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ABSTRACT

This dissertation chronicles the experiences of five high school students with autism who type to communicate as they navigate the terrain of high school, adolescence, and identity through collaboration and dialogue with one another, their school support team, and the inquirer (researcher). This study employs a multilayered approach to narrative inquiry to unravel and (re)present the students' (co-inquirers) individual and collective stories as constructed through observation, performance, dialogue, and art. While acknowledging the importance of families and school personnel, the students' storied lives and perspectives—as well their participation in constructing the inquiry process—are foregrounded to supplement research dominated by adult, and/or spoken voices. Grounded in a disability studies in education framework, this work traverses the institutional, performative, and dialogic landscapes that the students help to shape (and are shaped by) to reveal the complex interplay between diverse ways of being and communicating, dominant discourses of normativity, and resistance through advocacy, inclusion, and research. The reader is invited to follow along as the students cultivate community through (inter)action grounded in shared experience, inclusive educational contexts, and emerging ownership of their situated identities as individuals with autism who communicate in diverse ways. They/we feel compelled—by default and/or design—to put these perspectives and stories into the world as counter-narrative(s). In both content and form, the (re)presentations emerging within/out of this inquiry start a conversation about the constraints of research and inclusion understood solely as practice, advocating for a broadened conception of both as co-constructed, relational experiences.

BLAZING TRAILS, BEING US: A NARRATIVE INQUIRY WITH FIVE HIGH
SCHOOL STUDENTS WITH AUTISM WHO TYPE TO COMMUNICATE

by

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Dissertation

Submitted in partial fulfillment of the requirements for the degree of

Doctor of Philosophy in Special Education.

Syracuse University

May 2016

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For Anne
and her shadow(s).

ACKNOWLEDGEMENTS

This dissertation is rooted in relationships. I cannot begin (or end) without acknowledging the impact of the connections I was witness to and part of during this inquiry. To my five co-inquirers, this document is as much yours as it is mine. The conversations, collaboration, and trust you shared with me go far beyond the call of research participants. I am both intent on finding words to thank you and aware that they will always fall short. Please know I am forever changed by and grateful for our time together. May you (we) continue to blaze the trails you (we) traverse, always with an eye toward a world where doing so is unneeded.

To my co-inquirers' families, thank you for welcoming me into your homes, sharing your stories, and allowing me to join this journey with you. I move on with a deepened understanding of "commitment" that I attribute to you and the efforts you have made to ensure your children know, and are known through, equitable educational opportunities.

While this inquiry centers on the perspectives and experiences of/with the student co-inquirers, I want to recognize that those things emerged in the midst of and in interaction with the school and personnel who occupied it. Without the support of the Cedarbridge administration and staff this research would not have been possible. I am so appreciative for the crucial work that you do and for your willingness to allow me into your lives to understand it. I also value and acknowledge the Syracuse University School of Education and the John P. Hussman Foundation, both of which contributed generously in opportunities, funding, and resources to this research. And to Jackie Adamo, artist, teacher, and friend, thank you for your time and creativity.

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individuals with disabilities and assured me that, because of my background, I belonged here. I wish he could witness me admitting that he was right; that email, his teaching, changed my life.

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My immediate, extended, and in-law family members have never wavered in their availability, guidance, and support. They have appreciated my presence and understood my absences during this process with grace and without consequence. My brother E.J., in particular, deserves recognition for stopping at nothing to ensure that I never miss out on *all* of life’s frivolity. To my trusty canine companion, Lotus, thank you for keeping me calm.

I am surrounded by incredibly strong women. My grandmother, who passed in the midst of this dissertation, was my sunshine because I was hers. I miss her terribly, but have been comforted during this process by reminders of her in fortuitous encounters with beautiful things, my previously untapped resilience, and an affinity for all things chocolate. My mother and editor extraordinaire has, for the majority of my academic career, stayed up just as late as I have reading drafts of written work (including this one) for grammar, fluidity, and those pesky but essential words (like “the”) that I tend to forget. Mom, you have taught me how to be indomitably loyal, focused, and humble all while creating the kind of memories—stories—worth

telling. I, and my writing, would be incomplete without you. MJ, my “adoptive” mother, has always treated me like an equal, while also letting me act my age as her daughter’s best friend. She is a tireless advocate with a knack for living in loopholes and standing firm in the fight(s) for justice. MJ, thank you for teaching me that who we are and what we know are not objective truths, but are built in the connections we make with others and how we exhibit those bonds. My best friend and soul sister, Anne—whose friendship has stretched across time, distance, and life’s complex twists and turns—has led me by example and insisted that I be the version of myself I see reflected in her eyes. It is because of you, Anne, that I am most comfortable in experiences and relationships that defy categorization (and words) and intent on challenging the world to be flexible enough to make room. For them, for you, for us. I am grateful.

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PROLOGUE

Beginning, at the End(s)

I am seated in a sea of tasseled mortarboards and green and white robes; under mine I am wearing a sundress and heels. Around me parents, siblings, family, and friends, whoop and holler as their loved ones, my classmates, make their way down the side aisles toward their seats at the front of this large amphitheater. My family is in the back; I hugged my Grandma and smiled for my parents' new Canon point-and-shoot as I passed by them on my way here. My best friend Anne wears the same white robe I do and I wear the same pink rose corsage she does; her mom, MJ, got one for each of us. Anne and MJ are seated near the aisle about 10 rows behind mine, surrounded by our classmates. I smile, remembering how in elementary school this kind of physical distance between Anne and myself was both rare and anxiety producing for me. As I think about the three-hour car ride that will separate us next Fall when I leave for college, my heart sinks; maybe I am still working on being okay with being apart sometimes. I guess not much has changed since that day we met in second grade.

After the class President, Valedictorian, and Salutatorian give speeches that all end with "We did it!" the graduating Seniors and I cross the stage one by one in alphabetical order; 657 students file up the stairs on one side and down the stairs on the other. When Anne's name is called, MJ pushes her in the wheelchair with the same hot pink riggings she's had since we met, out from backstage where she has been waiting her turn. Even amphitheatres are not universally designed.

The Principal leans down toward Anne and attempts to hand her a diploma. When she does not respond verbally or reach for it immediately he stands frozen in a hunched over position at her eye level, waiting as the crowd cheers. Anne rocks her upper body back and forth twice, her way of accepting his gesture. Only after Anne's shoulders have stilled does MJ—in one fluid movement—artfully reach around her, slip her hand under the

I am seated in a sea of tasseled mortarboards and blue robes, but I am only wearing a sundress and heels. Around me, parents, siblings, family members and friends whoop and holler as their loved ones make their way down the center aisle toward their seats at the front; my mom is seated next to me, in town for an aptly timed visit. I see more smartphones than cameras poised ready to capture each student as they pass by and my brain flashes the image, caught by my parents' old Cannon point-and-shoot, of me looking over my shoulder and smiling as I walked down a similar aisle on my way to my graduation stage; I hope each flash of an iPhone camera catches something equally memorable. I have a clear view of the processional from my ground floor seat at the back of this vast sports arena, a coveted position for those hoping to catch a glimpse of a graduate as they pass. Though typically reserved for students' families, the Wibbles (my co-inquirer, Ralph's parents) were resolute about me joining them in this section when I arrived, insisting "today, you are our family."

My eyes search the stream of graduating Seniors, seeking the ones for whom I am poised to cheer. From their seats close by, two of my other co-inquirers, Peter and Henry Golden and their parents, are watching for the same two faces that I am. Were Carlee not out of town on vacation, all five co-inquirers, their families, friends (many of whom are also mine), the school staff, my mom, and I would all be under one roof, at the same time; a collision of my worlds in the best possible way. The students in blue robes pass in pairs, moving ahead to the melody of Pomp and Circumstance. Finally, after a large gap between the previous group, Ralph and his tall blonde peer lead a line of students down the blue carpet. He walks slowly looking ahead, focused; the students behind him match his pace. He is followed a few minutes and about 40 student pairs later by Martin, who tilts his head and gently waves his arms near his shoulders as he processes in. In each

diploma, and deftly rest it on the arm of the wheelchair, before propelling Anne forward. Even now, I swear Anne got the loudest, and longest, whoops and hollers; word had gotten around that up until a few days prior, Anne had been told she did not belong on that stage. Those cheers said otherwise. When, 11 alphabetical groups later, it is my turn to accept my diploma, my mind is somewhere else. I shake the Principal's hand, my lips form the words "thank you," and my feet take me across to the other side, but all I can think about is what will happen after the last of my peers take their seats.

Once the music and chatter have quieted, the class Secretary and Treasurer take the stage in a ceremonial tradition to present the class gift on behalf of the Student Council. But they stand at the podium only briefly to announce a deviation from the program: I will address the crowd instead of them, an arrangement made with and familiar to a select few of my peers, teachers, and family members in the audience. I am shaking when I approach the podium; I look out into the crowd of peers, friends, family, teachers, and administrators, seeking the comforting sight of the pink rose corsage that matches mine. I am scared beyond words; I have never broken the rules in front of 5,000 people. I have never done something so big without telling Anne first, not to mention something that relates to her/our shared experiences. I look to my left and see the Principal scowl; for a split second I flash to the moment weeks ago when he declared Anne could not attend this graduation, the opposition that prompted my classmates and I to develop this mural as a means of resistance. I think about the fight that ensued, like those that had come before it and those I know will come after, about Anne's right to be included alongside her peers. I smile, reflecting on how many others have joined her over the years in insisting that she is an integral part of this community who deserves to be here, there, and everywhere; if this school were Hogwarts we would all be members Dumbledore's Army, rebelling against the status quo and vying for justice.

I recite my memorized words slowly and with a confidence I did not know I had. I am focused on my task: to announce the surprise plan for a full wall

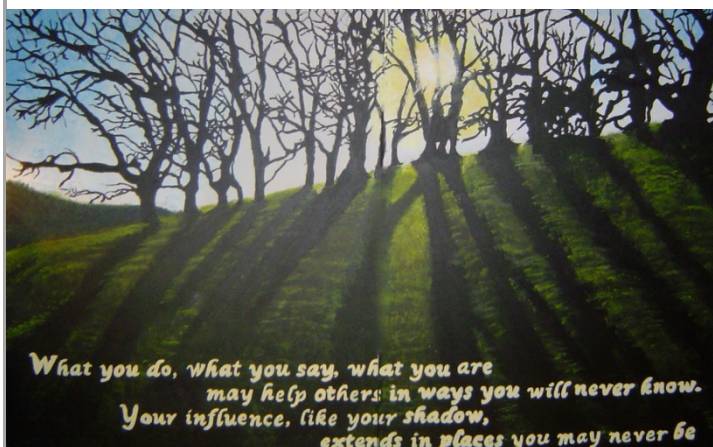
instance, I can just barely make out their respective Teaching Assistants (Ms. Hamden and Ms. Grecco) as they follow behind, far back enough to make vague which blue-robed student they accompany, but close enough to reach out a hand and give a nudge in the back prompting Ralph and/or Martin to continue moving forward. I cannot help but smile in these moments as I watch all of the students behind them stop and start walking in synchrony with Ralph and/or Martin's brief pauses. Later, when they cross the stage in alphabetical succession with their peers to accept their diplomas, both Ralph and Martin do so independently. Their respective turns in the spotlight are as different as their personalities. Martin soaks in the moment, drifting across the stage slowly with his diploma clasped in his hands at his chest, while Ralph moves more quickly in a zig-zag pattern and upon receipt immediately opens his diploma case, examining its contents. Once again, when Ralph and/or Martin hesitate in their movements (which both do), or take circuitous routes as they navigate the line of administrators' outstretched hands, the students behind them pause too. When Ralph and/or Martin seem unsure of which direction to go, the administrators discreetly show them the way with a tap on the shoulder following their respective handshakes. **This** is inclusion.

We cheer loudly until all the students have taken their seats. Leaning into the aisle, my eyes are drawn to the front and center of the arena where at the end of the blue carpet, flanked by folding chairs now filled with tasseled mortarboards, leaning against the stage is a familiar burst of color on an otherwise white canvas. I well with pride and emotion because I had something to do with its creation, but nothing to do with it being here; the potential impact of its presence is beyond my control and imagination.

Once the music and chatter have quieted, the Principal, Mr. Grazioli takes the stage. My mind wanders as he introduces administration and school staff by name and lists the accomplishments of the school's various student clubs, organizations, and athletic teams. In his concluding thoughts, he begins congratulating the students and imparting wisdom for them to hold on to as they leave high school.

Without warning or expectation, I hear the names of

*mural to be painted by students and donated to the high school in Anne's name and honor. I am committed to my/our purpose: to counter the opposition to inclusion of individuals like Anne, whose bodies, minds, and communication methods challenge normative notions of what it looks/sounds/feels like to be a student, an ideal upheld and too often conveyed by those in power throughout our educational journey. I am clear in my/our intent: to co-create and install/instill a visible, lasting reminder for future classes (and their administrations and staff) of what inclusion **can** be, a sentiment made salient in/through the mural's epigraph: "What you do, what you say, what you are may help others in ways you will never know. Your influence, like your shadow, extends in places you may never be."*



the students that I know as my co-inquirers, followed by my name, referenced as co-constructors of the mural leaning against the stage, toward which Mr. Grazioli directs the audience's attention. I listen as he insists, "when you meet students who have a different learning and communication style...one must presume competence. Class of 2015 as you go through life never look down or believe the other person is not capable or able to be like you or better. 'What you do, what you say, what you are may help others in ways you never know. Your influence, like your shadow, extends in places you may never be.'"



These narratives and images represent two important points on the journey around which my inquiry is framed. They describe events that occurred a decade apart, nearly to the day. They both took place in stadiums full of high school students, teachers, friends, and families. They each represent ends and beginnings. In the first narrative, I describe standing on the stage of my high school graduation, a position I co-opted, against the administration's wishes and to their surprise, with the help of a few well connected teachers, school board members, and the support of many of my classmates. In my stolen two minutes, I spoke about a mural that would be

painted and donated by our graduating class to recognize the importance of inclusion, acceptance, and community that our classmate, my best friend Anne, had modeled. In a segregated system, at the insistence and commitment of her mother, she had been the only student with a disability fully included with her peers from Kindergarten to graduation. Sad but true. My act of supported disobedience, like the mural, was meant as a political statement to those who had doubted and resisted the idea that Anne, or others like her, belonged.

Ten years, many ups and downs and in between, a lot of hard work and bit of serendipity later, I found myself again at a graduation. And again, there was a mural that I had a hand in creating, meant as a reminder to future classes about the importance of inclusion, acceptance, and community. And again, the message, like the mural, was political. But this time, I was not the one on the stage. The two-minute speech was not stolen time, but delivered intentionally by a Principal who already believed in the value of its sentiment. No one was arguing about the importance of inclusion, or the rights of students like Martin, Carlee, Ralph, Henry, and Peter (my dissertation co-inquirers) to equal opportunities and meaningful experiences. This time, *I* was the one who was surprised.

These are the bookends of my inquiry. Juxtaposed here, they illustrate the complicated ways that my story and those of my participants, or co-inquirers, interact and intersect. My dissertation chronicles, explores, and shares the moments that bridge, and build, these two experiences.

CHAPTER 1: LITERATURE REVIEW

Introduction

“We’ll take what we can get...” I heard MJ say before she trailed off, filling the two miles that separated our phone lines with a telling sigh that she punctuated with, “...for now.”

I had been sad before about my physical separation from my best friend Anne.¹ I was disappointed that the school district felt that our unique situation—her needs as a student with a disability who did not speak and mine as a student whose high levels of anxiety about school only skyrocketed at the prospect of being separated from the supportive relationship we had built—did not warrant an exception to the zoning boundaries that placed her in one building, and me in another as we transitioned from Elementary to Middle school. After having been together in every class—literally, side by side—since we met in second grade, the quarter mile distance between the two separate middle school buildings felt insurmountable. I had struggled with these changes that meant that I would no longer see her every day, would not hear her familiar sounds, catch the rocking of her shoulders in my periphery, lock with her eyes and share a quiet, calming smile. I had trouble dealing with the new arrangement of talking to MJ, her mother, on the phone after school and hearing Anne chime in only from the background with noises that came through muffled and distant. I was reassured only by our commitment to maintain regular visits, what came to be known as our “Girls’ Days,” after school. But now to hear that in this new school, with new people, without me, Anne was provided only with a standard sized desk—one that barely accommodated the width of her wheelchair—now I was sad and angry. How would she participate? How would she make new friends? How would anyone hear her voice?

I remember when I first noticed that big table set up in my second grade classroom. I probably thought we were doing an art project, some kind of construction papered cut and paste extravaganza yielding a creation that would inevitably decorate (help to hide) my parents’ dilapidated refrigerator. I learned quickly that that table created something much more important. That’s where Anne sat: the perch from where she participated, made friends, was positioned as a member of our school community. From that year on, that table was in every one of my classrooms. MJ sat at it also, to Anne’s right; she was the arranger of the index cards, laminated list of math of operations, color-coded vocab words, multiple choice boards, etc. Once the materials were laid out across the table, MJ would extend her palm to rest beneath Anne’s right elbow, whispering encouragement and repeating questions quietly until Anne’s right hand arched downward towards the table and landed on her choice. Sometimes the heel of her hand would end up slapping at the index card with a thud; we all knew when she had the answer. Other times, especially if the card she wanted to select was situated on the right hand side of the table, she would wind up and stretch her arm across her mom—knocking other materials off the table and onto the floor—until she reached her final destination. In her swift, magician-like manner, MJ would reset and rearrange and they would move on to the next question with the rest of the class. That table—with its hard

¹ Pronounced “Annie”

grey surface and trapezoidal shape—was Anne’s way of showing what she knew. And everybody knew it.

So when the middle and high school administration continually insisted that there wasn’t space for a table like that, did they mean, also, that there wasn’t room for Anne’s kind of communication? And when teachers tried to tell MJ that the curriculum was too complex and unwieldy to be whittled down to index cards and choice boards, did they mean, too, that they felt it was beyond Anne’s intellectual capacity? And without a means to show them otherwise—without that table—weren’t they, then, able to convince themselves of what they thought they already knew? In an era of “education for all,” were they saying that she belonged there only if on their terms, not hers?

I know the end of this story. And I know that that table never came back. Not in middle school. Not in high school. Not even after graduation. I also know that Anne found—insisted on—new ways to participate, on her own. Sometimes they were misread. Other times they were ignored. Many times, they were engaged, followed up on, and appreciated. Always, she worked to make her presence known, demanded membership in those classrooms. But the onus was on her and the people who cared to listen. It was a choice.

And she took what she could get.

This dissertation, as well as my interest and work in general, is closely linked to this story. Having watched and been a part of the (often downward) shifts in access, opportunities, and expectations as Anne moved up from grade level to grade level, our lived experience reflects the reality that the conditions of inclusion become increasingly contingent in the middle and high school years (Lund & Light, 2007; Shapiro-Barnard, 1998). At the same time that most of my peers and I were constructing and sharing our identities through our developing voices in our growing social and academic networks, Anne’s opportunities to do the same were greatly limited by the obstacles and/or obstinacy she faced to her communicating in ways that would have otherwise allowed her to participate. This did not make sense to me then. It does not make sense to me now.

And yet Anne, along with the support of her mother, friends, and a group of committed educators, resisted the opposition she faced to her inclusion. She showed up and participated in

class. She was a member of and helped to shape the school community. It was Anne's ever-evolving journey that helped me to conceptualize education as something that is collaboratively constructed with/for, rather than practices carried out upon, students. So many years later, when I watched a handful of students with communicative experiences similar to Anne's face similar resistance to their inclusion in their home school districts, I paid careful attention. And when those students' experiences converged and led them all to enroll in the same public high school that welcomed, included, and supported their needs and preferences, I followed them.

This perplexity about the varying degrees and conditional nature of inclusion is where my inquiry begins. Armed with my own experiences, stacks of books and articles, and collaborative relationships with the students, their families, and the high school staff, I set out to understand what inclusion looked like, how it was constructed, and how these five students (my co-inquirers) experienced it over the course of three years. Having witnessed these shifts in access as students like Anne and my co-inquirers get older, as well as families' often drastic measures (i.e. moving) to ameliorate such inconsistency, I see prioritizing research about the high school years and experiences of students who communicate in diverse ways as critical to improving the ways that future students like them will live out high school lives. After all, even if communication systems and supports are in place in primary grades, the work of adapting/maintaining those supports for and in transitions to secondary school settings and beyond is equally crucial. Looking closely at the ways that high school students with disabilities who bring an element of communicative diversity to schools (like my five co-inquirers) participate meaningfully in academics, interact socially, develop and convey a sense of self, and demonstrate agency during this pivotal period in their lives is a necessary complement to existing and future studies done with and about the individuals who surround and support them.

Given that this study is a narrative inquiry (see Chapter 2), I frame it not with research questions, but as a research puzzle initiated by the following wonderings (Clandinin, 2013):

- 1) What experiences do high school students with autism who type to communicate deem most important to share about their school lives?
- 2) What are the cultural, institutional and social narratives that shape the experiences and stories of high school students with autism who type to communicate?
- 3) What can the experiences of five high school students with autism who type to communicate teach us about inclusive secondary practices?

To contextualize my own experiences and my inquiry, I looked to the literature on both inclusive education for students who use augmentative and alternative communication (AAC) and disability studies in education (DSE); I put myself in conversation with these two overlapping fields and these two bodies of literature in conversation with each other. In Part I, I lay out the primary topics and trends in the literature on inclusion of students with complex communication needs in high school, while also identifying and responding to the gaps calling for more and different kinds of research in this area. In Part II, I juxtapose this literature on use of augmentative and alternative communication in schools with an introduction to disability studies in education. I explore the key tenets of DSE as a theoretical framework and highlight the ways that such principles are related, and could contribute, to further research and practice around AAC in inclusive high schools. Finally, I argue that the lens of disability studies in education calls attention to the importance and current dearth of the voices² of adolescents who use AAC in the literature on their own experiences.

² I consider “voice” to include any form of representation chosen and utilized by individuals to convey ideas, preferences, identities and experiences. I recognize, however, the danger in relying on a term that has traditionally been connected to one particular mode of communication: speech. It is my hope that readers see my use of this term, and my research, as an intentional and transgressive choice aimed at

Part I

Context around Augmentative and Alternative Communication

What is AAC? Included under the broad category of Augmentative and Alternative Communication (AAC) are all forms of communication other than speech used to convey ideas, thoughts, opinions, needs, wants, etc. Individuals with disabilities with complex communication needs that have limited or no reliable functional speech often use a combination of low and high tech means to convey their messages and intended meanings. Known as “a set of procedures and processes” (ASHA, 2002) rather than an isolated method, AAC systems are multidimensional and fluid across time, contexts, and relationships (Beukelman & Mirenda, 2005; Light, 1997). Despite a communication aid (device) often being the most visible component, individualized AAC systems involve an interplay between four distinct elements:

- 1) Symbol (i.e. line drawings, photographs, letters, words, gestures, signs),
 - 2) Aid (i.e. letter board, whiteboard, speech generating device, computer, tablet)
 - 3) Strategy (learning process: i.e. role playing, software education, mentored training)
 - 4) Technique (the process by which an aid is accessed: i.e. signing, scanning, pointing)
- (Beukelman & Mirenda, 2005).

While recognizing the complexity and breadth of available AAC options—and nodding to the reality that technology is rapidly changing—I focus primarily on literature relating to the use of alpha numeric, rather than picture-based, symbol systems that involve access through Speech Generating Devices (SGDs), also known as Voice Output Communication Aids (VOCAs); this most closely mirrors the communicative experiences of my co-inquirers, who all type to communicate on iPads with a range of physical, communicative and emotional supports.

challenging those conventional assumptions of what constitutes voice. I further and more specifically call forth the complexities around voice in Chapter 2 (Methods).

Although AAC is useful for individuals whose complex communication needs are rooted in or related to a wide spectrum of disabilities, and although the needs associated with each disability experience and communication approach can be considered vastly different, I primarily focus on access to and school use of AAC broadly in an effort to synthesize and draw connections to promising practices and perspectives in literature across disability categories.³ I also touch on autism and facilitated communication, as these are the experiences and communicative vehicles through which my co-inquirers interact and participate.

AAC in the law. Access to and use of AAC systems in school is driven and mediated by the Individuals with Disabilities Education Act (IDEA 2004) which mandates that all students with disabilities receive a “Free and Appropriate Public Education (FAPE)” in the “Least Restrictive Environment (LRE)” with the provision of those services and supports deemed appropriate based on their needs established in an “Individualized Education Plan (IEP)” (20 U.S.C. §1412(a)). Given the LRE requirement that “...To the maximum extent appropriate, children with disabilities... are educated with children who are not disabled” (20 U.S.C. §1412(a)(5)(A)), placement in inclusive general education settings with meaningful access to the academic and social aspects of schooling is considered an identified goal for students with disabilities who use AAC (Kasa-Hendrickson & Kluth, 2005). Studies have shown the effectiveness AAC has had both in maintaining the inclusion of students with disabilities in general education classrooms (Finke, McNaughton, & Drager, 2009; Soto, Muller, Hunt, & Goetz, 2001a; Stoner, Angell, & Bailey, 2010), as well as in requiring the need for unique

³ I am aware that such a decision could potentially flatten or over-simplify my analysis. I understand the complexities, nuances, and vast differences in experiences of individuals with different disabilities and in no way mean to suggest that those differences are not valuable or relevant. However, I am looking to broaden my lens about this phenomenon with an understanding that compartmentalizing based on disability identity also can be a disadvantageous and limiting approach to exploring and engaging with literature (and people).

instructional approaches to support incorporating such communication methods (Calculator & Black, 2009; Myers, 2007; Soto, Muller, Hunt, & Goetz, 2001b).

The right of students with disabilities to be educated alongside peers without disabilities is a foundation established in IDEA (2004), reinforced by the requirement that aids and services for students' communication and support be identified, explored, provided, and cultivated. Educational teams are required to consider both "the communication needs of the child...[including] opportunities for direct communications with peers and professional personnel in the child's language and communication mode" and "whether the child needs assistive technology devices and services" (34 C.F.R. § 300.324 (a)(2)(iv, v)) during IEP development. The association of "communication needs" with "assistive technology devices and services" is critical to educational experiences of students who do not communicate effectively through speech and for implementation of the law, since it requires exploration of potential supports for those students (Ashby & Kasa, 2013).

Under IDEA (2004), an Assistive Technology Device is considered "any item, piece of equipment, or product system [...] that is used to increase, maintain, or improve functional capabilities of a child with a disability" (20 USC 1401§(1)). An Assistive Technology Service is defined as, "any service that directly assists a child with a disability in the selection, acquisition, or use of an assistive technology device" (20 USC 1401§(2)). AAC systems (and the evaluation, training, and maintenance services that support them) fall within the bounds of these definitions. By requiring that needs, devices, and services be taken into consideration as part of IEP development and implementation, the law sets the stage for a dynamic and individualized approach to access, education, opportunities, and support for communicative vehicles most appropriate for a student. Perhaps most significant is the potential for "Assistive Technology

Services” to include ongoing training for *both* the student and his/her team members to continually develop skills, strategies and age appropriate access methods for using AAC systems. The provision of such training can contribute to the collaborative nature of the inclusive educational process.

Although the framework constructed by law suggests promising opportunities to develop more equitable educational experiences for students with disabilities, it can be—and often is—interpreted and enacted in highly varied (Agran, Alper & Wehmeyer, 2002; Kasa-Hendrickson & Kluth, 2005; Ryndak et al., 2014; Skrtic, 1991) and even oppressive (Beratan, 2006) ways. For example, the LRE requirement has often been utilized to justify segregation of students with disabilities (Ferri & Connor, 2005; Ryndak et al., 2014; Taylor, 2004). Even when included in school, levels of participation of students with disabilities are often disparate and contingent (Simeonsson et al., 2001). In light of this malleability and varied application across educational levels, there is often a divergence between elementary and secondary settings in the ways that students with disabilities are included with their peers and receive supports in general education classrooms (Downing, 2005; Shapiro-Barnard, 1998; Sturm & Koppenhaver, 2000; Udvari-Solner & Thousand, 1996). The structure of high school—with fleeting social opportunities, multiple classes, quick paced curriculum delivery, and standardized tests—poses challenges for many students and the educational personnel that support them, resulting in inconsistent service delivery (Ashby & Cosier, 2012; Belenardo 2001; Mastropieri & Scruggs, 2001; Smith, 2005; Thousand, Rosenberg, Bishop & Villa, 1997). Since individuals with complex communication needs are often presumed to require the most multifaceted supports, this group of students is particularly at risk of being seen as “difficult” to include in secondary general education settings (Downing, 2005; Kent-Walsh & Light, 2003; Light & McNaughton, 2012).

As a result, examples of meaningful academic inclusion of high school students with disabilities who do not speak, but use AAC, are uncommon in both research and practice (Bennett, 2011; Mastropieri & Scruggs, 2001). This is not only a product of the material difficulties of deciphering different kinds of communication, accommodating needs, adapting curriculum, responding to “behavior,” and cultivating social opportunities across such vastly visible (and audible) differences, but is also constructed by cultural practices for categorizing and controlling bodies (Foucault, 1977; 1980). Underlying these challenges is a long-standing, often unquestioned association of not speaking with not thinking (Ashby & Causton-Theoharis, 2009; Biklen & Duchan, 1994; Broderick & Kasa-Hendrickson, 2006). Thus, an absence of reliable (socially translatable) communication has traditionally led to presumptions of incompetence and resulted in inequitable educational opportunities (Biklen 2005; Biklen & Kliever, 2006).

So when students do gain access to educational opportunities at the secondary level—a space where stakes are high and proving competence is a priority—their experiences are impacted by the novelty of their presence. In many ways, these students must write their own stories; paving the path for those like them who will hopefully come after they have gone. In other ways, they are resisting the history that continues to keep people like them out—out of school, jobs, and relationships. Often, they are reliant upon the decisions made about them, as well as opportunities provided for what, how, and when they access elements of high school life that many students take for granted. And when these students are included in the conversations, there are still forces at play dictating the value that is placed on their presence. I am interested in these students’ experiences; I want to know how they make sense of, feel about, make meaning of, and construct the day-to-day lives they lead in the halls and with the personnel of schools to

which they, by nature of their unique forms of communication and expectations of a meaningful education, are new and different.

State of the Research on AAC in High School

The body of literature on the educational trajectories of students who use AAC, though primarily centered on the elementary school level, has contributed to an understanding of the fundamental elements of inclusive environments for those students' access to academics. Together, these studies lay out foundational characteristics critical to the inclusion of students who use AAC in a broad sense, including: collaboration, training, support relationships, peer connections, and expectations. While interrelated, I explore each element separately and in depth to make clear how I have constructed my own understanding of what constitutes the inclusion I set out to observe in my co-inquirers' high school experiences.

Collaboration. Collaboration, or collaborative teaming, is discussed with perhaps the greatest consistency across studies as being a pivotal element in providing students who use AAC to access academics (Downing, 2005; Giangreco, 2000; Hunt, Soto, Maier, Muller, & Goetz, 2002; Soto, et al., 2001b). This is consonant with the literature on inclusion more broadly,⁴ evidenced by the fact that much of the research on inclusive practice establishes that its "...success in large part relies on collaboration among staff members with parents and others, and that failures can typically be traced to shortcomings in the collaborative dimension of the services to students" (Friend, 2000, p. 130). However, the unique educational support needs of AAC users suggest that collaboration in this context takes on a particular meaning and form (Hunt et al., 2002). In fact, the role of collaboration across "stakeholders who share a common

⁴ i.e. Friend, 2000; Giangreco & Doyle, 2000; Villa, R.A., Thousand, J. S., Nevin, A. I., & Malgeri, 1996

vision and overall mission” is central to Calculator and Black’s (2009) inventory of best practices for service provision and support of AAC in inclusive settings (p. 330).

As a result, traditional notions of who should be present on educational teams supporting inclusion of students who use AAC has grown to include family members (Bacon & Causton, 2013; Myers, 2007; Rackensperger, 2012; Thousand & Villa, 2000), speech and language pathologists (Giangreco, 2000; Soto et al., 2001b), classmates/friends (Downing, 2005) and students themselves (Ashby & Kasa, 2013; Bausch & Ault, 2008; Light, 1997), in addition to teachers and teaching assistants (Giangreco, Broer & Edelman, 1999; Soto et al., 2001a). A team approach to collaboration that inherently includes a diversity of perspectives and “equal footing” of all members is vital to maintaining constructive decision-making (Soto et al., 2001b, p. 71). In other words, teams must value contributions from all constituents rather than playing by often arbitrary rules of hierarchy and power. Collaboration of this kind includes open and ongoing communication, problem solving, clearly defined roles, and flexibility (Downing, 2005; Giangreco, 2000; Soto et al., 2001b; Utley & Rapport, 2002).

Communication across team members is also essential and characterized by commitment to consistency across environments (Kent-Walsh & Light, 2003). Establishing regular team meetings is an effective strategy for maintaining the open communication necessary for collaboration, despite challenges of finding common planning time (Friend, 2000; Hunt et al., 2002; Sonnenmeier, McSheehan & Jorgensen, 2005; Soto et al., 2001a). In addition to preemptive planning afforded by consistent contact, extempore problem solving—particularly around technology (Stoner, Angell & Bailey, 2010), academic access (Jorgensen, McSheehan & Sonnenmeier, 2007), behavior (Kasa-Hendrickson, 2005) and peer relationships (Rossetti, 2011)—is a critical element of collaborating to support inclusion. As Stoner, Angell and Bailey

(2010) note, “student success depends on the team’s ability to communicate effectively and act quickly to resolve implementation challenges” (p. 123). The explicit connection here between team responses to issues that arise and student “success” suggests the influence that team members hold to make or break educational access or participation. As a result, a “built in accountability system” is an additional component of effective collaboration (Hunt et al. 2002).

Despite the extant literature supporting the importance of collaboration, the realities of scheduling and additional constituent responsibilities often make it difficult to maintain the aforementioned recommended level of consistent team contact (Downing, 2005; Sonnenmeir, McSheehan, & Jorgensen, 2005). However, example cases such as Stoner, Angell, & Bailey’s (2010) study of Joey—a high school student with Cerebral Palsy, who was introduced to a Dynawrite⁵ device during sophomore year—serve as reminders that prioritizing team collaboration is a worthwhile and critical venture if students who use AAC are to receive the most meaningful supports for academic access. Ultimately, Joey’s is a case where things fell apart: “this study emphasizes the necessity of collaborative teaming even when an AAC user demonstrates technological proficiency. Consistent collaborative teaming was not present in Joey’s case, and AAC was not fully and effectively implemented” (p. 133). As the researchers note, there was not a system of accountability in place, nor was there a perceived need for such in light of Joey’s demonstrated ability to navigate his device. Joey’s experience points to the harsh reality that “merely saying the word [collaboration] is not necessarily the same as carrying out the action” (Friend, 2000, p. 130). These findings also suggest the danger in viewing collaboration as a discretionary, rather than an ongoing and evolving system of support.

⁵ A speech generating device with a full QWERTY keyboard, visual screen and audio output.

Training. Appropriate training of all stakeholders is also critical to the collaborative process and inclusion of students who use AAC (Costigan & Light, 2010; Kent-Walsh & Light, 2003; Lund & Light, 2007; McNaughton & Bryen, 2007; Soto et al., 2001a; Stoner, Angell & Bailey, 2010) since too often students with complex communication needs end up in general education classrooms with teachers and staff who are not adequately prepared to support their unique ways of learning, participating, and socially engaging (Sonnenmeir, McSheehan, & Jorgensen, 2005). Given the essential nature of communication to education (Balandin & Duchan, 2007; Beukelman & Mirenda, 2005; Light, 1997), training around supporting students to use AAC in school must be ongoing and fluid, with priority placed on fostering and maintaining students' participation and interactions (Ashby & Kasa, 2013; Downing, 2005). This includes, but is not limited to, a working knowledge of how to use and problem solve around technology issues (Costigan & Light, 2010; Kent-Walsh & Light, 2003; Light & McNaughton, 2012a; Lund & Light, 2007; Rackensperger, Krezman, McNaughton, Williams, & D'Silva, 2005). It is also often the case that when students do receive access to technology for communication, their use of it is impeded by a lack of training or support from educational staff to do so (McNaughton, Bryen, Blackson, Williams, & Kennedy, 2012).

It is also true that while important, technology itself is just one element of a system of support; thus training around it must be part of a greater purpose (Lund & Light, 2007). A narrow focus on training to stay on top of rapidly developing technology "...will be of little value unless the barriers to participation in the wider community and the strategies that are effective in supporting increased participation are better understood" (Smith, 2005, p. 77). It is therefore important that team members fuse training on AAC with an understanding of the complex and multifaceted ways that a student prefers to produce, and is most effective in,

communication (Williams, Krezman, & McNaughton, 2008). Centering the personal details, preferences, and personality of the AAC user him/herself can help keep the individual, rather than the device, at the center of the training process (McNaughton & Bryen, 2007).

Understanding the AAC user and his/her daily experiences as part of training can help identify the ways that his/her individual disabilities create unique needs and circumstances to navigate.

In addition to training staff, training for the student who uses AAC is also critical to the collaboration and inclusion processes; proficiency with his/her device and establishment of reliable choice making can facilitate the communication process and position that student as expert on his/her own support system (Broer, Doyle, & Giangreco, 2005; Light, 1997; Marcus & Shevin, 1997; Rackensperger et al., 2005). Putting AAC users in leadership roles and acknowledging that with appropriate training they can be the best resources on how to support their own communication, recognizes their competence and agency in constructing the support they receive (Rossetti, Ashby, Arndt, Chadwick, & Kasahara, 2008). As Williams, Krezman, & McNaughton (2008) point out, such involvement must run deeper than surface level: “Beyond the level of decision-making about their own personal AAC systems, individuals who use AAC also have a right to be present, receive clear information, and provide input regarding best practices in training for AAC professionals and the research and design of new systems” (p. 202). This model has implications for a paradigm shift in the way that students with complex communication needs are treated and the opportunities they are presented within schools.

Support relationships. The role played by those who directly support students’ communication is particularly complex and deserves focused attention (Bennett, 2011; Douglas, 2012; Kent-Walsh & Light, 2003; Robledo & Donnellan, 2008; Sonnenmeir, McSheehan, & Jorgensen, 2005; Woodfield, Jung, & Ashby, 2015). Paraprofessionals’ (also often referred to as

educational assistants, teaching assistants and/or paraeducators) proficiency as effective communication partners who can navigate AAC devices and implement best practices is a key component of inclusion, since these support persons are in place to aid the communication, participation, academic access, and social access of the students with whom they work (Binger, Kent-Walsh, Ewing, & Taylor, 2010; Bingham, Spooner, & Browder, 2007; Calculator & Black, 2009; Douglas, 2012; Kent-Walsh & McNaughton, 2005; Light, Dattlio, English, Gutierrez, & Hartz, 1992; Soto et al., 2001a). Yet there remains a scarcity of comprehensive approaches to training them how to enact the kinds of multifaceted supports necessary to facilitate students' full and meaningful participation. While there have been attempts to focus on developing isolated skills and strategies for communicative support and outcomes—i.e. promoting communicative interactions (Light, et al., 1992) and device proficiency (Bingham, Spooner, & Browder, 2007)—a training model with a more holistic approach has not been widely used or researched (Binger et al., 2010; Kent-Walsh & McNaughton, 2005). This inconsistency in training approaches across the nation, states and even within districts, is complicated by the high turnover rate of those who take on this kind of direct support work in schools (Ghere & York-Barr, 2007).

Kent-Walsh and McNaughton's (2005) use of strategy instruction to develop an eight-stage communication partner training model represents one of the first, and few, generalized approaches to one-on-one support training that attempts to navigate the complexities and responsibilities associated with direct communicative support, specifically in schools. This model was further developed into the ImPAACT (Improving Partner Applications of Augmentative Communication Techniques) Program, a form of which has proven effective in two studies focused on *parents* as communication partners (Binger, Kent-Walsh, Berens, Del Campo, & Rivera, 2008; Kent-Walsh, Binger, & Hasham, 2010) and one study with educational

assistants working with AAC users in early elementary school (Binger, Kent-Walsh, Ewing, & Taylor, 2010). Though more studies are needed, particularly at different grade levels, it appears that the holistic approach to training paraeducators has promising implications for students' communicative outcomes through supported use of AAC.

It remains true, however, that the experiences of paraprofessionals who support communication are not well accounted for in the literature in the context of communication support (Kent-Walsh & Light, 2003), nor are students' perspectives of them (Broer, Doyle & Giangreco, 2005; Tews & Lupart, 2008). There are also varying stances on the type and duration of support relationships that teaching assistants and students develop (Bennett, 2011). Many argue for the importance of training and utilizing multiple communication partners (Light, 1996; Smith 2005; Stoner, Angell, & Bailey, 2010), while others acknowledge the benefits of support provided by a teaching assistant that remained consistent across several years (Kent-Walsh & Light, 2003). Though ideally a support system would envelop the critical elements of both these scenarios, it appears that the development of effective communication partnerships is determined by the support *relationship(s)* itself (Marcus & Shevin, 1997), a reality that becomes increasingly complex for those using AAC during the adolescent years (Smith, 2005).

The primacy of personal connection to good support, specifically for students with autism who use AAC, is aptly captured in Robledo and Donnellan's (2008) assertion that, "effective bonds center on mutual feelings of liking, caring, and trust. Techniques and strategies alone are not sufficient. Instead, greater focus should be on building and maintaining relationships" (p. 307). Similarly, Kliewer and Biklen (2001) discuss the notion of "local understanding" as a critical element in supporting and engaging with individuals whose complex communication needs and disabilities experiences have yielded, or threaten to result in,

presumptions of incompetence. They note local understanding is a product of “caring, interactive and interdependent relationships in which both participants infer valued capacities and competence on the other” (p. 4). While much of their study focuses on the ways that familial relationships foster local understanding, such closeness is also important—albeit conceptualized and approached differently—in the context of direct communication support in school. As the authors point out, these close relationships “allow those in positions of relative authority or power to see in idiosyncratic behavior demonstrations of understanding that are otherwise dismissed or disregarded by more distant observers” (Kliewer & Biklen, 2001, p. 4). If paraprofessionals are to facilitate students’ participation, interaction, and membership in school communities, a local understanding of those students’ unique ways of interacting with/in their environments can deepen their ability to support them.

Despite the possibilities inherent in these communication support relationships, there are notable barriers to creating (and subsequently created by) them in school settings. These barriers include the implication that such close proximity of an adult has for the development of student identity (Giangreco, Edelman, Luiselli, & MacFarland, 1997), peer relationships (Giangreco, Yuan, McKenzie, Cameron, & Fialka, 2005; Malmgren & Causton-Theoharis, 2006), creativity (Causton-Theoharis & Burdick, 2008) and academic access (Causton-Theoharis, 2009). Additionally, paraprofessional proximity can negatively influence general education teachers’ perceived accountability for students with disabilities; when paraprofessionals are consistently close to students, teachers tend to be less engaged and demonstrate less responsibility for those students (Giangreco, Broer, & Edelman, 2001; Giangreco, Edelman, Luiselli, & MacFarland, 1997; Marks, Shrader, & Levine, 1999; Tews & Lupart, 2008). Related to (and potentially a result of) this imbalance of responsibility, paraprofessionals often provide a significant amount

of direct instruction, a task for which they are neither trained nor theoretically expected to perform (Causton-Theoharis, Giangreco, Doyle, & Vadasy, 2007; Giangreco, Broer, & Edelman, 2001; Patterson, 2006). As a result, paraprofessionals are often charged with the task of stepping back and fading support as much as possible to foster independence, peer interactions, and shared accountability for academic access (Tashie, Shapiro-Barnard, & Rossetti, 2006; Causton-Theoharis & Malgrem, 2005a).

Yet the relationship between student and paraprofessional becomes more complicated when complex communication needs demand that support be present in order for the student to participate in all aspects of school. The desire for faded support does not diminish. Instead, the reality of more consistent, close proximity can be a key element—even if also a barrier—to student engagement and participation (Bennett, 2011; Woodfield, Jung, & Ashby, 2015). As such, communication support relationships in school must involve ongoing negotiation, a collaborative act that necessitates a respectful and cooperative relationship. The few studies that have solicited student perspectives on the meaning and elements of good support relationships (or lack thereof) can serve as important resources in constructing these collaborative support relationships that address issues of proximity with productive and empowering outcomes (Ashby & Causton-Theoharis, 2012; Broer, Doyle, & Giangreco, 2005; Robledo & Donnellan, 2008; Tews & Lupart, 2008; Woodfield, Jung, & Ashby, 2015). These studies start a conversation about navigating the incongruities faced by individuals for whom communication support is the primary kind of support desired/required for self-expression and participation. This becomes increasingly important as students enter into the social landscape of high school.

