The Lived Experience of Using a Speech-generating Device

by

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Abstract

The field of Augmentative and Alternative Communication is emerging understanding of both practice and praxis. Speech-generating devices (SGDs) are becoming smaller, more powerful and more accessible to people with complex communication needs. There is a growing body of evidence based practices that speech language pathologists, teachers and families can draw upon to understand how best to support people who use these devices to effectively communicate throughout their daily lives (Beukelman & Mirenda, 2013; Drager & Reichle, 2010; Light & McNaughton, 2014). Despite these exciting advances, there is still little understood about the phenomenon itself, that is what is it really like to speak with/through a SGD?

Research Question: What is the experience of speaking with a machine by one who is severely speech impaired? This essential question is explored by employing the existentials of lived relation (relationality), lived body (corporeality), lived space (spatiality), lived time (temporality), and lived things and technology (materiality) (van Manen, 2014).

Method: This study draws upon the phenomenology of practice (van Manen, 2014) as a method of researching lived experience in order to glean insights into what it might be like to speak through a device, the meaning of this phenomenon in the lives of those who use SGDs, and implications for pedagogical practice. Phenomenological studies seek to shatter the taken-for-grantedness of everyday life by stepping back from preconceptions and theories and invoking an attitude of openness and wonder to the meaning of experiences for people as they actually live through them.

Participants in this study include young people with cerebral palsy who use so called, *high tech* devices to communicate using computer synthesized speech on a regular basis. Their experiences with their devices have been collected through interview, their written descriptions, and close observation. Additional lived experience material has been gathered from published accounts of other device users both from traditional print media.

Texts ("Findings"): This inquiry resulted in four manuscripts where I have explored various meaning-aspects of what it is like to speak with a SGD. The first text, *Phenomenological Investigation Into Speaking With A Machine,* borrows McLuhan's notion of extension and amputation as heuristics to explore the phenomenon at hand. The orientation is toward *postphenomenology* (Selinger, 2006) as it explores human-technology relations; how these devices both extend the user's ability to speak while simultaneously amputating what might be considered access to meaningful communication through voice. The second text, *The Speech-generating Device Thing,* presents an exploration of the SGD as a *thing* in the Heideggerian tradition (Heidegger, 1971). This paper explores the question of what an SGD is as it is called upon to do the ordinary every day task of speaking for one who cannot. How does the experience of SGD use contribute to the essential meaning of this phenomenon? Text number three, *Out of time in the classroom,* focuses particularly on the existential theme of temporality reflecting on how time is experienced when speaking with a SGD. In the final text, *What does the non-speaking child say?* aims at going beyond perceptions of people about, and of, SGDs to provide educators and other professionals with a glimpse into the phenomenon of speaking with SGD in the lifeworld of a child. This text in particular was aimed at those in the field of special education, and will hopefully be accessible and useful for those who may come into contact with a non-speaking child in the classroom.

Concluding Comments & Significance: Through these texts I explored possible experiential realities from a pedagogical perspective, challenging educators and related health professionals to consider the unique, yet recognizable, experience of a child who uses a SGD in order enter into the taken for granted world of one who speaks, must do so through a machine. The texts also have implications for adoption and development of value-sensitive design practices for the field of rehabilitation technology. The study addresses a gap in augmentative and alternative communication literature, as there is little qualitative research in the field, particularly as it relates to the experience of people who communicate through augmented means. Finally, this research also addresses a significant gap in the philosophy of technology, as assistive technologies are decidedly unrepresented in this area.

DEDICATION

This work more than any other in my life is dedicated to my parents, Edward Look and Gail Marie Sitler Look. It is through their experiences that I was called to be begin it, and through their strong and ongoing *presence* in my life that I was able to finish it.

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Chapter 1: Coming to the Question

A Lifetime of Assistive Technology

My journey to this study began more than thirty years ago. In 1982 I was hired to work as a communication consultant at a school for children with what was termed in the day *severe and profound* disabilities. These were children with the most challenging conditions: cerebral palsy so severe that they could not control any parts of their body; traumatic brain injuries that resulted in complete paralysis; and intellectual disabilities so significant that they had been deemed not only *uneducable* but *un-trainable*. The categories into which people with intellectual disability were placed in the early late 1970s and early 1980s were educable, trainable, or profound (Alper, 2003). While there were programs for children who were deemed *trainable* or *educable*, and in fact even curricula for these children in Alberta, there was little to no thought given to educating children who were identified as *profoundly mentally handicapped*. This was the time in many places around the world, including Alberta, where these children were just gaining the right to go to school, never mind the right to be included in their neighborhood schools. Looking back, we had few resources to draw upon as we sought to provide learning experiences to these students.

My background in psychology, especially behavioral psychology, and psycholinguistics was by no means specific or even usual preparation for such a position, yet most teachers and speech-language pathologists (SLPs) of the day were ill prepared to meet the complex needs of these extraordinary children. What I brought to the position was a strong background in behavior and behavioral analysis and the belief that every child could and would learn. I believed I could shape communicative behaviors through operant conditioning. I also came with a strong background in linguistics and language. It seems rather strange to me now that radical behaviourism (Skinnerian psychology) and Chomskian understanding of language and language acquisition somehow merged in my mind when considering children with significant disabilities.

I had moved from the study of Psychology to Psycholinguistics precisely because I felt language was somehow different, somehow a uniquely human endeavor that could not just be reduced down to the mands and tacts of Skinner's analysis (Skinner, 1957). Yet, at the school I found myself drawing upon my behavioral psychology training far more than cognitive psychology. These were children whose innate ability to acquire language was so hidden by the challenges of their physical beings or their intellectual abilities that at the time I had little to no understanding of how to provide them the opportunities to partake in the language and literacy experiences that today we know are so key to their learning (Erickson, Clendon & Hatch, 2010).

Along with being a time of significant change in education, it was also a time of significant advances in technology. Rehabilitation engineers were designing specific technologies, which we now call assistive technologies, to help people with various disabling conditions compensate for the challenges of their bodies. Computer synthesized speech was being developed and marketed to people who were blind and had visual impairments (Rowe, 2010). Ray Kurzweil had developed the *Kurzweil Reading Machine*, the first print-to-speech reading machine in 1976 and was working on speech recognition technologies (Erickson, Clendon & Hatch, 2010). Technologies that would compensate for physical disabilities were also coming to market. There were devices like the Zygo 16™ and the Zygo 100™ that allowed people with limited movement to scan through an array of 16 or 100 (hence the names) symbols or words to communicate. There was no voice output to these systems merely lights that indicated which symbol was selected. There were also electric typewriters, and these enabled some people with physical disabilities to strap on head sticks to type to communicate (Creech, 1992; Nolan, 1987; Rush, 1986). Perhaps the most significant adaptive technology of all was the invention of the adaptive firmware card (AFC) in 1977 by Paul Schwejda and Judy McDonald (Stevens, nd.). This remarkable technology allowed people with disabilities to access the Apple 2 computer in a variety of ways including multiple modes of switch access and alternative keyboard access. The AFC was for people with physical disabilities what screen reading technologies were to the blind - life changing.

In the fall of 1983, one year into my tenure at the Child Development Centre, I was given $1000 to spend on assistive technologies that might benefit the students. I set upon purchasing a variety of these early assistive devices. While researching what tools I should add to the Centre's AT toolkit, I happened to hear that a rehabilitation engineer from California had been invited to speak on computers and their use by people with disabilities. It was this talk, arranged by Elaine Heaton and given by Dr. Al Cook, that I must say changed the course of my career. That day Dr. Cook not only convinced me that what I really needed to buy for the centre was an Apple computer and an AFC, he also convinced me of the liberating power these technologies might afford the children I was working with.

While I did take (and barely passed) a computing course in my undergraduate degree program and completed my Master's thesis using Textform on a remote terminal connected to the university's mainframe computer, this was the extent of my computer knowledge. Suddenly I was going to training sessions on the AFC in Boston and learning how to insert the AFC into the motherboard of the computer, develop programs in Apple Basic, and even building switches! I was becoming a techie!

What was far more astonishing however was what the students I was working with were able to do. I recall a young boy with cerebral palsy who was one of the so-called *boat people* from Vietnam that had come to Canada as refugees during these years. He was unable to speak and had extremely limited control of any part of his body. But he laughed at jokes, and his eyes shone with understanding, even though English was not his first language. I believed he had much to say if we could only find the way for him to say it. We positioned a switch under his chin, and he was able to play the Frog & Fly game and to find the letters of his name from the array the AFC displayed at the bottom of the computer screen. While we didn't ultimately hear his voice, we certainly were able to see that there was a child with much potential in that little challenging body. And we allowed him to engage and have fun in ways that without technology he would have never been able to do.

I recall a young girl engaging in a simple math activity using the numbers 1 to 10 that I had programmed to input through the *unicorn* adapted keyboard. While she seemed pleased with herself, it was her father's face and the faces of her teachers that told the story of this young lady. With technology, she was able to show that she was much more capable than her body could express. She was now considered in this new light of ability. These were heady times in the emerging world of assistive technologies, and certainly exciting times for me as I had found what I felt was the key to unlocking the potential these children had to actively and meaningfully interact with the world.

Augmentative And Alternative Communication.

Early years. My formal introduction to augmentative and alternative communication (AAC) also happened in the 1980s. My primary role at the Centre was to support the development of communication skills of the children. Every one of them had what would today be referred to as complex communication needs (CCN), and I was from my first day interested in AAC, although I did not yet know it was really a thing in which someone could be interested.

The reason I was hired to work at the Centre when typically it would have been a position filled by a speech-language pathologist (SLP), was my educational background and interests. My passion for alternative means of communication began when in my university studies I was introduced to the work being done in the 1970s to teach apes to communicate through symbolic language. I was fascinated by this work, and in many ways, it was the studies of Washoe and Koko being taught to sign (Gardner & Gardner, 1969) and Sarah being taught to use symbols (Premack & Premack, 1972) that led me away from behavioral psychology and into psycholinguistics. What I came to understand through the ape studies is that it was not only humans who could learn to communicate using abstract symbols. What did seem to be evident from the early studies with the great apes, however, was that none of them acquired a robust language that went beyond that of a human toddler (Hixon, 1998). This was intriguing to me. Did this indeed mean that humans were uniquely capable of a robust language system? This notion that language was indeed the one thing that made us unique as a species was what drew me away from a behavioral psychology and toward psycholinguistics.

During my graduate work in psycholinguistics, I also became interested in studies of Deaf aphasics. Although ASL had been widely accepted as a *language* by many for years, it was such a different mode of speaking that psychologists, linguists, and psycholinguists were and are still interested in studying ASL speakers. So it can be said that throughout my studies of language, I was never much interested in those who can speak with their voices. When I was faced with children who could not communicate with their natural voices I was nonplused – I had always been more interested in non-speech forms of communication than speech forms anyway.

Interestingly, during my research for this study, I became re-acquainted with the work of Mary Ann Romski and Rose Sevcik. During the time that I was working at the Centre, Drs. Romski and Sevcik were researching their System for Augmenting Language (SAL). SAL was built by integrating the findings of research from the Yerkes Regional Primate Research Centre and the emerging voice output communication technology that was developing in the field of language intervention (Romski & Sevcik, 1996). Theirs was some of the first work that truly focused on the importance of voice output devices (speech-generating devices). In re-discovering their work on this journey, I have drawn from their research projects both in lived experience material and in my analysis.

In 1982, just shortly after being hired for the position of communication therapist I was sent to an international conference on AAC. It was an amazing event in my life. I came away with ideas, many ideas, beyond speech and sign language that I could apply to support the children at the Centre in communication. The most important of these was the idea that we could use pictures and pictographic symbols. While I had read about the Premack symbols that were used with the chimp Sarah, and I heard a little about Blissymbolics^{TM} the first graphic system to be adopted for widespread use in AAC (Glennen & DeCoste, 1997), this was the first time I had seen a symbol set that I believed my be appropriate for the children with whom I was working. The PIC (Pictogram Ideogram Symbols) symbol set consists of 1,500 white-on-black *picto-images* that are designed to reduce figure-ground discrimination difficulties (Maharaj, 1980 cited in Beukelman & Mirenda, 2013).

Figure 1. Example of PIC Symbols

I came back from Toronto with a box of 400 of the black and white PIC symbols ready to photocopy into communication displays (see Figure 1.). This symbol set was originally developed in Canada by Subhas C. Maharaj (Abledata). There are now several other symbol sets available (e.g., Picture Communication Symbols, Symbolstix, Widget symbols and many others (Buekelman & Mirenda, 2013)) in colour, and online so the days of photocopying communication boards have long since passed. I do still find myself looking back at the simple black and white PIC symbols and wondering if for some students these still might not be the easiest to use visually. Perhaps that is just nostalgia – does one always like one's first discovery best?

In 1983 I attended the first International Society for Augmentative and Alternative Communication (ISAAC) in Toronto, which was a direct outgrowth of the 1982 conference. The field of AAC like my career in AAC was emerging. At this conference I was excited to confirm that there were many others around the world who were seeking new ways for people with complex communication needs to find their voice. By 1983 the first real AAC devices were being used. There was the Canon Communicator™, which was essentially a hand held typing machine that output a ticker tape like a printout. So for those who were literate and those who could access the small keyboard it was a marvelous invention (Hudak, 1986). The real *breakthrough* however came with advances in speech synthesis. The first mass-marketed communication aid, the Phonic Ear Handivoice™, was developed in 1978 (Higginbotham, 2010).

Like the Canon Communicator^{TM,} the Handivoice^{TM} was primarily useful to those who were literate and who could access the keys by pointing. So, for the students I was working with while these devices were exciting to consider, they were not providing them with access to a voice. The children were not literate, and many of them could not directly access a device by pointing with their fingers.

What was useful was the combination of alternative keyboard dubbed “the Unicorn keyboard” connected through the AFC to the Apple computer that now with the added invention of the Echo^{TM} speech synthesizer could “talk”. The Unicorn keyboard, so called likely because many who used it used a headstick to access it, was the precursor to today’s Intellikeys^{TM} keyboard. It was a large (14 inches by 21 inches) yellow touch sensitive keyboard that had 128 programmable cells.

Figure 2. Example of Unicorn Keyboard connected to Apple computer through Adaptive Firmware Card

I could program a cell or group of cells to send a message to the computer and then to the Echo speech synthesizer thereby creating a system that would, in fact, be a large, definitely not portable, speech-generating device. There were now many students who could come into my office and touch pictures that I had pasted onto the Unicorn board to request toys, or games, or food. The things I imaginded they would want to say if they had a voice. In actuality the Apple 2, AFC, Unicorn keyboard, Echo speech synthesizer system that I had put together and programmed to say a few words was not so much a communication device as a testing device. In those days, as is still often the case today, children with complex communication needs (CCN) had to prove themselves able to use a SGD. What I was essentially trying to do was to teach the children about a picture based voice output device so that perhaps someday one of them would be deemed capable enough to acquire one.

It was the time of the candidacy model of AAC (Loncke, 2014). In the 1980s it was believed that there were a series of decision points to go through to decide if a child/person with an impairment of speech was or was not a candidate for AAC (Musselwhite & St. Lous, 1988). The thinking, at least in the early 1980s, was that a child must demonstrate at least Stage 5 sensorimotor intelligence, and if they could not, AAC systems were not recommended (Glennen & DeCoste, 1997). Given this thinking, the children I was working with would not be candidates because of their intellectual disabilities or at least their ability to demonstrate any intellectual abilities they possessed. In 1982 a provincial team of specialists had been established in Alberta to provide services to students with severe disabilities. There were professionals from a variety of disciplines in this provincial team, including SLPs who were to serve students with severe speech impairments. However, for a student to qualify for speech-language services, and therefore specialized AAC, we had to prove that their expressive speech delay was not related to their intellectual disability. There was in fact even a *formula*. To gain access to AAC services it had to be shown that a child's expressive language ability was half that of their intellectual ability. Of course, this was extraordinarily hard to prove.

The words of the 2012 documentary *Certain Proof: A Question of Worth* (Ellis & Ellis, 2010) ring true for the students at the Centre: “What if you couldn't speak? Or use your hands? How would you prove you understand? That you can learn? That you matter?” Today I often use these words to open talks I am giving on AAC, but I think I felt the poignancy of it far more when I was back at the Centre in the early 1980s. I was trying my best to prove to the teachers, the parents, and perhaps even to the children themselves that they could communicate, that they could have a voice, and that we were so very interested in hearing it in whatever modality they had available.

During my tenure at the specialized school myself and some other early adopters of AT and AAC came together regularly to share what we were learning about using the computer to support language and communication skills. We called ourselves *Apple Babble*. The outcome of this little group was a series of conference presentations and ultimately a chapter in a conference proceedings (Howery, Lopushinsky, & McCarthy, 1987). Looking back on this chapter today I both smile and grimace as, strangely enough, what we were saying thirty years ago seems to need still to be said.

> 1. *The computer is only one tool that can be used to foster language and communication development. Interactive methods of language therapy should remain a focus, with computer programs used only as a supplement where appropriate.*
> 2. *The computer should not be seen as an end in and of itself.*
> 3. *The computer can be used to simulate various augmentative communication aids, but is often not the aid of choice due to portability and mounting consideration.* (Howery, Lopushinsky, & McCarthy, p. 38)

We are still reminding people that the computer, iPad, even AAC device is only one part of an AAC system. Anyone who uses AAC also needs access to many ways of communicating, high tech, low tech (e.g., letterboard), and no tech (gestures, facial expression) (Williams, 2004).

The real communication comes not from the technology but from the interaction with others, and sometimes, the technology can actually get in the way (Pistorius, 2013).

I continue to be surprised by people who state that the goal for their child is to get an AAC device. I once read an Individual Program Plan (IPP) that stated as a goal – to get a communication device. Of course, such a goal to be written on a student's IPP is absurd considering the student has no way to get themselves a device. Gaining access to a SGD for a child only happens through the actions of adults. The goal for any person with CCN is to become a more capable communicator. Today this question tends to be, "what AAC app should I get?" However, it is not the acquisition of an app that is so important but the expansion of the person's communication partners and abilities (Gosnell, Costello & Shane, 2011).

Finally, the interesting question of the computer, or perhaps today we might substitute in the iPad, as maybe not being the device of choice. The whole question of iPads as communication devices is much discussed today. The parallels in the conversations we were having in the 1980s and 90s around computers and the conversations that are going on today about using iPads as AAC devices are interesting, to say the least. While the computers were hardly portable, needed external speakers, posed great problems in mounting, and had limited battery life many people looked to them because they were less expensive and easier to acquire than the specialized speech-generating devices of the day (Pistorius, 2013). Today the iPad and other tablets are lightweight, definitely portable, relatively easy to mount, and there are hundreds if not thousands of apps available that provide some kinds of AAC support. But tablet computers are not dedicated devices, their speakers are not created to project sound across the room, and perhaps comparable to older personal computers they were made to be multi-functional. The multi-functionality tends to be lost when one needs to use an iPad to talk. While there are ever increasing numbers of people who are using them as communication devices, there are many who point to the fact that they may be reasonable tools to simulate a SGD but they fall short of equating to one (Abbott & McBride, 2014). One may not be remiss in suggesting in the world of AAC technologies, the more things change, the more they stay (surprisingly) the same.

Phase two.

Shifting towards inclusion. In the 1990s I was working in an early childhood education program with a focus on including children with significant needs in their neighborhood preschools and kindergartens. Interestingly, this program had been started some years before by parents of two children who were attending the Child Development Centre but who wanted something different for their children. So in some real sense, I was moving along with those parents to an offshoot program that served children in their home and community, not in a specialized Centre. This was in tune with the movement towards inclusive education at the time (Winzer, 2007). While the 1980s saw legislation that gave every child a right to an education, the 1990s were a time when special schools and special classrooms were being closed, and children with all abilities were being educated in their community schools.

In line with this movement toward inclusion, Alberta's various specialized curricula for students with disabilities were replaced with a series of resources for *Programming for Students with Special Need*s (1995). This series was developed to provide practical suggestions about instructional strategies, classroom management, preparing individual program plans and understanding the nature of special needs (Alberta Education, 1995). The discontinuation of the specialized curriculum meant there was only one curriculum for all students in Alberta, the *Alberta Programs of Study*. This series guided teachers in planning from the Programs of Study to meet the needs of all students.

It is of interest to note that the issue of how to appropriately provide for the educational needs of students with differences, especially intellectual differences remains at the forefront of educational conversations today. In Alberta, we no longer talk about *special education* but rather have embraced the term *inclusive education*. Inclusive education, and how to appropriately design and deliver quality educational opportunities to students with disabilities, remains an issue of much challenge and controversy in Alberta (Alberta Teachers Association, 2014) and across Canada (Thompson, Lyons & Timmons, 2014).

AAC advances. In the early 1990s the AAC technology and the AAC field had made great strides. The AAC journal, launched by the International Society for Augmentative and Alternative Communication (ISAAC) in 1985, was well established and filled with articles. The first of what would be many textbooks written by David Beukelman and Pat Mirenda on the subject was published in 1992. Several other texts were also being published in the area providing clinicians and educators with a store of information on assessment, implementation and ongoing support of AAC.

In 1989, Janice Light had published her seminal work on communicative competence for individuals using AAC systems. She challenged the field to think about the competencies that are necessary if one is to be successful in communicating with AAC. These include the competencies needed by all of us (linguistic and social) but also competencies in employing strategies to engage in successful interactions given the limitations of any AAC system, and the competencies required in learning to operate the devices. Light pointed out that for people who use AAC systems linguistic competence means both the ability to understand the oral language that is being spoken all around them and the ability to understand and use symbolic language of their AAC system. Social and strategic competence involve a whole new set of demands given the challenges of AAC. People who use AAC may only have a limited number of words available to them on their systems and therefore have to be strategic in what they can say that will be understandable and appropriate. People who use AAC must be strategic in their social interactions, as many of the means of expected social engagement may be difficult to engage in (small talk) or not possible (looking at a person while speaking to them, as the device user must be looking at their device). Light’s work greatly influenced the field of AAC and certainly had profound impact on my own understanding of what we as educators of children and youth with CCN and their families were tasked. Yet, much of what I needed to learn in this regard was yet to come in my professional and personal life.

During this time work in aided language stimulation was being first published by Goossens, Crain & Elder (1992). Aided language stimulation is a technique whereby the communication partner points to the symbols on the communication display as they are interacting verbally. This approach supports a contextualized naturalistic mode of language learning that had been abandoned by more strictly behavioral approaches. Goossens, Crain & Elder’s (1992) book *Engineering the Preschool Environment* became something of a guide book during the time I worked in the inclusive early education program. Modeling of the AAC system to the child and with the child became a mantra. I had educators label things in students' environments with the symbols they were expecting the children to learn and use. And I encouraged activity-based communication boards to be made for and used in all the child's classroom routines. Like so many things that we did in the early days of AAC, the notion of activity specific communication displays has gone out of favour. Instead, today the field is embracing more generic communication displays that focus on core vocabulary that can be used across a variety of settings (Fallon, Light, Kramer Paige, 2001). Once again this has been a reminder to me that focusing on how all children learn and use language is the key to understanding how our practices in AAC should be guided.

Aided language stimulation has been shown to be a critical component of AAC supports and services (Dada & Alant, 2009; Drager, Postal, Carrolus, Castellano, Gagliano & Glynn, 2006; Romski & Sevick, 1996) for children with CCN, including those who have autism. Despite this clear evidence, encouraging teachers, assistants and even parents to model on the device while talking to a child who is learning to use AAC was difficult for me in the 1990s and remains a challenge today. While it is not that people do not want to do this, or disagree with the concept, it is truly just difficult to slow down and intentionally speak with the child in the system that we are expecting them to use to speak with us. As will be seen in the chapters that follow, speaking with a device is not easy. Not for a child who must use one to speak, and definitely, it seems not for the persons around them who themselves are speakers.

Phase three. In 1996 I took a position at the Assistive Device Service (ADS) at the Glenrose Rehabilitation Hospital. During my time with the ADS, I established what came to be known as Computer Play Days. These were opportunities for clinicians, teachers, parents and children to come in and explore the specialized equipment, devices, and software that they may be considering purchasing. I also was actively involved in providing ongoing professional learning activities for people throughout the province. As a result, both hands on learning and professional development remain a key feature of the I CAN Centre for Assistive Technology today.

In my second year at the ADS I had the opportunity to visit several Assistive Technology Centers in California, and spend a day at the Bridge School. The Bridge School was established in 1987 by Neil and Pegi Young as a specialized school program where children with severe physical disabilities received the support they required to communicate effectively (https://www.bridgeschool.org/about/history.php). In order to assist educational teams in overcoming the challenges involved in educational inclusion of students with AAC needs, the Bridge School was created as a place where students would come for a *short term* (could be years) placement with the primary goal to provide students with appropriate AAC technologies and functional communication skills so that they are sufficiently prepared to continue their education in their own local school districts (Hunt-Berg, 2005, p.117). The work of the Bridge school has been and continues to be influential in the field of AAC. For example, the Social Networks planning and implementation tool was developed in collaboration with the Bridge School (Blackstone & Hunt-Berg, 2011) and research on outcomes of students who attended the school have informed the field in terms of critical practices in AAC implementation and teaming (Hunt-Berg, 2005).

Given the success of the Bridge School, I was determined that we should try to create a similar opportunity for Alberta students. While we could not amass the financial resources to create and run such a specialized school, I believed we could try to recreate some of the experiences for children, their teachers and their families by setting up short term immersive AAC and technology learning experiences at the Glenrose, using the resources of the ADS. Thus began what was to be a series of *camps* where we brought in students, their teachers, educational assistants and parents to help them support the students in the context of their schooling. Today various camp models are described in the literature (Dodd & Gorey, 2014; Dodd & Hagge, 2014; Kent- Walsh, Binger & Malani, 2010). AAC camps are proving a popular and seemingly viable way to provide students who use AAC devices with immersive experiences, as well as to help train the communication partners who are so important in AAC success.

While at the ADS my primary focus came to be more on literacy and less specifically on the AAC devices. It was becoming clearer and clearer to me that the students we were serving needed to have meaningful access to literacy supports and well as communication supports. In retrospect, I now see that many of the approaches I took in providing access to literacy did not in fact support the students in developing actual literacy skills. I was *symbolating* text constantly (putting symbols with text), which we now understand not only does not help with learning to read, but in fact decrease the likelihood that students will learn to read (Erickson, Hatch & Clendon, 2010). I was also encouraging the students to write using their AAC system. While this provided them with more practice in using their systems to communicate, it made it *easier* to bypass learning to write with the only symbols set where you can truly say anything you want – the alphabet. I have come to understand that the approaches I was advocating for were in fact at best *emergent* literacy behaviors and if people with CCN are to become truly autonomous in their communication moving from emergent to conventional literacy instruction is key (Koppenhaver, 2000). While we talk today about 21st century learning, and digital literacies, without the ability to read and spell children and youth who SGDs will never be able to say what they want, to whom they want, whenever they want. The alphabet is the only truly generative symbol system for a person who relies on AAC. This fact has become more and more apparent to me as I have embarked upon this research and as I continue to engage with people who use AAC both in my studies and in my life.

Coming to the study

The final road taken to this study began September 3, 2008 when I embarked upon doctoral studies. This day was especially important in that it was also a day where clearly unbeknownst to me, I was to be thrust into experiencing having *voicelessness* in my personal life. On September 3, 2008 as I was settling into my assigned office at the university, and attempting to write an application for financial support, my apparently vibrant and healthy mother was being admitted to the Royal Alexandra hospital. She died three short months later, on a respirator, without the power of speech. While I did not yet understand the personal impact that interacting with *speechless* loved ones was to have on me, I would over the next two years come to understand it deeply.

Upon entering my doctoral program, I had no intention of focusing on AAC. Indeed, my plan was to be doing a multiple case study on Universal Design for Learning (UDL). I had been doing work across Alberta in the area of UDL and had become something of an expert on this *new* approach to designing accessible learning opportunities. I was, I thought, coming back to graduate school to gather empirical evidence to support what was at that point a much touted promising practice. But, as the John Lennon lyric suggests, life is what happens when you are busy making other plans (Lennon, 1980). Life for me was about to take unexpected turns, and my plans to dig deeply into the promise of UDL in practice became sidelined by what I see now was an ever more insistent call to go back to the passion of my heart, AAC, and to be compelled to consider what it is really like.

Whispers of the Question

Where is your device?

After leaving the I CAN Centre, I would on occasion bump into some of the young people who attended our early “camps”. Children who I had been so sure were going to be *competent* communicators with their devices. I recall meeting one of the girls and her mother at a summer festival. I was surprised, and I must admit a bit disappointed, to see that she didn't have her device with her. I went up and said, hello and after chatting a bit with her mother a bit, I chided her for not having her "talker" with her. Her mom said it was kind of useless to bring the device to the event because it was all outdoors. She reminded me that the devices are rather ineffective outside as the screen is all but impossible to see in the bright sunlight. That gave me pause as I considered how much my children and I were conversing about the goings on at the festival. How frustrating I thought it is that the technology is so poor that one is only enabled to speak indoors. My response was to *fix* the problem. I suggested to her mother (interestingly not to the child herself) that perhaps an umbrella strategically placed might provide enough shade. She smiled and said that she would try that, but somehow as she walked away I got the distinct impression that I was being placated. I never considered that the *well positioned* umbrella while perhaps allowing her to say a few words with her device would also very likely impede her view of the marvelous goings on at the festival. I think about that now; I didn't think about that then.

On another occasion I encountered another of the children at a local shopping mall. Once again, no device. This time when I asked where the device was, her mother's answer was that they had just left it at the AT Centre as it had to be sent in for repair. Again I was in problem solving mode. I asked why they didn't have a loaner device. The child's mother shrugged and said by the time they sorted out a loaner the other device would most likely be fixed. I understood that she was probably quite correct, but still I was somewhat annoyed and unsettled that the child was left without a voice. I asked if they had complained to the company about the device not being robust. Again the mother smiled at me and assured me that this was just part of the deal. Something she, and I suppose her child, had just come to see as an ordinary event in their lives.

Looking back, I see that while I was a bit disturbed by these encounters, my only response to them was to think that we had to come up with better solutions! More reliable technologies must be the answer. I had still not really stopped to consider what it might be like to not be able to *see* your voice, or to have to send your voice away for repair. For me the real question was only beginning to take shape in my mind. What was going on that these young people who I saw as so capable with their devices were so often without them? And what must it be like for them to once again be rendered *speechless*?

The story of the Diving Bell.

In 2007 the book *The Diving Bell and the Butterfly* was made into a movie. The book tells the story of Jean-Dominique Bauby, the editor of *Elle*™ magazine, who suffered a brainstem stroke rendering him paralyzed. While his mind is still perfectly alert and able, his body is absolutely non-responsive; it is called locked-in syndrome. He only had one movement that he could control: he could blink his left eye.

I first read this book a number of years before. It was suggested to me as it told the story of a man who communicated by blinking his eye, a story many reasonably expected I would be most interested in reading. The method of communication he used was what we in the field would call *partner assisted (auditory) scanning*. The partner (hearer) would slowly recite the alphabet and he would blink when the letter that he wanted was spoken. Painstakingly slow. Extraordinarily demanding for both of them.

I was at the time of reading this book still working at the Assistive Device Service and the book did not sit well with me at all. Reading the book at the time actually made me angry that someone had not provided him assistive technology. Why the heck was he relegated to this eye blink system that was so slow and kept him so dependent on another human being to be his interface with the world? In fact, my anger and annoyance at what I saw at the time as being a huge gap in his services actually got in the way of my reading the book. I checked the date of publication thinking that perhaps is was written many years ago, before such technology had been developed. But no, it was published March 1997. While the technology was not as advanced as it is today, there was certain assistive technology available. So why didn't somebody get it for him? What I took away from the experience of reading the book was frustration at the failure of people to provide him with technology, not the story of an indomitable spirit of survival as is suggested on the cover leaf.

Thankfully in 2006 I had another chance to enter into Bauby's story. It was in a theatre in San Francisco. I was there at an assistive technology conference and had taken a colleague along to the conference to show her the positive powers of assistive technologies for students with disabilities. We decided one evening to go to the movies. *The Diving Bell and the Butterfly* was playing.

As the story unfolded on the screen in front of me I found myself beginning to think the same thoughts. Why don't they give him technology? In one scene he is left alone in the hospital bed with the TV. I cannot recall if someone turned it on and left or turned it off and left, but either way, I remember him being left alone without any means of controlling what he would or could watch. My frustration kicked in! He could have an environmental control unit, he could have a switch, he could at least turn the TV on and off instead of being left so very alone and helpless.

As the story continued, he was introduced to the partner assisted auditory scanning system that he came to use to communicate and to write his book. Once again I was annoyed by what I was seeing. Surely someone could do better than this painstakingly slow system. However, as I sat in that movie theatre something utterly new occurred—not in the storyline, but to me. As I was watching him slowly methodically one letter by one letter communicate with his attendant. She spoke the letters a – b - c – d – e – f – g and he blinked his eye to select "g" then a – b- c – d- e – onward to "o", blink, G O, "good?" she would ask, "blink" he would "say". But here is what I saw:. a man and a woman in a caring interactive relationship, together working tirelessly, hour after hour crafting his text. She would patiently and methodically say the letters, he would blink when she reached the one he wanted, she would write the letter down. The back and forth of their system relied on both of them working together to co-construct his words, his sentences, his book. What I was seeing before me was not the desperate need for technology but the amazing the power of two human beings communing to bring forth one person's voice.

With this method, partner assisted scanning, Bauby had forged a real connection to another human being. An intimate connection. The system was dependent on two human beings working together to create the messages he was conveying. It was beautiful and it was powerful.

As I watched I found myself considering what I would have provided for him had I had my way. It would be a scanning system, but one without the need of a human assistant. I would have attached a switch to his forehead or perhaps eyelid that would capture his movement, send it by a cable to an interface which would in turn allow him to choose letters from a computer which would provide a scan system. He likely could have written by himself. He would have had no need for a human interface - he would have been independent, but at what cost? What if I had indeed been his therapist, what if I had intervened? Rather than engaging for hours on end with a human being, would Bauby have been situated in front of a computer screen blinking his book to a screen? If I had had my way, would he have had close and regular human connection? Or would he have been left alone hour after hour while he composed his book on the computer with his eye blink? Would he have had the physical and emotional support to compose his book? Would he have even begun?

Hearing the Call

I mentioned my mother entering the hospital the same day I entered doctoral studies. I also revealed that she had passed away on a respirator unable to speak. She was in her last days not unlike Jean-Dominique Bauby, locked into a body that no longer could be willed to do her bidding. But, unlike Bauby, my mother was extremely ill, ravaged by an unremitting and unstoppable autoimmune disease that even the doctors did not really understand. In her last days in the ICU I asked her if she would like it if I brought her a device to try to say a few things. She shook her head, no. Of course she was so sick and so weak that she probably would have been unable to push any buttons to say anything. I have to say looking back I was not surprised in her refusal. What kind of talking device could I possibly provide her and teach her to use that she could use to talk to us when she was so sick? And, perhaps I was just a little afraid of what she would say. Was she afraid? How was she really feeling attached to all those tube? While I wanted to know, the knowledge that I was so utterly helpless to change anything someone made her imposed silence something of a relief. That is until the last day. The last day when we were asked what we wanted to do, to keep her on the life supports that she was on, or to turn off the machine. On this day I would have given anything to have been able to hear my mother's thoughts. Instead, what I heard was a physician's projections on the direness of the situation and the report from the palliative care doctor that my mom had indicated that she was tired and ready to go. There was no other course of action of course. But to this day I wish with every fiber of my being that I would have been brave enough to try harder to hear her voice.

Hearing my father's voice.

