer of 2021, as I was working with the boys, it was important to me that the respite workers that they worked with also encouraged literacy skill development. I found several excellent learning modules on modeling and shared reading, and I sent the links to the workers and paid them for their time to review them. This was well received by them, and they asked if I could continue to pass on any other modules I thought would be useful to them.

Throughout the Summer we were able to discuss different literacy-embedded ideas and I was able to give reminders to the workers to try and make everyday activities into literacy pursuits. One amazing opportunity arose when the respite worker pushed Alvin in the pool (which Alvin loved). He thought this was very funny and I suggested he could text about the incident and asked if he wanted to text to his respite worker’s wife and “tell on him” for pushing him. Giggling Alvin said, “Yes.” Figure 13 presents a screenshot of this text message.

Figure 13

Text Regarding Being Pushed in the Pool



“When his wife wrote back and said he was mean and then the worker said Alvin ratted him out Alvin was laughing and smiling. It was VERY funny.” (Reflection, Week 12, August 16-22)

This is an example of a purposeful and amusing interaction that became authentically literacy embedded.

Imposter Syndrome

Although I am proud of the advocacy that I have done with the school in terms of sharing resources and the successes and challenges of Alvin’s and Charles’s literacy skill development, I have imposter syndrome when it comes to making recommendations about literacy instruction to other educators. Imposter syndrome is the term that “refers to the notion that some individuals feel as if they ended up in esteemed roles and positions not because of their competencies, but because of some oversight or stroke of luck. Such individuals therefore feel like frauds or ‘impostors’” (Feenstra et al., 2020, para. 1). Although intellectually I understand that I have and deserve to have a voice, I often feel like because I am not a teacher, I will be questioned. I feel as though my thoughts and ideas might not have as much impact or weight as they would if I were a teacher. Sometimes it feels like I am pushing to have a voice at the table, if I did not persist, I would not be asked.

This worry about being an imposter is not all in my head. I have noticed that with the backdrop of me working on my MEd, I have been taken more seriously by educators than I have in the past. Even though some of my previously made ideas have been taken up by educators in the past, I have also been made to feel like these ideas were not valid. Many times, I felt that my comments, concerns, and recommendations were passed off as coming from “just the parent” and sometimes I felt patronized. For instance, many years ago, I made suggestions regarding a speech goal for Alvin related to vocabulary development, and it was not considered.

Interestingly, the SLP made the same suggestion soon after and it was then implemented in the school.

Another example of my suggestions not being acknowledged was years ago when I was excited that the teacher had implemented a non-verbal way for the students to let the teacher know they were going to go to the washroom. If students had to use the washroom facilities, then the students could put a small pylon cone on their desk and leave. The teacher would know where the students were and there weren't so many interruptions of students asking for washroom permission during class time. I was eager for my son to try it as it was something he would be able to do and not draw attention to himself or be stigmatized and centred out. Unfortunately, when I mentioned how pleased I was that this prompt would be in place, the teacher informed me that the school district told her that my son needed to be evaluated by a SLP to see if he would be able to use this method. I was shocked. When I inquired, they said that they needed a professional opinion to determine if he would be able to determine when and how to put the cone on his desk. They also questioned his abilities to know what to do when he was in a different room (i.e., the library) other than the classroom. I was exasperated. I ensured them that he was capable of knowing what to do when he had to go to the washroom as he has been doing that for years. They would not take my perspective and insisted on an assessment for my son prior to using this prompting method with him. I escalated the expression of my concern, and, in the end, they rescinded the entire method for the whole class. I felt deflated. This example illustrates that not only was my opinion and point of view not valued, it was not even believed. No other student had to prove that they understood the pylon concept. Yet even though I assured the district that he would understand, he could follow the instructions, they did not believe me and instead of trialing him and giving us both the benefit of the doubt, they decided to terminate the entire idea for the class. I felt very diminished in those meetings.

However, now I feel as if my pursuit of an MEd degree and interest in literacy have aided my perceived validity during discussions with educators. An example of this is when I recently discussed with the school librarian about purchasing more age-appropriate and age-respectful books for the students who are at an emergent literacy level. The school librarian agreed to meet with me. I was anxious at first as the school librarian didn't know anything about me and I was worried he might think I was a parent meddling. I lacked confidence as I was not a teacher, and I had no idea how books were purchased for the library and the decision-making behind the purchases. I offered to apply for grants for them as well. I also didn't want to sound like I was dictating to the school librarian what to do or criticizing him and his role.

The school librarian was very receptive to all of my suggestions. He took notes on all of my publisher suggestions as well as genre recommendations. He offered to review what books he had in the library already and displayed them in a more accessible manner. He also agreed to order some new books that reflected our discussions.

That week I was told when my sons' class went to the library, they noticed some changes. Charles was happy to look at the books that were organized by genre and he was able to self-select an interesting *National Geographic* book. He regarded his trip to the library as his favourite part of the day when he wrote to me that day. I wrote in my reflections.

I am SO SO SO SO excited. I heard from Charles's teacher that they made some "changes" at the library and they told me that Charles picked his trip to the library as his favorite part of the day. I can't express how empowering it is to have someone listen to your suggestions and then actually act on them. Then to see Charles actually like going to the library is HUGE. Historically, I love a bookstore and a library and the boys do not. In fact they are usually aversive and Alvin has become behavioural. However, with the

changes of organizing their books differently it made a difference to Charles. Also, hopefully other students enjoyed the changes as well. (Reflection, Week 23, November 1–7)

I hope that an impact of my discussion with the school librarian is that there are some sustained changes to the display and accessibility of some genres that will benefit other students who are emergent readers as well. I believe that as I pursue my MEd degree that I am acquiring not only knowledge but also, I am gaining a perceived respect when discussing literacy support with other education professionals.

Educator Confidence. When coding, categorizing and representing these data, a finding that came to resonate with me was my realization of how much more confident I have become as a function of developing teaching skills and experience with literacy interventions. Initially, I found that I fumbled and muddled through facilitating some of the emergent literacy interventions. As I tried new approaches, my confidence in my abilities grew and I saw improvement in my instructional performance. As I relaxed, I was able to have fun and make the learning interactions more enjoyable. I shifted my beliefs about perfection, and I increased my dedication to engagement and personalization during instruction.

As the boys made gains with their literacy skills and moved into the early the phase of conventional literacy learners, I again faced a lack of confidence in how to facilitate the conventional interventions. However, this was short lived as I quickly gained the confidence I needed once I had more practice and opportunities to keep growing as an educator.