Peer interaction and relationships. In addition to close and constructive support relationships, the development of peer connections is critical to consider in the experiences of

students who use AAC, particularly in high schools. While the need to belong is a natural phenomenon (Kunc, 1992), adolescence is a particular time marked by the desire to “fit in” (Broer, Doyle, & Giangreco, 2005; Martin, Jorgensen, & Klein, 1998; Smith, 2005; Wickenden, 2009; Williams & Downing, 1998). Though the where, why, what of the “fit” is contextual and individualized, the role of peer acceptance and connection is paramount. Yet, peer relationships are built on interaction, which is difficult to perform across communication barriers without proper support and mutual respect. As Smith (2005) describes in high school, conversations:

...serve as the glue that holds together cliques and groups. Conversations occur with no advance notice, yet require sophisticated planning, timing and self-regulation in their execution. Successful navigation of conversations requires skills in both verbal and nonverbal interactive behaviors including complex eye gaze behaviors, nodding, and body movements. (p. 71)

These characteristics of social interactions in high school illustrate the potential barriers to peer relationships for students who use AAC. What is at stake in these limited opportunities for social interaction and opportunities to develop peer relationships is substantial, resulting in social isolation, loneliness, lack of confidence, and an absence of peer support networks (Jorgensen, 2006; Rossetti, & Goessling, 2010; Smith, 2005).

Given the connection between communication and social interaction, it is not surprising (though nonetheless discouraging) that one of the areas noted to be of greatest difficulty related to the educational inclusion of students (particularly those with autism) who use AAC is the development of peer relationships (Broer, Doyle & Giangreco, 2005; McNaughton et al., 2012; Smith, 2005; Strully & Strully, 1985; Wickenden, 2009). Students who use AAC have consistently referred to this as an element of their experiences that is both wanting and

challenging (Ashby & Causton-Theoharis, 2012; Broderick & Kasa-Hendrickson, 2006; Broer, Doyle, & Giangreco, 2005; Rossetti, 2011). As will be evident in Act III, my co-inquirers' experiences were no different. As Broderick and Kasa-Hendrickson (2006) reported about the experiences of individuals with autism who type to communicate, "this mode of expression does not lend itself easily to participating in informal social networks with peers in ways that might support the construction of social identities as a desirable friend" (p. 181). Some of these barriers are rooted in the time required to produce typed/pointed messages versus spoken conversation (Broderick & Kasa-Hendrickson, 2006; McNaughton et al., 2012; Rossetti, 2011; Smith, 2005). Jamie Burke (an individual with autism who types to communicate and reads aloud his typed text) captures the reality of this quandary:

Kids are mostly good at talking but listening is not an asset they use. If I am able to talk, it still is not very good, as time is fleeting and so are they...[T]yping is again so much slower than quick use of an athletic tongue which spits out the words without so much as a jog around the jaw. By the time I can formulate a verbal answer, they have left to move onto another class. This leaves me with my response and no one to respond to. (Biklen & Burke, 2006, p. 169)

As Jamie suggests, the rigor, schedule, and pace of high school affords few peer interaction opportunities that are conducive to AAC users' needs such as time, structure, and support for initiation (Carter, Siseo, Melekoglu, & Kurkowski, 2007; Rossetti, 2011). This communicative gap is compounded by the fact that fewer opportunities to participate in classrooms often preclude students who use AAC from being perceived as integral, equal parts of classroom communities, memberships from which friendships typically emerge (Williams & Downing, 1998). It is not surprising, then, that peer interactions and friendships between students with and

without disabilities are more prevalent in elementary than in high school (Carter, Hughes, Guth, & Copeland, 2005; Lund & Light, 2007; Rossetti & Goessling, 2010; Strully & Strully, 1985).

The complicated logistical elements of communicating in diverse ways are compounded by a peers' general unfamiliarity with interacting with students who use AAC; this often results in either avoidance or (mis)direction of conversation toward a paraprofessional (Downing, 2005; Kent-Walsh & Light, 2003; Martin, Jorgensen, & Klein, 1998). In many cases, interactions between students tend to take the form of either "obligatory" or charitable "helping" relationships (Kent-Walsh & Light, 2003; Kishi & Meyer, 1994; Meyer et al., 1998), which can create or evolve into problematic power dynamics between peers (Van der Klift & Kunc, 1994). In fact, Hughes, Carter, Hughes, Bradford, and Copeland (2002) found that when high school students were assigned instructional roles as partners with a peer with a disability, these partnerships tended to center solely on assigned activities and students with disabilities demonstrated less initiation. On the other hand, when peers with and without disabilities were assigned into social partnerships, interactions were conversational, frequent, higher quality, covered a wider range of topics, and initiated more often by the students with disabilities. These results highlight the likelihood that social opportunities between peers with and without disabilities have implications that transcend those observed during the interactions themselves. They also suggest that there is a delicate balance to foster between the complexities of peer supports and supportive friendships, or what Bogdan and Taylor (1989) characterized as "accepting relationships" [in which]...the disability, does not bring stigma or discredit. The humanness of the person with a disability is maintained. The difference is not denied, but neither does it bring disgrace" (p. 137).

Given the challenges associated with interactions and friendships between peers, it is in

this context that adults—particularly paraprofessionals—must make use of and carefully navigate their positions (Causton-Theoharis, 2009; Causton-Theoharis & Malgrem, 2005b; Giangreco et al., 1997; Martin, Jorgensen, & Klein, 1998; Tews & Lupart, 2008). In fact, writing specifically about peer relationships for students with autism and other developmental disabilities, Rossetti and Goessling (2010) note that many high school students without disabilities look to “paraeducators as models for how to interact” (p. 69); this suggests that adults can play important roles in modeling and facilitating appropriate interactions between peers across varied communication systems and lived experiences. They could also serve to hinder these relationships. The key differences between these two outcomes include: intentionality, cognizance of position, subtlety in facilitating interactions, and efforts to step back at opportune times (Ashby & Kasa, 2013; Causton-Theoharis & Malgrem, 2005a; Harmon, Kasa-Hendrickson, & Neal, 2009; Rossetti & Goessling, 2010; Rossetti, 2012). As Downing (2005) notes, “peers, whether tutors or classmates, appear to need some training in recognizing unconventional means of communication and then responding in the most facilitative manner” (p.143), a role that adults can also play while fading their own supports.

Peer support. Students without disabilities will not *always* need look to a model for interacting with their peers with disabilities, but modeling can be a way of opening the communicative doorway for such interactions to occur and evolve more naturally, particularly at the secondary level. Rossetti’s (2011) description of the following interaction between high school friends Megan (does not identify as disabled) and Shaffer (a young adult with autism who types to communicate and reads aloud what he types) captures this possibility:

One day Shaffer and Megan walked down the same hall together. As they neared the stairwell Shaffer began to talk to himself and wiggle his fingers in front of his chest,

flapping his hands a bit as he did so. Megan placed her right hand on Shaffer's left shoulder. He looked at her, seeming to snap out of another thought pattern, and they continued walking down the stairs... Megan explained that she knew Shaffer did not mean to do that and she did not want the other students staring at him. Shaffer had asked for and appreciated this support for that reason. Megan learned to enact the physical prompt from watching Mrs. Nelson [paraeducator/communication facilitator]. (p. 30)

Here, not only does Megan acknowledge the importance of learning from the paraprofessional's actions as a model, but it is also clear that Shaffer's voice has been present in discussions about the kinds of supports that Megan, as a friend, could provide. In enacting support here, Megan's regard for Shaffer and knowledge of his needs, which stem from watching his paraeducator and discussing support with him, positions her as a model for her peers. Rossetti further notes that such supports—"friendship work"—become "second nature...so that all of the supports mel[d] together with the social interactions to become part of the fabric of these friendships" (2011, p. 31). The careful development of supportive relationships, grounded in a revised understanding of what friendship means and entails (Traustidottir, 2000), is a starting point for fostering ongoing relationships (Carter, Siseo, Melekoglu, & Kurkowski, 2007; Martin, Jorgensen, & Klien, 1998).

The above example stands out as a model of how adults intentionally position themselves to facilitate and support relationship building between students with and without disabilities. It captures the complexities and possibilities inherent in re-crafting the role of adults and peers that mirrors both my own experiences as Anne's friend, as well as those that I witnessed during observations in my co-inquirers' classrooms throughout this inquiry. When peers without disabilities are encouraged to conceptualize "support" as a natural and critical element of friendships with their classmates with disabilities, as opposed to being just the things done by

adults during class-time, opportunities are more fertile for meaningful relationships to evolve. Thus when adults can model that support is grounded in relationships it becomes less intimidating; friendly explorations into supported social engagement become part of and contributing to these developing friendships.

High expectations. Research has established relationship between the effective inclusion of students who use AAC and the social and academic expectations placed upon (Broderick & Kasa-Hendrickson, 2001; Kent-Walsh & Light, 2003; Lund & Light, 2007; Sonnenmeir, McSheehan, & Jorgensen, 2005). In fact, “teacher expectations about students’ ability to learn—communicated in both explicit and subtle ways—can be more influential on learning outcomes than the students’ inherent abilities or the teachers’ instructional methods” (Jorgensen, McSheehan, & Sonnenmeir, 2007, p. 249). Although, based on the aforementioned importance of collaboration, I argue that expectations placed upon students by *all* team members (peers included) contribute to shaping students’ experiences. This can be seen through affirmative examples in which educational personnel do, or learn to, approach students who use AAC as capable and contributory members of classroom environments.⁶

Kasa-Hendrickson’s (2005) qualitative study analyzes the ways that four teachers approach the inclusion of nonverbal students with autism in ways that “resist interpreting [them as] mentally retarded and seek to form a new understanding of ability” (p. 55) by presuming competence (Biklen, 2005; Biklen & Burke, 2006). By identifying the strategies through which teachers re-conceptualize, navigate, and maintain expectations that situate their students as competent, contributory members of the classroom, Kasa-Hendrickson shows the connections between optimistic conceptions of student ability, opportunities for participation, and academic

⁶ e.g. Broderick & Kasa-Hendrickson, 2001; Kasa-Hendrickson, 2005; Kasa-Hendrickson & Kluth, 2005; Sonnenmeir, McSheehan, & Jorgensen, 2005

outcomes. Teacher participants in Kasa-Hendrickson's study did identify challenges in setting and maintaining expectations of students that pushed back against the prevailing assumptions of their inability to meet those expectations, particularly when it came to instances of difficult behavior. However, the alternative set of expectations proved a tool in navigating these challenges, since "the teachers understood that difficulty in performance in one area did not mean that students were incompetent or incapable in many other ways. In other words, ability and performance were seen as dynamic and contextual" (p. 66). Kasa-Hendrickson's study underscores the possibilities that emerge from believing in students' abilities, while confronting prevailing (mis)conceptions of those abilities despite the (individually or culturally constructed) evidence against them. This study also illuminates individuals' power to resist those presumptions that threaten to categorically exclude, which parallels the experiences and work of my co-inquirers and the school team that supported them (see Acts I-III).

Where Kasa-Hendrickson examines teachers whose pre-existing commitment to constructing competence of students with complex communication needs in inclusive settings set them apart, Jorgenson, McSheehan, and Sonnenmeir (2007) reveal the possibility for shifting attitudes of teachers who did not originally have commitments to presuming competence. Through their implementation of the "Beyond Access Model" with educational teams serving five elementary school students with Intellectual and Developmental Disability labels who use AAC, the researchers identified increased evidence of presumed competence in the construction of IEPs as well as growth in the amount of time students spent in general education classrooms post-intervention. This study remains one of the only attempts in the literature to operationalize and measure the degree to which the nuances of presuming competence can be taught, learned, and enacted in meaningful ways.

Studies that highlight an *absence* of high expectations and/or presumed competence in educational settings also evidence the connection between high expectations and increased opportunities, as well as the negative consequences associated with setting the bar too low (Ashby, 2010; Kent-Walsh & Light, 2003). Kent-Walsh and Light (2003), for instance, reveal the danger in teacher participants' expressed uncertainty around the "appropriateness" of including students who use AAC at secondary levels, warning that their participants' comments must be "weighed carefully" against the importance of high expectations established in the research. They also note that individuals who use AAC assert that "high expectations are often not put in place in special education settings" (Kent-Walsh & Light, 2003, p. 118), indicating that the alternatives to high expectations in school often translate not only into low expectations, but also segregation. Ashby (2010) illustrates the dangers of privileging normative performance over more meaningful academic engagement for middle school students with intellectual disability and autism labels that manifest in complex communication needs. She notes that focusing on speech, copying work, and/or "product over process" (pp. 354) serve not only to perpetuate low expectations for students with disabilities, but also feed a societal preference for perceived normalcy, a construct further addressed in Part II.

Presuming competence: What it is and where it came from. Underlying the discussion around expectations of students who use AAC is a connection to the prevailing association of an inability to speak with an inability to think (Ashby, 2011; Biklen & Burke, 2006; Biklen & Duchan, 1994; Broderick & Kasa-Hendrickson, 2006; Goode, 1994; Kliever, Biklen & Kasa-Hendrickson, 2006; Mackay, 2003). Cultural constructions of what intelligence looks and sounds like have contributed to the tendency for those who do not measure up to be pushed to the margins. In educational contexts, this has resulted in students' segregated placements with low

expectations for academic achievement. Segregation further serves as a justification for a continued lack of educational opportunities (Donnellan, 1984; Jorgenson, 2005; Kliever, Biklen, & Kasa-Hendrickson, 2006; Mirenda, 2003; Shapiro-Barnard, 1998). Though scholars have worked to highlight inaccuracy of assumptions about individuals' competence based on their communication and provided positive examples of the impacts of presuming competence (under a variety of labels),⁷ a propensity for individuals' intelligence to be judged through and because of the ways that they communicate persists. This tendency to equate communicative competence with intellectual ability is particularly true of communication needs associated with disability labels grounded in measures of intelligence (or perceived lack thereof) such as autism or other intellectual and developmental disabilities. It is not surprising then that 75% of people with autism were historically assumed to also have intellectual disabilities (Carpentieri & Morgan, 1996; Jacobson, Mulik, & Schwartz, 1995; Rapin, 1997; Volkmar & Cohen, 1985). The cyclic relationship between communication barriers, presumptions of incompetence, low expectations, and inequitable educational opportunities is not just persistent, it can be life-altering for those with disabilities who have difficulties with performance, initiation, and communicate in diverse ways (Biklen, 1990; Biklen & Burke, 2006; Donnellan, 1984; Goode, 1994; Kliever, 1998; Kliever, Biklen, & Kasa-Hendrickson, 2006).

To resist the educational consequences of presumed incompetence, Donnellan (1984) developed the "criterion of the least dangerous assumption...[which] holds that in the absence of conclusive data, educational decisions ought to be based on assumptions which, if incorrect, will have the least dangerous effect on the student" (p. 142). Later scholars have taken up Donnellan's (1984) criterion as a socially just lens for approaching the education and support of

⁷ e.g. "presumption of competence" (Biklen, 2005; Biklen & Duchan, 1994; Biklen, & Kliever, 2006; Kliever, 1998); "a concept of intelligence [grounded in] human dimensions" (Bogdan & Taylor, 1976); "Social construction of humanness" (Bogdan & Taylor, 1989); "mindedness" (Linneman, 2001)

students with disabilities that manifest in complex communication needs, positioning the act of presuming competence *as* the least dangerous assumption in educational contexts (Jorgensen, 2005; Jorgensen, McSheehan, & Sonnenmeir, 2007; Shapiro-Barnard, 1998). Others, however, take this a step further by contending that presuming competence is not enough; opportunities to demonstrate competence must also be intentionally constructed (Ashby & Causton-Theoharis, 2012; Ashby & Kasa, 2013). As Ashby and Kasa (2013) insist, “School personnel need to actively construct competence and create contexts wherein students who do not speak can engage meaningfully in instruction, demonstrate their understanding, and make that understanding available to others” (p.147). Positioned here as deliberate actions, efforts to presume and construct student competence are inextricably rooted in and the result of maintaining high expectations for student performance and participation in school.

Competence and facilitated communication. Perhaps nowhere else has the significance of and discourse around presuming competence been referenced more consistently than in the writing of and literature about those who use facilitated communication (FC). A form of AAC, FC⁸ is a method of accessing a communication device that involves a dynamic combination of physical, emotional, and communicative support provided to an individual (FC user, or typer) by a communication support person (facilitator) (Biklen, 1993; Crossley, 1994; Institute on Communication and Inclusion, 2000). FC is the communication method used by the five participant co-inquirers in my inquiry. The technique is considered fluid and progressive, with the goal of increased independence during the training process (Institute on Communication and Inclusion, 2000). Through use of this method, some individuals have been able to achieve increased levels of independence and exert agency over their lives (Rossetti et al., 2008; Rubin et

⁸ Also referred to as facilitated communication training (FCT) or supported typing

al., 2001). Some individuals can now type without any physical support from a facilitator (Ashby et al. 2015; Rubin et al. 2001). Some have developed the ability to read their typed text and/or engage in short spoken conversations (Broderick & Kasa-Hendrickson, 2001, Kasa-Hendrickson, Broderick, & Hansen, 2009). Others have been able to meaningfully access education, some progressing on to higher education (Ashby & Causton-Theoharis, 2012; Bennett, 2011; Biklen & Burke, 2006).

Despite these documented experiences and outcomes, as well as other research evidencing the reliability of the method (e.g. Cardinal & Falvey, 2014; Cardinal, Hanson, & Wakeham, 1996; Emerson, Grayson, & Griffiths, 2001; Grayson, Emerson, Howard-Jones, & O'Neill, 2012; Marcus & Shevin, 1997; Tuzzi, 2009), FC remains controversial. In fact, the controversy over FC continues to pervade the opportunities and lived realities of individuals who use (or could use) this method as their primary mode of communication. This resistance to FC is literally rooted in a series of early studies that failed to prove the authorship of individuals using FC and suggested that the potential for facilitator influence (e.g. Bebko, Perry, & Bryson, 1996; Bomba, O'Donnell, Markowitz, & Holmes, 1996; Crews et al., 1995; Greene & Shane, 1994; Kezuka, 1997; Klewe, 1993; Montee, et al. 1995; Regal, Rooney, & Wandas, 1994; Shane & Kearns, 1994; Smith, Haas, & Belcher, 1994; Wheeler, Jacobson, Paglieri, & Schwartz, 1993). However, the controversy continues ultimately because of the challenge that FC poses to long held assumptions about the intellectual capacity of individuals labeled with intellectual and developmental disabilities, those for whom the method is often appropriate and useful; the cloak of incompetence still clouds their experiences. For some students who use FC, the controversy over the method has resulted in a lack of access to any communication supports, or opportunities for academic and social engagement in schools (Bennett, 2011).

Even as I engaged in and write about this inquiry, the controversy around FC flared up in public media⁹ and academic journals,¹⁰ re-ignited by a court case that centered on an individual who uses the method. This focus on proving authorship also resurfaced (repurposed) in the form of critique, and dismissal, of research methods (often qualitative methods including: narrative, life writing, autoethnographic, ethnographic, etc.) used to do research with and about the experiences of individuals who use FC (Mostert, 2014; Singer, Horner, Dunlap & Wang, 2014; Travers, Tincani, & Lane, 2014). Those who oppose the use of FC disregard the fact that alternative methods, such as eye tracking (Grayson, Emerson & Howard-Jones, 2012) and lexical analysis of typed text (Tuzzi, 2009), have been used to “validate” typed communication in recent years. Instead, they continue to insist that double-blind and message passing studies are the only means to “prove” authorship and establish “evidence” that this communication works. Yet, as noted by typist and self-advocate Amy Sequenzia (2015),

There are not many of us [individuals who type to communicate] in academia. Our stories and experiences might be dismissed as ‘just anecdotes’ but this how we experience our progress, the changes FC brings to our lives, the day-to-day message-passing that we don’t need to record, report or have validated by every single Very Important People, usually privileged, non-disabled people, who call themselves ‘experts.’

⁹ See Auerbach, 2015; Engber, 2015

¹⁰ In 2014 *Research and Practice for Persons with Severe Disabilities* (RPSD), a leading journal in the field run by TASH, an organization that supports the inclusion of individuals with disabilities, released a Special Issue on facilitated communication. Of the four featured articles, three explicitly opposed the use of FC. While exploration of this most recent iteration of the controversy is beyond the scope of this project, it is important to note that this is the current climate in which my inquiry unfolded. The community of individuals who use FC, their allies, and scholars who do research to understand their experiences rallied in a response to these, and other subsequent, biased representations of the method in a venue that had traditionally supported the rights of individuals to choose their preferred communication method, including FC. The debate is ongoing and is very much related to what constitutes “evidence” and what research methods are most conducive to demonstrating “evidence based” practices.

It is not surprising, then, that when individuals who use FC *have* had opportunities to share their perspectives in research and in practice, they have frequently articulated the necessity of proving they are smart, dissociating from the labels placed upon them and the assumptions made about their abilities in an absence of access to communication (Ashby, 2011; Biklen, 2005; Biklen & Burke, 2006; Biklen & Duchan, 1994; Broderick & Kasa-Hendrickson, 2006). Similarly, when the perspectives of individuals who type to communicate have been included in publications, they have often been present in the form of resistance to the challenges to their authorship, identity, and competence stirred up by the controversy around FC. Based on the continued debate that has surrounded FC and the resultant necessity for researchers and individuals with disabilities to “defend” themselves in their choice to explore the method, FC literature tends to take on characteristics and address topics—i.e. presuming competence—at a depth that is not present in the work on AAC more broadly. It is possible that these characteristics are what align work on FC with disability studies and attract disability studies scholars to examining the method; disability studies is far less often and explicitly taken up in research focusing solely on AAC. I therefore see this as the juncture at which literature grounded in a disability studies in education framework diverges most significantly from a more traditional approach to research on the experiences of individuals who use AAC and those who support them (a discussion that will continue in Part II.)

FC and autism. I remain committed to using this literature review to explore inclusion and communication in secondary schools across a spectrum of communicative diversity; this is partly in resistance to the tendency for the experiences of those with autism who use FC to be excluded from that larger group in research and practice. However, because individuals like my co-inquirers, those with autism who do not use speech to communicate, make up a large

contingent of those who find FC the most reliable and effective form of AAC to meet their needs and preferences, I want to touch on the nuances of autism to better situate my co-inquirers' experiences communicatively, educationally, and relationally. In our deficit based culture around disability (see Part II), autism has been constructed as a diagnostic category comprised of a combination of observable communicative, behavioral, and social "impairments" or "deficits" (American Psychiatric Association, 2013). It is also common for individuals with autism labels to also receive intellectual disability labels. This deficit based perspective has contributed to the evolution of other "myths" about the autism including that individuals with autism lack theory of mind (or exhibit "mindblindness"), or the ability to understand others' views or feelings (Biklen, 2005; Baron-Cohen, Leslie & Frith, 1985; Frith, Happe, & Siddons, 1994). Presumptions of incompetence, combined with diagnostic criteria and assessment mechanisms that do not accommodate for communicative and behavioral diversity that would allow individuals to prove themselves otherwise, have continued to perpetuate these widespread these beliefs about the autism experience.

However, the lives and stories of individuals with autism themselves have begun to shift the narrative and re-constructed knowledge about autism. Of particular relevance here are the stories of individuals with autism who have learned to type to communicate through FC. Primary accounts of FC users' experiences, such as those captured in books (i.e. Biklen, 2005; Higashida, 2013; Sequenzia & Grace, 2015), documentary films (i.e. Biklen & Rossetti, 2005; Biklen & Wurtzburg, 2010; Wurtzburg, 2004) and narrative-based research (i.e. Ashby & Causton-Theoharis, 2009; Biklen, 2000; Broderick & Kasa-Hendrickson, 2006) not only serve as resistance to the pathological perspective of autism, but also put forth accurate accounts of what constitutes the autism experience as they live it. Because of these documented experiences, as

well as individuals' collaboration on/in research, we are now coming to better understand the neurological, motor, and sensory experiences that are barriers to communication and engagement (Donnellan, Hill, & Leary, 2013; Hussman et al., 2011; Leary & Donnellan, 2012; Savarese, 2013; Torres et al., 2013); all of this work continues to support that for those labeled with autism “the problem is not one of understanding, but of doing” (Biklen, 2005, p. 267). In other words, the often unacknowledged challenges associated with organizing and regulating one's body in response to sensory information and movement demands (i.e. those required for speech or independent pointing) are becoming more widely understood as the experiences underlying those actions and behaviors associated with autism (Donnellan, Hill, & Leary, 2013). A focus on sensorimotor experiences has helped to reconstruct autism as a challenge of movement, rather than of cognition (Biklen, 2005; Donnellan, Hill, & Leary, 2013; Leary & Donnellan, 2012; Savarese, 2013). For individuals who use FC specifically, the growing understanding of sensory and motor challenges, augmented by documented stories of others similarly situated, has implications for better understanding the need for physical support for typing, how to most effectively fade that support over time, and what other strategies (i.e. to support sensory and movement) can augment communication.

Paralleling and intersecting with FC user narratives is an expanding movement rooted in, though not exclusive to, the autism community—comprised of individuals who speak and/or use AAC—to resist deficit based perceptions and position autism as a cultural identity representative of the diverse neurology of human beings. Termed “neurodiversity” and proliferated via social media, blogging, and publication (Savarese et al., 2010; Silberman, 2015; Walker, 2014), this

social justice movement has contributed to an understanding that individuals with autism¹¹ or other non-normative ways of being¹² are “neurodivergent,” a term coined by multiply neurodivergent blogger and activist Kassiane Sibley. Those who do not identify as neurodivergent are often referred to as “neurotypicals” (or those who do not experience life with autism/disability). The neurodiversity movement has made waves through activism, advocacy, and scholarship (Kras, 2010; Ne’eman, 2010; Silberman, 2015; Savarese & Savarese, 2010). It has also given rise to the neurodiversity paradigm, a philosophical framework based on the more activism centered neurodiversity movement (Walker, 2013). Those involved continue to push the boundaries of what constitutes disability and community, while re-imagining what counts as evidence and knowledge. Together with new and different kinds of research and an increasingly active disability studies field (see Part II), the concept of neurodiversity converges with my own, and my co-inquirers’, priorities and experiences in this inquiry.

Gaps and Limitations in the Literature

Despite the promise of this movement to honor narrative and neurodiversity, particularly around autism and FC, broadening the lens to consider inclusion and AAC reveals a persistent gap. Studies directly addressing the lived realities of high school students with disabilities who use AAC in inclusive spaces are limited. What follows is a breakdown of the methodological characteristics commonly found, and an articulation of what is missing from, the current literature on this topic.

¹¹ While I use person first language here, some people do choose to privilege their autism as a primary identity by referring to themselves as “autistic people” or “autistics.”

¹² While often associated with autism experiences, the neurodiversity movement is actually comprised of many different kinds of people who move through the world differently for a variety of reasons. As blogger Cas Faulds (2016) notes, “Neurodivergent does not mean autistic. It includes everyone whose neurocognitive functioning differs from that of the social standard of ‘normal.’ It’s an inclusive word. It acknowledges that there are many different forms of neurodivergence, without creating any form of hierarchy of neurodivergence.” However, for relevance I am focusing on neurodiversity and neurodivergence in the context of this conversation on autism.

Elementary focus. Though the fundamental nature of communication access and educational opportunities has been established (Balandin & Duchan, 2007; Beukelman & Mirenda, 2005; Light, 1997), research on the inclusion of students who use AAC is heavily weighted toward investigations at the elementary level (Beck, Bock, Thompson, Bowman, & Robbins, 2006; Binger et al., 2010; Hunt et al., 2002; Hunt, Soto, Maier, Liboiron, & Bae, 2004; Jorgenson, McSheehan, Sonnenmeir, 2007; Kasa-Hendrickson, 2005; Myers, 2007). This pattern of focusing on elementary schools is related to both a shortage of students who have access to AAC and are effectively included beyond elementary school (Downing, 2005; Kasa-Hendrickson & Kluth, 2005; Kent-Walsh & Light, 2003) and the perceived complexities of inclusion given increased academic demands of middle and high school (Mastropieri & Scruggs, 2001; Shapiro-Barnard, 1998; Smith, 2005).

Wickenden (2011) and Bennet's (2011) studies are a welcome counter to this trend in their focus on high school students who use AAC. Wickenden's ethnographic study exploring the lifeworlds of teenagers who use AAC included observations and interactions in their school environments as part of the research. This work contributes an understanding that these particular individuals prioritized being seen as family members and teenagers over their disability identities; an important factor for me as in considering my co-inquirers experiences. Like Wickenden, Bennett (2011) too focused on lifeworlds of teenagers who use AAC, specifically FC, and homed in on how inclusion and/or exclusion in school impacts their constructions of identity. In interviewing students and families, Bennett found that his participants experienced more exclusion in school than not. His participants included three teenagers with autism who utilize FC, mirroring my co-inquirers' positions.

Yet, scholars have acknowledged that studies focused on high school like these, are few and far between, captured in Smith's (2005) analogy:

... the field of AAC could itself be viewed as coming through the late adolescent period, gradually growing, maturing, and developing as an independent and confident field. It is perhaps appropriate, therefore, that researchers in AAC now turn their attention in more focused ways to the needs of adolescents who use aided AAC. (p. 76)

As a result, Smith and others cite inclusive strategies for students who use AAC at the secondary level as a recommended area of research.

Types of research. Schlosser and Raghavendra (2004) note that evidence based practice in AAC “is still in its infancy” (p. 18). Yet, neither AAC nor students with complex communication needs necessarily lend themselves to methodologies currently required to establish an evidence base, such as randomized controlled trials or large group designs. Moreover, AAC users are a heterogeneous group and there are likely few AAC users within any given context (Calculator & Black, 2009; Binger et al., 2010; Schlosser & Raghavendra, 2004). As a result, studies on AAC in schools tend to employ single subject research or case study designs (Horner et al., 2004; Schlosser & Sigafos, 2006; Snell, Chen, & Hoover, 2006) or utilize qualitative methods. Just as some teachers have reported difficulties assessing AAC users' academic performance (Kent-Walsh & Light, 2003), conducting large-scale empirical studies through which evidence based practices would otherwise be established has also proven difficult (Binger et al., 2010; Calculator & Black, 2009; Calculator & Jorgensen, 1991; Schlosser & Raghavendra, 2004). The use of qualitative methods to explore the experiences of AAC users in school has proven more fruitful (e.g. Ashby, 2011; Ashby & Causton-Theoharis, 2012; Jorgensen, McSheehan, & Sonnenmeir, 2007; Kasa-Hendrickson, 2005; Kasa-Hendrickson &

Kluth, 2005; Kent-Walsh & Light, 2003; Soto et al., 2001a, Soto et al; 2001b; Stoner, Angell & Bailey, 2010). Perhaps a reevaluation of what constitutes evidence is in order for this area of inquiry. To broaden the literature base, Miranda (2008) argues we should, “be bold—not conservative—in formulating research questions and executing studies that push existing boundaries and test hypotheses that may be unconventional but may also lead to new insights and applications” (p. 229).

Student perspectives. Compounding this methodological imbalance is the fact that the research identifying effective inclusive practices for students with complex communication needs has centered on the actions and perspectives of adult educational team members and parents, rather than AAC users themselves (Robledo & Donnellan, 2008; Wickenden, 2011). Some scholars have attempted to fill this gap by intentionally privileging the voices and experiences of students who use AAC (Ashby, 2011; Ashby & Causton-Theoharis, 2012; Biklen, 2005; Biklen & Burke, 2006; Bennett, 2011; Broderick & Kasa-Hendrickson 2006; Rackensperger et al., 2005; Rossetti et al., 2008; Wickenden, 2011). While some critical narratives of inclusive and non-inclusive experiences as told from students’ perspectives are available to draw on, they are not often utilized as resources for practice (Ashby, 2010, Bennett, 2011, Biklen, 2000). Additionally, there have not yet been studies exclusively focused on the daily inclusive experiences of high school students who type to communicate using FC. Research that has included the participation of adolescents who use FC has instead highlighted and explored important related topics such as notions of normalcy in education (Ashby 2010), identity development (Bennett, 2011), the presumption of competence (Biklen & Burke, 2006), and the complexities of communicative development (Broderick & Kasa-Hendrickson,

2001). Yet generally, research that centers students' voices, even within the few studies that do address inclusion at the high school level, is limited or noticeably absent.

The emphasis of research on observable outcomes over narrative accounts seems incongruous with premises that often underlie such studies—namely, that students who use AAC have the right and ability to participate and succeed alongside their peers (Beukelman & Mirenda, 2005; Light, 1997; Wehmeyer, 2005; Williams, Krezman, & McNaughton, 2008). Thus, what we “know” about the inclusive educational experiences of AAC users has been dependent on how they visibly perform, whether on tests, during interventions, in peer interactions, or during classroom activities. While this is undoubtedly important work, there must also be an attempt to establish a complementary set of knowledge derived *from* the students' perspectives that runs parallel to and intersects with research being done *about* them. In other words, students' lived and told experiences need to be considered and schools implementing student-centered approaches should be identified and modeled. If studies exploring inclusive opportunities for students who use AAC fail to include and emphasize the importance of the lived experiences of those students, do they not threaten to contribute (even if peripherally) to the continued exclusion of those very individuals themselves?

Most of the research on the inclusion of AAC users reports on, but is not explicitly critical of, the current state of affairs. While many of these studies contribute significantly to a more nuanced understanding of AAC use, they often do not explicitly highlight perspectives and practices in educational settings that serve to break down (or create) barriers, disrupt (or perpetuate) misconceptions, and raise (or limit) expectations for students who use AAC. *I've found my place*. Situated in this gap in the literature, I identify with those who have brought their

critical perspectives to this work on communication in education.¹³ To further develop my position, I move on to discussing the framework of disability studies in education and how it can help to bridge gaps in the literature on the inclusion of students who use AAC in high school.

Part II

Disability Studies in Education as a Tool for Work with and about AAC Users

In this section, I make connections between disability studies in education (DSE) and the educational experiences of students who use AAC. I begin with an overview of the fundamental tenets—the tools—that comprise the field, including social construction, combating the culture of ableism, and a troubling of normalcy. As I do so, I highlight areas of contention with the historical, practical, and institutionalized oppression of students with disabilities in the educational arena, pausing to explore the manifestation of these concepts in the lives of students for whom speech is not the primary means of expression. I conclude by addressing the characteristics of DSE research and the emphasis in the field on lived experiences and narrative.

What is DSE?: Key ideas. Disability studies in education (DSE) is characterized as an “intellectual and practical tradition located at the intersection of *disability studies* and educational research, creating a general orientation to disabilities as social and political phenomena that manifests within activities of education, schooling, and learning” (Danforth & Gabel, 2008, pp. 3-4). The philosophical underpinnings upon which the field of disability studies rests are shared by and oriented towards educational contexts to create an area of inquiry particularly concerned with what disability means and how it is experienced in schools. DSE scholars operate from a social justice framework (Connor, 2012; Gabel & Connor, 2009; Hulsebosch, 2009; Rice, 2008) as they look critically at and seek to “unlearn restrictive notions

¹³ For example: Biklen, Broderick, Ashby, Causton-Theoharis, Erevelles, Kasa-Hendrickson, Kliever

of ability, recognize difference as natural human variation, and better understand the complexities underlying the implementation of inclusion” (Valle & Connor, 2011, p. x).

Disability studies, then, presents an understanding of social justice in the context of education as “both a process and a goal” (Bell, 2007, p. 2) that aims to:

...enable people to develop the critical analytical tools necessary to understand oppression and their own socialization within oppressive systems, and to develop a sense of agency and capacity to interrupt and change oppressive patterns and behavior in themselves and in the institutions and communities of which they are part (Bell, 2007, p. 2)

Disability studies and social justice frameworks can be seen not just as related, but inherently connected to one another. Thus, the DSE focus on developing those critical analysis tools to deconstruct oppressive ideas about ability necessarily departs from conventional notions of special education and its associated practices, which have historically been grounded in, and helped to perpetuate, a medicalized understanding of disability-as-deficit (Baglieri, Bejoian, Broderick, Connor, & Valle, 2011; Brantlinger, 2004; Connor & Ferri, 2007; Gallagher, 2008). However, “Disability studies is not intended as a replacement for special education. Rather, it provides discursive tools for making sense of disability and engaging in the critical conversations necessary to re-envision education for all” (Ashby, 2012, p. 98).

Social construction. Like disability studies, disability studies in education (DSE) revolves around an understanding of disability and ability as social constructions. In other words, the meaning of disability is and has been made by human beings in interactions with one another and the world (Baglieri, Valle, Connor, & Gallagher, 2011; Shakespeare, 2010; Taylor, 2008). Disability thus reflects the contextual and interpretive nature of how individuals with

impairments experience, and are often oppressed by, social, structural, emotional, institutional, historical, and political aspects of the environment (Charlton, 2010; Garland-Thomson, 1997).

Disability studies scholars have explored, for instance, the social construction of “mental retardation” and its associated assumptions about intellectual ability and competence (Bogdan & Taylor, 1976; Bogdan & Taylor, 1994; Danforth, 1997; Linneman, 2001). These inquiries into “retardation” and competency intersect with those related to communication, since an individual’s failure to produce the latter has historically associated them with the former (Biklen & Duchan, 1994; Kliewer, Biklen, & Kasa-Hendrickson, 2006). Bogdan and Taylor’s (1976) pivotal argument that the meaning attributed to the label of mental retardation, “...depends on those [the ‘judges’] who use it to describe the cognitive states of other people [the ‘judged’]” (p. 47) foregrounded their call for a better understanding, not of clinical judgments, but of the experiences and voices of those for whom such labels are so often arbitrarily used to describe (Bogdan & Taylor, 1994). They also identified the ways that social constructivist perspectives can be and have been actively engaged to construct “humanness” in relationships with individuals whose appearances and labels threaten to otherwise undermine them (1989). This resistance to clinical judgment and prioritization of lived experience parallels the aforementioned shift led by the autism community toward a neurodiversity paradigm that hinges on a presumption of competence (see pp. 32-34).

This notion that meaning is made—that all knowledge is situated and political—stands in stark contrast to the deficit-based, medicalized ways that socio-cultural systems, including education, have traditionally understood and been structured around disability (Ashby, 2012; Danforth & Gabel, 2008; Ferguson & Nusbaum, 2012). This belief about social construction, a primary tenet of DSE and the social model of disability, asserts that “disability is not a ‘thing’ or

condition people have, but instead a social negation serving powerful ideological commitments and political aims” (Connor, Gabel, Gallagher, & Morton, 2008, p. 447). DSE scholars do not deny the lived realities of embodied difference, but instead assert that it is, “...what we make of those differences that matters. Ultimately, this has an impact on the material consequences of people with disabilities” (Baglieri, Valle et al., 2011, p. 270). The consequences of a deficit-based perspective are those that situate students with disabilities as broken and in need of service or repair (Ferri & Connor, 2005; Garland-Thomson, 1997). As Ferri (2009) notes, this clinical approach to understanding and interacting with disability “transmogrif[ies] different ways of moving, learning, behaving, and being into individual pathologies” (p. 421).

This, the medical model approach to disability (which currently persists as the primary mode of understanding it) is rooted in positivism and hinges on the identification of deficit while seeking measures of remediation, or cure—if not outright separation (Ferri, 2008). It locates the problem within the person and constructs its presence as one to be mourned, feared, and/or pitied (Garland-Thomson, 1997; Linton, 1998; Mackay, 2003). In response, DSE scholars and allies work to widen the lens by incorporating the contextual, subjective, and socio-cultural aspects of disability, including elements that serve as “disabling” to an individual (Erevelles, 2008; Ferri, 2008; Garland-Thomson, 1997). Acting as “critical watchdogs” (Danforth & Gabel, 2008, p. 1), DSE scholars and allies survey the social, cultural, and educational terrain for clues to the oft-unquestioned assumptions and barriers in place that situate difference as deviance. They critically analyze and work to break down these barriers by exposing and resisting their limitations, and putting forth alternative, more empowering frameworks and creative practices.

Ableism and normalcy. As part of this watchdogery, DSE scholars also turn a critical eye to the existence of universal expectations of individuals’ performance. Originally termed

“handicapism” by Bogdan and Biklen (1977), the notion now referred to as “ableism,” captures critical awareness of the oppressive nature of value-laden assumptions and their (individual, institutional, social, cultural, and material) consequences, about disability (Ashby, 2012; Bogdan & Taylor, 1994; Ferri, 2008; Hehir, 2002). More specifically, ableism involves:

Deeply rooted beliefs about health, productivity, beauty, and the value of human life, perpetuated by the public and private media, [that] combine to create an environment that is often hostile to those whose physical, mental, cognitive, and sensory abilities fall outside the scope of what is currently defined as socially acceptable. (Rauscher & McClintock, 1997, p. 198)

With influence drawn from and intersecting with other paradigms of oppressed identities, such as racism, sexism, classism, homophobia, ageism, and religious oppression, etc., the existence of ableism is characterized and perpetuated by its in(di)visibility (Baglieri, Valle, et al., 2011; Erevelles & Minear, 2011; Ferri & Connor, 2005; Gabel & Connor, 2009). Ableist ideas about preferred (read: better) ways of moving, being, looking, interacting, communicating, and experiencing the world contribute to the physical and social structures that serve to keep individuals with disabilities at the margins and solidify existence and prioritization of those “without” disabilities, as the norm or the center (Brantlinger, 2004; Garland-Thomson, 1997; Hehir, 2005). As Smith (2008) aptly notes, “In the same way that Whites forget they are ‘colored,’ so too do Normals forget they are differenced” (p. 423), or (en)abled, given how those with disabilities are constantly reminded of their positions and identities as such. Baglieri, Bejoin et al. (2011) further capture the pervasiveness of this experience:

The state’s goal of a ‘normal’ (desired) population is still projected on individuals at every turn: how we walk, move, talk, act, interact, think, dress, eat, learn, and so on—in

addition to being inscribed into a host of other pressurizing discourses such as nationality, race, ethnicity, gender, and sexuality. Every day, thousands of interactions with other people (real and/or virtual via media) clearly convey acceptable and unacceptable ways of being in the world. The force on individuals to conform is enormous, and once normalcy is attained, it requires a degree of conscious maintenance. In most instances, all of us self-regulate (and therefore self-normalize) in the pursuit of social acceptance. (p. 2131)

In schools, the unquestioned prioritization of “able” minds and bodies results in teaching practices, expectations, and curricula that are geared toward the “normal child” —an idealized student compared to those who are seen as difference and perceived as unequivocally “less than” (Ashby, 2010; Baglieri, Bejoian, et al., 2011; Brantlinger, 2004). Modes of presentation, assessment, and documentation of learning are constructed based on the supposition that the student receiving them hears, sees, walks, talks, eats, breathes, sits, etc. in “normal” ways; those who do not conform are thus positioned as a problem (Hehir, 2005). DSE as a field calls attention to and resists notions of normalcy, ableist attitudes, and the consequences that emerge from both in schools. Acknowledging ableism, as Hehir (2005) argues, is a primary step toward creating more equitable educational environments. Therefore, the idea that DSE can be considered, “a counter-narrative to the prevailing and intertwined hegemonic discourses of normalcy, deficiency, and efficiency operating in (special) education” (Connor et al., 2008, p. 455) suggests that those primary steps (movements away from oppressive discourses) are grounded in politics, intentionality, and the hope for more inclusive futures.

Normalcy, agency & AAC. The privileging of speech as the preferred and expected mode of communication in schools represents one example of the power of normative expectations and

the ableist practices that result (Ashby, 2010; Broderick & Kasa-Hendrickson, 2006; Rossetti et al., 2008). As Sue Rubin (an individual with autism who types to communicate) describes, a failure to produce intentional speech—and associated presumption of incompetence—has implications for the educational opportunities (or lack thereof) for students like her:

When I was in school autistic people like me were usually placed in separate schools or special day classes with other disabled students (and) were not allowed to learn academic subjects. Because of the way we move and our lack of speech we were assumed to be retarded. (Rubin et al., 2001, p. 419)

Even when students who do not speak gain access to general education in inclusive environments, there is a tendency to prioritize the development of speech and other means of normative performance over augmentative and alternative vehicles of participation, further perpetuating myths about the capabilities and competence of those individuals (Ashby, 2010; Baglieri, Bejoian, et al., 2011; Broderick & Kasa-Hendrickson, 2006; Mackay, 2003). Capturing the ramifications of this propensity, Ashby (2010) notes that, “when product is privileged over process, when completion is the goal, opportunities for authentic learning are lost” (p. 350).

Broderick and Kasa-Hendrickson (2006) further demonstrate the pervasiveness of normalized communicative expectations in describing their own difficulty (and sometimes failure) to resist the entrenched assumption that speech is the preferred or ideal means of communication for all. Studying the experiences of individuals previously labeled nonverbal as they began to develop and use speech functionally, the researchers candidly acknowledge the “deeply embedded” assumptions of their research: that developing speech was inherently positive, liberating, and exciting for participants. They admit that beneath these assumptions lay a “...deep cultural valuing of speech [...] something that we initially failed to recognize in our

own language and actions and that we eventually came to appreciate only by listening carefully to our participants' collective stories" (p. 179). Ultimately, it is those participants' stories that help bring to light not only the researchers' subscription to normative expectations, but also new ways of thinking about the purpose, process, and place of speech within an AAC system. It is often the individuals themselves that model resistance to ableist norms upon which disability studies in education rests. As Broderick and Kasa-Hendrickson (2006) acknowledge, we would all do well to listen, and follow suit.