A year after my mother's death I was to once again face having a parent in the ICU without the ability to speak. In November of 2009 my father fell, broke his neck, and post-surgery to fuse his spine was on a ventilator. My father was not sick like my mother had been the previous November, but he was paralyzed from the nipple line down and would be for the rest of his life. His mind, however, was completely intact and this time I was determined to hear his words!

In the spinal cord ICU I was able to find a letter board, but little else in terms of tools to help patients who were temporarily voiceless communicate. My father could sort of hold a marker in his right hand and point at the letters but it was difficult for him to be precise and it exhausted him. On the third day post-surgery things seemed to have taken a turn for the worse. He had pneumonia and was having a very hard time coming off the vent. This was also an 81 year old man who had lost the love of his life who would now be a quadriplegic once he did get out of the ICU. While given my background and expertise in assistive technologies, I could have certainly helped him to learn to participate in the world to some degree, but it would have been an extremely difficult life for my once vivacious and active father. I needed to hear what he wanted. So I went to the I CAN Centre and borrowed an E-tran (see Figure 3. below). This seemed to work well. Dad understood easily what he was to do, and was able to direct his end of life care by spelling it out to me with his eyes.

Figure 3. An example of an Etran communication board in use.

There is some irony in this story as my father really never learned to read and write in English. Despite running a successful business and being a very engaged citizen he was a terrible speller and had my mother to do any reading and writing of substance in his life. I only came to understand the extent of this after her death. He needed me to write out simple things like cheques for him. Now here he was using his minimal spelling skills to tell me, “I have had a good life”, “I want the tube out”, and “no religion”. The last directive was for his funeral and was so clearly my dad’s voice that I must say it made me smile to hear it. So based on his instructions we took out the ventilator. The doctors had told me he would probably live for awhile afterward, perhaps even months, but no he had decided, and was gone within moments of being left to breathe on his own.

While this was a horrific event, and a horrible decision to have to make, knowing his wishes and being able to communicate with him in a fashion beyond yes and no questions meant the world to me! Ironically, I can say there are no words to express the comfort this gave to me and, I believe, to him. I was so grateful I had the knowledge and the resources to listen to his words. There were so many others in the ICU whose families did not.

There have been several studies into the use of AAC in the health care (Blackstone & Pressman, 2016; Costello, 2000). Over my career I have heard several stories of failure to provide access to communication for people with CCN who are hospitalized. On one occasion when I was still working at the AT Centre, I had asked a young woman who had a SGD to do some practicing on it when she went back to the ward that evening. She was staying in hospital for a few weeks to recovery from a surgery and I was hoping to use this opportunity to help her practice using her device. The next morning when she came to see me it was apparent that she had not accomplished what we had agreed that she would. I was annoyed with her and told her so. For whatever reason, perhaps because she didn't have the words, or perhaps I didn't have a way to listen, she didn't really tell me why she had not prepared. Later that day I went to the ward and asked the nurses if they could help ensure she had some time so she could practice. They informed me that she didn't have her SGD with her while she was on the ward. They locked it away so that it wouldn't get damaged or stolen. They only gave it back to her in the morning when she was going back to see me. I was horrified, mostly at the fact that I had scolded her for not doing what I had asked. But also that in the rehabilatation hospital where there was a specialized AT service, the nursing staff would not understand the importance of having one's voice with them at all times. Of course, I had to admit that their concerns were genuine as the device cost several thousand dollars and they would not want to be responsible for it being lost or damaged. I was left with the reality that she would not be able to practice talking or learning her system or doing any other "homework" while on the ward. The next day my student received an apology from me for taking her to task on not practicing. How could she practice speaking when her "voice" was locked away in the closet?

There is a growing recognition that people with CCN who use AAC are among the world's most vulnerable populations in health care settings (Blackstone & Pressmand, 2016, p. 69). Yet it seems that what I experienced when my parents were without voice in acute care settings is common, as few health care workers know how to communicate with them (Blackstone & Pressmand, 2016). There is a growing understanding in the field that work needs to be done to build awareness and provide solutions for both short term and long term voicelessness. Studies out of Boston report on intentional work to ensure that people who need AAC over the long term, or for just the time post-surgery are being provided with SGDs (Costello, 2000). How wonderful it would have been if in the days before my mother was forced to go to the ICU we could have developed and/or practiced some form of AAC is being done in the hospital in Boston (Costello, 2000). There is increasing recognition of the value of supporting AAC systems during hospital stays in that without being able to effectively communicate patients health, both medical and physical, is at risk (Blackstone, Beukelman & Yorkston , 2015). I cannot help but reflect on how I might have not have ever really been called to consider what it might *really be like* to be without a means of clear communication if I had not been called upon to hear my father's voice.

Attending to the Call.

While the world seemed to be sending me the message that I needed to focus my doctoral work on the field that first spoke to me nearly three decades earlier, it was not until I was sitting in a Educational Technology lecture in early 2010 that my direction really began to change. That lecture was given by Dr. Catherine Adams who was, unbeknownst by me at the time, to become my early muse and my continual mentor on this latter part of the journey.

In that lecture Dr. Adams was speaking to us of the philosophy of technology. She introduced us to Heidegger's (1962) hammer and the McLuhans' (1988) tetrad. The very idea that there was a "philosophy of technology" was beyond anything that I had ever conceived. I was wrapped in something that I can call skeptical fascination. In the class we were asked to use McLuhan's tetrad to explore a technology that was of particular interest to us. Despite the fact that my paper for this class was to be looking at text-to-speech supports for struggling readers, the technology that I chose was a SGD.

When I was called upon to share my attempt at exploring McLuhan's mode of analysis I talked of a SGD as *extending* voice, *reversing into* a toy, *obsolescing* communication boards but I could not imagine anything that it might *retrieve from obsolescence*. In retrospect, it was a very shallow analysis, but the very process was so far from the ways I had been taught to consider any technology that I felt like I was swimming in very deep but strangely inviting waters. Happily, Dr. Adams was seemingly pleased by my attempt but she was intrigued by the technology that I had chosen. The following week I found myself having coffee with her. In that coffee shop we continued the dialogue we began that evening in the Ed Tech class for some two hours. At the end, she had convinced me to take Max van Manen's final graduate seminar in phenomenological writing and research. And, that my topic of inquiry was to be the experience of using a SGD.

Heeding the Call

Coming to phenomenology.

I certainly never came to phenomenology, the most I can say is that phenomenology has come to me. It is an approach, a philosophy, and a method that I am still far from truly understanding but which I am continually seeking to understand.

Max van Manen's doctoral seminar put me in a state of confusion and wonderment that I cannot say I had ever experienced in a class before. How could one possibly *reflect on the pre-reflective?* What did that even mean? And how could one possibly seek to understand something by stripping away your theories rather than working from them? The gleam of hope that I hung on to was that I had heard of Husserl, the father of phenomenology, during my courses in psycholinguistics. I had a vague memory of understanding the meaning of things through their thingness. For some reason the example of what is a chair stood out for me. In my time in linguistics we were doing semantic mapping, and we had to try and sort out what made a chair mean chair. How was a chair different from a couch or a stool? What was it that made it a chair without which it could not be a chair? It was this memory of the semantic analysis of chair with all its weblike structures that ultimately helped me to find an entrance to Husserl, Heidegger, Merleau-Ponty and most importantly to van Manen. Once again my earliest interests and my current destination seemed to be realigning.

I came to understand that the goal of phenomenology is not to provide evidence or to theorize but, rather, to evoke a sense of wonder in the familiar. To wonder deeply about what one had heretofore taken for granted. This was the transformational power of the seminar for me. I was led to be curious about the technology and the area of practice that I thought I *knew* well. I thought I understood much about SGDs and the practices that surround them. I suppose I do. But as I tried to understand phenomenology through the process of *doing* a preliminary study, I was surprised again and again about how I didn't know, how perhaps I couldn't begin to know, without having sought the lived through experience of using a SDG to speak.

Understanding the pedagogical imperative.

My year long struggle in coming to a place where I would truly feel confident enough to embark upon a phenomenological study has far too many moments of marvel to be recounted here. I must, however, address my reconceptualization of pedagogy at the hands of Dr. van Manen. His phenomenology is *of practice*, and that requires an understanding of the pedagogical orientation of one's work.

The word pedagogy was one that I had seldom heard during my early career. We did not speak of pedagogy in the field of AAC or even in the field of special education. We spoke of evidence-based practices and of interventions. Then I worked for a time at Alberta Education and the word pedagogy was used incessantly. People spoke of pedagogy as the methods of teaching or the practice of teaching. Good teachers had good pedagogy. They knew how do design and teach a lesson in a way that was engaging and appropriately challenging to the students in their classroom. For my world at the time good pedagogy meant appropriate use of technologies in the classroom including assistive technologies, and good pedagogy meant embracing the principles of UDL and putting them into practice in your classroom.

But this was not the meaning of pedagogy that I was introduced to by Dr. van Manen. For him, pedagogy had a different, broader, and most certainly a deeper meaning. Pedagogy describes all those affairs where adults are living with children for the sake of those children's well-being, growth, maturity, and development (van Manen, 1991, p. 28). This notion of pedagogy then extends well beyond educators and the knowledge and scripts that they employ in teaching. Pedagogy in van Manen's view related to the caring and reflective practices of all those who may be involved in bringing a child forth into the world of adulthood – parents, teachers, educational assistants, therapists, psychologists. For the children in my study, the children with CCN, it is not uncommon for scores of professionals play a role in their lives. And their interactions with the children had impact, not always positive. I was to consider how an approach that included pedagogical thoughtfulness might be brought to bear on my practices and ultimately to my field.

What I learned (and still am learning) is that to act with pedagogical thoughtfulness involves being a competent professional, with training and skills relevant to one's particular domain, but that is not enough. To come into a pedagogical relationship to a child one must also care deeply about the child and what they *are becoming* as they learn and grow. To come into a pedagogical relationship to a child one must have abiding hope and trust in the child's possibilities. And to come into pedagogical relationship to a child one must take, and be granted, caring responsibility that ensures the child's well-being and growth towards mature self-responsibility (van Manen, 1991). These notions go far beyond the notion of putting in place evidence based practices, or teaching parents and educators how implement AAC strategies. This understanding of pedagogy means entering into relation with the child, seeking to understand the meaning of their experience in their developing lives. Pedagogy also demands careful self-reflective approach to one's practices involving children and their families. It is this type of pedagogical orientation that guides and shapes the phenomenology of practice. It is the taking on of such an orientation that can result in one being changed in one's practice. I know this because seeking to understand and act pedagogically during the course of my research into the meaning of speaking through a SGD in the lives of young people with CCN has forever changed how I understand my work and what I understand my work to be.

The Question

I began with an overall question in mind. What is the experience of speaking with a machine by one who is severely speech impaired? While this certainly remains the driving question in my study, many other questions have arisen during the course of my investigation into this phenomenon. I have been guided by the lifeworld existentials (van Manen, 1997). How are SGDs experienced as *things* by those who use them to give voice to their thoughts? How do those who speak with an SGD experience speaking *space*? What is the *embodied* corporeal experience of speaking with a SGD? How does a SGD user come into relation with their device? What kind of relation is it? What is the experience of *time* when one must speak using a SGD? And perhaps the most important overall question is one of *lived-relations*? What does speaking through a SGD do to and for relations with others?

This study is primarily an account of the lived experiences of those living a profoundly technologically mediated life. The participants in my study move about in powered wheelchairs, write exclusively with the use of keyboards, and perhaps most crucial to their being in the world, they *speak* using a machine. Our ability, to speak to and with each other, may be the most important thing in the life-world of humans (Locke, 1998). If voice is indeed the most primary means of contact between human beings (van Manen, 1991, p.174), then what is the meaning of voice when one is called to express it through technologically mediated means? What is it really like to speak with (or perhaps, through) a machine?

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Chapter 2: Overview and Organization of the Text

This dissertation presents a series of papers focused various aspects of the life world of young people who augment communicative abilities with speech-generating devices. Each paper offers up different insights about the phenomenon of speaking with a SGD; each is also aimed at slightly differing audiences. All but one of the papers (Chapter 3) aims to maintain a primarily phenomenological focus. Some papers, directed more specifically to AAC professionals including speech language pathologists, educators and rehabilitation engineers, vary in method from what might be considered purely phenomenological writing. In this attempt to meet the expectations of the world of special education, and to make this study recognizable to the field as research based, the attunement to phenomenological writing at times veers more toward qualitative research that borrows from phenomenology, rather than being strictly phenomenological. Each paper is crafted to bring the reader ever closer to an understanding of the phenomenon at hand, and to be attuned to the thoughtful construction of texts that not only tell the reader something about the experience of speaking with a SGD but also to take one into the experience so that it may be understood and indeed so it might be recognized whether one is a *mouth talker* or an *augmented communicator*.

(1) **Communication and Literacy for Students with Complex Communication Needs.**

This article takes the place of what would traditionally be the literature review chapter of a dissertation. As the literature pertaining to the topic has been reviewed in of each subsequent papers, it was thought more valuable to have a chapter that would introduce readers to children and youth who have complex communication needs (CCN) and to the field of augmentative and alternative communication (AAC) in which this phenomenon is situated. This chapter also provides a review of some of the most current thinking in educational practices for students who use SGDs, in an attempt to bring to light some of the critical challenges they face in their school careers (and beyond).

This article is scheduled for 2016 publication in the *The Inclusive Educator*.

(2) **Phenomenology as the Method of Inquiry**

This chapter provides readers with an introduction to phenomenological methods as espoused by Max van Manen (2014, 2007). The particular methods and approaches used in this particular study were also described. Finally this chapter presents a reader unfamiliar with appraising a phenomenological text with some guidance to that end. While this chapter is not currently written as a publishable article, I hope to re-craft it as an example of *doing phenomenology* for the field of AAC.

(3) **Phenomenological Investigation Into Speaking With A Machine**

In this paper, I used McLuhan's notion of extension and amputation as heuristics for exploring themes that emerge from the lived experience descriptions of people whose abilities are extended through the use of Voice Output Communication Aids (VOCAs)[1]. This paper was one of my first forays into the phenomenon, one that was largely done during the phenomenology and writing doctoral seminar that I attended in 2010-11. The orientation is toward *postphenomenology* (Selinger, 2006) as it explores human-technology relations, and how these devices both extend the user's ability to speak while

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[1] In my earliest writings on this topic, I was referring to SGDs as VOCAs. While the field of AAC tends to use the terms somewhat interchangeably, in my more recent works I have intentionally chosen the term SGD as these devices would have computer generated (synthetic) voice, not digital recording of the voices of others. While not exclusively the case, it is far more common for the term VOCA to refer to devices (aids) that provide either kind of voice output.

simultaneously amputating what might be considered access to meaningful communication through voice.

This paper has been published in the proceedings of the *Centennial Conference 'McLuhan's Philosophy of Media'* (2012).

(4) **The Speech-generating Device**

This article presents an exploration of the SGD as a *thing* in the Heideggerian tradition (Heidegger, 1971). Borrowing from Heidegger's writing of *the thing*, the work of Peter Paul Verbeek (2005), and most particularly Ihde's writings on human-technology relations (Ihde, 1979), this paper explores the question of what an SGD is as it is called upon to do the ordinary every day task of speaking for one who cannot. In other words, what do SGDs do in the lives of the people who use them? This critical exploration of the transformational impact of SGDs is foundational to understand how they may mediate a person with severe speech impairments being in the world.

This paper has been accepted for publication in *Phenomenology & Practice*.

(5) **Out of Time in the Classroom**

This article explores the experience of lived-time for those who speak through an SGD. Lived-time is one of the existentials that can help in understanding the meaning of a phenomenon in the lifeworld of the person who experiences it (van Manen, 2014). van den Berg's treatise of *time* is used as a cornerstone for reflection. The work of Higginbotham and his colleagues is further drawn upon to provide insights and background to the phenomenon. The focus is to provide some understanding of the real demands of time placed upon young people who speak with SGDs, particularly the experience of time in the context of schooling.

The paper has been submitted to *Communication Disorders Quarterly,* and while the response was favourable, the editors asked that given its length that it be made into two papers. This will be attended to subsequent to the completion of my doctoral program.

(6) **What does the Non-speaking Child Say?**

This chapter focuses most particularly, although not exclusively, to the existential of lived relations. Unique in this chapter is a review of many of the published works from which anecdotes have been derived. It also presents reviews of studies that have sought perceptions of SGD use by adults who use them, by parents of children that use them, and by educators. While perceptions of device use are different from the lived experience of device use, these papers do help to establish what is currently known about what people think about SGDs. The chapter aims at going beyond the perceptions to provide educators and other professionals with a glimpse into the phenomenon of speaking with an SGD in the lifeworld of a child. It concludes with the presentation of a *key findings* that, while not strictly adhering to my chosen methodology, will hopefully make the chapter accessible and useful for those who may come into contact with a non-speaking child in the classroom.

This chapter has been published in the book *Advances in Special Education Technology* (Edyburn, 2014).

(7) **A call for pedagogical listening.**

The final chapter of this dissertation may be read as implications for practice in the broadest sense. This chapter calls for a pedagogical orientation to the phenomenon and to the children and youth who use SGD to communicate in their daily lives. Looking to the orienting methodology of phenomenology of practice (van Manen, 2014) and borrowing heavily from what has become known as *postphenomenology* (Rosenberger & Verbeek, 2015; Selinger, 2006) a call is made to professionals to seek the lived experience of those who use SGDs so that their inter-actions with them may come from both a cognitive or science focused knowledge base as well as an empathetic or personal understanding. This call is addressed not only to speech language pathologists and educators but also to the rehabilitation engineers who are tasked with developing the technologies themselves.

This chapter has not been written for publication but it is hoped that it may be subsequently re-worked for publication in *Assistive Technology: The Official Journal of RESNA*.

Chapter 3: Communication and Literacy for Students with Complex Communication Needs

Introduction

Most of us take the ability to speak for granted. To speak is to have a voice. To be understood by others through the use of our voice. From the time most of us are very young children, our primary means of communication is through speech. We talk with our friends. We whisper secrets. We shout and cheer at the top of our lungs and make our voices heard. We use our voice to share stories across space, and to tell our stories across generations. But what if you couldn't speak, or use your hands? How would you communicate? How would you prove that you could learn, that you have an opinion that you matter? (Ellis & Ellis, 2011).

As educators we may assume our students come to us with the ability to talk - to express themselves to us through speech. Spoken language is integral to almost every life experience, most particularly to schooling as "the basic purpose of school is achieved through communication" (Cazden, 2001, p. 2). Having speech and language (communication) skills allows children to express to others their wants and needs, and even more critically it allows them to interact socially with adults and peers (Locke, 1998). Speech and language provide the foundation for conceptual development and the foundations for more advanced language and literacy skills (Light & Drager, 2007).

But consider a child with complex communication needs, a child who can hear what is being spoken around them, but who, due to an unruly body, cannot coordinate the breath, sound and movement necessary to produce intelligible speech of their own accord. A child who in order to share their thoughts and opinions with the world must learn to express themselves through augmented means.

What is Augmentative and Alternative Communication?

Augmentative and alternative communication (AAC) includes all forms of communication (other than oral speech) that are used to express thoughts, needs, wants, and ideas (ASHA, n.d.). While it is not uncommon for people in the field of education to understand AAC as a tool or a device, the definition created by the American Speech and Hearing Association (ASHA) is much broader in scope:

> *... AAC refers to an area of research, clinical and educational practice. AAC involves attempts to study and when necessary compensate for temporary or permanent impairments, activity limitations, and participation restrictions of persons with severe disorders of speech-language production and/or comprehension, including spoken and written modes of communication. (ASHA, 2005)*

We, who use speech as our primary mode of communication, also use forms of AAC in our daily lives. We may jot a note to someone when it is not appropriate to speak to them out loud. We may draw a picture to further explain a concept where our words fail us. We are also constantly using gestures and other non-verbal communication to support (or perhaps refute) the messages we are sharing with our speaking voices. The difference is that those with severe speech impairments or complex communication needs (CCN) may find the use of AAC systems and supports critical to achieve their daily communication needs.

A distinction is commonly made in the field of AAC between aided communication and unaided communication (Johnston, Reichle, Feeley, & Jones, 2012; Loncke, 2014). *Aided communication* refers to the use of materials, equipment, and/or devices that are external to the communicator's body. Examples of aided communication include the use of a notebook and pencil to compose messages, communication displays that may use pictographic or orthographic (letters and words) symbols to select and compose messages for others to see and/or read, and/or electronic or computer based speech-generating devices that speak the composed selected messages out loud. Unaided communication refers to methods of communication that do not involve any additional materials. Examples of unaided communication methods include the use of natural speech, gestures and manual signs or signals. While *sign language*, for example American Sign Language (ASL), can be included as a method of AAC, it is important to note that sign language is exactly that, a language. If one is going to expect a child with complex communication needs to use *sign language* as their primary modality, this should take place in a context where it is also used by other people in the child's community (parents, teachers, peers, etc). More will be said on this topic when discussing the importance of immersive language learning.

Who are students with Complex Communication Needs?

The population who may benefit from both AAC and assistive technologies (tools for aided AAC) to support communication and language development are referred to as having complex communication needs (CCN). Perry, Reilly, Cotton, Bloomberg, and Johnson (2004) provide the following useful definition of complex communication needs:

> *People who have complex communication needs are unable to communicate effectively using speech alone. They and their communication partners may benefit from using augmentative and alternative communication (AAC) methods, either temporarily or permanently. Hearing limitation is not the primary cause of complex communication need. (p. 261)*

There are many important elements to note in this definition. AAC systems can *augment* existing speech skills. Some people who have CCN may indeed speak. Some may be very hard to understand and therefore use AAC supports to communicate with unfamiliar partners or in certain contexts. For example, a child with severe apraxia of speech may use a letter board to help people understand what they are saying in some instances, and a speech generative device when they are speaking to unfamiliar people or to a group of people. Some children with CCN do have a few words that they can speak, some may refer to these children as “minimally verbal”. These

few words, however, will not be sufficient to meet their daily requirements for interacting with friends or engaging in learning experiences. AAC supports will also be important for these children.

For some people AAC can provide an *alternative* to speech, for example people who cannot for various reasons produce intelligible speech. This may be because of severe cerebral palsy, or the result of an acquired condition such as amyotrophic lateral sclerosis (ALS), for example Steven Hawking, or it may be due to other conditions such as autism. As more is being learned about people with autism, there is evidence showing that there is a relationship between autism and apraxia of speech (Tierney, Mayes, Lohs, Black, Gisin & Veglia, 2015). While this relationship exists there are some people with autism who cannot speak (Rudy, 2015). There is emerging evidence that the provision of AAC systems, and in particular voice output systems (for people with autism plus CCN) not only help them communicate but such systems also have a positive effect on reducing challenging behaviour (Ganz et al, 2014; Kasari et al, 2014).

AAC supports speech (and language) development.

AAC supports may be required for a lifetime or may only be needed for a shorter time. For a child with severe cerebral palsy AAC supports may be their primary means of communication throughout their lives, as their bodies may never allow them to coordinate the various muscle movement to produce intelligible speech. For some children, AAC supports will be a temporary scaffold to use while they are acquiring the ability to be understood through speech. A common myth is that using AAC, especially for young children, will delay their speech development. In fact studies show that the use of AAC actually improves speech development where possible, and providing and supporting AAC *improves language development* in all cases. Schlosser and Wendt (2008) undertook a systematic review of the research in the area and found that the best evidence indicated that AAC interventions *do not* have a negative impact on speech production in children with autism. Romski and Sevick (2005) looked specifically at the provision of AAC supports to very young children and also concluded that providing AAC supports to young children do not delay speech and may enhance development of spoken communication.

AAC is a joint venture.

Perry et al.'s (2004) definition points out that AAC involves both the person with complex communication needs and their communicative partner(s). Communication is a dynamic process involving two or more partners. People with CCN must rely on the skills of others to help them be a part of a conversation (Iacono, 2014, p. 83). Due to their unique and complex communication needs, the roles of communication partners and their need for training are particularly important (Goldbart & Caton, 2010).

The importance of instruction for communication partners is widely recognized in the AAC literature (Binger, Kent-Walsh, Ewing & Taylor, 2010; Bruno, 1997; Kent-Walsh, Murza, Malani & Binger, 2015). While the focus often seems to be on the person who requires AAC, without partners who understand how the AAC system works, how to model and support its use in context, and the opportunities and challenges the system involves for the user, success in using the system will be limited (Light, 1998). Research shows that for many individuals with CCN, typical interaction patterns include taking relatively few turns in a conversation, infrequently initiating or even responding in an interaction, asking few questions, and using a restricted number of linguistic forms (Chung, Carter, & Sisco, 2012a; De Bortoli, Arthur-Kelly, Mathisen, Foreman & Balandin, 2010; Myers, 2007)

Kent-Walsh, Murza, Malani and Binger (2015) undertook a meta-analysis of the effects of communication partner instruction on the communication of individuals using AAC. They found that communication partner instruction has positive effects on communication performance of individuals using AAC, and that communication partner interventions can be effectively implemented across a range of communication partners, including caregivers, educational assistants, parents, peers, and teachers. The authors conclude that partner instruction should be viewed as an integral part of AAC assessment and intervention.

Hearing impairment alone is not the issue.

While people with CCN may indeed have hearing impairment, hearing impairment alone does not constitute complex communication need. People who are hearing impaired may use AT such as hearing aids to help them learn language and communicate effectively. People who are Deaf may learn ASL. People with hearing impairment may indeed become bi-lingual, communicating in both ASL and English (for example) even though their language learning and use is in one primary modality. But for people with CCN it is more complex than just requiring AT or learning another language in which to communicate with other speakers of that language. For people with CCN they are getting language input in one modality (spoken language) while they are having to learn to express themselves in another (AAC symbols or text). This makes learning to understand and use language much more complex. While people who speak or use sign language to communicate must become competent in the linguistic structure of their language, people with CCN who use AAC must gain competence in the auditory language that is spoken all around them, while also gaining competence in an aided language system to express themselves. Janice Light (1998) suggests that people who use AAC must develop this dual track linguistic competence as well as social competence (pragmatics), strategic competence (what they can say with the "words" they have in their system), and operational competence of the aided system. All communicators must develop linguistic and social competence (Hymes, 1972) but people with CCN who use AAC have additional competency burdens to become effective communicators.

So who are these students?

In her exploration of what it means to have complex communication needs, Teresa Iacono (2014) suggests that due to the "unfair nature of disability" (p. 82) challenges often come in multiples. Students in our classrooms with CCN may also have vision impairment, hearing loss, physical challenges, intellectual disabilities or some combination of any number of impairments that impact their lives and learning. As the complexity of the disability increases, so does the complexity of communication needs, finding an appropriate alternative system (Iacono, 2014, p. 83), and adequately preparing their communication partners.

In the early years of AAC the primary recipients of AAC systems and devices were people with severe physical limitations due to conditions such as cerebral palsy. Today there is a growing understanding that children and youth with developmental disabilities, autism, and those who have multiple disabilities may also require AAC in order to support the development of their communication and language abilities (Ganz, Earles-Vollrath, Heath, Parker, Rispoli & Duran, 2012; Wilkinson & Hennig, 2007). There is also a growing understanding of the value of

AAC supports and services for infants and toddlers at risk of developing complex communication needs (Romski, Sevcik, Barton-Husley, & Whitmore, 2015). While the number of children with CCN is relatively small (Binger & Light, 2006; Matas et al, 1985), there is a growing understanding that many of the students who we used to consider *non-verbal* or *minimally verbal* should be provided with AAC systems and supports in order to help them communicate, grow their language, and support their literacy development.

Foundational beliefs

Providing communication and literacy for every child is based on the foundational belief that every child communicates, every child is capable of learning a symbolic language system, and that every child is capable of learning at least emergent literacy skills. When the field of AAC was first developing it was believed that a child (or adult) needed to demonstrate certain skills and/or abilities to be seen as a “candidate” for AAC. For example, in the early 1980s the belief was that a child must demonstrate at least Stage 5 sensorimotor intelligence, and if they could not, AAC systems were not recommended (Glennen & DeCoste, 1997). Today, in contrast, we understand that any person with complex communication needs is a candidate for AAC. In fact, research clearly shows that the provision of AAC supports and services can benefit every child with CCN (Ganz, 2015; Romski & Sevcik, 1996).

Why the Programs of Study (curriculum) matters.

For many years in the field of special education there was a belief that some students would need a specialized curriculum, often referred to as functional or life skills. With the movement in the United States, in particular, to every child needing to make progress in the *general education* curriculum, this notion of a specialized curriculum has been brought into question. While in theory a specialized or personalized curriculum may not appear problematic, the reality is that such a curriculum often lacks continuity because its content depends on the preferences and philosophies of educational staff (Beukelman & Mirenda, 2013). When a teacher creates a new individual plan every year that is not based on the programs of study, there is a great chance that the student's education may be lacking the scope and sequence, and recursive structure that is built into a well designed curriculum. Many times when children are "not in curriculum" they are at risk of developing splinter skills. For example, in the world of special education there has been a tendency to teach students with more significant disabilities mastery of one isolated skill, such as memorization of the alphabet or list of sight words in the hope that they may appear more age-appropriate (Kraderavek & Rabidoux, 2004). The special education literature is replete with studies demonstrating that individuals with significant disabilities can learn to identify sight words in isolation (Browder & Spooner, 2006), yet there is question about whether these skills contribute to future conventional reading and writing abilities. Current thinking suggests that students should be actively involved in constructing their understanding of print, language, and the connection between the two by interacting with more literate others across multiple contexts for multiple purposes (Erickson, Hatch & Glendon, 2010). This is exactly the kind of thinking that is involved in the development of the current English Language Arts Programs of Study in Alberta (see http://www.learnalberta.ca/ProgramOfStudy.aspx?lang=en&ProgramId=404703#) where it states:

> *Language development is continuous and recursive throughout a student's life. Students enhance their language abilities by using what they know in new and more complex contexts and with increasing sophistication.*

We now know that this is true for every child including students with CCN and significant developmental disabilities. While student with CCN may take longer to be successful with symbolic communication, language, and literacy, research shows that with high expectation, comprehensive instruction and the support of assistive and communication technology, even children labeled as being intellectually disabled acquire literacy skills and demonstrate intelligence beyond what would have been predicted by their test results (Bilken & Cardinal, 1997; Erickson, Koppenhaver, & Yoder, 2002).

Presuming Competence.

Without doubt the most important thing we can do to help every child communicate and gain literacy skills is to presume competence. Presumed competence, according to Bilken and Burke (2006) is a kind of contract between the teacher and student to choose the most optimistic stance possible. We presume competence when we provide a child with CCN with an AAC system that includes a robust *language system* instead of a limited number of words. We presume competence when we provide a child with CCN and developmental disability with comprehensive literacy instruction beyond sight word memorization and copying text. We presume competence when we provide alternative pencils to children with physical disabilities who cannot pick up a pencil, so they may engage in scribbling and other emergent literacy activities. It is commonplace for parents and educators to approach children without disabilities as competent. Teaching literacy is carried out within the expectation that most, if not all, children are capable of developing communication and literacy skills (Bilken & Burke, 2006). Traditionally for too many students with disabilities (including many with CCN) we may have presumed *incompetence* and forced the person with a disability to prove they can before they are provided the opportunity to try. Donnellan (1984) suggests that presuming competence is the *least dangerous assumption*:

> *Given that the long-term goal of education is to ensure that students acquire the skills necessary to be able to live, work, and recreate as independently as possible as adults;*

> *and given that there are a variety of educational means or strategies currently available for instruction; and given that, through the lack of conclusive data, we are currently forced to make assumptions about relative impact of various strategies on the long-term goals, which assumptions will have the least dangerous effect on the likelihood that the goal will be attained. (p. 148)*

Yet is seems educators may fall into the presumed incompetence model where issues of *readiness* may stop educators from providing rich and challenging experiences that will support students with CCN to become more competent. The *readiness* paradigm might lead educators to hold students back from language and literacy experiences until they can demonstrate certain skills and abilities. Yet even today there is little evidence to support that students with disabilities learn differently than any other student. We certainly do not make students without disabilities prove they can learn before we let them try, therefore as Donnellan (1984) suggests the least dangerous assumption for every student is to presume they can learn, given robust communication supports and comprehensive literacy instruction.

Communication, Language & Literacy

> *For people with disabilities, the consequences of not being able to speak or not being understood are far-reaching and often serious. Their complex communication needs require urgent attention. (Iacono, 2014)*

Communication matters!

Communication is both a basic need and a basic right of all human beings (American Speech- Language-Hearing Association, 2014; United Nations, 2008). Any consideration of quality of life must take into account the degree to which individuals can effectively communicate with, and thus be full participants in the community in which they live (Brady et al., 2016). Communication is the transmission of a message or information from one to another person. Communication may or may not be intentional. Someone's facial expression may communicate unintentional information to another person when one is trying to keep a secret or is telling a lie. Communication for all of us, including those with CCN, may involve conventional or unconventional signals, may take linguistic or non-linguistic forms, and may occur through spoken or other modes (Brady et al., 2016).

Communicative behaviours begin as soon as a child is born. Parents respond to the movements, coos and smiles or tears of their infants, attributing meaning and giving meaning. A parent may say to a squirming child, “oh I see you are uncomfortable”, and the child may then learn a word for the feeling of their body that caused them to move. A parent may see a young child rubbing their eyes and tell them, “I think you are tired, time for bed”. In this instance it is usually not the case that the child was trying to communicate that message, but their body movements spoke for them.

Pointing may be the singularly most important gesture for young children both as an expressive means of communication (look at that, I want that) and to gain receptive understanding of the world (when they point mommy labels what they are pointing at). Spoken language develops as these non-verbal methods are being used and responded to by the speakers in the child’s world. While there is evidence that children come to the world with certain predispositions that enable them to become fluent in language, if they are not in a language-using environment, they will not develop this capacity (Bransford, Brown, & Cocking, 2000). While all children may be *primed* to learn language, they cannot do so in a language vacuum. Language does not grow out of silence (Zangari, 2016) and this may be particularly challenging for children and youth with CCN.

Aided Language Stimulation.

Children with CCN may not be able to provide or respond to the non-verbal and early verbal modes that typically developing children do. They may be challenged to point, or follow a point to jointly attend to something. They may not be able to produce verbal word approximations that will be responded to by those around them as meaningful. They may be developing in a world that is bereft of the natural modeling and responding that is provided to children who will become speakers (or signers if they are deaf growing up in an ASL environment). While adults and peers *speak* to children and youth with CCN, it is not yet common to have people communicate with them using an aided language modality. Yet, just as young children must be exposed to speaking models (or signing models) children with CCN have to be exposed to AAC before they can be expected to use it themselves (Sevcik & Romski, 2002).

There is now a substantive body of evidence supporting the idea that adults (parents, teachers, SLPs, assistants) should be modeling the use of a child’s AAC system just like we model the use of our oral language system for typically developing children (Dada & Alant, 2009; Harris & Reichle, 2004; Jonsson, Kristoffersson, Ferm, & Thunberg, 2011). Typically developing children learn language not only through structured explicit opportunities in supportive interactions but also implicitly, through over-hearing and observing language in their environment (Smith, 2015). Children with CCN are no different in how they learn. Yet, despite this robust evidence base, aided language stimulation or modeling of the AAC system is not often the norm in practice. Children and youth with CCN are expected to learn to use to communicate in symbols with little or no exposure to seeing others use these systems communicatively. And too often, if children with CCN do not quickly express themselves using the AAC system, the determination that they are not capable of using it may be made. When one considers that a typically developing child may take up to two years of being immersed in speech before they speak a word, it is rather strange for us to expect a child with a disability (especially a cognitive disability) to use an AAC system expressively with minimal to no exposure. Talking to children with CCN using AAC systems to let them know how you are interpreting their communication (intentional or not) can help them to learn about the communicative process in general, and about symbolic methods that can lead to increased communication and importantly to language development.