One of the activities that I was able to see my marked growth in was in my ability to facilitate a strategy called Anchor-Read-Apply. As I previously described, this was one of Alvin's favourite interventions and I think that I enjoyed using this strategy as I witnessed his

enjoyment and I saw a great deal of learning transpire. I wrote, “I am really liking Anchor-Read-Apply and I think I am getting a bit better at it” (Reflection, Week 29, December 13–19). This also reveals how connected I am to how the boys respond to their own learning. When they are enjoying and engaged with what I am doing, my confidence increases. I then started to think that this is probably how educators similarly feel affirmed in their role.

I have also been emboldened by the instructional approaches that I have tried and I have posted about some of the projects that I have been doing with the boys on social media. Prior to this study when I posted about some of the activities, I worried about how these posts might be perceived. I post hoping to give ideas to other parents and perhaps teachers on different ideas for emergent and conventional literacy. Based my experience in this ethnographic study, I am more assured in the efficacy of the content of what I post, and I am happy to give others additional suggestions.

Researcher

I love learning. I am delighted when I am learning new concepts, new practices, and having thought-provoking conversations. I am also enjoying the process of researching. Although due to the COVID-10 pandemic, I had to pursue a few variations of my proposed research due to the Research Ethics Board (REB) process, I have learned a great deal from responding to the REB’s questions and clarifying the application. I experienced a sense of tangible accomplishment when I was able to submit a completed REB application and get approval. I also enjoyed discussing and reviewing possible research methodologies with my thesis advisor. Although my thesis study design changed a few times, I believe that my research study has worked out for the better. As is often the case, the best laid plans become futile, and the reality is better than expected. These experiences have all contributed to my researcher

identity. This section is divided into the themes of Lesson Planning and Questioning, and Transformational Learning and Mindshift.

Lesson Planning and Questioning

When re-examining my reflections, it became apparent how much I enjoy and how comfortable I am doing lesson planning and resource preparation. When a lesson is received well, and the boys seem to have enjoyed it, I also take away great satisfaction. Indeed, I find it challenging to continue with a lesson if the boys don't seem to be motivated to learn.

I am a gold star type of person, meaning I like outward external validation, if the lesson doesn't go well or I think I am not doing a good job my instinct is to stop and learn more, prepare more, read more, buy more educational supplies as that's what I am good at, comfortable doing. When the boys aren't enjoying themselves, when the lesson don't go smoothly, I fumble. As soon as I started this comprehension, I kept going back to learn more about this level. (Reflection, week 11, August 9–15)

To prepare for this research study, I completed many professional development activities. Aside from reading the resource book about the framework (Erickson & Koppenhaver, 2020), I attended conferences, workshops, and webinars. One of the positive outcomes of the COVID-19 pandemic is that I was able to attend many conferences as they were all virtual. I also took online courses, joined book clubs, listened to podcasts, corresponded with Dr. Koppenhaver, had discussions with my thesis advisor, and read numerous other resources.

This constant desire to continue to read, learn and research more about literacy instruction still elicits some nervous apprehensions within me. When I reflected on my notes, I realized it stems again from thinking that there is so much I don't know about. What if I was a “real teacher”; would I already know this? I have bought several books and I have read them and

tried to memorize all the concepts. Of course, what has ultimately ended up happening is that I have forgot much of it. This dovetails with my imposter syndrome as it relates to my identity as a researcher. I have the constant desire to ensure I am knowledgeable and current with not only the topic of literacy but also AAC as well. I never feel like I know enough.

No matter how I learn about reading and how you teach reading and writing I always feel like I am not knowing enough. There is still more to learn. I feel like if I just read more or taken a reading course or if I had taken a teaching degree it would be so much easier, and I would have so much more information to benefit my boys. I do know that my experience and knowledge so far can help them. I just think I wish I had of taken teaching as I feel like I and therefore my boys are at a disadvantage as I am toiling my way through all the information for them. (Reflection, Week 25, November 15–21)

At this point in time, I have resigned myself to continue to learn, but not in a panicked, voracious way. I enjoy reading about literacy and of course, I want to stay current. I am not perfect as a parent or educator or researcher and trying to be is unrealistic. I am learning to try my best and that is going to be good enough!

I have also realized that just because the boys do not always enjoy, understand, or engage with an activity doesn't mean that it is because of my instruction necessarily. I am their parent first and foremost and also as their educator I am trying to present material in an engaging way but many other factors could be contributing why they are not ready to learn such as timing, logistics, not understanding the instruction, illness, worries, et cetera. Now, as a function of engaging in this ethnographic study as a researcher, I have seen the value in gathering data on one's practice. In particular, I find reflection is so important for me as I can examine what was

happening before, during and after our instructional time and this helps me to look at the big picture.

Transformational Learning and Mindshift

One of the most surprising discoveries when analyzing my identity were the convictions that I have when I have discussions with others about the *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* (Erickson & Koppenhaver, 2020) and the impacts that I have documented as a function of my study. This has buoyed me when I have been apprehensive to engage in both informal and scholarly discussions. For example, I have a tremendous fear of public speaking. I find I often get transfixed in my fear that I start thinking about it while I am speaking and then I lose my train of thought. This causes even further embarrassment and stumbling and stammering of my words. I have always felt this fear of public speaking so at the beginning of my graduate degree, I made the determination that I was going to embrace a growth mindset (Dweck, 2016) and attempt to embrace more opportunities for presenting and speaking, especially related to the resource that I was gaining confidence using.

My thesis advisor helped me commit to submit a proposal to Ontario Council for Exceptional Children Conference 2019 and encouraged me to go through with the poster presentation. She was very supportive, believing in my ability and reassured me that I had something worth saying. As a parent presenting to educators, academics, and other professionals, I questioned this. Prior to the poster presentation, I could barely sleep the night before and I had dry mouth and clammy hands. On presentation day, I could hear my heartbeat right before the first person came to speak with me.

After the first poster presentation, I was hooked. Once the initial nerves went away, I found I was astonishingly enjoying myself. I have presented a few other times and each time I

am trying to change my mindset to the enjoyment of sharing information and gaining more knowledge from others as well. After another poster presentation I wrote:

I spoke to a teacher who teaches elementary, and I told her all about the book. If the students were taught how to read in elementary then more doors would be open to them in high school. I am wanting more and more people to hear about my research which is a huge shift to me. I think back to Dr. Koppenhaver writing in an email correspondence that he thinks that my autoethnography might contribute to the field and I am SO energized to do more. (Reflection, Week 27, November 29–December 5)

Of course, I still get nervous and must build myself up each time I put myself out in a public venue. I still have imposter syndrome but thinking about how literacy experiences have improved for my sons, has given me confidence. I think that perhaps if I share my research with others, then it might assist or encourage someone else to try the *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* (Erickson & Koppenhaver, 2020) framework with their child, student, or client.