What studies like these help remind us is that enforcing conformity to the norm often serves to flatten, hinder, and obstruct meaningful participation by individuals whose ways of moving in and interacting with the world often in and of themselves challenge normative expectations of the spaces and people they encounter (Brantlinger, 2004; Garland-Thomson, 1997). Such enforcement of norms fails to capture the socioeconomic, cultural and structural realities of students' families: intersecting elements that contribute to the availability, development, utilization, and support of individuals' communication systems (Lund & Light, 2007; Rackensperger, 2012). These studies also serve to remind us of what we are missing when we fail to see, or seek, value in experiences that challenge what has come to be unquestion(ed)able (Bogden & Taylor, 1976; Bogdan & Taylor, 1994; Couser, 2011; Ferri, 2009).

Intersectionality. Understanding ableism and normalcy as it relates to disability requires consciousness of the complex intersections of disability with other identity markers and experiences of oppression (Erevelles & Minear, 2011). While at the same time fighting for disability's place "at the table of diversity" (Connor & Gabel, 2010, p. 202) given its historical exclusion from it, DSE scholars continually aim to consider, write of, teach about, and engage

critically with/in these intersections and the ways they manifest in schools. This intersectionality is aptly captured in Clare's (2010) insistence that:

Gender reaches into disability; disability wraps around class; class strains against abuse; abuse snarls into sexuality; sexuality folds on top of race...everything finally piling into a single human body. To write about any aspect of identity, any aspect of the body, means writing about this entire maze. (p. 563)

Some DS/DSE scholars have used an intersectional lens to consider the ways, for example, that race, class, disability and narratives of normalcy interact and contribute to overrepresentation of students of color in special education and an underrepresentation of them in post-secondary settings (i.e. Artiles, Kozleski, Trent, Osher, & Ortiz, 2010; Artiles & Trent, 1994; Collins, 2003; Ferri & Connor, 2006; Harry & Klingner, 2005; Reid & Knight, 2006). Collins' (2003) 18-month case study of Jay, for example, juxtaposes the researcher's records and reflections on interactions with a student (Jay), with the deficit-driven "institutional biography" constructed by his teacher. She paints a compelling picture of the ways that assumptions about race, gender, socioeconomics, and ability overlap and intersect to construct presumptions of incompetence that manifest in exclusion.

Others have explored the relationships between experiences with sexuality and disability (i.e. Erevelles, 2011a; Ferri & Connor, 2010; Gill, 2015; McRuer, 2010), which has situated DS/DSE alongside feminist, queer, and critical race theory in "...making it possible as well as strategically important to begin an analysis that could connect each group's sexual oppression to that of other groups while attending carefully to the specifics of each group's experiences, sexual images, and their relation to material practices" (Wilkerson, 2011, p. 202). In addition, a neuroqueer perspective, emerging out of the neurodiversity movement, has recently gained

momentum (Walker, 2015). Positioned as both a noun and verb, “neuroqueer(ing)” involves an intersection between neurodiversity (or the positioning of human neurological difference on a spectrum diversity rather than as disability) and queerness (as it is understood as a political act and identity via queer theory and/or queen activism) (Walker, 2015). Scholars that focus on the intersections of gender and disability (Erevelles & Mutua, 2005; Ferri & Connor, 2010; Garland-Thomson, 2011) grapple with such questions as: “what is the relationship between gender and disability? What role does gender play in the experience of disability? How is gendered disability and dis- or en-abled gender racialized? How do institutions, global economic inequalities and ideas of citizenship and the nation produced gendered, raced, and classed disability?” (Hall, 2011, p. 7). Still others call forth connections between social class and disability (Brantlinger, 2001; Erevelles, 2011b; Preece, 2010); this is a particularly relevant intersection for me to consider given the importance of thinking about socioeconomic status and access to resources in the context of assessment, devices, training, and support for AAC, as well as inclusive opportunities to use it.

For instance, students who do gain access to opportunities (in this case, both AAC and inclusive education) are often the most privileged within the group (Crenshaw, 1989). This is illustrated by the reality that three of four of my co-inquirers’ families¹⁴ had the resources to uproot their lives to secure inclusive educational opportunities for their children. To capture this positional complexity, critical race and legal scholar/activist Crenshaw (1989) asks us to imagine a basement full multiply marginalized individuals, a particularly apt and ironic analogy to consider given the historical tendency of segregated special education classrooms to exist in the basement of schools. In that basement, those who are “disadvantaged” by a single element of

¹⁴ Two of my five co-inquirers are twin brothers, so there are five students across four families.

their identity (i.e. disability) sit/stand on the shoulders of those who are oppressed because of more than one factor (i.e. disability, race, class *and* gender). When given the opportunity, those individuals closest to the ceiling are the ones who can crawl through the trap door to the floor above, where those otherwise privileged reside (Crenshaw, 1989).

All of this work around intersectionality moves towards exposing the overlapping and interweaving ways that notions of normalcy play out in the lives of those whose identities serve to complicate a monolithic understanding of disability. In light of the aims of such analyses housed under, but emanating out from DSE, Erevelles & Minear (2011) assert that, “At the intersections of race, class gender, sexuality, and disability, we will find that collective resistance is more fruitful than individualized forms of resistance” (p. 120). As spaces in which these intersections overlap with one another, schools present particularly cogent opportunities for the cultivation of “fruitful” and “collective” opposition to pressures for conformity and compartmentalization. Research in/about schools, then, can too be fertile ground for resistance.

DSE in Research: Experience at the Center

DSE research is grounded in the above tenets of the field and DSE researchers attempt to do justice to the intersectional experiences of those about, for, and with whom research is conducted. One way that DSE researchers have attempted to engage with/in these complexities is through transgressive research methods that privilege the experiences of people with disabilities.

A focus on experience. Attending (in whatever form most conducive) to the storied experiences of individuals whose ways of moving in and interacting with the world often in and of themselves challenge the normative constructions and expectations of the spaces and people they encounter holds promise for generating more inclusive opportunities (Ashby & Causton-Theoharis, 2009; Ferri, 2009; Smith, 2013; Solis & Connor, 2008). Despite the disability rights

movement mantra, “nothing about us without us” (Charlton, 1998), along with the foundational tenet of DSE on centering “the voices of those closest to the disability experience” (Danforth & Gabel, 2008, p. 10), there continues to remain a paucity of those voices in research. In fact, the aforementioned gap in the research on AAC resulting from the absence of student perspectives can be considered reflective of this broader trend in the literature on disability experiences overall. In both areas, the voices of professionals and parents continue to be utilized as the primary interpretive vehicles of students’ experiences with disability and education, rather than those students themselves being solicited for feedback (Donnellan & Robledo, 2008; Wickenden, 2011). A stated objective and critical element of DSE is to change this dynamic (Baglieri, Valle, et al., 2011; Danforth & Gabel, 2008; Gabel & Connor, 2009). As Baglieri, Valle, Connor & Gallagher (2011) note,

Of primary importance to DSE scholars is taking great care that we do not use research as a means of excluding the voices of people with disabilities...[Rather] we aim to use research as a vehicle for their voices so that they can tell their own stories and share their own goals, aspirations, and needs. (p. 273)

Ultimately, a continued failure to comprehensively seek narratives of/with students with disabilities themselves, or to construct research agendas reflective of their worldviews threatens to perpetuate the medicalized, deficit-based positioning of them as objects of care, rather than agents of change (Ferri, 2009). Even within the disability studies literature to date, there have been few studies (though more so than in the special education literature) that center on voices of students (Ashby & Causton-Theoharis, 2012; Connor, 2007; Ferri, 2009; Jones, 2004; Solis & Connor, 2008). Many such studies conclude with a call for more that follow their lead, reflecting

the importance of Slee's (2000) imperative: "our struggle is to change the power relations of knowledge-authority, to consider whose voices carry weight and who never gets heard" (p. 128).

Voices of AAC users. While the work being done within DSE has begun and promises to continue privileging students as co-constructors and participants in the literature, those with complex communication needs represent a particularly underrepresented group (Wickenden, 2009). Of the complexity AAC adds to doing research, Danforth and Gabel (2008) point out,

The disability studies value of allowing disabled people to 'speak' for themselves becomes complicated when speaking for oneself entails the use of assistive or augmentative technologies. This is particularly true when those technologies require the support of nondisabled communication partners. (p. 11)

Rather than preclude individuals who use AAC from being heard, DSE drives us to reframe the questions being investigated, while also calling for a reconsideration of how we ask them. Researchers are pushed to critically consider conventional understandings of independence (Ashby, 2011; Ashby, Jung, Woodfield, Vroman, & Orsati, 2015; Rossetti et al., 2008) and develop methodologies (Cowley, 2012; Wickenden, 2011) that leave space for the level of interdependence necessary to highlight the voices and stories of individuals who rely on such broadened conceptions of support. They are also driven to draw upon perspectives of individuals with disabilities as resources and advisors in the process of developing research questions and methods surrounding experiences to which they can relate.

Studies creatively engaging with diverse voices. Illustrating these collaborative recommendations, in her study of the identities of teenagers who use AAC, Wickenden (2010; 2011) worked with a group of adult AAC users as research advisors to design and carry out the study. Additionally, her use of multi-modal—"mosaic" or "distributed"—ethnographic data

collection methods included a collaborative DVD project focusing on the experiences and views of the teenage participant AAC users that made visible and provided opportunities for revisions of narratives of experiences collected along the way.

Scholars like Jones (2004; 2007), who co-authored “Personal Life Presentations” with her female participants labeled with “emotional disturbance” (ED), and Connor (2007), who collaboratively developed “portraits in progress” of eight urban students of color labeled “Learning Disabled” (LD), are both examples of researchers working to explore complex intersections and develop methodologies that foreground the experiences of students in radical ways. In so doing, both scholars position students with disabilities as experts on their own lives, make space for alternative narratives, and demonstrate the value of engaging with, rather than merely including, those student voices. I also have much to draw from studies such as Cowley’s (2013), which utilized “supported collage” as a starting point around which the voices of girls with intellectual disabilities told the stories of their experiences and self-conceptions during their transition to adulthood. Her work—grounded in Luttrell’s (2003) use of self-portraits, journaling, and collage with pregnant teenage girls, and Mehta’s (2010) use of “life mapping” in her study on the experiences of Indian students with disabilities—demonstrates the importance of working to facilitate the voices of participants rather than giving up on them, or boxing them out through methods not conducive to their conveyance.

Ashby & Causton-Theoharis (2012) illustrated the importance of follow up and clarification in their investigation of experiences of college students who type to communicate. The authors, who conducted participant observations and supplemental interviews with relevant constituents, describe how they utilized a “different style of interviewing” that responded to the communicative preferences and realities of their participants who typed to communicate (p. 265).

They cite the importance of sending questions to participants ahead of time, structuring interviews around fewer topics over longer periods of time to accommodate for the laborious nature of communicating through typing, and ongoing opportunities for clarification.

Biklen's (2005) *Autism and the Myth of the Person Alone* is a visible collaboration between researcher and participants, so much so that the seven participants are listed as contributing authors. Biklen's approach to soliciting and clarifying perspectives varied by each participant based on their individual preferences and needs, a collaborative process he explains in the introduction to each author's chapter. Although he recognizes that presenting the contributors' work as separate chapters does not protect him against the potential to overpower their voices, he argues that his decisions to do so are grounded in his belief that, "...hearing perspectives that have been less available is imperative from the standpoint that it allows for an expanded dialogue with prevailing ideas as a matter of equality." He insists that he is not the facilitator of such equality, but that the authors "establish their own authority to be read and appreciated" (Biklen, 2005, pp. 5, 17).

DSE scholars, such as those whose research is discussed above, encourage readers (including students, developing educators, scholars, professionals, and parents) to expect first person accounts of students' experiences and when they are not present, note—or, moreover, feel—that absence (Connor, 2007; Solis & Connor, 2008). In other words, DSE acknowledges the importance of working to comprehensively include student voices as the expectation for, not the exception to, the rule—also providing the theoretical and methodological tools with which to navigate what is, unfortunately at this point, uncommon ground (Ferri, 2008). As models and motivating forces, the pioneers of this field continually call attention to the fact that the lived experiences of students need to be documented so that there can be a more thorough

understanding of how they move through and interact with the world. They also call for a growing corpus of “counter stories” to those narratives that have otherwise been built (up) around students with disabilities (Connor, 2007, p. 3).

Given my inquiry’s focus on the experiences of high school students with autism who type to communicate, and the gap in the research on this pivotal time period in these students’ lives, I view addressing this void as particularly fertile ground and in urgent need of exploration. If we look to students as valuable resources in the construction of educational opportunities and experiential elements of adolescence, we cultivate schools and communities where all, including students who communicate differently, have a say and are valued. An important reminder in this effort is Thomas’ (2005) assertion that, “All stories have something to teach us. What is most important is to learn to listen, not simply hear, the words that storytellers have to share” (p. 241), capturing the necessity of this endeavor. However, I would add in this case that not only do the contents of these students’ narratives “have something to teach us,” but that we also have much to learn about “listening” from the mode through which they must/choose to tell those stories.

Where Does that Leave Me/Us?

I, like my inquiry, reside in the liminal space of inquiring into lived and told experiences as they unfold in the midst (Clandinin & Connelly, 2000), while striving to maintain a critical DSE perspective that attends to the historical underpinnings, intersecting identities, and contextual factors grounding those experiences. Educational opportunities for individuals who use AAC have vastly improved over the last two decades (Light & McNaughton, 2012b). Education is now an expectation and legalized obligation (IDEA, 2004). The push for inclusion and the cultivation of peer relationships have become more forceful and widespread, with communication access theoretically championed as critical to that process (Ashby & Kasa, 2013;

Kasa-Hendrickson, 2005; Kunc, 1992). Yet much of the discourse around communication in schools remains centered on access and best practices (Calculator & Black, 2009). There is far less analysis aligned with DSE perspectives (Ashby, 2010; Kasa-Hendrickson, 2005; Broderick & Kasa-Hendrickson, 2006), of communication as a human right (Light, 1997; TASH, 2000; Williams, Krezman, & McNaughton, 2008), a social construct (Hall, 1997), and a means to cultivating community or a politicized identity (Hunt, Hirose-Hatae, Doering, Karasoff, & Goetz, 2000; Strully & Strully, 1985). Communication is not commonly discussed as a social justice issue in and of itself. I feel strongly that it should be.

During a TASH keynote panel presentation (Leadership Panel on Inclusion, TASH 2012), Norman Kunc convinced me I am not alone. Making a convincing and impassioned case for the power of communication, he articulated its importance to the educational lives of students and argued that communication is a vehicle of power and an absence of power serves as a barrier to exerting agency. His most striking message was succinct, but cogent: “When you don’t give people the ability to communicate you undermine their ability to achieve power. Inclusion without power leads to benevolence” (Kunc, 2012). We have seen benevolence before; DSE aims to move away from it, towards empowerment, agency and community. Prioritizing and reconceptualizing the diversity of communication as intensely political and a critical element of community is a step in the right direction.

But how? It is one thing to say that we have to bridge theory and practice related to the experiences of individuals who communicate in alternative ways. Such sweeping statements are easy to put on paper. It is a goal worth stating here, but if such a bridge exists—now or in the future—its purpose should not only be to act as a joint between theory to practice, but to form a pathway to be continually traversed back and forth from the critical to the practical, victories to

challenges, and the personal to the political. It must be a structure strong enough to hold us all as we (re)explore these uncertain and often overlooked territories of inclusion, identity, and community with and between individuals across a range of communicative diversity. In line with DSE and narrative inquiry methods (see Chapter 2), I look to these individuals' stories—the experiences that often result from and are reflections of such uncharted territories—as the blueprints. I also acknowledge that to do so in a world that privileges speech, associates the absence of such as an indicator of inferior intellectual ability, and moves at a pace faster than typically affords for messages to be conveyed in augmentative and alternative forms—this takes work. That said, as a friend, researcher, educator, and community member, I believe it is work worth doing, and I thus embark on my inquiry from t/here.

While writing in a coffee shop I had never been to before, I felt like giving up. Sick of citations. Tired of talking about others' ideas, certain that I have nothing to add to them. Straying from my point. Losing sight of my purpose. Convinced that I don't belong (t)here, shouldn't be doing what I do. Feeling the fraudulence of the last too-many-to-admit years of grad school oozing out through my skin for my fellow caffeine consumers to see. All this while sipping black coffee calmly—staring inquisitively at my computer screen through my wire rimmed readers that blur everything else around me—looking quite poised, I am sure.

How many years of school would it take to become an interior designer, instead?

If it is not yet abundantly clear, I was knee deep in this literature review; a “write of passage” (Noy, 2003) I'm convinced was invented to test the patience, commitment, endurance and the ability to metabolize large amounts of caffeine of budding scholars like myself. It is an endeavor that consistently challenges us to not do what I did: to not lose ourselves in the past, but securely situate ourselves in the future of the fields. Yet with the voices of scholars who have seemingly done-it-all swirling in my head, my own words—and conversations with them—became hard to form. I lost my voice.

The irony is that I was writing about student voices. I was reviewing work done—and attempting to articulate what has not yet, but soon will be written—about students with disabilities who communicate in alternative ways. I was in the midst of identifying “promising practices” related to their access to secondary education and grappling with the realities I have experienced that tell me that for some adolescents I have known whose disabilities preclude them from using speech, inclusion in high school is contingent. Or non-existent. I was fighting with my memories as they flashed before, threatening to distance me further from my work: that table there, then not; games of mum-ball (Anne's favorite) building relationships and engaging with content all at once, but only until grade 5; the way that Anne threw (still throws) her shoe at me, a reminder that she's got my back. I was wondering how to merge my personal observations and

experiences about inclusion and exclusion with literature that starts from the point of assuming either one or the other. I was struck by the absence of discussion about why planning for and welcoming communicative diversity in high school matters, but convinced it was too big a conversation for me to start. Abandon ship; I wonder whether I could cut it as a barista?

My Pandora radio station—the white noise blocking out the white noise I sought by working at the café—had long ago stopped asking, “are you still listening?” despite the firm placement of the buds in my ear. My coffee was cold in a paper cup that cautioned, “Contents may be hot.” And then my computer faded to black, exposing the blankness of my stare. But as my glazed eyes remained fix on the unlit square in front of me, that dark, empty space filled with something new: a glimmer of white font reflecting off its surface, or emerging from the depths of its vacuum. I couldn’t tell.

What was so wrong with that broadcast journalism degree I decided not to pursue?

And then I realized I was being ridiculous. I closed my computer, put it in its case. I gave up and told myself I would try again tomorrow. And as I turned around to my left to unplug my self laptop, the swirly white font I saw on my black screen was right there, hanging on the wall:

How to Build Community

Turn off your TV

Leave your house

Know your neighbors • Greet People

Look up when you’re walking

Sit on your stoop • Plant flowers

Use your library • Play together

Buy from local merchants

Share what you have • Help a lost dog

Take children to the park • Honor elders

Support neighborhood schools

Fix it even if you didn’t break it

Have pot lucks • Garden together

Pick up litter • Read stories aloud

Dance in the street

Talk to the mail carrier

Listen to the birds • Put up a swing

Help carry something heavy

Barter for your goods

Start a tradition • Ask a question

Hire young people for odd jobs

Organize a block party

Bake extra and share

Ask for help when you need it

Open your shades • Sing together

Share your skills

Take back the night

Turn up the music • Turn down the music

Listen before you react to anger

Mediate a conflict • Seek to understand

Learn from new and uncomfortable angles

Know that no one is silent

though many are not heard

Work to change this.

As I read down the list—twisted in my chair and mid-unplug—naturally, I started evaluating myself.

“Yup, I buy from local merchants at the farmer’s market.”

“Score! I brought that lost dog to its owner last week.”

“Hm. I talked to Doug the Mailman last year, but promptly deleted the phone number he gave me. Does that count?”

“Wow, my Gram really had the ‘listening to birds thing down.’ Hopefully it is hereditary.”

“I always sleep with the shades open. I even wrote a college paper about it. Nailed it.”

“I think I need to work on ‘seeking to understand.’”

And along the way I concluded that I was indeed a pretty good community member. Do you need a graduate degree to do grassroots organizing?

But when I got to the bottom, I paused. I felt guilty for my self-centeredness, then thankful for the reminder: “Know that no one is silent though/many are not heard. Work to change this.” The words shot through my retinas and made a beeline to my heart. I smiled at my fortuitous encounter with this sign; I can hear James Haywood Rolling, Jr. assuring me of the serendipitous nature of this event. In this café. Today of all days. After, only after, I had given in to the pressure. Lost my cool. Lost sight of my convictions. Lost faith in myself.

The point? I’ll always be working on it. But it has something to do with—and is rooted in—this sign’s purpose: community. If I am reading, researching, writing about, and enacting inclusion of certain “voices” in certain settings, am I not also talking about the fundamental nature of belonging-to-something? Of cultivating communities? And doesn’t school provide unparalleled opportunities to do so? Doesn’t community hinge on communication? And doesn’t that, in and of itself, reveal why we should care about who gets in, who speaks up (out), and how they use their voices in educational settings?

It is probably deeper than that. And I will probably need some citations. And caffeine. And some partners to journey with me as co-inquirers. But at least I can keep working on—toward—my purpose. My place. My (our) voice(s).

CHAPTER 2: METHODS

As will be described in this section, narrative inquiry is a relational methodology in which researchers (inquirers) and participants (co-inquirers) enter and co-exist in the midst of each other's lives. Narrative inquirers cannot be separated from the phenomena they study, but instead come to participate in and help shape the landscapes of their inquiries. In light of this, I begin this section with my own "narrative beginning" (Clandinin, 2013), an account that provides insight into both my identity as a researcher and the background of my inquiry. I then recount my experience in what was intended to be the pilot study for my dissertation and discuss its evolution leading me to explore narrative inquiry as a methodological framework. I follow this with an extended consideration of voice in qualitative research and examples of studies that have problematized and pushed the boundaries of such. I conclude with an account of my data collection and analysis processes.

A Narrative Beginning

"...What you need to know about the next piece is contained in the last piece. The place to learn about your materials is in the last use of your materials. The place to learn about your execution is in your execution. The best information about what you love is in your last contact with what you love. Put simply, your work is your guide: a complete, comprehensive, limitless reference book on your work. There is no other such book, and it is yours alone. It functions this way for no one else. Your fingerprints are all over your work, and you alone know how they got there"

—Bayles & Orland, *Art and Fear*, pp. 35-36.

This study starts with a page from my "book;" a set of experiences and stories that have steadily—though often circuitously—guided me toward the spaces in which and people with whom I belong. It is a "reference" I have long resisted seeing as (academically) relevant, but which I am coming to respect and trust as unapologetically inseparable from my "work."

I don't know when I realized just how important narrative is to me. It might have been when I was a kid and would write pages and pages of stories based on my daily (and very

mundane) experiences, but always told through fictionalized eyes of a character with a much cooler name, like “Annabelle” or “Victoria.” Maybe it was when I was in high school and decided that a worthwhile goal to work toward (in between homework and cheerleading, of course) was to write down my Grandmother’s story about being a German war-bride, immigrating to America, losing her husband to a tragic early death and remaining the most positive and passionate woman I knew. Maybe it was in college when I started choosing to read memoirs for fun. Or maybe, probably, it started when I met my friend Anne when I was seven. I once jotted down the thoughts that I had never admitted, but always remembered:

[At first, I thought she might be deaf. I think it was the only disability I thought existed. Everyone who was not like me must be like Helen Keller. Obviously, that’s why her mom was always around...a modern day Anne Sullivan. That didn’t last long. I walked up to the side of her wheelchair, my seven year old girlish frame barely taller than her armrest, and yelled [What did I yell? Does it matter? I yelled]; watching for a sign that my message was received. Her piercing not-blue-not-green eyes told me it was, and they told me to quiet down. They told me she hears (is) just fine and that we could be friends as long as I remembered that. They smiled right along with her mouth and I felt like the luckiest girl in the world, to learn a secret language that I thought no one else could hear.]

Over the years (decades), I have come to shape my personal and professional goals around the things I have learned from and experienced with Anne. Starting at probably too young an age to be believable, I became keenly aware of the systems at play that deem her somehow “less than” me. I have strained my eyes and ears and brain and heart to not only piece together her perspective as she chooses to present it, but also to understand the meaning behind the varied responses to her—body, voice, presence—in the spaces we occupy together. I have become angry and frustrated and sad and confused time and time again that those around us—the ones whose gazes linger too long, or the parents who tell their kids (loudly) not to stare—don’t know, or don’t care to know, her story. I have become impatient with the impatience I see in these places where efficient forms of communication are prioritized; crowding out those who must, or

choose to, take a little longer to figure out, or be figured out by, what they have to say and how to say it.

So when I met some other people who share similar communicative experiences with Anne, I wanted to know their stories. I wanted to learn to understand them and their ideas. I also wanted to share with them my perspective; tell them what it feels like to be in my position—an uncomfortable place rife with perceived corporeal and cognitive privilege—and try to better understand theirs. I wanted to acknowledge that I know what kinds of assumptions are made about them, as well as about the choices I make to surround myself with friends and colleagues whose communication systems and behavioral tendencies often result in distance between themselves and others. But I also wanted to acknowledge that I do not know what that distance feels like. I cannot articulate how it feels to not be able to communicate without support; to not be able to share my thoughts with those who don't know how, don't have time, don't care to listen. I do not identify as having a disability, and I cannot relate to what it's like to have no choice about being perceived with that identity at the fore. The opportunities I have been presented in life—educational, relational, professional, familial and otherwise—have not hinged on my ability to prove myself smart or well-behaved enough to meet expectations placed upon me. Theirs have. No one looks at me while out with friends or family members and assumes that those who accompany me must be paid to be there—providing a service by being in my presence. However, I know that when I am out with my friends who look and talk and eat and move differently, I am assumed to be the service provider, the benevolent volunteer, the obligated family member. When I am at a loss for words, people wait for me to find my voice. When Anne, or others like her, cannot form words with their mouths, people assume they have no voice worth waiting for.

I know these things are true because I have lived and witnessed them, but only from where I stand as a conventional communicator whose body does not challenge traditional conceptions of ability. I know these things because I have chosen to stick with those on whom so many have given up before they even start to get to know. But this is all I know. For now.

Background of the Inquiry

This study grows out of these experiences and interactions. When I came to this University, I did so with knowledge of, and an intention to contribute to, its history of supporting individuals with complex communication needs. I came here looking for more people with experiences like mine and Anne's. I came here looking for validation that our stories are part of a larger fabric of narratives about diversity, inclusion, identity, friendship, and community. It did not occur to me that I would become part—meet and make friends in—that community of people whose lives would unfold alongside and intersect with my own. I did, and they have.

It thus seemed a natural step for me to focus my research on the inclusion of individuals who use augmentative and alternative communication (AAC) in school. My position as Research Assistant at the primary research and training Institute on facilitated communication in the United States afforded me opportunities to cultivate these relationships and become immersed in—part of—a community of individuals who type to communicate and their families, whom I envisioned looking to as resources in this research process. Yet even before doing so, my participants quickly presented themselves to me when I learned that three of these local typers,¹⁵

¹⁵There are a variety of ways that individuals who type to communicate using FC have been referenced in both literature and in practice, including “FC Users;” “supported typers,” “AAC users,” “individuals who type to communicate.” While I recognize and respect the rights of individuals, families/supporters/allies and researchers doing this work to self-select terminology, for consistency I have chosen to maintain the use of either “typers” or “students who type to communicate” within this dissertation, reflecting the ways that the students described themselves and/or were most consistently described by those closest to them.

Martin, Carlee and Ralph¹⁶—all adolescents between the ages of 16 and 18 who carry the label of autism—were attending (and being academically included in) the same public high school: Cedarbridge. A year later, this group expanded to five when twin brothers, Peter and Henry, transferred into Cedarbridge seeking similar supports. Most striking was the fact that all but one of these five students moved into the school solely for the inclusive and communicative supports the district was gaining a reputation for. Though Martin had been educated in this district since Kindergarten, Carlee and Ralph enrolled in the high school over the course of two years (Carlee in Summer 2011, Ralph in 2012) after their families, frustrated with a lack of academic and communicative access provided in each of their respective home districts, relocated to within Cedarbridge’s zoning boundaries. These events coincided with an increased awareness and support of Martin’s communication, which was not comprehensively in place until middle school. In Fall 2013, during the time I was conducting what I refer to as Phase 1 of this research (see Data Collection section), twin brothers Henry and Peter transferred in to Cedarbridge for the same reasons and separately joined my inquiry over the course of that year. Though the idea of families taking drastic, geographic measures to secure better educational opportunities for their children is not a new phenomenon, particularly in relation to inclusive education (Kluth, Biklen, English-Sand, & Smukler, 2007), this influx of students seeking such similar supports sparked my curiosity about these students’ experiences.

Participants/Co-Inquirers

Before I proceed, let me introduce the students, my co-inquirers (see also Table 1). Despite the fact that I did not engage in an intentional sampling process, the five students in this study are a relatively diverse group, consisting of one female and four males, one of whom

¹⁶ All names of participants, schools, and locations are pseudonyms. The students selected their pseudonyms, a process described on p. 69.

(Ralph) was born and raised in India and two (twin brothers Peter and Henry) whose parents immigrated from India to the US prior to their birth. Martin and Carlee are both white and of European descent. Their families come from a range of backgrounds and are marked by relative degrees of social and financial capital. All five students ended up at their current location after years of varying levels of segregation, misjudgment about their competence, and lack of consistent access to communication; their intersecting journeys were each impacted by their own and their families' advocacy efforts for more equitable educational opportunities. Since part of this inquiry's purpose is to highlight these five students' experiences and stories, they will introduce themselves more thoroughly through their individual narrative accounts in Act II. However, the brief introductions below serve as a means to familiarize you with each student through glimpses of their distinctive personalities and priorities, in their own words. They also, perhaps most importantly, suggest the spaces not known to me (and maybe, also, to them?).

My name is Henry Golden.¹⁷ I am a tenth grader at Cedarbridge High School. I am really trying to be young man as each day goes by. A real passion of mine is philosophy. I love reading books which is a back bone of my life. Real yearning of mine is to learn meditation from a real guru; waiting for one to ace my wants, anvil my anger, and rid my hatred. Want my asking for ascending spiritual ladder really a great guru. With lots of love and support from my family and school really I'm able to ride the tumultuous waves of my life.

I am Peter V. Golden.¹⁸ Even though I can speak, I prefer to type to express my true thoughts. I recently started regular ed at Cedarbridge High School. I love real education and the possibility of a real diploma is exciting for me. Of course in my own life, I am able to communicate to my parents and family better. I each day thank God for the blessings that have happened in my life. Really in all of my life, I have never been happy like this.

Hi my name is Carlee Sanders. I go to Cedarbridge high school. I type. I cannot speak. I'm a deep thinker and feel emotions strongly. My autism is who I am. I love painting my

¹⁷ Henry and Peter are twin brothers.

¹⁸ Having speech, although repetitive at times, it was assumed that that was Peter's preferred and most efficient means of communication. However, when he expressed the desire to learn to type alongside Henry, it became clear that typing with support opened up a communicative channel not previously experienced by Peter.

feelings trying to really show thoughts coming out through my hands. I love photography it makes me feel immortal and at the same time ephemeral it captures instants of life to remember forever. Being in my world is to do problem solving all the time. I'm really happy to be in high school and have lovely people everyday who help and support me. I strive to get good grades. My ability to do this has to do with my team at school. School is a great place to be. Finding those who can see past my sometimes odd behaviors is difficult. I want to be accepted for me just like anyone else. My goal is to become an advocate and teach people to love autism.

I am Ralph Wibble of a country called India on the other side of the globe. I am high school student in Cedarbridge school district. I have great divine things to fit in my life after coming here to this great country, especially my communication through typing and through acquiring knowledge by study of subjects. I like many things about school. My intelligence is recognized and am able to access all inclusive [General Education] level classes. It gives me confidence at being seen as any teenager and not a person with a label. I advocate equality and justice for people of all abilities. I am forgetting to say that I have autism but would add that you need to ignore my weird behavior resulting to this. Needless to say I love meeting people and making friends and doing activities like hiking biking swimming and skating. Someday, I want to be an accountant.

My name is Martin LaMuncha. I have gone to the Cedarbridge district all my life. I love school! I want to go to college and study law. I have had a great deal of support from a lot of people. Although, I have made many advances academically, the social piece is still hard. I still have a hard time making friends. The Ipad has changed my life! It has given me a voice. Now with the help of my support person, I can type and be heard! Education is the key to the world understanding Autism!

Pseudonyms. Because this inquiry centers on the purpose of privileging the perspectives and experiences of these students as my co-inquirers, it was fitting that they be given the chance to choose their own pseudonyms. At the end of my time in the field, I individually asked each student (in person via Google Hangouts) to choose a name, and express their preferred terminology around autism, that I could use when writing this dissertation:

- Casey:** 1) As you may know, some people with autism or other disabilities prefer to be referred to with person-first language, for example "I am a person with autism." Others prefer to center their autism or other disability as a primary part of their identity, for example "I am an autistic person." How do you prefer to be described? If there is another preference you have, let me know.
- 2) To maintain confidentiality in writing my dissertation, I'll use pseudonyms (fake names). Often researchers choose these for their participants, but I'd love it if you would tell me what name you'd like me to use. You can give me just a first name if it is easier and I can make up the last name, or you

can give me both. It can be a completely random name, or a name that has meaning to you (i.e. the first name of a childhood friend) Or, if you just want me to make it up for you, I can. But I want this to be your choice.

To my surprise, despite their diverse national and ethnic backgrounds, all of the students selected seemingly Western names. I was left with the choice between honoring their preferences and encouraging them to (re)select pseudonyms that more closely aligned with what I knew to be their ethnicities. Really it was not much of a choice. I used their self-selected pseudonyms, and consider it an interesting phenomenon that I acknowledge as potentially reflective of their contextual, social, and temporal realities at that time.

Table 1: Student participants

Name	Age at beginning of study	Grade entered Cedarbridge	Observed Range of Physical Support Level¹⁹	Educational Label	Preferred Language
Martin LaMuncha	18 years/11 th Grade	K	Elbow- Upper arm	Autism	Person with autism
Carlee Sanders	16/10 th Grade	9 th	Shoulder - No touch	Autism	Autistic person
Ralph Wibble	18/10 th Grade	10 th	Shoulder- No touch	Autism	Autistic person
Henry Golden	16/9 th	9 th	Forearm-Elbow	Autism	No preference
Peter V. Golden	17/10 th	9 th	Wrist-Forearm	Autism	Person with autism

While this inquiry centers on the experiences of the five student co-inquirers, there were also a number of family and school personnel who not only impacted each students' experiences, but also participated in the research through interviews, observations, and/or collaboration.

¹⁹ Information in this column indicates the location on the student's typing arm where I observed his/her TA/Facilitator providing support. A range is provided to account for the fluid nature of the support I saw over the course of this inquiry. Overall, I noted that the students tended to require less physical support (i.e. higher up on the arm, or no touch) while working on structured, short activities and responses, while open-ended conversations and tasks required increased physical support (i.e. lower on the arm).

Table 2 describes each individual, their primary role, and the student(s) with whom they worked and/or were associated. Unlike the students', I selected pseudonyms for adult participants.²⁰

Table 2: Family and educational staff participants

Name	Role	Associated Student
Ms. Lara Sanders²¹	Parent	Carlee
Mr. Don Sanders	Parent	Carlee
Ms. Vicky LaMuncha	Parent	Martin
Mr. Jeff LaMuncha	Parent	Martin
Ms. Sati Wibble	Parent	Ralph
Ms. Veeda Golden	Parent	Peter and Henry
Ms. Sue Grecco	Teaching Assistant	Martin/Ralph/Carlee
Ms. Erin Roland	Teaching Assistant	Carlee/Henry
Ms. Molly Hamden	Teaching Assistant	Martin/Ralph
Ms. Kayla Kozlow	Teaching Assistant	Carlee/Peter
Mr. Daniel Meyer	Teaching Assistant	Henry
Ms. Paula Hotchkins	Teacher- Earth Science* ²²	Martin/Carlee/Ralph
Mr. Mark Hotchkins	Teacher- Environmental Science*	Martin/Ralph
Mr. Kevin Connor	Co-Teacher- Earth Science	Henry
Mr. Jacob Richards	Co-Teacher- Earth Science	Henry
Mr. Josh Ferretti	Teacher-Business Law*	Martin/Ralph
Mr. Jack Mason	Teacher- Global Studies **	Carlee
Mr. Carl Williams	Co-Teacher- Biology*	Martin/Ralph
Ms. Maura Collins	Co-Teacher- Biology*	Martin/Ralph
Ms. Sheila Sousa	Teacher- Global(long term sub)**	Martin
Mr. Stan Smith	Teacher- ELA**	Martin/Carlee
Ms. Jane Engelman	Teacher- ELA**	Martin/Ralph
Ms. Angela Kessler	Teacher- ELA*	Carlee

²⁰ You'll notice in Table 2, and throughout the dissertation, that the participation of the co-inquirers' mothers outweigh that of their fathers. I felt and continue wrestling with that imbalance as well. Though all five of these students' fathers were/are present and involved in their lives, it was the mothers who primarily took responsibility for endeavors related to school; this inquiry project was one of them. All of the fathers were invited to participate, but either due to work schedules, language barriers, and/or deferral to their wives, most of them were not as involved in this study as the co-inquirers' mothers. I know from becoming familiar with all of these families, that this is not the case in other parts of their children's lives. The two fathers listed on the table, Jeff LaMuncha and Don Sanders, are so because they were interviewed (Jeff LaMuncha) or opted to write about their experiences in lieu of an interview (Don Sanders).

²¹ Full names (pseudonyms) are listed on this table. However, for clarity students are referred to by first name only, while family and educational staff are referred to as Mr. or Ms. (surname) throughout the dissertation.

²² * Indicates a General Education classroom; ** Indicates a Prioritized Curriculum classroom

Table 2: Family and educational staff participants cont.

Name	Role	Associated Student
Mr. Dylan Waring	Teacher-Creative Writing*	Martin
Mr. Pat Romano	Teacher-Clay*	Peter
Ms. Rhonda Rizzo	Teacher-Cosmetology*	Carlee
Mr. Steve Peters	Head Teacher- 2012-2014	All students
Ms. Monica Farber	Head Teacher	All students
Ms. Leslie Adelstein	School Psychologist	All students
Ms. Brittany Tanner	Speech Language Pathologist	All students
Ms. Kerri Cipriani	Administrator- Director of Special Ed	All students
Mr. Gary Grazioli	Administrator- Vice Principal	All students
Dr. Dalia Desimone	Administrator- Superintendent	All students

reCollection of Data: Phase 1²³

Setting out to privilege the voices and stories of these students—to hear from them and the stakeholders who support them—about what it *means* to be an adolescent with autism who types to communicate in high school, I utilized qualitative methods (Bogdan & Biklen, 2007) to collect data between Fall 2012 and Spring 2014. Because this study grew out of a project that Carlee, Ralph, and Martin were participating in through the research Institute at which I served as a Research Assistant—a study on the development of independent typing skills that I helped design and conduct—IRB approval had already been secured. I amended our original IRB and continued to renew it over the course of my inquiry. I also received approval from the Cedarbridge district that remained active throughout. Following these approvals, a combination of formal and informal qualitative interviews (Bogdan & Biklen, 2007) with students, team members, and parents, videotaped classroom observations, self-representational artifacts (i.e. personalized PowerPoint presentations), academic work, reflective follow-up interviewing

²³ I recognize that it is unusual to discuss data collection methods prior to describing my methodological framework. However, my choice to do so here is an effort to help the reader understand how and why my methodological choices were informed by this initial data collection experience.

around significant moments captured on video, researcher memos, and email correspondence began to build into what I intended to extend into my dissertation study.

Yet, as I sifted through, analyzed, and attempted to write my research apprenticeship manuscript on the inclusive experiences of these high school students with autism who type to communicate using the corpus of data I had collected, it became increasingly clear that despite fervent assertions about my focus on the students' voices, the professional and parent perspectives predominated. My study was becoming just like those I aimed to resist that hinge on adult interpretation of student experiences. In reflecting on my methodological choices to date, I confronted the reality that no matter how hard I tried to be informal during what I had been referring to as "check-ins" with students, those get-togethers often felt like formal interviews. This was partially due to the nature of their communication and need for a certain level of structure, which often yielded what seemed like quick-fire question and answer sessions. I was also faced with a striking imbalance of typed (student) versus spoken (adult) interview data, the latter far outweighing the former in terms of the quantity of text produced per conversation.

Having interacted with each of these students previously (some, for years) as part of the local community of typers and after continuing to see them often in spaces not initially included as "sites" of my research, I felt that I had come to know them well. Yet I was not seeing the richness of their unique personalities come through in my data and initial analysis. Instead, our conversations often centered on, or came back to, either academics or the difficulties of social interactions; they never yielded enough information to suggest the meaning of those experiences for the students or how that meaning is manifested within their conceptions of themselves and their lives. I also worried that the students felt pressure to answer my questions in certain ways, or did not feel comfortable (convinced of my interests in?) their *stories* and *experiences*.

I therefore began thinking about and seeking out different ways to engage with the students moving forward. In the Summer of 2014, Phase 2 of this research, I piloted a student Inquiry Group with the help of a colleague and faculty member, Beth Myers, which helped me to explore and develop a plan for the remainder of my inquiry. We modeled this Inquiry Group on Myers' (2012) dissertation research, which focused on how adolescents with autism navigate identity through autobiographical work produced during weekly meetings in an afterschool Inquiry Group centered on crossing boundaries of identity and media. Myers' group used varied, collaboratively determined modes of representation including: writing, drawing, photography, video and multimedia projects. Aligned with my own intentions for this inquiry, Myers operated under an expanded conception of voice and story to include a vast range of communicative vehicles, which she captures in the term "narrative works" (2012, p. 46). Her work and our collaboration served as a starting point from which I (re)collected the remainder of this dissertation study data and continued cultivating my relationships with my five co-inquirers.

In the section that follows, I respond to the complexities brought forth in and by Phase 1 of my study with an exploration of the elements of narrative inquiry as the methodological framework that drove, and made room for, the research experience Martin, Ralph, Carlee, Henry, Peter and I worked toward, together, over the course of this inquiry. I begin with a discussion of what constitutes "story," followed by a description of the theoretical grounding and primary tenets of narrative inquiry. I then consider—and aim to trouble—the notion of voice as it relates to qualitative methods in general and narrative inquiry specifically. Finally, I look to existing studies that have spent time traversing within and across these boundaries while engaging with methods and voices considered to be "transgressive" (Mazzei & Jackson, 2009, p. 4).

Exploring Narrative Inquiry

The story depends upon every one of us to come into being. It needs us all, needs our remembering, understanding, and creating what we have heard together to keep on coming into being. The story of a people. Of us, peoples.

- Trinh T. Minh-Ha, 1989, p. 119

Experience in/as Story

Narrative inquiry is an approach to qualitative research that hinges on and values story and experience, including all the ways that they interact and intersect. As Clandinin and Caine (2013) explain, narrative inquiry is "...first and foremost, a way of understanding experience. It is also a research methodology. It is, then, both a view of the phenomena of people's experiences and a methodology for narratively inquiring into experience" (p. 166). While the storied nature of existence is not a new phenomenon, the consideration of story *as* a research phenomenon is:

Human beings have lived out and told stories about that living for as long as we could talk. And then we have talked about the stories we tell for almost as long. These lived and told stories and the talk about the stories are one of the ways that we fill our world with meaning and enlist one another's assistance in building lives and communities. What feels new is the emergence of narrative methodologies in the field of social science research (Clandinin & Rosiek, 2007, p. 35).

The interplay of experience and story is one that is both pivotal to and difficult to define in descriptions of this methodology. While the terms "narrative" and "story" are often used interchangeably and carry multiple meanings across fields (Riessman, 2008), central to an understanding of narrative inquiry as methodology is the fundamental belief that "...humans, individually and socially, lead storied lives" (Connelly & Clandinin, 2006, p. 477). We carry

with us and (re)construct our stories in relation to others in narratives; fragments of the past, of ourselves, and of our circumstances that are braided together toward the goal of co-constructing our situated and storied identities (Clandinin & Connelly, 2000; McAdams, 1993; Rolling, 2004; Rolling & Brogden, 2009).

For the purposes of this inquiry, my own and my co-inquirers' stories are rooted in narratives comprised of any combination(s) of: observational field notes, shared experiences, interview transcript-maps, interaction, artifacts, email correspondence, self-(re)presentations, art and art-making, non-verbal expression, etc. Following from Mishler's (1999) hesitancy to "police the boundaries" of narrative inquiry as a methodology, I see it as less important to narrowly define the sources and forms that count as data (field texts) or, ultimately, as final research texts. Rather, it is more salient for me to focus on the underlying foundation for valuing and facilitating co-constructive, relational understandings of experience through research, operating under Richardson's guidance that:

If we wish to understand the deepest and most universal of human experiences, if we wish our work to be faithful to the lived experiences of people, if we wish for a union between poetics and science, or if we wish to use our privileges and skills to empower the people we study, then we should value the narrative (1997, p. 35).