Communication is more than making choices and requests.

A very common way that AAC supports are introduced to students with CCN is to provide a symbol or series of symbols that the student can use to make requests (e.g. PECS, choice boards, etc). While expression of wants and needs is one of the functions of communication and language, it is for most of us far from the most important one. Consider the last time you had a conversation with a friend or perhaps even a new acquaintance. Did you make requests or express your wants and needs?

Perhaps, but it is far more likely that you asked some questions, answered others, made comments, shared information and/or shared your feelings. It is critically important that we provide opportunities for students with CCN to engage in the full range of communicative functions using their AAC systems. This means modeling of, and providing for, the full range of communicative functions that all children engage in as they are learning to be competent communicators: answering questions, asking questions, making comments, giving directions, sharing feelings, sharing information, protesting, refusing and making requests. Yet despite this, research suggests that for students with disabilities we are focusing almost exclusively on teaching students with speech-generating devices requesting skills (Jenkins Rispoli, Franco, van der Meer, Lang, Pimentel & Camargo, 2010). This may be because teaching commenting and other social functions is more difficult (Brady et al., 2016) but if we expect children and youth with CCN to become competent communicators and to gain the language skills they need to participate in learning, it is critical that we support them in developing all functions of communication.

It is also important that we provide opportunities for children and youth with CCN to refuse, to say no (Loncke, 2014). This skill is particularly important to support development of a sense of self, agency and autonomy. It also may be an important skill to keep them safe. People with CCN may be particularly at risk of abuse (Sobsey, 1994), so learning to say “no”, along with having the ability to share real information with others, may be some of the most important life skill we can provide.

Language is the key to literacy.

Oral language is the foundation of literacy. Through listening and speaking, people communicate thoughts, feelings, experiences, information and opinions, and learn to understand themselves and others. Oral language carries a community's stories, values, beliefs and traditions (Alberta Education, 2000).

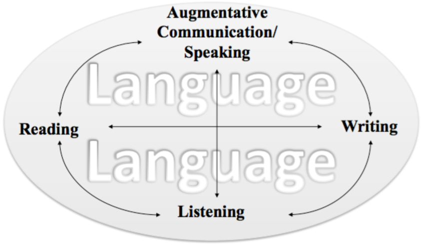
Children who need AAC in order to express themselves in and through language are often at a significant disadvantage as they enter into school. Unlike speaking children who come to school ready to build upon the foundation of their oral language skills, many (most) children with CCN do not come to school with means of expressing (oral) language as they have not yet been provided with an AAC system upon which their language can be built. They have been immersed in a spoken language environment but must develop and use an expressive language system in another modality, one in which, as previously noted, they may receive limited input

(Romski & Sevcik, 1993, as cited in Smith, 2015). Even for those who have an AAC system that includes a speech-generating device (SGD), there are still many challenges in using their systems to speak (Look Howery, 2015; Smith, 2015). Speaking through a SGD requires additional physical and cognitive skills and abilities.

The interconnectivity of language development.

The figure below presents the model developed by Koppenhaver, Coleman, Kalman & Yoder (1991). This model explicitly shows that language develops in the interconnections between speaking/augmentative communication, listening, writing, and reading.

Figure 4. Oral and Written Language Development in the Common Core (Koppenhaver, Coleman, Kalman & Yoder, 1991)



Oral and Written Language Development
In the Common Core
(Koppenhaver, Coleman, Kalman & Yoder, 1991
adapted from Teale & Sulzby, 1989)

Students with CCN who are using AAC systems need to experience talking about books they are exploring/reading, talk about their writing, and talk about what they are hearing and learning through listening. This is all a very interactive process that requires support across time and environments. Like all students, students with CCN need ongoing comprehensive instruction in reading, writing, speaking, listening, and language (Erickson & Koppenhaver, 2015, personal communication). This instruction is based on the intentional use of robust AAC systems that are supported through modeling and intentional teaching of vocabulary in and across multiple contexts.

Core vocabulary.

A relatively recent approach to providing language intervention for students with CCN who may not have a robust language system is to provide them with access to core vocabulary across a variety of contexts.

> *Among the many changes that the AAC field has experienced in the last decade is the notion that core vocabulary is (or should be) an integral part of any AAC system. We grew to understand the limitations of AAC supports that consist primarily of nouns and descriptors, realizing that those kinds of communication displays restricted our clients to requesting and labeling. (Zangari, 2013)*

A core vocabulary is comprised of the words that are used most commonly in expressive communication (Yorkston, et al., 1988). Fallon, Light & Kramer Page (2001) found that for typically developing pre-schoolers, the 250 most frequently occurring words accounted for 89% of the total sample of language used by the children. In fact, a mere 25 most frequently occurring words were found to account for 44% of the entire sample. Their findings and the finding of others who study word use in context suggest that a relatively small set of words make up the bulk of speech, and that these *core words* can be used across multiple context and for multiple purposes (DO IT, WANT IT, GO THERE, NOT GO THERE, etc). Fringe vocabulary, which is also required in a complete language system, involves the words we use to communicate about specific topics in specific contexts (e.g. scissors, paper, and marker for art class; fork, drink, and napkin for meal time). Zangari (2013) notes that teaching words like *it, do*, and *not* is a lot different than teaching words like *cookie* and *bubbles*. However, throughout the day there are many more opportunities to model, use and teach these core words than using the once pervasive activity boards made up of nouns. Core vocabulary also lends itself to many repetitions of use of vocabulary in many different contexts and with many different people. This is the kind of learning that supports understanding (Erickson, 2015, personal communication).

Literacy

For a person who uses an AAC system to be able to construct novel messages outside those that are stored in their device, they must have some literacy skills. Yet, students with CCN are at risk in multiple areas of development, including the development of literacy skills (Light & Drager, 2007; Smith, 2005). In 2000, David Koppenhaver challenged the field of AAC to embrace the notion that literacy is *included within* AAC.

> *If "communication is the essence of human life" (Light, 1997), then literacy is the essence of a more involved and connected life. (Koppenhaver, 2000, p. 270)*

He points out that AAC users communicate through composing – that is they create texts either by stringing together a series of picture symbols or by stringing together letters and words. Sometimes these texts are then spoken aloud through the use of text-to-speech software, sometimes they are understood (or not) by the communication partner who is following along in the text (message) construction. Literacy is *in* AAC (Koppenhaver, 2000) and literacy development is vital to AAC users (Hetzroni & Tannous, 2004; Erickson, Hatch & Glendon, 2010; Light & McNaughton, 2014; Smith, 2005).

Literacy is a critical goal for children and youth with CCN for a number of reasons:

1. Literacy is a foundational skill for learning (Alberta Education, 2000).
2. Without the ability to spell, even the most advanced AAC users may not be able to say what they want due to the limitation of vocabulary that is available to them on their device (Look Howery, 2015).

3. Opportunities for meaningful and interactive participation in inclusive educational, work, or social environments are severely restricted when AAC users cannot produce or interpret texts (Koppenhaver, 2000).
4. Literacy affords access to the social media experiences that are integral to the lives of children and youth in the 21st Century (Hetzroni & Tannous, 2004; Light & McNaughton, 2014).

There is increasing evidence suggesting that even children and youth with CCN and significant intellectual disabilities can learn literacy skills at the emergent level (Erickson, Koppenhaver, Yoder & Nance, 1997; Erickson, Glendon, Abraham, Roy & Van de Carr, 2005; Fallon, Light, McNaughton, Drager & Hammer, 2004). For children with CCN, emergent literacy skills may take longer to develop and will take intentional and explicit instruction. Students who are at an emergent level of literacy are working to understand functions of print and print conventions, phonological awareness, and alphabet knowledge (Erickson, Hatch & Clendon, 2010). Students with CCN may also require time spent in shared reading, which involves active interaction with/in the reading experience. In order to be actively engaged in emergent literacy activities, the modeling and use of AAC systems is critical. Students cannot talk about the books, ask questions about their learning, comment and share about their explorations of text without symbolic representation of language using their AAC system.

Research also clearly demonstrates that students with significant intellectual disabilities can make progress in conventional literacy when they have access to comprehensive instruction (Erickson, Hatch & Clendon, 2010). Yet the fear is that students with CCN rarely have access to comprehensive instruction. When they do receive conventional literacy instruction, it tends to involve mastery of lists of sight words or skills taught in isolation (Erickson, Hatch & Clendon).

Koppenhaver and Erickson (2007/2015, personal communication) argue that daily instruction that includes use and modeling of AAC systems, guided reading, word study, writing and self-directed reading is critical for students with CCN to develop conventional literacy skills.

Literacy is the key to autonomy.

The question of which symbol set will provide a student with CCN the ability to generate autonomous authentic messages often arises, especially now that so many AAC applications (apps) with various language sets are available at relatively low cost. The answer is that there is really only one truly generative set of symbols, and that is the letters of the alphabet (26 symbols in the case of the English language). Until a person with severe speech impairment is able to spell what they need to say, until they are literate, they are limited by the words they have in their device. Once children with CCN can use the alphabet, even if they are not proficient spellers they can generate their own messages rather than being limited to choosing from the words and phrases that are provided for them by others. Selection of vocabulary has long been a challenge in the field of AAC (Beukelman & Mirenda, 2013). Today with the understanding of the importance of aided language stimulation (modeling the child's language system) the field is beginning to recognize that even emergent communicators need to have access to a language system and see this system in use. Until the child is literate, the words and phrases are always given to them, not truly acquired in the way a typically developing child would acquire vocabulary. Becoming literate, understanding how to combine those 26 symbols (letters) to make understandable words/word approximations is the key to having an autonomous voice in the world.

When the field of AAC was emerging 30 years ago, the focus was primarily on maximizing the communication of children and youth with CCN in face-to-face interactions.

Today there is increased recognition that communication needs extend to written communication to meet the demands of school; share media experiences such as Facebook, establish membership in peer communities through texting, expressing updates and opinions through Twitter, and the like (Light & McNaughton, 2012).

Literacy means literacy.

A common practice has been to provide access to information through symbolated text and access to writing through use of AAC systems. What we now know is that providing symbols with words, while perhaps helping students to gain access to the meaning of the text, does not help them learn to read (Erickson, Hatch & Clendon, 2010). In fact, there is evidence to show that putting symbols with words interferes with childrens' literacy learning as they pay attention to the symbol not the text (Erickson, Hatch & Clendon, 2010).

Another common strategy to help students with CCN *write* is to have them use their communication devices as keyboard emulators. That is, they send words to a document by choosing symbols on their devices. While this has the appearance of writing (i.e. the text appears as text) the student is at best practicing communicating with their device, and perhaps at worst coming to the conclusion that they and/or their teachers do not see the need to spend time and effort learning to write in conventional methods. But without the ability to spell, people with CCN can only say or write with the words they are given. This will not give them the ability for autonomous speech, or get them actively into the world of social networking (Facebook, Twitter, etc.), both of which are so important in their developing into active and engaged citizens in today's technological world (Additional information on supporting literacy development for students with CCN and/or significant disabilities studies can be found at: https://www.med.unc.edu/ahs/clds).

Best Practices in AAC Supports

The historical context in which educational teams have operated meant that students with CCN were often not viewed as capable learners upon entering school. Literacy may not have been a significant component of their special education programs, or certainly for their ongoing school careers. It was not understood that children who could not speak were capable of learning and applying phonics. Moreover, skills were often taught in isolation through repetition (massed trials) and feedback (Erickson, Koppenhaver & Yoder, 2002).

It takes a team!

The AAC literature clearly supports the establishment of a multi-disciplinary team to provide AAC supports and services (Beukelman & Mirenda, 2013; Loncke, 2014; Lund & Light, 2007; McSheehan, Sonnenmeier, Jorgensen, & Turner, 2006). For children and youth who use AAC systems, the educational team must work together to integrate an often complex array of technologies used for learning, mobility, and classroom participation (Erickson & Koppenhaver, 1995; Soto, Muller, Hunt, & Goetz, 2001; Stoner, Angell & Bailey, 2010). The ability of teams to successfully collaborate has been linked to positive long-term outcomes for students with complex communication needs (Lund & Light, 2007). Bailey, Stoner, Parette and Angell (2006) found effective teaming to be a primary facilitator of effective AAC device use by students in junior high and high school. Collaborative practice involves more than having a group of professionals linked together as a team. Teams that supported effective AAC use functioned well together, communicated frequently, and were focused on increasing the communication skills of their students. The majority of research suggests collaborative relationships are highly valued and even encouraged. Despite these findings, the reality in the classrooms suggests that successful partnerships often elude educational teams (Fallon, 2008). Teaming often takes the thing that is most challenging for educators to find, time. But without time to develop teams, work as teams, and problem solve as teams, the child who needs AAC to communicate, participate and learn may never get the instruction, supports and services they need to succeed. This participation and learning time is something these students may lose forever.

Parents and peers are also critical members of the team. Research suggests that too often parents are not actively engaged in decision making around AAC and/or not supported helping their child learn the system (Bailey, Parette, Stoner, Angell, & Carroll, 2006; Cress, 2004; Goldbart, & Marshall, 2004). Parents have critical knowledge of their children that must be sought in developing an AAC system. Also, much of the ongoing responsibility of ensuring use of, and support for, AAC systems falls to parents and family members.

There is a growing body of literature on the importance of peer interactions for children and youth with CCN, and how to foster these critical social interactions (Chung, Carter, & Sisco, 2012a; Chung, Carter, & Sisco, 2012b). While the evidence to date suggests that students with CCN engage with paraprofessionals and other adults far more than with their peers, there are promising practices such as intentional engagement of peer supports (Carter, & Sisco, 2012b) and creation of communication circles (Musselwhite, 2013) that may help children and youth with CCN to more actively and successfully engage with their peers. Today we know that with the intentional provision of teaming, time, and appropriate instructional practices that "no student is too anything to be able to read and write" (Yoder, 2000. DJ-Albenet Lecture, ISAAC).

It takes time!

By 18 months of age babies have heard 4389 hours of spoken language, yet we do not worry if they have not spoken even one word (Korsten, 2011). If AAC learners only see symbols modeled for communication twice weekly for 20-30 minutes, it will take *84 years* for them to have the same exposure to aided language as an 18 month old has to spoken language (ibid). It takes time for any child to learn a language, understanding comes first (receptive language) and use (expressive language) follows years of exposure and exploration in form, function and purpose. For children and youth who need to use AAC supports and strategies expressively we often expect that they should be using their device or their language system right away, yet if one considers the context this in fact seems rather absurd. We need to give children time to learn the system and time to explore using the system, just as we do for typically developing children. And given the complexity of learning a *second* language system (the AAC system) with the additional cognitive and operational demands of speaking with AAC it seems we most likely need to give our students with CCN much more time to explore and understand their systems, certainly not less.

The same point must be made for the time it may take students with CCN to develop their literacy skills. Expertise occurs only with major investments of time for any learner, no matter what abilities or *dis*abilitites the person brings to the task (National Research Council, 2002). While every child can learn, it may take some longer, sometime a great deal longer than others.

Given many issues that they may face, not the least of which may be inadequate instruction, it may take children and youth with CCN many years to gain emergent literacy skills and many years after that to become conventional readers and writers. There is some evidence that for some students with CCN their greatest gains in literacy may come in their early teens (Erickon, 2015, personal communication). This makes sense given that they may have been spending much of their lives learning to use their AAC systems, and learning language. Yet, too often by the time students with CCN are in junior and senior high the focus has moved from literacy instruction to *life skills*. Given the primacy of literacy as a life skill for a person with CCN, educators and SLPs must assume competence and believe that it is never too late to provide comprehensive literacy instruction to any student, no matter what challenges they may have.

Teaching involves setting the context for learning.

> *Precisely because of the history and power of behavior analysis in shaping the field of special education, professionals have not given a great deal of thought to how students with severe cognitive disabilities think.*
>
> *Kleinert, Browder & Towles-Reeves (2009, p. 305)*

Much of how we teach children and youth with CCN, especially those with developmental disabilities, is at variance with how we teach typically developing children. The world of special education has relied heavily on a behavioral paradigm, whereas theories on how children learn, especially how they learn language have refuted strict behavioral models in favor of cognitive and social learning theory. In the so called *general* education paradigm we understand that children need to attach the new to the known, they learn through doing, and that learning is a social activity that is best supported by a more knowledgeable other (Miller, 2002). While in the past, primary emphasis was on drill and practice, modern theories of learning and transfer retain the emphasis on practice, but they specify the kinds of practice that are important and take learner characteristics (e.g., existing knowledge and strategies) into account (National Research Council, 2002). The research suggests that “arranged contrasts can help people notice new features that previously escaped their attention, and learn which features are relevant or irrelevant to a particular concept" (National Research Council, p.60). While massed trials, and repeated exposure with choice making (e.g., food choices, clothing choices) and communication introduced through requesting have long been staples in the educational menu provided to students with significant disabilities, recent information suggests this may not provide the conditions for learning that are required for success. We now understand that learning happens when we learn patterns through experience, not isolated drill. We also know that slight variations in a known pattern are likely to cause a learner to pay attention, something that is new but not so new that we cannot assimilate it into our current schema (Burkhart, 2015). A confirmation of this comes from a recent study exploring perceptual learning in people with autism. It not only confirms that the benefits of slight variation in learning stimulus is beneficial, but that repetitive presentation of the same stimulus to high-functioning adults with ASD actually reduces their efficiency in learning (Harris et al., 2015).

Learning happens best when children are supported by more capable others who respond to where they are at and provide experiences and scaffolds that help them extend their understanding through repetition with variety (Erickson & Koppenhaver, 2015, personal communication).

There is no magic technology.

> *Mere access to the content is inadequate as an AT unless that access is mediated by instructional design supports appropriate for the specific disability of the user.*
>
> *(Boone & Higgins, 2007, p.138)*

Perhaps, especially into today's world of pervasive technologies, it seems that the most important thing is to provide a child with CCN with assistive technology and most particularly a speech-generating device of some ilk. While access to appropriate assistive technology tools and access to voice output systems may indeed have significant benefits to students as they engage with print and books and as they are provided opportunities to share their voices with others (Erickson, Hatch & Clendon, 2010; Romski & Sevcik, 1996) technology alone will do little to help a child learn to communicate, learn language and become literate. Learning to use assistive technologies and AAC devices takes effort and time, there is no magic (Higginbotham & Caves, 2002). But the research clearly shows that technology *in conjunction* with a comprehensive approach can make a huge difference in the lives of people with CCN. The statement made 20 year ago by the Alliance for Technology Access is as important or perhaps more important in today's world of apps and high powered tablet computers.

> *The success of technology has more to do with people than machines. All the right parts and pieces together won't work miracles by themselves. It is people who makes technology powerful by creatively using it to fulfill their dreams. (Alliance for Technology Access, 1996, p. ii)*

It will be through the concerted efforts and dedicated time of parents and educational teams that children and youth with CCN become competent communicators, active learners, and ultimately adults who can self-advocate and have an autonomous voice in the world.

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Chapter 4: Phenomenology as the Method of Inquiry

> *In all research, including in traditional (experimental or more positivistic) research, there comes a moment when the researcher needs to communicate in writing what he or she has been up to* (van Manen, 2014, p. 363).

The purpose of a methods chapter is to inform the reader about how the study was undertaken while providing some evidence that the path was well constructed and sound. In the fields of special education and rehabilitation medicine the reader of a dissertation methods chapter may expect a particular structure.

In human science inquiry the purpose of a methods chapter is similar – to communicate with others what the researcher *has been up to* – but the discussing or sharing the methodological procedures or perhaps better stated pathways, may well deviate from what is commonly expected in the domains of science, education and social sciences. Phenomenological scholars such as Heidegger and Merleau-Ponty warn of an over reliance upon or expectation of a set of standard strategies and techniques. Heidegger (1982) suggests that each inquiry demands a unique approach in order to provide access to the objects (phenomena), and that once used that approach becomes *obsolete*. Merleau-Ponty (1958/2002) seemingly contradicts these statements by suggesting that there is some method to phenomenology, indeed he tells us that “phenomenology is only accessible through a phenomenological method” (p.viii). So what can be made of this? You do the study by doing it? And once you have done it, is that approach obsolete, of no further value? This all may seem rather strange. Yet perhaps not strange at all if one recognizes that phenomenological studies do not seek to be replicated or provide definitive answers to questions. Phenomenology seeks to understand not to explain but to help elucidate understanding. Yet, that understanding will always be tentative and incomplete. Having studied a phenomenon in one way or perhaps even several ways one may have arrived at some deeper understanding, but there is always something more to learn – to take a new approach to the question, to look at the thing in another way. Each looking will give us further understanding but as we look again we will inevitably find something more that needs to be explored.

How then to explain to others a method that seems without methodology? Van Manen (2014) suggests:

> *it may be best to think of the basic method of phenomenology as the taking up of a certain attitude and practicing a certain attentive awareness to the things of the world as we live them rather than as we conceptualize or theorize them, and as we take them for granted. (p. 41)*

It is the goal of this chapter to communicate in writing the ways that I have taken to gain glimpses of understanding into what it is like to speak with/through a speech-generating device (SGD). These glimpses are shared in four papers that compose the main body or *results section* of this dissertation. Each paper attempts to look at the phenomenon of speaking with a SGD using a somewhat varied lens, while adhering to the phenomenological method.

I will share how I have attempted to enter into a phenomenological attitude and practice attentive awareness to the phenomenon of speaking through a device in order to clear away that which may preclude my making contact with the world-as-experienced by the individuals who use such devices in their everyday lives. While I will attempt to make the journey recognizable and familiar to readers who come from fields of more traditional or positivistic inquiry, I will nevertheless also attempt to stay true to phenomenological method that I have sought to employ.

A brief discussion of van Manen's (2014) phenomenology of practice, which guides this study, follows. I will provide an overview of what characterizes a phenomenological study outlining how this work also borrows methods from the social sciences including the use of interview and observation. I will then explain the processes by which I gathered lived experience descriptions both from research participants, and from other sources. I will share how the illustrative stories or *anecdotes* were crafted, and the process of reflection that ultimately aims to show what is essential to the phenomenon in its singularity while illustrating what is universal in our experiences as human beings regardless of our particular abilities or dis- abilities. Then, I discuss how the writing is the research – how the crafting of a phenomenological text is in itself the research project; I outline briefly by what means a reader may evaluate the quality of a phenomenological text. Finally, I will end as I began with the focus on the phenomenology of practice as described and practiced by van Manen (2014), as the purpose of this dissertation is not to provide a philosophical treatise but a practical study that may inform the ethical and pedagogical practices of all those who enter in to the lifeworld of young people who speak through a machine.

Phenomenology of practice

> *Phenomenology of practice is meant to refer to the practice of phenomenological research and writing that reflects on and in practice, and prepares one for practice. (van Manen, 2014, p.15)*

This study draws upon a qualitative research methodology, phenomenology of practice, as developed and articulated by Max van Manen (2014). A *phenomenology of practice* can be understood as a form of inquiry that addresses and serves the practices of professionals through providing important insights into everyday life. This research seeks to provide pedagogical insights that may also inform parents, educators, speech language pathologists and others who gather around the field of augmentative and alternative communication. While the phenomenon at hand, speaking through a speech-generating device, is a decidedly uncommon experience, it is hoped that the understandings gleaned may speak to the common human experience of connection through language and speech.

Elements of phenomenological inquiry

> *The practice of human science is never simply a matter of procedure. (van Manen, unpublished manuscript, p. 139)*

Phenomenology as a method investigates the lived experiences of those who have experienced a certain phenomenon (Litchman, 2006, p. 70). In the simplest terms, phenomenology may be described as the study of lived experience (van Manen & Adams, 2010, p. 450). As a method of inquiry, phenomenology varies from *method* as understood in the usual scientific sense of the term. The scientific method prescribes a common set of tools, rules, treatments and procedures. Husserl, a founder of phenomenology, argues that while scientific methods are very appropriate for the natural sciences, when the subject matter involves the structures of human meaning a different approach is required (Husserl, 1900/1970). This approach involves taking up of a certain attitude and practicing a certain attentive awareness to the things of the world as we live them rather than as we conceptualize or theorize them (van Manen, 2014). It is therefore argued that phenomenological methodology cannot be reduced to a prescribed set of strategies or techniques. Rather, that phenomenology as a reflective method is the process of the *reduction* or *bracketing* - brushing away that what prevents us from making primitive contact with the concreteness of the lived reality (van Manen, 2014). The goal is to produce a phenomenological text that reawakens, evokes or shows the lived quality or significance of a given experience in a fuller or deeper manner. Stated differently, phenomenology gives us insights into meanings of experiences that we may have been previously unaware, but that we can recognize (Richards & Morse, 2007).

Adopting a phenomenological attitude.

> *It is all too easy to take language, one's own language, for granted – one may need to encounter another language, or rather another mode of language, in order to be astonished, to be pushed into wonder, again. (Sacks, 1989, p. xi)*

While one may suggest that any research study begins with wonder--wondering about a topic or wondering about an answer to a question--in a phenomenological inquiry, adopting an attitude of wonder has a singular importance. The term *natural attitude* refers to the taken for grantedness with which we experience things, situations, persons and facts of everyday life. For example, as it pertains to this study, as people who can speak, we tend to utterly take for granted this ability. We may engage in a lengthy conversation with a friend with never a moment’s thought to the actual processes of speaking. In fact if we do think about speaking while we are doing so, we may find ourselves unable to carry on such a conversation. We are in the natural attitude of life, not questioning or thinking about speaking: we just are talking.

To engage in a phenomenological inquiry one needs to enter into or perhaps seek to embrace a *phenomenological attitude*. This is means questioning the every day activities and events in which we live. To enter into the phenomenological attitude one must (try to) suspend one’s beliefs and preconceptions about a thing and look at them anew. This attitude is about finding the meaning of the day-to-day things in life instead of just accepting the things around us as they are without any thought as to why they are this way and what makes them so.

To return to the example of speaking, taking up the phenomenological attitude would likely cause one to question, *what is speaking anyway?* Is it merely the projection of sounds through the lungs, larynx and oral cavities or is it something more? How is speaking different from say writing? What is unique about speaking? What is the meaning of speaking in the lifeworld of one who does it? There are hundreds of questions one can ask about speaking once one strips away its taken for grantedness and begins to look at the phenomenon in other ways. As Oliver Sacks states it – to be pushed into wonder (Sacks, 1989, p. xi).

Orienting to the phenomenon.

Upon adopting this way of thinking, phenomenological research begins with the identification of a question of significant interest and wonder that is of abiding concern to the researcher (van Manen, 1997). Orienting to a particular phenomenon has to be driven by strong and personal interest in it (Saevi, 2005). If one is not deeply and personally interested in the phenomenon, it may be difficult to maintain engagement with it in the ongoing and intense manner that is necessary to complete the project (van Manen, 2014).

In the case of the present study, I have been interested in the field of AAC and in particular is the use of SGDs by students for several decades. It was, however, not until I began talking about my experiences and the experiences of the people I knew to a phenomenological researcher that I ever really was pushed to wonder *what is it really like to talk with a machine?* My orientation to this field had been that of expert, advocate, teacher, researcher and even at times problem solver, but the questions were always of evidence-based practices and seeking ever better processes, never of experiential *essence*. I never considered really what it would be like to speak through a machine.

As I began to explore this topic I at first found myself clinging to my old familiar ways of thinking. I was looking for evidence, using and creating my own and acquired theories to explain what I was reading and seeing in the experiences I had been gathering. It was not until several months after beginning a doctoral seminar in phenomenology that I began to become open to the phenomenon itself. I began to let go of my assumptions about the inherent value of SGDs. I began to peek around my beliefs that experiences of SGDs would and could validate my theories about application and use, and I began perhaps for the first time to hear the voices of participants through an unfiltered ear. To began to question the expectations of those of us who seek to support these young people in making their voices heard. Should not our practices be better informed by understanding of the experience? My orientation slowly changed from one of *expert* diagnostican seeking solutions, to one of empathic novice seeking understanding. My orientation to my study became pedagogical. I sought to obtain and maintain active attention to the implications of this understanding for parents, educators and health practitioners who support children and youth who use SGDs.

The Study of Experience as Lived Through.

The past is always too late to capture the present as present. (van Manen, 2014, p. 59)

The value of phenomenology is that it prioritizes how people actually experience the world. All its efforts are concentrated upon re-achieving a direct and primitive contact with the world (Merleau-Ponty 1945/2002, p. vii).

> *[Phenomenology] tries to give a direct description of our experience as it is, without taking account of its psychological origin and the casual explanations, which the scientist, the historian or the sociologist may be able to provide. (Merleau-Ponty 1945/2002, p. vii)*

This direct description is undertaken by trying to capture the living moment or the *now*, but of course it as soon as one tries and capture the now it has already past. It is always too late for us to be in the moment. The paradox here is that despite the effort to see the world as it is immediately experienced, it can actually only be grasped retrospectively by reflecting on the already passed (past) experience. So the data of a phenomenological study is lived experience descriptions that try to recall and recreate the *concrete* lived experience. While not ever really achieving a description of what it was like, it can be possible to get close. It is this seeking of the concreteness of life as lived that lets phenomenology show possible meanings of the experience in the lifeworld.

Abstaining from assumptions, theory and pre-conceptions (openness).

It is a matter of describing, not of explaining or analyzing (Merleau-Ponty, 1962, p. viii).

Bracketing can be described as the act of suspending judgment about the natural world to instead focus on analysis of experience. To put aside what you know or think about a phenomenon so that you may come into closer contact with it as it is. Bracketing does not mean that one ignores the theoretical or scientific information about the phenomenon being studied, but rather that one attempts to make them explicit in order that they might be examined for ways that they either can be used to extract phenomenological sensibilities or conversely ways that they obscure our understandings of the concrete.

Aiming to grasp the essence of the phenomenon.

Essence is that what makes a thing what it is (and without which it would not be what it is) (van Manen, 1997). The eidetic method can assist in uncovering the invariant meaning (eidos) of a phenomenon. This method involves looking at other related phenomenon to see how they might be the same yet different. The comparison can help to *pull away* the meaning structures that are common to related phenomenon leaving us closer to discovering what is unique about the experience. This Husserlian tradition of phenomenology recognizes that we can never see a thing from all sides or perspectives at once, so the full essence of a thing can only be appropriated in transcendental or pure consciousness – in some sense abstracted from the perception of the experiential world.

Alternatively, the meaning of a phenomenon may be understood by its mode of being. Things can be understood in terms of their *thinging*– their being in the world.
Heidegger argued that Things are not, as Husserl proposed, first of all phenomena that are constituted in consciousness. Rather, the essence of things comes from the ways we encounter them immediately in the world where we use them. This study will take a largely Heideggerian

approach to understanding how the phenomenon of speaking with or through a device shapes the user's being in the world. The basic Husserlian methods of seeking the invariant meaning of a phenomenon will be used when exploring how speaking through an SGD is a unique experience of speaking that has elements of what it is to speak while presenting as different and clearly a unique way of conveying one's thoughts through audible means.

The Reduction (dynamic play of showing and hiding).

The method of the reduction is to bring the hidden, invisible, originary aspects of meaning that belong to the pre-reflective phenomena of lifeworld into visibility or nearness (van Manen, 2014, p. 221). However, as Levinas (1969) suggests what presents itself in consciousness is always haunted by the alterity of what withdraws itself as absence and so always presupposes an *othering*. So the task is to engage in a descriptive dance, showing the *whatness* of a phenomenon while constantly being aware that it is also being hidden from our view in that we can never actually get to the experience in its pre-reflective *originary* state. The reduction, or perhaps better said the series of methods undertaken to achieve the reduction, is to systematically and intentionally enter into this activity of uncovering so as to come as close as we can to something that will always ultimately allude us.

Employing a series of methodological devices helps to accomplish the reduction. In fact it can be said that all the elements of the method discussed thus far are various types of reduction: creating a sense of wonder (the hueristic reduction), bracketing one's preconceived notions or feelings about the phenomenon (the phenomenological reduction/ epoche), stripping away theories which overlay the phenomenon are all types of reduction (the heurmenutic reduction), seeking the invariant essence or meaing comparing the phenomenon with other related but different phenomena (eidetic reduction), and explicating the modes or ways of being that belong to the phenomon (ontological reduction). The main work of a phenomenological study, the research itself, is done in the methodological and vocative reductions which are sought through the process of writing and rewriting texts.

Writing as research.

> *One aimed for the light of insight, but one ends up facing the darkness of the night (van Manen, 2006, p. 721).*

The phenomenological process of emulating the pre-reflective experience is preformed through writing. The intent of writing a phenomenological text is to produce textual *portrayals* that resonate and make intelligible the kinds of meanings that we seem to recognize in life as we live it (van Manen, 2014, p. 221). The challenge of writing is that one only has words in which to bring into presence this phenomenon, and no words will never truly be able to accomplish this. Despite this, one must seek to find the words and phrases, styles and traditions, metaphor and figures of speech that may work together to bring the phenomenon to life and to let the reader be addressed by the writing such that they may recognize both what is unique about the phenomenon as well as what may call to us as universal in our understanding of the human experience.

The path of this inquiry

Gathering the *data*.

Phenomenological research data can be generated from a variety of sources. This may include:

- the investigators own experiences,
- collecting the experiences of others through interview,
- seeking experiences of others through close observation of their life as they live it,

- borrowing experiential material from literary works, tracing the etymological meanings of words that gather around the phenomenon in question,
- gathering myth and metaphor, and
- looking to phenomenological texts for insights they may bring to uncovering the meaning structures of the phenomenon.

Phenomenology has been described as the reflective study of the pre-reflective or lived experience (Adams, 2008). This means we are seeking to study the moments of the now as we are living through them. Yet those moments are only accessible to us to be studied as reflections on the now as the true now is elusive, gone the moment we try to describe it to someone. The moment we try to put into words any experience we are defacto already reflecting upon it. The words themselves are necessarily an abstraction of what the actual lived through experience was. In trying to get as close to the actual experience as is possible, phenomenology seeks concrete descriptions of experience to reflect upon. This is different from other qualitative methods such as for example Narrative Inquiry as people's perceptions about their experiences is not what we seek but clear concrete lived through descriptions of the thing, the moment, the phenomenon.

In phenomenology we are interested in *possible* experiences. That is to say we are not so concerned with the factuality or actuality of an experience, but with the recognizability of the experience of the phenomenon by the reader. This recognition is what Butendijk (1970) refers to as the "phenomenological nod" (p. 596). This search for possible experience allow for phenomenological data to be gathered from a variety of sources including published accounts (books, blogs) and even literary renditions (novels, movies). What is important is that the data be a concrete description *of* an experiences as opposed to a perception or remembrance *about* an experience.

My lifetime experience of Augmentative and Alternative Communication (AAC).

As I have worked in and around the field of AAC for over thirty years. During this time, I have been with many SGD users. Observational experiences not first person experience of the phenomenon, however as I reflect back to those moments I found myself recalling many experiences that I have found useful in constructing anecdotes.

Upon the advice of a colleague I also undertook to spend a day speaking only through a device. While this particular experience is not one that I ultimately chose to share for this study, I learned so much from it. Mostly perhaps that speaking only through a device had the effect of rendering me silent.

From published accounts.

This study began with a search for experiences of speaking with or through SGDs in the published literature. There have been several books written by people who use speech-generating devices to communicate with others. These include the wonderful *Reflections of a Unicorn* by SGD using speech pathologist Rick Creech (Creech, 1989) that I first read many years ago but came to experience in a new light, *I Raise My Eyes to Say Yes* the story of Ruth Sienkiewicz-Mercer (Sienkiewicz- Mercer & Kaplan, 1996) and in what may be the story that first awakened my questioning of what I thought I knew or understood, *The Diving Bell and the Butterfly: A Memoir of Life in Death* (Bauby, 1998). I also was thrilled to find the eloquent and insightful memoir of Dr. Albert Robillard, an anthropologist who wrote about living with motor neuron disease that left him unable to speak with his natural voice (Robillard, 1999). And most recently I have been drawn to *Ghost Boy* by Martin Pistorius as a source of amazing first hand accounts of what it is like to become voiceless and then to be (re)given the gift of speech through the acquisition of an SGD (Pistorious, 2011).