The most significant contribution to my positive mindset that I have received was through email correspondence with one of the *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* (Erickson & Koppenhaver, 2020) authors. Dr. Koppenhaver said that “an autoethnography of your experiences will make a wonderful contribution to the field”; my perspective is a contribution to the field! (Reflections, Week 24, November 8–14). I was thrilled and encouraged by his words; this will resonate in my mind whenever I think about sharing my research. I am growing in my confidence, in my knowledge, in my experience, and my identities. I am starting to feel like perhaps I can contribute to the field and my identity can include a researcher identity as well.

Summary of Chapter Four

Responding to two research questions was the focus of this chapter. The first research question asked: What are the experiences of a parent educator who has been teaching literacy awareness and skills to her adolescent sons who both have autism and use AAC devices? To answer this, two themes were presented. The first theme is Planning and Questioning and is divided into four subsections: Comprehensive Framework; Lesson Planning and Questions; Accessibility; and AAC. The second theme is Transformational Learning and Mindshift and is divided into three subsections: Comprehensive Framework; Planning; and AAC.

The second research question examined how this experience has shaped my identity as a parent, educator, and researcher. Data analysis contributed to themes that have described my three identities. The first identity was Parent and the theme identified was Parental Concerns with the subsections of Woulda, Coulda, Shoulda; and Friendships and Transitions. The second identity is Educator. The theme identified was Advocation with subthemes for both School and Respite Workers. The second theme was Imposter Syndrome with the subthemes Educator Confidence. The final identity analyzed was Researcher. This identity considered the themes of Lesson Planning and Questioning as well as Transformational Learning and Mindshift. The next chapter will discuss these findings and their implications.

CHAPTER FIVE: DISCUSSION AND IMPLICATIONS

Chapter 5 will provide a summary of the thesis, with a discussion of the findings, and will offer theory, education as well as research implications. This study allowed me to reflect on myself as a parent, educator, and researcher. The autoethnography was an exceptional research method to use for this topic and for this researcher as I offer a unique perspective of a literacy passionate parent with two adolescent sons with autism, who also use AAC to communicate. I was able to give a detailed account of my experiences teaching literacy to my sons. I described my process of planning and questioning focusing on the *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* (Erickson & Koppenhaver, 2020), lesson planning and questions, accessibility, and AAC. I also examined my transformational learning and mindshift and focused on the resource, planning, and AAC. I was also able to see how this experience shaped my identity as a parent, educator, and researcher. I will now discuss these issues by re-examining the literature.

Experiences of Parents as Educators

Through reviewing the literature of parents of special needs students and their experiences as educators, two studies were of special significance to my current work: Greenway and Eaton-Thomas (2020) and Kidd and Kaczmarek (2010). Pertinently, in both studies, it was interesting to read that these parents had similar experiences to me as was educating both my sons, however, naturally, some of the circumstances were different.

Greenway and Eaton-Thomas (2020) examined parent experiences of homeschooling their child with special needs during the COVID-19 pandemic. And although some of their negative experiences were due to being thrust in a situation with no preparation and warning due to the lockdown, other revelations were about adjusting to working with their children at home. I

experienced similar feelings to those of the parent participants in their study with respect to educating your children at home. For instance, balancing an already busy home schedule and commitments, as well as dealing with your child's emotions and behaviour difficulties was what I had experienced and what was experienced by the majority of the parents in the study as they all had children with ASD. Similar to what was reported by the parents in Greenway and Eaton-Thomas's (2020) study, I also had to learn to be more flexible in my planning. For example, when lesson plans didn't work out as expected or someone wasn't feeling well, I needed to pivot and change the plans.

Another similarity I had with the majority of the parents in Greenway and Eaton-Thomas's (2020) study was that they involved their children in deciding the focus of lessons. I too involved my sons in determining lesson topics as I found it was a major motivator for them. Whenever I planned around their interests, I had much more buy-in from them rather than when it was an arbitrary activity or one with low interest.

The parents commonly noted "feelings of inadequacy, lack of knowledge, and concern about letting their children down" (Greenway & Eaton-Thomas, 2020, p. 529). This was a feeling I also experienced during my time educating my sons. I often would wonder if I knew more or if I was a "real" teacher I would be excelling in this role and thereby positioning my sons for more literacy success. I was able to work through some of these negative thoughts by journaling my reflections and analyzing my entries. Self-reflection was important for maintaining perspective during this time.

Finally, a small number of parents reported positive aspects of working on educational activities with their children noting some academic improvements as well as a "joy in homeschooling and spending more time with their children" (Greenway & Eaton-Thomas, 2020,

p. 530). This positive feeling and connection was one that I also felt during literacy engagement with my sons.

In an older study that focused specifically on a mother's experiences educating her child with ASD at home (Kidd & Kaczmarek, 2010), I also resonated with some common experiences. Importantly, this study also reported on similar experiences related to mothers of children with ASD worrying about their children's long-term educational learning outcomes. The mothers in the study also commented on the complexity of managing the education of their children while also performing the day-to-day operations of the house (Kidd & Kaczmarek, 2010). As mentioned previously in this thesis, I found this multi-tasking challenging especially as it pertains to literacy education. One way I managed this was to include literacy as much as I could throughout our daily activities. This not only served the purpose of additional educational opportunities but also aided in emphasizing purpose and meaning of reading and writing in authentic and purposeful ways.

Examining Identity

Through reviewing the literature, I was able to examine other parents who focused on their parent identity, parent educator identity, and parent researcher identity. These studies will be reviewed below.

Parent Identity

There is a common expression in the autism community, that is often cited, from a professor who has autism himself, Dr. Stephen Shore, who coined the phrase for when people are talking about people with autism, which is "when you've met one person with autism, you've met one person with autism" (Montgomery & McCrimmon, 2017, p. 187). This emphasizes that people with autism are not a homogenous group and reinforces that heterogeneity prevails as

individuals with autism are all unique. The same can be written about the parents of individuals with autism. Although the love and general well-being for their children are the same as it is for all parents, however, parents of children with disabilities, need to embrace their children's differences and deem what is important to focus on. Singh (2019) comments on his identity as a father of a child with a disability, noting that "preconceived ideas regarding disability will directly impact the manner in which a parent takes on the challenges and opportunities associated with children with disabilities" (p. 840). Further, he had similar experiences to me where professionals undermined him and attempted to dissuade him into courses of action for his child. Similar to me, he was able to educate himself and had the resources to advocate for his beliefs and for his child. Through reflection, I understood the importance of obtaining resources and often had the same questions as Singh, where he wondered about the parents who did not have the resources, education, and advocating skills to be able to question the professionals (Singh, 2019). Although there are the day-to-day challenges of being a parent of a child with a disability, there are the added responsibilities that these parents need to have beyond just parenting skills; they need to be able to embody a "complex set of skills necessary for parents to understand and operate within the context of multiple systems. ... [This] paradigmatic framework by which parents make decisions for their children, and for themselves, is in and of itself a form of identity (Singh, 2019, p. 841).