The Primary Tenets of Narrative Inquiry

While descriptions of narrative inquiry (NI) twist and turn, diverge and intersect within and across different studies and fields, the starting point is always to "value the narrative." The current understanding of NI as a methodology and phenomenon stems from a broader narrative turn in qualitative research (Chase, 2005; Clandinin & Connelly, 2000; Kim, 2016; Polkinghorne, 1988; Riessman, 2008). It has been informed by pivotal work around narrative

knowing and experience, including: Bruner's (1986) notion of paradigmatic and narrative knowing; Bateson's (1994) focus on the personal, relational and improvisational nature of anthropological inquiry; Carr's (1986) assertions of the narrative structure of existence; Coles' (1989) emphasis on narrative as life and the importance of trust; Geertz's (1995) use of the metaphor of the parade to emphasize positionality and the inevitability of change; MacIntyre's (1981) narrative unity; and Polkinghorne's (1988) struggle to bridge research and practice along with his discussion of distinguishing elements of explanatory and descriptive narratives. Each of these scholars have provided critical and informative works in helping to establish an understanding of where and what narrative inquiry is in relation to other forms of social research (Clandinin, 2013; Clandinin & Connelly, 2000). What follows is an extended analysis of the primary tenets and characteristics of narrative inquiry in educational research, which I draw upon in this inquiry.

Grounding in Dewey's theory of experience. Despite the importance of the aforementioned ideas in positioning narrative inquiry as a research methodology, it is Dewey's theory of experience (1944) that provides the ontological and epistemological framework that most clearly sets narrative inquiry apart as a distinctive approach in educational research, where I am situated. Based on Dewey's work, which characterizes experience as comprised of an interplay between *continuity*, *interaction*, and *situation* (Dewey, 1944), narrative inquirers understand "experience as a narratively composed phenomenon" (Clandinin, 2013, p. 16).

The principle of *continuity* relates to the idea that "every experience is a moving force" influenced by those experiences that have come prior and transformative of those that will follow (Dewey, 1944, p. 31). Continuity, then, illustrates the impact of experiences on other experiences and the self. The past, present and future(s) we embody and encounter contribute to the

emergence of and responses to our own and others' experiences. Continuity sets the stage for an understanding of experience as situated and a narrative inquiry as "in the midst" (described below). As Clandinin and Rosiek (2007) point out, "continuity is not merely perceptual; it is ontological. Experiences do not simply appear to be connected through time; they are continuous" (p. 40). An expectation of continuity, then, helps to position narrative inquiry as "an act within a stream of experience that generates new relations that then become a part of future experience" (Clandinin & Rosiek, 2007, p. 41) rather than an exploration into objective "truth" or invisible forces driving the experience itself.

The complementing principle of *interaction*—the "lateral" aspect of experience, intersecting with its "longitudinal," continuity (Dewey, 1944, p. 44)—captures the contextual nature of experience. As Dewey states, "An experience is always what it is because of a transaction taking place between an individual and what, at the time, constitutes his environment;" hence, it is composed of/by the negotiation of internal and external forces (p. 41). Experience is thus seen as the product of the interactions between individuals and their previous experiences, as well as the social, political, spiritual, relational, temporal, and material elements of their environment. Experience is conditional and fluid. Dewey's interaction principle provides the frame for narrative inquiry's emphasis on the relational nature of experience and contributes to the attention paid by researchers to their own positioning.

At a point of intersection between continuity and interaction lies what Dewey terms *situation*; this is the metaphorical and/or physical place of experience (Dewey, 1944). For narrative inquirers, situation is often the site of inquiry and evolves into the context within which further experiences emerge. In this inquiry, for instance, Cedarbridge High School is the overarching site of experience, comprised of a set of smaller contexts (i.e. classrooms and our

dialogic interspace; see Data Collection section). Based on Dewey's notion that situation is the junction of interaction and continuity, it also extends the meaning of experience to include the social and personal, becoming an amalgam of extrinsic and intrinsic factors (1944). This has contributed to the widely known call by Clandinin and Connelly (2000) for inquiries to move "inward and outward, backward and forward and situated within space" (p. 49).

Given this grounding within a Deweyan ontology of experience, over the last two decades, scholars at the forefront of this methodology have continually reflected on and reevaluated what constitutes narrative inquiry, (re)defining its position within and beside other research methodologies. The rootedness in Dewey's theory of experience has delineated narrative inquiry from other forms of social research that utilize narrative data, or engage in narrative analysis (e.g. Riessman, 2008). As Clandinin & Rosiek (2007) lay out, "Dewey's ontology is not transcendental, it is transactional. The epistemological implications of this view are nothing short of revolutionary," since the aim is the creation of new connections through, rather than an isolated depiction of, interaction constituting experience (p. 39). They add, "In this pragmatic view of knowledge, our representations arise from experience and must return to that experience for their validation" (p. 39), a helpful image that accounts for my own cyclic inquiring and writing processes. The focus on understanding the nuances of particular experiences—within which the inquirer her/himself is deeply entwined—differs from the aim of generalizability often sought in other research methods (Clandinin, 2013; Kim, 2016; Riessman, 2008). Instead, holding fast to Dewey's assertions, narrative inquiry is intricately tied to the relational and subjective nature of experience and the representation/reflection of it, a phenomenon that is in and of itself worth studying.

The three-dimensional narrative inquiry space. Uniquely situated within a Deweyan ontology of experience, narrative inquirers like myself position themselves and their inquiries in “three dimensional narrative inquiry spaces:” methodological locales comprised of the interplay between temporality, sociality and place (Clandinin & Connelly, 2000; Schaafsma & Vinz, 2011) (see Figure 1). While attention to these components of experience (known as “commonplaces”) is present in and central to other qualitative methodologies, what distinguishes narrative inquiry is “the simultaneous exploration of all three” (Connelly & Clandinin, 2006, p. 479). Since my time in the field as well as my writing processes hinged on—developed through—attention to these commonplaces, I describe each in detail using areas of tension encountered during my inquiry to illustrate how I approached engaging with these elements of the methodology.

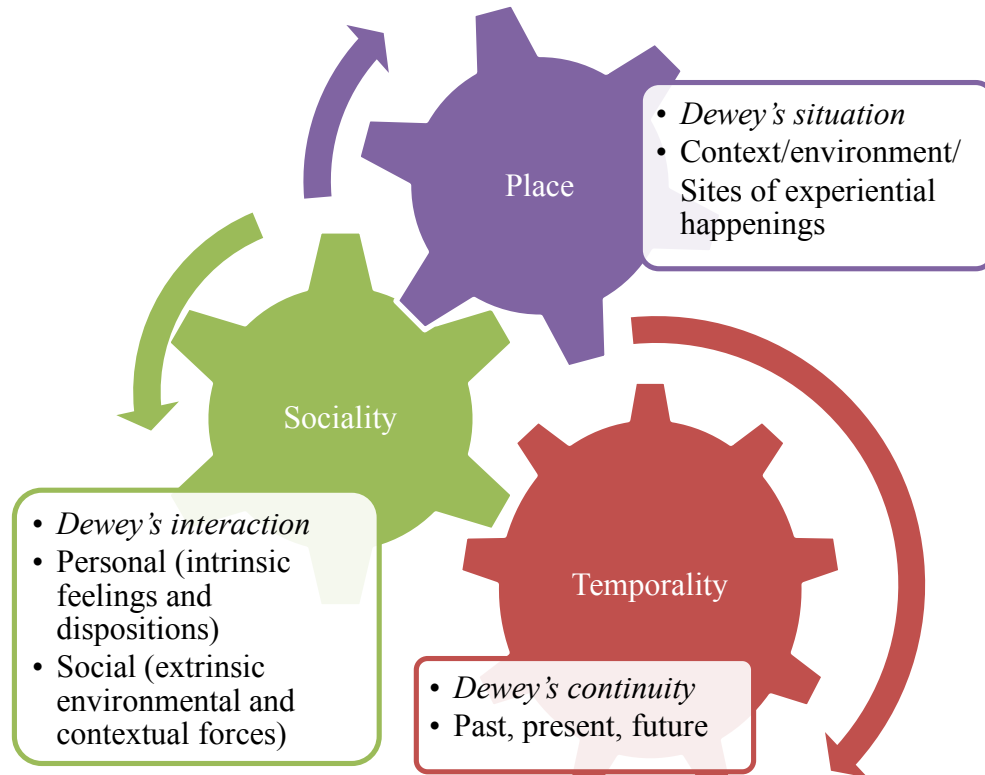


Figure 1: Narrative Inquiry Commonplaces

Temporality. The temporality commonplace most directly relates to Dewey's (1944) notion of continuity. It involves the understanding that a happening does not occur in a vacuum, but instead has a unique and interrelated past, present, and future. As Richardson (1997) aptly notes, "Everywhere, people experience and interpret their lives in relationship to time. Time is the quintessential basis for and constraint upon the human experience" (p. 29). If I, like other narrative inquirers, accept this as a given, then I must also consider "temporal histor[ies]" in order to fully (re)present an observed or (re)told experience (Connelly & Clandinin, 2006, p. 479). To do so recognizes that experiences are shaped in/by a continuous movement of time, in interaction with others' (institutional and interpersonal) lives.

The importance of attending to temporality emerged during this inquiry in both visible (my observed responses to) and methodological (my own rumination over) ways during instances of students' (perceived and self-described) challenging behavior. I use the experiences of co-inquirer Henry as an example, but want to be clear that elements of any of the co-inquirers' experiences could be used to illustrate this point in different ways. Henry began typing with support to communicate at age 14. His family enrolled him in Cedarbridge High School when his neighborhood school refused to support his communication method. Despite his newfound access to communication, his first days and months were marked by behavioral incidents that tested his support team at school. He ran through the hallways, damaged expensive audio-visual equipment, and did not demonstrate the respect for others' personal boundaries that was expected of students in this high school. He was, in the words of his head teacher at the time, "on a path of destruction." I do not aim, here, to evaluate the response to these incidents; the point rather is that these instances of behavior, considered temporally, become meaningful windows into collective experiences of Henry, his family, school staff, and myself as relational researcher.

Later, upon acclimating to the school and sorting through the transition into his new home, Henry articulated through typing that much of his behavior resulted from him “forgetting [he] has a voice” and wanting to acclimate to school and academic expectations faster than his body (and subsequently the school staff) would allow. After 14 years of communicating solely through his behavior, Henry found it a difficult habit to break. Yet, how differently does Henry’s initial transition appear when considering his “temporal history” and its implied future (Connelly & Clandinin, 2006)? What is gained when his behavioral manifestations—as temporal events—become framed by questions like: What happened between when Henry woke up and came to school, or the day, weeks, years before? What future do these behavioral niches also begin to carve out? Moreover, how are the responses to such questions framed by the temporal histories of those in immediate proximity to Henry at the time of the action? And what about the impact of my own history on this research story, as recipient of the (re)tellings of these incidents at this particular moment in time, rather than a year prior or a year from now? Henry’s behavior, in this context, can be understood temporally in that it serves to shape the event itself, as well as place experience within a continuum in relation to the experiences of others.

Sociality. The sociality commonplace characterizes attention paid to the personal, or intrinsic feelings and dispositions of participant and/or inquirer, and social conditions, or extrinsic, environmental and contextual forces, that impact experience. As Connelly & Clandinin (2006) note, this commonplace is particularly distinctive to narrative inquiry in that it:

...allows narrative inquirers to distinguish their studies from highly personal studies that focus mostly on a person’s thoughts and feelings... [and those] that focus mostly on social conditions that may treat the individual as hegemonic expressions of social structure and

social process. A narrative inquiry attends to both. The sociality commonplace reminds us of both. (p. 480)

In its emphasis on the contextual, co-constructed nature of experience, the notion of sociability is derived from Dewey's principle of interaction. By attending to the various social, cultural, political, institutional, familial narratives that frame and intertwine experiences and our narrative (re)tellings of them, we are helped in understanding both the contingent nature of events and the broader connections between the person(s) and the literal and figurative place (Clandinin & Connelly, 2000; Clandinin & Rosiek, 2007; Schaafsma & Vinz, 2011). The sociality commonplace situates narrative inquiry as an exploration into a particular experiential landscape, to be traversed through simultaneously moving (thinking) "backward and forward, inward and outward" (Clandinin & Connelly, 2000. p. 49). Additionally, sociality is the product of the relational nature of human existence, providing a means to exploring that which it represents. Narrative inquiries hinge on these relationships between inquirers and their participants, often even considering them, as I do, co-inquirers. In "bracketing themselves into an inquiry" (Connelly & Clandinin, 2006, p. 480), inquirers become part of the experiences they seek out; they, too, are a subject of or subject to the inquiry.

To illustrate this, I return again to Henry. I did not witness Henry's behavioral events during his initial transition to Cedarbridge; I was introduced to them only through my existing relationships with members of his support team at school. In fact, it was because of his ostensible difficulties transitioning to the school—and the team's stated challenges in supporting him—that I initially allowed the distance between us to remain. Though I had known Henry as part of the local community of typers for a year prior, he did not begin actively participating in this inquiry until one semester after arriving at Cedarbridge. Yet stories about him (primarily related to his

behavior) continually infiltrated those told to me by the other students and staff. Once he joined the inquiry and I developed a relationship with him and his family that was more grounded in their participation in the study, I learned from Henry's mother that the following sequence of events was also occurring around the same time that he entered Cedarbridge and was exhibiting such challenging behavior. She shared that Henry was in the early stages of learning to type after having no formal communication system for 14 years. His family had relocated across town from his childhood home to a rented apartment within the Cedarbridge zoning boundaries and away from the district that he attended K-8th grade; the staff there did not believe he was capable of the academic work that has since proven able to do. The family's rented apartment reeked of cigarette smoke, the carpets needed to be shampooed and deodorized, and the walls needed to be repainted within weeks of their initial move. Henry's grandmother and grandfather were also both hospitalized, pulling his mother's attention in multiple directions.

I knew from my year and a half spent at Cedarbridge that Henry entered the school as the fourth student who types to communicate. I learned from talking with Henry and his mother that staff at Henry's prior school used the (lack of) opportunities presented to him, in combination with his autism and absence of formal communication, as enough evidence of his incompetence to bar him from academic classes. Conversely, Cedarbridge staff and teachers assumed he was competent and that he would develop as a learner. Having supported three other students who communicated in similar ways for years, the expectations of Henry's academic and behavioral performance were quite high, based on what they had seen other students achieve. Again, I do not aim to interpret or critique here but simply to demonstrate the conditions surrounding Henry's transition experiences. What kind of narratives would he have told me during this time, had he been given the opportunity or been able to articulate his feelings? In comparison, how

does he reflect on those same experiences now? What impact did his home life, his internal anxieties and/or uncertainties, coupled with the school's high expectations have on his behavior? Although it is not relevant to the purpose of this inquiry to look at this issue from a cause/effect, past/present standpoint, placing it in the three-dimensional narrative space reveals that the relationships Henry did or did not have at this time cannot be separated from his experiences and my understating of them.

Place. Narrative inquiry's third dimension, place, accounts for "the specific, concrete, physical and topological boundaries of ... where the inquiry and events take place" (Connelly & Clandinin, 2006, p. 481). While the temporality and sociality commonplaces home in on more intangible contextual conditions, the notion of place draws the inquirer's attention to the distinctive sites of experiential happenings. This contrasts with directives that research move from the particular to the universal. Instead, discrete aspects of place contribute to the research event and are integral parts of the inquiry, uniquely linked to the experience of co-inquirers (Clandinin, 2013; Connelly & Clandinin, 2006). Guided by Native American poet and novelist Marmon Silko's (1996) words, "viewers are much a part of the landscape as the boulders they stand on" (p. 27), Clandinin (2013) helped me understand that the notion of place reveals that I cannot escape, and therefore should not ignore, that which surrounds me as an inquirer.

I've established that Henry's experiences navigating and responding to a new set of spaces are reflective of the temporality and sociality commonplaces, but they also are intimately related to place. Particular places act as characters in his story—physical constituents that he interacted both in and with at this point in his life. The spaces he entered as a result of his responses to those places are also players. For instance, in an effort to reduce the disruption caused by Henry's behaviors, he was not permitted to enter the small classroom, B13 (referred to

as “home base”) that the other students that type to communicate use during free time and study periods. Instead, a desk was placed in the small space that connects the doorways of the segregated Special Education room and B13; Henry literally sat in a space between—that defied—categorization. This small space—not a room, not a closet, not a hallway, but just a space between two other spaces—was determined to be his place for as long as his behavior continued to be problematic. It was there that he and his TA spent most days that semester working independently when he could not “make it through” a whole eighty-minute class block. Because he was located there, he was not even visually part of my inquiry at that time.

On a broader scale, Henry is a character in the story of this school: a place that has shifted and changed in response to and because of the students it has had to make room for. It is a place filled with a particular level of class privilege, marked by its suburban location and the fact that three of these four students’ families could afford to pick up and move (two of the three of them, without selling their existing homes) to secure enrollment for their children. And it is a place that, in an era of accountability and standardization, has demonstrated a level of flexibility in its physical and philosophical mapping that in many ways resists dominant educational discourses. It is also a place that in some ways represents and perpetuates those dominant narratives, as seen in Henry’s early experiences of conditional (physical) participation and normative expectations for behavioral compliance. It is a place, for those reasons, that attracted my eye as an inquirer as an interesting space in which to situate my study: an inquiry that ebbs and flows between the place (this school) itself and the experiences of those who navigate it.

Be[come]ing in the midst. The Deweyan ontological and epistemological underpinnings, which converge and interact to constitute the commonplaces of this methodology, also contribute to the importance of understanding what it means for an inquirer to enter in the midst of their

participants' lives, while acknowledging that the inquirer, too, is in the (often obfuscating) midst of uncertainties surrounding his/her own life (Clandinin, 2013; Clandinin & Caine, 2013; Clandinin & Connelly, 2000). Inquirers have to attend to the temporal, social, and place-related elements of *both* their own and their participants' lives. At the center of this vigilance around position is the notion that the lives we live are "nested...[So we] need to think about the ongoingness of institutional, social, cultural, familiar, and linguistic narrative in which each of our lives is lived and is being lived, which are also in the midst" (Clandinin, 2013, p. 44). Not only does narrative inquiry call attention to the contextual and contingent nature of experiences, but it also situates the inquirers' and participants' lives in a contiguous relationship, unfolding as part of the inquiry landscape.

Once initiated, at the core of a narrative inquiry is the researcher's aim "to obtain 'data' from a deeply human, genuine, empathetic and respectful relationship to the participant about significant and meaningful aspects of the participant's life" (Josselson, 2007, p. 539). This proximate relationship of the narrative inquirer to the site of inquiry and the lives of participants is both a distinctive element and the most common site of criticism of the methodology (Clandinin & Rosiek, 2007). In fact, the Institutional Review Board application process, grounded in a medicalized approach to disability and to research designs that privilege high levels of precision and efforts toward objectivity, frequently proves to be an area of tension for narrative researchers (Craig & Huber, 2007; Josselson, 2007). Yet, Connelly & Clandinin's (1990) account of experiencing the inquiry process suggests that this relational nature of inquiry, sometimes seen as problematic, is in fact at the core of its (our) being(s):

We found that merely listening, recording, and fostering participant story telling was both impossible (we are, all of us, continually telling stories of our experience, whether or not

we speak and write them) and unsatisfying. We learned that we, too, needed to tell our stories. Scribes we were not; storytellers and story lovers we were. And in our storytelling, the stories of our participants merged with our own to create new stories, ones that we have labeled collaborative stories. The thing finally written on paper (or, perhaps on film, tape, or canvas), the research paper or book, is a collaborative document: a mutually constructed story created out of the lives of both researcher and participant. (p. 12)

Here, the co-constructive nature of experience and being human blurs with and into the fluidity of a narrative approach to inquiry, revealing the necessity of drawing or highlighting the existing connections between the two. In order for this to happen, conventional expectations around research itself must be troubled and (re)shaped into a milieu to (re)position notions of authority, voice, and knowledge (Ashby, 2011; Lather, 2009; Mazzei & Jackson, 2009). In the following section, I begin that process by exploring—and troubling—conceptualizations of voice in qualitative research, specifically focused on the place of voice within narrative inquiry.

Troubling Voice

When I think about my position in relation to my friends, colleagues and co-inquirers who communicate in diverse ways, I think of the actions of catching and releasing. In an interactive instance (a conversation, an interview, a shared experience), I have two cyclic roles: 1) to put my contribution into the space between us and 2) to position myself to receive, grasp, the response to it before beginning again. Sometimes the latter looks a lot like a child attempting to catch minnows in the shallow part of a lake, with each excited movement of her impatient little limbs or splash of her plastic net startling and scattering the school of tiny fish. Other times, after some practice or when the moment is right, catching looks more systematic—like a photographer on safari who has shut off the sounds of her mind and camera and exercises the quietest of patience in the minutes, hours, days before the moment worth capturing presents itself. But more often than not, it looks a lot like Harry Potter playing Quidditch. Let me explain.

As the Seeker on a Quidditch team, Harry's sole responsibility is to catch—even if only for the briefest moment—the Golden Snitch, which is, in his words, “very small, very fast, and difficult to catch” (Rowling, 2000, p. 107). About the size of a walnut with tiny silver wings, the Snitch is enchanted to dart about and above the Quidditch field avoiding imminent capture by the Seeker, which marks the end of a game. Its size and speed make it nearly impossible for spectators to see from a distance and it is only through determined focus and purpose that the Seeker is able to spot, and subsequently chase, the

Snitch. Sometimes, after long and twisting pursuit the Snitch slips through the Seeker's fingers and flashes away through the air. The process thus begins again. Though it may seem that the Snitch and seeker are rivals, I would argue they are not. The Snitch maps the Seeker's course with its movement. It makes its presence known with the whisper of its fluttering wings and the subtle breeze of its flitting by. It pushes the Seeker to listen, look, feel and focus in ways that do not often come naturally. It asks the Seeker to follow the path it lays out and trust that it will lead somewhere worth going. When the Seeker finds the Snitch, gets close enough to touch it, and clasps it in his/ her hand, one has not overcome the other; they have worked together to overcome the opposing (perhaps less attentive, less committed, less patient) team. And though the Seeker's act of catching the Snitch is often referred to as a "game ending" feat, I feel it more appropriate to refer to it more broadly as the "game changer." The effects of and skills developed during the experience linger far beyond the conclusion of the match.

So sometimes I feel like Harry as I am seeking to catch, put together, respond to and release bits of communication that initially elude me, whisper past me and leave a coolness on my skin that demands me to tighten my focus, try harder, and commit more firmly to working together towards greater (mutual and collective) understanding. And as I seek, always, I am hoping for a game that is infinitely more fair. A game without bludgers threatening to throw its players off track (or broom). A game that doesn't imply and perpetuate power dynamics. A game without rules that say one wins and others lose, but one instead that everyone plays together because as long as there is something to seek, no one cares how, or by whom, it is caught. A game that does not end, because after each catch comes a release.

My gravitation towards narrative inquiry feels like a response to the above phenomenon:

an effort to make room for the unique communicative experiences I have had, and have observed of others, in interactions so many deem non-normative (Garland-Thomson, 1997). I have been struck by both the alignment of my research experience with the tenets of narrative inquiry, as well as the absence of reference to voices like those of my co-inquirers in others'. Yet, I cannot help but notice that despite the inherent versatility and critical qualities of this research approach, which promise to stretch and (re)mold traditional notions of what constitutes data (fields texts) and my analysis of them, many of the studies described in the methodological literature hinge on conventional communicative methods that uphold standard structures: oral histories; face-to-face spoken interviewing; written narratives (Chase, 2005; Clandinin, 2013; Clandinin & Connelly, 2000; Josselson, 2006; Maynes, Pierce & Laslett, 2008; Schaafsma & Vinz, 2011). This tension

is palpable in my own initial forays into this research as well. I know that there is space for varied and alternative forms of communication, new and different ways of (re)presenting stories. My endeavor in/through my inquiry has been to find, or create, it. As Clandinin and Caine (2013) remind me, “Within each inquiry, researchers attempt to represent the multiplicity of voices and signatures, which are reflected in the importance of diverse textual structures and accounts” (p. 175). Yet, the tenuous place I found myself in while designing and engaging in this inquiry, and my discomfort with that position, means something. In this section, therefore, I explore the tensions around voice in qualitative research and seek out ways that other researchers have grappled with these methodological complexities. In so doing, I make clear how and why my approach to/through my own narrative inquiry aims to resist and (re)frame “participation” and “voice,” as informed by individuals who do not speak, but communicate in diverse ways.

What Voice ‘Does’ in (for) Qualitative Research

Given that narrative inquiry hinges on experience and story, the notion(s) of voice becomes an underlying, but critical vehicle of those elements. Relatedly DSE scholars have called for the infusion/inclusion of voices of students with disabilities as co-constructors of research (Ashby & Causton-Theoharis, 2012; Connor, 2007; Ferri, 2009; Solis & Connor, 2008). Yet, a call for voice in research with/about students with disabilities for whom speech is not a reliable form of communication must also be problematized and approached with intentionality and vigilance (Ashby, 2011; Biklen, 2005).

Ushered in by feminist theory, the exploration of research methods that foreground voices of marginalized groups has become a distinctive element of qualitative research (Bogdan & Biklen, 2007; DeVault, 1999), as has an ongoing examination of the ethics involved in all research (Ellsworth, 1989; Jackson & Mazzei, 2009; Orner, 1992). The notion that qualitative

interviewing is an empowering approach to “provid[ing] a metaphorical space for stories not always available,” is in many ways what makes this kind of research appealing to both researchers and participants that are members or allies of historically oppressed groups (Bogdan & Biklen, 2007, p. 214). Yet, as Bogdan and Biklen (2007) caution, “the romanticized view of purely giving voice is not an accurate description of what researchers do” (p. 214). Nor is/was it my aim. Despite efforts to expand notions of what constitutes voice through varied data collection methods, attempting to emphasize the plurality of voice(s), and including raw data speaking for itself, qualitative researchers continue to hold to relatively limited perceptions and expectations of what voice is and what it can do in (for) research (Mazzei & Jackson, 2009). While “some of this questioning has resulted in narrative research,” this methodological gravitation does not, in and of itself, “result in a straining of voice in ways that complicate meanings, that tangle our voices with those of our participants, that produce different understandings, or that save us from ourselves” (Mazzei & Jackson, 2009, p. 2). Further questioning, reflection, and collaboration are in order. My inquiry prompts and engages in this line of questioning as both an exploration into and model of diverse/diversifying conceptions of voice in and through qualitative research broadly, narrative inquiry specifically.

Privileging speech and challenging deviations from it. In qualitative studies in education, we have consistently heard—and privileged—the stories of teachers, parents, administrators and educational assistants, because those who speak and are in positions of authority do so in ways that often cannot go unnoticed (Broderick & Kasa-Hendrickson, 2006; Mitra, 2007). Routinely, the voices that are most normative are the most sought out, despite researchers’ best intentions: “...in our zeal as qualitative researchers to gather data and make meaning, or to make easy sense, we often seek that voice which we can easily name, categorize

and respond to” (Mazzei & Jackson, 2009, p. 4). In response, there has been a push to include student voices in research aimed toward constructing more empowering and equitable methodological spaces (Bragg, 2001; Mitra, 2007). Yet committing to include those students, particularly those with disabilities, does not inevitably translate into co-constructive, authentic and/or liberating experiences (Bragg, 2001; Mazzei & Jackson, 2009; Mitra, 2007). Neither their voices nor their stories can be separated from the power dynamics, organizational realities, and contextual nature of their experiences. As I’ll explain, I learned this the hard way.

Add to this the fact that when those students communicate in diverse ways, such as through AAC, conversations, interviews, and interactions tend to yield significantly less content than those with the speaking individuals that surround them. This logistical challenge threatens to minimize impact and space made for their voices in research (Ashby, 2011; Wickenden, 2011). Admittedly, own early experiences with data collection during this inquiry personified these logistical difficulties and resulted in disproportionate set of data. As I experienced, the result is an imbalance and a tendency to supplement with interpretations of speaking participants’ (in my case adults) interpretations of students’ experiences rather the students’ accounts. This disproportion is complicated by the risk of attributing undue weight to the contributions that students who type to communicate do produce (Ashby, 2011), a possibility I negotiated through ongoing collaboration and clarification with the students and their support networks. It is also often the case, particularly during moments of high stress, that some individuals’ ability or opportunities to communicate are contingent upon time, space, noise, contextual factors, word retrieval, sensory needs/preferences, and movement challenges (Donnellan, Hill & Leary, 2013).

As a result, constructing a context that is both structured enough to be conducive to communication of stories, but open-ended enough to draw out the pieces of them that are most important to the individuals themselves was an important consideration in my data collection methods. Rather than seeing these complexities as limitations to/in research, I embraced them as sources of creativity and opportunities for growth (Hansen, 2013). To do so, I first continually positioned the student participants as my co-inquirers, took their opinions and requests seriously, and adapted my methodical approach based on their feedback. I also purposely provided opportunities for multimodal forms of autobiographical storytelling to further expand notions of voice and engaged ongoing collaboration with the students. Ultimately, I learned through the process (see Data Collection and Act III) that “providing” these opportunities versus “being open” to the students bringing them forward on their own led to very different outcomes.

My desire to accommodate and create space for diverse forms of “voice” became increasingly complex, yet essential, in light of my co-inquirers’ personal histories as individuals with autism who use facilitated communication (FC) as their primary means to communicate. As noted, those who challenge FC ultimately do so based on the belief that the person typing does not—or could not—“own” the voice they demonstrate with the physical, emotional, and communicative support of another person. Instead, critics believe that the typed content must belong to, or be controlled by, the facilitator. What does this mean for research participants like Martin, Carlee, Ralph, Henry, and Peter, whose communication must sometimes be supported by others? How do personal and cultural histories of being presumed incompetent and rendered incapable of accessing communication impact the way that they navigate the communicative opportunities they are afforded (Ashby & Causton-Theoharis, 2009)? And what do I, a researcher, *do* with the presence of the third party (facilitator), who is necessary for the students’

communication and often needed to explicate or prompt the student to fill in the gaps in their communication (Ashby, 2011)? These questions swirl unanswered, but not unacknowledged, especially by students who type, families, researchers, and allies. What is clear is that the interplay of communicative logistics, cultural expectations, sources of resistance, and levels of interdependence embodied by my co-inquirers' pushed me as a researcher to *ask* questions and believe that the answers exist only in dialogue—in whatever form it takes—with my co-inquirers. As illustrated in the data collection section, the students often encouraged me to make choices and shift the methodological course that drove us toward this kind of fruitful dialogue.

Fragmentation of voice. The idea that there exists a wholeness of voice that qualitative researchers (re)search and seek to capture is another area of tension I considered. The notion that authentic voice exists and can be “found,” through engaging with others—rather than emerging from and in such interactions—is a problematic assumption (Ellsworth, 1989; Jackson, 2009). Some have begun to explore more conscientious approaches to explicitly highlight fragmented nature of voice, an approach grounded in the notion that representation of self and experience are bound by (and unbound within) the limits of space, time, language, and relation (Lather, 2009; Mishler, 1986). Capturing/questioning this delicate relationship between language, representation and being, I find Scottish poet W. S. Graham's (1979) words provide an illuminating (starting) point:

What is the language using us for?

I don't know. Have the words ever

Made anything of you, near a kind

Of truth you thought you were? Me

Neither... (p. 165)

Bound by the use of language, Graham illustrates the inherent incompleteness of representation, a reality that has vast implications for the collection and interpretation of voiced experiences in qualitative research. In particular, consideration of the in(never)complete nature of voice drove me to question what to make of my co-inquirers' communicated (re)presentations of themselves, which often seemed abbreviated when compared to vehicles of exchange perceived as more normative. Was I to take their typed (re)presentations, even those constructed piecemeal over time and directed toward public audiences, as the(ir) whole story? How could I make room for forms of language—those unspoken literacies neither comprised of, nor articulated in, words—that play in the construction of their, and my, (re)presentations? And what dangers lie in the space Graham mentions between what such individuals' "words ma[ke]" and researchers' quest for the "whole?" Even with the advantage of hindsight, these remain unanswered questions that lingered with me/us throughout the inquiry. In response to them, like the Seeker in the Quidditch arena, we "navigate[d] a stir of echoes" (Rolling, 2014, personal communication) as we, the co-inquirers and I, sought to catch-and-release the fragments of our (lived and told) experiences.

(co-)Located voice(s). Researchers often attempt to navigate these complexities around voice by reproducing participants' "exact words," as if they evidence an inherent wholeness and emerge in a vacuum. Yet, Mazzei and Jackson (2009) assert that such verbatim transcription, "...is a move that fails to consider how as researchers we are always already shaping those 'exact words' through the unequal power relationships present and by our own exploitative research agendas and timelines" (p. 2). This argument parallels philosopher Linda Alcoff's (1991) discussion of "the problem of speaking for others," and the premise of "epistemic salien[cy]," which is derived from the "growing recognition that where one speaks from affects the meaning and truth of what one says, and thus that one cannot assume an ability to transcend one's

location” (pp. 6, 7). Although Alcoff does not specifically discuss disability, instead grounding her work in critical race and feminist perspectives, I often came back to her ideas, applying a disability studies lens, when considering my own methodological choices, relationships, and experiences in this inquiry. For me, Alcoff highlights the importance of considering the social, political, physical, and cultural locations of participants, those who support their communication (i.e. facilitators), and of those who inquire into their experiences in relation to my own social location. Location becomes particularly significant when considering that researchers inquiring into the lives of individuals with disabilities often do not share those identities and/or similar ways of experiencing the world with their participants (Ashby, 2011).

As a researcher I cannot be separated from interactions with and interpretations of my participants/co-inquirers’ stories, specifically when it comes to (re)presenting those experiences, just as my co-inquirers’ stories are further entangled in webs of environmental, social, cultural, political, and power-related forces that surround them. The result is a necessary vigilance in navigating this phenomenon that parallels the aforementioned principle of interaction in Dewey’s (1944) theory of experience and the associated interplay of Connelly and Clandinin’s (2006) narrative inquiry commonplaces—temporality, sociality, and place. Taken together, these situate the inquiry and composition processes as built upon attention to locations of participants and inquirers as “epistemically salient” (Alcoff, 1991, p. 7). Yet, such assertions of inherent mindfulness cannot be taken as justification for less prudence in connecting with participants/co-inquirers. Instead, I view(ed) it as a starting place for more complex understandings of the evolution and co-construction of their/our stories. As Maynes, Pierce, & Laslett (2008) assert:

...analyses of personal narratives are most effective when, rather than conceptualizing narrators as autonomous agents whose testimony offers transparent insights into human

motivation, they explicitly recognize the complex social and historical processes involved in the construction of the individual self and, more deeply, of the ideas about selfhood and human agency that inform personal narrative accounts. (p. 16)

So positioned, I, as a narrative inquirer engaging with my co-inquirers' co-constructed and voiced (re)presentations, approached my work in this inquiry as a means to honoring the tangled tensions and relational realities of the study of experience, and the experience of studying, rather than seeking the truth buried beneath the mess (Geertz, 1998; Lather, 2009). Keeping close the advice James Haywood Rolling, Jr. gave me as I muddled through the messiness of this inquiry, I situate myself as a narrative inquirer “not seeking *the* ‘truth,’ a flayed specimen dissected, analyzed and pinned to a laboratory table; rather [I am] seeking to honor the experience of catching and wrangling and releasing a swarm of implicated and imbricating truths” (2014, personal communication). It is all in how I—we—play(ed) the game.

Pushing Boundaries of Voice in Qualitative Research through Narrative Inquiry

These tensions around voice—what it is, and what it is used for, particularly in the context of individuals for whom speech is not the most reliable form of communication—have prompted both methodological guidance (Ashby, 2011; Lather, 2009; Mazzei & Jackson, 2009), and examples of studies engaging in such complexities (i.e. Ashby, 2010; Biklen, 2005; Broderick & Kasa-Hendrickson, 2006; Cowley, 2012; Petersen, 2011; Wickenden, 2011). Ashby (2011) advocates that qualitative researchers shift their approach altogether by moving away from attempting to “give” voice, and instead “aim[ing] at working with the person to facilitate their construction and presentation of self” (Agency and voice, para. 5). While the former risks a reification of power dynamics between the researcher/inquirer and the participants/co-inquirers whose voices are positioned as liberated through the work, the latter leaves space for ongoing

collaboration, and exploration of the role of the facilitator in this inquiry. Essentially, she suggests that researchers focus on creating spaces and using methods conducive to the needs and preferences (communicative and otherwise) of participants. In order to do so, however, participants must be included in the co-construction of the research process (Ashby, 2011; Wickenden, 2011), which I aimed to do by continually soliciting my co-inquirers' feedback on the structure and content of our conversations (see Phase 2 and Phase 3). Although making room for participants to contribute to the design of research inquiries into their lives holds promise for broadening the notion of what voice can *do* in qualitative research, availability of space does not automatically yield productive collaboration (Jackson, 2009).

Take for instance, the complex communicative dynamics in my inquiry as a result of the presence of the third party (communication facilitator) necessary for the participation and contribution of my co-inquirers. Although facilitators are taught to be "absent" as they support the communication of another individual, their presence cannot be erased or ignored (Woodfield, Jung, & Ashby, 2015). Regardless of their intentions and efforts, they remain a presence both in communicative interactions and in this inquiry. Therefore, the TA/facilitators that supported my co-inquirers are as much part of this research as they are a part of the ways and moments that the students chose to (re)present themselves. They are here/there, they make a difference, and they, too, are co-constructors of this work; that said, I/we consistently endeavored to ensure that their voices did not usurp, but only supported, those of the student co-inquirers. One such effort manifested in our shift to using Google Hangouts as a forum for conversation (see Phase 3). The re-location of conversation to the digital, visual realm lessened the need for the TA/facilitators to (verbally) clarify the intended recipients of their respective students' message (previously shared via their iPad's audio output). Not only did this minimize the TA/facilitators' otherwise

uninvited participation in the students' conversations, but it also allowed them to contribute (when necessary or desired) in ways that mirrored the co-inquirers' conversational experience: via typing. The TAs' presence in the dialogues thus shifted from (often overlapping) audible (re)directions of student messages and otherwise unrelated interjections, to relevant contributions labeled and documented in the digital interspace.

It was my grounding in narrative inquiry, and careful attention to the dynamics around voice, that provided me the necessary tools to explore these possibilities for co-inquirers' participation and collaboration that incorporated, not ignored, the complexities around voice, expectation, support, and interdependence. I also acknowledge that the act of collecting, and co-constructing, stories with participants directly impacts the kinds of narratives they will produce. As my inquiry moved "inward and outward, backward and forward and situated within space" (Clandinin & Connelly, 2000, p. 49), I often mulled over Josselson's (2006) question, "Does the interpreter/researcher privilege the voice of the participant, trying to render the meanings as presented in the interview—or does the researcher try to read beneath...for meanings that are hidden, either unconscious or so embedded in cultural context as to make them seem invisible?" (p. 3). Her query took on a particular meaning for me given the history of misinterpretation, misrepresentation, and missed opportunities experienced by individuals—my co-inquirers included—whose conveyed messages challenge conventional notions of voice. While I hope that my methodological choices, guided by narrative inquiry, left space for elements of both approaches to which Josselson refers, my inclination was (is) to focus primarily on her notion of "privileging the voice of the participant" (p. 3). I did (do) so following Ashby's (2011) recommendation that, "We have to remember how often these voices that do not speak have been overlooked, dismissed or even discounted as invalid. This increases our responsibility to proceed

with care” (Facilitating Agency in Research Methods section, para. 7). In the following section I lay out my research story, which grew out of the complexities, risks, relationships, and work I have discussed to this point. By chronicling the methodological evolution of my inquiry, and the associated shifts critical to that process, I hope to make transparent the ways that I did “proceed with care” to construct a fruitful and collaborative inquiry experience.

Moving into the Inquiry Landscape(s)

Data Collection: In(to) the Midst

As previously noted, the trajectory of my data collection veered and changed course over the three years I was actively engaged in this inquiry (see Appendix A). While I did not set out to have, nor did I end up with, three clear cut “phases” of data collection, I have retroactively labeled them as such to account for the shifts in methodological approach, most often driven by the co-inquirers themselves.

Phase 1: What is going on here? Since many of the details of this Phase were described previously, I focus here on the nuts and bolts of my approach during this time. During Phase 1, my initial foray into the field, my stated intentions were to center the students’ perspectives on their high school experiences, supplemented with contributions from those who support them, to better understand what made Cedarbridge an environment that attracted families to relocate into the district. My interest was in figuring out, “What is going on here?” and how students felt about it. To do so, I drew on optimistic qualitative research methods (Biklen, 2005; Bogdan & Biklen 2007; Bogdan & Taylor, 1989; Kasa-Hendrickson, 2005) to explore the experiences of students and their support teams. The optimistic approach to qualitative research has proven particularly helpful in exploring the lives of individuals with disabilities in that it, “involves the researcher deciding to look at situations that others have identified as ‘successful’ and then

learning from them” (Biklen, 2005, p. 10). By examining what was working, how it was structured, and who enacted which roles and responsibilities at Cedarbridge, I aimed to better understand how the experiences of the students who type to communicate were being constructed and supported.

Data (or field texts) collected during this Phase utilized a combination of initial semi-structured interviews of students, parent(s), and school personnel (Bogdan & Biklen, 2007), videotaped classroom observations, and follow-up reflective interviews centered on significant moments of video extracted from observations. I also collected artifacts (i.e. student work, photos) and engaged in reflective journaling. The observational field texts were gathered in classroom settings across each participant. Martin, Carlee, and Ralph were all observed 7-12 times (80-minute blocks) in at least six different courses between January 2013 and May 2014. Because they entered the school later, Henry and Peter’s observational data were not as robust during this time; Henry was observed in two classes (80 minute blocks) during Phase 1 and Peter (who did not begin attending academic classes until Fall 2014) was not observed during this Phase at all. However, I did continue observing classes during Phase 3. The format of classes I observed ranged from general education (some co-taught), prioritized curriculum (PC),²⁴ and core support (resource)²⁵ sessions.

²⁴ Prioritized curriculum classes are taught by a teacher, certified in special education, highly qualified in the academic content area. While all of the students qualify for special education services, the curriculum is in line with the general education standards and the students take the same exams at the end of the year as their non-disabled peers. These classes are referred to as prioritized in that the teachers do not cover the full spectrum of content, focusing instead on the core necessary for success on degree requirements. Some DSE scholars have been critical of these classes in that they tend to perpetuate justification for segregation of students with disabilities rather than inclusive opportunities (see Bacon, Rood & Ferri, forthcoming)

²⁵ Time spent in core support sessions involves one on one work time outside of class time for students and their TAs to follow up on class notes, complete assignments, start on homework or test administration. It is not a replacement for class time, but acts as a support before or after it.

I interviewed the students a minimum of twice each and parents and adult team members at least once. Interviews with parents, teachers, teaching assistants (TAs), teachers, and students, were started with the stated intention to get a well rounded picture of the perspectives on school from each student and his/her support network. While questions varied across participant and role (see Appendix B), I always began with the following statement: “I have some guiding questions, but I am really just interested in hearing the things you’d like to tell me about your experience with (student/school).” During interviews with students, I also always asked for their ideas and preferences about how to share their stories with me, growing increasingly aware that the interview format was not conducive to that.

All interviews were 60-90 minutes and were either audio recorded (staff and parents) or video recorded (students) and transcribed using a process that acknowledged the impossibility of verbatim transcription. Audio-recorded, spoken interviews were transcribed according to traditional qualitative methods (Bogdan & Biklen, 2007), capturing the interviewees spoken words, with my own comments inserted about context as well as (perceived) significant changes in body language, tone, physical location and/or additional sounds present. Because all of the students used an iPad communication app (SpeakIt) that allowed for voice output of their typed text, their comments were transcribed based on the audio in the video recording. Students also emailed the typed text to me directly after the interviews to allow for confirmation of the audio output. In addition, the video allowed for descriptions of changes in physical location, sounds, and notable prompting from the students’ facilitators to be documented in the text of transcript. During observations and interviews conducted with students at school, teaching assistants (TAs) served as facilitators, while parents or guardians supported the students for home-based interviews. This remained true for all interviews conducted during the entire inquiry.

In addition to observations and interviews, I also collected students' self-representational artifacts (i.e. personalized PowerPoint presentations), samples of academic work, and email correspondence with school personnel, families and students. I regularly wrote memos and narratives throughout this time, which began accumulating into an ever-growing methodological log (Gallagher, 1995). The data collected during this phase yielded important information and remains a critical part of this research (see Act I). It helped me understand the high school context and afforded me the opportunity to witness the shifts in it as the students entered (or exited), transitioned, and grew. However, like much of the research on this topic, it was dominated by adult perspectives and spoken voices, despite my intentional efforts to avoid that. As a result, I moved forward with even more purposeful attempts to situate this work as a narrative inquiry, beginning during Phase 2 of the research.