Lived experience descriptions were also borrowed from empirical studies in the area of Augmentative and Alternative Communication (AAC). These descriptions were found embedded in the findings of a qualitative study where the participant gave a glimpse into a concrete lived moment (for example Doreen's accounts in Smith-Lewis and Ford, 1987) or in papers written about speech-generating devices and the people who use them (for example, Emma Brocke's 2005 interview with Stephen Hawking, and first person accounts of SGD use in Jeffery Higginbotham's (2010) chapter on the role of speech synthesis in Augmentative and Alternative Communication).

Stories of SGD use were taken from blog posts and online videos. Colin Portnuff's beautiful talk about speech and voice technology in AAC was one of the most important accounts I uncovered as I began this journey. From the same site I was re-acquainted with a talk given by Michael Williams, an AAC user who writes and speaks widely about AAC. In addition, while listening to CBC radio one day, I was given the gift of Lee Ridley. Ridley is a comic with cerebral palsy who goes by the name *The Lost Voice Guy*. His wonderful comedy sketches speak volumes about the reality the world of speaking through a device. Lee's sketches are posted on YouTube, and he has an insight and very funny sketch about speech-generated voices on the website on AAC Scotland's website (http://www.aacscotland.org.uk/AAC-Videos/).

Finally, some stories of SGD use in this study came from fictionalized accounts of young people who use these methods of communication. In particular the novel *Out of my mind* by Sharon Draper (2010) provided evocative and telling descriptions of what it might be like to be a young woman who breaks through her silence to speak through a machine.

From young people who use SGDs.

Participants in this study included nine people who currently use SGD in their daily lives and who have had the experience of using said device in the context of their school experience. The participants ranged in age from 18 years to 40 years. Eight of the nine participants have cerebral palsy and have had severe speech and communication impairments throughout their lives. The ninth participant came to use a SGD in middle school as she lost the ability to communicate effectively through speech as a result of an acquired degenerative condition. All participants used some type of SGD, although one young man suggested he had never been able to find one that really met his need for communicating, so he chose to speak to others primarily through the low tech system of pointing to a letter/word board that he constructed for his personal use. His story in particular will show itself as I write about the demands of the SGD. All other participants used sophisticated dedicated SGD and were competent in the use of their device and the language system their device employed. All participants were able to read and write to some degree, although only the three eldest participants could be described as truly literate. Participants used their device to engage in the interview process and/or to further engage in dialogue through electronic medium (Facebook, email, and/or text messaging).

Gathering experiential material.

Interview. The primary method of gathering lived experience descriptions from participants was through unstructured interview. These interviews were conducted both face-to-face and online, although in every instance the first and primary interview took place in a face-to-face method. In most cases the interviews were face-to-face. The participant would respond to my questions using their device in combination with non-verbal communication modes such as head nods, grimaces, and shoulder shrugs.

Wherever possible interviews were recorded, and many were video recorded so that I could review not only the words but the non-verbal communication associated with the messages from the SGDs. Each participant participated in at least two face-to-face interviews with some participants participating in several more over the course of the study.

Interviews tended to start out with questions such as *can you tell me about a time* you remember talking with your device?, or *can you remember a particular time you used your device to speak to someone?* These questions seemed difficult for participants to answer at first. They tended to answer with what they thought of their devices. For example, “It helps me to say what it in my head”, “It’s great!”, “sometimes it doesn’t work so good”. Pulling out concrete moments of device use was challenging perhaps as one participant said, “no one has ever asked me to talk about my life like this before”. This statement is revealing about what it may be like to speak through a SGD. The simplest of conversations may never happen for one who speaks through a device. Yet van Manen (2014) suggests that this is a common challenge, not only for those who speak through a machine. People tend to be able to share easily their impressions of a thing, their beliefs about a phenomenon, or their opinions about an experience. However, to describe the experience as one experienced it can be quite challenging, even when one can speak.

To help participants understand that I was seeking concrete remembrances of their actual lives, I asked that they tell me about a particular time/event, so that I could see it like a movie. Alternatively, I asked them to tell me about it in the manner of a story told to someone who wanted to know how to talk with the device. These types of instructions helped to extract the concrete moments of device use, but typically those only emerged after the second or third face-to-face interview.

Interviews took a great deal of time, many times several hours. This is the nature of communicating through a device. It is slow. The interviews themselves became material for LEDs, as will be seen in the subsequent chapters of this text. The very process of participating by talking through/with a SGD gave rise to many concrete moments that illustrated what it was like. For me each interview was a constant reawakening of wonder. I had never, despite my decades of working in the field, spent such dedicated time actually conversing with a SGD user. Consequently, I had never really understood what using a device to communicate is like.

Online interactions. As face-to-face interviews were so time intensive, asynchronous modes were also heavily drawn upon for this study. Many of the LEDs were obtained through online modes, with email and Facebook messenger conversations being the most common. In one instance a participant was interviewed via Skype which one could consider face-to-face but that lacked the access to the fullness of the experience that subsequently speaking in person offered. Colin Portnuff's (2006) thoughts on online interactions explain this phenomenon well,

> *There was a period when e-mail acted as the great leveler. People who could not speak could correspond via e-mail asynchronously. It didn't matter how much of a struggle it was to enter text, because we did it on our own time. Then along came chat capabilities, and we were back to disabled. And then the nuclear bomb hit. Voice chat. Just when we thought it was safe to turn to our PC for a level communication field.* (*http://aac-rerc.psu.edu/index.php/webcasts/show/id/3*)

A listening gaze (close observation). In their book *Nursing and the experience of illness: Phenomnology in practice,* Irena Madjar and Jo Ann Walton (1999) coin the term "the listening gaze" to explain how it is in nursing when one has adopted a phenomenological stance. Such a gaze, they suggest, allows nurses to hear the sound of a patient coughing and recognize not only the nature of the cough but also the tiredness of the exhausted patient (Madjar & Walton, p.12).

It is with such a gaze that I set upon to involve myself with close observation of participants going about their daily lives also provided phenomenological data for this project.

I spent the days with participants as they went about their day at school, as they interacted with their friends at the bowling alley, as they attended appointments with AAC professionals, as they interacted with their families and as they joined me in attending local events. Observation was most often done in the context of school settings to keep in tune with the pedagogical orientation of the study. I spent several entire days at school with the participants who were attending school at the time of my study. Encounters with SGD users outside of the school context were also documented. Some of these were planned parts of the study, others by happenstance as my work and my world offered up opportunities to be with adults and young people who used SGDs in various contexts.

In each of these encounters with my participants and their world, I strove to maintain a *listening gaze*. By listening not only with my ears to what my participants were saying to me and others, but also with my eyes I was able to see past the often few words that they spoke to more complete meaning of what speaking with a device might be. Adopting an attentive listening gaze helped me to see the toil of their bodies speaking with a device might entail, the response or non-response of others, and the moments of connection and disconnection that their words alone could have never expressed.

Constructing Anecdotes.

One rhetorical device used in phenomenological writing to evocatively reveal the themes to the reader is the *anecdote*. Anecdotes are carefully crafted from the lived experience data to allow the phenomenon to be made comprehensible, to bring it to life - to evoke the *phenomenological nod*. A well crafted anecdote will evoke in the reader a sense of *I have* *experienced that* or a sense of clarity and understanding of the phenomenon in its concreteness, pre-reflectively, as lived. In the case of this study anecdotes were crafted from the lived experience descriptions obtained through the various data collection methods. The anecodotes were crafted so that they might evoke a sense of recognition in persons who use SGDs as well as, in some instances, a sense of recognition in all of us who seek to be understood by others through our words.

The notion of anecdote may seem problematic to some as crafted *anecdotal evidence* is often not seen as acceptable to empirical generalizations. It is important to keep in mind that generalization is never the aim of a phenomenological inquiry, rather the aim is to evoke a sense of recongition of a universal truth that is revealed by a well told story of a concrete lived experience (anecdote). A good anecdote will show the *particular* while really addressing the *general* or the *universal*.

Checking in: Is this what it's like?

While member checking is not an expected process in phenomenological studies, I did in most instances ask participants to let me know if I *got it right* when I crafted an anecdote from their lives (told of or lived through). This was important to me as often the lived experience descriptions were not as detailed as I would have hoped to be able to obtain. As will be shown in the subsequent papers, speaking with an SGD is not easy. Many times participants gave me severely truncated versions of their experiences and it was my job to fill in the details that would have taken them so much time and effort to add in themselves. It was, therefore, very important to me that my anecdotal material remained true to the stories they were telling me.

I also had occasion to share my constructed stories with several participants whether they were the originators of the story or not. In these instances I asked if they *recognized* that experience, or if it *seemed right*. One instance of checking in stands out for me in this process. I was visiting one of my participants at her home. She knew that I had recently done a presentation of my study at a conference and asked me if I would share the presentation with her. She and her mother watched with apt attention as I shared the anecdotes and reflections that I had worked through for the conference. Upon finishing we sat a moment or two in silence then she turned to me with a big smile and constructed her response. "THAT'S JUST WHAT IT IS LIKE FOR ME!" That provided me with a strong sense of validation.

Reflection and Reduction.

Thematic analysis.

The reflection involves methods of seeing or perhaps uncovering meanings in the texts (anecdotes). This begins with a search for themes although these themes should not be confused with the themes that emerge from other types of qualitative inquiry. Themes are not derived from the number of times that they emerge from the data. Grasping and formulating a thematic understanding in a phenomenological study is not a rule bound process but an act of *free seeing* that is driven by the epoche and the reduction (van Manen, 2014).

Thematic analysis is the process by which structures of meanings that are embodied and dramatized in the experience (speaking through a device) are recovered from the textual descriptions of the phenomenon. Thematic analysis derives first from a holistic reading of the text to capture in a phrase the main significance (eidetic, originary or phenomenological meaning) of the text. This is then captured by a phrase which may introduce the overall theme. Then, a more selective reading is done searching for statements or phrases that seem particularly revealing. These statements are highlighted or captured as they are particularly useful in reflection and the crafting of the text. Finally, every sentence is looked at to explore what each may reveal about the experience being described (van Manen, 2014). This line by line analysis involves asking what does this sentence say about the experience of speaking through a device. Answers to the questions posed provided further fodder for analysis and reflection.

Using Lifeworld Themes: The Existentials.

The notions of lived relation, lived body, lived space, lived time, and lived things and technology are existentials in the sense that they are belong to everyone's life world – they are the "universal themes of life" (van Manen, 2014, p. 302). These existential themes were used as guides for reflection in the research/writing process. The exploration of lived things and technology (materiality or as Don Ihde suggests *postphenomenology*) are explored through all reflection and analysis but are predominant in the paper "The Speech-generating Device Thing." The themes of lived body, lived space, and lived relations all play heavily in exploring the meaning of voice in the lives of people who use SGDs. Lived time has particular meaning in the lifeworld of those who speak with a device and therefore a complete paper is devoted to exploring this existential theme and its impact on lived relation.

Conceptual Analysis.

A useful method of reflection on the phenomenon is to explore the meaning of the words that adhere to it or gather around it. Insights may be gained from seeking the original meaning of words used to describe the experience or phenomenon. For example, in this study many of the resulting texts explore the meaning of words such as speaking, talking, generating. Is speaking the same as talking? Are they both part of the experience of using a device? Are they somehow understood differently for someone who speaks in alternative modes?

In some instance words that come from the anecdotes will be explored to gain insights to what it is like to speak with a device. The word *dumb* for example is explored in chapter 7 for its original meaning in Old English “silent, unable to speak” and its related notions of “defective perception or wits” (Dumb, n.d.). What can these meanings of this word tell us of what it is like to speak through a machine? And what of being *slow*? What does the word slow mean, and how does the meaning shape the lived experience when one speaks, albeit very slowly, through a SGD?

Phenomenological Texts as Insight Cultivators.

Reading phenomenological (and other) texts was done to cultivate insights into the phenomenon itself as well as insights as to how the methodological reduction could be accomplished. Each paper presented in the subsequent sections draws upon various phenomenological scholars as well as scholars in the field of AAC. Heidegger is called upon throughout the resulting texts both as guide to existential phenomenology (1962) and to gain insights from his exploration of language, his exploration of things (1971) and his discussion of technology (1977). The writings of Merleau-Ponty have been drawn upon heavily in this work as he touches on speech, language and language learning (Merleau-Ponty, 1964) and particularly speech as an embodied phenomenon (2009). The work of Don Ihde was particularly useful in exploring the relationship between the human and the technology that come together in the unique configuration that allows a speech impaired person to become one who speaks (Ihde, 1979). van den Berg (1970) is referred to in the paper which explores the existential experience of lived time, and Levinas (1985) and Verbeek (2005; 2011) help to provide understanding of the ethical and moral demand that seemingly come into being around the use of SGDs.

Drawing upon the AAC literature. Insights from the works of other scholars in the field of AAC and linguistics have been infused into the resultant texts. In particular Janice Light’s seminal work on communicative competence (1998), provides the current theoretical framework in the field of AAC and therefore is referred to often throughout this dissertation. Jeff Higginbotham and his colleagues have written much on the issue of time and timing in AAC (1999; 2002), as well as issues of computer generated voice and benefits and challenges therein (2010). Numerous additional scholars from the field of AAC are cited in each of the subsequent papers.

Crafting a Phenomenological Text: Writing and Re-writing.

We find in texts only what we put into them (Merleau-Ponty, 1962, p. viii).

Writing is the process through which the analysis happens, and writing is, of course, the product of the process. Writing a phenomenological text involves putting words on paper but it also involves turning words and concepts around in one's head. I have been writing and re-writing these texts for several years. I have written many drafts on my computer but have also been compelled when I have been particularly challenged to grasp at meaning to take my pen in hand and write my words down on yellow legal pads (my favourite paper on which to work things out). I have also been writing as I have hiked up mount Tzouhalem on Vancouver Island and as I walked my little dog around our neighborhood. I have found myself writing as I sit beside two young children on a plane and am reduced once again to wonder as I listen to them emerge as speaking beings. “Susie look we are going up!” says the child that may not be yet quite three years old. A sentence that is quite ordinary given the circumstance, and yet it is amazing the clarity and ease with which this young child can express herself. I am struck again by how different the phenomenon of speaking is when one can speak naturally than when one must speak through a machine. I began writing about the rarity of a child of three with severe speech impairment having access to a SGD through which she could express such thoughts to her sister. And the realization that any three-year-old would be moved to share their excitement about going up in the air in a plane through words. The difference and the similarity of talking whether naturally or through a device is put in front of me at every turn, as I am pre-occupied with the phenomenon at hand.

While the research begins in gathering the stories, the true research, the analysis, happens during the writing process. As van Manen (2014) suggests a phenomenological study cannot just be written up. There are no *results* to write up; the writing is the process of analysis – of creating the *resulting* texts. Through the writing process one takes a lived experience description and shapes it (re-writes it) into an evocative anecdote to use to bring the experience into recognizable nearness. Then the reflection begins in earnest through writing. Writing about what the anecdote shows, perhaps bringing in some research from the area as a process of bracketing or making theories and presuppositions clear, looking for insights in meanings of the words that gather around the phenomenon, exploring similar yet different phenomenon to point to what is the unique meaning of the one being explored. All this is done through the writing process, and all this is indeed the research.

The process is iterative. I prepared many papers or versions of papers, written and rewritten in the hopes of presenting something close to a good phenomenological text. With each iteration, each beginning and each passing I have learned something about the phenomenon. I have often found myself astonished by the real experiences of speaking through a device, a phenomenon of which initially I thought I had so much knowledge. Yet, I remain fully aware that despite this constant preoccupation with and attention to the writing it will never be complete. There will always be more to learn about this phenomenon. While this condition may be daunting, and sometimes vexing, it is also rather liberating. I know now that I will continue to return to this question, these stories, these words and phrases throughout my career. It has been said that it is not what you can do with a phenomenological study but what a phenomenological study can do to you. Certainly that rings true as I have been forever changed through this enlightening process. I have also been called to use this research to illustrate to others who enter into the world of those who speak through a machine that our interactions must not only be shaped by our gnostic (cognitive) knowledge but pathic (non-cognitive) knowledge that causes us to be understandingly and empathically engaged in their lives.

Appraising a phenomenological text.

> *… one must evaluate it by meeting with it, going through it, encountering it, suffering it, consuming it, and, as well, being consumed by it. (van Manen, 2014, p. 355)*

As a phenomenological text may be different from that which many in the field of special education and rehabilitation medicine are familiar it may be useful to provide some criteria for appraising a phenomenological text. van Manen (2014) proposes a series of questions a reader might ask when appraising a phenomenological text either as the writer or as the reader. These questions are as follows:

> *Does the text induce a sense of contemplative wonder and questioning attentiveness to the phenomenon at hand? Do you find yourself wondering what this phenomenon is and then what is it really like?*
>
> *Does the text contain rich, concrete, descriptive experiential (narrative) lifeworld material? Are you taken into the experience in a concrete manner, such that perhaps you can see it unfolding or imagine what it really might be like to speak through a machine?*
>
> *Does the text show reflective allusions and offer you surprising insights that go beyond the taken-for-granted understandings of everyday life? Do you find yourself seeing beyond what is you might think you know or expect? Does the language of the text take your deeper into your understanding of the phenomenon?*

> *Does the text contain strongly embedded meaning? Does it* ***speak*** *to us and address our sense of embodied being? Phenomenology does not just aim for the clarification of meaning, it aims for meaning to become experienced as meaningful (van Manen, 2014, p. 373). Is the text itself experienced as meaningful to the reader?*
>
> *Does the text awaken prereflective experience through vocative and presentative language? Does the language chosen guide one towards the experience? Are the words chosen with care to illustrate and illuminate the experience?*
>
> *Perhaps most importantly for text that aims at the phenomenology of practice, does the study offer us the possibility of an intuitive or inspirited grasp of the ethos of life commitments and practices? Does the text awaken ethical and pedagogical questions and/or callings in the reader?*
>
> *In addition, one may ask if the text remains disciplined and constantly guided by a self-critical question of distinct meaning (eidos)? Does the text stay focused on the question, the phenomenon at hand, or does the author digress to questions or phenomenon that are unrelated to that which is being studied?*
>
> (van Manen, 2014, pp. 355-356).

I offer these up as questions that one might consider as one reads the papers in this study. It is my hope that they might come close to the achieving the rich, evocative pieces that leads one to wonder about, understand and care about the lifeworld of those who speak through a machine.

A practical phenomenological inquiry.

You've given me a burden I never knew I had. (Teacher, personal communication, 2011).

This simple, yet somewhat disquieting, statement was made by a teacher who heard me present some of my initial research into what it is like to speak with a SGD. She had worked for several years with a young man with CCN who was learning to use a SGD. She said felt compelled to talk to with me after I had presented. She had tears in her eyes, and was clearly moved by my presentation. At first I was rather shocked. My heavens, the last thing I want is to give teachers a burden! Teachers who have students with CCN in their classes have burdens enough to ensure their students gain language and literacy as well as have access to meaningful social interactions. I was certainly not seeking to add to their challenges with my work. As we spoke further I realized that perhaps it was not that I who was seeking to add to their burdens, but only attempting to make sure they understood what the challenges are for the students as well as what their challenges are as educators. It is seldom the case that educators hear the voices of their students in research, certainly it is very rare for them to hear the voices and experiences of children and youth with CCN. As we talked, I came to understand that this educator had probably just given me the best compliment I could have received. Even though she was something of an expert in teaching students with special needs, she had never before really been faced with the meaning of every child having a voice, a true voice, an audible voice, a voice that was heard. We talked for some time and I promised to keep in touch, which we have done. In retrospect, she has risen to the task, the burdensome understanding, she acquired that day so many years ago now with amazing vigor and remarkable success. The young man is being actively and carefully supported in the use of his device to speak, but more than that, the understanding of the meaning of speaking with his device is being considered in ways that never were before. The teacher tells me she was forever changed that day when she heard me speak, and it seems so was her practice.

This, then, is the ultimate goal of a research project that aims at the phenomenology of practice, to address and serve the practices of those in professions that gather around a phenomenon. In this instance it is hoped that the resulting texts might provide insights to parents, teachers, speech pathologists, and educational assistants who help children learn to find and share their voice both at home and at school. Phenomenological inquiries are decidedly rare in special education (McPhail, 1995). It is hoped this foray into the method may both inform and inspire others in the field to both take up and learn from phenomenological inquires. It is also hoped that these texts may speak to those in the field of rehabilitation engineering as they seek ever more human centered technological designs for SGDs. It is my desired wish that through the thoughtful reflection of the various meanings of speaking through a device that we can be called to reflect carefully on our practices and that we might invite others to do the same.

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Chapter 5: Phenomenological Investigation Into Speaking With A Machine

Introduction

Perhaps there is no more powerful example of how technology extends the range of the human body than assistive and adaptive technologies used by persons with disabilities. One such technology is the Voice Output Communication Aide or VOCA. VOCAs permit the storage and retrieval of electronic messages, allowing the user to communicate using human sounding speech output. These technologies provide the opportunity for extending the abilities of people who cannot effectively communicate through their own natural speech. This includes both those who have been speech impaired their whole lives, and those who have lost their ability to speak naturally due to an acquired disability.

Phenomenological research involves careful and systematic reflection on the lived experience. This paper presents a phenomenological investigation into the experience of using a VOCA to speak. McLuhan's notion of extension and amputation are used as heuristics for exploring themes that emerge from the lived experience descriptions of people whose abilities are extended through the use of these technologies. While it is clear that many technologies make the impossible possible, the VOCA goes perhaps farther, making the ordinary- the taken for granted - possible. Understanding the meaning of these technologies in the lifeworld of people who cannot speak has important implications for the field of augmentative and alternative communication as well as for philosophical studies into human technology relations.

Most of us take the ability to speak utterly for granted. To speak <u>is</u> to have a voice. To be understood by other through the use of our voice. From the time we are very young children our primary means of communication is through speech. We talk with our friends. We whisper secrets. We shout and cheer at the top of our lungs and make our voices heard. We use our voice to share stories across space, and to transmit our stories across generations. But consider what life would be without the ability to speak? Without your voice?

Such is the experience of people such as Dr. Stephen Hawking the famous British theoretical physicist. Dr Hawking is no longer able to use his natural voice to speak as a result of a progressive motor neuron disease. Or, the experience of people whom I have worked with most of my career, people with cerebral palsy. People whose bodies do not allow them to coordinate the breath, sound and movement necessary to produce intelligible speech. Imagine if in order to speak your words aloud you must speak with a machine?

> *First I think what to say, then I input the words into my device. Once I have constructed my message, I push "speak" so that I can speak those words out loud.*

Merleau-Ponty (1958) suggests when we speak we do not think about speaking, rather if we *think* at all, we think <u>of</u> *what we are saying*. We must, in fact, stop picturing the code or even the message to ourselves, and makes ourselves sheer operators of the spoken word. While this rings true for those of us who speak with our natural voices, it hardly seems the case for people who speak with a machine. So this then is the question of my study: what is it like to speak with a machine?

Transformational Technology

Twenty-five years ago VOCAs did not exist. When describing his experiences before acquiring a speech-generating communication device Rick Creech, who has severe cerebral palsy points out:

> *I did have a letter board that I could point to. It worked well with people who would take the time to talk to me; not too many would. To be fair, talking with a person who uses a letter board can be difficult. Most people are unable to put letters together in their minds*

> *to form a word. They certainly cannot remember the words long enough to form a sentence. (Creech, 1992, p.47)*

Communication for people with unintelligible speech was possible, but limited. Talking with text, sometimes written down, sometimes only written in the mind of the hearer. To converse with someone without voice was demanding and burdensome both for the speaker and the hearer. Then in the mid 1980s the first speech-generating computers were made available to persons with severe disabilities. These technologies were revolutionary. People with speech impairments could independently give voice to their thoughts.

> *I accepted as fact that only people who were familiar with me could understand my speech. Then a miracle happened, I was shown and then given a COMPUTER THAT CAN TALK! From that moment on I know that I had left my misfortune behind me. I knew that in this world, I could be a normal individual… If I wanted to talk to somebody I would no more have to wait for my mom or my brother to come and "translate" for me. Now I could be part of this world! (Fried-Oken & Bernsani, 2000, p. 102)*

This was a technology that provided the possibility of transformative experiences; experiences of being *normal*, being part of the conversations of the world, and doing so on one's own. Extending a speech-disabled person's ability to have an audible voice in the world. Extension that moves a person from silence to voice.

Voicing One's Being In The World

But what is this experience? Perhaps foremost it is that of voicing one's being in the world.

> *I recall the day that Josie came into the centre for the first time. She was coming to see about getting a VOCA. Here was a seven year old little girl who's eyes shone with expression but who had no speech. As we sat around the table discussing Josie's needs for a device I grabbed one from the back room and started to program in a few phrases. I then sat with Josie and modeled how the messages could be spoken aloud by touching*

> *the buttons. Before long it was obvious to me that Josie understood how the device worked… and then she took over.*
>
> *"mom look at me" Josie spoke aloud by pressing the button on device and looked at her mom to see if she was listening. No response. I whispered "try again Josie" and turned up the volume. She did - "mom look at me!" This time her mom heard. She looked up a little confused. On cue Josie spoke again "mom look at me". And that is when the magic happened. Her mom looked and Josie said "mom come here" with no prompting and giggled loudly. Her mother, now practically at the point of tears, came over. "mom look at me" said Josie. "I am looking Josie!"*

This anecdote speaks to the powerful impact of a child acquiring a voice. Her ability to voice her being in the world… look at me here I am! How strange when one considers that really the voice is not hers at all. In fact, in this instance, the words were spoken by *my* voice , an adult clinician's voice, as I had recorded the phrases into the buttons that Josie activated to "speak".

Is this giving voice to one's own self? How very different this experience is for one who speaks with a machine.

> *On the day that I got my new device I finally felt free to say anything that I wanted. I felt that way because I could speak the words by myself. That gave me a sense of pride because I found more words than I ever imagined. I think people truly know me for the first time because I was not hiding a big part of me like I was before.*

The freedom to express oneself and to let oneself be expressed. To translate what is in our heads and our hearts into expression that show who we are to the others. The freedom to speak our thoughts aloud, to show ourselves. Merleau-Ponty suggests even to know ourselves. For the speaking subject, to express is to become aware of: he does not express for others but also to know himself what he intends (Merleau-Ponty, 1964, p.18). When we speak we reveal ourselves, we even, perhaps, reveal ourselves to ourselves. Is this what Sharlene experienced speaking with the machine? A newfound freedom to reveal herself by finding her words.

Extending One's Space

> *With my new voice, my world began to open up. Finally connecting with people by spoken word. The first time I really saw the power of this was one day when I was with my sister in her back yard. She was gardening. Before, this would have meant that she gardened and talked, and I would watch and listen. In order for me to share my thoughts beyond a few vocalizations and facial expressions she would have to come over so she could read what I was spelling on my letter board. With the speech output device this all changed… that was the beginning of our conversations across the garden. A distance that we had never before been able to traverse. (adapted from Fried-Oken & Bersani, 2000)*

From being confined to a limited communicative space to conversing across a garden. With access to the word spoken aloud, there has been opening of an audible space in the world for these two sisters. What is created is an existential kind of real estate, a real ground, that cannot be obtained without the power given by the voice of the machine.

Finding One's Own Voice

The phrase *finding one's own voice* may seem cliché, but it is hardly so for those who speak with a machine. Consider the words of Colin who has lost ability to speak not through surgery but through the debilitating condition of ALS.

> *Much of what I have had to say today is related not to speech, but to voice itself. I would ask you to reflect deeply on how we come to associate voice with identity….I have heard from several physicians and speech pathologists that my voice suits me. This seemed initially to me to be somewhat preposterous. To me it is not my voice at all, but rather a tool that I employ to allow me to speak. But my family, friends, medical team and acquaintances have integrated the voice as a key part of my identity. In fact, my teenage daughter Lindsay is troubled when I change voices, or even when I correct some of the mispronunciations that she is used to and even has come to enjoy. I guess I am beginning to identify with the voice myself. (Portnuff, 2006*)

A person is recognized by their voice. It is perhaps as unique as a fingerprint and much more apparent to the world. Our voice is our own. Yet this is hardly the case for people using VOCAs. How interesting then is Colin's struggle.

Voices convey so much about us. It appears so does the voice of the machine.

> *This is the first device that I have had that actually has a female voice. It makes a difference as to whether people will take the time to listen. With the other voice people didn't connect it with me as a person. When I used the male voice it was like thoughts were coming from the machine not from me as person. Since I got the female voice people seem to understand it as my voice... I really feel like this is "my" voice.*

Sharlene suggests that her personhood was passed over before her female voice. The machine was in the foreground; she was lost in translation. Voice matters. Sharlene has at least come closer to finding her voice as a woman. The importance of this presentation of *her*self should not be understated. But what of the rest of her, of her size, her life's journey, her demeanor, her uniqueness? What is left unsaid when the voice is a machine?

But The Voice Is A Machine!

> *Talking to people with an assistive device is not easy. This Christmas my family was all here at our place. I had my new device and was I was feeling pressure to keep the conversation moving. I really feel that you can't ask people to stop talking while I get out what I have to say. So by the time I have my message made they moved on.*

McLuhan tells us where there is extension, there is amputation. Is this what is happening with the VOCA? In acquiring the technology that gives her the power to produce audible human sounding speech has Sharon been functionally excluded from interactions with others. Has her ability to connect been in fact lost by attempting to speak through the machine?

Speaking with a machine is an unnaturally slow process. The rate at which people comfortably hear and vocalize words is about 150-160 words per minute. If a VOCA user could compose their messages at the rate at which an average professional typist can typically type that would be about half that rate at 70 to 80 words per minutes. The reality is that most VOCA users can never hope to achieve speech anywhere close to that rate. Indeed, many can only speak at the rate of 5 or 6 words per minute. For Sharon to write these few sentences about her experiences at Christmas with her family it took her several minutes – not seconds minutes.

Talking with a VOCA puts you on the banks of a fast flowing river watching as the stream of conversation flows by. It also seems to make the people moving effortlessly through the flow of the conversation uncomfortable or anxious as they recognize that you are not one of them. The irony of this experience is remarkable. The very thing that the machine provides – the connection through voice – it also denies - the free flowing ease of human vocal interaction.

> *The first time I can recall using an AAC device was in 1993, when I wanted to give kind of a thank-you speech at my BA Grad party. The problem, as I found out while I was TRYING to deliver this speech, was that I had a very hard time keeping track of where I was in the key sequence. Consequently, I kept losing my place, repeating myself and/or skipping ahead and having to backtrack. At one point I became so flustered that I accidentally hit the VERY LOUD SIREN, sending half my audience–including those who were able-bodied–into spasm! It was certainly a MEMORABLE speech! But, a triumph of AAC? Well... No.*

When using a device to talk there is always a risk that it won't. There is always a risk that it might, but not exactly how you would intent it to. A machine is after all just that, a machine. When speaking with a VOCA you are reliant upon the machine. What do you do if the computer hard drive crashes in the middle of a conversation? What of asking for help? How do you explain what on earth is going on to people around you? You can't if your voice is the malfunctioning machine. And to what does the dysfunction hearken back to? Is it the machine that shows itself as defective or is it the person who is dependent upon it?

For now, I will leave as I began, listening to the words of one who speaks with a machine.

> *We have much to learn about assistive technology. About its power! About its potential! And, perhaps most of all, about its dreams deferred: about how much work you and I still have left to do to close the gap between its promise and every day reality. (Fried-Oken & Bernsani, 2000, p. 250)*

As I listen, I hear the call to close the gap between the promise and the practice. I hear the call to keep dreams alive. I hear the call to listen. Is then, when all is said and but surely not done, is the message of people who speak with machines that the real transformational power of technology comes when this extension allows the human beings, not the technology, to be heard? It is my hope that by exploring the realm of technological extensions through the unique and uncommon experiences of persons with disabilities we may be afforded a deeper understanding of technology and of ourselves.

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Chapter 6: The Speech-generating Device

> *"This is a communication device called a Macaw," Shakila tells me softly. "And if you can learn to use switches, then you might be able to use one of these some day."*
>
> *I stare at the box as Shakila turns it on, and a tiny red light flashes slowly in the corner of each square. The symbols are brightly coloured, and there are words written next to them. I can see a picture of a cup of tea and a drawing of a sun. I watch Shakila to see what will happen next as she hits a switch to select a symbol.*
>
> *"I am tired," a recorded voice says suddenly.*
>
> *It comes from the box. It's a woman's voice. I stare at the Macaw. Could this small black box give me a voice?*
>
> *(Pistorius, 2013, p. 28)*

In his autobiography *Ghost Boy* Martin Pistorius shares his first encounter with a speech-generating device. He is shown a small black box that offers him the possibility of a voice, something that as the result of a devastating illness Martin has not had for many years. A Macaw it is called, hinting at recognition of the thing as something like the brightly coloured species of bird famous for its ability to produce human sounding speech. And it too is brightly coloured, at least on its "face". The screen of the small black box displays symbols, pictographic symbols that are representations of words and phrases that someone who programmed them into the device thought may be needed or desired to be spoken aloud. A picture of a cup of tea to be selected if one was thirsty, and a picture of the sun to comment on the warmth or the beauty of the day. And then when called upon to do so by the well-timed click of a switch it does exactly what its name implies, it produces human sounding speech. Is it any wonder that a young man silenced by his body for many years might stare in awe at the possibility of this voice box?

But the voice is not just given, there are conditions that must be met in order to be able to use this "voice box". One must learn a way to speak that involves selecting symbols that are presented on the device's screen, and for Martin that is a challenge. Due to his physical impairments he is not able to reach out and touch the symbol as one of us may do when selecting an app icon on an iPhone. Martin must gain the ability to speak with the device in a decidedly indirect manner, selecting words to be spoken by clicking a switch. For the small black box to give Martin a voice it demands that he must learn to speak anew.

Technological artifacts help to shape human actions and perceptions, and create new practices and ways of living – ways of being in the world. Philosophers of technology and media have sought to understand the meaning of many devices or things in the lifeworld of the humans that come into relation with them. Reflecting on a simple jug, for example, Martin Heidegger (1971) inquired into the question of what a *thing is*, and how in its *thinging*, it comes to mediate and condition our experience of the world. Phenomenological inquiries into the meaning of screens (Introna & Ilharco, 2006), the neo-natal isolette (van Manen, 2012), ultrasound machines (Verbeek, 2011) and Powerpoint software (Adams, 2008) are examples of scholars questioning beyond what a device *is* in the mere *instrumental* or tool- like presentation of itself to the *essence* of the technology or the *meaning* of the particular technological device in our lives.

There have also been a handful of forays into understanding the *thingness* of devices that are specially created for people with impairments of their physical body. Maurice Merleau-Ponty's (1962) *Phenomenology of Perception* presents the blind man's cane to show how an artifact (tool, technology) can extend one's bodily perception beyond the limits of the finite body. Karl Mulderij (2000) helps us to understand how for a child with motor disability a wheelchair is experienced as an extension of his or her body. Mobility becomes possible not with one's own two feet and legs but with one's own four wheels. Don Ihde has explored both eye glasses and hearing aids (2007) as examples of technologies that help us overcome the physical impairments or constraints of our own bodies and allow us to (re)gain specific perceptual abilities. They become an extension of ourselves, our bodies, acting to transform one who is disabled (of sight or hearing) into a technology mediated enabled entity. Ihde refers to such human-relations as embodiment relations.