When searching the literature for the experiences of parents of AAC users, there is background on what parents tend to prioritize. For instance, communication activities are prioritized over other areas to be focused on such as level of skills with the AAC device (Marshall & Goldbart, 2008). Further, it is compulsory and vital to the child's use and success using AAC that the parent not only accepts that the child needs to use their AAC but also that

they embrace it and value it (Park, 2020). Educating parents on and using AAC consistently is imperative and crucial to the AAC success of the user (Park, 2020).

As a parent identity and as an AAC user advocate, I focused on learning as much as I could about AAC, about the devices my sons used and I wanted to be an expert for them on how to use the device. However, I often grappled with how to balance time for AAC use and literacy activities and consequently, I tried to incorporate AAC into our daily activities as much as possible. I felt guilt when I spent more time with one child versus another child or on a particular activity at the expense of not working on other activities. Parents of AAC users in the literature noted similarly that they “experience the insufficiency of time which makes it difficult to achieve all that they would like to and they may feel frustrated and guilty about their children’s difficulties and what they are able to offer them. They sometimes see themselves to blame if they cannot understand their child” (Marshall & Goldbart, 2008, p. 95).

This was evident when examining my reflections. I once commented on feeling “lucky” when I was able to decipher what my son was trying to say when he could not find the words on his AAC device nor did he know his letters or sounds so he wasn’t able to type it. It was bittersweet as I knew there were countless other times where I was unable to figure out what he was trying to communicate. Not being able to understand your child effects the most basic aspects of your identity as a parent.

Another aspect that I have had to come to come to terms with for my sons was the willingness to advocate and educate others about encouraging the use of AAC with my sons; this does not come easily to me. Over the years, a common recurrent problem is that sometimes their AAC devices are left in their backpacks or on our kitchen table for the whole day, and as such rendering them with minimal ability to communicate throughout the day. Like some other

parents, there have been struggles with the level of knowledge and assertiveness necessary to be able to access what their child needs in terms of AAC use (Marshall & Goldbart, 2008).

Parent as Educator

When reviewing the existing literature, it was challenging to find perspectives on parents as educators; however, there was one article written by a teacher who changed her way of teaching when she had her own child with a disability (Messer, 2010). Specifically, having a child with special needs changed her as an educator as she gleaned lessons from her child to use in her classroom. This resonated with me as I also learned similar lessons on being an educator because of my two sons. I thought it was particularly fascinating that she learned to not underestimate any students and to keep high expectations for them all (Messer, 2010). I know firsthand how setting the right expectations is crucial for my sons as when setting the bar too low, they will sink to these low expectations.

Another lesson learned was to acknowledge and praise all learning accomplishments as some tasks might be considerably challenging (Messer, 2010). I too have found that by acknowledging the challenges that come with learning literacy as well as the ineffectual ways they have been taught in the past have led to some of my negative feelings. I try to praise my sons as I know that learning to read and write is extremely difficult so sometimes an educator must be a cheerleader as well.

Analyzing the home learning context and looking at potential concerns that might be impeding a good learning environment was another lesson learned from her child with a disability (Messer, 2010). Similar to my experience, Messer (2010) found that by looking at the world from the perspective of the student with disabilities adds to their learning. With this perspective, making the content to be learned accessible and focusing on their interests, will yield more natural teaching moments, which is key to teaching (Messer, 2010).

Another finding in the literature that mirrored my experiences was involving advocacy for education in literacy. I have had to advocate for both of my sons countless times and I know I will continue to advocate for them for the rest of my life. Similarly, the literature reveals that parents of children with ASD need to advocate continually for services and access to programs in the community, in healthcare settings, and for education (Smith-Young et al., 2022). I have been continuously reminded of how I must advocate for literacy education for my sons to the various professionals they have encountered. Sadly, I was told by a few professionals not to try to teach them to read and write. I learned that in order for my sons to receive education in literacy I needed to educate myself and then educate others on their potential. Another reason to advocate, which is similar to what I have done, is to advocate to “share their experiences and educate others as a means of promoting advocacy for parents of children and youth diagnosed with ASD to provide better outcomes for children in their life-long journey with ASD” (Smith-Young et al., 2022, p. 9).

Furthermore, the literature has resonated with me as I think about my reflections related to my lack of confidence. Goldman et al. (2020) note how intimidating it is for parents to advocate for education within the school system as the “higher status given to school personnel’s (supposedly objective) professional knowledge as compared to parents’ (supposedly subjective) personal knowledge about their child. ... These factors work together to present barriers to parents and other caregivers advocating on behalf of their own children” (p. 158). I often felt imposter syndrome discussing literacy interventions with my sons’ teachers. However, the school and program that they currently attending is very welcoming and accepting to parent communication.

It is therefore imperative for parents and schools to foster a relationship of open communication and collaboration so parents can feel more self-assured in advocating for the

education of their children. Beyond this thesis research, I am continually trying to push boundaries in advocating for literacy as a life skill.

Parent as Researcher

I am just beginning to identify as a researcher. When reading my reflections, I realized it has taken me some time to see my capabilities in areas other than being a parent. I reviewed the literature regarding other parent-researchers, and I found that Kabuto and Martens (2016) compiled a book that encompassed parent-researchers and their studies examining teaching literacy. They found that like me, the parent-researchers of literacy wanted to advocate for their children regarding literacy as well as to educate their child's teachers on their child's abilities, interests, and what the parents were seeing at home (Kabuto & Martens, 2016). Further, although the book was not a book of autoethnographies, it was a book regarding parent-researchers and therefore like me, the researchers expanded "on the spirit of ethnographic traditions that place culture and observation at the center of their work... [and] provided insights into the life experiences of their child-participants and the complexity to which daily activities are constructed through a cultural framework" (Kabuto & Martens, 2016, p. 2).

One of the fascinating comments made by Kabuto and Martens (2016) was that in their compilations of parent-researcher cases they realized, as I did, when researching in your own home context, things aren't always going to go as planned. That there is a messiness to life and that the parent-researcher needs to acknowledge that learning in a natural environment within the family will be different than how they are learning within the school environment (Kabuto & Martens, 2016).