Phase 2: What's your story? In addition to the prevalence of adult perspectives, Phase 1 of the inquiry revealed a gap in the social opportunities of students' experiences, which will be described in Act I. Not only did the co-inquirers consistently reference their desire to make friends in their respective classes (and frustration with the process of doing so) I noticed that there were rarely instances during the school days in which they could interact with each other. During Summer 2014, I shifted to more intentionally employ the elements of narrative inquiry, and provide space for such interactions, by collaborating with colleague and faculty member Beth Myers on a 6-week student-run Inquiry Group to include all five of the existing co-inquirers. Each student was supported, in communication and otherwise, by a Teaching Assistant. The Inquiry Group met bi-weekly for one-hour sessions during six weeks of summer school (9 meetings total). One meeting was held in the library, while the remainder took place in the students' "home base" classroom, B13. All meetings were video recorded from two angles

and work produced was either collected, duplicated, or photographed. The video recorded meetings were transcribed into text-based documents by combining the students' typed contributions (either emailed to me, hand-copied, photographed directly from their iPads, or derived from the audio output from their devices) with spoken contributions from myself, Beth and/or TAs. Because the co-inquirers move so often and use sound as both a form of expression and a means of regulating their bodies, it was not possible to capture in words each student's every movement or sound-based contribution. The videos were helpful in allowing for repeated viewings during transcription in order to determine which movements/sounds were relevant to describe in detail in the transcript. This effort was worthwhile, particularly in the way it prompted me to think critically about the act of and inherent assumptions about transcribing, it yielded an incomplete product. However, I was not able, or willing, to rely on the text-based accounts of these meetings as the primary data, or field texts, to analyze. Thus, during the analysis process (described on p. 112-122) these transcripts acted more as textual maps, the students' typed contributions being the markers leading me back to (re)view the minute details around how and when those contributions were produced.

The who. Drawing on Myers' (2012) previous work, the Inquiry Group design was intentional in its unpredictability; its purpose was to make space for and support the students' agency as co-inquirers, but what that looked like was, literally, up for discussion. I envisioned our time together as a mechanism for sharing stories and considered negotiations of the process and forms by which those stories got told to, also, be part of the co-inquiring experience. In many ways responding to the absence of social interactions (with one another and their other high school classmates) and me feeling that I was not adequately capturing the students' lived and told experiences through interviews, I began exploring ways to create a new kind of space

that could do both of these things. My vision was for this to be a consistent gathering of my co-inquirers, as well as a handful of their chosen classmates, centered on facilitating discussions about high school life. I had high hopes that these conversations would bridge the social gaps I had noticed and also help me better understand what the students prioritized as important to discuss about their high school lives. But I have gotten (am getting) better at being wrong.

As I teased out the logistics of our Inquiry Group, I solicited the students' feedback about the who, what, when, where, and how of what our time together might look like. It was at this point that our relationship as collaborative co-inquirers developed more fully. Though their answers varied around whether or not to hold our gatherings in or out of school, during or after the school day, and what kinds of things they wanted to *do* during our meetings, one answer was unanimous: they wanted the group to consist of "just typers." In a dissertation study about inclusive experiences set in not only an inclusive high school, but *this* high school (with a reputation for inclusive education that prompted three out of four of these families to uproot their lives to secure enrollment for their children), here I was helping to create a space open to "typers" only. My internal dialogue and tensions around doing so swirled.

[I am forced to confront what I value more: the students' preferences about who they want to be surrounded by or my own beliefs in the value and possibilities of inclusive spaces in the classroom and beyond? I know that they need to lead this experience in their own way. If they are saying they want to be surrounded by each other, then that is what this needs to be. Just because my most cherished friendship epitomizes cross-difference relationships, does that mean that friendships between students with disabilities themselves are not equally, if not more, valuable? I also know that it is their voices and choices that I have to lean on. This decision was not mine. And what would I have done if it had been? What if I had been the one making the choice and had crafted a space that didn't align with these students' needs, hopes and preferences, in the name of modeling my idea of "inclusion." Could they ever trust, or respect, me again? Could forced inclusion be as unjust as segregation? These things that I am glad I cannot answer are the things that keep me up at night. But I know what matters is that I am listening. And learning. I did not expect "just us typers" to be the students' answer to my question about "who they envisioned being part of a collaborative Inquiry Group about high school experience," but damn am I glad I asked.]

This tension between my ideological commitments and my desire to construct a space over which the students had ownership is one that I continued to feel throughout our time together as a group during Phase 2 and beyond. Not because something was missing; we had rich and lively discussions over the course of our (25 total) meetings. The tension was inside of me. I grappled with what my responsibility was as a co-inquirer and co-creator of the group. Should I be continually “making sure” that the students still wanted the group to be “just us” (thus potentially instilling a sense of doubt that I supported their choice), or should I let it go? My compromise was to do neither. Instead, I reminded the students on a few occasions throughout the summer that they could change the dynamics and members of the group at any time and I journaled about the tensions I felt about facilitating—and thoroughly enjoying—a group that contrasted with my initial visions. In hindsight, I can not think of a better testament to the students’ leadership and our collaborations than my discomfort.

The what. Beth Myers and I collaborated on planning, and on encouraging one another to not over plan, the structure of the meetings of this first iteration of the Inquiry Group. We met weekly to generate ideas for activities and agendas, but intentionally embedded flexibility for students to form the inquiry process themselves, which was an important element of her previous work (Myers, 2012). Aiming to make the Inquiry Group space as collaborative and student-led as possible, we spent two separate sessions brainstorming “ways to tell a story” together. The first was an opportunity for the students to generate broad ideas about telling stories in general; the list produced during which is represented in Appendix C1. The ideas compiled here on the first day of the project included a range of mediums and involved things that (we learned in follow up conversations) the students both had and had not worked with previously. The second list (Appendix C2) was produced during our third meeting, after the students had agreed as a group

upon exploring the themes of “what it means to be a typer in high school” and “how I feel when I go to class.” This list was therefore targeted toward determining what story-telling mediums most lent themselves to telling *their* stories about *this* topic. Interestingly, the preferred modes of storytelling that the students volunteered during this more focused conversation were more limited in scope and each in some way centered on, or involved, typing.

Despite Beth’s previous work (Myers, 2012), my desire to employ/explore transformative arts-based/informed methods (Cowley 2012; Kim 2016; Lutrell, 2003; Rolling, 2013; Sava & Nuutinen, 2003), and our mutual intention for this to be a multimodal experience for/with the students, this narrowed list of preferred storytelling mediums pushed us to reframe how we facilitated our meetings and what we expected to see produced during our time together. As a result, we began leading the students in activities that involved composing text-based pieces via typing, sharing those with the group, and receiving feedback from one another. Beth and I, too, provided feedback to the students, which we found ourselves often giving verbally to each individual during the time the others typed their responses to him/her.

Reframing. With our focus on telling stories through typing, we continued to lead the students through autobiographical, writing-based activities with the unanimously chosen topics of “what it means to be a typer in high school” and “how I feel when I go to class” at the center. Activities included free-writes, structured discussions, and written reflections (in list and/or paragraph format), some of which were intended to be completed outside of meetings and brought in for feedback and expansion. While these prompts and activities produced rich written representations of the co-inquirers’ priorities and experiences, I was once again faced with the need to reframe my approach to this inquiry when Martin shared with the group halfway through the Summer (Week 3), “*I not like this it’s like going to English.*” When prompted to explain, he

shared his desire to “*Just talk with the kids the teenagers.*” This statement evolved into an open and honest conversation, spanning the course of two meetings, in which all of the students subsequently requested that we restructure the meetings to be more conversational; the activities Beth and I suggested were to be considered prompts for discussion rather than the focus of it. Accordingly, the following decisions around structure and our roles were made: Beth and Casey would “*kee[p] track of the conversation and subject,*” incorporate “*choices*” and facilitate “*activity-based*” discussion. In order to clarify the difference between activities we had proposed in the past and those we may propose in the future, we brainstormed a list that the students agreed on as most conducive to stimulating conversation, including: theme based discussions, online chat format, art (specifically text-to-art) and ice cream socials. So, we shifted course and the remaining sessions took the form of conversations that Beth and I supported and documented (often by copying student contributions onto large poster paper at the front of the room). This negotiation experience is part of our story and something I would like to explore further in another venue, but for the purposes of moving into a description of Phase 3, it is important to note that this shift was made and was the starting point for Spring 2015 Inquiry Group meetings.

Phase 3: Living out (in) our stories. We ended the Summer 2014 session with plans to continue meeting once a week throughout the Fall semester. But the beginning of the school year came and went. My queries to the school staff about scheduling time for our Inquiry Group meetings were continually met with reference to the challenges of finding common time among the five students’ academic schedules.

Casey: I wanted to follow up on the possibility of adapting and continuing the group meetings from the summer in some way/shape or form so I'd love to discuss that with those of you that would be involved in helping me to arrange that.

Ms. Farber (Head Teacher): I am hoping to hold off the group starting back up for now, if that is okay. The students' schedules are all over the place, with very little common

time, and they are all using their core support for academics. (Email correspondence 9/24-9/25, 2014)

Ultimately, the gap in social opportunities that had contributed to my developing awareness of the value of the Inquiry Group in the first place was re-created. Disappointed, I began thinking about ways to get the students together after school, or re-frame my project (again). I certainly was not lacking in data (as I was reminded—often—by my Chair. And friends. And family.) I could have called it quits, started writing on the experiences we had had to date and pretended like this never happened. But I felt like there was more to this story, so I hung on.

I continued my observations in and collaborations with the school throughout the Fall 2014 hoping that being present might help me better understand why the academics were being prioritized at this particular time and how the students felt about that. Midway through the Fall 2014 semester, Ms. Farber (Head Teacher) reached out to discuss the possibility of resuming the Inquiry Group sessions in January 2015. After thanking the dissertation powers-that-be, I agreed to a meeting, during which Ms. Farber made clear that the students had expressed missing these times to converse with one another. She told me that the intense, and narrow, focus on their academic work (which extended into their “free” core support periods) was overshadowing the students’ social needs and desires; the group camaraderie we had developed over the summer was dissipating in the absence of opportunities to foster it. In response, she worked out the scheduling for the Spring 2015 semester to allow for a shared core support period during the last block of third day of the rotating four-day weekly schedule.

The result was 16 weekly Inquiry Group meetings held for one hour in the students’ home base classroom, B13. Again, each student present was supported, in communication and otherwise, by a Teaching Assistant. Ms. Farber typically sat in for all or part of each meeting, and Ms. Adelstein (School Psychologist) occasionally dropped in, only ever for brief periods of

time. Because Carlee was not physically attending school at this time (see Act I, Sequence 2), she participated remotely via Skype and, later, Google Hangouts. She was supported by an experienced facilitator that visited her temporary home in Georgia. Honoring the students' previously stated desires to "just talk" to each other, I intentionally remained flexible in structuring this group. However, also acknowledging their prior requests for some level of structure, I compiled a list of topics gathered during the summer as potential things to discuss throughout the semester, emphasizing that this list was a fallback in case the students wanted additional structure (See Appendix D). The intention was to have the co-inquirers direct the content and flow of conversation. We began our Spring 2015 meetings by discussing this list of possible topics, developing priorities for the group time, and revisiting and revising the ground rules for conversation developed over the Summer (see Appendix E). The following planning conversation captures the essence of our negotiations during this initial discussion. In it, I reference our past experience and the students work to ensure their current preferences are heard:

- Ralph:** I want to see more talking like you and me talk. To just talk about our lives like people do. Why a subject based conversation.
- Casey:** That's a great point. And I would love that more than anything if we could just come in here and chat. And the reason that I have structured it this way is based on our experience this summer. Because some people were really okay with just chatting with no structure and then for others, having some structure to begin with was really preferred. So my plan for the semester is to try to balance that to maybe come in and make a suggestion about where we start. So for example, today I think it would be an awesome idea for us to have a conversation about change and transition,²⁶ but I don't really want to tell you how that conversation happens. Does that sound like a good compromise?
- Peter:** We are all teens we love to talk it out and hang out
- Casey:** I would love that
- Carlee:** yes
- Casey:** Thanks Carlee

²⁶ Ms. Farber talked with me prior to the meeting about the fact that this notion of "change" had been weighing heavily on some of the students individually, but they had not yet had an opportunity to discuss it with one another. She suggested that I throw that topic out there as a starting point to see if they might want to do so.

Martin: Yes
Carlee: Yes, cool

Ultimately, both the need for structure and my suggestion of topics proved unnecessary as the students took ownership of the content and direction of most of our Spring 2015 conversations. Nonetheless having this initial planning discussion was important in that it was an opportunity for me to show the students in my words and actions that they could trust that their needs and preferences—both previously expressed and not yet known—were a priority. These hour-long meetings may have been a result of my presence, but this space was theirs.

All Spring 2015 Inquiry Group sessions were video recorded from two angles. At the students' request²⁷ I always provided a loose agenda for our time together. The first three meetings of this Phase were set up similarly to those during Summer 2014; each student sat at their respective desk and shared comments via audio output of their iPad. In addition to participating, my role was to organize and keep track of these (often multiple and overlapping) conversations. These three Inquiry Group meetings were transcribed/mapped according to the process described in Phase 2. The other 13 conversations took place in Google Hangouts.

Moving into a digital interspace. After the nine Inquiry Group meetings during the Summer 2014 and the initial three during Spring 2015—along with a significant amount of reflection on the muddiness of communicative logistics—I proposed to the co-inquirers that we try moving our conversations to the digital realm by utilizing Google Hangouts. My suggestion to do so is aptly captured in a memo straight from the pages of my methodical log:

[I have been thinking a lot about the logistics of conversation (and the role of TA/facilitators in that). I have repeatedly noticed here and in other contexts that when a group of typers are conversing, chronology just doesn't happen; it is almost irrelevant. As someone who speaks and hears speech as a means to conversing, this is uncomfortable for

²⁷ I checked in with them twice throughout the course of the semester to make sure they still wanted the structure of beginning with a visual agenda.

me. I'm not so sure that matters, but I'm not sure that it doesn't. Primarily, I think, this lack of linearity relates to the time it takes for a typed response to be constructed. Jamie Burke has commented on this phenomenon in relation to his speaking peers who move on too quickly for him (Biklen & Burke, 2006), yet I see this happening in typed conversations as well. So much so that prior to sharing each comment typed by each student in our group, his/her TA has to call out who the comment is directed toward and what it was typed in response to, because others have since moved on to another topic. I have always assumed that this is what "works" for these students, presumed their competence to untangle the mess we create, together. But the discomfort I keep feeling—and my own difficulty following the course of our discussions—makes me wonder if conversation is this way because it just always has been.]

In response to this complexity, I suggested entering into a digital realm that would prioritize the visual aspect of the students' conversations and lessen the need for (verbal) adult interjection/clarification. Since we had previously discussed the possibility of an online forum being conducive to typed discussions, this was not a completely new idea. However, getting the students set up with their own accounts, the app downloaded on their iPads, and a photo avatar uploaded did take some coordination in the week(s) before we actually began using the app for conversation.

The remaining 13 meetings, and all individual conversations between myself and each co-inquirer, took place in Google Hangouts, which I refer as our "dialogic interspace:" both a play on (digital) words and a reference to the three-dimensionality of Sava & Nuutinen's (2003) multimodal conversation. Our dialogic interspace, then, is the space (we created) between word and image, inquiry and experience, digital and corporal, visual and audial. During the Inquiry Group meetings using Google Hangouts, the co-inquirers, their TAs and I all sat around a folding table that was set up for this purpose in the center of B13. Carlee signed on from Georgia. We used only the text-chat function of the app, as video calls on five iPads in the same room provided too much audio feedback. All sessions continued to be video recorded from two angles. Throughout the semester, I checked in with the co-inquirers about their experience with

the conversational modality and was consistently met with positive feedback, sometimes even when I didn't ask for it. For instance, "I love this so much guys lets do this outside of school too" (Peter); "I love it... We don't interrupt each other" (Peter); "no I like quiet talks" (Martin, in response to my question about whether they missed voice output); "This is great" (Ralph).

Using Google Hangouts changed our dialogic and research experience in a number of ways. First, it lessened the impact of Carlee's physical absence from school; though she was not present in the classroom, her participation in the conversations looked very similar to that of the other co-inquirers. Second, as I had hoped, it significantly decreased the need for adult interjections. In fact, we all agreed to an arrangement that anyone who wanted to contribute to the conversation had to do so within the Google Hangouts. TAs and/or other adults who did not have their own accounts were also instructed to announce themselves (i.e. "Hi this is Ms. Farber...") if they contributed from another person and/or student's iPad. As Ralph described in a presentation that we later collaborated on as a group (using Google Hangouts), "We just stared using google hang out its great something happens when you talk on this. The room gets so quiet you can hear a pin drop."

Like Ralph's intimation about the audible difference between pre and post Google Hangouts conversations, the transcript-maps created from these dialogic experiences also looked very different from those crafted from our previous more audio-based dialogues (see Appendix F). Because Google Hangouts provide a running record of all text, its sender (including photo avatar and full name), as well as a date and time stamp,²⁸ it became unnecessary for me to interact with the students' typed text as I had previously in the creation of transcript-maps. While undoubtedly incomplete, the time-stamped Google Hangouts transcripts provided me an initial

²⁸ I have removed dates from all excerpts reproduced in this dissertation for formatting reasons. Time-stamps remain to convey the flow of conversation and capture the time between each response.

map of these meetings, which I filled in with contextual details drawn from my field notes, reflective memos, and repeatedly (re)viewed video recordings. These details included: pronounced and/or consistent sounds, (particularly those also referenced in the text of the conversation), audible verbal support provided by TAs to students, audible conversations between adults in the room, physical entries and exits of students and/or adults into/out of B13, and anecdotal notes on the context of the conversation.

Moving from Field text to Research Text(s): Analysis and Interpretation

As is typical of narrative inquiries, Phases 1-3 yielded a large and varied corpus of field texts. Because narrative research is “always interpretive at every stage” (Josselson, 2006, p. 4), each set of data were preliminarily analyzed within their respective chronological Phases (which then contributed to the evolution of the methods and transition into each Phase), yielding an additional set of interim research texts (Clandinin, 2013; Clandinin & Connelly, 2000). When it came time to synthesize all of the field texts and interim research texts into a final research text, I looked to other narrative inquirers to help me organize such diverse data, keeping in mind that the purpose of interpretation in narrative inquiry is both “to understand the phenomenon under study [and] to facilitate an understanding of the phenomenon under study for the reader” (Kim, 2016, p, 195). To do so, I drew upon multiple modes of analysis to explore and honor the experiences and stories that constitute this inquiry.

Acknowledging the ways that these varied field texts collected and co-constructed across different times and contexts during this inquiry interact and intersect, I found it helpful to start by categorizing them according to their primary purpose. I did an initial sweep of each field text for the sole objective of determining what *role* each type of field text did, or could, play in the (re)presentation of this inquiry experience. Throughout this sorting process I realized I had three

distinct types of field texts: contextual information about the students' high school experience at Cedarbridge, students' self-(re)presentations to outside audiences, and our individual and collective stories as co-constructed through conversation (see Figure 2).

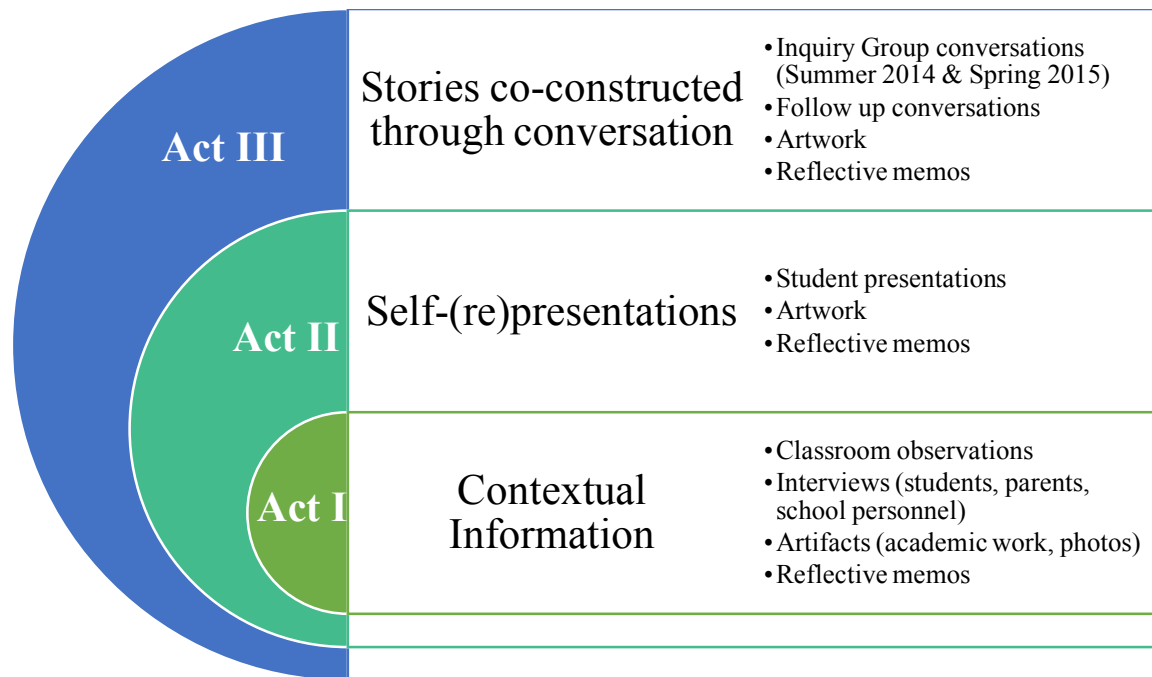


Figure 2: Categories of field texts

Each of these sets of field texts became the foundational structuring of this research text; three distinct “landscapes,” each serving a unique purpose and (re)presenting different—but interrelated—terrain along this ever-evolving journey. My use of the landscape metaphor draws its origins from the inquiry experience and related field texts (see Act III, Sequence 2) in which the students often refer to themselves, and are subsequently referred to, as “trailblazers.” It is also aligned with Clandinin and Connelly’s (1995) work, in which they note that thinking about landscapes, “allows us to talk about space, place, and time. Furthermore, it has a sense of expansiveness and the possibility of being filled with diverse people, things, and events in different relationships” (p. 4). To capture how I interacted with, explored, (re)presented these

three landscapes through my analysis, I describe my approach to analyzing, interpreting, and writing about each set of field texts separately, while emphasizing that during the inquiry itself such a linear process was neither possible or desirable.

The high school landscape. Field texts labeled as “contextual information” included videotaped classroom observations, interviews, correspondence and school related artifacts (i.e. academic work) from across all inquiry Phases. My subsequent analysis of these field texts drew upon Polkinhorne’s (1995) analysis of narratives, which Kim (2016) terms “paradigmatic mode of analysis,” as well as the process of identifying resonant threads (Clandinin, 2013). This exercise aligns with more traditional approaches to qualitative analysis, in that the field texts were coded (and re-coded) for common themes and patterns, or resonant threads (Clandinin, 2013). Because I approached this inquiry from a disability studies in education (DSE) framework and was most interested in the students’ experiences of/with inclusion, my approach to coding centered around the practices (both observed and described) supporting inclusion. Transcripts of interviews (i.e. text-based documents) were coded by hand and using Dedoose, an internet based coding platform. While Dedoose does also accommodate visual data (photos, videos), I chose to code video in Studiocode, a qualitative coding software that allows for tagging and exporting of video excerpts, which helped me to “slow down” moments (Huber & Clandinin, 2005), or scenes, to analyze or (re)present further. It is not typical for narrative inquirers to utilize coding software. However, I did find the visual interfaces and ability to organize, store, and excerpt my coded field texts to be a helpful exercise to my interpretive and writing process.

The initial round of this analysis yielded a set of action-based codes, or threads, that captured what was *happening* in the students’ school lives at the time. I then refined the coding framework, and applied that narrowed scheme to the full set of “contextual” field texts. As I did

so, these larger collapsed codes evolved into five primary thematic threads supported by action-based codes that seemed to group around specific roles within the school setting (see Table 3); a process based on which I have structured Act I.

Table 3: Thematic threads and associated role

Thread	Action	Primary Related Role
“I’m going to give Sarah an opportunity”: Intentional Inclusion by Teachers	<ul style="list-style-type: none"> • Strategic access methods; Making up time • Cultivating a culture of respect. 	Teachers
“They are our way to show that we are there”: TAs’ role in participation	<ul style="list-style-type: none"> • Materials management • Building relationships • Bridging relationships • Re-writing the job description 	Teaching Assistants
“Imagine the coordination...”: Managing the space(s) between	<ul style="list-style-type: none"> • Scheduling, staffing and space • Logistical management 	Administration, Head Teacher, School Psychologist
“Nice not having my voice disregarded”: Students at the center of it all	<ul style="list-style-type: none"> • Prioritizing communication (student & home) • Collaborative decision making • Students as resources 	Students, supported by all players
Supporting Whole Students	<ul style="list-style-type: none"> • Making friends. • Prioritizing well-being 	All Players

Keeping in mind where I was methodologically and relationally when most of these field texts were collected, this process and written (re)presentation felt more structured than the others.

Constructing a (re)presentation of the high school landscape around each set of roles—comprising a cast of characters—critical to this inquiry’s setting and experiences within it, allowed me to consider and demonstrate the interconnected nature of support, while still recognizing the individual perspectives and purposes of different players. Though distinctive, each position-based set of scenes reveals how the experiences of and support for the five co-inquirers bring to life the teaching and support practices critical to these students’ experiences, as

well as how those involved pushed back against the oppressive ideologies that are prevalent in educational settings.

Using this set of “contextual” field texts, I also constructed a timeline of events to better orient readers to the chronology of this inquiry and give a glimpse into the personal histories that brought each student to Cedarbridge. The parents’ mini-narratives included on the timeline were identified using the same process of searching for resonant threads across multiple interviews. They were then organized and stitched together by means the same literary construction process (Barone, 2001) used to co-compose their children’s narrative accounts in Act II: The Performative Landscape, as described in the next section (see below).

The performative landscape. Field texts considered to be within the Performative Landscape (Act II), include those drawn from students’ “self-(re)presentation to others.” As will be referenced throughout this dissertation, all five of the co-inquirers participated in a variety of performative self-(re)presentations throughout this inquiry. I acknowledge that all interaction and (re)presentation are performative.²⁹ In fact, attention to storytelling as performance represents a distinct approach to narrative inquiry that is growing in popularity and complexity (Kim, 2016; Reissman, 2008). Here, I utilize the term “performance” in reference to performative autobiography, or “the direct communication of the personal between the writer or performer and the reader/spectator” (Miller & Taylor, 2006, p. 169). I do so to highlight the fact that these instances of the students’ storytelling were often, literally, staged for/to public audiences in the form of conference panel presentations, introductory PowerPoints to classmates, artwork (written, sculpted, painted, and otherwise). They were performances crafted and controlled by

²⁹ I’ve thought long and hard about the ways in which for these students’ in particular—marked by visible, behavioral and communicative differences that (threaten to) set them apart and often manifest in surveillance by others—experience is performative in unique ways. The students are always being watched. They are also constantly watching, learning from, each other.

the co-inquirers for the purpose of telling their stories to others, on their terms; what they left out is as important as what they (re)presented and I wanted to replicate, respect, and honor those choices.

For those reasons, I used only these self-(re)presentative field texts, as well as some of my own autoethnographic writing, to collaborate with each student on co-constructing a narrative account (Clandinin, 2013). The purpose of these narrative accounts are to: 1) introduce the co-inquirers in a way that mirrors how they chose to do so in public venues, acknowledging that in writing this dissertation I am again placing them in front of an audience and 2) synthesize how each co-inquirer (re)presented themselves on a variety of topics, in different contexts, across time. Since none the (re)presentational field texts in and of themselves were long or thorough enough to stand on their own as narrative accounts, I combined them to shape a better picture of each co-inquirer's unique personality and experiences, as well as what they consistently chose to tell others about their life. Because I was using *their* words, but blending and rearranging the pieces into a more cohesive narrative for the purposes of my audience, I laid out a careful writing and collaboration process to minimize potential misinterpretation and misrepresentation, outlined in Figure 3.³⁰

³⁰ Martin's narrative account was an exception to this, since he wrote and published such a comprehensive autobiographical account of his experiences as part of a school project. My process of adapting this self-(re)presentation into his narrative account began at the "Fill in" step.



Figure 3: Construction process for narrative accounts

Through this careful and creative process, I transitioned these field texts to interim and final research texts using a literary based approach to narrative inquiry (Barone, 2001; Kim, 2016) to (re)craft the data into a product that provides analysis through, rather than drawn out from, the data. In particular, I utilized Barone's (2001) strategy of literary construction, grounded in a process similar to Polkinhorne's (1995) narrative analysis. Like Barone, I "experimented" with the raw data, particularly through formatting and arrangement of the narrative. This process sometimes felt like I was creating collages from disparate words and pictures, placing and replacing them into a (perpetually incomplete) big picture. Other times, strings existing words lent themselves to poetic (re)arrangements (Connor, 2006; Petersen, 2012; Rolling, 2004a, Rolling, 2004b). Along the way, some of the co-inquirers chose to include their own art (painting, sculpture, and/or poetry) to supplement their written words. Finally, drawing on the work of Rolling and Brogden (2008), Lather and Smithies (1997), and Sava and Nuutinen (2003), I use the footer space of each document to fill in gaps with my own autoethnographic writing, foregrounding the co-inquirer's story but acknowledging the ways that my own—temporally, socially, contextually, and literarily—intersected with it. Like Lather and Smithies (1997), I do so to "practic[e] a kind of dispersal and forced mobility of attention by putting into play simultaneously multiple stories that fold in and back on one another" (p. 220).

These narrative accounts remained tentative and fluid until each co-inquirer individually edited and approved them—at which point the process was paused—yielding a mutually agreed upon, collaboratively composed snapshot of each co-inquirer and his/her experiences. Just like their (our) stories, these narrative (re)presentations remain intentionally incomplete; even in co-constructing them together, we created a new direction, a new chapter in the story. Thus

alongside the narrative accounts themselves, this process by which the co-inquirers' words and mine interacted to produce a product is as much a part of the story as the story itself.

The dialogic landscape. The third set of field texts—"stories co-constructed through conversation"—consisted of all transcript-maps and videos of our Inquiry Group meetings, as well as individual conversations between myself and each co-inquirer. Together, they comprise the dialogic landscape (Act III). My use here of conversational forms of narrative aligns with another recent turn in narrative inquiry that zeroes in on "small stories" (Bamberg, 2006) or "narratives in context" (Georgeakopolou, 2006a), and is considered to "...allo[w] us to pay attention to inconsistent, fragmented, immediate yet important short everyday conversational narratives that may otherwise go unnoticed" (Kim, 2016, p. 262). This shift has been most common in socio-linguistics and psychology, particularly around issues of identity development. The move to examining "small stories," alongside or instead of "big stories" (i.e. life story, biography/autobiography), is attributed to Ochs and Capps' (2001) work on "living narratives," in which the authors draw on anthropology and psychology to make a case for the importance of interaction, since these "less polished, less coherent narratives... pervade ordinary social encounters and are a hallmark of human condition" (p. 57). My decision to facilitate Inquiry Group meetings as part of this research was not initially guided by this turn to small stories in narrative inquiry; as previously noted those choices were grounded in the evolving collaboration with the students along with my own gut feelings about what was, and was not, working. However, learning about this shift toward small stories was validating and informed my analysis process. I found reassurance in knowing that the things I—we—were feeling and doing were not "off base," and in fact were "on trend."

With one foot rooted firmly in the realm of educational narrative inquirers like Clandinin and Connelly and the other in this developing realm of small stories, my process for analyzing our Inquiry Group conversations took both approaches into account. As I did with the contextual field texts (Act I), all transcript-maps of these conversations were mined for resonant threads. The documents were archived and coded in Dedoose, which allowed me to tag large chunks of each with (often multiple) labels, or threads, and then excerpt those threads by topic. Although using Dedoose helped me develop a framework of resonant threads, I ultimately found myself re-coding the transcript-maps by hand. While this extra step was based on personal preference (I felt more connected to the data when I could flip back and forth through it chronologically *and* by coded thread), it did serve as an unintended reliability check for the framework of threads that I pulled forward the first time. My process of identifying threads was primarily centered on the topics discussed across and within our Inquiry Group conversations. A follow-up round of coding drew upon Georgakopolou's (2006a, 2006b) work with small stories, which attends to the characteristics, or function(s), of interaction. Working off of the sets of topic-based excerpts, I (re)visited the field texts to determine what function each students' contribution(s) served within each instance. Throughout this entire process, I continually referred back to the videos to (re)view the temporal, social, contextual, and auditory details of each co-constructed scene.

Let me be clear, however, this process was not linear; it epitomized Clandinin and Connelly's (2000) call for inquirers to move "inward and outward, backward and forward and situated within space" (p. 49). I often shifted between foregrounding, and refining, the topical threads and the interactive functions co-constructing them until I had settled on a set of field-texts that, when grouped together by thread, told a story representative of our group interactions. While I had many electronic resources available, including transcript-maps coded in Dedoose

and video data archived on hard-drives, once a group of interactive moments—scenes—had been identified, I often found myself working with them by hand: arranging and rearranging them on walls (and floors), taping and tearing down, sorting and sifting and (re)playing, zeroing in line by line, then zooming out again as I worked to (re)tell and (re)present a big picture comprised of small stories. Finally, I consulted each co-inquirer individually for feedback about and approval of the conversations I (re)present in this final research text. The result is an Act (III) comprised of four sets of scenes (Sequences). These interrelated but distinct dialogic moments come together to (re)present the topical threads and conversation types most prominent across all of our interactions, while also tying back—weaving into—the contextual and performative landscapes.

[Do me a favor: squeeze the last 25 pages between your fingers. Rip them out, feel the weight of them in your hands. Thumb the edges, watch the words—a blur of black and white with an occasional flash of colored shapes—dance in front of you; a methodological flipbook. Grab a pair of scissors and snip off the top right corner of this stack of paper; watch the pages numbers—the order—float to the floor like a paper snowstorm in April. Shuffle the pile. Cut. Shuffle again. Deal. Go fish(ing); see if you can (re)collect the sequence from this stack(ed deck), make your way through the white(out) into the clarity of process. Are you spinning? Is it blurry? Can you make (out the) meaning from the mess? If I told you that you could—if I started here, not there—would you trust, go with, me?]

Ethical considerations. This work was messy and beautiful and collaborative and isolating. I often felt energized by time spent with my co-inquirers, only to feel more confused and alone when I sat down to write about our experiences. Those were the feelings that convinced me I was doing this—a narrative inquiry—well; they were also inklings that tugged at my conscience and reminded me that with relationality comes a need to attend closely to ethics. As is typical for narrative inquiries, I came into and out of my co-inquirers' lives for an extended period of time (three years), across variety of contexts (school, home, community, and dialogic interspaces) and in relation to those with whom they are closest (families, school team, friends,

peers). They shared with me their hopes, dreams, struggles, and victories across space and time. I participated in their lives during moments of great accomplishment, frustration, disappointment, frivolity, raw emotion, and sheer mundaneness. Along the way, they saw me through my own ups and downs, including my engagement, wedding, and associated challenges of living apart from my spouse to complete my graduate program. I shared with them details about my own past and relationships that, I felt, intersected with theirs. Such openness cannot be overlooked, for this intersubjectivity built and changed the experiences of which we became part. Yet I also acknowledge that the resultant relationships exist in a liminal space that is difficult to define (Clandinin, 2013; Clandinin & Connelly, 2000; Ellis, 2007; Schaafsma & Vinz, 2011).

Narrowly outlining a process for navigating the ethical complexities of narrative inquiry would serve to contradict the nature of the methodological approach itself. In fact, the very attentiveness to and honest confrontation of the murkiness of ethical boundaries within this work can be seen as a critical step in decision-making; it certainly was for me. In many ways, the intersections of continuity, interaction, and situation that comprise Dewey's criteria of experience, the combination of the temporality, sociality, and place commonplaces, the position of being in the mi(d)st, collaborative meaning-making, and intimate relationships all intersect to inform and mold the ethical decision-making of each particular inquiry. My experience was no different. Following other narrative inquirers, I responded to these complexities throughout the inquiry by keeping ethics at the fore, attending to measures associated with Institutional Review Boards, as well as relational ethics that stem from my "hear[t] and min[d]" (Ellis, 2007, p. 4).

Procedurally, while my perspectives on disability did not always align with those of Institutional Review Board, particularly the medicalized understanding that characterizes my co-inquirers as "vulnerable," we shared the goal of minimizing harm to participants. Given my co-

inquirers' identities as individuals with autism, this becomes particularly relevant in light of the historical mistreatment of individuals with disabilities through research. I made continual efforts to confirm my co-inquirers', along with their family members' and support teams', willingness to participate in this inquiry, reminding them of their option to stop at any time. Because the inquiry spanned three years, all student and adult participants (if they had previously participated) signed new consent forms each time my approved IRB was renewed or amended. This process involved me providing a written consent and/or assent form, reading and/or summarizing its contents, and answering any questions posed. I worked to ensure privacy by keeping all electronic data on a password protected hard drive and/or within my password protected Google account (for online conversations). Hard copies of documents were stored in a locked filing cabinet.

Relationally, as I navigated the transitions—backward, forward, inward, outward—through this inquiry, my aim was to foreground my co-inquirers' well-being. These efforts manifested in the ongoing dialogue with the students about the purpose and structure of our time together in the field, as well as a co-constructed writing process that yielded the final research text(s) (re)presented in this dissertation. A key consideration in that process was the co-inquirers' and others' privacy. By using pseudonyms for all participants and locations I made those efforts visible, but even then the highly personal nature of this work and our relationships blurred lines between theirs/mine/our stories. Add to this the complexities of my choices to interweave my own stories—which are intimately tied to my friend Anne's and her mother, MJ's—into these documented experiences. I draw on my memories and reflections on our relationship as a mechanism of context; it is a way of connecting my past, present, and future to the unfolding lives and experiences of the co-inquirers. Everything about this inquiry, and about me as a researcher, scholar and person, is deeply entwined with who we are individually and together, so

I could not have told this story without Anne and/or MJ. But I also will tell this story *about* them. They are neither participants nor narrators. Like the details of our unique relationship, I will say nothing more about their place in the text other than to say that they are here and their presence does something through (and is mediated by) the lens of my recollection and writing about them. Like this personal decision, the choices I have made in handling the documentation of my own and the students' narratives involve ongoing attention to their purpose and potential to uphold privacy.

In so doing, I often imagined myself as one of Ellis' (2007) students, to whom she directs the following guidance about embarking upon complex inquiries with intimate others:

'Strive to leave the communities, participants, and yourselves better off at the end of the research than they were at the beginning [...] In the best of all worlds, all of those involved in our studies will feel better. But sometimes they won't; you won't.' I tell them that most important to me is that they not negatively affect their lives and relationships, hurt themselves, or others in their world. I tell them to hold relational concerns as high as research. I tell them when possible to research from an ethic of care. That's the best we can do. (2007, p. 25)

While the notion of "care" is a fraught term from a disability studies perspective, Ellis' ethical guidance on this topic both motivated and challenged me throughout the inquiry. My resultant efforts not only manifested in attempts to center the comfort and collaboration of my co-inquirers through my words and actions, but also in my reflexive attention to myself in relation to them. Kim (2016) introduced me to the idea of "reflexive *askēsis*," reflexivity grounded in Foucault's (2005) *askēsis*, or "care of the self." Drawing on Foucault, Kim (2016) makes clear that reflexivity can be constructed as a complex, evolving process of self-care that translates into the

way we treat others: “when we take care of ourselves through Foucauldian reflexivity, we also pay attention to others, which is an indispensable, ethical task” (p. 253). Throughout this inquiry I used reflexive writing as a tool to situate myself and my understanding of my co-inquirers, as well as a meditative, restorative exercise. Doing so brought forth my memories and otherwise tucked away tensions that impacted the ways I paid attention to, interacted with, and grasped my co-inquirers’ experiences in light of my own. Ultimately these multilayered ethics of caring for self (with) and for others yielded my own ethical (re)commitments to continue writing/ exploring/learning/puzzling the tensions that led me to think about ethics in the first place. My attempt to do is captured in/by this inquiry and the experiences it (re)presents in/through writing.

On Structure

Since you have made it this far it should come as no surprise to you that this dissertation is not a clear-cut, six chapter and a conclusion kind of text. You may even notice the ways my writing oscillates between adherence to and divergence from the expectations of academic (dissertation) writing. I hope you feel the tensions I felt, faced with an academic task and a research experience that didn’t quite fit the mold. Rather than retrofitting my initial approach to (re)presenting this work, I choose to take you on that journey with me. I bring you along the starts and stops, the shifts in my priorities, the changes in my voice, for they, too, are part of this story. But, you should know why the remainder of this dissertation will look even more different.

I have loosely structured the data chapters like a (text-based) three-act documentary film; a set of stories told sequence by sequence, scene by scene, jumping across space and time that I both narrate and contribute to as a character. My choice to (re)present this research story as such is grounded in an acknowledgement of the critical part that video played across all Phases of this inquiry, as well as the key role that documentary filmmaking has played in the lives of

individuals who type to communicate. As the aforementioned controversy around facilitated communication has swirled in academic journals and public media, documentary films have provided counter-narrative(s), focusing the lens on the lived experiences of the individuals themselves. Documentaries like Academy Award Nominated *Autism is World* (2004), an account of Sue Rubin's life before and after learning to type, and *Wretches and Jabberers* (2010), a chronicle of typers Larry Bissonnette and Tracy Thresher's journey around the world to change minds about autism, communication, and competence, have helped to shift the conversation on a global scale. Other short films like *My Classic Life as an Artist: Portrait of Larry Bissonnette* (2005), *Kayla's Voice: Empowering People with Autism* (2010), and *Inside the Edge: A Journey to Using Speech Through Typing* (2002), all of which highlight the personal stories and experiences of individuals who type, have circulated as teaching tools, resources for families, and solidarity for others who type to communicate, including my co-inquirers. In a nod to the role that filmmaking has played in this narrow slice of the field and in the lives of individuals who comprise it, the remainder of this text is crafted to mimic that medium, acknowledging the limitations inherent in using only text and images to do so.

[I am sitting in the audience of a film festival, watching clips of documentaries that never get old (to me): "Wretches and Jabberers," "My classic Life as an Artist," "Autism is a World." Is this really my "job?" Pinch me. In the years since I first watched them, the subjects of these films have become my friends and colleagues (though I'll admit that each time I see them I still get star struck). I am listening to the producer of these documentaries, one of my mentors, discuss his process and make a case for the use of film as a form of research. I am thinking about my dissertation, trying to figure out how to turn lived experiences, complicated relationships, hours of video, conversation, and art, into something to (worth) read(ing). I wonder if it is a futile endeavor? My ears perk up during the Q&A when I hear a too-familiar question leave the lips of graduate student I'm not too familiar with in the back row: "So if facilitated communication is so controversial, why don't you do research to prove it works? It is obvious from watching these films that these people are producing their own typed words. How could it be that hard to prove? Can't we do something to quiet the critics?" I sense him stirring up a revolution in his head; welcome to the club, my friend. Up at the podium, my mentor smiles knowingly and I wonder how many times he has had to smile that smile. I wonder

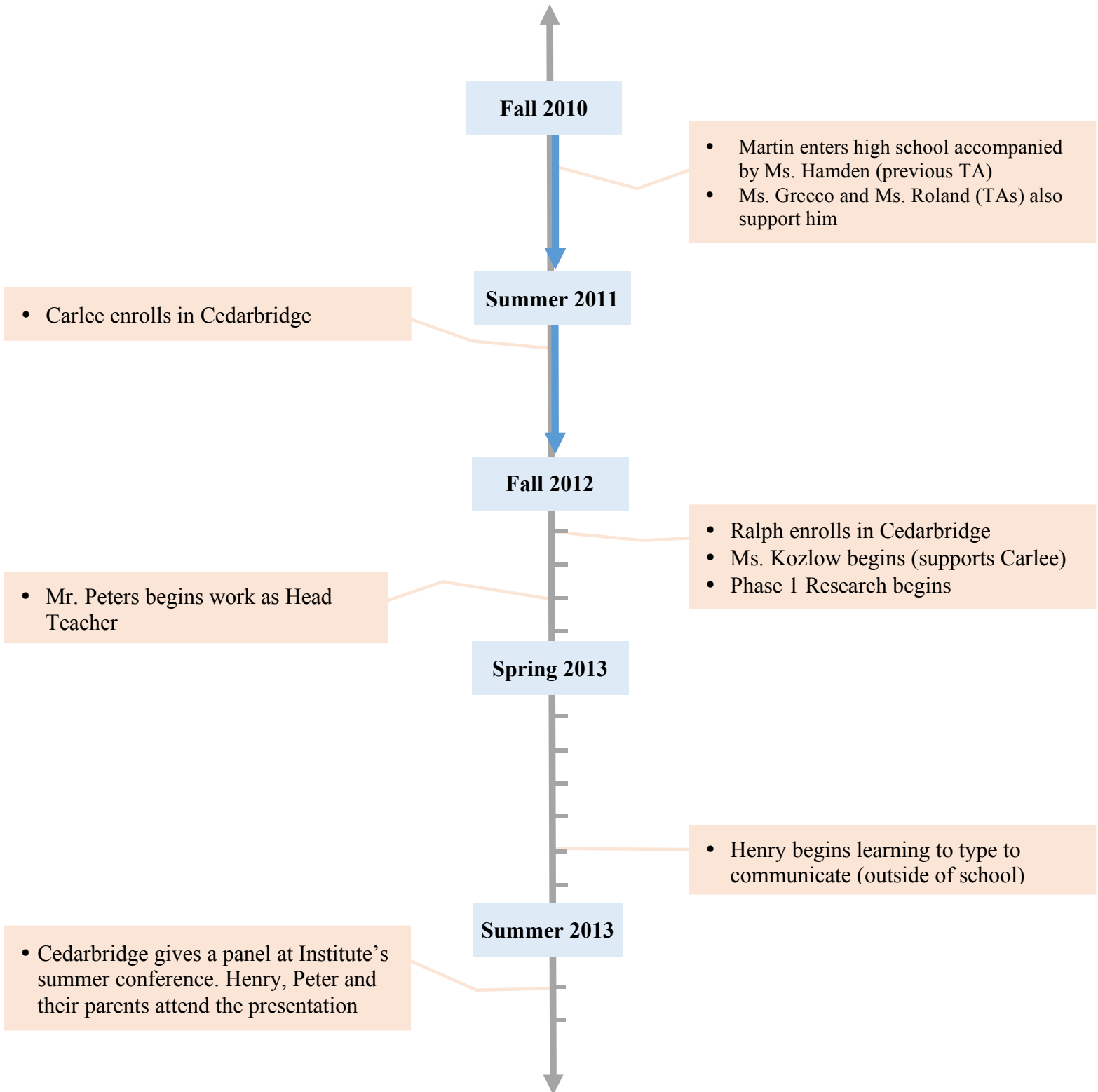
how he is going to gently point out that he has been researching this for nearly three decades and that there is an Institute just a mile down the road dedicated to doing just that. I wonder if he is going to argue that the skepticism around this method of communication is the tip of an iceberg grounded in a history of misconceptions about and oppression of people like those whose lives are captured in these films.