Drawing upon Ihde’s insights regarding human technology relations, and embodiment relations in particular, this paper explores what a speech-generating device is and how a SGD may act to mediate and condition the everyday lives of those with speech impairments who use them. Gathering insights from over thirty years of working with children and youth who use speech-generating devices in their daily lives as well as published accounts of adults who have written about their experiences with these devices, I seek to present a glimpse into how this technology gives itself in the every day reality of people who use them to give audible voice to their thoughts.

The SGD as object

To exploring the *thingness* of the speech-generating device, it is helpful to first paint a picture of the device itself. While something of an idea has been given from the encounter with the Macaw above, the question of what a SGD *is* may remain. In her novel *Out of My Mind,* Sharon Draper (2012) describes a speech- generating device through the imagination of the main character of her book, an 11 year old girl who has thousands of words swirling around in her head yet due to an unruly body, not a deficient mind, has never been able to speak a single word aloud.

> *First of all, it would have to talk! Oh, yes people would have to tell me to shut up! And I would have room to store all my words, not just some common ones that have gotten pasted onto my dumb plastic board. It would have big keys, so my thumbs could push the right buttons, and it could connect to my wheelchair. It would have to be limegreen.*
>
> *Draper, 2010, p.*

This imagining of a SGD suggests all its component parts. Computer generated speech to allow it to *talk*, a memory where words (vocabulary) can be stored, keys or other input options to access or retrieve the words from said memory, and connectivity to one's self in this case to the wheelchair. The device must be able to be carried relatively effortlessly if one is going to be able to use it to talk throughout one's day. Sometimes that means attachment to a wheelchair, sometimes that simply means a handle. Finally, the young girl endows it with a unique and bold colour, not the black box that Martin Pistorius encountered but a lime green device to personalize its look as well as its vocabulary.

A speech-generating device is as she describes. It is a dedicated computer based system comprised of a display, a means of input such as a keyboard, a memory where the vocabulary is stored, a processor that does the work of transforming the key input into spoken output, and speakers for output. The SGD presents a number of icons, pictographic symbols or text presented in a tabular form very similar to today's handheld touch devices such as a smartphone or tablet computer. While such touch technologies present a neatly organized grid of icons that, when touched, launch us into the virtual space of an application or *app*, the screen of the SGD presents pictographic symbols and words that when touched speak the stored word or phrase aloud.

A non-speaking child may be invited to touch the icon of a green arrow to say the wants to "GO" or the image of a child waving to say "HELLO" to a passing friend. To expand on these one word utterances a child might choose the icon portraying a *happy face with a balloon* with the word "fun" which launches a new grid with variety of activities thought by the designer of the system to be fun: go for a walk, listen to music, play catch and the like. Computer software then transforms the text entered by the child into human sounding speech which is *spoken* through the speakers housed in the device. The speaker (technical object) then it seems becomes the speaker for the child (human).

When explaining these devices and their complexity to people they may say, "Oh like Stephen Hawking." Dr. Hawking, the eminent physicist indeed speaks with a SGD. He has a progressive neurological disease that has taken away his ability to speak with his natural voice. He has made many media appearances, including the popular television show *Big Bang Theory*. People may even recognize the computer-generated voice he uses as the voice of Stephen Hawking even though in actuality the Neospeech ™ voice he has chosen to use is one that any number of other augmented speakers may also be using. Counting on this familiarity, a recent radio advertisement for cell phones seemingly evoked Dr. Hawking using the same computer generated voice has come to be known as his voice. While his name was never mentioned, the voice it seemed was used to help us *understand* that it was Stephen Hawking who was speaking. One wonders if they had to get his permission to use *his* voice to create this illusion, or if because it could have been any SGD user that was speaking if the need for personal permission becomes a moot point. Interestingly, the voice of the SGD is, in some ways, a shared voice — anyone with a SGD may use it — unlike the natural human voice that is singular and unique.

When listening to Dr. Hawking speak on TV or other media, we may be lead to believe that the SGD enables him to engage in conversation very like those in which we engage in everyday. But his own words tell us that the process is much different.

> *…David Mason, of Cambridge Adaptive Communication, fitted a small portable computer and a speech synthesizer to my wheel chair. This system allows me to communicate much better than I could before. I can manage up to 15 words a minute. I can either speak what I have written or save it to disk. I can then print it out, or call it back and speak it sentence by sentence. Using this system, I have written a book, and dozens of scientific papers. I have also given many scientific and popular talks. They have all been well received. I think that is in a large part due to the quality of the speech synthesizer. (Hawking, 2009, cited from Mullenix & Stern, 2010).*

A speech-generating device allows one to generate speeches. Like the verbatim notes one may write when preparing to give a lecture or a toast, speeches can be stored in a SGD to be delivered at some later date or delivered in a relatively synchronous time. The generation of the speech comes through the textual input of the user. Compared to the natural rate of speaking, however, it is painstakingly slow. The speaking rate of those of us who can speak naturally is estimated to be between 150 words to 170 words per minute (Yuan, Liberman, & Cieri, 2006). A far cry from the 15 words per minute that Dr. Hawking seems to be so pleased with. And yet, Dr. Hawking's rate is the norm for one who speaks using a SGD (Newell, 1987).

Dr. Hawking's account tells us that the device allows for speaking in a manner quite unlike speaking with one's natural voice. While the words are those he has written, in order to give them as a talk he depends of the voice of the device. The device has in the language of Ihde, transformed him into a speaking person once again. And he suggests given the quality of the voice of his device one who has been well received by his listening audiences. It is now to this exploration of the *speaking* of the speech-generating device that I will turn. Seeking to understand not only what it does— that is, to speak the words of one who cannot do so of one's own accord—but also to how it may speak in a variety of ways as a thing in the world.

The Speech-generating Device as Thing

> *I accepted as fact that only people who were familiar with me could understand my speech. Then a miracle happened, I was shown and then given a COMPUTER THAT CAN TALK! From that moment on I know that I had left my misfortune behind me. I knew that in this world, I could be a normal individual… If I wanted to talk to somebody I would no more have to wait for my mom or my brother to come and "translate" for me. Now I could be part of this world!*
>
> *Fried-Oken & Bernsani, 2000, p. 102*

> *For most of my life I never gave a second thought to my ability to speak. It was like breathing. In those days I was living in a fool's paradise. After surgeries for cancer took away my ability to speak, I was forced to enter this virtual world in which a computer did some of my living for me.*
>
> *Roger Ebert, 2011*

Don Ihde (2007) tells us that "when we as humans use technologies, both what the technology 'is' or may be, and we, as users undergo an embodying process – we invent our technologies, but, in use, they re-invent us as well" (p. 243). He also reminds us that such transformations create both amplification and reduction in the experience one may have ordinarily, in this case the ordinary experience of speaking in the natural mode.

The two accounts above exemplify very divergent transformational experiences. On one hand the device seems to hold the promise of re-creation, on the other the reality of bereavement. From one who is speech disabled and dependent to one who is *normal* and who can speak for oneself - free to be part of the normal speaking world. And yet for Roger Ebert, who lost his power of speech due to cancer surgery, the impact of the device is decidedly reductive, forcing him to feel that he has given up a part of living as he knew it. Forced rather than drawn into a new world - a world where the computer (SGD) has reshaped and re-constituted his life.

What is it then that speech-generating devices do as they are taken into relation with a person who relies on them to make their voices heard? It may well be that speech impaired persons encounter the SGD as an embodied amplification of themselves, voicing their being in the world. Yet the reductive pulls of the device may still be heard by those who can not speak with their own voice. When one enters into relation with a speaking machine, may it be that the demands of the devices speak as loudly as the voice allows one to find.

Offers One Voice.

> *When I got my talker the first thing I did was to listen to the voices. I saw the one named Jill, I like that name… but it was so old. That's not my voice it sounds like an old grandma. Okay so I thought maybe I would try Samantha… she sounds like a baby. I am not a baby! Then a saw a voice that didn't have a name. It was called 13 cool girl. I listened to that voice. That was it. That's my voice, a cool kid voice. Just like mom always says I am one cool kid.*

Finding our voice, not something that speaking persons are commonly concerned with, or at least not in the literal sense. We may metaphorically speak of finding our voice when we are seeking a certain way or manner of expression. We do not have to find our actual speaking voice, it is something we are given or perhaps that we grow into. The sound of our voice may result from many factors, our sex, our size, our geographical upbringing. One might say we develop our own voice through its use.

Yet as is illustrated in the anecdote the SGD allows for, or perhaps demands, one choose a voice. Indeed it is one of the first things that a user is asked to do as they are setting up their system. In this instance the young woman listens to the voices available to her on her new device to find *her* voice. A girl's voice first, the voice must establish her as female as certainly that would be important for an adolescent girl, and it must not sound to old or two young. But one wonders no matter how "cool" *13 cool girl* may sound could this really be *her* voice.

Speech-generating devices offer up a myriad of voices to choose from. There are male voices and female voices, there are children's voices, teenage voices and even *Will the Old Man*. There are voices that have accents: *Micah*, the Texan male adult voice, *Lisa*, the female Australian English and *Deepa*, the female Indian English voice, and voices which are identified as happy (*Peter- Happy*) or sad (*Peter – Sad*). There are even voices that have a pre-assigned personality, take for example *Saul* the hip hop speech synthesis voice. *Saul* is a voice that one young woman I know chooses when she wants to sound particularly authoritative, as a natural speaker may do by changing the cadence of their voice. The first time I heard her speak using the *Saul* voice I laughed out loud in surprise as *her* voice resonated across the room. The voice captured everyone's attention and most certainly mine.

Each voice offered by the SGD can be listened to as they *introduce themselves* suggesting "I am.... efficient fast and of very high quality. Why not try me out with your own words". And while those invitations to select the voice sound gently inviting, one must choose one of them. In setting up the device for use the device, one may say, insists upon the choice of a voice. The device will not speak until a voice is chosen.

Might it be that the SGD puts one in the three bears house as Goldilocks in search of comfort, trying on the synthetic voices, not too old, not too young, just right. But one must wonder how it could be just right this voice that introduces itself with a name? Whose voice is it, and can it really come to be one's own?

Yet the voice is not my own.

> *I was watching a YouTube video where another girl who uses a SGD was interviewing Tatum Channing. It was so fun and so weird at the same time. Even though she has a different device than I do she is using the same voice as me. When I closed my eyes it was just like I was interviewing him!*

While the voices offered up for selection by SGDs are varied they are also finite. It is not uncommon for two people who use SGDs to use the same voice. In fact it seems that many of the young women SGD users I have encountered speak with the same voice. Literally the same voice! They tell me it's because it is the one that people can understand the best. And certainly this is important. Voices generated by an SGD while of increasingly high quality are still not human and do not carry all the nuanced information that our natural voices do.

> *It was perhaps the biggest event of my life - my first talk to a group of students and educators. I had prepared my speech carefully and delivered it in what I hoped with be an engaging manner. When I done there was polite applause and the principal thanked*

> *me for my speech. No mention of what he learned from the speech, which is how I had generally heard thank-yous done. It wasn't until I was in the hallway and the kids were going back to their classrooms that I really understood what the problem was. Two young men were walking, "Did you understand anything that guy said?" "Nope, he sounded like a robot to me, I barely understood a word." That was the last time I delivered a speech with a computer generated voice. My message was getting lost in text-to-speech translation.*

To have a voice that you can use but that no one understands may be like having no voice at all. Given the primacy of being understood, one might understand the selection of an understandable voice over a *cool* or unique voice, and why that voice is the one that everyone chooses.

For those of us who speak with our natural voice, our voice is as unique as our fingerprint and as personal. It seems that the SGD strips the uniqueness of one's audible voice away, at least using current technologies. Computer scientists and rehabilitation engineers are working on the problem of voice for SGD users. Some are working to allow more emotive voices and voices that can be imbued with tonal variety (Hennig, 2016; Pullan, 2009). Others are taking whatever sounds the speech-impaired person can make and extrapolate a voice that might be more truly theirs. The company VocalID™ claims that with their software BeSpoke Voice ™ a speech impaired person need only provide them with three seconds of vocalized sound and from this they can create a synthetic voice that is as unique as fingerprints (Patel, 2013). This is all possible for a mere $1249 US dollars. The unique voice of a SGD may be given, but at a price.

Stores One's Words.

To use the chosen voice of the SGD one must of course have something to say and a means by which to say it. The device must house and store one's words in order to allow them to be selected for *voicing*. As Melody hoped the device would "*store all my words, not just some common ones that have gotten pasted onto my dumb plastic board*." Prior to the computer chip based communication devices, people with severe impairments of speech were often provided with a paper (or in some instances plastic) communication board. Such boards might have the same pictographic symbols that are now used to represent words in SGDs or they might have printed words and/or the alphabet to allow the user to spell words if they were literate.

> *I did have a letter board that I could point to. It worked well with people who would take the time to talk to me; not too many would. To be fair, talking with a person who uses a letter board can be difficult. Most people are unable to put letters together in their minds to form a word. They certainly cannot remember the words long enough to form a sentence (Creech, 1992, p. 47)*

Prior to the invention of the SGD, communication for people with unintelligible speech was possible, but limited. Talking with text, sometimes written down, sometimes only written in the mind of the hearer. To converse with someone without voice was demanding and burdensome both for the speaker and the hearer. It seems that humans are attuned to put words together into sentences when engaging in conversation. The demand to put letters together to create the words of the sentences may be just too taxing. Letters it seems are for linking one by one in a permanent record of oral language, oral language comes to us in waves of words.

Of course people typically speak long before they are expected to have learned to use letters to create text. So, many of these communication boards displayed pictures and words instead of or in addition to the alphabet. But as one can imagine the number of symbols available would be severely limited by a single paper display. The solution for non-spelling users was to have communication books, pages and sometimes scores of pages with symbols and words. Symbols that had to be carried about in a sometimes hefty binder of words, and then leafed through in the hope that someone would pay attention to your attempt to converse with them, an attempt that while having the possibility of communication was without sound. With the acquisition of a speech-generating device that all could change.

Offers words to express oneself.

> *Before I got my device I never felt I could say anything that I wanted. But on the day that I got it everything changed. I found more words than I ever imagined! And now I was free to speak those words by myself. Now people can truly know me because for the first time. Now I don't have to hide a big part of myself like I was before.*

How wonderful it must be to be given a means to express oneself with the words that one *knows* but cannot speak. To have the words to say what is in one's mind and perhaps in one heart. Due to the amazing advances in computer technologies, SGDs can be small enough to fit in one's hand yet hold thousands words. More words than it may seem imaginable to one who has been confined to using the words pasted into a communication binder. The device it seems lets someone speak for herself in a manner that shows who she really is.

This may be like learning a new language, having a few words *stored* but certainly not enough to express yourself deeply or well. The things I can say in French for example are very limited. I can get by at a very cursory level, saying *hello*, asking a couple simple questions, *how are you? what time is it? where is it?* But, to really have a conversation with someone about something on any depth I would be at a loss. My knowledge of the French language is one might say infantile at best. I would never be able to say anything I wanted. That is unless I spent a great deal of time and had a great deal of practice learning the language.

Of course, today as an emerging French speaker I too could use a device to help me find my words, to help me translate my thoughts in French so I could speak my mind. On my hand held device I have several apps that can translate from English to French. I can even speak that phrase out loud with my device. The problem is that I am still not really sure of what I am speaking. So while I might seem to be speaking French, I certain understand little of what I might be saying.

Here then is the unique offering of the SGD. It presents the words that the speech impaired person already *knows* for their use. Words that may be swirling around in their mind unvoiced and unsaid. Words that upon being discovered in the program of the device can be used to communicate to the world what one really knows and who one really is. That is of course if one can recognize the words as re-presented on and by the device.

Requires Language Learning.

In order to be used to speak, the SGD device requires that one must learn both the linguistic code of the oral language in which one is immersed on a daily basis and to learn, find and use the codified language of the device.

> *That year I got my first talking device, which was called a Touch Talker. My therapist, came in to school to teach me how to use it. I feel she did a great job teaching me where the icons were and what they meant. She did not teach me how to express myself with it. For example, one particular day I was sent out of the classroom for drooling but really I had sneezed out some muffin. For the life of me, I couldn't find the words to say that I had just sneezed.*

The SGD may restrict the ability to express oneself if the words one seeks cannot be found. What can be expressed is dependent on accessibility of their system and the vocabulary stored within. Despite having the ability to physically push buttons, the demands of recalling where the words to say "I just sneezed!" may remain beyond reach leaving one misunderstood and vulnerable in her silent search for words.

Unlike a person who has learned to speak naturally and therefore have *acquired* their words, a child who uses a SGD is *given* their words. First the words that come pre-programmed in the device. This may be a few hundred words or more commonly in today's devices a few thousand. Upon acquiring a device a person must learn how the words are represented and where they are in the system. Then parents, therapists or teachers may add vocabulary (words) into the devices but unless someone is adding every day of the person's life there is a vast asymmetry between the words the device user *knows* and the words the device offers up for use (Loncke, 2014). This is an entirely different way of learning to find words to say than a naturally speaking person would experience. As a speaking person we learn our words and in so learning we *store* them to use the computer analogy in our minds to retrieve again when we are engaging in conversation. Our words are ours.

In conversation with a mother of a young device user she tells me that they are busy adding new words to her daughter's device. And there are 100s of words that she wants to *have* that are not there. Words like *divine*, words like *horrifying*, words like *vampire*. Her daughter loves poetic language, and she is a fan of all things macabre (perhaps another word she should have!). While her device came programmed with over 7000 words, those words are standard words, common words, and not necessarily the words she has learned from listening to words being spoken throughout her life, and quite possible not the words she wants or needs to express *herself*. Consider this story of not having the words one needs to say.

> *The nice but serious man came to my house and asked me what I wanted to happen when I turned 18 years old. I told him I wanted my wonderful, loving parents to be my* ***garden ships*** *and when they are too old my very nice and amazing cousin Nicky. The man was very happy that I could understand him and he said it was nice that I had a plan.*

Despite the thousands of words that have been stored in and added to this young woman's device *guardianship* is not one of them, and yet she has found a way to express it using the words that her machine holds –*garden* and *ship* – *garden ship* not quite the word she wants but when spoken aloud by her device happily close enough for her to be understood and for her wishes to be heard. But consider these two words that she has cobbled together, they have no semantic relation to the concept of guardianship. Indeed she tells that *I find garden under fall and then in the activity row. Ship is under drive then the activity water vehicles*. While the device allows her to generate words she does not have, it certainly demands that she develop a unique path to doing so.

One wonders if speaking with or is it through a speech-generating device is like entering into Grand Academy of Lagado (Swift, 1726) and being forced to take up the practices of the learned language professors? As Gulliver tells us in Lagado the professors have decided to save their voices by packing about bags of things to bring out when they were required to engage in discourse with one another. He notes that while many of the wise professors of the academy adhere to this new scheme, there is one not insignificant inconvenience:

> *that if a man's business be very great, and of various kinds, he must be obliged, in proportion, to carry a greater bundle of things upon his back, unless he can afford one or two strong servants to attend him. I have often beheld two of those sages almost sinking under the weight of their packs, like pedlars among us, who, when they met in the street, would lay down their loads, open their sacks, and hold conversation for an hour together; then put up their implements, help each other to resume their burdens, and take their leave.*

Estimates of the number of words *normal* nondisabled adult speakers *know* and can use range between 50,000 and 70,000 (Loncke, 2014). Estimates of the number of words offered up by even the most *word rich* SGD would be a mere fraction of that number. While clearly the small and portable packaging of today's speech-generating devices vastly increases the words that can be *carried about* by people with speech impairments, one wonders if perhaps they too might be burdened by not the weight of their pack but by the sometime unbearable weight of still being at a loss for words.

The device may announce itself.

> *I am having a chat with a young SGD user when suddenly alarms go off on her device.*
> *Startled and more than a little concerned I ask what is going on.*
> *My voice is running out of gas!*
> *There is a gas meter.*
> *The doo doo doo – you can't shut it off.*

I am trying to talk but my body is spazing out on me…
It is a race between me and my battery.

I am running out of gas. You must plug me in soon or I will no longer speak for you the machine announces not with the gentle inviting voice used to help one select a synthetic voice, but with a loud alarm. In response the young woman enters into a race with her machine that sends her body and quite likely her mind into spasm. The spasm in turn taking precious energy and time, both of which may be in short supply if she is going to get out what she wants to say before the the pronouncement of death of the battery becomes reality.

Speech-generating devices come equipped with long lasting batteries, batteries that are meant to see one through a day's worth of conversation. But yet for a myraid of reasons they may not. Perhaps someone forgot to plug it in last night. Perhaps it is a day where the person using it to speak has been particularly chatty. Whatever the reason, the battery life of the machine is limited. And when it's limits are close to being reached it reminds one that it must be plugged in. It must be connected to an energy source or silence of both the alarm and the voice of the machine will ensue.

We can imagine that our natural voices may speak for themselves on occasion. Our hoarse voice may tell that we have been talking to much being or are unwell. Our voice is under some kind of strain. But it would be a strange thing to have our voice suddenly outright fail us - die on us. As our voice is of us not at thing separate from us but *is of us*, we may tell a friend we need to stop talking for a bit because we need to rest our voice. But it is the person that runs out of steam not the voice.

Yet the voice of the device, indeed the device itself, may *die* at any time. Or at least at times when the user has not paid sufficient attention to its battery life. This could happen in the middle of a quiet interlude in the person's day, breaking the stillness with a most disturbing alarm or in the middle of a conversation breaking the flow in a most annoying way. The device sounds the alarm… doo doo doo doo doo. How disruptive and indeed how demanding. You must plug me in or I shall no longer carry or voice your words. Yet once it is again plugged in all is well the voice is again empowered. That is, all is well enough if one is content to be tethered to the wall for the time it takes to recharge.

Contact

There is another kind of power that is not taken by electronic device but that may be given. This is the amazing power of voice to bring us into contact with one another. Calling out to one's friend with an excited hello announces one's presence and elicits a recognition perhaps even before one sees the face of the caller. Hearing the voice of a loved on over the telephone brings us into contact with them despite their being thousands of miles away. The audible voice has much power. Something of this power is offered by the voice of the device.

The device allows me to reach across the room with my voice.

> *I like to use my talker to bug kids in my class, especially kids like Mike. We were in Science class together.*
> *He was sitting right in front of me. I was thinking Boron the moron so I typed it into my device BORON. It was quiet in class so all the kids heard, and everybody started laughing. I could tell by his face he knew I was talking to him- he got all mad and called me a nerd.*
> *I called him Boron for the rest of the year!*

Lingis (2005) reminds us of the extraordinary power this power of voice to put us in contact with another, to reach across an audible space to shout hello or to beckon someone near. And what child has not used their voice to tease another, especially another from whom he seeks particular attention? In this instance the voice from the SGD has allowed this child to reach across the quiet space of the classroom to do just that, to call out to her friend gaining both his attention and perhaps more importantly the attention of the class. The voice from the device allows her to make her presence as a witty and intelligent person heard and duly noted. “Boron is an element you know”, she told me with a grin when she recounted her story.

Unlike devices that transform one’s perception of the world such as glasses or the blind man’s cane, SGDs it seems transform other’s perceptions of those who use them. She is able to show herself as present, smart, and one might even say sassy. And with the laughing response to her *insult* she has made contact not only with the young man she sought to *touch* with her word but also with her whole class. They all laughed!

As I write this piece a new television show has just been aired. It is called Speechless, a comedy about a family that includes a teenage boy who uses an augmentative and alternative communication system - an augmentative and alternative communication system but NOT a speech-generating device. He has a letter and word board that he points to with a laser pointer attached to his glasses. In order for his thoughts to be spoken he relies upon others to follow the beam connect his chosen letters and words into phrases and then speak his words aloud. One of the main tenants of the show is that his family is moving to a new school where he will have an assistant. Someone who his mother says will “be at your side reading from your board wherever you go – *a voice*”. The promise is that he will at 16 years of age finally be able to speak for himself as he will have a human voice interpreter following the laser beam on the board and faithfully voicing aloud what his is writing. We have early touched on the challenges of a communication displays and letter boards as modes of talking, but in the first episode of this show other aspects can be heard.

Upon entering his new class with his “voice” (assistant) duly by his side he encounters a well-meaning but clearly overzealous teacher and classmates who decided without asking him or indeed without knowing him that he should run for class president. Annoyed with this state of affairs he “types” out on his board EAT A BAG OF ----- , but his “voice” (the assistant) flustered by what she is reading says instead “he is flattered and he’ll think about it”. Not his words, and certainly not his intended message. The human assistant has altered his words and clearly his meaning to be more polite, more appropriate.

Contrast this to the young woman who called her friend Boron. With a device as her *voice* she could speak for herself. But what if she would have instead been given a human assistant? What, if anything at all, might have been said in that Science class if she did not have the SGD? Would an assistant reading the word Boron as she was typing it really have shouted that word out across the classroom or would it be more likely that she would have shushed her saying you can’t say that. Or you can’t say that now. Even if an assistant had been true to the calling of being the child’s authentic voice, would the clever retort be attributed to the child from whence it came? The voice from the device will speak what is entered, there is no judgment made, no one stopping it from being said aloud. Judgments and even consequences may arise based on the words emanating from the device, as judgments and consequences arise for any child who speaks out in class. With the device the speech-impaired child is given the ability and the authority to invite them all.

Yet the voice from the device may also mask my presence.

> *One time I tried to use my device to call Handi-bus. I called them and somebody picked up the phone at Handi-Bus. I said I want to be picked up this Friday at 1:30. My address is 3 4 5 3 Apple Way. The Handi-Bus person said, “What do you want?” I repeated my message: I want to be picked up this Friday at 1:30. My address is 3 4 5 3 Apple Way. The line went dead. Maybe they thought I was a crankpot ? I don’t know. Anyway, I thought okay, that didn’t work… next… I guess I wait till Mom comes home and she can call them. I think they will know she is a real person.*

Using his SGD this young man was trying to do what any of us might do on any given day, place a call to another human being to request a service. We may be calling for a taxi or calling for a pizza. When doing so we pay attention to why we are calling, the message we want to convey. Our voice announces us, but unless we have a malady such as a cold or laryngitis, our voice is passed over unnoticed except to bring ourselves into meaningful contact with the other human being on the line. But what may happen if the voice is generated not by a naturally speaking person, but from a SGD? It seems that perhaps the voice itself may have done some of the speaking.

Today we may often hear synthetic speech on the other end of the telephone line. "This is your bank calling with an important message", "thank you for calling someone will be with you shortly", "estimated wait time is approximately 10 minutes". A recent commercial for a Canadian bank plays upon this common experience. The woman who is on the phone with her bank comments to her husband on how amazing the computerized voice is. She is then surprised and somewhat embarrassed to discover she is actually speaking with a real person. Contact with computer-generated voices has become such a regular experience that the bank can show itself as unique in providing *the human touch – a real human voice*. Something that the SGD can mimic but at least as yet cannot produce.

Given that even the most sophisticated computer voice still is noticeably synthetic we may in the first few moments of being addressed by such a voice recognize it as computer generated. This is different from what we notice when we have a poor connection. A poor connection can cause us to misunderstand or not hear at all the voice on the other end of the line. But still we are aware that there is a human being actually speaking. When we are greeted with synthetic speech, while we may well be able to understand the message, that is the message is *clear*, we may from our now numerous experiences with robo-calls or other computer generated speech many of us may be tempted to do exactly what was apparently done by the Handi-bus operator when confronted with a computer generated voice, hang up. A computer generated voice may speak for itself, telling the person on the other end that there is really no one present on the call, but rather what we have come to refer to as a *robo-call*. We are not compelled to listen, as we may believe there is really *no one* there with us on the line.

The give and take, the amplification and reduction, of the SGD seems here clearly at play. The very technology that allows a speech-impaired person to join in the world of speaking beings has itself spoken on his behalf. Rendering him once again to call upon a naturally speaking person to make the call on his behalf, using the voice of a real person.

The Silent Partner?

A recent augmentative and alternative communication textbook has the title *The Silent Partner? Language, Interaction and Aided Communication* (Smith & Murray, 2016). In their introductory chapter the authors explain their title by noting:

> *When a communication aid is introduced into a communication situation, its presence changes the nature of the interaction… Even when it is not actively used within the interaction, its silent presence exerts an influence… The title of this text – The Silent Partner – has been chosen to focus attention not on a communication aid as an entity in itself, but … on how this silent partner role affords and shapes developmental opportunities over time*

Without perhaps realizing it the authors have pointed to the very important understanding of a SGD not as an object (entity in itself) but as a thing, a silent partner that affords and shapes the lifeworld of one who uses it. This kind of noticing, of the device as a partner in the communication experience, has gone relatively unnoticed and unheard in the field of augmentative and alternative communication. The field speaks of devices as tools (Cook & Polgar, 2008) adopting the instrumental view of the device. Yet it has been shown that the SGD is hardly a mere tool. To borrow the language of Heidegger, it seems that indeed the essence of (this) technology is by no means technological (1977). The essence of the SGD can be found in its shaping of the lifeworld of those who are called up to use it. The SGD speaks for the person who uses it, and it speaks of him. The SGD makes demands upon the user that if met can afford wondrous transformation from a silenced person into a speaker. And as Jeffery Higginbotham, a social scientist and long time researcher in the field points out

> *…more than any other application of assistive technology, speech synthesis is charged with the responsibility to serve as a major expressive modality during social interactions….this responsibility goes beyond that of merely being a tool to convey information*
>
> *Higginbotham (2011)*

What I have attempted to show with this glimpse into what SGDs do, is that the instrumental understanding is far from complete. And while it seems with the sentiments expressed by the authors of *The Silent Partner* express this lack of understanding, there is the question if one can understand the SGD as silent. If we focus our attention to the way it offers and demands, expresses and masks, speaks and silences, the SGD seems to have a very loud presence in the lives of those who use it to convey their speeches to the world.

To take up once again Ihde's embodiment relations, one might now ask does the SGD allow one to speak *with* it as might be implied if it is a partner in the exercise of speaking or does it allow one to speak *through* it? Does it, can it, ever become passed over un-noticed in its amplification of speaking abilities? Embodiment of a SGD, while apparent, remains far from transparently achieved. For "there is, as yet, no technology that can transform thoughts held in a person's brain directly into speech" (Venkatagiri, 2010, p. 29). There is, of yet, only ever smaller, ever more powerful, ever more expressive *voice boxes* that can be called upon to speak for those whose voices cannot carry the burden of audible expression so greatly valued in the daily life of any human being. And so I finish as I have ever begun carefully listening to the voices that are made present through the voice of the machine. It is my fervent hope that you may be called to listen too.

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Chapter 7: Out of Time in the Classroom

It was the first day of school and the first day that Jennifer was in my class. Of course I had seen Jennifer wheeling around the school before. I had even been at an assembly where she spoke with her communication device. I remember thinking wow that's just like Stephen Hawking. Now Jennifer was wheeling through my door.
Good morning Jennifer, I said, welcome to Room 10.
Jennifer looked down at her device and pushed some buttons.
Beep,
beep,
beep,
THANKS
Her assistant, who like always was right behind her, said we will need to have space for me to sit beside her.
Sure we can do that and I glanced around the room noticing that it suddenly seemed smaller than it was when I first came in.
I could hear the
beep
beep
beep of Jennifer's device.
How about over there?
MICHELLE
You want to sit by Michelle I asked?
Her aide said She sat with Michelle last year.
beep
beep
NOT
You don't want to sit by Michelle?
Her aide looked at me and shrugged her shoulders?
beep
beep
beep
Jennifer was still looking down at her device …
beep
beep
beep
HERE
As if on cue the bell rang and the rest of the kids started coming in.
Hi Ms. M.
Hey Ms. M aren't you glad to have me again this year.
Joe are you in this class, that's sick!
Hi Ms. M.
Hey Megan, come sit over here!
Behind the voices of the kids excitedly filing in, I could hear the faint but somewhat incessant
beep

beep
beep
of Jennifer working away on her device.
Jennifer I said, maybe for today you can just sit here by the door. Michelle will probably be here soon.
She continued to look down at her device…
beep
beep
beep …
The kids were all here now, and the room was so full of their excited voices that I could no longer really hear Jennifer, although I could hear that in between the beeps she was also speaking words.
Okay guys quiet down, I said... As they did so, I heard
SICK. From Jennifer.
Hey Jen, ya Ms. M is way sick…
Well that's neat I thought, she even has the kids slang down.
Her aide was now looking at her device. Oh did you guys talk last night?
Now I was really confused.
Jennifer looked up at me, and with one more beep on her device told me what she wanted me to know
MICHELLE NOT HERE TODAY SHE IS SICK.
Wow, this is going to be more complicated than I thought!

The beginning of every school year brings teachers into contact with new students, children that they may know nothing about and others that come to them with at least some measure of their story already told. And each year, teachers attempt to make contact with these students, to reach them and teach them. It is an exciting time, teachers meeting new students, teachers greeting past students, and students chatting expectantly with each other. For Ms. M this first day was perhaps more exciting than usual as it was the first time she had Jennifer in her class. Jennifer is an extraordinary student, different from any students that had entered into Ms. M's class in so many ways. First, Jennifer does not walk into the classroom, she rolls in, in her wheelchair. Secondly, Jennifer brings with her another adult, an assistant who also will now be part of the social and physical makeup of the classroom. But perhaps most importantly, due to her physical disabilities, Jennifer cannot speak with her own voice. In order to speak her thoughts aloud, Jennifer must do so with a machine, a speech-generating device.

The speech of the classroom is fast paced and demanding. Educators expect students to enter in with the ability to keep up, if not with the academic demands, certainly with the conversational ones. Based on her past experience with Jennifer this teacher had not been expecting anything else from Jennifer. She had heard her speak, not in conversation perhaps but giving speeches. She perceived Jennifer to be able to speak. She in fact had an example in her head that allowed her to see Jennifer as a capable speaker. What she did not expect was that speaking with a device does not make one capable of meeting the timely demands of *just* speaking.

Ms. M believes she knows much about Jennifer. She seen her moving about the school in her wheelchair and has heard her speak. She has, one might say, a favorable impression of Jennifer, after hearing her give her assembly speech. As may be the case for many people, Ms. M's expectations of what it is like to talk with someone who uses as SGD have developed through their encounters with Dr. Stephen Hawking the eminent physicist. Dr. Hawking has used a speech-generating communication device for close to thirty years. During that time he has made several public appearances. Recently he made a cameo appearance on the popular television show the Big Bang Theory. In this spot Sheldon, one of the main characters in the show, and a devout Stephen Hawking "groupie", gets the opportunity to meet the physicist and discuss his dissertation with him. The conversation, while not quite *normal*, in that before each utterance Dr. Hawking makes with his device there is a beeping which tells us that he is doing something with it and his computerized voice is without the richness of inflection and tone of a natural voice, seems otherwise unremarkable. Sheldon and Dr. Hawking converse back and forth in much the same way any budding scholar and distinguished researcher might, with bits of humour thrown in; as after all it is a situation comedy. Having seen this familiar conversational flow enabled by Dr. Hawking's use of his speech-generating device, it is perhaps no wonder that Ms. M expects that Jennifer will be able to converse in much the same way. What Ms. M and the rest of us watching the Big Bang Theory or listening to Dr. Hawking give lectures with his device are not privy to is the reality of what such a conversation would really entail. What it is really like is so very much different. These productions are scripted and edited to take out the time, often many minutes, that it takes Dr. Hawking to construct and then speak even a short sentence aloud (Brockes, 2005; Hawking, 2008). The Dr. Hawking that we are brought into contact with through the media presents an idealized or perhaps we could even say a sanitized view of what it is to speak with a device. What Ms. M was confronted with on the day that Jennifer entered into her room was a face-to-face real time glimpse of what it is really like to speak through a machine.