In another study that looked at parents as researchers, Hackett (2017) noted that parents found that a large commitment was necessary to observe and record the research data. However, the parents also noted that although it was challenging, it was also beneficial as it allowed "new

ways of knowing and talking about their children's experiences. ... All parents were surprised when looking back over their data by how much was there, and how much their children seemed to have done and learned" (Hackett, 2017, pp. 492–493).

And finally, one of my most salient observations is that the basis of my research is the need to be "reflexive means asking difficult questions of oneself as we make our subjectivities, belief systems, and motivations visible not only to ourselves but also to others" (Kabuto & Martens, 2016, p. 12). This was challenging at times as I knew others would be reading this research and thus felt vulnerable sharing past details of our lives, my thought processes, my worries, and my beliefs. It was necessary and I learned a great deal about my experiences and my identity; however, there was an element of trepidation when I first started to make my reflections and then subsequently analyze them.

Implications for Theory

There are theoretical implications of my research. My study's framework is positioned in Vygotsky's (1978) sociocultural theory of development. My teaching strategy mirrored Vygotsky's *zone of proximal development* where I met my sons where they were in terms of understanding of a particular problem and then *scaffolded* them (Brunner, 1978). I was able to explicitly note how I problem-solved to help them and I documented how as a parent educator, I came to appropriately address their learning needs. It is through the use of *think alouds* where I would say out loud my thought process, that they could start developing their own understanding and their own thought process (Davey, 1983). This was evident when I worked on predictable chart writing as each of the steps were clearly articulated while I was writing and I was thinking aloud as I did all the prescribed steps. My sons were able to see what, why, and how I wrote the sentences and they were able to try this for themselves. Thus, when examining my findings I am able to see how Vygotsky's theory influenced my lesson planning, and reflections.

Another key aspect of Vygotsky's (1978) theory that directly impacted my research was his theory of the development of the *inner voice*. By talking through the instructional steps out loud what would normally be thought in my head, I was able to help the boys hear my inner speech. I tried to help develop their inner speech by encouraging them to *say it in your head*, *read in your head*, and *think in your head*. This was evident when I used Jones et al.'s (2013) guide to explicitly teach alphabet letters and letter sounds. As noted above (see Appendix A) one of steps in the guide is for the teacher to show a letter and focusing on the capital and lowercase letter formation as well as the sound it represents. Erickson and Koppenhaver (2020) emphasize adapting this guide for students who are not able to verbally say the letter name and sounds to *say it in your head* as the teacher is saying it out loud.

Prior to employing the strategies in the *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* (Erickson & Koppenhaver, 2020), I had always tried to have Alvin say it out loud as he is able to minimally verbalize. However, I did not find he was able to produce the letter sounds spontaneously, he was only able to copy my sounds. I felt that he was just mimicking me and not connecting the sound to the letter. I always believed he was actually thinking about how to physically make the sound and not that it had anything to do with the actual letter symbol. I believe that my sons should be able to recognize the letter name and letter sounds and not worry about how to physically make the sound. I believe that they should focus on learning words not speech to utilize their AAC device. I want their *inner speech* to be the focus. As Charles is not able to make any letter sounds, this guide was extremely helpful.

This is a great lesson for other educators when teaching letter names and sounds. When teachers identify the letter and letter sound out loud, students are able to hear and identify them in their heads. They can continue to develop this skill as they learn about each letter name and

sound. Further, when there is an instructional goal to read silently, it makes sense to remind students to *say it in your head* and to focus on the development of their *inner speech* (Erickson, 2003). For instance, I was able to continue to teach *say it in your head* through the gradual release of responsibility (Erickson & Koppenhaver, 2020; Farrall, 2021). This approach is also great application of teaching to Vygotsky's (1978) zone of proximal development. Jane Farrall (2021), an SLP and expert in AAC and literacy, outlines how to do this. Using some of these guidelines, I read a passage out loud and then read it again to Alvin asking him to read along in his head and finally he read the passage by himself in his head. I was able to build on what he knew by scaffolding what I knew, and this was a bridge to his zone of proximal development. As reflected in my journal, I was able to see how this strategy was beneficial during AAC and how much more Alvin was able to understand. It accentuated to me the importance of explicitly teaching Vygotsky's (1978) *inner speech*.

As noted above, Vygotsky's (1978) theory supports the interpretation of my findings in how I planned, in my reflections as a parent educator and in my observations. I contend that Vygotsky's (1978) sociocultural theory of development should be used as a cornerstone when other educators (including parents) are planning and working with individuals with similar learning profiles as my sons. This theory was instrumental in working with my sons as it guided me in my practice.

Implications for Practice

A possible implication for practice is that Erickson and Koppenhaver's (2020) *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* might be adapted within the school setting. I have received positive feedback from the boys' teachers who not only witnessed the boys' learning gains but also saw the transfer of skills into the projects that they brought it for discussions and presentations. As a reference, it might be

helpful for the resource *Comprehension for All Framework: Teaching Students With Significant Disabilities to Read and Write* (Erickson & Koppenhaver, 2020) to be available for special education teachers and EAs to access and draw on. There is additional information, videos, and resources on the interventions that are also helpful in the implementation process. This might also be beneficial not only for the educational staff and students but also for other parents who might be interested in literacy resources to use at home with their child. I recall that I would often go to teachers looking for ideas and suggestions so by having these resources, they can help other parents who are similarly interested.

Many years ago, when Alvin was in early elementary school, I attended a literacy conference that included both the Catholic and public-school boards in the region. It was mostly teachers that attended; however, parents were invited to attend as well. Although there has not been a similar event recently, a similar conference might be timely in light of the recent response to the Ontario Human Rights Commission's (2022a) *Right to Read* report. Specifically, according to the CBC news, the Ministry of Education stated that Ontario "will provide a \$25-million investment in evidence-based reading intervention programs" (Casey, 2022, para. 5). As they are now aware that reading is a human right, school boards will need to offer some type of intervention for all students and parent education is an important supplement. In particular, I am hopeful that school boards will offer more guidance and education to teachers and parents to teach students with ASD and use AAC to read and write.

I am part of the *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* (Erickson & Koppenhaver, 2020) Facebook book club. I would strongly recommend other parents to join this or any book club or groups. The group consists of parents and professionals with the common goal of improving literacy for their children, students, and clients. I hope to lead a book study within the school on the *Comprehensive*

Literacy for All: Teaching Students With Significant Disabilities to Read and Write (Erickson & Koppenhaver, 2020). It would be amazing if both teachers and parents could be part of a local book club to share ideas, concerns, suggestions, and support.