But he doesn't say any of that. Instead, he gestures toward the screen behind him, pointing out that the people about whom these films were made have started a movement; they have taken ownership of their experiences and have become public figures doing the work of changing minds. Their meaningful lives have become all the "proof" they need to do so. He says they are the ones that do, and will, create change. He says he will never stop doing work to support them; he points out that there are many others like him who continue to research and write and document in efforts to counter the pervasive misbeliefs that whirl around them. But in the end, he says, he has faith that it will be the people themselves—the ones whose communication and movement and unique worldviews have been underestimated by too many for too long—that will lead us into a new era. "The people will win," he insists. "The people will win."

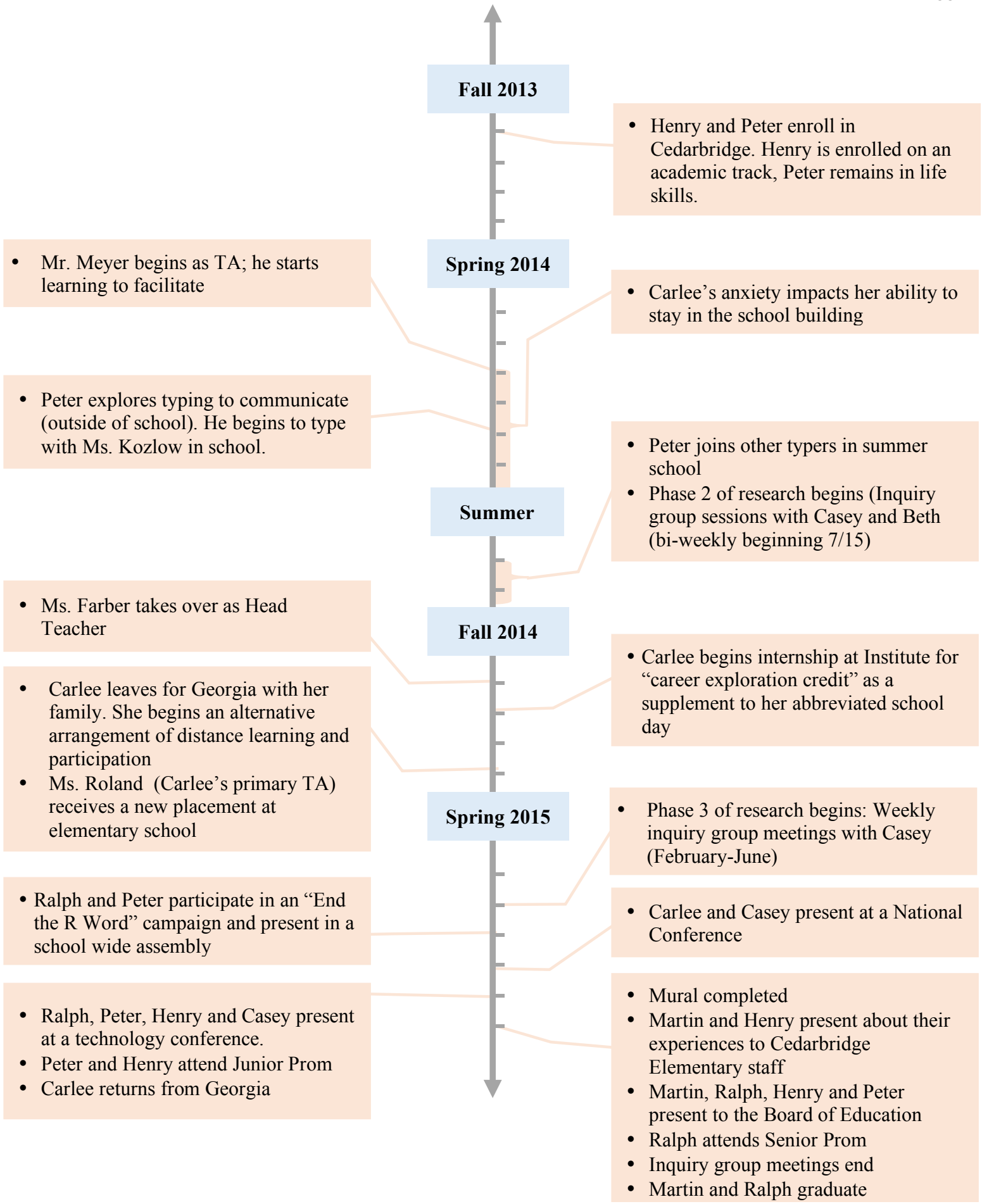
May this collaborative document(ary) contribute momentum and solidarity to that growing movement.]

Act I
The High School Landscape

Sequence 1a: Abbreviated Timeline of Events (September 2010-June 2015)³¹



³¹ With the exception of Fall 2010-Fall 2012 (marked by blue arrows), this timeline is divided by academic semesters: Fall (Sept-Dec.); Spring (Jan-June); Summer (July-Aug.). Each notch on the grey timeline corresponds with one month.



Sequence 1b: Extended Timeline of Events (September 2010- June 2015)

Sept. 2010

- Martin Enters High School accompanied by Ms. Hamden (previous TA)
- Ms. Grecco and Ms. Roland (TAs) also support him

Vicky & Tom LaMuncha: In elementary [the school] did not realize how much Martin knew because he wasn't able to communicate. When he had a speech evaluation when he was elementary they said he communicated fine, which he didn't. We suspected, or knew, that he could read and write, even though the school didn't understand him and didn't think that he could do any of that. So, whatever academics they gave to him, it was kindergarten, first grade stuff and he was upset a lot because he didn't want to be treated like a kindergartener. So we decided that we really needed to hear some other opinions. We had two comprehensive speech evaluations done and it turned out that, not surprisingly to us, he was very proficient with augmentative communication devices. So he did have a Dynavox [AAC device] from kindergarten to second grade. The school bought it and [broke often]. [Ultimately] they just used [communication] boards with him... which you can only do so much with. From third to fifth grade that's all he had. Those were tough years for him. Martin could've stayed in elementary another year, but we said 'no.' After fifth grade, he went to the middle school. Those teachers were more willing to help and the speech pathologist seemed open to other modes of communication.

We have watched Joe [a local individual with autism who once typed with support and now types independently and speaks his typed text] develop since he was 12. The first time we watched him, he and his mother were doing a presentation and we went to see it. We weren't even sure what it is that we were watching. It was new to us. Martin was about five. We were brand new to being a parent of a child with special needs. But, it was like a foreshadowing for us. Even though Joe was *using* FC at the time, the presentation [only] got us thinking about augmentative communication technology. What we should've been thinking about was FC *and* technology. It didn't occur to us to think about the facilitation component of that until after when he was having the struggles in elementary school. [It wasn't until years later that] we sat down and decided Martin should be evaluated [for FC]. At that point, Martin was older and Joe's success became more pronounced. We remembered [back to seeing] him and his mom and we were like, 'Maybe that's the way to go. Why can't Martin do that? Let's see if this will work for him too.' They were very similar.

So we asked for an outside evaluation and one of them was from the City and then Marcy [local trainer] did one too. And then, we had two sources that said FC worked for Martin. So he got a LightWriter [AAC device] and *we* got training before he started 7th grade. We had to take the initiative to go to the school and say "We need you guys to work with us on this." Back then and even now there's still a stigma regarding FC, which you have to get people to get over. I mean I hear horror stories all the time about parents in other districts where they try to approach the officials and the only thing they hear is, 'We don't do that,' and that's *it*. The only way to [change that] it is by actually participating in workshops and watching and seeing it happen. We had to convince the administration at that time that they needed to see and learn about FC in action. We invited the teacher, an administrator and the school psychologist to an [FC Training] workshop. They watched Marcy [type with another FC user]. They were like, 'Wow.' They were receptive. We're lucky that we had that. They agreed to bring in Marcy for some training [in the middle school] and Martin really took off. Prior to Ms. Hamden [TA] being involved in, he had another teaching assistant who really worked with him hard on the facilitation and he just blossomed. He really did. The administration made that happen. How many times do you hear about the district actually making those things happen?

Once he started using FC in the middle school they realized how much he knew and then he was able to push into a couple of classes. Of course [some people] had to come a long way before [they] really understood that it was Martin's voice that they were hearing. [When it was time for Martin to transition to high school, they automatically put him in] life skills and maybe [having him do] one [academic] class and he said 'no, I don't want to do it.' He did that in middle school and he did not like it. At all. He wanted all academics. He has told us for many, many, many years that that's what motivates him. His best typing comes when he's working on academics. There were a couple of teaching assistants [at the high school] that were willing to [learn to support him] and then Ms. Hamden came with him from the middle school.

While our intent was to help our son, it has helped other people, too, which we think is really great. What we want are the opportunities. For kids. We have seen other young men and women be successful out there through FC and/or other support and it should be no different for Martin. And in this community if a success story gets out there, it spreads

July 2011

- Carlee enrolls in Cedarbridge

Lara Sanders: Carlee went to... a model pre-school for students of all abilities to be together. As parents we know that after pre-school you're out in deep water. [So] when your kid is graduating from [this preschool], on the last day you all cry. We were proud of our children but we're fearful of what's going to be happening next because we hear horror stories that even kindergarten is tough. If that's tough, then what about fourth grade? High school? I didn't even want to think about it. After Preschool, the nightmares began. Carlee went to elementary school in Lakeview [her home district,] but they wanted her to go SNAPP [segregated program for students with autism] from day one. We said 'no.' She was in that district for Kindergarten through fourth grade, but it was not good. In third grade, they [really] pushed us. They wanted her to go to this self-contained classroom with five kids or something like that. The Special Education teacher was working with her there and I went into the classroom once to see and it was like, 'Carlee, this is a picture of a bird, touch the bird. Carlee, this is a picture of a something, touch the something.' I said 'No way. I will not agree for Carlee to do that.' [So they put her in a general education class for third grade]. That was an amazing year because Carlee was supported. The assistant was facilitating with her, but so was that *teacher*. But things fell apart. The TA left; there was a new assistant who came in. The teacher changed the desk formation in the room. It was very bad. Carlee was having a lot of problems and was suspended from school the day or two before the last day of school, so she wasn't allowed to participate in the last day of school. Fourth grade was pretty much Carlee and an aide over in the corner of a supposedly inclusive class. It wasn't. That's the worst kind of segregation, I think. They talked in front of her; treated her so terribly. We had a lawyer at that point and they wanted to send her to the SNAPP program, which is a program for people with behavioral problems. We said 'no way.' But they told us those were our options: SNAPP or nothing.

[So we transferred Carlee] to a private, a multi-age K-6 school. It's very small, work in a lot of pairs, a lot of small group kind of thing, a lot of individual work. They basically told us, 'if you can get a one-on-one with her, she can come to school here.' I don't think they thought we could get a one-on-one, but Lakeview was supportive in wanting to get her out of there. So she got a one-on-one, but it was provided through Rawling, because the private school is in the Rawling school district. We paid Marcy [local trainer] to go in an hour a week to train the one-and-one and teachers to [support Carlee to type]. By the end of 6th grade she might have started typing with somebody, but it was up and down. It wasn't really consistent typing.

When Carlee was in 6th grade, they added a 7th and an 8th, so she was there for [four years]. But, in 8th grade, Rawling sent a new TA and forbid her touch Carlee to support her to type because 'they didn't espouse facilitated communication.' So, that's where it stood and there was nothing that we could do. She stayed at the private school and we tried to get around [Rawling's resistance] as much as we could, which wasn't that much. We were really pleased just because Carlee was still going to school and she wasn't going to SNAPP. We had the attitude, of beggars can't be choosers, so we didn't really push too hard.

We knew Carlee would have to go somewhere else for high school, but] we didn't know what to do. The teachers at the private school would often visit other schools for the students who are graduating, [so they did that for Carlee] and we also added Marcy to that team. [Marcy had been supporting Martin at Cedarbridge, so she knew what they were doing]. They went to Cedarbridge and met with [the Special Ed. Director, the School Psychologist and the School Counselor] to talk about Carlee. They all said 'This could be a wonderful place for her.' Then, the team from Cedarbridge went to observe Carlee and [confirmed] that, 'yes, this could be a wonderful thing for her.' So, then Don and I met with the team, [who told us] 'we'd be able to support this, especially there was another student who was using facilitated communication.' [But] we had to be residents or pay \$40,000 a year in tuition. So, we bought a house in Cedarbridge so Carlee could go to school there. We closed on the house right before summer school started. But how unfair is [that]? We bought a house and we moved. We were able to do that, but what about all the families who can't? Those kids are really under served.

That's the story, but that's not even the half of it. We've been through such nightmares. And school's still not perfect, but she's participating now in class. She's got teachers who respect her. She has the ability to communicate. She's got the possibility of a brighter future, because before she didn't have *anything*. Those people didn't believe in her. Not all the way. Cedarbridge is a large school district and that they are addressing students in the way that they're being addressed, puts me in awe. And my daughter is part of this. Overall, I think what she's gained here is her sense of being a person— a respected person.

Sept. 2012

- Ralph enrolls in Cedarbridge
- Ms. Kozlow begins (supports Carlee)
- Phase 1 Research begins

Sati Wibble: Ralph has been [advocating for himself] from the beginning. In fact, whatever I did I did it because he wanted it. I was kind of adding force to [his requests], but it all came from him. It started when he was at [Charles City Elementary school] when he was put in a basement [with] six students and eleven adults. It was horrible. It was the first year we were typing. And he kept asking, ‘why have we come here from India? I am in a more worse situation.’ When I asked ‘why?’ He told me, ‘at least I had loving people around me.’ That room that he was in was even worse than what it was in India. Not only the people surrounding him, but also the content. ‘Why did we come here?’ When he asked me that question, he broke my heart.

Every day I would cry myself to sleep; ‘my God why does this happen?’ I made my husband leave his job. I left my job. I came to this other end of the globe and my son asks me ‘what are we doing here?’ I didn’t know what to do. This was a new place. I hardly knew anything about the rules and regulations. So [initially] whatever [the school] did I just followed. [But when Ralph] said this, I got fired up. This is something I [had] to take up. And I was just a persistent woman. I said ‘I am not taking this lying down. I’m going to fight it.’

When it was time to move on to high school, a [local FC trainer affiliated with the city schools] told us, ‘you have to be careful where you end up. You should choose someplace where they believe in FC.’ [My husband and I went on tours of all these schools] and Ralph ended up in [Charles High School] because of [the teacher we met] there. He’s a gem of a person. When we walked into his room he was so welcoming that we decided this would be Ralph’s best place. I mean even after Ralph left that school, he still said that he missed [that teacher] the most. [Even though] of all the schools, it was the best choice to be in his classroom, the administration [was] not good enough. So it ended up not getting us really where we wanted to be.

The whole setup [was a mess]. They never had a back-up TA; even in summer school they weren’t giving Ralph the right support. Everything was a struggle. I used to go in there every other day throughout the year because only then Ralph succeeded. Whatever he did there was all because of me telling them what they needed to do. I would go in during the last hour of the day at least once or twice a week and problem solve with the teacher, TA, and speech therapist who were all supportive of FC, but didn’t always know how to help Ralph. Supporting a student who types was sort of a new thing for them. They hadn’t done it for a high school student in the way I expected them to do. Including Ralph fully and having him write the Regents was something they had never done before. So, they were really thrown off about how to fit him in there. They did try their best, but sort of it was a half-baked thing.

It was very good that they were open to my suggestions and they would take whatever I [said] seriously, [but] the administrators were not very much into [listening]. In the end, the feeling I got was that [the administration] didn’t think that Ralph would get the Regents diploma, which left me very much apprehensive that things wouldn’t work out for [him there]. Even getting him to write the *one* Regents test they allowed him to take, the way they setup the test was all a mess. Though they were very otherwise open, I got that feeling that they were really not serious about [his goals]. That made us make the switch. Ralph was losing time; he didn’t have many years left in high school. So I couldn’t just wait and watch. That’s why we took this mission to move to Cedarbridge where things were more organized, at least as far as FC was concerned. They had a setup already in place, which I had to really help the other district to set up from scratch. It was a big decision and transition for Ralph to be at that stage and move out of that school. But he too was very, very frustrated. [So we decided to move. We rented an apartment in Cedarbridge so Ralph could enroll in Cedarbridge High School]. It’s a good thing we left. The [other] district has really gone to the dogs. [Staying] wasn’t worth it.

Now when we came to this school district, I knew that everything wouldn’t be rosy. There will be things which we will encounter here too but maybe not to that extent as at Charles School. I thought I would just be a back-bencher sort of like, just sit and observe how things are going. I found that they were really good at many things. And Ralph, he was okay. In fact he was so happy because he felt he’s come to his life’s desirous place. He got that. The first meeting with Cedarbridge I could see it; he was smiling and seemed relaxed. I think he sensed that whole acceptance of his ability, like the presumption of competence.

Nov. 2012

- Mr. Peters begins work as Head Teacher (part time position)

Veeda Golden: We were in [another state] for pre-K and basically we moved [here] for Kindergarten so that [Peter and Henry] could have better services. My husband wanted to do fellowship so we applied to the areas where they have better services. This seemed to be a better place; it was like a day and night difference because they much have more funding than in the area where we were from. So we were very happy that we are in a good area with a lot of services and support system, but we didn't know it [could] be better.

The reason [we chose] Eastville was the concentration of Indian families there. We were having some trouble with my older son because we lived in a really tiny little town that was all only Americans, not many foreigners, and also very closed minded. They [were] nice but they would be like anybody born outside of the U.S. is a foreigner. He had a lot of issues with his identity [and] we wanted him to feel comfortable being in his own skin. So we chose Eastville so he would have more Indian families and he would see more Indian kids going to school. That way he would feel more comfortable.

So all three kids were at Eastville and basically I knew the school was doing something like a day care [for Henry]. But I knew he was smart. [His] smartness would come out [in the ways he would try] to figure out what wanted and how he could manipulate us to get it. That showed [me] that there was some smartness there but we had no clue he had observed all the language that was going around him. He knew so much. We had no clue. If we had known, we would have done something.

Eastville gave him an iPad a few years before we moved to Cedarbridge; they didn't mind doing that as long as he [could] do it by himself. And we tried, but he [couldn't] do it. He would do the stimming apps by himself but even in Proloquo2Go [app] he would only [point] repetitively to food items or whatever he likes.

So everything [really] started with Ralph presenting at [a local adult services agency] two years ago when Henry was 14. Our [MSC at the time] also worked with Ralph and encouraged me to go see him. So I went. I was so impressed because he was independent at that time. After that, we rushed to have Marcy [local trainer] do an evaluation for Henry [who recommended he start learning to use FC]. Sati [helped get us started] in the practice room [at the Institute]. I was so thrilled. Two days after the evaluation, [we] had [Henry's] CSE meeting. [Marcy] emailed her report. We were so excited, but even before we opened our mouths the [school staff] said, 'oh we don't want to hear, we don't believe in FC.'

We decided to get started [with typing] and if Henry [became able to type independently] then we [could] ask [the school again] and then they [would] do it. I didn't realize at that point of time that it takes more time and effort to get to independence and he may not get independent with everyone at the same time. It depends on the facilitator. With each one he could be at a different level. So it was more like back and forth. I think it's a cycle, because he doesn't get to practice in school, he's not getting better. [Since he would not be] able to practice in [that] school, we thought "okay let's go." That summer we went [to work with] Marcy once a week so that [Henry would have an opportunity to type]. We had a really rough summer because Henry had found his new voice and he was not able to express [himself]. [Because I was still learning how to facilitate with him] he had to wait to see Marcy to pour his heart out.

At first, I didn't know Cedarbridge offered a support system. I knew Carlee and I knew Ralph moved there from [other schools], but I didn't know the real reasons and I never really had time to linger and chat after [events]. So once I learned [about the support Carlee, Ralph and Martin received at school] I wanted to go and ask [Eastville again]. When school was done, my husband and I both went last summer and asked the Special Ed director of Eastille [why they couldn't provide the supports that Cedarbridge could]. She said, "as long as I'm here we are not going to allow FC". That's exactly her words. So when she put it that way, we saw this as her final kind of ultimatum.

We had two choices. One to stay [there]; file a grievance and all that. It would take time and go to court, spend thousand[s] of dollars. Henry did not have that time. He was already fifteen and we didn't want to lose one more year let alone three or four years [with] no guarantee. It is a very big district and a powerful one and we couldn't really assume a victory. If Henry was in maybe kindergarten or first grade and we knew about this we could have stayed there and fought it, but he was not. He didn't have that time so we had to move. So that's what we did.

April 2013

- Henry begins learning to type to communicate (outside of school)

July 2013

- Cedarbridge school personnel, the three students who type, and Carlee's mom present as a panel at Institute's summer conference
- Henry, Peter and their parents attend

Veeda Golden: Actually I called for an appointment with [Ms.] Cipriani [Director of Special Ed at Cedarbridge] and she said only in end of July will they give an appointment, [which I thought] might be too late. [But then] I saw them at the panel presentation [at the Summer Institute]. So I talked to Ms. Cipriani [about our situation] after the conference was over. I [followed up with her via email] and then she got back to me. Everything was decided in a week's time. It was a rush, and we were going to buy a house. We were looking, looking, looking but [we didn't find anything] we were comfortable with, so we rented and moved [into a small apartment].

September 2013

- Henry and Peter enroll in Cedarbridge to obtain support for Henry's typing
- Henry is enrolled on an academic track along with other typers (B13), Peter remains in life skills

Veeda Golden: We kept our house in Eastville and we go back there during all school breaks. It's a tough life but once we kept doing it we become more efficient at it. And [Henry and Peter] got used to it. In the beginning Henry was quite confused. He said that he was feeling like [our house] was home and this [apartment was] not home. He had a rough time and said 'I don't like the stinky place. I want to go to my calming big home.' So we would drop him off there after I picked him up from school and come back [to wait for Peter to get off the bus]. [Slowly,] it got better and we [started staying in the apartment] until Peter [got off the bus], then went. Otherwise, I basically I couldn't do anything else except just getting Henry to [and from] school, that's it. Now it's better. Henry likes to have his own space and he likes where he's at in the school. He likes to be busy, he likes to be productive, he likes to show everyone how smart he is, and those things. I think it worked out well for us. We don't regret not for one minute moving him.

More than anything I think [he's gained] a willingness to endure whatever to get to where he needs to go because I think in his mind he has had enough of this life, his whole life. One time he had a really, really rough day in school and I was sick of those rough days and I said [asked him], 'would you rather go back to Eastville?' He said, 'never, never, never, never again.' He's done with that. He's gone to the next level and he's really working very hard and I think he deserves every word of praise. He's really good.

March 2014

- Mr. Meyer begins as TA; he starts learning to facilitate

March-June 2014

- Carlee's anxiety impacts her ability to stay in the school building

May 2014

- Peter explores typing to communicate (outside of school). Begins to type with Ms. Kozlow in his existing classroom and expresses desire to be on a more academic track

Veeda Golden: Henry got a much better tradeoff than Peter did. Peter was very comfortable at Eastville. Here at Cedarbridge, [he started out with] the same programming [he had at Eastville]. For him, the biggest challenge was that he was torn between leaving the familiarity of Eastville. He left everything in Eastville that was familiar to come to Cedarbridge to be with Henry. He immediately won over the staff members, but he [had a harder time] connecting with [his new classmates]. His peers at Eastville had known him since kindergarten. He has his own ways of trying to make friends and they understood that, even though it is not [the] typical way of making friends. But now [if he's trying to be] funny, it sounds kind of weird for a person who doesn't know him.

So he found it hard [to make friends at first] and I think that [really affected him.] He likes to be very busy, socially. At Eastville, he would go to every event, every little thing. [When we moved, he was missing all that.] And I worried [about him], but Peter's [desire for a social life was] more of a want than Henry's [need for communication]. For fourteen years, Henry didn't have a life and there's no way we could do that to him [knowing we knew now]. And we couldn't have two private residences and two kids in two different schools. But Peter was given a choice. He could have stayed in Eastville with his grandparents and gone [to school] there. But he didn't want to do that; he wanted to come [with us] too. Honestly I wanted him to come too. I didn't want to be without him and I thought that Cedarbridge could be something better than Eastville for him.

I know a part of Peter was yearning to be something better. I think part of the anxiety was that he saw how much Henry could express himself and [the opportunities he was getting], but Peter just couldn't say, 'hey I want to type too.' Henry is the one who brought it up. He typed, 'my brother is as intelligent as I am and if you try typing he will wake up as I did.' That's what he said.

I talked to Marcy about it and told her Peter learns new words and is trying to use new words but I want him to break free from that obsessive compulsive thinking pattern. So I don't know if [typing would help him] to come out of it [but we could try.] So we did. We started working in the practice room with Sati [Wibble] and in the Spring of the first school year, Ms. Kozlow started trying to type with Peter in his classes, but it was a process. Looking back [it is clear] that he was resisting everything so much because he was having [conflicting desires for familiarity and change]. When he did start typing, it was rough for him. He didn't immediately get good support, there were all of a sudden academic expectations and all the relationships and expectations he had started to get used to changed again. All that added up. But having [Ms. Kozlow] as a support source calmed his fears quite a bit.

July-August 2014

- Peter joins other typers in summer school
- Phase 2 of research begins: Inquiry group sessions with Casey and Beth (bi-weekly beginning 7/15)

Woodfield: In Phase 2, I narrowed my approach to focus more directly on capturing individual students' conceptions of their experience, i.e. 'what's your story?' I re-evaluated my methodological approach and collaborated with Beth Myers to pilot a six-week inquiry group that was comprised of intentional efforts to engage with multimodal, autobiographical representation.

September 2014

- Ms. Farber takes over as Head Teacher

Ms. Farber: [Taking on this role] has been a huge change...because there's not as much direct teaching any more you know. And I've been a teacher for twenty-two years so I'm enjoying it much more than I thought. I did have some concerns would I enjoy it, what would my role be, you know would it be more just monitoring the adult and making sure that...but I make sure that I interact with like the kids a lot.

November 2014

- Carlee begins internship at Institute for "career exploration credit" as a supplement to her abbreviated school day

December 2014

- Carlee leaves for Georgia with her family at the end of December. She begins an alternative arrangement of distance learning and participation
- Ms. Roland (Carlee's primary TA) receives a new placement at elementary school

Lara Sanders: Carlee was in school for the Fall [2014] semester. Because she had such a difficult time the year before, the idea was that she would go with a limited schedule. She took two classes: Participation in Government and English. And then she left. She actually left three weeks before the class ended because class ends the third week of January. She finished her final paper and had done enough that the teacher was able to give her credit.

We have this house in Georgia where we've been going the last five seasons. What we've been doing with Carlee is, because she's at school, she's back and forth. Last year, I think that was part of her falling apart was when we were in Georgia. It was that challenging for her when we were [away]. Actually at the CSE [meeting], I wasn't sure we could even take her out [of school]. She was 18 though at that point. [Ms. Cipriani] is the one who said, 'Lara, I don't think there's any way that you could *not* take her [with you].' That was really nice to have that encouragement.

February 2015

- Phase 3 of research begins: Weekly Inquiry group meetings with Casey resume with a new focus (February-June)

Woodfield: My approach was revised when the students called to my attention to the fact their priority was socializing with one another, not writing down or documenting their stories. It was at this point that my inquiry shifted with an understanding that as I moved forward I needed to become more ingrained in the process of living out *our* stories, with conversation and relationships as the vehicle through which we would construct, represent, and watch them unfold together.

March 2015

- Ralph and Peter participate in an “End the R Word” campaign and present in a school wide assembly

Peter Golden: When I did the speech for stop the r word made a huge difference in my life. The reasons why are simple, it was a huge opportunity to show the students how smart we are. Since then I have made so many new friends because their eyes were opened to what we are as students it is amazing.

April 2015

- Carlee and Casey present at a national conference

May 2015

- Ralph, Peter, Henry and Casey present at a technology conference. Presentation was prepared with contributions from all 5 students.
- Peter and Henry attend Junior Prom
- Carlee returns from Georgia

Carlee: I want to say I am home
Peter: Awesome Carlee
 [...]
 Henry: Good.
Ralph: I am happy Carlee is here. Welcome back!
 [...]
 Henry Yes.
 All here.
 It is.
 Nice.

June 2015

- Mural completed
- Martin and Henry present about their experiences to Cedarbridge Elementary staff
- Martin, Ralph, Henry and Peter present to the Board of Education about their experiences
- Ralph attends Senior Prom
- Inquiry group meetings end
- Martin and Ralph graduate
- End of field time

Ms. Cipriani [excerpt from email to four of the students and their parents]: [The BOE presentation] was a unique opportunity to share the struggles, victories and triumphs for students who experience school through alternative communication and the lens of Autism.

Martin- clearly the mentor and role model -the communication trailblazer

Pater- the smile of engagement forging an immediate connection with everyone

Henry- so thoughtful and able to communicate clarity and depth in his writing

Ralph- driven to be hard working, fast talking [iPad output] with an accumulated list of well deserved accomplishments

All with a wonderful sense of humor!

Again, I feel most fortunate to be part of this incredible team and so grateful for your willingness to advocate. The echo of your advocacy will be far reaching for so many students who will follow.

Ralph: What am I going to do before [college] starts?

[..]

Martin: enjoy your summer. we are graduating

Ralph: I won't go to summer school this [year]

[.....]

Martin: Ralph im good at relaxing want me to help?

Sequence 2: Exploring Cedarbridge

[*Fade in*]

The chiming sound of five gentle but rapid beeps denotes the end of first block and students pile into the hallway in front of you; ten seconds prior, you would not have been able to tell from the deserted hallways that this school holds over 1,000 9th-12th grade students. You have heard this building is arranged in a star like pattern, with hallways branching out from the center. How hard could it be to navigate?

Ahead of you, the crisp white tiling of the walls is broken by posters, art projects, glass display cases, and chains of paper rings of which you cannot see the origin or the end. Yet as you move forward, the grey-blue paneling of the convex auditorium walls, which sit directly across from the wood trimmed double glass doorway of the library, give you the sense that you are passing through a tunnel. The not-so-gentle nudge of a heavily-cologned freshman rushing past reminds you that you are in fact still in a school, as does the intense sunlight bouncing off the white walls just up ahead at what you assume must be what they are referring to when they say, “the atrium.” You pause and pull up your email on your iPhone to “double check” (for the tenth time this morning) the room number you are looking for. Let’s face it, you’re lost.

You lean against the cold tiled wall, half-hoping for a familiar face to appear and half-conceding defeat to the hustle and bustle of the transition period. You alternate moving your eyes from the email you have now memorized to the students passing by. That 8 out of 10 of them appear to be White is not surprising; you have become familiar with the demographic divide between the city and suburbs in this area. Yet you still cannot help but pause on the striking irony that just six miles up the road the demographics are nearly reversed, a phenomenon that is not unique to this geographic region. You also notice a number of students move through the atrium in a variety of ways—a few using wheelchairs, a few rocking their upper bodies, some with adults lingering a few feet behind, others on their own—and you wonder whether or not you take note of this visible presence of disability because that is what you are here to notice. It will not be until months later that you look up the school’s official enrollment data to file in your records and realize that this high school’s population of students with disabilities is 19%, seven percentile points above the national average.³²

The onslaught of students has died down, reduced to just a few stragglers. Another set of five rapid beeps signal the start of second block and you return your attention to orienting yourself, fighting to ignore the knots in your stomach reminding you that you are now late to the class you are supposed to be visiting. You look back to the main doors you entered through and, though embarrassed, you consider asking the woman at the front desk to escort you to your destination. As you make the decision to do so, around the corner of the hallway ahead comes Carlee, the student you are here to observe. A few steps behind, her TA Ms. Roland follows and waves to you, saying to Carlee, “look who it is!” Carlee smiles and rolls her head from side to side as she moves towards you.

³² For the 2012-2013 academic year 6.4 million students, or 13 percent of total public school enrollment, received services under IDEA (NCES, 2015).

You make a mental note to figure out why Carlee is heading to class after the bell has rung, but for now you focus on lightheartedly admitting to her and Ms. Roland that you are lost and thankful that they rounded the bend when they did. You follow them the rest of the way to room J10, Mr. Smith's English class, trying to inconspicuously memorize your path to avoid future tardiness.

Carlee enters the room first, followed by Ms. Roland and then you. Mr. Smith says, "Hi Carlee" as she passes by him on her way to her seat in the back of the room. He nods at Ms. Roland and smiles at you as you approach him and whisper, "Thanks so much for letting me come in. I'll just set up in the back of the room if that's okay." He says it is and then casually introduces you to the class, reminding them that he mentioned you would be visiting and to "be respectful." You pull an empty chair from a nearby desk and place it strategically behind Carlee, close enough so you can just see her iPad screen, but far enough away so that it is not completely obvious what, or who, you are looking at. A few feet beyond your chair you attempt to unobtrusively as possible set up the tripod you bought at Target last week and your borrowed Canon camcorder, hoping beyond all hope that the batteries don't run out for the next eighty minutes. You return to the hard metal classroom chair and take out your favorite blue pen and the small 4x3 inch notebook you have designated as your official research notebook. You wonder if the ornate floral pattern on the outside cover makes you look unprofessional (what kind of notebooks do "researchers" use anyway?) and make a note to opt for the boring solid cover next time. You never do, though.

Over the next three years you will fill up 15 of those 4x3 notebooks with fancy patterned covers. You will rig multiple borrowed camcorders and various iterations of tripods to capture classroom happenings from different angles, sometimes two at once. You will spend quite a bit of time wandering—trying to memorize—those hallways, an effort that leads you to be more comfortable with being late if nothing else. You will observe 45 classes, interview 19 school personnel, hold 25 Inquiry Group conversations, attend school wide assemblies and performances, CSE meetings, a school board meeting, and a prom. You will help to bring students together to create a collaborative mural that ends up displayed prominently in the main hallway of the school. You will spend time observing and discussing practices with all involved in constructing "inclusion" for five students who type to communicate in this school and you will piece together, with their help, a big picture of who and what contributes to the day-to-day workings of it. You will do all of these things while slowly developing lasting relationships with the students and staff who welcome you here, constantly reflecting on and re-negotiating your position in-relation to these spaces—lives—even as you become part of them.

And while by the end of it all, you are confident that you could find your way around these hallways on your own, you still always hope for—and usually do find—a friendly face to round the bend and go with you the rest of the way.

[Welcome to Cedarbridge High School.]

“I’m Going to give Carlee an Opportunity”: Intentional Inclusion by Teachers

My belief about inclusive instruction is that instructors’ lesson planning should be thoughtful enough that inclusion happens as a matter of planning, not a matter of who is in your class. So if I can plan my course to include elements of technology that become inclusive if the need is there, or they include new methodologies or modalities for kids to communicate multi-modally I don’t see how that’s anything but a benefit to everyone’s experience. (Mr. Waring, Creative Writing teacher)

The teachers you meet at Cedarbridge come from a range of backgrounds and represent various areas of expertise. Some are formally trained in Special Education, while others are general educators with little prior experience with inclusive education. The classes you observe vary from those considered prioritized curriculum (PC), to content specific general education courses, vocational training electives, and arts-based courses. As you get to know and observe many of Martin, Carlee, Ralph, Henry and Peter’s respective teachers over the course of your time at the school, you see that across their different classrooms they are united by their intentional efforts to include the students who type. Most often you see them creating openings, providing wait time, giving advance notice, and recognizing contributions. Many of these practices have been identified as helpful specific access strategies for inclusion of students who type to communicate (Ashby & Kasa, 2013). In addition to the adaptation of classroom activities to suit the participation needs of students who type to communicate, you also note teachers modeling diverse and varied interactions as a means of cultivating a culture of respect.

Strategic access methods; Making up time. The ways you observe teachers utilizing strategic access methods (Ashby & Kasa, 2013) most consistently serve the purpose of creatively using, managing, and negotiating time. As Mr. Connor, an Earth Science co-teacher, describes to you,

Time is huge. Just the wherewithal to sit down and then be accepting that someone just requires extra time...it does take some thought and some, you know, maneuvering to

make sure you give that time. Like giving Henry a heads up, ‘hey let’s share this one with the class.’ Just him sharing with the class is a huge step for people to hear his voice and see what is inside his head is wonderful.

You notice creative uses of time, like those that Mr. Connor describes, span nearly all of the observations and conversations you have in and about classrooms. This practice is crucial, since individuals with autism have reported difficulty with initiation, thus making timely contributions to academic and social conversations challenging (Biklen & Burke, 2006; Donnellan, Hill, & Leary, 2013). It is necessary, then, for space and time to be made for their voices to be included. Some of the ways you witness teachers doing so include directly soliciting students’ answers and opinions throughout classes and actively encouraging their participation. Such efforts do not go unnoticed by the students; as Carlee commented after viewing and reflecting on a video clip from her global class, “I love how he [the teacher] encourages me with questions.”

Creating openings. Both your conversations with teachers about practice and observations of them in action are replete with examples of phrases such as, ‘What do you think?’; ‘If you have something to share, I’d love to know;’ ‘Want to help me with number ____?’ These intentional efforts to individually encourage Martin, Carlee, Ralph, Henry and Peter’s participation—whether the students choose to contribute in response to them or not—suggest an awareness that these students’ voices risk being overpowered by their peers’ and reveals these teachers’ attempts to counteract such possibilities in their classrooms. You find this particularly evident during a discussion of a local trial in Martin’s Business Law class:

Mr. Ferretti asks whether anyone has empathy for the suspect. Many students shake their heads. A male student yells, ‘No!’ Mr. Ferretti turns to Martin and asks, ‘How do you feel Martin?’ Martin immediately moves his hand to his iPad and begins typing. Mr. Ferretti says, ‘More thoughts while Martin is typing. More thoughts.’ Three minutes later (after adding additional details about the case) Mr. Ferretti calls on Martin, who has his hand raised. He independently presses the SpeakIt button on his iPad and the digital voice reads, ‘I feel bad that he never had a good day.’ Mr. Ferretti repeats, ‘that he never had a good day? Agreed. True.’ He turns toward the rest of the class, ‘Can you imagine?’

Here, Mr. Ferretti's request for Martin's feedback recognizes that had he moved on from his initial question with only nodded and spoken responses, he may have precluded Martin from responding. Yet Martin's immediate movement towards his device indicates that he does in fact have something to contribute to the conversation. By creating an opening, giving Martin time to respond (or not), and acknowledging the relevance of his eventual response, Mr. Ferretti demonstrates that Martin's contributions are equally important to the class, even if they are sought out in more directed ways or take more time to compose.

Providing wait time. Ralph describes to you that a good teacher is one who, "... meet[s] the students' shortcomings in a thoughtful way to help him overcome them and not highlight it in a negative way. Have great regard for my teachers who show immense patience with me." Along those lines, you find the provision of wait time to be one of the most frequently demonstrated examples of effective engagement during your time at Cedarbridge. This is particularly significant given that high school classrooms are characterized by their quick pace of instruction and academically rigorous content (Downing, 2005; Mastropieri & Scruggs, 2001). While you do find these qualities present, you also note the consistency with which teachers navigate the challenge of keeping instruction moving while leaving time for typed contributions.

Sometimes, you witness teachers making space for Martin, Carlee, Ralph, Henry and/or Peter to type answers in real time. This is most common during review activities requiring short, predictable responses (single words or phrases). For instance, during an Earth Science lesson Ms. Hotchkins leads a vocabulary review with the whole group:

Ms. Hotchkins asks for the term that means 'two plates that come together,' and stands behind Martin. Ms. Grimes [TA] opens SpeakIt on the iPad. Martin's hand immediately moves toward the keyboard and Ms. Hotchkins waits as he types 'convergent plates' and presses the SpeakIt button to have the iPad read it out loud. She said 'Yes, perfect' and moves on with the activity.

By taking Martin's hand moving toward his iPad as a signal of his willingness to participate, and subsequently waiting—thus requiring his classmates to wait—Ms. Hotchkins ensures that she carves out space for his contributions.

You encounter situations, as well, that evidence ongoing negotiations between providing the students who type adequate wait time, while encouraging them to do their best to meet the pace demands of class activities. For example, in an English Language Arts (ELA) class, Ms. Kessler plays four popular music videos for the whole group before dividing them class into groups (each group will analyze one song according to a set of guiding questions):

As the students transition to their assigned groups, Ms. Kessler approaches Carlee's group. While her three other group members readjust their desks and chairs to face hers, Ms. Kessler asks Carlee to choose the song that her group will analyze: 'Carlee can you get us started? What song did you like best?' Carlee seems distracted by the noise and movement of the students moving. Ms. Kessler asks again, 'Carlee we need your leadership. What song are you choosing for your group?' Carlee directs her attention to her iPad and begins typing. Ms. Kessler remains bent forward over the right side of Carlee's desk as she does so. Even though she is watching Carlee type, Ms. Kessler waits until Carlee has typed her full answer, 'U 2' before she says aloud, 'Excellent choice. You guys are *I still haven't found what I'm looking for.*'

Here, you witness the layers of intentional uses of and negotiations around time by both students and teacher. By asking Carlee to choose her group's direction and remaining positioned, expectantly, at her desk, Ms. Kessler makes clear that she wants Carlee to produce an answer while she waits. When Carlee does not respond initially, Ms. Kessler ups the ante of her request by situating Carlee's participation as a source of leadership. And, she continues to wait. When Carlee does begin to type her answer, you see that she too works to navigate the competing forces of producing a response quickly and the time and labor necessary for her to do so via typing. By responding only with her chosen song's artist (U2), Carlee fulfills Ms. Kessler's request in an efficient way, adapting to the demands placed on her by a fast-paced

activity and a teacher willing to slow it down to make room for her “leadership” and participation in it.

You also note that the use of wait time goes both ways. Because the students who type often work on assignments or prepare comments prior to class, and some of them are more keen on sharing their work with their classmates, it is periodically the case that teachers ask the *students* to wait. For example, in algebra class Mr. Harper negotiates with Peter when he eagerly asks to share an answer too early on in the lesson.

Mr. Harper is going over the homework on graphing ordered pairs using the Promethean board at the front of the room. Peter types on his iPad to Ms. Kozlow (TA) ‘can I do one?’ She whispers, ‘raise your hand.’ Peter raises his hand. Mr. Harper finishes what he is saying and calls on Peter, ‘Pete do you have a question or do you want to give an answer?’ Peter presses SpeakIt: ‘can I do one?’ Mr. Harper responds, ‘Yeah I will have you come up in a minute.’ He goes on to remind the class that the first step in answering the problem is to label the X and Y axes. [*two minutes later*] He then adds, ‘number one asks us to find the coordinates of the indicated point. So Pete, you said you wanted to do one right? Do you want to come up and give us the coordinates of point A?’ Peter picks up his homework and pushes back out of his chair, replying ‘yes’ verbally as he stands up. Mr. Harper says, ‘come on up.’

At the front of the room, Mr. Harper hands Peter the stylus. He says, ‘okay so give us the coordinates of point A.’ Referencing his homework as he writes, Peter writes (3,-4) next to the letter A. Mr. Harper says ‘awesome.’

Mr. Harper acknowledges, but does not concede to, Peter’s eagerness to share his work. By staying on his planned timeline, but following through with meeting Peter’s request to give an answer, Mr. Harper shows that time can be a tool utilized for teachers’ purposes as well as students’.