At first nothing seems that different. Jennifer's response to Ms. M's welcome to the classroom is just what any child might say and it is only slightly delayed. The delay is *filled* with the beeping sound from the machine telling Ms. M that Jennifer is working on a response. As Jennifer attempts to deliver the information she has been asked by her friend to convey to her new teacher, her message gets broken by the single *word bites* that are misconstrued amongst the fast flowing pace and the myriad of exuberant voices of the classroom. It is little wonder that Ms. M is taken aback with the reality of what it may be like to have Jennifer in her class.

Then consider what it might be like to be Jennifer. She has been greeted warmly by a new teacher and at first she is given some one-on-one time to get her message across. She works diligently to do so, to share something with her teacher that her friend is relying on her to convey. But as each word is spoken it is taken on it's own and it's meaning constructed not in relationship but as a separate unit. The time delay is too great to connect the words for Ms. M, yet the time speed is too quick for Jennifer to even begin to keep pace. Then, as is the norm in a classroom, the other voices, voices of students who can speak in real time, enter in. The room becomes full of voices all speaking with, to and in some instances on top of one another. Jennifer's word-by-word delivery is drowned out by the exuberant chatter that fills the space and time of the classroom. Her assistant, because she is at her side and can read the message on her device as Jennifer has constructed it, is the first to *hear* her actual words. It is actually the assistant's quick response to Jennifer's message which seems to draws her teacher back to Jennifer. Because of the unexpected words of the assistant her teacher now wonders what it is that Jennifer was really trying to say. And in taking the time to note Jennifer's words she is both surprised by their meaning and unnerved by the greater message conveyed about the real complexity of making an auditory space for Jennifer in the classroom.

Background

This paper explores the unique unfolding of time in the life world of young people who, due to unruly bodies, cannot make themselves understood with their natural speech alone. Young people who in order to speak their thoughts aloud must do so using a speech-generating device. This particular inquiry on time and timing of speaking through a device is taken from my dissertation research where through phenomenological methods I asked what it is like to speak through a machine. In phenomenological investigations researchers may often use the experiences of lived body, lived space, lived relation and lived time (commonly known as the existentials) to gain insights to what it might be like to experience the phenomenon at hand. This paper focuses most particularly on the experience of lived time. However, as human speech is such a fundamental experience of bringing ourselves into relationship with one another, lived relations will also be seen to be at play in the experience of speaking through a device.

The anecdotes presented in this paper are derived from stories told to me as I gathered lived experience materials for my research project. My participants included nine young people who due to physical disabilities used SGDs in their daily lives. They were visited and interviewed, both face-to-face and through electronic means, over a period of approximately two years. The participants were all proficient users of *high tech* SGDs and were currently or had recently used these communication devices in a K-12 school setting. Participants were asked to share their experiences of using SGDs, particularly those that involved their memories of school. In addition to interviews, lived experience descriptions were gathered through observation of these young people's use of SGDs in the context of school, in their homes and naturally during the interview process itself.

Drawing on the approach to phenomenological inquiry as articulated by van Manen (1997; 2014), this paper aims to help practitioners in the field of AAC, teachers, and parents better understand the experience of speaking with a SGD most particularly the experience of time in the context of school and the communication and social relations that are so critical to students' positive experiences in the classroom (Cazden, 2001; Chung, Carter, & Sisco, 2012).

Coming to the study.

I have worked for over thirty years with young people like Jennifer who cannot create intelligible speech with their own bodies. Young people who must use aided methods to express themselves to others. For the vast majority of that time I have focused on supporting young people in their use of augmentative and alternative communication (AAC) systems in the context of the classroom. For many of these children, although certainly not all, these systems included a speech-generating device.

Throughout this lifetime of AAC I have had many experiences interacting with children and youth who use SGDs. I been caught by surprise as a twelve-year-old boy who speaks with his SGD took control of the room by interjecting “excuse me I am not finished yet – I have more to say”. And I have watched in despair as a teenage girl, desperate to *fit in* in her junior high, struggles to interject a few words spoken with her device as her classmates carry on a conversation that moves too quickly for her to hope to ever catch. I have listened patiently as a teenager tells me with the voice of her device how excited she is that she got two new kittens, and I have listened uncomfortably as that same young girl becomes silenced by the chatter of the lunchtime conversation of her classmates. Despite these recurring events in my interactions with these extraordinary students, my focus had always been on practices and interventions that the research suggests will help them to speak faster, better, more independently. In my efforts to intervene I seldom paused to really consider what it might be like to speak with a device.

Many questions emerged. How are the temporal demands of speech experienced by SGD users? What is the meaning of time in the lifeworld of those whose *talk time* may be so different from *talk time* we may take utterly for granted as natural speakers? In particular, what might this be like for young people who speak through SGDs. What is speaking with a device like in the context of the class time? What about together time with their friends? And what is the meaning in their lives of always being out of time?

Reading about time.

In hoping to get a greater understanding of the meaning that time and timing takes on when one uses a SGD I have sought insights from various literatures. I draw upon the phenomenological insights about *time* itself so eloquently presented by J. M. van den Berg (1970), about *speech and speaking* as explored in Merleau-Ponty's writings (2009), and finally about issues of *human-technology relations* as described by Don Ihde (1990). From the field of linguistics I have looked to authors who have written about the pace of human speech (Bellugi & Fischer, 1972), the time delay in between utterances that is acceptable in human speech (Stiversa, et al., 2009), and the discourse of the classroom (Cazden, 2000) to understand better the reality of talk time both inside and outside of the classroom.

Finally, I have gone to the AAC literature for insights about time and timing in AAC use itself. There are several authors who touch on the issue of time. Higginbotham and his colleagues have written extensively on the constraints of time imposed upon people who rely on any form of AAC to communicate (Higginbotham & Caves, 2002; Higginbotham, Fulcher, & Seale, nd; Higginbotham & Wilkins, 1999). Others in the field of AAC have touched on the impacts of time on children who use AAC in interactions with caregivers, teachers, and peers (Baxter, Enderby, Evans and Judge, 2012; Beck, Bock, Thompson & Kosuwan, 2002; Clarke &Wilkinson, 2007; Light, Collier, & Parnes, 1985; Lund & Light, 2003, Smith, 2005).

By bringing this divergent yet related literature to bear in reflecting upon the lived experiences that have been shared with me with and through SGDs, it is my hope to gain a more experiential understanding of what it might really be like to be constantly out of synch with the talk time of the world. In consequence, hopefully awakening those of us who have the opportunity to support children and youth with complex communication needs to understand what *their* experience is really like.

The challenge of time

We as *speaking people* may never give a moment's thought to the process of speaking. We do not take the time to think about entering our words into the flow of our speech. Our thinking and speaking is simultaneous, intertwined and interwoven. As Merleu-Ponty (1964) suggests "to make of language a means or a code for thought is to break it" (p. 17). In order to speak we must stop picturing its code or even its message to ourselves, and make ourselves sheer operators of the spoken word (p. 18). If we had to think about producing each word or even each sentence it may seem so cumbersome and time consuming we would hardly be able to speak at all. For those who speak there is not thinking about speaking there is only speaking what we are thinking. Navigating in the time stream of spoken language seems quick and easy and effortless. Yet this hardly seems to be the case for people who in order to speak their thoughts aloud must do so through a machine. Let us listen as Gabby tells us about speaking with her SGD.

> *Talking to people with an assistive device is not easy. First I have to think what to say, then I enter those words into my device. Once I have finished my message I push speak to say the words out loud.*

Gabby tells us that speaking with a machine is not like speaking. It is a multi-step process, one that is decidedly thoughtful and unnaturally slow. Speaking with a SGD seems to involve a *first-then* series of actions far removed from the *ordinary* actions of speaking. When speaking thoughts aloud Gabby must first decide what she wants to say, then find those words in her device, pick each word in the sequence necessary to turn thoughts into words and then words into phrases. To get the task of speaking accomplished she must finally push the *speak* button. The device must be told a great many things for it to speak intelligibly. Each of those things take *time*. For Gabby to provide that short response to my query about how she talks with her device it took close to four minutes. Time that is not taken when a *speaking person* speaks, and time clearly not expected by one who can speak naturally.

Bellugi and Fischer (1972) suggest a speaking person produces between 4 and 5 words per second. This analysis would suggest a speaking rate of 240 to 300 words per minute. However this rate is seldom achieved as conversations are filled with pauses and fillers. Yuan, Liberman and Cieri (2006) suggest a more realistic estimate of speaking rates would be between 150 words to 170 words per minute. The reality for people who use AAC is that their communication rate never can achieve anything even approximating these rates. Communicating with an SGD may be from 15 to 25 times slower than spoken speech rates (Beukelman & Mirenda, 2013, p. 60).

If a person speaking through a SGD could compose their messages at the rate at which an average professional typist can typically type that would be about half of the *normal* speaking rate at 70 to 80 words per minutes (Wikipedia, retrieved July,2014). Most SGD users can never hope to achieve speech anywhere close to that rate. Even using today's methods of user interface optimization and rate enhancement methods, communication rates achieved by a device user are often less than 10 words per minute (Newell, Langer & Hickey, 1998).

Given this significant disparity in the rate between speaking and speaking through a device, what might this device imposed speaking rate mean for a child who in order to be heard must speak using an SGD? How might this slow rate be understood when they enter into the fast-paced world of speaking children? Let us listen to Rebecca recount her first day with her SGD and her fleeting conversation with her friends.

The delay speaks of me

> *I was in grade 7 when I got my first device. I was so excited. But as I got to school and tried to talk to my friends I just couldn't get the words out fast enough. I am not a slow thinker, but even with my new device I am a slow talker.*

Imagine getting a voice for the first time as a young person. No wonder Rebecca is excited, likely bubbling full of things to say to her friends with her new wonderful talking machine. Any teenage girl may say I was so excited to tell my friends my exciting news that I couldn't get the words out fast enough. Indeed on many occasions I had to ask my own teenage daughter to slow down - I know you're excited but you are talking so fast I can't understand you. Yet for Rebecca, due to the imposition of the demands of the device, those words do not flow or bubble out like those of an excited young girl. Despite her quick and excited thoughts, she is rendered *slow*.

What does it mean to be slow? A dictionary definition tells us it means "taking a long time to perform a specified action"; "moving or operating only at a low speed; not quick or fast". (Dictionary.com, retrieved July 22, 2016). Slow also has other meanings. To be *slow* to not be prompt to understand, think, or learn (Dictionary.com). Indeed the origins of the word from the Old English *slāw* had the meaning of being sluggish, torpid, lazy, and dull-witted. To be *slow* is then perhaps understood as something more, something not to do with time itself but to do with the person herself. To speak slowly may send a message that we do not know of what we speak, that we are struggling to get our thoughts out, or perhaps something more.

At a recent family gathering some of my great aunts and uncles spoke. My cousin commented on how difficult it was to listen to one of the speeches because the woman was speaking so slowly. She described it as painful, wondering quietly if perhaps the woman had some cognitive impairment. My uncle laughed and said no she's as smart as a whip it is just the Mennonite drawl. A style of speaking, a custom of speaking slowly, yet so far from our expected norms that it was painful to listen to. Nevertheless, my slow speaking relative was still speaking at a pace that far outstripped anything that Rebecca could possibly achieve with her shiny new device on that exciting day in grade 7. Were messages of her *capability* being conveyed by the sluggishness of talking through a machine? Speaking through a device is slow no matter how quick and lively one's wit and wits may be, and no matter how excited and motivated one may be to speak. It may be that the speed speaks for itself.

There are rules that govern spoken interactions. There is, for example, consensus that across languages there is a *minimal-gap minimal-overlap rule* (Stiversa, et al,, 2009). These researchers found systematic cross-linguistic support for the view that "turn-taking in informal conversation is universally organized so as to minimize gap and overlap, and that consequently, there is a universal semiotics of delayed response" (p. 10591). A speaker in any language tends neither to overlap nor delay a response by more than a half-second – the length of time it takes to produce a single English syllable. One half-second! How very far this is from the four-minute delay I afforded Gabby in answering my question. How far this is from the multi-minute delay, that, although filled with a beep beep beep, was necessarily invoked when Jennifer was attempting to speak with her teacher on her first day of school. How far it seems is this from what is remotely possible for one who speaks with a machine. Is it any wonder then that Rebecca could not get the words out fast enough? Fast enough, it seems, may be impossible given the expectations we have of talk time. Let us listen again to Rebecca as she tells us more about the day in grade seven when she got her SGD.

I pretty much just stop talking

> *At first my friends waited to hear what I had to say, but after a couple of sentences they lost interest and had moved on to something else. I was always behind, or always making them wait for me. Most of the time when I got out what I wanted to say it really didn't even make sense any more cuz they were three topics ahead of me. So after of few times of that, I pretty much just stopped talking.*

Rebecca is falling behind as her friends move quickly through the time stream of speaking children - dynamic, shifting and above all fast-paced. At first they wait, but not for long. Before she can speak more than a couple of sentences it seems that they become tired of waiting and move on. Van den Berg (1970) shows us that time is a strange and wondrous thing. It moves quickly if we are pressed to accomplish something by a certain time, it drags on incessantly if we are waiting for something or someone to arrive at our door. Time for one using a SGD to talk seems to have this contradictory dimension one might say at the same time. For Rebecca time is moving quickly, pressuring her to hurry up and get her message out. Yet she is keenly aware that *her time* demands *wait time* for others. Of course this push and pull of time may well be experienced by any of us who feel the need to get a message out quickly. We may feel we can’t talk fast enough. Yet speaking with a device seems render one to *always* be pressed for time, to always have to have hurried speech, and still there is never quite enough time.

Despite her scrambling to get out what she wants to say in the flow of the conversation her delayed comments make no sense in the fast paced flow and quickly changing topics of adolescent speech (Smith, 2005). The time for her message has long past. One can imagine how difficult this might be. Consider what it might be for her friends to be talking animatedly about a perceived slight against them by a teacher, then moving on to a discussion of a new television show that debuted the night before, and then to the cute boy that that just walked by. Rebecca finally speaking “That’s pretty stupid” as a comment about the first topic, the slight of the teacher, might well be greeted confused looks at best or misinterpreted at worst to mean she is making a derogatory comment about her friends taste in boys. Rebecca has spoken, but not in the talk time of her friends. A pause of more than two seconds can break the temporal threads of a conversation (Higginbotham & Wilkins, 1999), or perhaps as in Rebecca’s case, extinguish the life of the conversation completely. It has become embarrassing to be so out of synch with the conversation. The temporal demands of the device have spoken. Rebecca is rendered silent. A silence she chooses to save herself from the perils of being too slow or sounding too strange.

Adolescent social communication takes place largely in conversations, which serve as the glue what holds together cliques and groups (Smith, 2005). Yet given the very real time challenges it may be that this *social glue* never gets the opportunity to set. Studies exploring peer interactions between children who speak naturally and children who use SGDs tells of the many challenges in these interactions. Romski, Sevcik, and Wilkinson (1994) described the peer-directed interactions as primarily involving responses, and noted that students used augmentative communication less often than other communication modes such as facial expression or gesture. Certainly as I watch the young people who are speaking with me about their experiences *talk* with their friends I notice much more non-verbal communication used on their part than actual speech from their device. One of the most effective communicators rarely says a word using her device, unless specifically prompted to do so. Instead she smiles and points and nods at exactly the right times to keep up with the conversations she and her friends are having. While research into children's use of SGDs has often focused on issues of intelligibility of the computer generated speech produced (Drager & Reichle, 2010), yet it may be that what gets in the way of being heard is not the intelligibility of the speech produced but the timing. Recently, Chung, Carter and Sisco (2012) investigated the social interaction of students with disabilities who use AAC in inclusive classrooms. Their findings were similar in that students with CCN used facial expressions, gestures, and vocalizations far more frequently than electronic devices. How ironic that may seem when these are the types of communicative behaviors that were afforded these children before they obtained their augmented systems.

What is also apparent across the AAC research is that students with CCN are far more likely to engage in communicative interactions with adults than with peers, and to be *passive* in their classroom interactions (Clark & Wilkinson, 2008). It has been hypothesized that these asymmetries observed in interactions between students who use SGDs and others are related to the slow rate of communication aid use (Light, Collier, & Parnes, 1985c). Yet, if one were to ask Rebecca might she say she is talking just as fast as she can?

I asked Gabby if she remembered a time when she felt the pressure of time in talking she retorted:

> *All the time. I don't have any one time, it's always like that. If I am talking in a group if I don't hurry they will have already moved on to something new. If they stop and wait the silence makes me want to hurry more because I know they are waiting on me.*

As previously noted Smith (2005) tells of many challenges adolescents who use aided communication encounter, not the least of which is time and timing. She notes that conversations occur with no advance notice, yet they require sophisticated planning, *timing,* and self-regulation. Smith (2005) reports that adolescents averaged approximately seven turns per minute of conversation with topics changing frequently, ranging from 1–2 topic changes per 5 min period, to two topics per minute (p. 71). Recalling that even the *fastest* SGD user may only achieve rates of are often less than 10 words per minute, it is little wonder that Gabby feels she is always pressed, or maybe stressed, by time.

Talking with a device puts you on the banks of a fast flowing river watching as the stream of conversation flows by (Higginbotham, nd). It also may make the people moving effortlessly through the flow of the conversation uncomfortable or anxious as they recognize that you are not one of them. The irony of this experience is remarkable. The very thing that the machine provides – the connection through voice – it also seems to deny - the free flowing ease of human vocal interaction.

The broken conversation

> *I remember my teacher would try to make sure to talk to me at least once every day. She would often ask me what I had done the night before, or if I had any interesting news to share. One time I was really keen to tell her that I had seen a movie hoping that maybe we could talk about it. While I was creating my message one of the other kids in the class came up and asked her a question about an assignment. Then my friend Jane came over and started to tell her about what she did last night. The two of them kept talking about what Jane did the whole time I was making my answer. When I pushed speak to say "I went to see the new Star Wars last night" my teacher looked at me all confused. It was like I was interrupting. Then I guess she remembered that she had asked me a question and she asked if I liked the movie. As I started making my answer, she went back to her conversation with Jane. I wondered, as I tried to stay focused on our conversation, who she thinks she is talking to?*

Gabby's teacher has set aside time to talk with Gabby every day, something that Gabby seems to appreciate, especially on this day when she has something exciting to share. Yet as the conversation continues it seems that this time is not really set aside for Gabby, as her teacher engages in other conversations with children in her class while Gabby is answering her question. She is in fact so engaged in the other conversations, which flow at the natural pace we are used to, that when Gabby answers her question she appears to have forgotten what she asked, or maybe even that she asked it. While Gabby is working to stay focused on the conversation with her teacher, it seems that her teacher attention has been focused elsewhere. Is it any wonder then that Gabby questions who her teacher thinks she is talking to? Perhaps one can even question if this special time for Gabby is really given.

Conversation is the most important and frequent social activity of human beings. (Higginbotham & Caves, 2002; Locke, 1998). Chances are that if you find two or more people together anywhere on earth, they will soon be exchanging words (Pinker, 1994). Conversation is so important to the human experience that some have referred to it as our *cultural bricks and mortar* (Caves, 1996 as cited by Higginbotham & Caves, 2002). How very different the experience of being in conversation seems to be when one enters in through a mediated means – talking with or is it through a SGD.

Conversations are also, one might suggest, the lifeblood of interacting and learning in the classroom. Teachers and students converse regularly, certainly daily. Teachers are always trying to find time for all the children in their classroom. To make time to listen to their stories, to have a conversation with them, even if it is just a brief moment of conversational contact. In early grades time is set aside for conversations, it is typically called *sharing time*. In *Classroom Discourse* Courtney Cazden (2001), suggests sharing time is special as “it may be the only opportunity during the official classroom “air time” for children to compose their own oral texts, to speak on a self-chosen topic that does not have to meet criteria of relevance to previous discourse” (p. 11). As we have heard from children who speak through SGDs, meeting the criteria of relevance to a topic may be precluded by time constraints. It seems that sharing time may well be an extension of a moment where they can really talk. One student gets the floor to share something interesting and important to them with the teacher and the class, the other students are taught to listen respectfully to the sharing, to not interrupt the speaker, knowing that their turn too will come. Indeed this may be one of the early lessons of school, when it is your turn to talk and when it is not.

Gabby’s teacher is trying to find time every day where she will intentionally take the time that is required to have a conversation with Gabby, even if that time is much more than what would be required in chatting with any of her talking students. But the kind of sharing time set aside for Gabby seems different. While in this one-on-one time she takes the time to listen to Gabby she is also apparently comfortable in attending to and listening to other children in her class. This is something one wonders if she would allow if she were conversing with a speaking child.

One can perhaps imagine this happening in any classroom. A teacher may ask a particular student a question and then without waiting for the response another child my chime in with an answer, or even with a completely unrelated bit of information. The teacher would be very likely to ask the second child to wait their turn while she listens to the answer from the first child. It would seem extremely rude and quite chaotic if there we no rules that governed both the timely response to a question and the necessity to not interrupt – to wait until one conversation is finished before another can be started. However, these are not the rules of engagement that seem to be in place when her teacher is talking with Gabby. It seems perfectly acceptable if not quite understandable for the silent void created when Gabby is constructing her answer to be filled by other quick paced conversation that can fill the gap. And yet the conversational gap seems only to exist for the speaking partner, for the person speaking with a device, for Gabby, there seems no gap, just one continuing conversation filled with conversations of others.

In undertaking this study I have spent many hours in conversation with young SGD users as they recount their memories of speaking through a machine. In several instances I found myself to be acting just as Gabby’s teacher, asking a question and then having a what might be referred to as a *sidebar* conversation with the participants mother, or educational assistant, or even classmates. It seems that when speaking people are in proximity to one another silence demands to be filled with conversation, and when conversing with one who speaks with a machine the time of silence far outstrips the time of talk.

Yet despite being compelled to talk to others while I await their responses, I have always been bothered by how rude it seems to be to speak to others while I am still actually in conversation with someone else. As Gabby asks I too have wondered what conversation I am actually in. Though even more, I have wondered what it is like to hear conversations going on *on top of* the one you are in, filling up the time to you need to talk. In response to my query about this seeming breaking of the polite rules of conversation, Gabby tells me

> *It doesn't bother me that people talk when I make my sentences. I like when people talk I don't like the silence, it puts more pressure on me.*

Gabby suggests that she prefers that the time that she takes to talk be filled by other conversations. It seems, as it were, to take the pressure off. One could imagine this would be the case. Being asked a question, to come up with an answer especially if you don't have one readily at hand, can be stressful. The longer it takes for one to respond the more stressful it may become. One can imagine that having someone else jump in and change the topic may be a great relief giving you a moment to gather your wits and figure out what exactly you want to say. In such a situation, though, it may be that the filling of the pause by others may well save you from ever having to answer. For one who speaks through a device the chatter of other people may be a relief giving time. Yet one might still ask wonder what kind of conversation this really can be. And what it might be like to never be able to talk without the pressures of time.

Planning to talk tomorrow

> *I mostly don't talk in class. Sometimes though my teacher will give me a question that she's going to ask the next day. And then I put my answer in my device that night so that when she asks me the next day I'll be able to answer. Most of the time this works pretty good. The kids think I'm pretty smart because I have an answer ready when the teacher asks me!*

This memory is of a time where Juliette's teacher has conspired with her to open a space for her to seemingly naturally speak with her device in class. While this script is in fact not much different from sending a child home with a homework assignment to hand in the next day, in this instance Juliette experiences something more. Her teacher has thought of her specially and acted for her specially. As we have already heard it is difficult for children who use devices to enter into the flow of the classroom conversation. It is no wonder, therefore, that most of the time Juliette does not talk in class. There is no space in the fast flow of time unless of course her teacher acts to open up a space not through slowing down the classroom pace, but by planning ahead so that Juliette is *ready* with a timely answer.

By setting up a situation where Juliette is given the time she needs to find the answer to an upcoming question, and to create the response in her device, her teacher seems to have stopped time for Juliette, or at least shifted the time demand. In providing this special affordance of time she has allowed her speaking success in the classroom, and it seems a moment where Juliette can shine. By planning to give Juliette an opening in the time space of the classroom, she can be called upon and can answer that call in a timely manner. She can have confidence and trust that she will succeed and everyone will understand that she too is capable. What happens if this time too slips away?

A race against the clock

> *One time though it didn't work so good. We were just starting a new unit on the environment. My teacher told me she was going to ask me the question " what is an*

> *example of an ecosystem?" The next day in Science class I was ready. I had looked on the internet and had programmed in my response: "An* ***ecosystem*** *is a community of plants, animals and smaller organisms that live, feed, reproduce and interact in the same area or environment. An example is a fresh water ecosystem where algae, fish, snails all live together in fresh water." This was probably the longest answer I had ever created on my own. I started to prepare it just after supper, but I was done before bed so that was awesome. But I was soaked in sweat. Mom said I couldn't go to bed like that all sweaty, but I didn't care. I was so excited to tell Miss R my great answer!*

In experiencing the belief that her teacher has placed in her Juliette has literally worked herself into a sweat to make sure she has an answer worthy of her teacher's trust. It is really not such a long answer. A mere 40 words. But those 40 words took her more than two hours to compose. First, like most North American children in the 21st century, Juliette gathered the answer to her questions from the Internet. Also, like most children, she needed to transform that information into the answer to the question that her teacher posed. For a speaking child this might be as quick as jotting down a few notes so that when called upon she should recall the answer. For a child who must enter her speaking notes or more correctly her complete speech into her device the task is not quick and does not involve a few notes to jog one's memory. It involves the slow, and apparently laborious process of finding then entering the words to be spoken into the machine.

For Juliette to have an answer ready to share the next day she spends her entire evening in preparation. Not only the preparation of research which any child may do, but also the preparation to be able to talk in a timely manner. For her, though, the sweat and toil seems worth it. That is unless the appointed time gets swallowed up by unexpected changes in the flow of the class.

> *All class I was waiting for my teacher to ask me the question that I had prepared the answer for last night. It was hard for me to pay attention to what she was saying because I was actually just listening for my question. As it turned out, the other kids started asking questions about other stuff that day. So Miss R ended up talking about that, but not the stuff that I had the answer for. It was almost the end of class when she glanced over at me. Her wide-eyed look told me that she had just remembered our plan. Just as she seemed to be going to say something the bell rang. As the students got up to leave she came over. Juliette I am sorry, can we do the question next class? I nodded and smiled but as I wheeled out of class I had to hide my face as my smile turned into angry tears.*

To have an answer to a question that you hope a teacher might ask of you is likely to be familiar to any of us at one time in our school experience. I hope she asks me about the Canadian Shield we might think if we had done our assigned readings the night before, or maybe moreso if we had only done part of the readings – the chapter on the Canadian Shield. If the question is not asked we may also feel disappointed that we have not been able to show ourselves to our teacher and our classmates as clever or perhaps as diligent in our studies. But would our disappointment be expressed with a mere shrug of the shoulders knowing full well that before very long we will again have the opportunity to raise our hand and speak of things we know or at least believe we do.

We may also have experienced a time in class when we were to prepare something to share with the class in the manner that Gabby has been afforded. In our case this might be called a presentation. I can well recall my time as a school student, waiting my turn to give a presentation to the class, but strangely for me a presentation was an anxiety provoking experience at school. I would wait my turn, not unlike Juliette, but not with anticipation, but with dread. While I loved being the one to have an answer, I loathed being the one who had to stand up and give a speech. For Juliette is seems the later experience may be the only one she can have. While she may indeed have an answer in the moment, the moment will fly by too quickly for her to chime in with her speech-generated response. It seems anxiety for Gabby not that she will be called upon to speak her answer to the class, but that time may slip away and she will once again be unheard and unnoticed.

What might it be like to be listening so hard for the one question you can answer that you cannot pay any attention at all to the rest of the conversation? Is this distraction? In some ways it clearly seems so. Gabby is so distracted by her desire to seize the moment and give a well-spoken answer that she finds it hard to attend to her teacher's talk. Yet she is listening intently for the question she knows she can answer - for the instant where she can jump successfully into the class discourse. What might Gabby be missing by planning to talk, and waiting for the plan to unfold? Other children may be listening intently too, and perhaps for their chance to chime in with a response, but for them they are listening for ideas that they can speak to in the moment, not for one particular cue to speak.

As stated so eloquently by Bob Williams (2000), who is a device user himself, "the silence of speechlessness is never golden" (p. 248). Clearly for Gabby the silence imposed by the voices of her classmates was not golden but heartbreaking. As anyone who has been in a classroom knows, topics of conversation may go in many directions. A classroom full of students with their own answers and often their own questions may call upon a teacher to seize the moment and discuss something she had never planned for that period. A comment or question from a student may cause her to veer from her plans for the day and talk about something she understands will be instructive or meaningful, though it was not on her agenda to do so. Such is the way of speech, it can move quickly in many directions. That is of course if you can speak!

For Juliette veering off course meant was she once again not fast enough to dip into the flow of the conversation. Even with the promise that she will be called upon to talk tomorrow, burning tears of frustration brim to her eyes. All her prepared work to talk, to be heard with a timely answer to a challenging question, has all disappeared as the clock on the wall says it is time to move on, and who can ever tell if there will really be time tomorrow.

The silence of one who cannot speak naturally may not be a chosen silence, but an imposed one. Merleau Ponty (date) suggests “one keeps silence only when one can speak” (p. #). And it appears speak in a *timely* manner. Repeatedly, we hear that when speaking with a device, it seems that time itself is silencing. The expectations of timely retorts, the ever so real demands to speak in a given window of time, the constant lack of time imposed by the constraints of the classroom all serve to dis-allow one who speaks with a device not only the choice to speak but in a very true sense it seems also the choice of silence.

Text Time

> *I am chatting with Tim online. In Facebook messenger. I am not sure if he is entering his text using his SGD or via keyboard. I think to ask him but then get engaged in our conversation. I type a question into the message window: do you remember any particular times when you used your device when you weren’t at school? Hitting the return key sends my question to him. I then turn my attention to my Facebook page to see if there is anything of interest. Ping, the message comes ‘I used my v at Stampede” ‘any good stories for me?’ I type in. After hitting return I go and get a soda from the fridge. His response is waiting for me “now i go vecoa every day” Okay I think he doesn’t want to talk about Stampede, this is something else. “what’s that?” I ask. After a few more exchanges that are interspersed with my checking email and facebook messages I learn that he is attending a new day program. “That’s exciting” I say! We go on to chat about a few more things before I realize what time it is and that I better say goodnight. We*

agree to talk again soon. I can't help but think this is one of the best conversations I have ever had with Tim.

Tim and I are engaging in a conversation, albeit a very different conversation than would be possible if we were face to face. I can type in a question for him with little to no expectation as to how long it might take him to respond. In fact I readily turn my attention elsewhere knowing that it will take time, perhaps a long time, before I hear the ping of Facebook messenger telling me Tim has replied.

Chatting with Facebook messenger seems to allow a different kind of communication time, text time. Not the face to face conversation between a device user and a speaking person, but a technologically mediated conversation in which the issue of time and timing seems to loosen its pull. There is no urgency to respond, in fact no expectation that a response will come in any particular time frame. When a person who is using a SGD is conversing with others they are usually the only ones who are interacting in a technologically mediated manner. But when having an online conversation this is different. Both Tim and I are interacting with each other in a mediated fashion. We are both using some technological methods to enter text to converse with each other. This mutual technological mediation appears to create a new temporal opening for a conversation, one where the time constraints of talk time no longer apply. A conversational time space where time is allowed, time can be taken, and conversations can be interrupted without creating uncomfortable silences or broken conversations. Perhaps through this jointly mediated experience Tim and I have found what Clark (1996) calls "common ground" (as cited in Higginbotham & Caves, 2002).

It is little wonder that the young people who use SGD often prefer to communicate with me via text or Facebook. It seems that by using these text-based modes they have entered into a new experience of time, one where their device can indeed fade from notice. Text time takes over from talk time and for everyone who enters time slows down. A pause, even a lengthy pause is expected. There are no longer broken conversations, only asynchronous ones where it seems talk time has slowed to whatever pace one chooses, or one needs. How wonderfully liberating this jointly mediated time must be for those who speak with a device.

Implications for Practice

The purpose of this paper is to provide some insights into the real demands of time placed upon young people who speak with (or is it through) SGDs so that we as the speaking people who are supporting them, interacting with them, and teaching them may be able to use these understandings in practices. Clearly speaking through a SGD is not like the kind of speaking we as speaking persons take for granted. Yet we are often exposed not to the reality of the experience but to the experience as played out in when we are privy to edited conversational time or when we hear people with SGDs give speeches. These constructed experiences may lead those of us who support children and youth with complex communication needs to make assumptions about speaking with SGDs that no one, not even the most competent SGD user could ever fulfill, not because they are incapable, but because the technology is. As Higginbotham and Caves (2002) state:

> *Although people use AAC devices for real-time conversations, these technologies have not been designed to meet the temporal and interactive demands associated with face-to-face conversation. (p. 46).*

Clearly the stories shared here tells us that this true. There is not, as of yet, any technology that can come close to allowing a person with a severe speech impairment to meet the expectations and demands of talk time. Until a technology is created that can transform thought held in a person's brain directly to speech (Venkatagiri, 2010) people who use SGDs will always be out of synch with the talk time that rules that govern human conversation expect. That is, we have seen, unless they are afforded the now perhaps not uncommon time of text conversation. To be sure, one who speaks through an SGD must text to talk.

Yet even as I write this paper, I am confronted daily with the expectation that if we can just get a SGD for a child who is speech impaired, that all will be well and they will be able to join into the chatter of the classroom and the conversations of their lives. Recently a teacher told me she just wanted her young student to be able to speak in full sentences like the other grade 1 students in her class. She was confident he was able to do so intellectually, he just needed the device to do so practically. And largely due to her determined advocacy, this young man was provided with a SGD that he very quickly understood how to use and desperately wanted to use. However, like the experiences recounted here, he was soon relegated to interjecting one or two words, not the full sentences of which his teacher expected, or that he was capable given time. In being confronted by this reality, the teacher asked me if perhaps we had the wrong device, surely there was one that would allow him to speak faster. My assurances that the system he was using had the most up-to-date rate enhancement capabilities possible did not seem to satisfy her. She walked away from our conversation convinced I must be mistaken, and that there must be some better system out there, so that he could speak in the way she knew he was intellectually capable of. It appears that it is a common expectation of technology, that it can be called upon to solve our problems, to make up for our deficiencies, to make the handicapped whole (Talbott, 2007).

What we have seen is that is it not the technology itself that is needed for young people with CCN to speak, but it is the *time*. Time needs to be *given* so they can construct the messages they are so desperately trying to convey quickly enough to be heard. Time needs to be *taken* to listen to their words and phrases and complete sentences. While listening to bits and pieces of their message may suffice on occasion, it is important that like other children learning language, they are sometimes afforded the opportunity to speak in full sentences. Without this time to speak in fully grammatical sentences, their language development may in fact be delayed or may be allowed to develop to the degree to which they are capable (Lund & Light, 2003). While the technology allows them to show us what they know through speech, without being given the time they need to talk to us and with us, all of the important benefits of school time may be at risk. As Cazden (2001) tells us, “while other institutions such as hospitals, serve their clients in nonlinguistic ways, the basic purpose of school is achieved through communication” (p. 2), communication that is primarily done through speech.

We must find ways to manipulate the time we have so that children who use SGDs can engage at least to some meaningful extent in the chatter, the conversations, and the speeches of the classroom and of their lives. Yet it may appear to us that time is the thing that we have the least ability to manipulate. As popular sayings go: time marches on; time waits for no man; time flies (from the Roman *tempus fugit*). But does it have to?