Another possible implication could be the development of an AAC book club for users that would also include parents. There are many types of book clubs offered to the general public; however, a book club that could encourage emergent and early transitional readers using their AAC would be novel. This could be beneficial for teachers, students, and parents. In terms of literacy skills, a focus on a book for shared reading or a book and discussion on a particular strategy such as Anchor-Read-Apply could be endeavoured. The book club could end on an activity that was related to the story. For example, if it was a story about making pizza then perhaps the group could make pizza to relate the story to themselves. This could potentially be beneficial for the AAC user in terms of social and language development as the students would be around other students who are using AAC in a social setting. Further, parents would also learn the intervention as well as contribute to their child's literacy skills development. The parents could also network and share ideas with other parents.

Finally, I was able to learn a great deal about myself as a parent and educator by examining my reflections. It is a great idea to encourage other parents to reflect on themselves, and their teaching practices while working with their children. Parents might need some background on how to reflect as it is a process that does not come naturally to all.

Implications for Research

Many of the implications for practice could also have an element of research as well. Perhaps with a book study, research could be done on the experiences of parents and differences in the students from before the book study and after. A study could be done based on the parent perspective and if there were any changes they witnessed comparing prior to and post-book

study. The parents could look at changes in the literacy skills of their children. Another research approach might be parents researching their own autoethnographies and examining themselves in terms of parent, educator, and researcher. Based on my experience, I learned much by examining my reflections about teaching literacy skills.

Another research implication would be a study that would focus on research highlighting the students' perspective. Students would be asked to contribute their thoughts on reading and writing and different interventions. It would be so valuable to gain the firsthand perspectives of students to help inform better teaching practices.

Another implication for research is that this study was an autoethnographic study limiting the participants to just the researcher. Future research could look at the implementation of the *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* (Erickson & Koppenhaver, 2020) within schools. Research could be done pre- and post-implementation of the intervention to examine if there were any differences from the baseline before the intervention, versus after the intervention. The teachers could engage in their own self-studies or action research projects and be introspective of their teaching practices, how their lives have been shaped by what they believe and how they identify themselves as a teacher and researcher. As there is not a great deal of research regarding teaching adolescent students with significant disabilities literacy, research focused on this age group is imperative.

Additionally, it was extremely difficult to find literature on perspectives related to being a parent of a child with special needs, as an educator or researcher. Although I wasn't surprised, I find it disconcerting that there is this void as the voices and perspectives of parents are essential. As I highlighted in my reflections, parents are the one constant throughout their child's life. They coordinate all the systems and services for their child in healthcare, in education, and other community services. They have a wealth of knowledge and are the expert about their child. It is

very important to hear the voice of parents as a partner within the educational system and within the community agencies that the child will attend. Accordingly, it is essential to have more research with the parent at the forefront. Research on the parent perspective is not only necessary to inform practice it is also essential for parents to know they are not alone. Being a parent of a child with a disability can be isolating. Researching parent perspectives also allows other parents to see they are not alone and that their struggles are felt by others.

When I first started my MEd and began reviewing the literature on literacy, ASD and AAC users, I was surprised that the literature reflected what I was seeing as a system-wide barriers for children with disabilities as it relates to literacy. Although this current research focused on adolescents, I think it would be worth examining the implementation of the *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* (Erickson & Koppenhaver, 2020) with adults with significant disabilities. The framework could be adapted to support literacy learning in settings where adults meet socially or for those who live at home with their caregivers. Furthermore, the perspectives of the support workers or caregivers could also be researched. They could engage in an autoethnography on their perspective teaching literacy to adults and how they see themselves as an educator and researcher.

Limitations

There are distinct limitations to this study. The first is related to the research method of as an autoethnography. There are drawbacks to this method as “due to a lack of distance that results from the subject and the researcher being the same person, because it can be challenging to translate personal experience into sociocultural and political action” (Lapadat, 2017, p. 589). Further, autoethnographies can have a limited scope due to the unique position of the person who is writing the autoethnography (Lapadat, 2017). This study was based on my interpretations of

experiences and my reflections. My findings might not be generalizable to other parents, educators, or researchers.

Another limitation, which was mentioned in Chapter 1, is that I declared my confirmation bias towards the resource *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* (Erickson & Koppenhaver, 2020) as well as my belief that all students regardless of disability can learn literacy skills. Therefore, with this belief in mind I had strong feelings prior to the study that my sons will eventually learn literacy skills and that it was just a matter of finding the best way to teach them. As I had tried several other programs and resources, I was galvanized when I saw promising results when I worked with my sons during the COVID-19 lockdown using the *Comprehensive Literacy for All: Teaching Students With Significant Disabilities to Read and Write* (Erickson & Koppenhaver, 2020). This I am certain influenced me during the study and is my self-declared bias.

Other limitations to autoethnography are outlined by Chang (2008) who focuses on five potential hazards: “excessive focus on self in isolation from others; overemphasis on narration rather than analysis and cultural interpretation; exclusive reliance on personal memory ... [for] data source; negligence of ethical standards regarding others in self-narratives; and inappropriate application of the label ‘autoethnography’” (p. 54). I tried extremely hard to keep these autoethnography obstacles at the forefront of my mind to help mitigate falling into some of the hazards when undertaking this study and thesis.

Furthermore, it is also important to note that I understand that my life experiences and values are embedded and manifested in how and what I view as important to teach my sons. Kabuto and Martens (2016) concur based on their work related to parent researchers and add that the “parent–researchers learned to navigate the ethical maze that constantly changed and developed as they participated in their research with their children” (p. 12). As I worked with my

own children, there is always the element of being subjective when describing them and what they have accomplished. I did my best to be honest and sincere when reflecting on my sons' learning. As typical of most parents, you never want to leave anyone with a negative impression of your children, so it seems natural to highlight positive accomplishments and smooth over the challenges. In this study I tried to be authentic in regard to my reality teaching both boys literacy.

As noted, bias is a limitation of autoethnography. Poerwandari (2021) notes that as the researcher and the participant are one and the same, the bias is that being the researcher you might want to present what you write in a way, intentionally or not, that can sway the reader by giving an impression or lead the reader to a conclusion the researcher wants them to have. Further, "the story might cover up things that are not intended to be shared with the public, even though the disclosure is important to provide a fuller understanding" (Poerwandari, 2021, p. 313). I tried to be as authentic and honest in my writing and research. Nonetheless, I also knew I was going to be judged based on what I worked on, thought about, reflected on, and how I parented. As previously mentioned, parents choose different areas that are important to them to focus on. I know that there are some that might have not focused on what I did or teach things differently. Further, I know other academics might read my work and question why I was not teaching the concepts the way they would have taught them. Consequently, I can state unequivocally, that I tried to quiet the 'what will others think' narrative in my head. Although I did at times feel vulnerable and exposed being so honest, it is based on my belief that I deemed it worth putting my authentic self forward.