Advance notice. During class discussions requiring more open-ended responses, you observe teachers either providing advance notice, or calling on and coming back to, the students who type. Ms. Engleman captures the essence of using advance notice, when she describes her own approach to it in her English classroom:

I would do a lot of...advanced notice questions that I was going to ask [the students who

type]. So if we were going over a particular assignment and I would kind of go around the room and everyone would answer a question. So early on I would say something like ‘Martin you’ll have number seven’ and then I’d start with number one so that he could put his answer into his iPad and be ready to give it when it was his turn. I would do different things like that a lot. So you know ‘Ralph I’m going to ask you in a minute how you feel about the characters’ actions in the third part of the chapter. Let me know when you’re ready.’ And then I’d go on with the discussion and then come back to him when he was ready.

You also see advance notice effectively utilized in action during one of Ms. Farber’s Algebra lesson’s on slope:

As she pulls up a worksheet on the Promethean board, Ms. Farber says, ‘Henry, I am going to ask you to get ready because when we get to question 2 I am going to ask you for the definition of irrational.’ She then continues on with the first problem about rise over run. As she does so, Mr. Meyer (TA) repeats the question in a whisper and brings the iPad, which has SpeakIt open, closer to Henry. Mr. Meyer types the question into the iPad and Henry brings his cupped hands toward his face, hunching over and tensing his body for a brief moment before lowering his hands and beginning to type.

Nearly three minutes later, Henry finishes typing, makes a loud sound and brings his cupped hands to his face twice. Mr. Meyer turns up the volume on his iPad and moves it further from Henry on the desk to make room for the worksheet. He whispers ‘good job.’ Ms. Farber finishes the previous problem and has trouble navigating the Promethean board to reveal the next. Henry reaches for his iPad and pulls it in front of him. After about one minute of struggling Mr. Farber succeeds and says, ‘Henry, thank you for your patience. [I] was having technical difficulties. The question is which number is irrational? Do you have a definition of irrational for us?’ Henry presses the SpeakIt button and his iPad reads (in a male voice with an English accent) ‘Irrational number. A never ending non repeating decimal.’ Ms. Farber writes ‘non repeating, never ending’ on the board as she says, ‘Perfect Henry. That’s the definition we learned way back in the fall. A non-repeating never ending decimal. [*to the rest of the class*] If you did not remember that I suggest you write it on your paper.’

In addition to Ms. Farber’s use of advance notice to ensure Henry’s participation, her narration of her technical difficulties and gratitude for his patience contributes here to a reconceptualization of what constitutes productive uses of time in a way made evident to others in the classroom as well. The three minutes between Ms. Farber’s heads up to Henry and the point at which he finishes his answer are seamlessly built in to the lesson. Yet Ms. Farber’s time spent wrangling with technology (eating up only sixty seconds of that class time) is constructed

as intrusive and warranting an apology for making Henry wait, an illuminating moment that foregrounds just how intentional and valuable wait time for typing is constructed in this classroom.

Recognizing contributions. In addition to advance notice, you witness many varied examples of teachers calling on and coming back when students who type to communicate indicate they have something to contribute. For instance, during the wrap-up of a group activity in Carlee’s global class, Mr. Mason poses the following question to a male student, “What did the Iron Curtain separate? Or figuratively separate or divide?” The following scene captures the spirit of the activity and evidences how Mr. Mason chooses to use wait time to engage Carlee:

Mr. Mason: What did the Iron Curtain separate?

Male Student 1: France?

[The classroom erupts with a number of voices speaking at once.]

Male Student 2: *[Loudly]* I know! Steal!

[Ms. Roland (TA) brings the external keyboard in front of Carlee, who raises her hand and begins typing.]

Female student 1: North and South

Mr. Mason: I'm not looking for a place, I'm more looking for...

Male Student 2: STEAL!

Female Student 1: You don't get to steal.

Mr. Mason Hold on, I'm going to give Carlee an opportunity to type it in and then you can steal it.

[30 seconds pass, during which Mr. Mason explains why he is ‘doing this in depth questioning.’ Upon noticing Carlee has completed her typing, he addresses her again.]

Mr. Mason: Carlee, you were typing. What've you got, dear?

Carlee: Communist and Democracy *[via iPad’s electronic female voice output]*

Mr. Mason: Awesome. The Iron Curtain was separating Communism and Democracy.

[To Male Student 2] Was that your steal?

Male Student 2: Yes.

Here, once the first male student fails to answer correctly, the noise level in the classroom increases and other students shout out in attempts to “steal” the answer. You watch and listen as this activity escalates and threatens to privilege not just a spoken answer, but the loudest, most quickly provided spoken answer. Instead, Mr. Mason notes that Carlee is working on her “steal”

answer and provides her the time needed to complete it; moving on, but not forgetting to come back to her after she finishes. Also significant is Mr. Mason's narration of his decision to "give Carlee the opportunity to type" before calling on another student. Not only does his phrasing gently remind Carlee's classmates that her participation requires a restructuring of the activity's timeline, but his referencing her doing so can be seen as a subtle reminder that their hasty (and loud) attempts to respond themselves could jeopardize other students' opportunities. Here, wait time serves both a functional purpose for Carlee and an instructive moment for her peers.

Cultivating a culture of respect. While the efforts you have come to know as "strategic access methods" (Ashby & Kasa, 2013) described in detail above served functional purposes in the class participation of the students who type to communicate (and can be argued as good teaching practice in general), it is clear that these teachers' actions serve a broader role in modelling and maintaining a culture of respect, particularly around interactions with the students who type to communicate. Some of the most regularly observed examples include greeting the students, asking their opinions in academic *and* non-academic discussions, speaking to them in age appropriate ways, and addressing them directly, as opposed to speaking to the adults supporting them. You also note many instances of teachers directly addressing other students' behavior that serves to exclude the voices of the students who type. For instance, in Algebra,

Ms. Farber asks, 'What are integers?' Carlee starts typing immediately. Ms. Farber says, 'looks like Carlee is working on something.' When two boys in the front begin talking, Ms. Farber taps one of their desks and says, 'She's typing, guys.' Carlee presses the speak it button and the device reads, 'positive or negative.' Ms. Farber responds 'Right. Integers are positive or negative whole numbers. No fractions.'

While many of the aforementioned actions seem common sense and otherwise inconsequential, they are essential for active participation and, according to the students and their families, are often uncommon in other parts of their lives.

In conversations with you, teachers emphasize the importance of modeling respectful interactions; you also observe them engaging in practices that support such endeavors. Mr. Waring, Creative Writing teacher, describes confronting his own discomfort in an effort to not only engage with Martin's unique form of communication, but as a means to showing his classmates how to do so as well.

I think there is this innate desire when someone does not communicate back, when you don't see immediate reciprocity, it shuts down social procedure. Fighting that was probably the hardest thing that I had to do, which is to continue the line of dialogue with him to have what seemed like a one-sided conversation even though it was a delayed conversation. So [Martin] would finish the communication sometimes days later, sometimes minutes later but forcing myself to be comfortable in a space where I don't get immediate verbal reciprocity in the conversation. That was perhaps the most challenging piece, but also I think one that when we push ourselves into that space it actually creates a better sense of comfort for all of our students, especially for the student like Martin... I think one of our responsibilities as instructors is to show students how to be, whether it's how to be academic or how to be professional or how to be a writer or how to be thoughtful. And I think laughing when Martin says something funny, that helps to break some of that ice. Asking hard questions of Martin when an answer falls short of his capability and then allowing students to engage with him, I think it breaks down all of the social barriers that really are kind of like glass ceilings and glass walls. There's nothing there except mostly our own fears. So I think if I can model how to move around that students tend to come on board and have honest dialogues and I think that makes inclusion actually inclusive...

In an anecdotal example, Ms. Engleman shares with you that one of her most poignant memories of having Martin in class was observing his relationship with another student, Brad, evolve from a bit of a rocky start:

And [Brad] said to me at one point while he's looking directly at me and Martin is sitting next to him... 'does Martin like baseball?' I said 'Martin is sitting right next to you, ask Martin.' And then they started a conversation and I kind of helped to facilitate you know... He would ask Martin more questions and he would answer back and whatever... [T]hen eventually that became kind of a routine for them. So at the end of class or at the beginning of class they would chit-chat.

You have seen the scenario (someone speaking over or around individuals with disabilities) Ms. Engleman recounts often in the lives of individuals who type to communicate, but her chosen

response, less so. Her decision to confront the issue in a casual, but direct, way not only changes the outcome of that conversation for both students, but it opens the door to others.

“They are our Way to Show that We are There”: TAs’ Role in Participation

Mr. Meyer (TA): I think every day you’re constantly picking up something new and learning, it’s not anything you can ever be stagnant with and you always have to be progressing towards the next thing, not only the student but the teacher as well in working towards independence because I guess that’s the main goal, right? Once you get comfortable facilitating it’s time to lessen your support and make it a little bit...

Casey: Uncomfortable?

Mr. Meyer (TA) Yeah, just like all education. Once you’re comfortable with something it’s time to up it a little bit, make it a little more of a challenge.

Over the course of your time at Cedarbridge, the team of teaching assistants (TAs) trained as facilitators grows (and shrinks) in number to accommodate the entrances (and/or exits) and shifting needs of the, first three then five, students who type to communicate. Their ages, backgrounds, and levels of experience vary, though none of them have training as facilitators prior to supporting their respective students who type at Cedarbridge. They all receive such training (albeit at different times) and ongoing assistance from both the Institute, as well as a highly skilled consultant trainer. Four out of five are female, one is male. While each individual TA works primarily with one or two of the students who type to communicate, over the course of the three years you observe them becoming increasingly flexible and proficient in supporting the communication of each of the five students.

The role of teaching assistant (TA) has been noted as particularly complex for those who also serve as communication support persons for students who use AAC in school (Robledo & Donnellan, 2008; Woodfield, Jung & Ashby, 2014). Your classroom observations and interactions with TAs and students solidify both that TAs play a critical role in students’ participation and that the responsibilities and boundaries of a TA who is also a facilitator remain relatively hazy. Despite this, the TAs who support the five students who type to communicate at

Cedarbridge effectively enact their roles by managing materials, muddling through daily logistics, building and bridging relationships. They are adroit at facilitating consistent engagement of the students through the means most conducive to their unique styles of communication and participation, as well as carving out new space and effective practices for professionals similarly situated.

Materials management. In classrooms, you consistently notice not only the complexity of the task of managing materials required for students' participation, but also the deftness with which each TA navigates these intricacies in ways tailored to each student's individual needs. This involves managing access between iPads (sometimes with separate stand and external keyboard) for communication, printed or electronic copies of content-related handouts, vocabulary terms and definitions (either pre-programmed Proloquo2go³³ or handwritten on index cards), a separate space for assignments to be recorded, writing materials, visual reminders (i.e. of routines and participation expectations), and fidgets for sensory stimulation during class.

For example, the following scene from Earth Science captures Ms. Grecco (TA) assisting Martin by arranging materials and prompting him in ways that enhance his ability to participate and engage with content.

Ms. Grecco sorts Martin's vocab cards into piles on the lab table, then opens Proloquo2go™ on his iPad, where a series of definitions and words comprise a screen of buttons. She holds up the vocab card and verbally cues Martin to point to the definition. He does and the device speaks the definition. Then she verbally instructs him to go back to the home screen. He looks at her and does not point. She says, 'I'm not pressing the button for you.' Martin looks back at the iPad and independently presses the button to return to the screen with the words and definitions.

Not only does this instance provide a glimpse of the multiple types of materials necessary for participation in a classroom activity, it also evidences the constant push and pull of providing

³³ A symbol-based augmentative and alternative communication iOS app that can be customized to include relevant symbols and text to an individuals' interests and contexts.

enough, but not too much, support. To that end, the TAs regularly reference the centrality of supporting the students' independence both specifically in communication and more generally for participation. They acknowledge that doing so often involves them negotiating the physical arrangement of materials during class time and continually adjusting levels of their support.

Managing and making use of technology. The importance of device proficiency in supporting students who use AAC has been noted (Light & McNaughton, 2012; Lund & Light, 2007; Rackensperger et al., 2005), and you too observe this to be a critical element of the TAs' roles as a more specific kind of materials management. You note the tasks of programming and switching between apps based on context to be the most common manifestations of technological proficiency. For instance, Ms. Roland (TA) explains that she utilizes routine classroom opportunities to program Carlee's iPad "whatever chance [she] get[s]" so that she does not have to keep the device overnight or take it away from her during the day. She cites access to the class website, and times like the beginning of each global class when students watch CNN Student News, as opportunities conducive to unobtrusive iPad programming. Her description and your observations of how she makes use of these online and real-time resources to ensure that Carlee's device has relevant content for class units reveals a commitment to preparedness, and an understanding that to do so during class or other academic or social times throughout the day would hinder Carlee's ability to participate. Once programmed, the devices serve multiple purposes within class sessions. The two primary uses are for typed communication and content-related participation; it often falls to the TAs to toggle back and forth between them. Thus, device management can be seen as an art based on both technological and logistical proficiency.

In addition to programming for alignment with academic content, the TAs often utilize the students' devices to provide subtle, yet consistent and crucial, support during breaks in class

activities, or when students express the need (verbally, gesturally, or behaviorally) for additional assistance during class time. Serving the dual purpose of leveling the communicative playing field and discreetly checking in with one another, TAs and students frequently engage in typed conversations. As Peter shares in a group presentation, “We can type back and forth so if we [students] are not regulated they [the TA] may type our strategies or a plan to get us through without everyone in class finding out.” You observe many of these quiet conversations in a variety of classroom contexts; it is a strategy used across all of the TA/student pairs. Sometimes they take the form of brief check-ins at the beginning of class or the start of the day, such as the scene between Ms. Kozlow and Peter early in the school day prior to heading to his first class.

Ms. Kozlow: How are you doing today

Peter: I am very excited. It is hard to concentrate

Ms. Kozlow: I understand there is a lot of excitement in the building today many of your classmates feel the same way. Prom is a very exciting day but we need to push through and concentrate on our classes. If you stay busy I believe it will help you stay focused on your task.

Peter: Koz if I need breaks may I ask for them?

Ms. Kozlow: Of course! Make sure you are asking for breaks in an appropriate way.

Peter: Awesome thanks Koz

Other times, these conversations are more sensitive and provide space for students to advocate for their physical or emotional needs in real-time. For instance, when Martin becomes “unregulated” as a physical response to his disappointment in his peers’ behavior during math class, he shares with Ms. Grecco the root of the issue:

Ms. Grecco: What is wrong?

Martin: I am not happy

Ms. Grecco: Tell me more

Martin: I not regulated

Ms. Grecco: How can I help you?

Martin: I can’t today

Ms. Grecco: Tell me more

Martin: I can’t regulate.

Ms. Grecco: Do you need to go home?

Martin: No

- Disrespectful kids.
- Ms. Grecco:** Tell me more
- Martin:** I can't do it. Its not good.
- Ms. Grecco:** ...
- Martin:** The math kids no good.
- Ms. Grecco:** Tell me more
- Martin:** I not like yelling, no standing for pledge. They need to not be mean to teachers.

Still other conversations evidence the complexities of navigating academic and personal well-being across school and home environments. For instance, during an Environmental Science class, while the rest of the students take a quiz that Ralph will complete during his free block later that day, Ms. Grecco checks in with him:

- Ms. Grecco:** did you want tell me something?
- Ralph:** I am so glad to be with you for all of my tests in here.
- Ms. Grecco:** well thank you. I am going to ask Mr. Hotchkins if we can waive the review sheet because of the passion project. I think you have way too many other things to do. I will ask. Is that okay?
- Ralph:** no
- Ms. Grecco:** okay how will we get this all done?
- Ralph:** no
- Ms. Grecco:** no what?
- Ralph:** anger
- Ms. Grecco:** tell me more
- Ralph:** home do questions
- Ms. Grecco:** what questions
- Ralph:** mom did not help me with 3,4
- Ms. Grecco:** she said you read it. Did she explain the things you didn't understand?
- Ralph:** no just told me those sections. But I need them to not need help
- Ms. Grecco:** no worries I can read them to you today and Mr. Hotchkins is going to go over it today in class. So I will take care of writing the notes on [sections] 18.3 and 18.4. Don't be angry this is being rectified
- Ralph:** I knew to and are you angry
- Ms. Grecco:** Absolutely not this is a minor bump. We can fix this. We can catch up 3rd block. You know you don't need to worry about this.
- The plan:
Read 18.3 and 18.4
Then do quiz with notes
Work on passion project.
- Ralph:** love you for all you do to help.
- Ms. Grecco:** this is the final part of your high school career. Do not worry. You got this!

- Ralph:** you are not a slouch
Ms. Grecco: thank you. Nor are you. Let's figure out how you could have fixed this at home.
Ralph: I need to explain to mom that you read and explain it.
Ms. Grecco: yes my friend. It's called re-teaching. If you would have explained it to mom she would have helped you understand the reading.
 Your mom is your best advocate. She has had your back for 20 years.
Ralph: I know but I was trying to be ok on my own.
Ms. Grecco: that's not what you do when it involves your education. If you need help you have to ask.
Ralph: I bite off more than I can chew sometimes.
Ms. Grecco: I know that, that is why I am here to keep you on track.
Ralph: mom is very understanding
Ms. Grecco: I know that.
 Next time ask her please.

These informal typed interactions serve functional purposes related to academic work, communication across environments, and provide opportunities for the students to take charge of their physical, mental, and emotional needs. They also help to minimize the auditory presence of the TA by transferring what would have otherwise been verbal prompts or questions into the visual realm. This compromise can be seen as an effort to negotiate the fact that adult proximity is critical for communicative engagement, but can also be a barrier. Finally, while these conversations are, by design, unobtrusive and brief, their frequency and rootedness in shared knowledge situates them as both evidence of and opportunities for relationship building.

Building relationships. Despite debate in the literature and practice about the purpose, proximity, and appropriateness of one-to-one support (Giangreco et al., 1997; Malmgren & Causton-Theoharis, 2006; Rossetti, 2012), the students often remind you that the development of close relationships with their TAs is essential. Early on in your inquiry Carlee shares, "I think that it's important that you understand how is the relationship with the teacher assistant." When prompted to explain, she expresses that because "it takes time to trust," once a relationship has been established between her and her TA, she finds it easier to "stay" with them and focus on

“getting [typing] independent faster.” Peter, too, echoes this when he tells you, “A bond between a typer and supporter is huge for success” later adding, “I think to tie everything together it is about trust.” The layers of complexity between developing trusting relationships as a means toward independence, at the risk of potentially becoming too dependent on one person, are many. During your time at Cedarbridge you witness the students and adult team members work collaboratively in response to this quandary; you watch as they try to balance the need for multiple TAs for each student so as to help develop students’ flexibility, while respecting the very real consequences of relying on a support person with whom a relationship, and typing proficiency, has not yet been established (Woodfield, Jung & Ashby, 2014).

A conversation that you have with Ms. Roland (TA) captures the reality that the students are not the only ones who feel the tensions associated with balancing the primacy of secure relationships and the implicit potential that their presence serves to be a hindrance:

And I know that in the school’s eyes they don’t like to keep you with the same person [student]. I remember that second year they were not going to let me [stay] with her [Carlee]. And I remember telling [Carlee’s] parents or they had found out and they were like [uncertain] because this really is dependent on that relationship. Not to say they [the students] shouldn’t be building more relationships... You know build those relationships, build them with as many people as you can. It’s hard because everybody works differently and we know the energy of one person may not mesh with theirs, which we did find out. You have to be calm. My way of building relationship was talking about who I am and what’s meaningful to me and who is that?...my family, my kids, [my husband], my parents. That’s where they [the students] want to make that connection with you. They want to know that you’ve got their back and if you’re going to share this about yourself then maybe they can take a chance on trusting you. The problem with that is we’re not supposed to. It’s just a big circle and that’s where I get caught. I really do, I get caught in that circle because I want them to trust. I want the parents to know that their kid is in good hands.

What Ms. Roland, as well as Carlee and Peter, touch on in their comments are the intangible elements of building, and maintaining, TA/student relationships that require the provision of support to communicate. The cyclic pressures associated with the students’ needs to develop

proficiency in communicating as independently as possible; the importance of “trust” in order to develop those skills; the institutional expectations to uphold boundaries of perceived professionalism; and a lack of precedent all become entangled in the day-to-day ways that these students and adults interact, or don’t, as a means to participate in school.

Bridging relationships. While echoing his peers’ notion of the importance of trust, Ralph qualified the relationship with his TA in describing, “TA’s role in the classroom is in a way very crucial to our success but they need to be in the background and not take over the delicate balance of supporting the student,” a reminder of the gravity of negotiating the impact of adult proximity, even in circumstances that require communicative support. You witness this to be particularly salient in the ways that the TAs hone in on and facilitate opportunities for peer interactions. You recall a scene during the unseasonably warm spring day when you observed Peter participate on the school’s clay team during a regional clay competition held at Cedarbridge Community College campus.

During the lunch break, students and adults scatter around the competition area; some buy lunch, some eat what they brought from home. Peter, Ms. Kozlow (TA) and I sit on the pavement just beside the Cedarbridge team tent. Ms. Tanner (SLP) is talking with another student behind us. Seated on the curb a few feet away, two girls on the Cedarbridge clay team are unpacking their lunches. Ms. Kozlow leans in and quietly asks Peter, ‘do you want to go sit with Aubreigh? You can go if you want.’ Peter verbally responds, ‘Yes.’ Overhearing, Ms. Tanner approaches and writes ‘Aubreigh can I sit with you guys?’ on a 2x2 laminated card attached to a binder ring. She asks Peter if he wants to practice. He looks at the card and says verbally, ‘I can sit with you guys.’ Ms. Tanner whispers, ‘no, say Aubreigh, can I sit with you guys?’ and Peter repeats ‘Aubreigh, can I sit with you guys?’ He stands up, approaches Aubreigh and Sophie and says ‘Can I sit with you guys?’ both girls synchronously respond ‘yeah!’ and Peter sits on the corner of the curb next to them.

Ms. Kozlow and I remain seated on the curb chatting while Peter eats lunch with the girls. From a distance, I can just make out them asking him if he is excited for the upcoming prom. He responds that he is going with Larissa but ‘she doesn’t know what she is wearing yet and that’s okay. I know what I’m wearing.’ They laugh and continue talking about prom. With her back now to Peter, Ms. Kozlow looks at me and smiles.

Ms. Kozlow’s encouragement and support for Peter to initiate and engage in an interaction with

his peers not only reflects her awareness of the potential for lost opportunities, but also the line between where she is needed and where she is not. Because Peter had previously been working on using his speech to have short conversations with his classmates, Ms. Kozlow's choice not to accompany him over to where the girls are sitting reveals that, in this moment, distance from an adult takes precedence. Casually remaining an earshot away, however, suggests that she is prepared to step in to support his typing should he indicate (through words, gesture, or body language) that is desired or necessary. Though here an example of prioritizing faded support, Ms. Kozlow's ability to read situations and Peter's willingness to put himself out there also ties back in to the importance of nurturing secure, professional, and respectful relationships between students and their TAs that allow for negotiation and ongoing reevaluation of support.

Re-writing the job description. The complexities and challenges of adult support comes up often as a prominent topic addressed in your interviews, observations, and interactions with the five TAs, but it also surfaces in interactions with and observations of the students. As noted, constructing and navigating these adult/student relationships that involve supporting communication for students with autism (often across gender, cultural, and age differences) is particularly challenging due to the lack of clarity around the expectations and guidelines associated with that role (Woodfield, Jung & Ashby, 2015). As Ms. Roland reflects on her role, "it's not the cookie cutter [job description] 'you're an assistant to the teacher and the teacher to the student.' It's not that at all. We define everything that we do because we're not just TAs."

For instance, Ralph and Peter's preparations for their respective school dances provide you with glimpses of the expansive and fluid notions of support enacted by their TAs. In addition to promoting Ralph's budding relationship with his prom date by fading proximity (see Act III), Ralph's primary TA, Ms. Grecco, also helps him learn to dance, at his request. He excitedly

shares this arrangement with you and the four other students who type during a group Google Hangouts conversation about senior ball (“Grecco [TA]...is trying to teach me [to dance]”). He also references his ongoing progress in three subsequent conversations during the Spring 2015 semester. This ancillary type of support illustrates the ambiguity and creativity associated with the TA/student relationships and evidences a task that extends beyond what is typically considered within the boundaries of a TA’s job description.

In another illustrative scene, after sharing his excitement about being asked to prom, Peter describes the unique way that his TA, Ms. Kozlow, helps him wrestle with insecurities around his appearance and anxieties associated with having his picture taken.

Peter: Casey, Henry, Larissa, and I are going to prom
Casey: I know I'm excited for you about prom. Are you and Larissa going to take pictures together?
Peter: Oh yes Koz [TA] and I have been practicing in speech how to smile
Casey: Peter why are you practicing smiling?
Peter: I force a smile and look like a horse
Casey: Hahaa Peter I think you have a nice smile!
Peter: When I don't try
Casey: So you are practicing for the photos?
Peter: Yes arm around the waist

Peter describes how he is using his allotted time in Speech class to practice his smile with the help of his TA, Ms. Kozlow (Koz). In sharing this not only does Peter expose his inhibition (“I force a smile and look like a horse”) but he also implies that his TA considers it within the realm of her capability and role to help him navigate those insecurities in a safe space through inventive problem solving catered to his needs. Both Ralph’s request that Ms. Grecco help him learn to dance and Peter’s described support from Ms. Kozlow around prom pictures suggest a level of trust and flexibility at the root of their relationships.

Much like these ever-shifting approaches to their roles and responsibilities the TAs often cite owning, and supporting one another through, the uncertainties associated with their positions. They come together as a team to assist one another in ways that mirror how they support the students: in a hands on, collaborative, and flexible manner. In fact, three of the five TAs (Ms. Grecco, Ms. Hamden, and Ms. Roland) not only become highly skilled facilitators through training and practice, but also voluntarily seek out opportunities to participate in workshops to further their skills as trainers of other facilitators. As a result, they not only become on-site trainers to more novice TA/facilitators in the high school, like Mr. Meyer and Ms. Kozlow, but they are seen as resources within classrooms and the school district more broadly. In fact, many teachers tell you that they find the presence and knowledge of the TAs helpful and welcome additions to their classrooms. As Ms. Hotchkins notes about having the TAs in her Earth Science class, “That was a nice dynamic too, for me to not know the answers. So that allowed me to take some chances because I wasn’t the expert. So maybe that was something that was really important in the recipe.”

Evidencing their expanding role and reputation, in the Spring of 2015 Ms. Grecco and Ms. Hamden give a district wide Professional Development session on supporting students with autism who type to communicate. To the same point, when Carlee leaves the area to complete her school year remotely from Georgia in December 2014, Ms. Roland is transferred to the elementary school and placed with a kindergartener who is believed to be a candidate for FC. While her official title is TA, she is assigned to this particular student with the expectation that she will also be a resource for on-site training and support to school personnel as a skilled facilitator and trainer.

Most often, however, you witness as the TAs (particularly those who go on to become trainers) draw on their experiences with the students who introduce them to the unique role of TA/facilitator as their guide. As Ms. Roland and Ms. Grecco describe below, hands-on experiences become constructed in conversation and in practice as foundations for their own personal and professional evolution, as well as motivation for their continued exploration and development of this niche; in many ways they work to resist professional hierarchies in schools.

Ms. Roland: I don't have a master's degree; I don't even have an associate's degree. I have lots of credits and stuff. What I do have are life experiences. What I do have is that I have gone and embraced this thing called FC and supportive typing and dove right into it.

Ms. Grecco: I just think sometimes [others] forget. You know we're not just sitting there and doing nothing. We're smart, educated people. That's a really big misnomer that people don't understand that we have more training and have been to more schooling, not college, but we've been through a lot of things and we learn a lot of stuff. I mean throughout our history...I mean I've been doing this since 1981. I know what I'm doing and if I don't I'm certainly going to find out how.

Ms. Roland and Ms. Grecco echo one another's level of consciousness around the misconceptions about their role and skill levels. Yet, their choices to continue learning and your observations of them encouraging others to do so suggest that like the students they support, these TAs too embark on a journey through uncharted territory.

“Imagine the Coordination...”: Managing the Space(s) Between

It is difficult, I think, with the type of the inner workings of a team like this. The emotions are high a lot of times and there are some hurt feelings at times too when there is a differing of opinion and whatnot. I think it's hard one of the things in terms of TA and teacher, psychologist, speech therapist, you know to be able to work together as a team and [be] able to keep your roles. It's a hard thing I think because at any given time you step in, like I've been in a classroom when they've needed help, they needed a supporter to go in. So it's kind of like we all interchange but that's a piece of the puzzle...we're constantly working on trying to figure out the right fit for students and that changes depending on where they are at. And that's a hard thing because everybody is great at what they do but it doesn't mean that they're going to be great at what they do with a specific student. (Ms. Adelstein, School Psychologist)

All of these conversations, practices, and experiences—these illustrative scenes—do not happen in isolation; they take place against the backdrop of administrative commitments and culture that supports their development. You witness this primarily in the form of decision making about and ongoing reevaluation of the more logistical elements that set the stage for these five students' participation. All team members take part in and are impacted by the logistical management of the students' school experiences. However, these efforts are primarily mediated and overseen by those at the administrative level and reflect the overall culture of respect that both drives and results from their decisions. Because the Director of Special Education, Principal, Assistant Principal, and Superintendent all play a role in each student's experience, the collaborative problem solving and logistical management you observe and describe are instances in which these administrators' presence and support are critical.

Scheduling, staffing and space. You notice that fine-tuning schedules proves crucial to the students' experiences. Evident in the following portions of three separate interviews (with Martin, his mom, and his TA) scheduling is constructed early on as an individualized and collaborative process with implications for students' behavior and academic performance.

Ms. LaMuncha (Mom): The afternoon is when he gets tired and that's usually when it's hard for him. So, the only thing he has in the afternoon might be gym class, but everything else, all the academics, are early so he can either rest if he wants to in the afternoon or do his homework or if he needs to come home, he can come home.

Ms. Grecco (TA): "Martin's schedule is made specifically for him. And if you notice, his fourth block is free every day. So if he is frustrated or DONE for the day, he just can't do anymore, he's exhausted, [mom] will come and pick him up.

Martin: Acceptance and understanding of my position. When I need a break, I am finding devotion to my request.

Also notable is the consistency that runs through these excerpts, suggesting that scheduling can be a tool in supporting students (or hindering participation), that there is flexibility in constructing schedules, and that doing so is a team effort. While leaving school early is not ideal for any student, the fact that Martin's tendency to fatigue is responded to as a logistical, rather than behavioral, challenge suggests that his team members see him as a competent learner and are open to cultivating environments conducive to his needs. The school staff later draws upon this experience with Martin to adjust and reevaluate scheduling decisions for and with the other students who type to communicate. These decisions prove particularly salient as the newer students transition into the school, and an academic course load, from other places where expectations were previously not as high. The team's approach suggests an understanding that the demands and timing of academically rigorous courses can have an impact on the behavior, performance, and comfort level of the students.

Connected to course scheduling and its implications for student participation are decisions about who supports which students and when. Over the course of the three years you are present, the team is committed to developing the proficiency of multiple communication support people for each student for many reasons, including the danger in relying on one person and high levels of (both student and TA) fatigue. However, they also identify challenges associated with such an endeavor: (1) supporting students to participate in academically rich

courses requires that the TA be able to support his/her communication, (2) becoming a trusted and skilled facilitator for an individual who types requires training and time, (3) a student cannot wait, or be limited in the ways he/she can participate in class, during this training period. The team develops a strategy of using less communicatively intensive classes already in the students' schedules (i.e. Phys. Ed., Cosmetology, Art) as opportunities for communication practice and relationship-building between the TA and the student. They also ensure that when possible during core support periods³⁴ (where students do much of their academic homework and testing) more experienced facilitators are available for hands on problem solving and support.

In addition to the fluid use of scheduling and staffing, you are also present for a shift in the way space is allocated and utilized by these students and their team. The expressed desire for a “home base” comes up in nearly all initial interviews with TAs and administrators during your first year at Cedarbridge. At the time, they are operating out of a segregated special education classroom and venturing to the OT room (if it is available) or other designated “safe spaces” (i.e. the Principal’s office) on occasions when students are unable to physically stay in class. By the second academic year (when Martin, Carlee, and Ralph are all present), the school designates a small room—B13—as “home base” for the students who type and their TAs.

Ms. Adelstein (school psychologist): Their [original] home base was our 12:1:4 class because that was the space we had and there was a teacher already in there. We didn't have a teacher assigned to just students who were using...supported typing. And so I feel like that was a huge shift...we were seeing a lot of behaviors and I remember talking with [Ms. Cipriani, Director of Special Ed.] and saying ‘we just need a space because before it was either the Principal’s office was their safe space or 12:1:4 class and neither were the best setting for these students.’ And I was so thankful that there wasn't even any you know no argument or anything. It was like ‘okay let's figure it out then.’ And I did see a shift. I mean to be able to have their own space in a classroom, their safe spot where they can do what they need to do and then get back to class. That was a big defining moment.

³⁴ The term the school uses for “resource” periods. Time spent in Core sessions involves one on one work time outside of class time for students and their TAs to follow up on class notes, complete assignments, start on homework or test administration. It is not a replacement for time in class, but acts as a support before or after it.

The room is equipped with multiple seating options, a pile of mats, a rocking chair, sensory fidgets, and an individual desk (decorated with items of their choice) for each student. The overhead lights are typically turned off, leaving the room lit by daylight filtering through frosted glass windows that overlook the front lawn of the school; each student has a lamp at their desk that they opt to turn on or off based on their preferences. At any given time, it is unusual to see more than one or two of the student/TA pairs utilizing this room for extended periods; it serves as a drop in space used for quiet work, sensory breaks, and problem solving during times of high anxiety and/or social, emotional, and/or physical dysregulation. It also later becomes the physical site of the group Google Hangouts conversations.

Just dig in. You notice that the most significant schedule, staffing, and space changes for each student occur in response to manifestations of actions often labeled (by students and staff alike) as “behavior,” and are particularly centralized around each student’s initial transition into Cedarbridge High School from their previous school. Perhaps most drastic, for instance, is Henry’s tendency early on to dart away from his TA and cause damage to school property, often putting himself in unsafe situations—an automatic response that he later articulates to be the result of a combination of years of low expectations without access to communication, the unfamiliarity of his new situation, and discomfort at home (see Chapter 2, Methods). Over the years, and with more experiences with similarly situated students, the team reveals a level of preparedness and creativity in looking past actions perceived to be challenging behavior as rooted in the student and focuses on adjusting the environment and expectations as key to students’ comfort and success. Superintendent Dr. Desimone tells you that she and the team believe that,

...[T]hose initial behaviors are symptoms. They are not behaviors that need to have a consequence. We need to respond to them, those behaviors, and we need to certainly make sure that the learning environment is safe for all in doing so. Those behaviors are symptomatic that we've not yet designed the learning environment, the support systems or the instruction to best meet that student's needs in a way in which they feel safe, supported, and can take the risk in demonstrating their understanding or their learning... I think that that's quite often where at times other school districts, or other schools, or other school systems may give up relatively early because they don't think that they can determine what the source is and they can. They clearly can. They just have to have an antenna that's seeking that type of information rather than to be shutting that off and just reacting to the behaviors themselves.

The creative use of scheduling, staffing, and space all reflect efforts to problem solve through these initial transitions, or other challenging situations, in order to set the students up to be productive and contributory members of the school community.

Logistical management. The responsibility for managing such individualized schedules and supports is, initially, shared across the team members. As the Director of Special Education, Ms. Cipriani, notes early on about Martin, Carlee, and Ralph, “These are three students dealing with about 18 different individuals throughout the day, so you can imagine the coordination that took.” In response to the growing complexity of managing logistics, Mr. Peters is brought in halfway through the first year of your inquiry (Spring 2012, see Timeline pp. 132-143) as case manager for Martin, Carlee, and Ralph. He describes this role as constantly evolving “direct consultation support” that translates the students’ IEPs into classroom and support experiences. By starting mid-year, and in a newly created position, Mr. Peters is faced with the challenge of carving out a role for himself that streamlines, rather than complicates, the existing functioning of the team. He serves as a liaison between students and teachers, problem solves alongside the team, and is the main point of contact between home and school; responsibilities previously, but unofficially, assumed by the TAs. The key element, he tells you, is keeping the lines of communication open between and across team members, including, and especially, the students.

Despite an initial adjustment period, the team functions smoothly with the addition of a head teacher, so when Mr. Peters moves on to another position he is replaced by Ms. Farber during the Fall of 2014. Early on, she describes how she conceptualizes her role, exposing continued vagueness around it:

Ms. Farber (Head Teacher): I've had some conflictive feelings with it. Sometimes you know I've been told 'well you're the lead teacher.' I've been called the program manager. I'm still trying to figure out what my role is. Sorry I'm being vague. I really don't fully understand...It's been a lot of meeting with the general ed. teachers, kind of educating them about the B13 room, about supported typing... You know the unknown can be scary and I think they (trails off)—I'm glad that they can vocalize their concerns with me and then it's kind of helping them see that being non-verbal doesn't mean you know that they [the students] are not competent... That's why I call myself an ambassador. That's what I think has been the focus of September is educating them that these kids are above and beyond intelligent. They're extremely competent and a little patience goes a long way.

Formerly a special education math teacher (who previously, but separately, had Carlee and Henry in class), Ms. Farber expresses having trouble conceiving of hers as a job more centered on managing adults. So, in addition to being an “ambassador” or liaison and managing the logistical elements of the students' days (i.e. scheduling, communication with home, problem solving with TAs and other personnel) Ms. Farber constructs her role as one that involves direct support for the students. She becomes a trained facilitator and learns to type at least structured conversations with each of the five students. She also spends time tailoring her relationship with each student based on their expressed preferences. For instance, she focuses on assisting in Ralph and Martin's transitions to college, while Henry requests that she attend Speech class with him as an additional source of support. She works with Peter on his stated goal to manage his anxiety and develop more reliable social interactions using speech and she plays a major role in coordinating logistics of Carlee's off-site high school curriculum. In all of these ways, the Head Teacher role is crafted for and around the students who type to communicate, while it also exists as a means to streamlining communications and processes across adult team members.

‘Nice not Having my Voice Disregarded’: Students at the Center of it All

My voice is thought to be important by the school whenever I attend the school meetings and note down my thoughts (Ralph Wibble)

In interviews about and observations of logistical decision making and day to day problem solving, it is evident that the school personnel solicits, responds to, and honors the students’ voices. The school’s administrative philosophy, which hinges on a mission to prepare all learners to meet the highest academic and ethical expectations “in a caring and collaborative learning community,” as well as a stated goal of “develop[ing] students, not programs” sets the tone for valuing student contributions in the construction of their learning and support. You see this philosophy personified most saliently in the way that students’ voices are engaged in school and through collaboration with home.

Prioritizing communication. An awareness of the importance of communication access permeates your observations and conversations with students, families, and school personnel. It is clear that space is continually made for students to act as advocates for and experts on their own communication. The presumption of students’ competence (Biklen & Burke, 2006) here allows for problem-solving around behavior, as well as the lived experiences of autism and adolescence in creative and respectful ways.

Martin has been in the district his entire educational career, and is relatively familiar to and with his classmates from the start of your time there, which he candidly points out: “You have to understand I’ve been at Cedarbridge all my life. It’s different for me.” According to his dad, Martin’s presence seems to have had a domino effect:

I think [Martin’s] success opened a lot of eyes to the fact that students like him truly have a voice and they have a desire to be independent. They have a desire to learn. You’ve just got to give them the environment to best make that happen.

Even given this, Carlee, Ralph, Henry and Peter's status as new to the school during their respective transitional periods place them in a position to introduce themselves to their teachers and peers. As a way of navigating this unfamiliarity, Ralph creates a PowerPoint that captures the most important things for people to know about him during his first semester at Cedarbridge. Business Law teacher Mr. Ferretti not only makes space for this, but reconfigures his plans to require that each student in the class constructs a similar "vision presentation;" an assignment he considers "a great icebreaker because, in this class, a lot of participation goes on." Not long after (despite already having been enrolled at Cedarbridge for a year), Carlee adopts this strategy and creates a PowerPoint about herself that she shows at the beginning of each new class she enters. Henry and Peter follow suit when they begin their experiences here. These four students continue to use their introductory presentations in the beginning of each school year and/or at the start of new half-year long courses, at their discretion.

The fact that this strategy is developed by, not imposed upon, these students as their chosen way to represent their identities captures their positions as contributory members of their educational community. Are there alternative ways that the students could introduce themselves? Of course. Would you recommend that from now on each student who types to communicate be required to create a presentation summing up who they are and what is important to them? Absolutely not. The point here is that it is their choice, and that choice is honored, cultivated, refined, and supported. Significantly, Martin's decision *not* to partake in such an undertaking also evidences great respect for and individualization in considerations of student preference.

Martin, Carlee, Ralph, Henry and Peter's involvement in constructing their schedules, daily needs, and interactions also extend to the research observations conducted for this inquiry.

The students appear so comfortable and confident expressing themselves in school that during numerous scheduled observations you are met with direct requests from the student that you reschedule. For example, when Carlee types, “I am having a bad day. Don’t want [observer] to come today. I am having a bad day,” the school psychologist approaches you before you are to enter Carlee’s classroom and notifies you that Carlee wants to talk, escorting you to the hallway where she waits with her iPad and TA. One of the adults could have reiterated Carlee’s words to you. You would have to trust that the message is Carlee’s and that it is not misinterpreted; that it is her bad day and not someone else’s. Yet, the adults honor that this request is Carlee’s choice, that her participation in this study is her decision.

Home/school communication as central to practice. The above example brings forth the importance of home/school collaboration and communication. You later learn that Carlee’s bad day is rooted in stress around a shift in home support, a circumstance that her parents and team discuss often. You see parents engaged as collaborative problem-solvers and bridges to eliciting and clarifying student perspectives. There is a fine line between relying on parents to pick up the pieces when things fall apart and depending on them to help understand why, and when, some things work and others do not. You find the latter to be the overall approach to home/school collaboration, one visibly driven by the aim of keeping the students central. This relationship is most apparent during instances where communication breaks down. In one case, the school reports to Carlee’s mother (Ms. Sanders) that Carlee refuses to stay in Art class for more than “ten minutes.” At home, Ms. Sanders prompts Carlee to explain:

Ms. Sanders: . . . at home she said [typed] that ‘the environment was painful.’ ‘What do you mean?’ She said it ‘hurt her eyes.’ ‘Is there anything they could do?’ and she said, ‘put material over.’

Carlee’s typed explanation of her behavior relates to her difficulty managing her sensory needs

in that particular classroom. Ms. Sanders describes essentially becoming a messenger of Carlee's request, reporting back to the school and problem-solving ways to ameliorate the environmental situation or find an alternative class. In this, and other instances, the school team demonstrates a propensity for reading behavior as meaningful, a willingness to recognize communicative gaps that they cannot reconcile alone, and a respect for parents as potential bridges leading to (not replacements for) the students' explanations.

“A moat works on both sides”: Collaborative decision making. The data—including experiences, interactions, documents and memories—you compile is brimming with small moments of students and their families advocating for their individual needs and/or preferences, and school personnel taking those communications seriously. From conversations between students and TAs to individualizing course selection, scheduling, and staffing based on student feedback or physical/emotional/mental demands and beyond, these five students' contributions to the construction of their (individual and collective) high school experiences hold noticeable weight. One particularly striking example occurs in Martin's senior year, related to the publication of his autobiographical creative writing piece in the school magazine. In it, Martin vividly describes his feelings and actions during what he labels as his “tantrums,” including the line: “I start hitting my chin, then my head, finally I hit my supporter.” While all constituents are encouraging of the publication of his written work, selected through a vote by his classmates, there is some debate among adult school personnel about the consequences of these candid descriptions for Martin's upcoming college transition. There is discussion about excluding the section about “tantrums” from Martin's published piece. Martin's writing teacher, Mr. Waring recounts,

And one of the spaces that became really interesting was that there was conversation about removing a paragraph [about ‘tantrums’] from his piece for Martin's

sake. And we spoke to Martin and said ‘you’re a twenty-year-old man, you get to make this decision, like you and your family get to decide what’s best for you. This is not about propagating the success of a program. This isn’t about a cost benefit analysis. This is about your voice and do you see the benefit of this piece being something that you want or would you like to edit based on some of the recommendations you’ve heard elsewhere.’ And he was quite insistent that this was to be shared as it is written. And that was cool...

I mean there’s this system here that’s built to support and protect all of our students from our most able bodied to some of our most struggling students whether that’s academic or physically. But sometimes those systems create such deep hedges for protection that a trench or a moat works on both sides, right? It’s harder to get in, it’s harder to hurt, but it’s also harder to get out. And I think what we saw in Martin was he crossed that on his own. That to me was wildly encouraging. You know the family felt torn and he made a decision, and then the decision was honored. And the decision was honored at my end, at [Ms. Grecco’s] end, at his parents’ end, at the administrative end at Cedarbridge.

And I think one of the things that I learned is that these support systems are fluid and we’re constantly renegotiating our positions in order to benefit students and not benefit ourselves. And that to me was maybe the most powerful thing I’ve experienced with *any* student...