In today’s classrooms students commonly carry their electronic devices, and most seem to engage in texting with one another, sometimes at the cost of actually talking with one another (Turkle, 2011). Might this be one answer to the question of how we can make time? Can we allow our students with SGDs to talk, not by making them enter into our talk time, but rather by demanding of ourselves and other children that we enter into *their* conversational time, text time? Many educators are moving to online, asynchronous environments. Many more are also using chat forums to provide a text-based modality for students to have, as they are referred to, backline chats in the classroom. Recent research lauds such classroom modalities as they “allow time for in-depth reflection- students have more time to reflect, research & compose their thoughts before participating in the discussion” (TeacherStream, 2009, p.#). Will the technologically mediated classroom, create a type of common ground that Higginbotham and Caves (2002) tell us is needed in human communicative interactions? Alternatively, will the affordance of text time, give young people who communicate with SGDs common ground at least some of the time?

Our most important job as people who wish to hear students who need to use devices will want to make ourselves slow down. As Chelsea Hagen, a young woman who speaks with a device tells us:

> *You should always have patience and listen to someone speak, or you might miss out something brilliant they had to say. (Hagen, personal communication, 2015)*

In our classrooms this is surely among the most important things that we are trying to do. To make sure we take the time, give the time to let every child be heard. Of course this is a lofty, and often difficult goal for any teacher, whether she has a speech-impaired student in her class or whether she has a group of chatty exuberant speakers. The time accommodation takes may always seem to be greater than time allows. Yet can greater understanding itself open up a space where we slow down at least long enough to recognize that it may well be the demands of time that silence our children who speak through devices? It has been said that it is not what can be done with phenomenology that matters as much as what a phenomenological inquiry can do. My hope is that this use of phenomenological methods may evoke a call – a call to make time, take time and perhaps shape time so that every child make be given the gift of time to be heard.

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Chapter 8: What does the Non-speaking Child Say?

> *If I were granted one wish and one wish only, I would not hesitate for an instant to request that I be able to talk if only for one day, or even one hour (Sienkiewicz-Mercer & Kaplan, 1989, p.13).*

Ruth Sienkeiwicz-Mercer, a woman whose severe cerebral palsy affected her ability to speak, expressed this desire in her memoir *I Raise My Eyes to Say Yes*. Unlike Ruth, most of us take the ability to speak, to be understood by others through the use of our voice, largely taken for granted. From the time we are very young children, our primary means of communication is through speech. We easily and effortlessly produce meaningful sounds through our mouths by controlling the expulsion of air but our experience of speaking is not simply the experience of speech production. Merleau-Ponty (1964), a noted phenomenologist, suggests that when we speak we do not think about speaking, rather if we *think* at all, we think about *what we are saying*. We must, in fact, stop picturing the code or even the message to ourselves, and make ourselves sheer operators of the spoken word. While this rings true for those of us who speak with our natural voices, it is not the case for people with severe speech impairments who must use a machine to speak their thoughts aloud. Consider the words of Gabby, a young woman who uses such a machine to speak:

> *First I think what to say, then I input the words into my device. Once I have constructed my message, I push send so that I can speak those words out loud.*

Machines that produce speech for people with disabilities are referred to as voice output communication aids (VOCAs) or speech-generating devices (SGDs). These devices change text or the written word, into speech or the spoken word. Each act of speaking must be composed first through text, or through images that represent text, then spoken as a subsequent act. The experience of speaking with a machine is first message construction, then message delivery. This process can hardly be understood as merely the production of speech. The human being composes the message; the device generates the speech.

Today, some 30 years after Ruth expressed her desire to speak, there are scores of devices that could grant Ruth at least a partial fulfillment of her wish. Currently, we have SGDs that enable individuals with severe disabilities to use audible speech to communicate and engage in home, school, and community activities in ways that were previously unthinkable (Johnston, Reichle, Feeley & Jones, 2012).

This chapter presents an exploration of the phenomenon of speaking with, or perhaps better stated, speaking *through* a device. Autobiographical works and other published accounts of perceptions of SGDs by persons who use them are reviewed. Drawing from my research of lived experiences of several young people who use SGDs, I explore themes emerging from their stories to illustrate the meaning of these devices in their lives. The chapter concludes with a discussion of what can be learned from carefully listening to the voices of those who must use technologies to speak and how this type of inquiry can inform practice, particularly in the fields of education and rehabilitation engineering.

Who are the people who might use SGDs?

When describing people who might need SGDs, most people say, “Oh like Stephen Hawking?” Yes, Dr. Hawking, the eminent physicist speaks with a SGD. He has a progressive neurological disease that has taken away his ability to speak with his natural voice. Unlike Stephen Hawking, however, the people focused on in this chapter have not *lost* the ability to speak with their natural voices - the ability to speak was never afforded to them. While there are many people who may use SGDs due to other challenges of communication (e.g., autism or other developmental delay), this chapter focuses on those whose physical disability is the primary reason they are not able to communicate effectively through their natural voice. Specifically, they are those who have severe physical disabilities as the result of cerebral palsy (CP) that affects their abilities to control their oral motor or breathing muscles. They are children and youth who, due to an unruly body, cannot coordinate the breath, sound, and movement to produce intelligible speech.

Speech-generating Devices

A SGD is comprised of three essential elements: 1) an input screen; 2) a processor; 3) speakers for output. The input screen is a keyboard but the keys do not generally represent single letters as on an ordinary keyboard. Each key has a symbol that represents a word or phrase with an iconic image. This may be an image of a child waving *hello*, to invite a non-speaking child to touch it to greet a friend. There may be an image of a frowning face that can be selected to say *I am not happy about that*. There may also be icons that must be touched in sequence to have the device *speak* words in a desired order. In each case the messages are *spoken* by the device into the audible space of the conversation.

Devices may be relatively simple electronic systems, where a message is recorded by a speaking person for play back by the SGD user. Alternatively, the devices may be sophisticated computers, where the *voices* are generated by synthesized tones that mimic a human voice.

For a more thorough exploration of AAC systems in general and SGDs in particular, the reader may wish to refer to some of the excellent textbooks that have been written in this area. Examples include: *AAC: Supporting Children and Adults with Complex Communication Needs* (Beukelman & Mirenda, 2013), *AAC Strategies for Individuals with Moderate to Severe Disabilities* (Johnston, et al. 2012), *Augmentative and Alternative Communication: Models and*

Applications for Educators, Speech-Language Pathologists, Psycholinguists, Caregivers and Users (Loncke, 2014), or *Handbook of Augmentative and Alternative Communication* (Glennen & DeCoste, 1997). Ball et al. (2005) also provide an excellent overview of AAC devices in their chapter on AAC in school settings in the *Handbook of Special Education Technology Research and Practice (*Edyburn, Higgins, & Boone, 2005).

Listening to the Voices of Non-Speaking People

Autobiographical Accounts of SGD Use.

There are several published memoirs of people who have used AAC and SGDs (Creech, 1992; Fried-Oken & Bersani, 2000; Portnuff, 2006; Robillard, 1999; Rush, 1986; Sienkiewicz-Mercer& Kaplan, 1989). See Table 1 for an annotated listing.

Table 1. Memoirs and personal accounts of persons with severe speech impairment

Author	Title	Type	Synopsis
Creech, Richard D. (1992)	Reflections from a Unicorn	Autobiography	This autobiographical account of a young man's life with severe cerebral palsy includes essays on his experiences, independence, and technology, poems about his family and about some of his unpleasant experiences, and poems that are reflections of himself.
Fried-Oken, Melanie and Bersani, Hank A. (2000)	Speaking Up and Spelling It Out: Personal Essays on Augmentative and Alternative Communication	Compilation of personal essays	In this compilation of personal stories, twenty-eight diverse individuals who use AAC, from teens to senior citizens, give first-person accounts of how living with AAC has affected them. Through their essays contributors reveal what using AAC is all about, what works and doesn't work for them as they face the daily challenges of communication.
Portnuff, Colin (October 18, 2006).	AAC - A User's Perspective	Presentation/ Webcast	A talk presented by Colin Portnuff, a man with ALS, as part o the AAC-RERC Webcast series. He shares some of his techniques for managing conversations, and presents some interesting and provocative information about

			the application of speech and voice technology in augmentative and alternative communication.
Robillard, Albert B. (1999)	Meaning of Disability: The Lived Experience of Paralysis	Autobiography	A detailed autobiographical account of a university professor who becomes paralyzed in mid-life due to Motor Neuron Disease. The book focuses on his quest to achieve and maintain meaningful interactions as Dr. Robillard struggles to maintain his identity in his now impaired body.
Rush, William L. (1986)	Journey Out of Silence	Autobiography	A chronicle of a young man with cerebral palsy's journey through childhood and young adulthood. The story focuses on his struggle to be integrated into society and achieve full participation in all aspects of life.
Sienkiewicz-Mercer, Ruth and Kaplan, Steven B. (1989)	I Raise My Eyes to Say Yes: A Memoir	Collaborative autobiography	A account of the experiences of a woman with severe cerebral palsy. Beginning with happy childhood experiences with her family, her story moves through a period of perceived incarceration at a state school to finally primarily through her introduction to AAC she is able to enjoy a fulfilling and connected life.

The autobiographies all include accounts of personal experiences with some of the earliest versions of SGDs. Many of the accounts speak to the challenges of using these early devices, for example, Robillard (1999) recalls a most unsuccessful foray into the use of "artificial voice machines" (p. 125). He found the devices entirely inadequate to express more than a few simple requests, and despite significant pressure from therapists, he adamantly refused to use them, relying instead on a lip-reading system he developed with his wife. Ruth Sienkiewicz-Mercer describes trying to learn to use a Handi-Voice, one of the earliest voice output systems, as difficult and physically exhausting. Yet despite her trials she states, "it was exciting to generate even simple speech" (p. 210).

This message of excitement, hope and ability are strong themes in the accounts of SGD users in the personal essays compiled by Melanie Fried-Oken and Hank Bersani (2000) *Speaking Up and Spelling It Out*. Janice Staehely, one of the writers, shares her joy in learning to use her SGD by saying "with my new voice, my world began to open up" (p.11). Another of the authors, Gus Estrella, recalls that with a VOCA "I started to have real conversations with people with whom I had always wanted to talk" (p. 37). Additionally, Solomon Vulf Rakhman expresses his excitement in being provided with his first SGDs:

> *A COMPUTER THAT CAN TALK! From that moment on I know that I had left my misfortune behind me. I knew that in this world, I could be a normal individual… If I wanted to talk to somebody I would no more have to wait for my mom or my brother to come and "translate" for me. Now I could be part of this world! And that is the greatest feeling of all ladies and gentlemen! (Fried-Oken & Bernsani, 2000, p. 102).*

As Kent (1998) suggests, these first autobiographical accounts of SGD users are important as they provide a genre of literature that compliments and extends the more traditional research and practice books that may be more familiar to educators and clinicians.

Research Perspectives on AAC and SGD Use.

Along with these first hand accounts there has been a growing focus within the research community on gathering the perspectives of SGD users and of their families, beginning with work focused on seeking individual user's perspectives (Smith-Lewis & Ford, 1987) to more recent studies that are focus on the impact that AAC has on the construction or de-construction of disability (Wickenden, 2011). Readers are referred to Table 2 for a summary of these articles.

Table 2. Studies focused on perceptions of AAC users and/or their families

Reference	Design & Participants	Research Contribution
Bailey *et al*.	Survey of 100	This study presents several factors parents perceive to be of

(2006)	parents of AAC users; USA	particular importance to their child's AAC device use. These include: (a) the process of AAC selection and training, (b) family members expectations around AAC device use, (c) support received by professionals, (d) time and effort required to program the device and (e) perceived benefits and barriers to device use.
Huer and Lloyd (1998)	Content analysis of 187 reports of perspectives of 165 AAC users: 36 children (12 years and below), 44 teenagers and young adults (ages 13-24 years), and 48 adults (25 years and up); varying diagnoses; USA	This study analyzes a wide range of studies to explore perspectives of AAC users. Findings suggest individuals who use AAC experience frustration at not being able to communicate, have had negative experiences with professionals, communicate most frequently with family members, and greatly value the ability to communicate through a variety of AAC techniques.
Hodge (2007)	Interviews with thirty-one individuals: twelve children (and their parents), 19 adults: UK	Drawing on findings of a research study that explored the experiences of people who use AAC, this paper looks at the various problems that people encounter in using communication aids. It identifies the lack of consistent, structured support as a key overarching issue. The author goes on to argue that for the potential of AAC to be realized attention needs to be given to the development of coordinated systems of support within the policy domains of education, health and social services.
Marshall and Goldbart (2008)	Interviews with eleven Caucasian, English speaking primary caregivers of children who were using or starting to use AAC; UK	This study gives insights into the experiences of families whose children are in the early stages of learning to use a formal AAC system. The study suggests that while families have extensive knowledge about their child which may not be valued by professionals. This research also highlights the burden that parents of AAC users are under and calls for greater consideration of their needs by professionals who are working with their children.
Murphy (2004)	Observation and interview with 15 individuals with Motor Neuron Disease (MND); UK	This study examines the communicative interactions between people with MND and their communication partners. Key findings: (a) participants desired to use their own voices, seeing no device as ever adequately replacing their natural ability to talk, (b) social closeness was of paramount importance, devices were perceived to get in the way of that

		experience, (c) training and support for various methodologies was inadequate, resulting in frustration with and abandonment of devices and strategies.
Rackensperger *et al.* (2005)	Internet focus group with seven adults with CP; USA	This study highlighted the need for a consumer- driven approach to assessment that included an opportunity for individuals to discuss issues with individuals who use AAC devices. Focus groups discussions highlighted the benefits of their AAC devices but stressed the challenges and frustrations they experienced while learning the system and how to used it. Several suggestions were given to how to improve and enhance the experience of learning to use an AAC device.
Smith-Lewis and Ford (1987)	Series of in-depth interviews with an individual with CP and severe speech impairment; USA	Drawing upon the reflections of a young woman with CP on the effectiveness of devices provided for her during her school years, this study points to the need for professionals to give greater attention to the needs and desires of persons for whom AAC systems are designed. Systems designed for this woman had limited utility and she refused to use them despite significant pressure to do so. Her profound desire to use her natural voice rather than devices was discounted by educators and health professionals.
Wickenden (2011)	Interview and observation of 9 children and youth as primary informants, and from 15 additional teenagers and 3 adult research advisors as supplementary informants. All had similar impairments and all were AAC users; UK	This inquiry highlights issues of identity, voice and representation arising from a broader ethnographic study of disabled teenagers who use AAC. Focusing more narrowly on how teenagers perceived the use of their AAC impacted their identities, how their individual voice emerged in conversations that were co-constructed by themselves and their communication partners the author points to the importance of having a voice while also highlighting the limitations of the devices and the challenges the young people face in using them. Wickenden suggests that the teenagers have a "love/hate" relationship with their technology. Loving it when they can express themselves, hating it when it breaks down or gets in the way of real expression.

Perspectives of AAC Users. The first formal investigation into the experiences of SGD users was reported by Smith-Lewis and Ford (1987). They sought the perspectives of a young woman (Dawn) with cerebral palsy who was provided with a relatively early device: the *Canon*

Communicator and a language (letter, word and phrase) board. Smith-Lewis and Ford drew attention to many issues/challenges that confronted AAC users. These included: the domination of professionals in the process of deciding which device would be most appropriate; the expectation that the device completely take the place of natural speech instead of augmenting what natural speech a person may have; the overreliance on assessment data to drive decisions while discounting the importance of user acceptance and commitment to the chosen device; and perhaps most significantly, the importance of having a social milieu that supports not only device use but communication and language development.

Following in the path of this initial qualitative study, Huer and Lloyd (1990) expanded this line of inquiry by gathering perspectives and experiences of AAC users as they had been described in the published literature between 1982 and 1987. The authors reviewed a total of 21 journals, newsletters, magazines and other periodicals as well as six books, seeking personal descriptions of AAC users, "personal feelings, descriptions, fears, frustrations, joys, concerns, attitudes, and day-to-day encounters faced by the AAC user or potential user, as reported by the user or a third-person" (p. 241). Their search resulted in a bibliography that included 165 first-person accounts from individual users, third-person reports from family members, case studies, and anecdotal articles from professionals who work with AAC users. The authors provide demographic information on the individuals whenever possible, including age range and diagnosis. Approximately two-thirds of the individuals where age was able to be determined were children or youth (80 respondents of 128). While the majority of the individuals were reported to have CP (80 out of 153 reported diagnoses), there were also individuals with degenerative conditions including multiple sclerosis (MS), amyotrophic lateral sclerosis (ALS), developmental delays such as autism, mental retardation (sic), and multiple disabilities in the sample.

Despite the diversity represented in the age and diagnoses of their informants, Huer and Lloyds' (1990) review reported very similar themes to those expressed by Dawn in Smith-Lewis and Ford's (1987) earlier investigation. In the present study, AAC users expressed feelings of frustration at not being able to communicate effectively, shared that dealing with medical and educational professionals was challenging, and that the supports and services provided were often inappropriate. The AAC users indicated that their primary communication partners and strongest advocates were often their immediate families and suggested that the ability to communicate is crucial whether through speech output or by other modalities such as letter boards or other nonverbal techniques. In contrast to Smith-Lewis' and Ford's account of Dawn who valued her ability to speak with her natural voice even though her communication partners were challenged to understand, Huer and Lloyd (1990) suggest their study shows that "users emphasized the power of each aided technique for opening new opportunities for communication" (p. 246).

More recent studies (Murphy, 2004; Rackensperger, Krezman, McNaughton, Williams, & D'Silva, 2005; Wickenden, 2011) gathered the perceptions of adults SGD users. Murphy (2004) followed 15 adults with motor neuron disease who had been learning to use their SGDs, for three years. She found that her participants' successful use of SGDs was less than might be anticipated and speculated that their desire to once again be able to speak aloud may have hampered their progress. A number of reasons were given including the need for social closeness, which may not be possible when using a device, and the complexity of learning how to use a high technology device combined with inadequate training. Again, it is important to note that these participants were replacing their lost ability to speak rather than providing a new ability to produce audible understandable speech of their own accord.

Other researchers used an online focus group discussion to gather the perspectives of SGD use from seven individuals who had cerebral palsy, had acquired basic literacy skills, and who used AAC technology (Rackensperger, Krezman, McNaughton, Williams, & D'Silva, 2005). The SGD users reported on the difficulty they had in learning to use their device and the challenges the experiences in finding expertise and in shaping their own learning experiences. As the title of their paper suggests, Rackensperger, et al. suggest that learning to use a SGD device is not easy. The individuals were literate and had achieved at least a high school diploma. Despite this they all found learning to effectively communicate through a machine is challenging and often frustrating. They point in particular to the need for personalized and specialized supports and training opportunities for new users, and to the potential value that could come from having experienced users help guide those who are learning to use a SGD.

Researchers in the area of disability studies have in recent years taken interest in how disability and technology intersect (Moser, 2006; Moser & Law, 2003; Patterson & Hughes, 2003; Wickenden, 2011a, 2011b). Mary Wickenden's exploration of identity and *lifeworlds* of teenagers who use AAC is an excellent example of this work. She employs participant observation and other flexible qualitative methods to investigate how young AAC users see themselves and are seen by others. Her findings suggest that the teenagers often have mixed or ambivalent feelings about their SGDs. They found their devices useful in some contexts but also felt the strong need for non-technological systems, especially when communicating with family and close friends. Their SGDs were important in their lives to show their personalities, to help people realize that they were clever, and participate in the everyday gossip that is a part of teenage life. Yet the teenagers were often excluded from conversations due to the time it took for them to *speak* and frustrated by the behaviors of others when they were using their devices.

Parents' perspectives on their child's use of AAC. Several studies have sought the views of parents on their child's use of AAC and, in particular, SGDs. Themes and issues raised by parents are consistent with those raised by AAC device users themselves. Many focus on parents' struggles to be heard and valued by AAC professionals (Angelo, Kokoska & Jones, 1996; Marshall & Goldbart, 2008). Challenges with AAC device use are also shared by parents. These challenges include: the amount of time and energy it takes to learn to use the device; the lack of support by educators and others in the community for device use; and the lack of access to trained professionals who could support their children in learning and using their SGDs (Bailey, et al., 2006; McNaughton, et al, 2008).

Investigating the Experience as Lived Through

This section present findings from my doctoral research which employed a qualitative research methodology, *phenomenology of practice* (van Manen, 2014). *Phenomenology* as a research method is focused upon exploring a human experience (phenomenon) *as it is lived through* rather than how people may conceptualize, theorize, or reflect on it (van Manen, 2013). Phenomenology of practice refers more specifically to inquiries that address and serve practices of professionals. This approach prioritizes the questioning of the meaning of a phenomenon in the lives of those who experience it above seeking explanations, drawing conclusions or establishing theory.

Primary data for this study was gathered over a period of eighteen months. Key participants were five young people (ages 17 to 26) and two adults (30 to 40) with CP. They were recruited through local AAC Centres or through personal connect with the researcher or professionals working in the field of AAC. All participants had SGDs, were proficient in their SGD, and had used them in school settings. The five young people used their devices on a daily basis in primarily at school and the adults used their SGDs occasionally as part of their overall AAC systems and to supplement their natural voices.

Lived experience descriptions were gathered through interview and close direct observation. Participants were asked to recount specific events in their lives that involved the use of SGDs. In some instances participants also shared moments where their devices were not available to them. Observations of participants during their day-to-day lives were also engaged in to gather experiential material and inform interview questions. To gain greater insights, in some instances the parents of the young people were also asked to share their stories of observing or participating in the experience. Finally, the researcher's personal experiences with SGD users over the past thirty years of practice were also used to inform the study.

The construction and use of anecdote is a device used in phenomenological research (van Manen, 1997). When using their devices to share their stories, participants often used elliptical or individual styles of messaging requiring the researcher to reconstruct their story into understandable anecdotes for reflection. In order to validate the anecdotes constructed from participant interview and observation, checks were done with each informant. Participants were asked if the way the story was written represented their experience. If the story did not reflect the experience accurately, the anecdotes were reworked until it was deemed satisfactory by the participant. Once the anecdote received a "yes that is it, that's what was like," it was included in the study.

Phenomenological inquiry involves systematic reflection on these anecdotes in order to unearth the meaning of the experience in the lives of the people who are living them. Reflection includes bracketing or trying to become aware of one's own preconceptions and theories so that by looking at them and attempting to set them aside, one can be open to what shows itself in the study. By exploring variants of the experience to show what is both common to other experiences yet unique to the particular phenomenon at hand, one hopes make an experience recognizable to more than one subject. Otherwise stated, to gain an understanding into what "make(s) an experience what it is and without which it could not be" (van Manen, 2013, p.15).

What is it like to speak through a machine?

What does a non-speaking person say?

What message does a person who cannot speak with their natural voice send to those around her? Let's listen to Gabby a 17-year-old SGD user as she recalls her experience of being without her device, without her voice, at a medical appointment.

> *One time I had to go to the hospital for tests and I didn't have my communication device. The nurse asked my mom "does she need a diaper?"! I was so angry. I showed her my angry face! She asked my mom what is it and mom said she is mad because she has been trained since she was two and she understands everything that you say. She came over and talked to me very slowly and loudly just like I couldn't hear. I think if I had my device this would not have happened. People think when you can't talk you are dumb.*

Gabby was a teenager when she entered into the hospital that day, yet the assumption made by the nurse was that she was not yet been toilet trained. In voicing this assumption the nurse bypassed Gabby completely and addressed her mother with the question. Even when she understood from Gabby's *angry face* that something was wrong, the nurse continued to address the mother. Upon being told that Gabby understands, the nurse does address Gabby directly, but in a manner suggesting Gabby was hearing impaired or intellectually delayed. As Gabby suggests the nurse treats her as though she was *dumb*.

How interesting when one considers the many meanings of the word *dumb*. The history of the word suggests it was first used to describe someone who was "silent, unable to speak" (Online Etymological Dictionary, retrieved from http://www.etymonline.com/index.php?allowed_in_frame=0&search=dumb July 22, 2016) Without her device Gabby is certainly *dumb* in that meaning of the word. In today's usage the other meaning of *dumb* is far more common. To be dumb is to have "defective perception or wits" or to be "lacking intelligence or good judgment; stupid;dull-witted" (Dictionary.com, retrieved July 22, 2016). It seems that to be unable to speak of one's own accord may bring forth both understandings of the word. While Gabby's mind is hardly defective, her body sends a different message to the nurse. One that Gabby is powerless to correct, as she is, without her device, voiceless.

Is this a common misperception? Do we automatically assume that non-speaking persons are unintelligent? Gabby's mother tells of a time that indicates that it may well be. And that by using (or not using) SGDs young people with severe speech impairments presents themselves as intelligent (or not). As Gabby's mother noted,

> *We were out for dinner with Lil. Gabby had her device with her and was using it to talk a lot. Lil did not have her device. She was communicating with us but through her body and her facial expressions. After dinner a gentleman came over to talk to me. "Your daughter must be very smart!" he said. "It is amazing to hear her be able to speak her mind with her machine. Too bad about that other girl."*

Gabby's mother was sharing memories of the difference the SGD has made in her daughter's life. She suggests that since Gabby has been able to use her device more proficiently and in in a variety of context, like out in the community, people have seen her as being so much more capable then when she was "that girl in the wheelchair". This occasion was particularly poignant for Gabby's mom as they were out for dinner with another girl (Lil) with cerebral palsy who is an excellent device user. They conversed about Lil's experience at the community from which she had recently graduated. Lil had not brought her device with her on this occasion and despite the fact she was an extremely competent SGD device user, she was seen on this occasion as more *dis*-abled and less capable. It seems that in presenting oneself as a capable competent person, having a voice, an audible voice, matters.

Romski and Seveik (1996) illustrated the power of SGD on perceptions when they reported the case of one of the participants in their study who had severe cognitive disabilities ordering lunch using his SGD at a local fast food restaurant. "If you children can use computers, they must be pretty smart" (p. 445). The ability to use a speech output device, even a relatively simple device such as that used by the child in this instance to do the simple task of ordering food demonstrated competence and ability that may well have not been perceived had the young man pointed to a paper display and had an assistant voice his request. The ability to be heard, of not being *dumb*, it seems is generated by the machine along with voice output.

John recalls a time when having his SGD with him allowed him to correct that misperception. With his voice at hand John announced himself as himself to his principal, changing his relationship with him at that moment and for the duration of his school days.

> *The first day I met the principal he acted like I didn't even have my talker. He just talked to my aide even though I was right there. This made me mad and I put my head into gear. Hey I can understand everything you say you know! Mr. Birch stopped talking in the middle of telling Ms. H where my homeroom was. He paused and looked at me for a minute, then smiled. John, he said I am sorry, I should be telling you this, shouldn't I. After that he made sure he talked to ME!*

When a child typically enters into the principal's office on the first day of school he is welcomed, addressed, he is spoken to and spoken with. John tells us a very different story - a story of being not only unheard, but perhaps of being unseen. It is only through the audible assertion of *himself* not only as present in the room, but a person who will not be passed over in silence, does his principal readdress himself to John. How interesting that the audible voice has this power. Would it have been the same if John had gotten his assistant to say those words by pointing to letters on a board? How might he have been perceived if he had tried to indicate he was annoyed through other non-verbal communication? Without his device could John has articulated his capable presence through the conversation being carried out by the two adults about him? Alternatively, would he be forced to sit in silence, unheard and unseen as a passive listener?

Despite this wonderful example of determined self-advocacy, the literature does not suggest that students who use SGDs commonly use them to initiate verbal interactions in the classrooms (McGregor, 2007; Thirumanickam, Raghavendra, & Olsson, 2011). When interactions are initiated, they tend to be with staff assigned as their primary support (Chung, Carter & Sisco, 2012). Such communication patterns would perhaps explain John's principal's predisposition to addressing John's aid and not John himself. If SGD users are not commonly interacting with and addressing partners other than the paraprofessionals who support them, expectations of their ability to speak for themselves remain low. Happily for John he was able to speak up and speak out.

Voicing my being in the world

I recall the day that Josie came into the centre for the first time. She was coming to see about getting a VOCA. Here was a seven year old little girl whose eyes shone with

> *expression but who had no speech. As we sat around the table discussing Josie's needs for a device I grabbed one from the back room and started to program in a few phrases. I then sat with Josie and modeled how the messages could be spoken aloud by touching the buttons. Before long it was obvious to me that Josie understood how the device worked… and then she took over.*
>
> *"mom look at me" Josie spoke aloud by pressing the button on device and looked at her mom to see if she was listening. No response. I whispered "try again Josie" and turned up the volume. She did - "mom look at me!" This time her mom heard. She looked up a little confused. On cue Josie spoke again "mom look at me". And that is when the magic happened. Her mom looked and Josie said "mom come here" with no prompting and giggled loudly. Her mother, now practically at the point of tears, came over. "mom look at me" said Josie. "I am looking Josie!"*

This anecdote speaks to the powerful impact of a child acquiring a voice. Her ability for the first time to give voice to her being in the world - look at me here I am! How strange this might seem, when one considers that really the voice is not hers at all. In fact, in this instance the words were spoken by the voice of the therapist who had recorded the phrases into the buttons that Josie activated to *speak*. Yet Josie certainly seems to have embraced the voice as her own, repeatedly and intentionally calling out to her mother. The little phrase, "look at me," seems to convey a larger meaning - *look at me, see me, I am talking to you!* Her mother is likewise nonplussed by another's voice coming from her daughter. Once she has heard Josie's call she recognizes it as being from her daughter. In fact, she seems delighted to have heard her daughter, at age 7, speak her first words.

A child uttering her first words is always a momentous occasion. But consider how much more momentous this might be for Josie's mother or any parent of a child with cerebral palsy who has waited years to hear those words. Parents like Josie's often place their children's names on long waitlists for access to services that will provide their children with the opportunity to access SGDs. The wait may be long, for some like Josie, long into their school lives. But the need for parents to find a way for their child to speak is great, and so it seems reading Josie's story, is the reward.

Both Josie and John may be expressing an innate desire to be noticed, acknowledged and valued as part of the human world. The desire to announce ourselves may be seen in many human endeavors. Consider, for example, introductory computer programming classes. A "Hello, world!" program has become the traditional first program that many people learn (Wikipedia, access date). While the instructors could choose any short phrase or even single word for their students to first *say*, saying *hello* is chosen. Is the programming made more enjoyable or more worthwhile when we announce ourselves to the world? Would budding programmers be less excited by their success if the phrase was *John Smith* or *It works!*? It appears we are driven to announce ourselves to the others and thereby to the world. Is this innate desire and ability only truly afforded to Josie and John through the machine?

But what is it to speak?

We might consider it to be the ability to express what a person wants or needs through audible language. But the stories thus far point to something different. To speak may not be about asking for something or giving an audible answer to a question posed by another. To speak it seems is to interact. Consider Katie's story and how she discovered it is not only having words on her *talker* that made the difference, but the power of the words themselves.

> *Gym classes the first time I really understood the power of having a voice. I remember my teachers had programmed things for me to say into some of my devices before. Things like saying good morning, things like answers to a math question, and things like a line from a page in a story. Somehow those things never really seem to matter. But that day in gym class with different.*

> *That day my teacher put two words into my talker. Only two words, stop, and go. Then she told the class that were going to play a running game, and that I was in charge. I was in charge? How would that work? And she said okay Katie, tell us what to do, I remember being confused but then just pushing one of the buttons.*
>
> *Go. And all the kids started to run. I kind of went into a spasm and hit the same button again, GO I said. And they went faster! Ha. Okay now I get it. I pushed the other button. STOP. It was noisy with all the kids running so they didn't hear me. I looked up my teacher. She turned the volume all the way up on my talker. STOP! This time they heard me and all the kids screeched to a halt. Some of them even yelling SCREECH. Then they all looked at me. I giggled…GO. This time Ms. Jackson push my wheelchair so I could go too. GO GO GO I said. And we all ran faster. STOP! And we all stopped, bumping into each other and laughing as we did. STOP STOP GO... I kept yelling with my talker. I was laughing so hard tears are streaming down my face. Finally Mrs. Jackson, said Katie I am pooped, and she blew the whistle. We all stopped for good.*
>
> *Jordan who never paid any attention to me before ran up to us. Katie that was fun! Mrs. Johnston can Katie tell us what to do a gym all the time!*

Katie's story shows how access to voice output devices can provide the opportunities for meaningful participatory interactions. Interactions help a child understand their own identity and agency, and allow other children to see them as real members of the school community. Katie has been able to use two single audible messages with great impact both on how she interacts with her classmates and the activity. Stop! Go! Such little words with such great power!

Studies of teenagers who use AAC devices echo Katie's thought in that the power of having a voice comes not with having the device per se, but how they used them and what they could say (Wickenden, 2011). Like Katie they valued phrases that were interactive and that had social impact: *I like chatting about boys in the corridor; I like having a moan! (p.12).* They wanted to speak words that had impact not just speak words.

It is clear however that despite the powerful impact of the little words Katie used to interact in gym class with her friends or the powerful simple phrases given to Josie as her *first words* to her mother, without access to a full and robust vocabulary children with CCN cannot truly speak for themselves. Too often it may be that despite their desire to speak, they may find that they have no words.

My words are not my own

Unlike a child who has learned to speak naturally and therefore in a true sense *have* their words. A child who uses a SGDs is *given* their words. Parents, therapists or teachers put vocabulary (words) into the devices, when children are learning to use their SGDs they must find the vocabulary that others have given to them.

I can't find the words.

Finding a word from a system that you have been given may be far from an easy task. Consider Jane's experience:

> *That year I got my first talking device, which was called a Touch Talker. My therapist came in to school to teach me Minspeak. I feel she did a great job teaching me where the icons were and what they meant. She did not teach me how to express myself with it. For example, one particular day I was sent out of the classroom for drooling but really I had sneezed out some muffin. For the life of me, I couldn't find the words to say that I had just sneezed.*

While Jane's story of not being able to tell her assistant she had sneezed may be as much a story of abuse than a story of not being able to find the words to say on her new device, it may be important to consider both together. The expressive language skills of children who use SGDs are often restricted by factors that are out of their control. What these children can express at any one time is largely dependent on the accessibility of their system and on the specific vocabulary that is available to them (Sturm & Glendon, 2004). There is much literature focusing on the choice of vocabulary for people who use AAC systems and SGDs (Brewster, 2013; Beukleman & Mirenda, 2013, Crestani, Clendon, & Hemsley, 2010; Fried-Oken & More, 1992; Loncke, 2014).

While most vocabularies offered to SGD users are derived from a combination of lists that reflect developmental and frequency data, the words offered also reflect the specific context(s) in which the individual might function and in some cases even words and phrases that reflect their personality. For example, Gabby, who loves to talk about and write about horror stories and films would need to have words that reflected her sometimes gory interests in her device. John, on the other hand, is passionate about hockey and plays wheelchair hockey whenever he can. He would need very different vocabulary to express *him*self than the bloody, creepy and screaming words that Gabby loves to use. As Fried-Oken and More (1992) suggest, the vocabulary selection process is influenced by sociolinguistic, biologic, and psycholinguistic variables that it is often difficult to find a starting point (p. 52).

The vocabulary selection process for a SGD is given to others, not the SGD user. This means that the SGD user must not only understand what words are available to them, but where and how to find those words in the system that others have created to organized their *lexicon*. On the day that Jane sneezed and was punished for the act, she was in the process learning a new system. While she had practiced with it and one might say even understood it, she had not yet truly acquired it. She could not find her words, perhaps because they were not yet hers. Despite her ability to physically push buttons, the cognitive demands of recalling where the words to say “I just sneezed!’ remained beyond her reach.

As SG technologies are designed with ever greater computing, storage, and display capabilities, message sets (words, phrases, and sentences) are increasingly being programmed into technology by manufacturers and software developers with make the assumption that message type is uniform for people who rely on AAC at various ages or stages of life (Beukleman & Mirenda, 2013). For example, the currently popular AAC application *Proloquo 2Go* (Assistiveware, Inc.) comes with a choice of vocabulary for emerging communicators or for those focusing on language development. This pre-programming, while helpful, does not allow the child to grow and develop their vocabularies as verbal, non physically disabled, children do. There is an extra burden placed on the child who must speak through a machine. Learning the words and then finding them in a system that they have not constructed.