Future Directions

Upon completing this thesis, I plan to continuously work with my sons regarding literacy. I will continue to advocate for both of them as they complete their high school career and transition into adulthood. As I am starting to learn about the adult services available in our

community, it has become very clear that many of the agencies have never worked with people who use AAC. I plan on using what I learned from this autoethnography to educate and advocate for AAC use and literacy skills within the adult programs that are available.

I am hoping to start a book club specifically for AAC users and their parents as I continue advocate for nonverbal adolescents and young adults to have access to literacy and be exposed to the joys of reading and writing. Hopefully, parents will be able to use some of the interventions that we discuss in the book club at home with their adolescents and young adults.

As the autoethnography focused on my experiences and reflections as a parent, I would like to explore ways to support other parents of children who use AAC and struggle with literacy. I would like to publish and present my findings as well as my lessons learned in working with my two sons at conferences, workshops, and forums that will have parents in attendance. I would also encourage parents to take the time to reflect on themselves while educating their children as this process has been immeasurably helpful. I am hopeful that it will be beneficial for other parents to hear that from my reflections as I discovered that I know more than I thought I did about educating my sons as well as their AAC use. I also realized that I am more resilient than I thought, especially when it relates to the interests of my two sons and my ability to advocate for what I feel they need—literacy skills.

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Appendix A

Enhanced Alphabet Knowledge Lesson Template

(Jones et. al., 2013, p. 83)

Explanation of Objective

Today, you will be learning the name, sound, and how to write the letter _____. Learning this letter will help you to read and write many words.

Instruction

Letter Name Identification: (~ 1-2 minutes)

1. This is the letter _____. This is the uppercase letter _____. This is the lowercase letter _____.
(Show and/or write the letter, explaining the form.)
2. Let's practice naming this letter. What is this letter? _____.
(Point to uppercase and lowercase letters in different order at least 3 times asking students to identify the letter name).

Letter Sound Identification: (~ 1-2 minutes)

3. The letter _____ represents the sound /____/. When I say the sound /____/ I place my tongue & mouth like this _____.
(Provide explanations/stories/key words to help students remember the sound.)
4. Let's practice saying the sound of this letter. The letter _____ represents the _____ sound. Say the _____ sound with me _____, _____, _____.
(Point to uppercase and lowercase letters in different order at least 3 times asking students to identify the letter sound).

Hint: For vowels, teach students the short vowel sound and explain that when reading words the vowel letter represents its name or its sound.

Recognizing the Letter in Text: (~ 3 minutes)

5. Now, let's see if we can find the letter _____.
(Students locate the uppercase and lowercase letter in text and state the letter name and sound each time the letter is located)

There are a number of alternatives for student practice with recognizing the letter in text such as:

- sorting through magnetic letters/tiles to isolate the particular letter
- identifying the letter in charts of classmates' names
- using a crayon to circle the letter in newspapers or magazines
- placing highlighter tape over the letter in easy-to-read children's books

Producing the Letter Form: (~ 4-5 minutes)

6. Let me show you how to write the letter _____. Here's where I begin on the paper lines to write the letter _____.
(Provide description and hints about how to write the uppercase and lowercase form of the letter).
7. Let's practice writing the letter _____ together.
Producing the letter can also use alternatives for practice such as:
 - using a transparency and marker to trace over the letter as it is identified in enlarged print from children's books
 - writing the letters on small white boards as the teacher dictates
 - producing the letter form with clay, pipe cleaners, wiki sticks

Note: Tasks such as using a rubber stamp and ink to stamp the letter or gluing items to an outline of the letter (e.g. gluing beans on the letter b) is not producing the letter form as the form has already been produced and students are not required to think about how to create the form.

Appendix B

Lesson Descriptions and Data Collection by the Week

Week	Description	Date
1	<ul style="list-style-type: none"> • Lesson Plans • Reflections • Field notes • Personal Memory • Photo <ul style="list-style-type: none"> ○ Page from “Charles’s Verb Alphabet Book” • Text <ul style="list-style-type: none"> ○ To respite workers 	June 1 – June 6, 2021
2	<ul style="list-style-type: none"> • Lesson Plans • Reflections • Field notes • Photo <ul style="list-style-type: none"> ○ 2 pictures of Charles self-selected independent reading ○ Props for shared reading “Piranhas Don’t Eat Bananas” • Email <ul style="list-style-type: none"> ○ To Community Living Ontario mentor 	June 7 - June 13
3	<ul style="list-style-type: none"> • Lesson Plans • Reflections • Field Notes • Personal Memory • Photos <ul style="list-style-type: none"> ○ AAC screen shot of Happy Father’s Day ○ Shared reading props “Piranhas Don’t Eat Bananas” ○ Predictable chart writing for “Piranhas Don’t Eat Bananas” ○ Alphabet book 	June 14 – June 20

- 6 pictures of instructions and Alvin completing his stepping-stone path project

- 4

 - Lesson Plans
 - Reflections
 - Field Notes

June 21 – June 27

- 5

 - Lesson Plans
 - Reflections
 - Field Notes
 - Photos
 - 2 pictures of alphabet game
 - 2 pictures of word family game
 - 5 pictures of accessibility and organizing of books
 - Pie that Charles made after reading recipe

June 28 – July 4

- 6

 - Lesson Plans
 - Reflections
 - Field Notes
 - Photo
 - Word wall
 - Portable word wall
 - Charles reading independently self-selected his alphabet book and sharing it with grandma
 - 2 pictures of Charles's alphabet Verb book

July 5- July 11

- 7

 - Lesson Plans
 - Reflections
 - Field Notes
 - Photos
 - 6 pictures of Alvin working on reading, writing instructions to make a fire ring
 - 2 pictures of shared reading of "There Was An Old Lady Who Swallowed a Fly" and props

July 12 – July 18

- 2 pictures of working on alphabet
 - Working on word families
 - Scrabble Jr game
-
- | | | |
|-----------|--|-----------------------|
| 8 | <ul style="list-style-type: none"> • Lesson Plans • Reflections • Field Notes • Photos <ul style="list-style-type: none"> ○ Tag on Cedars instructions on planting ○ 3 pictures of Alvin planting ○ 2 pictures of letter and letter sound game • Text | July 19 – July 25 |
| 9 | <ul style="list-style-type: none"> • Lesson Plans • Reflections • Field Notes • Photos <ul style="list-style-type: none"> ○ Workspace at the cottage ○ Instruction tag for planting cedars ○ 2 pictures of pamphlet on laying sod | July 26 – August 1 |
| 10 | <ul style="list-style-type: none"> • Lesson Plans • Reflections • Field Notes • Text <ul style="list-style-type: none"> ○ Alvin texting Grandma | August 2 – August 8 |
| 11 | <ul style="list-style-type: none"> • Lesson Plans • Reflections • Field Notes • Photo <ul style="list-style-type: none"> ○ 2 pictures of Anchor-Read-Apply “Crows on a Wire” • Text <ul style="list-style-type: none"> ○ To grandma | August 9 – August 15 |
| 12 | <ul style="list-style-type: none"> • Lesson Plans • Reflections | August 16 – August 22 |

- Field notes
- Photos
 - Shared reading “There Was An Old Lady Who Swallowed An Alphabet” props
 - Dominos (first letter)
- Email
 - Charless’ independent writing
- Text
 - 2 texts sent to his respite worker

13	<ul style="list-style-type: none"> • Lesson Plans • Reflections • Field Notes • Photos <ul style="list-style-type: none"> ○ Magazine instructions ○ Written out instructions and drawing of plot ○ AAC of instructions ○ 5 photos of making the fire ring 	August 23 – August 29
14	<ul style="list-style-type: none"> • Lesson Plans • Reflections • Field Notes 	August 30 – September 5
15	<ul style="list-style-type: none"> • Lesson Plans • Reflections • Field Notes 	September 6 – September 12
16	<ul style="list-style-type: none"> • Lesson Plans • Reflections • Field Notes • Email <ul style="list-style-type: none"> ○ Early conventional books 	September 13 – September 19
17	<ul style="list-style-type: none"> • Lesson Plans • Reflections • Field Notes • Photos 	September 20 – September 26

- AAC model words of the month
 - 2 pictures of elephant toothpaste
 - 4 pictures of Anchor-Read-Apply “The Coffee Lover”
 - Email
 - To Teachers and EAs re: guided reading
 - Video
 - Alvin and guided reading
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|-----------|---|--------------------------|
| 18 | <ul style="list-style-type: none"> • Lesson Plans • Reflections • Field Notes | September 27 – October 3 |
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| 19 | <ul style="list-style-type: none"> • Lesson Plans • Reflections • Field Notes • Photos <ul style="list-style-type: none"> ○ 2 pictures of alphabet and letter sounds • Email <ul style="list-style-type: none"> ○ 2 emails regarding library | October 4 – October 10 |
| | | |
| 20 | <ul style="list-style-type: none"> • Lesson Plans • Reflections • Field Notes • Photo <ul style="list-style-type: none"> ○ Game snakes and ladders ○ 11 photos of Tree Top Trekking Predictable Chart Writing and book • Email <ul style="list-style-type: none"> ○ AAC awareness month | October 11 – October 17 |
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| 21 | <ul style="list-style-type: none"> • Lesson Plans • Reflections • Field Notes • Photos <ul style="list-style-type: none"> ○ 2 pictures of maps for Anchor-Read-Apply “The Map” | October 18 – October 24 |

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| 22 | <ul style="list-style-type: none"> • Lesson Plans • Reflections • Field Notes | October 25 – October 31 |
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| 23 | <ul style="list-style-type: none"> • Lesson Plans • Reflections • Field Notes • Photos <ul style="list-style-type: none"> ○ Yes/No (True/False) for guided reading “Earthworms” ○ Yes/No (AAC) for guided reading “Earthworms” ○ 2 pictures worm life cycle for Anchor-Read-Apply ○ 2 Pictures label body parts for ○ 3 pictures Alvin feeding Worms ○ 2 pictures Charles in library at school ○ Charles’s shopping list • Email <ul style="list-style-type: none"> ○ Charles’s independent writing | November 1 – November 7 |
| | | |
| 24 | <ul style="list-style-type: none"> • Lesson Plans • Reflections • Field Notes • Photos <ul style="list-style-type: none"> ○ “Stories for Boys who Dare to be Different” ○ Venn diagram of worms vs Alvin for Anchor-Read-Apply ○ Supplies and list for shopping • Email <ul style="list-style-type: none"> ○ To school librarian ○ Reply from school librarian ○ To Dr Koppenhaver re: Independent Writing ○ Reply from Dr. Koppenhaver | November 8 – November 14 |
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| 25 | <ul style="list-style-type: none"> • Lesson Plans • Reflections | November 15 – November 21 |

- Field Notes
 - Personal Memory
 - Photos
 - Independently completed shopping list
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- | | | |
|-----------|---|---------------------------|
| 26 | <ul style="list-style-type: none"> • Lesson Plans • Reflections • Field Notes • Photos <ul style="list-style-type: none"> ○ Yes/No comprehension for guided reading regarding history of leaf blower ○ 6 pictures of shared reading and dessert imposters with AAC | November 22 – November 28 |
| 27 | <ul style="list-style-type: none"> • Lesson Plans • Reflections • Photos <ul style="list-style-type: none"> ○ Poster presentation | November 29 – December 5 |
| 28 | <ul style="list-style-type: none"> • Lesson Plans • Reflections • Field Notes • Photos <ul style="list-style-type: none"> ○ 2 pictures of Making Words ○ Anchor-Read-Apply “My Dog Buddy” | December 6 – December 12 |
| 29 | <ul style="list-style-type: none"> • Lesson Plans • Reflections • Field Notes • Photos <ul style="list-style-type: none"> ○ Anchor-Read-Apply “My Dog Buddy” ○ Systematic Sequential Phonics They Use book | December 13 – December 19 |
| 30 | <ul style="list-style-type: none"> • Lesson Plans • Reflections | December 20 – December 26 |

- Field Notes
- Personal Memory
- Photos
 - 2 pictures of shared reading “Oi Frog” and props for rhyming
 - 2 pictures of Anchor-Read-Apply
 - Alphabet book Charles is writing “Baking Through the Alphabet with Charles”
 - AAC screen shot for the “Baking Through the Alphabet with Charles”
 - Reading ingredients picture
 - 3 pictures of Charles making the jelly roll
 - 3 pictures of Alvin feeding his worm compost

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- Lesson Plans
 - Reflections
 - Field Notes
 - Photos
 - 2 pictures shared reading – “Gingerbread Houses”
 - Recipe for gingerbread
 - Baked gingerbread
 - Making Words
 - 3 pictures shared reading “Whose Nose”
 - 3 pictures of shared reading “Worms”
 - Page from “Baking Through the Alphabet with Charles” alphabet book
 - Video
 - Shared reading with Charles
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December 27 – January 2, 2022