I have no words.

People who use SGDs may know exactly what they want to say but not be able to say it. It may be because like Jane they struggle in locating the words in their device or it may be that the right words, the words that they know and want to use are just not there. Watching Gabby at school try to speak up when she had the perfect answer to the question posed by her teacher, but no words such words in her device, illustrates quite powerfully this uniquely challenging phenomenon.

> *I was observing Gabby in her Health class. The teacher was talking about healthy eating, exercising and other things that keep the body in homeostasis. When she asked the students if they remembered that word I noticed that Gabby had the balance scales in her speaking window. She didn't speak that aloud and I think I was maybe the only one who noticed she had gotten the concept right if not the word. The rest of class was goofing around taking about times they ate too much and got sick. The teacher then asked if there were other reasons that someone might get sick from eating. I noticed Gabby was*

> *clicking her way through the icons on her device. I then focused in on what she was saying – SALMON VANILLA were the words she spoke, this time out loud. Salmon Vanilla? Oh my god I thought she means Salmonella! She is trying to say salmonella. As the other kids were talking about drinking too much alcohol and other silly ways to get sick Gabby was finding the answer from her words. Salmon Vanilla indeed!*

Any student, or any one of us, may at some point have not be able to recall a word that we know we know. We refer to it as having something on the tip of our tongue. This phenomenon is well known and has been studied by psychologists for many years (Brown, 1991). When experiencing this phenomenon we know we know the word, but we just can't recall it. We might recall the first letter or be able to express words whose meaning is similar, but the word itself remains illusive. For Gabby in health class the experience is oddly similar yet interestingly so very different.

Gabby knows the exact word she wants, she has recalled it in her mind. The problem that confronts her is that she also knows she does not have that word in her device. She has it in her memory but she does not have the capability to speak it. Indeed all through that health class Gabby understands the vocabulary her teacher is introducing to the class, but sharing her understanding, even with her high-end speech-generating device, is not possible. Not possible that is until she creates a new way to say one of them. Salmon Vanilla…. Salmonella. Gabby clearly has the correct word, and beyond that she clearly has an understanding of the sound of that word. How clever to put two totally unrelated words, that she did happen to have in her device together to generate a new way to speak what is in her head. How clever but how challenging such a dilemma would be: to jostle between demonstrating understanding with words that relate conceptually (weigh scales for homeostasis) and expressing understanding phonetically (salmon vanilla for salmonella). Gabby has apparently constructed a unique method to express words she needs to say, a system that her device, not the language she understands, demands.

Gabby's experience while decidedly different from Jane's is in many ways also sadly similar. Until a person with severe speech impairment is able to spell what they need to say, until they are literate, they are limited by the words they have in their device. If they are very clever like Gabby and can fill the gap with a phonetically appropriate articulation they may be able to be speak beyond their device's means. But how many cannot? How many may search like Jane and realize the word they need is truly out of *speech* but not cognitively out of reach.

Out of time

Speaking with a device takes time, often a great deal of time. Time that is not expected by people conversing with the SGD user, and as Gabby's mother tells us, time that they ultimately may not be afforded to her.

> *Sometimes strangers get so comfortable talking with Gabby that they get talking too much and then they are confused that she can't answer back really fast. That's when they kinda back away and start asking me. That dead silence while she's answering has always been tricky.*

Speaking with a machine is an unnaturally slow process. While Gabby is initially included in a conversation with others, the dialogue falters due to the uncomfortable and unexpected and un-understandable silence that ensues as Gabby constructs her responses. The conversation is killed by the dead silence that appears to be Gabby's answer. What was initially a comfortable interaction becomes a confusing predicament for Gabby's conversation partner. They then readdress themselves to one who can answer without delay, rather than the person with whom they were initially engaged, the person who must answer through the machine.

Interactive verbal communication is dynamic, multimodal, and fraught with nuance and precise timings, the use of a SGD introduces additional media-related constraints which may disrupt this system (Higginbotham & Caves, 2002). Constraints imposed by the device that may create uncomfortable silences include the time for message construction and expression and the need for the user to concentrate on the device itself rather than their conversation partner. Having a conversation with a person using a SGD is therefore often challenging for even an experienced partner. When interviewing device users for this project I timed some responses to my questions. I was asking one young lady to recall experiences talking with her parents. She shared a time she got to say the "words bottled up in her head". One of her verbatim responses was "That time I finally matured. I understood it is not about the time it takes but what you say." Those 19 words took close to 4 minutes to generate. Four minutes of empty auditory space. Space that between two typically speaking people would be not tolerated. During that four minute silence I found myself thinking a myriad of other things: the work I had to do that afternoon; what I should make for dinner; the ticking of the clock on the wall, which captured my auditory attention; and that I really would not have time to complete the interview that afternoon. When the young lady finally did share here answer I found myself having to go back to my notes to recall what it was that I had asked. Our conversational connection had, at least for me, been broken and I had to go back in time to attempt to gather its threads to understand what is was we were talking about.

What about from the point of view of the SGD user? How might they experience the conversation lag that seems to inevitably be a part of speaking with a device? Consider Jane's experience when her boisterous excitement of acquiring a device too soon silenced by the *un-timely* demands of her device.

> *I was in grade 7 when I got my device. I was so excited. But as I got to school and tried to talk to my friends I just couldn't get the words out fast enough. I am not a slow thinker, but even with my new device I am a slow talker. At first my friends waited to hear what I had to say, but after a couple of sentences they lost interest and had moved on to something else. I was always behind, or always making them just wait for me. Most of the time when I got out what I wanted to say it really didn't even make sense any more cuz they were three topics ahead of me. So after of few times of that, I pretty much just stopped talking.*

Jane's initial excitement to chat with her friends soon gave way to frustration and resignation as she recognized that no matter how hard she tried she could not keep up with the chatter of her friends. She could not keep their attention or capture their interest long enough to allow her to join into the conversations. Perhaps more embarrassingly to a young girl when she was able to interject her comments or thoughts, they no longer made sense. The slow talking made her appear to be a slow thinker.

The rate at which people comfortably hear and vocalize words is about 150-160 words per minute. Even using today's methods of user interface optimization and rate enhancement methods, communication rates achieved by a device uses are often less than 10 words per minute (Newell, Langer, & Hickey, 1998). Even a person with very dexterous hands can only type at approximately one-third of the normal speaking rate, with disability often reducing that *speaking* rate to excruciatingly slow speeds (Newell, 1987). Indeed, many can only speak at the rate of 5 or 6 words per minute. As Newell (1987) predicted in this paper on the subject of communication aid design, despite many researchers ongoing work on the problem a solution remains to be found. Talking with a device puts you on the banks of a fast flowing river watching as the stream of conversation flows by (Higginbotham, 2009). It also may make the people moving effortlessly through the flow of the conversation uncomfortable or anxious as they recognize that you are not one of them. The irony of this experience is remarkable. The very thing that the machine provides – the connection through voice – it also seems to deny - the free flowing ease of human vocal interaction.

Don Ihde (1983), a philosopher of technology, speaks of mediation of human experience through technology. In his discussion he points out that all technological media simultaneously amplify and reduce ordinary human experience. Ihde's example is that of a telephone conversation. It amplifies in that it allows a conversation across vast distances. It reduces in that the face-to-face richness of the conversation is now a mere voice. How much more poignant is the amplification and reduction experienced by the VOCA user. The ordinary possibility of a real chat with friends and teachers exist, but only at a pace at which reduces the participatory experience to that of always behind and usually off topic. The barrier taken away with the voice of the machine is replaced with speed bumps so cumbersome as to make the pace of the speaking journey a new obstacle in and of itself.

Discussion

Key Findings.

The stories of SGD users shared in this chapter point to four possible understandings of the meaning of SGDs in the lives of persons who use them: 1) expressing oneself through speech is more than just speaking words; 2) speaking with a SGD enables a user to have a *voice,* actually and metaphorically; 3) for users who are not literate, their words are not their own, they are provided and learned rather than acquired and developed; and 4) speaking through a device creates inevitable time constraints that human conversation does not expect and may not accept.

In being heard I am seen. Being able to speak in an audible human voice is important to people with severe speech impairments (Fried-Oken & Bersani, 2000; Huer & Lloyd, 1991; Portnuff, 2006; Romski & Seveick,1996; Wickenden, 2011). This study suggests that the ability to voice one's presence in the world allows SGD users to not only be heard but to be seen. The voice from the machine announces themselves as capable, allowing them to express that they have ideas and opinions that must be listened to, and that they will not be passed over in silence. With a SGD people are able to speak for themselves, actually and metaphorically, providing a sense of agency and self that may otherwise be hidden.

I can interact with a voice. Speaking through a device provides more than a voice; it provides the means of interacting with the world and the people in it (Heur & Lloyd, 1998; Wickenden, 2011). Having the ability to gossip, comment and interact with the voice from the machine affords connections that may otherwise be muted for people with severe speech impairments. Most day-to-day human interaction happens through vocal and auditory means. It seems that it is not so much the particular words that are shared that matter, but rather, that words *are* shared that fosters interaction. Indeed most of what we say is not to share information but rather to build and establish social relationships (Locke, 1998). The ability to produce audible voice is important to people who have severe speech impairments as a means of making contact with people in their lives. Even the simplest phrases when uttered aloud can reach across a room and touch a fellow human being.

My words are not my own. Having a voice from a machine does not equate to being able to easily and effortlessly speak with one's natural voice. In order to speak with an SGD, people must have the words available to them. As such, this not only means they have to have the words in their own lexicon but they must also be able to find its representation within a device - outside of themselves.

In reality, the child who speaks through a device must *write* to speak (Erickson, Hatch & Glendon, 2010; Light & Drager, 2002). A SGD user must have access to, be able to find, and select graphic representations of the auditory symbols they are immersed in (oral language). Even a preliterate user must choose a symbol on the display of the machine in order to choose between calling her mother to "look at me" or to "come here". This is a task not required of a child who can speak without the need of a SGD. The child who speaks through a SGD must learn two systems, one that is based on auditory information and the other based on graphic representation.

I am out of time. The timing of real conversations cannot be achieved through a SGD. As has been suggested by several other studies, speaking with a SGD does not allow users to converse in the manner expected by the speaking population (Higginbotham, 2009; Meyers, 2007; Wickenden, 2011). Using SGDs requires time devoted to message construction that is not part of the day-to-day world of speaking persons. Coming up with an audible response to a teacher's question or chiming in with a tidbit of gossip with your friends in the cafeteria occurs in microseconds. The demand for, and expectation of, the normal give and take of a conversation puts a burden not only on the person who is using the device but also on their communication partners. A lengthy pause is uncommon and uncomfortable for natural speakers, and makes the experience of speaking through the device far more challenging than mastering the device. Even for users who are literate, communication with a SGD can never begin to reach a rate of speech that comes close to participating in the give and take of a conversation (Newell, 1987). A SGD user may be relegated to the sidelines with the verbal world streaming past them.

Limitations

This chapter presents an important contribution to the field by presenting the experience of speaking through a device as lived through. The intent is not to generalize, theorize, or explain, but rather to foster understanding of the experience by reflecting on concrete real life examples of what it may be like to speak through a SGD. To that end, it is important to note that the stories presented in this chapter are stories of individual experiences. It is hoped that they are told in such a way that they illustrate elements of what is universal in the phenomenon itself. No claims can be made that these stories represent what is true for every SGD user, only that they may point to something that is at the essence of what it is like to speak through a machine.

It is important to note that the SGD users focused on in this chapter do not represent the entire population of persons who may have need of a SGD to communicate. Other SGD users include persons who have severe speech impairments due to acquired disabilities (e.g., head injury), people with autism, or other developmental disabilities. Their experience of device use may be quite different from people whose speech impairment is due to physical disability.

Future research

The most important voices are often the hardest to hear (Blackstone, Williams & Wilkins, 2007). Heeding recent calls to include the voice of augmentative and alternative devices users in research (Williams, et al., 2008) may require that we look beyond the more traditional means of scientific inquiry to those which draw upon interpretive and ethnographic methodologies. To truly understand what the experience of speaking through a device it may be important to seek not what people *believe* to be true but what people *actually experience* in their day-to-day lives. This type of research involves gathering experiential data in an ongoing manner from participants in order to *see* how it is to speak through a device rather than asking what they *think* about speaking with a device. To expand this type of inquiry and to include a wider range of people who use SGDs, researchers need to go beyond traditional modes of interview, focus group participation, and survey to include those whose experiences have thus far been not explored (Ajodhia-Andrews & Berman, 2009; Owens, 2007; Susinos, 2007).

Implications for practice

Many disciplines are involved in the field of AAC, including educators, speech language pathologists (SLPs), and rehabilitation engineers (Beukelman & Mirenda, 2013). Understanding what it is really like to speak through a SGD challenges those of us who take up these professions to be more *care*ful, more empathic and more open to the opportunities and the demands that the use of these technologies entail.

As educators, we may seldom give a momentary thought to our students' ability to talk or to express themselves to us through audible speech. Speech is something that the vast majority of students have mastered before they come into our classrooms. In general, the task of the teacher is to bring these verbal young people into the world of literacy, to build on their speaking and listening skills, and to nurture and guide them into the word of text. The experiences of SGD users challenge educators to pause and reflect on what we can expect and how we must act when a child who must speak through a device enters into our care. For a child who must write to talk literacy becomes perhaps even more central to their education. Yet teaching a child who cannot speak or write requires many skills that many educators may not have (Light & McNaughton, 2012). Karen Erickson and her colleagues at the Centre for Literacy and Disability provide educators with many wonderful resources to help develop literacy skills of non-speaking children and youth (Erickson, Hatch & Clendon, 2010).

Educators are also challenged to create opportunities for interaction and verbal participation for students in their classrooms who use SGDs. Classrooms are busy, sometimes boisterous places that often are full of many conversations. Students who use SGD must be provided with audible spaces to share their voices. These spaces do not happen naturally; educators must create them.

Finally, educators must provide children with SGDs the opportunity to talk to and with many people. Most often children with SGDs speak only with people closest to them (Meyer, 2007). In classrooms, this may be their educational assistant (Chung, Carter & Sisco, 2012). Yet, the research reported here tells us that children and youth value the ability to participate in the chatter and gossip of classroom life. Intentionally implementing interventions that support interaction between students with severe speech impairments and their peers will be critical if children who use SGDs are to be able to be part of conversations of their lives.

SLPs are usually tasked with choosing and implementing AAC systems for people with severe speech impairments. Listening to the voices of those who use the devices tells us that SLPs must work hard to help SGD users to understand their systems – to be able to find and express their words. To support SGD users we must listen to their desire to express themselves, seeking ways to allow them to build and develop their own vocabularies.

Perhaps most importantly for AAC professionals, device users tell that as wonderful as these technologies are, they remain tremendously inadequate in providing a true alternative to speech. SGDs do not afford people with severe speech impairments the ability to speak in the way a natural speaker can. It may be important for AAC professionals to help family members, educators, and the speech-impaired persons themselves understand what they can expect from these machines. The stories of SGD users will be instrumental to this task.

Finally, the lived experience of SGD users can inform the work of rehabilitation engineers in their quest to design devices that come ever closer to providing the opportunity for production of real speech. Certainly the challenge to increase the rate of speech generation for SGD users remains a top priority. But beyond this, can devices be created in a way that allows users to develop their language rather than being given a language?

People who use SGD need access to words, words that matter to them and to the situation at hand, words that they can find, and words that they can use to say loudly and boldly “please wait, I have something to say.” This task is far from easy and despite our desire to believe in technological solutions, it may not be the technology that holds the key. It may be our real understanding of what it is like to speak through a machine that guides us to richer more careful pedagogical interactions. Understanding can influence how we respond, how we can seek to make contact with the person’s mind as well as the person’s body.

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Chapter 9: A call for pedagogical listening.

In this study, I have called upon phenomenology of practice (van Manen, 2014) and insights from postphenomenology (Selinger, 2006) to contribute to the field of AAC. I have looked to postphenomenology (Rosenberger & Verbeek, 2015) to extend more traditional phenomenological understandings to gain entrance into this unique, some may say cyborgial, reality. Postphenomenology is, according to Don Ihde generally understood to be the *father* of this approach (Selinger, 2006), "a philosophical style of analysis which deals with science and technology studies" (Ihde, 2015, p. vii). Postphenomenologists explore the relationships that develop between humans and their technologies (Rosenberger & Verbeek, 2015). Many insights into what van Manen refers to as the lived experience of things (van Manen, 2014) can be found in the works of Ihde, Verbeek and others whose work focuses on human-technology relations. By exploring not only the extentials of lived space, lived time, lived relation and lived body but also the extential of materiality (van Manen, 2014) I have sought to provide a glimpse into the everyday experience of augmented speakers who use SGDs.

The primary focus of the study remains pedagogical. It is hoped, however, that these insights may also inform the practices of those who are tasked with creating and refining these specialized technologies. To challenge rehabilitation engineers to create machines that will take into account the lived experience of those who will use them to participate meaningfully in the world of speaking persons. However, no matter how *good* the design "having a communication device doesn't make you an effective communicator any more than having a piano makes you a musician" (Beukelman, 1991, p.2). The pedagogical practices of educators, parents, and others who support these extraordinary young people in voicing their presence in the world also need to understand what it is really like to speak with or is it through a machine. I hope this work may help all of us whose task it is to provide people who use AAC with an audible voice in the world to couch our practices in pedagogical tact based on this glimpse into their lifeworld.

The importance phenomenological understanding.

Sarah Blackstone a long time AAC champion tells us the most important voices for us to listen to are often the most difficult to hear (Blackstone, 2006). This research suggests for many reasons this may be all too true. We have seen that it takes time, and sometimes a great deal of it, to really hear what those who use SGDs have to say about their every day lives as technology infused speakers. The field of AAC has surprisingly few studies using qualitative methodologies (Weissling, Quach, McKelvey & Lund, 2016; Balandin & Goldbart, 2011; Wickenden, 2011) and fewer yet where the lived experience of augmented speakers is systematically gathered and explored. To date only two issues of the journal *Augmentative and Alternative Communication* have focused on qualitative methods (Baladin & Goldbart, 2011). The journal of the Rehabilitation Engineers Association of North America (RESNA) included even fewer qualitative studies, a relatively recent edition included articles where the stories of augmented speakers were added to enrich their work (e.g., Shane et al., 2012; McNaughton, Bryen, Blackstone, Williams & Kennedy, 2012). This may be because the field has not yet been influenced by the work of philosophers of technology. For example, while a 2009 *Readings in the Philosophy of Technology* text covers a broad range of areas concerning human-technology relations and interactions, it is silent on assistive technologies. The notion that there may be value in a philosophical inquiry into AAC may just not yet be part of the culture of the field.

When presenting some of my initial work at an international AAC conference, I was asked, “so what do you do with this kind of research?” I was taken aback by the question, firstly because I was still a beginner in this journey and didn't really have an answer that I thought would satisfy this predominantly science-driven audience. Secondly, because the person asking it was someone relatively famous in the world of AAC for whom I had immense respect and who I thought more than anyone in the room had the instincts of phenomenologist. I wanted to impress him and hoped that he would understand. I gave the answer that I had once heard given by Dr. van Manen: it is not what you can do with phenomenology that is as important as what phenomenology does to and for you. I am not sure if the answer satisfied the crowd in the room that day, nor if it even at that point in the journey satisfied me. It seemed somehow too esoteric to really mean anything, especially to a field still seeking models, theory, methods, and procedures that can be put in place to make the lives of people with CCN better. The very notion that it would be the researcher or the practitioner themselves that was changed, not necessarily the person who experienced the phenomenon of speaking with a machine, seemed utterly foreign territory. Looking back I can see that I was yet to understand what the aim and the potential value of a phenomenology of practice really was, even though I had adopted the words and phrases that might suggest I did.

While I am admittedly still on the journey of understanding (and hope I always will be), I have learned and seen much since that day. I have watched as the same AAC professional brought a young rehabilitation engineer to a subsequent talk, and nodded in his direction while I was talking as if to say “pay attention, this is important for your work.” I have heard from family members of persons who use SGDs how important they felt my talk was for them as family members. Most telling perhaps is the response that I have received from audiences as a whole when I have presented portions of this work. Most often when I finish speaking the response is silence. Not a stony cold silence, or an embarrassed silence, but a knowing silence that is also tinged with a bit of discomfort and perhaps a bit of awe. I believe if I had to attach a word to the silence of the rooms, I might call it empathy.

For those who are not in the field of AAC directly, the silence seems perhaps more tinged with wonderment and emotion. At one education conference, my presentation was in the middle of five studies on technology in 21st-century classrooms. While one speaker after another had spoken previous to my talk with not much as a pause, the speaker directly after me had to take a minute to regain her composure, telling me how moved she had been by my presentation. In two subsequent presentations of my work at assistive technology conferences, the nodding heads of the practitioners in the room while I talked, and their silent, knowing, slightly troubled faces told me they had been challenged to think about their work and their experiences with young people in a different light. In most every instance, my work is met with silence and stillness. That is until someone says thank you. It seems that they have been *touched*.

The gnostic and the pathic.

Van Manen (2014) speaks of the gnostic and the pathic ways of knowing. He uses examples from the field of nursing to explain the difference between these two ways of seeking knowledge in practice. A nurse's interaction with a patient may take on a gnostic dimension when she is gathering information to make a diagnosis or prognosis regarding the patient’s state of being and health. But nursing, or perhaps I could suggest good nursing, also involves the pathic dimension of understanding (empathy) and support.

Albert Robillard’s account of the nurses he encountered while in the ICU illustrates this dichotomy between the gnostic and the pathic knowing. As may be recalled from past excerpts from his book in previous chapters, Dr. Robillard was an anthropologist who lost the use of his speaking voice due to motor neuron disease. His account of communicating in the ICU focuses on what he refers to as “flying nurses” and “local nurses." The flying nurses were those who are not local and fly in from other places to work at the hospital. The local nurses were those who lived in the community of the hospital. The flying nurses, he tells us, were nearly impossible to communicate with.

> *The flying nurses treated me as a standard sick person, someone too sick to be working and in no command of his circumstances… the denial of my individuality was connected to the alphabet board. None of them would use it. A few would try, but they would become frustrated and stop…*
> *Anticipating these communication troubles, most flying nurses would say, “I am not even going to try the board.” Others would declare, “It is no sense in trying to communicate. I know what needs to be done and I am going to do it.” A few would remark, “ I have a job to do, so don’t give me any trouble by trying to talk.” The most memorable line came at a first encounter: “I am the nurse from hell and do not try any of that communication shit with me.” The nurses seemed to think that working with a patient in my condition could be carried out without any communication. (Robillard, 1999, p. 55-56).*

The flying nurses rely on their training and procedures for the information they need to care for patients such as Robillard. The flying nurses are too busy, to hurried, to procedural to take the time to communicate with a patient for whom it is so difficult and time consuming to do so. They had, I venture to say, the gnostic touch. They went about doing what they had been taught to care for a person with severe disabilities in the ICU; this did not it seems require them to care about or know this particular person with severe disabilities in the ICU.

The “local nurses” on the other hand seemed to bring a pathic dimension to their work. One that Robillard attributes to the shared local culture and social structure that they shared with him.

> *Authentic local nurses could – by glances, gaze, facial expression, vocabulary, syntax, cadence, dialect, body language, and topical reference – locate themselves and their*

> *patients as members of the same local culture and social structure…For these nurses, I had an individual personality. There was a reciprocity of highly detailed knowledge that located both me and them: we knew each other as unique, situated individuals. We did not deal in generic, universal categories.*
>
> *The local nurses would… use my board, perhaps because they had the knowledge motivational culture to formulate themselves conversationally as members of the same social space. (Robillard, 1999, p. 57-58)*

Robillard may well have been correct in his explanation that a sense of place and culture was what motivated the local nurses to communicate with him in ways that the flying nurses did not. What also seems at play, for whatever reason, is the patience and empathic attentiveness that he perceived from the local nurses that he did not from the flying nurses. It is this careful seeking to understand and act beyond what is intellectually or cognitively known that I have come to realize is what a pathic understanding is all about.

From knowing to understanding.

How many days were you a slave?
Long enough to know.
Long enough to know, not long enough to understand.
Game of Thrones, Season 6, Episode 4

I came to this study with considerable knowledge and experience in the field of AAC. I had read the books, followed the AAC literature, and I had worked with children who used AAC systems and their families. I believed that I not only knew about AAC but that I understood the opportunities and challenges that these less-than-perfect technologies presented to those that wanted to use them to speak. Looking back I see that I was coming to my practice situated in an orientation to the world that emerged from a natural science worldview. A view that prioritized the gnostic way of knowing, seeking logical systems that could be used to influence the behavior of human beings to improve the conditions of life (McPhail, 1995). Such is the orientation of special education, to prize what is observable, objectively *knowable*, and generalizable, and to discount or at least distrust anecdotal or subjective information. What I learned over these past years of adopting a phenomenology of practice is that while gnostic (clinical, positivistic) ways are important, they alone cannot lead to insightful practices that are founded in a strong pedagogical orientation. I have come to understand what is also needed in the fields of AAC, AT, and special education, is to understand the everyday lifeworld of those we seek to support, and that this understanding demands new ways of being in the world of special education itself.

Seeking pathic understanding.

> *The pathically tuned body recognizes itself in its responsiveness to the things of our world and to the others who share our world* ***or break into our world.*** *(van Manen, 2014, p. 269)*

In my years of practice in the field, I interacted with scores of children who used, or who were seeking to use, SGDs. I would see them mostly in the context of their school day, diagnosing problems that might be getting in the way of their becoming competent communicators. I would with others on my team make prognoses of what expectations we might have for a child to use a device or other methods to communicate. I was there to get information, to bring my knowledge to bear on situations, and to ultimately solve problems. This was typically achieved in a manner not unlike Robillard's "flying nurses." A short visit followed up by a consultation report that would impart my (cognitive) knowledge to the teachers, educational assistants, and hopefully to the parents of the particular child. When I explain myself to others these days I somewhat sheepishly refer to myself as the "fly by consultant." Never, not even once, did I ever just pause with a *listening gaze* (Walton & Madjar, 1999) to seek to understand the lifeworld of these children, and what the phenomenon of speaking through an AAC system mean for them. As the above quote from Game of Thrones suggests, I had taken the time to know, but had yet to give the time it takes to understand what it is really like.

Then, over the course of this study, I have spent considerable time with young people who speak using SGDs. I have sat quietly in the back of their classrooms for not an hour but for many days. I have followed them with a listening gaze as they interacted with their classmates, their educational assistants, and their teachers. I visited their homes waited, the sometimes minutes, often hours, it would take for them to tell me one simple story of their lives. Something that they had never been asked to do before - tell their stories, share their memories. Something so entirely taken for granted by those of us who can speak, yet apparently something exceedingly rare for a someone whose stories take such time to tell.

Research suggests that narrating events in our lives is essential to the establishment of one's selfhood (how you see yourself) and one's personhood (how others see you) (Wickenden, 2011). As children growing up we are guided in telling our stories to our parents, "what did you do today?" and by our teachers. What child has not been asked to write an “All About Me” book in their early years of schooling, or to share a story about what they did on summer vacation? The stories of our lives are told and retold as we engage with conversations with each other and indeed as we come to find ourselves as being in the world. How astonishing it is then to consider that these story telling opportunities had never been afforded to the young people I was listening to. It appears that no one had ever thought to ask what happened to you today, perhaps because they did not consider that the effort it would take the child to engage in this *small talk* would be worth it to them. Or perhaps it was because, as we have seen, it takes an inordinate amount of time for a child using an SGD to share even the simplest story of their day. Or perhaps, even if time were given, they did not have the words in their device to recount the story in their head.

The focus of this research, *to tell me about a time*, presented an opening to sharing their stories, and eventually after much time and some patiently guided practice they did. They shared stories of their experiences with their SGDs which was wonderful. But, there also came stories of abuse, not physical but certainly emotional at the hands of their teachers and assistants, stories of fear of being put under sedation and never waking up, stories of being afraid that they would be taken away from their parents when they became of legal age. There were also stories of themselves as themselves. I came to know these young people as autonomous individuals, to understand a bit about how they were trying to present themselves to the world. One young man shared that he desperately wanted to move out of home but that there was no place that he could afford given that he could not find a job. He was trying to become an adult, but the world that he was living in was getting in the way. A girl in high school shared that she was really afraid of getting a new assistant to work with her because she was so dependent on that person for so much of her day. And one young lady, in particular, shared how difficult it was to feel that she constantly had to perform for others to be deemed *competent* – "I am not a trained monkey" she told me as she recalled the story of trying to prove herself capable of using and therefore obtaining a SGD. All of these examples represent the singularity of the phenomenon of speaking through a device and the universality of what it means to be able to speak--to have a voice in and of your life. Our sense of agency is usually demonstrated through our talking with others, yet for people who speak with devices their expression of themselves seems so intricately tied to their relations to and with their machines.

Beyond an instrumental understanding.

The essence of technology is by no means anything technological
(Heidegger, 1977).

Philosophers of technology argue that to understand a technology or a device or a tool, one must look past the mere instrumental dimension of its use to what it does in the lifeworld of those who use it. One might suggest that there are no more life transforming devices than those which are specifically designed to compensate for some impairment of a person's body, assistive devices. Yet the field of AT, particularly the field of AAC are practically bereft of analyses of how these technologies shape the lived experiences of those who use them.

Coming to this study, I had never conceived of a technology being anything more than a tool. In my years of working in and teaching about AT and AAC devices I commonly would admonish people to remember that whatever technology I was speaking of at the time was just a tool. The technology was not magic. By itself, it could and would accomplish nothing. But, as I hope has been shown in this study, SGDs are something more. The consequences of SGDs in the lives of people with severe impairments of speech go far beyond a mere tool to produce understandable speech. Instead of a tool that extends or augments, like a hammer or a word processor, for those without speech, an SGD speaks for them albeit a grossly inferior version of that afforded to those of us who can *just* speak. By their demand for time, with their synthetic output, and by the mere fact that they are in fact machines, they may impose silence as well as give voice. Devices while giving the opportunity for audible voice may sometimes be as silencing as the impaired speech.

Still, there is something awe evoking about these technologies. They do so much more than produce human sounding speech for those who cannot. Through the use of an SGD, someone with CCN may be brought into contact with the speaking world. Once impenetrable gaps of space can now be filled with a call from a child to her mother or a comment to a sister across the garden. With a SGD a once non-speaking child can enter into the world of those who speak, not gently swaying over as Merleau-Ponty (1964) suggests, but suddenly and decisively as the pre-programmed device is set before them ready to speak for them with the touch of the screen or the hit of a switch. Perhaps then, if SGDs are not magic as I have so often stated, there is something none-the-less magical about them. Something transformational. But these corporeal and existential dimensions of the phenomenon of speaking with an SGD are largely unconsidered in the field of AAC. While there is a growing body of scholarly inquiry into various technologies and technologized ways of being in the world (Kaplan, 2009), including many forays into cyborgial bodies and the ethics of the enhancement of human beings through medical intervention and medication (Savulescu, 2007), there are very few who have taken up the call to explore the philosophy of assistive technology. Yet, one may argue that even in today's technology infused world there are few who are more technologically mediated in their being in the world than people severe disabilities physical disabilities. Deeper understanding of how technologies shape the lifeworld of people with disabilities is desperately needed if we are to grasp what is important in their world and in the world we all share.

Adopting a pedagogical orientation.

> *How does my grandson work? Why was he placed on this earth this way?*
> *The elderly man held the boy on his lap. There was a typewriter in front of them. The elderly man wondered "what can this boy do? How can I share my thoughts with him and he with me? How does this boy work?"*
> *The boy was no prize human being. He wriggled around an uncomfortably flailed his arms with abandon. The boy drooled too, even though he was well past the age of learning to swallow.*
> *The boy liked to bang on the downstairs piano and make a jumble of sounds until somebody moved him out of the range of the keys. He often visited the office and seemed interested in his typewriter. The boy started touching the keys of the typewriter. The boy*

> *noticed that they would go down if he hit them and sometimes this left a little mark on the paper in the typewriter. (Shane, Blackstone, Vanderheiden, Williams & DeRuyter, 2012, p.5)*

Michael Williams a prominent writer in the field of AAC who himself uses a SGD among other things to communicate shares this story as his introduction to written communication on the knee of his grandfather. I share it as a lovely example of a caring grandfather who is acting with pedagogical tact as he seeks ways of authentically understanding the child before him. Who is this child? How does this child work? How can I come to know him? How can we come to know each other? These are the questions that are guiding the grandfather as he places the child before the machine. Following the child's lead, and attending to his abilities in other areas (the *playing* of the piano) the elderly man takes the child onto his knee and provides the opportunity for access and for exploration. Exploration that would, as Michael tells us, ultimately would unlock him from a world of silence and enable him to begin his journey to becoming a writer and through text a speaker.

> *This was my introduction to written communication, the benefits of which would not be evident until later. That typewriter is one of the talismans of my life and remains so to this day. Even though its form has morphed into computers, electronic AAC devices, tablet displays and smart phones, my grandfather's typewriter represents the iconic potential to unlock the power of communication for folks who have been silent.* (Shane, et al., 2012, p.5)

van Manen (1991) describes "pedagogy… as a fascination with the growth of the other" (p. 13). Pedagogy is conditioned with a caring and loving orientation towards the child. Pedagogy is governed by hope, hope that gives us patience and tolerance, belief and trust in the possibilities for the child so that the child may grow to have belief and trust in him/herself.

Moreover, pedagogy is the taking up of the responsibility for the child. Responsibility that involves taking on a moral authority and a moral responsiveness in guiding the child in their journey from childhood to adulthood. Looking back, it is perhaps this recognition of responsibility for and to the children whose experience has been told through my work that silences the room when I present it.

Adopting a pedagogical orientation towards a child learning to speak, and speaking to learn, in the mediated world of one who uses a SGD presents unique challenges to parents and educators. We are challenged to look past the dis-abled body to seek to understand the growing child, a child who may have words bottled up in their head, but who, due to the limitations of the technology, cannot express those words. We are challenged to consider our understanding of technologies and our assumptions about their transformational powers. While they are indeed transformational, these technologies can be themselves dis-abling showing the child who uses them as a *cyborgial other* rather than a child who longs to be heard and enter into the conversations of the world. Perhaps most of all, we are challenged by time and the time it takes to talk when one's speech is generated by a device. Van Manen (1991) suggests that pedagogical tact is mediated through speech and also through silence. Yet the pace of speech and the kind of silence afforded by SGDs may involve a kind of pedagogical tact that can rarely be accomplished given the real-time demands of classroom conversations and human talk time interactions. How can we use this understanding in shaping our actions and interactions with children who use SGDs? Van Manen also suggests that pedagogical tact is mediated by an atmosphere. Perhaps here lies the greatest possibility and the greatest promise for our pedagogical practices with children with CCN. By creating an atmosphere where we show a child we believe in them, we understand they have much to say, and we create an openness and attentiveness to listen no matter how it is they wish to *talk* with us, can we pedagogically guide a child with CCN in their process of becoming. It is through the seeking to understand what it is really like for these children that reflection on how to create and maintain this atmosphere of active, pathic, and ultimately pedagogical listening may be accomplished.

Pedagogy is not much discussed in the world of AAC. Certainly, there is talk of principles and practices, but these are often guided towards strategies for implementation and supporting the development of communicative competence. Acting with pedagogical attentiveness takes on a somewhat different orientation, and perhaps more than anything it takes sensitivity to the lifeworld of the child – a sensitivity that can only be accomplished through the seeking to understand what it is really like for that child. Principles and practices governed by outcomes and efficacy may serve us well to know what to do to help a child speak *with* a device, but it is principles and practices that are guided by pedagogical tact that may help a child speak *through* a device.

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