Martin’s writing piece is published as it is written. This moment of restlessness surrounding its impending release serves as a notable example of both the challenges and ways of supporting student decision making, despite potential consequences and/or administrative dissent. As Mr. Waring points out, this is an instance that demonstrates the balancing act necessary to maintain “hedges of protection” while also upholding a stated value placed on student voice and power.

Students as resources. In addition to participating actively in constructing the logistical aspects of their individual and collective high school experiences, you watch as the students and school staff develop a symbiotic relationship around sharing experiences that could benefit other similarly situated students. As will be addressed in Act III, all five of these students express the desire to “advocate” and share their stories with others. As a result of this—combined with the fact that Cedarbridge is seen as a model school in many areas

(including digital literacy, technology, and STEM³⁵) and gets requests from other districts for guidance—the administration provides and/or aids students in developing varied opportunities to share their experiences.

Over the course of your time with them, you see these opportunities range from observations and consultative meetings with other school or district administrators, to a ribbon campaign to promote awareness of communicative diversity, to multiple conversations with a team from Apple interested in developing an app to support communication through typing, a school wide assembly to End the R word, as well as invited panel presentations at a national conference, local elementary school, and a Board of Education meeting. You observe that students are always given the option whether, and to what extent, to partake in these activities; the mix of who participates and does not ranges across time and context. Some, like the End the R Word campaign in which Peter and Ralph take part, are school wide and voluntary with a mix of participants collaborating to convey a broad message. Others, like the consultative meetings with the Apple team or the Board of Education panel, are specifically tailored to understanding how to support students who type to communicate. Throughout all of this advocacy work, you witness the school personnel, families, and students maintain open lines of communication to ensure that the students are able to share stories, when desired, without being positioned as objects on display.

Dr. Desimone: That's the part that I think we truly need to help others to understand that these are students who have a different way of communicating. Their knowledge and their understanding of the world in which we live [*trails off*]*—they have tremendous amount to share. They have unique and individual personalities, and they contribute to this world in many, many ways and we have to provide the education that will allow that to blossom.*

I think that's why the work that we're doing is just so important and I think that that's why their role and their advocacy is important. I think if the rest of the world could

³⁵ Science, Technology, Engineering and Math education

really truly see and understand what's going on that they would begin to recognize. I'm amazed each and every day... We are continuing to learn, there's no question about it. They'll present us with new challenges or new areas of growth and we'll continue to develop in that way. It's just an important place. I do think that they'll play an important role. Not only now, but in the years to come as well, because I think that they can be a vital resource in the future to better helping to understand how to meet the needs of the students who are, right now, in our kindergarten through 8th grade classrooms or who haven't started school yet.

As Superintendent Dr. Desimone makes clear, the students are seen as stakeholders and “vital resource[s]” in both their own and others’ educational trajectories. The fact that their experiences now are seen to have implications for the future is reflective of a school culture that both positions diverse ways of participating as valuable, and anticipates continued support for and with such varied student experiences moving forward.

Supporting Whole Students

I think, at least for me, their academics were so important because they wanted to be viewed as smart, but they also want to be viewed as young [adults], you know social beings too, so they are. (Ms. Farber)

You come to experience the ways that the students are undoubtedly regarded, particularly by school personnel, as contributory members of the school community. Their competence is presumed, their choices are honored, their participation is valued. However, you also come to witness the ways in which the school adjusts to accommodate the students’ other social, emotional, and/or physical needs.

Making friends. One of the most striking examples of this comes to fruition around students’ social lives and developing meaningful relationships with peers, an aspect of high school known to be challenging for students with disabilities in general (Kennedy, Cushing & Itkonen, 1997; Rossetti, 2012). Despite the ways that their voices and perspectives are recognized and valued in the school, the students often report struggling to be seen as “just teens” and describe being frustrated with the social aspects of their high school experiences.

They are seen as students, self-advocates, and trailblazers, but perhaps not friends and peers in the ways they desire. This is particularly salient during Martin, Carlee, and Ralph's early experiences, individually and together, at Cedarbridge:

Martin: Although, I have made many advances academically, the social piece is still hard. I still have a hard time making friends.

Carlee: Making friends has been hard. Finding those who can see past my sometimes odd behaviors is difficult. I want to be accepted for me just like anyone else.

Ralph: I am forgetting to say that I have autism but would add that you need to ignore my weird behavior resulting to this.

Though Carlee, Martin, and Ralph seem to locate their difficulties with peer relationships in themselves and/or their disabilities (i.e. behavior, autism), your time in the school reveals that the logistics and structure of their academic participation have implications for opportunities to make friends. In fact, some of the strategies you identify as promising—an individualized focus on the students' needs and preferences, close relationships with TAs, and thoughtful scheduling—could also hinder interactive opportunities with peers. For instance, all five of the students typically arrive between five and ten minutes late to their first block classes, allowing time for organization, sensory support and initial typed conversations necessary to prepare for the day. This arrangement reduces the time the students spend navigating the hallways during one of the busiest transitions, a period with which all of them have expressed having trouble. Though by the time they reach their first classes they are physically, emotionally, and logistically ready to participate academically, they have missed social opportunities in the hallways and classrooms before the start of the lesson. This is only one example of how the students' unique needs, logistical supports, and daily routines intersect and impact social opportunities, capturing the complexity of developing balance in this context.

Had your inquiry ended after that first year, you probably would have called this a gap in these students' experiences. You likely would have been critical of the ways that academic

participation is prioritized over social belonging. But the story does not end there. While relationships with peers perhaps do not develop at the pace, or to the extent, that the students express desiring, you do see them evolving over time and in relation to other factors. You also watch as the students' priorities shift from establishing themselves as academics to seeking more rich and varied experiences beyond the classroom. You capture moments on video and in your notes of each of the students working together with peers on class projects; Carlee and a female classmate joking over a Katy Perry song Carlee plays on her iPad; Ralph engaging in conversations about his past in India with peers in Science class. You recall Peter's aforementioned clay competition to be an especially poignant example of relationship building, in addition to his active participation as a team member. In an illustrative moment of this, you stand next to him there among his other teammates and introduce yourself:

I say to Dana (female leader of the team) 'Hi, I'm a friend of Peter's.' As soon as I say so, Ben (the male leader of the team) extends a hand and loudly remarks, 'well then we must be friends. Any friend of Peter's is a friend of mine!' I shake his hand, as well as introduce myself to the four other students nearby. I exclaim to Peter, 'Wow Peter, I think you have more friends than I do!'

You also watch four of the five students prepare for and attend school dances; Ralph and Peter are accompanied by female classmates with whom relationships develop in response to the End the R Word presentations. You watch as classmates across grades come together to build the mural that these five students design and execute at the end of your last school year with them. While these interactions cannot be positioned as evidence of meaningful friendships, they do reveal the possibility for the development of them.

Accordingly, over the three years of your experience at Cedarbridge, the school works more purposefully to find and refine a delicate balance of prioritizing academic participation, while accounting for the need to facilitate social relationships and support the students'

individual personal needs/goals. You, too, take a part in helping to construct opportunities and space to privilege the social aspects of their lives by working with the students and staff to carve out time dedicated to conversation in whatever form they choose (see Act III). This remains an ongoing and ever-evolving challenge, as well as a growing priority for the students and those who support them.

Prioritizing well-being. Navigating the need to balance staying on track academically, building relationships, and supporting students' emotional well-being proves a complicated task. Ms. Farber tells you that one of the most poignant moments she recalls in relation to Peter and Henry has to do with an instance that Henry uncharacteristically asks for his emotional well-being to be accommodated in the ways his communication has been.

Peter is so much more open and willing to share. Henry is quieter and I think a deeper thinker but keeps a lot in. And [recently] there was a medical issue with a family member. [The twins' mom] had given me a heads up and we talked to both boys and Henry actually was typing a lot about how he was concerned for his family and [he asked] 'could my brother and I spend the day together? I think that will help us just to be together.' ... So we did; we changed their schedules so they could spend the day you know in B13 together... They did their work, they just wanted to be together in the room... It was another one of those moments where you step back and go 'oh yeah.'

Inherent in Ms. Farber's "oh yeah" is the acknowledgment that the logistical and support efforts extend beyond students' academic progress.

Perhaps the example that most epitomizes the way all of these elements, and players, come together is captured in the response to Carlee's struggle with anxiety and difficulty staying in the school building, beginning during the Fall of her Junior year (2013). While the circumstances are very much in progress and unclear, what is important to know is that at this time, things start to fall apart for Carlee. This remains an ongoing problem solving process; no one, even Carlee herself, has been able to articulate clearly the roots of, or a conclusion to, this part of her story. There are many varied things happening in Carlee's life during this year, both

in and out of school, not the least of which being that she is approaching her 18th birthday.

While a milestone for any teenager, Carlee's impending entrance into adulthood is marked by her expressed bittersweet feelings, as it brings with it the reality that she will no longer be eligible to receive services through the international au pair program that has been a constant in her life. She starts to discuss with uncertainty what her future will look like. When her parents leave for their annual, extended trip to Georgia in December (a routine occurrence for Carlee), things get increasingly worse in Carlee's school life. She begins to lose the focus on academics that had previously been a source of great joy. Most significantly, she becomes unable to keep her "body regulated" in school; reaching a level of combined sensory overload and anxiety that result in behaviors that threaten to fracture her dignity. Her primary TA, Ms. Roland recounts,

I would just be like 'What direction are we going with this? What are we doing?' You know, you kind of start the question 'what are we doing and is it best for her?' Like what is this [State] test going to do for her right now? Nothing. She needs to be able to learn to smile again because she stopped smiling. She was always just quiet and if she wasn't just so consumed by anxiety that it ate her (trails off)—and I tell her that all the time. I'm like 'don't let this anxiety eat you. You have a way to get out of this.' But sometimes I think when she gets in that mode she falls back to what she knows and what's comfortable and that is [engaging in self-destructive behaviors].

Everyone rallies around Carlee, including you, problem solving ways to make her feel safe, valued, and comfortable so she can continue on the path that she had begun in high school. Her teachers provide her with work to complete outside of class time, when her anxiety gets the best of her and she is unable to physically stay in the classroom. The administration works closely with her parents and the rest of the team to make sure Carlee gets as much credit for her time in school as possible. But by Spring of that year (2014), Carlee is not in school often nor is she able to physically remain in the building for extended periods of time. She spends the last few months of the academic year on homebound instruction provided by the school in her house and at a local elementary school. She attempts to take the State exams she is scheduled for, but

ultimately testing proves to be the most anxiety inducing element of school for her. The following year, after returning to school part time during the Summer and Fall, the team works out an arrangement to allow Carlee to accompany her parents to Georgia for the Spring 2015 semester, working remotely and flexibly on her high school requirements. All the while, in all of her stops and starts, coming and goings, the school remains committed to supporting Carlee's well-being, in addition to her academic progress.

Ms. Farber (Head teacher): We can definitely play around with her schedule. I want Carlee to know though that it's really at her pace. She is the adult and she will let us know. I mean she made her point of view very clear, but I think that her going [to Georgia] was a wonderful thing for her... I think just having her in math a couple of years ago and knowing what maybe what two winters ago was like, you know sometimes academics aren't the number one priority and for your own health and well-being you know (trails off)—And I think being down there with her family was what she needed. The couple of times she Skyped in or whatever, I could see her she looks good. Things are going well. I'm happy for her. And she's close enough to graduating that you know missing a semester of high school is not a big deal in the big picture.

Carlee's participation and overall high school experience looks drastically different from those of her peers; in fact, it looks wildly different at the end of your inquiry than it does in the beginning. Yet, in a situation that is challenging and emotionally trying for all involved, you watch as the school's philosophy about and commitment to students, ways of collaborating with family, approach to behavior, individualized problem solving, and regard for Carlee as a whole person intersect, bump up against, and in many ways resist more widespread notions of what constitutes an educational experience. It is not a smooth ride; there are missteps and there are challenges along the way on this unmapped path. There are days when Carlee's behavior becomes too challenging for the staff to support in the school building; she has to leave and/or be taken out. There are moments when Carlee's parents express fear that her behavior, now, will change the school team's view of her abilities forever. There are instances when Carlee types, and acts like, she wants to give up. But no one gives up on her. The underlying belief in and regard for Carlee

as a student and person—not merely a set of inconvenient behaviors and challenges—remains firm and results in collaboration and problem solving grounded in respect and care.

The Overall Approach

[They are] students, treat them like students. Be merciful when mercy is what’s called for, be diligent when that’s what’s called for, be hard, be sharp, and don’t look at someone’s difference as an excuse to use differentiation as pandering to the lowest common denominator. Use it as an opportunity to find new ways to communicate and maintain a high standard that we believe that all students can achieve.

And I think if we push ourselves in that way who couldn’t be successful?

(Mr. Waring, Creative Writing teacher)

At the end of it all, you can confidently say that this particular high school’s approach to teamwork and support evidences promising practice by all involved. Yes, there are certainly areas upon which improvements could, or should, be made; spaces in the data that bring your identity as a disability studies in education scholar to the fore and prompt ongoing, critical discussion. For example, the aforementioned limited social opportunities, prevalence of adult support, and a tendency for the school to operate under the expectation that these students “fit in” rather than fundamentally change the nature of the classrooms they enter (see Act III). You watch as the school both resists and perpetuates dominant narratives around behavior, sometimes falling back on separation as a consequence and other times opposing that tendency by seeking new ways of understanding students’ behavior. You are also constantly struck by the incongruity of the fact that while these five students are actively included, next door to their home base classroom is a segregated special education classroom full of students with disabilities that are not. Despite these tensions, you aim for this introduction to the school space and its players to honor the voices of the students and the work of the school team members, whose intentions and efforts are focused on supporting those students in comprehensive and empowering ways.

You recognize this group of individuals as being at the forefront of a shift in

understanding how students who type to communicate experience high school. The teachers, TAs, parents, and administrators all play a part in constructing and refining this collaborative support model with the students always at the center. The teachers' intentional integration of strategic methods creates avenues of access and active engagement that allow these students to not only participate in academic contexts, but to make their learning available to others. The TAs are responsible for managing materials, providing on the spot accommodations and preparatory planning. These actions allow the students space and time to focus on the academic content and their contributions to class. All of this happens within a larger framework that includes school administrators and parents, operating on the periphery, providing guidance, information, and ideas within a culture of respect and trust.

Yet, by far, the most significant conclusion to be drawn from your experiences with and alongside this team is an understanding that theirs should be positioned as an exemplary approach to problem-solving rather than a model to replicate. Not only is each constituent continually negotiating day-to-day realities of supporting—and being—these individual students, they also collaboratively construct their roles and responsibilities as fluid; in a perpetual state of (re)emergence and revision. You see this focus on process as the primary contribution of this work. As a researcher interested in supporting students who type to communicate in school, you are often asked to provide examples of “programs” that could serve as exemplary models of effective supports for such students. You hope that the complexity evidenced in this brief journey through these experiences reveals that to claim Cedarbridge as a model would counter the very nature of what makes their practices promising.

As a whole, the team of adults that surrounds these students embody just that: a team in place to support these particular students and their specific needs. They do not call themselves a

“program,” but utilize an interdisciplinary approach to support that hinges on the students themselves. In observations and interviews, staff, parents, and students continually reference sequences of events rather than problems and solutions, indicating the amount of negotiation and collaboration that weaves through their experiences. Their words and actions reflect the thinking that what works for Carlee works for Carlee and not, by nature of their perceived similarities, necessarily for Ralph, Martin, Peter, Henry or any other student with autism who types to communicate. Ironically, it seems that this individualized approach and ongoing problem-solving is exactly what has drawn multiple individuals with similar needs into this space; a reality that tempts outsiders-looking-in to refer to theirs as a school with a “program” for students who type to communicate. Though nuanced, it is important to distinguish between this school as enacting an approach to programming worth modeling after rather than being a program to model itself.

Ultimately, it is the combination of philosophy and practical application that has made this work in the ways that it has for these students, in this school. It is possible that next year, or next month, the supports that one of the students finds useful now will no longer be the most effective approach for him/her. TAs may move on to other students. New teachers will lead new classes. The students will grow and change emotionally, physically, communicatively; you have witnessed such changes and responses to them. Yet it is the acknowledgment of and space made to prepare for the unpredictable evident in this school’s approach to problem-solving that ensures that they will continue to keep the students at the center, growing and moving with them. Ralph’s advice to other districts aptly captures the culture of this school is what he feels is most worthy of replicating: “In all this I see a lot of belief in students of all abilities as worthy of tutoring. I would want the other school districts to do the same and follow the right path of equality.”

[Fade out]

Act II The Performative Landscape

[You are a school board member. You are a teacher. You work for an adult services agency, trying to balance between doing what is legal and doing what is right for people with disabilities. You are a parent of a child who does not speak and who spends his/her day in a segregated classroom putting round blocks into square holes and you want more, better for him/her. You are that child, who has much to say (and is beyond tired of the whole block thing) but no way or opportunity to say it; you want more, better. You are any high school student in an auditorium full of your peers, hoping your crush notices your new (insert something cool) and grateful for the 30-minute reprieve from algebra class this assembly has provided.

You are a friend.

You are a researcher.

You pick up your iPhone and freeze frame the image in front of you; so much movement, so many sounds. At the same time, you wonder why you need a photo of five teenagers with autism with iPads propped on various stands and distinguished by a variety of (varying from colored to patterned to plain-black-leathered) protective cases in front of them. Across the long set of tables, handmade name tents are placed facing outward, presumably for your benefit. From your left to right, they read: Henry, Peter, Ralph, Carlee, Martin. But they are not alone; for each student there is an adult, each in a different position, each performing a different action, as you freeze them in time and save them to your camera roll.

Then you watch, and you wait, for their stories.]

[It takes you a while to figure out, but you eventually conclude that the faint, rhythmic humming you hear is coming from Henry. Though his body is mostly still and his mouth does not so much as twitch, he produces melodic sounds that make you want to move with them. As he does so, he drags his index finger across the screen of his iPad, lifting it only occasionally, as if he is tracing. Finally, his TA/facilitator, Mr. Meyer leans in and whispers to him. Henry lifts his right arm and brings the tip of his forefinger to the screen, a direct hit this time. As the iPad's digitized male voice begins reading his words, Henry raises his eyes to the audience, but you swear he is looking only at you.]

Riding the “Waves of Life:” An Introduction to Henry Golden

I am Henry Golden.³⁶ I am a tenth grader at Cedarbridge High School. I am really trying to be young man as each day goes by. A real passion of mine is philosophy.³⁷ I love reading books which is a back bone of my life. Real yearning of mine is to learn meditation from a real guru; waiting for one to ace my wants, anvil my anger, and rid my hatred. Want my asking for ascending spiritual ladder really a great guru.

With lots of love and support from my family and school really I'm able to ride the tumultuous waves of my life.

³⁶ *I first saw Henry at a gathering for local typers organized by the Institute. He was new to typing and I know that we did not exchange many formal words and if we did, I don't recall what they were. But I do remember his snacks. In the middle of the two-hour event, his mom laid out a series of items on the table in front of him. I could spot those wrappers a mile a way: gluten, dairy, soy free cookies. The ones I am too frugal to buy (or pretend to not want in an effort to be “healthy”) for myself, but wish that I had on hand more days than not. I remember thinking, “I don't know this guy, but I like his taste in snacks.” I like to believe our relationship has evolved beyond avoiding the same allergens and appreciating the same packaged foods, but I find it no coincidence that I have bumped into Henry and his family at my favorite local gluten-free cafe more than a few times. I felt a little guilty that this was my initial thought when I reflected on early memories of Henry. But looking back, it is appropriate that our relationship began with a connection over food. Rarely was there a conversation between us that wasn't preceded by, paused for, or concluded with something to eat. We bonded over the satisfaction of crunchy carrot sticks, the appeal of something sweet, and an irresistible urge for all things gummy.*

³⁷ *But to stop at describing his snacks would be a disservice, since I now know that those crunchy, sweet, gummy items are often what help Henry regulate his body, formulate his perspectives, and process his deep and contemplative ideas. Selective and methodical about when, how, and where he interjects with his typed words, when Henry contributes to conversations or classrooms everyone pays attention. A self-described philosopher, Henry's insightful interpretations of life, spirituality, and constantly evolving experiences have much to teach those around him, including me, about the importance of introspection, receptivity, and patience.*

Yes I have Autism³⁸

My name is henry
 Yes henry has autism
 But not me
 I am free in my essence
 But Not in my struggling presence
 each moment apprehensive
 As the senses go defensive
 Not knowing under whose missive
 Asking all my life
 Why why why

My Family, My Faith

Gita my ray of hope. Gita is our bible. Really a great hope for humanity. I need saying that [you]³⁹ try to read it. You will be changed forever. Really my family loves Gita and we read together. Those are the moments I look forward to every day. Really I am bearing a lot to do my daily duties and this book gives me the strength to deal with them. Real taste of Gita can make you each day a happier and complete person. Under my impression I ask everyone to read it at least once in their lifetime.

My Early School Days

I [want] to share my journey into the world of normalcy via typing. I have been really blessed to be here [...] because never in my dreams did I think that this day would come. I was born in [another state] and we moved [here] when I was 5 years old.

³⁸ *Toward the end of the inquiry, Henry began writing poetry. This is an example of one of his recent poems. He requested that it be reproduced here as part of his narrative account to give the reader an idea of this new area of exploration for him.*

³⁹ *As noted in the Methods section, the presence of brackets in students' narrative accounts indicates my insertions and/or edits to the students' original typed text. All of these changes were mutually agreed upon as necessary for clarification. In places where there are significant additions (i.e. full sentences), the content has been pulled from other sources (i.e. interviews with students and parents).*

Was my intelligence ever shown till now? No. I spent my school days trying to each day just getting by until it was time to go home. For the most part, I was in a glorified daycare.

[I wish I had been able to tell my childhood peers] that I was just like them and as smart as them; that I would have loved to interact and play with them. [I wish my teachers could have figured] out how to teach me. [But] I dwelled in my own world shutting everybody out and communicating only through behaviors. I was desperately trying to communicate. I wanted [everyone] to know: I am smart. I'm nonverbal not invisible.

My whole school life was frustrating because [no one] could communicate with me. My teachers were nice, but not very effective. I used to have lots of everyday anxiety about going to school wanting to stay home and be safe. I had a real tough time until typing came in my life when I was fourteen.

Learning to Type; Life with “New Everything”

I started typing about three years ago. Technology [...] has opened my portal of communication. Without iPad, my life [would] go back the way it was. It has given me voice and real education. My family moved to Cedarbridge to help me and my twin Peter two years ago. It was each day a challenge to adjust to new everything.⁴⁰ Since then, my life has become positively learning about life itself.

⁴⁰ *Henry's challenging transition into Cedarbridge High School is referenced throughout this dissertation. It was difficult for all involved, especially for him. Retrospectively, he was able to clarify that his behaviors came from a place of frustration growing out of a desire to push himself academically, combined with unfamiliarity of being able, and expected, to communicate through typing; behavior was his default, as it had been for fourteen years prior. While the school staff and Henry's parents worked hard to adjust his schedule and support him in navigating everything "new" in his life, Henry also attributes much of learning to his relationships with the other students who type to communicate.*

The past two years have been challenging for me but every day really I am proud of my progress. I am quite successful in formal education and have been getting averages in 90s. It's been a challenge since I was not sent to inclusive class since fourth grade in my previous school district. However, I thoroughly enjoy the challenge and math and science are my favorites. I find global the hardest because I'm not sure of what is important and what is not.

My biggest accomplishment is being able to stay in classes and participate in class discussions. I enjoy being able to express my opinions. Other typers helped me break free of my behaviors and control my impulsivity so I can stay in the classroom. I have come a long way. I even attended the prom and was able to interact with my peers. I [also] love chatting with other typers in my class. I presented in a technology conference conducted locally and also at Cedarbridge Elementary School. Really having a voice to express my thoughts has made [education] possible.

I am thoroughly enjoying real education and of course it won't be possible without my great support. I each day aspire to be the best I can and someday hope to be a philosopher and teacher.⁴¹

That is all about me.

⁴¹ *During a visit to his home, after a conversation about the good, the bad, and the ugly of his recent school experiences, I asked Henry my typical final question, "do you have anything else you want to ask me or tell me before we wrap up?" He typed, "You must average in your attitude and each time be happy." When asked to clarify, he simply stated, "be happy all days."*

And he says he wants to be a philosopher and teacher "someday"...

[Seated to his immediate left, the next presenter is clearly related to Henry; you can almost 193 guarantee they are twins. Almost. With the exception of the brief moments when he brings his hands over his face and presses his fingertips into his eyes before snapping them back down to his thighs, Peter has been grinning since he arrived. You can't decide whether you are more captivated by his smile or by the fact that, despite being introduced alongside the others as a student who types to communicate, when his TA/facilitator, Ms. Kozlow, whispers to him, he responds to her with spoken words. Yet when it comes time for him to tell his story, he does so by bringing his right forefinger to his iPad, allowing the device to read his words for him.]

An Introduction to Peter V. Golden

I am Peter V. Golden.⁴² I am a tenth grader, from Cedarbridge High School. I was born in [another state]. We moved to here in 2003 for my dad's new job. Both my twin Henry and I have Autism.

⁴² *I met Peter the same day I met his twin brother, Henry. He, too, attended the same Institute sponsored event, though I got the feeling he was there for moral support rather than as a participant. He would not begin his journey into typing until a year and a half later. Like many who first meet the twins, I had a hard time telling them apart; a reality I'm abashed to admit now that I know them both as individuals and would place bets on my ability to distinguish them based solely on their taste in clothing, if nothing else. And then Peter spoke. A lot. He followed me around the basement of that library asking questions as I took photos our Facebook page with my brand new DSLR camera. Do I like photography? (Yes, do you?) Am I a professional? (Hardly. But I make notecards, does that count?) What kind of camera is that? (The kind I could only afford by pooling Best Buy gift cards from multiple holidays.) Could he try taking a picture? (Yes [deep breath], but be very careful.) Could he be the official photographer at the next event? (Sure. Bring your own camera next time.)*

Though Peter would later join the group of typers around the table—turning his thoughts into text on the iPad—my initial pegging of him as “moral support” remains eerily accurate. Despite self-deprecating tendencies that would indicate otherwise, Peter's ability to motivate and rally those around him positions him as a true leader. From his constant joviality to his genuine concern for others' (often to his own detriment) it is easy for those who know him to understand why he showed up—continues to show up—as a moral support. He is the kind of guy who finds a way to make his otherwise flat, black and white text on a screen ring with humor just to make someone else smile. He is the kind of guy who cares as much about how people treat others as he does about how they treat him. He is the kind of guy who spends the afternoon before Valentine's day taping construction paper hearts on every single high school student's locker to “brighten their day.” And he's the kind of guy who will always be waiting—eagerly and with a smile—to set up your tripod and camera when you come to his school to visit.

My Communication

[I speak and type]. It really sets me apart from others. When I can express my needs quickly, speaking is an asset. When I am trying to make friends, it is a challenge. [It's hard for others to understand that the words I speak are not always what I mean, even though I can't help myself from saying them.] I [feel] very sad and anxious when everyone [thinks] I am speaking nonsensically. I sometimes feel typers don't like my talking; it's just a gut feeling. [My brother says I'm, "too sensitive; they are nice kids."] [It is hard to be in both worlds at once]. [When I speak] I can't [always] get what I want to say out exactly. [Especially] when I am not regulated [my brain is] like a soda can someone shook and opened [...] my words are like soda all over. By communicating and typing I feel I have more control. So, even though I can speak, I prefer to type to express my true thoughts; [it] helps me get my [ideas] straight. Someday I hope to connect my [speaking and typing].⁴³

⁴³ *I have witnessed Peter's relationship with his speech shift and evolve over the course of the inquiry. Initially a source of frustration and anxiety because of its unpredictability, Peter would often request that those around him discourage him from talking and remind him to type instead. At the same time, he would frequently grapple with feelings of not belonging fully to either group: typers or speakers. However, as his typing progressed I watched him begin to navigate and incorporate more of his speech into his interactions, particularly in social situations and during his clay class, when his typing hands were otherwise occupied. I saw him refining his use of and control over when, how, and with whom he chooses to verbally communicate as a supplement to his typing. This tension between Peter's conception of speech as both an asset and challenge remains ever present, constantly moving, and completely contextual—mirroring the qualities of the communication it characterizes.*

How I got Here

For the longest time [no] one knew exactly how smart I was. I was in a different school [than] Cedarbridge and sat in a small room and did puzzles and flash cards. I was so frustrated. My parents knew I was smart, but they didn't know how much. I moved to Cedarbridge high school [when my twin Henry started typing to communicate]. I was [first] placed in [a special education class here], but as the year went on the teachers realized how smart I was.

I [became] interested in typing watching my mom type with Henry. Henry typed that “I will wake up too” just like him if I also try typing. That pushed my mom to take me to the evaluation and from there we never looked back.⁴⁴

⁴⁴ *Peter and Henry's relationship could be a character in this inquiry in and of itself; like most siblings, it changes by the day. From playful to protective to begrudging to prideful, the ways that Henry and Peter interact with and react to one another evolved in interesting and unpredictable ways as they each began developing their typing skills and crafting identities both in relation to and outside of their relationship as twins. While it is not, nor was it ever, my intention to analyze their roles as siblings, like so many other elements of my own and the students' lives, it could not be separated from their experiences. What is most important to acknowledge is how the brothers pushed one another in productive and perceptible ways. In much the same way that Henry opened the door to encouraging Peter to learn to type, Peter's outgoing personality and desire to be in the spotlight prompted Henry to branch out socially and experiment with public presentations in ways he had not previously attempted. They are a great—yet still rivalrous—team.*

High School: “Real work”, Real Rewards

Now, I am typing with support and am able to take regular classes and participate in



Figure 4: HOPE Piece

artistic abilities. [In clay this year,] I made my HOPE [piece and it] means the world to me. It was the first time I could express my thoughts in clay the deep meaning that it provides a ton of strengths.⁴⁵

[I] find ceramics to be very therapeutic in helping [me] deal with the fear and anxiety that come with having autism. Art is an escape for [me]. [“The Art of Wanting Willpower”⁴⁶] sculpture was made to represent both fear and anxiety as well as hope for the future.

classroom discussions. I thoroughly enjoy it. My favorite class is clay. It soothes my senses and allows me to express my



Figure 5: The Art of Wanting Willpower

⁴⁵ *Clay class becomes the site of many important moments for Peter, which you will notice throughout Act III. It is there that he meets his prom date, becomes a member of a competitive clay team, merges art-making and storytelling in ways previously unavailable to him, and builds confidence in himself and his identity. He continues to progress through the courses offered at Cedarbridge, molding and shaping different pieces (of himself) constantly. In my opinion, we could all use the equivalent of Peter’s clay class.*

⁴⁶ *This clay sculpture (Figure 5) included here is an example of Peter’s work and the connections he makes between his art, identity, and experiences.*

[High school] is really lots of real work and makes me very happy and fulfilled. I have worked very hard and I currently have a 96 overall average. I received an achievement award for Science this year. My hardest class is really global. I find it challenging to read so much and remember. [I am also] learning to make friends. I [have been] able to participate in many wonderful events like, End the [R] Word campaign, Technology Conference, Rachel's challenge. I even attended the prom.

[This was a big transition. My outward actions didn't always match my inner feelings. But Ms. Kozlow] helps me with strategies to get through. I feel inner strength and peace when I chant with Rama or breath[e] instead of hurting. [Now] people look at me and smile instead of being scared. This year has been the best year ever thanks to my team, without them I would not be where I am today. A bond between a typer and supporter is huge for success; it is [all] about trust. It is it is thanks to all my supports family teachers and friends I can now feel the world.

New Possibilities, New Goals

I love real education and the possibility of a real diploma is exciting for me. I want to be accepted, graduate with a [General Ed. diploma] and continue my education in college. I would like to pursue my career in math and science. I love landscaping, cooking, and [baking pastries].

My biggest accomplishment is typing to communicate; it has enriched my life. It has changed my sad world to a better one with tons of new possibilities. It has given me a tool to offer my educated opinions in matters at hand. I am using iPad to give voice to my true thoughts and to study and participate in my classes. It helps me to communicate with my peers and I love group conversations. It has made my socializing easier. It has been a great pleasure to associate myself with [the] group [of typers]. Really in all of my life, I have never been happy like this.

A Proud Moment; My Call to Action

[This year] I did the speech to stop the r word. [It] made a huge difference in my life. The reasons why are simple: it was a huge opportunity to show the students how smart we [typers] are. Since then I have made so many new friends because their eyes were opened to what we are as students. It is amazing. [That day I asked my peers, and now I ask you too,] to take a moment to realize how words really hurt and realize that people all learn differently and deep down we are all amazing!

To me [retard] is the worst word anyone could ever say it impacts people with needs for the rest of their lives. When some one calls me a retard I am so sad and mad at the same time. It sticks with me forever. We need to stop and realize how much that word really hurts.

Do any of you actually know what the word retard means? It means to slow down the development or progress of something. I am far from slow. [As] a matter of fact things come to me quickly and I am smart like all of you. That word should not be said or written ever. [...] Let us accept this challenge [to] get rid of that word and rock it!

My Advice to Others

To me, each day is precious and don't waste it. I believe in working hard but having fun too in a more sensible way.

Thank you for listening to my story.⁴⁷

⁴⁷ *As the field time of this inquiry neared an end, bringing with it bittersweet feelings of new transitions for all of us, each student and I reflected on the time that had passed, important memories, and final thoughts. Peter ended this last Google Hangouts conversation between the two of us with: "Thank you for becoming my friend. Come places to see my exciting things." I returned the gratitude for his friendship and promised I would "come to see [him] wherever he [is]." He concluded, in typical Peter fashion, with "awesome sauce." And, that—he—still makes me smile.*

[When her name is announced the next presenter, Carlee smiles, hunches her shoulders forward, hangs her chin to her chest and rolls her head side to side. You hear her let out an extended, breathy sound that gets increasingly high pitched in synchronicity with her growing grin. She raises her head and pierces you—someone out there—with her hazel eyed glare, turning her head slightly sideways and bringing her finger to press into the outer corner of her eye, but not breaking the stare. Her TA/facilitator, Ms. Roland, turns to her and asks, “Are you ready?” pointing to the iPad elevated on a stand with eight “legs,” resembling an octopus. Carlee answers by squaring her shoulders to the iPad and extending her right index finger, exposing a calloused knuckle and hot pink nail polish. Ms. Roland gently pinches the fabric of Carlee’s floral patterned top and waits for her to bring her finger to the screen. So do you.]

An Introduction to Carlee Sanders

I type. I cannot speak. I'm a deep thinker and feel emotions strongly. My autism is who I am.

I am Carlee.

I love painting my feelings trying to really show thoughts coming out through my hands. I love photography it makes me feel immortal and at the same time ephemeral it captures instants of life to remember forever.⁴⁸

⁴⁸ *There is a photo of a young girl—6 years old, maybe younger—that is thumbtacked to the cloth cubicle that greets me in the office suite that I work in. I didn't put it there and I don't know when, where, or by whom it was taken. But I know it is Carlee. Seated and looking down at a table, her thin arms are spread far enough out to frame each horizontal edge of the large piece of paper you can just make out in front of her. I imagine she is sitting on her foot, elevating herself to a bird's eye view. Each of her small hands clutches a paintbrush and if you look long enough you can almost see them moving, making brushstrokes. Her face is barely visible and her short chin-length haircut falls forward with the bend in her neck, drawing her—and your—focus to her work (of art).*

Whoever took this photo, for whatever reason, could not have known for sure who this small painter would become, what kind of art she might create—be—down the road. They may not have known that the short haircut would grow into cascading locks that are usually intricately braided, pulling her hair away from her face, making space for a set of noise cancelling headphones with bedazzled ear buds and a colorful ribbon-wrapped headpiece (but only if she needs them). They could not have traced the ups and downs, starts and stops, that would mark her life in the years that followed. They may not have foreseen that though her frame would remain petite—often draped in creative combinations of bright colors, sequins, and eye-catching patterns—the impact of her presence on those who meet her would be infinitely bigger. And they may not have realized, but in this photo—in this “instant of life”—they captured the essence of Carlee.

School Experiences

I went to private schools before coming to Cedarbridge. I had my own room so if I stripped, it didn't matter. I spent my days with all aged kids, a Montessori style school. We did projects and figured out the world we live in. School was fun and I absorbed it like a sponge. I started reading pretty young, much younger than assumed by most.

But my first year in public school was interestingly difficult. Maneuvering through crowded halls terrified me. There were so many sounds, smells, faces and movement which made me cringe. Eating in the cafeteria made me want to rip my clothes off due to sensory overload.

Communication Journey

Communication is the root of necessity. Using an iPad to communicate is my means to convey my wants and needs. Being nonverbal I tend to use body language in times of crisis. Acting out is not always the best way when anxiety gets the best of me. Typing opens the door to a world of speaking people who take speech for granted. Imagine having lots to say but no way to get it out. When I was little I used basic sign language to tell someone basic needs like bathroom drink or eat. I use these still. I can speak a few words. Every human no matter their ability to communicate should be given the tools

*

When I turned eight, my parents learned about facilitated communication. As all parents believe in their children, mine knew I was intelligent. They knew that there was more to me than what they saw. That's when I met Marcy. She taught me how to type. It was an exciting time but

also hard. Finally I could open and share my world. I had so much to say to my parents. The first message I typed was about my fondness for candy. It has taken years of practice to type effectively. I've had many supporters to aid me.

Being in my world is like problem solving all the time.

You, a speaker, have no idea what it's like to not be able to let out thoughts and feelings. My only outlet was through my behavior. I'd flap, bite, strip, you name it. People around me knew something was wrong. I knew what I wanted or needed but telling that was hard. I pick my fingers and have other anxiety issues. I'm not sure if I will ever stop doing these things. I don't feel pain like others do. My body does not always cooperate with me.⁴⁹

The Ipad that is how I talk.

The seemingly simple act of pointing to letters as I write this requires focus and determination. My facilitator, Erin [Ms. Roland], has a big job. She supports me physically, academically but most importantly emotionally.

⁴⁹ *As described in Act I, Carlee's long-time struggle with anxiety reached a critical point during 2013-2014 school year. So much so that it became difficult for her to stay in the school building. It was hard for those around her to watch her be in such discomfort, including me. Undoubtedly, my relationship with Carlee had always been a bit different than those with the male members of our group. As a woman, I had bonded with her over the years around issues of femininity, conversations about boys, cosmetology class, and maternal instincts (she talked about her future family being a motivator for her). As she struggled with her anxiety, I felt an odd tension: not wanting to see Carlee go through something difficult because I cared about her and because I saw myself in her. Not only could I relate—for different reasons—to the inexplicable bouts of anxiety and feelings of worthlessness that I was seeing Carlee express, but I was having trouble negotiating my role in her life. I would get calls from her mom, have conversations with her primary TA, and touch base with administrators who constantly either needed to talk about Carlee's situation, or wanted ideas about how to support her. I felt wholly unqualified for that, but knew that if I could play a role as a member of her team, rather than observer of it, I would never forgive myself for not doing so. I began attending problem solving meetings with the staff, Carlee's family and Carlee, when she was up to it, to work through how to accommodate where Carlee was in her life at this particular moment.*

I met Erin three summers ago when I first came to Cedarbridge. She is not the only one but I'm closest to her. She has done so much above her job for me. My team at school is the best. My relationship with my facilitators is critical.

I'm really happy to be in high school and have lovely people everyday who help and support me.

Relating to Others

Finding those who can see past my sometimes odd behaviors is difficult. I want to be accepted for me just like anyone else. There is so much pressure to make friends. It's easier said than done. I love people. I like being with others. Finding people to have organic relationships is hard. Many times I'm set up with someone by another because they think we'd mesh. I find this forced friendship doesn't last. It's more obligation to the one who set it up. The idea is meaningful. I have found that finding someone to look past my things that may be strange or offensive is trying. I have many who care for me.⁵⁰

⁵⁰ *To meet Carlee's ongoing needs for support and activity, her family participated in an international au pair program. Carlee's family hosted a series of young au pairs (all female) from overseas (Ireland, Germany, France and Spain) to be full time, live in support for Carlee. All of the au pairs (I personally interacted with four of them throughout this inquiry) were trained and became proficient in supporting Carlee to communicate. While it is beyond the confines of this inquiry to examine the relationships or family system created as a result of this element of Carlee's support, acknowledging their presence in her life certainly evidences the kind of privilege and resources that her family has. It also reflects the efforts made by her parents to provide her with consistent opportunities to spend time with young women close to her age. While there is often tension around the authenticity of relationships between paid support and those with whom they work, particularly since all of the au pairs left after their 1.5-2 year commitment to Carlee, my observations and interactions with them evidenced the high regard and genuine affection they had for her. I would be remiss not to call them her friends and she, theirs. In fact, at the very end of this inquiry marked Carlee's departure for a three week "world tour" to visit all of these friends.*

I would love to have friends that are my age. I find the ones who know me best are my facilitators. My relationship with [my facilitators] is more than friends. Looking for someone to know me for me is what I need. Being in my world is lonely sometimes. I have friends they are typers too.⁵¹

Where I'm Headed

Facilitated communication has changed everything. Being able to express myself and my desires is the reason I'm sitting in a summer school general education English class as a junior in high school. My journey to graduate high school all started because my parents heard me. I have a long way to go but I'm on my way.

⁵¹ *Carlee spent the majority (January-May) of the Spring 2015 semester in Georgia with her family; an alternative arrangement made with her school team to accommodate her need for time away from the school building without derailing her educational trajectory. While she was away, nearly every single group conversation that she was not physically present for included a reference by the other students to "missing Carlee." When she returned to the area at the end of May, she entered the school building for brief intervals—initially, solely to join the group conversations—to reorient slowly, at her own pace, acknowledging that she "[was] not used to school." During those times the other typers reassured her: "don't worry it will come back to you" (Peter) "you need to get back into a routine" (Martin); "School is great we are here for you" (Ralph); "Yes we are a team" (Henry).*

Aren't "friends" people who miss you when you are gone and support you when you are in need?

Typing at school has been my savior. It's not easy but has been life changing. I've been accepted in my classes and they know I'm smart. I have come across teachers who assumed that I needed to be in special ed. I am lucky to have facilitators that speak up when I'm not quick enough to do myself. Please assume competence. I've had great teachers that gave me the chance to participate in class. It takes me more time to get my thoughts out so they give time to respond. It's gratifying for me to see and know that the others know I'm intelligent.

I want to go on and help others like me, just as Tracey Thresher has done for all FC users.⁵²

I'm teaching people around the world about FC. I type to communicate and am teaching people to love autism.

To be continued...

⁵² *Carlee's desire to tell her story and advocate for others has remained constant throughout this inquiry and beyond. Whether that be writing about her experiences, presenting to a crowd, consulting with new typers and facilitators, helping to lead FC training workshops, initiating a "purple ribbon campaign" to promote awareness of communicative diversity, or sharing her perspectives through painting, she is and has been reaching her goal to "teach people." I am one of those people.*

MY HEAD⁵³

INSIDE MY HEAD IS HARD TO SEE.
 ITS TOO BUSY TO UNRAVEL.
 TO ME IT IS CRYSTAL CLEAR.
 YOU SEE I'M AUTISTIC.
 MY HEAD TALKS BUT NOT MY MOUTH.
 I USE MY IPAD TO SPEAK FOR ME.
 JUST IN CASE IT IS NOT VISIBLE
 INTELLIGENCE IS MY VISION.
 ON MY MIND IS TRYING TO COPE.
 ANXIETY IS MY REALITY.

Pearls⁵⁴

When I told them I'd found a black pearl
 while diving in the waters
 that surround Tahiti
 the fishermen remarked
 that it is a rare occurrence,
 even in these waters,
 to discover pearls in the wild.
 And when I told them a buffalo
 at the Lakota Ranch had given birth
 to a white calf the elders
 said that the white buffalo is holy,
 and its birth is cause to celebrate.
 And when I told them I saw a falling star
 scratch against the sky like a chalk line
 on a blackboard, the stargazers said it was a sign
 that came with a wish. And I wished all
 blackboards were shrouded with sheets,
 and their master's stood beside them weeping
 in joy as our children passed among them endowed
 with super natural abilities in math and music,
 wired with extreme senses and the ability to see life
 through a kaleidoscope where every image is new,
 where numbers are people and colors are feelings,
 these children with angel like intuitiveness
 who turn from our gaze, because they can see
 in our eyes the brightness of a soul
 that overwhelms their sensitivity.
 So don't ask me to cast that which is sacred,
 the rare pearls of our hearts before those
 who will trample them under their feet,
 and then turn again, wanting to skin us
 for bringing them into the world.

⁵³ *When I asked Carlee to write a statement on "What I want my teachers to know about me," she wrote a poem.*

⁵⁴ *When I asked her dad if I could interview him about his experiences as Carlee's father he, too, wrote a poem.*

[Ralph presses the home button of his iPad rapidly and leans in close to his device until his nose brushes the surface, leaving (another) round smudge. He tilts his head to the side, bringing his left eye to the screen and exposing half of his toothy grin to you, the audience. He leans back, taps the hard surface of the folding table in front of him with his index finger four times, and you wonder how such a small part of his body can make a sound that echoes off the walls of the room. Still grinning, he turns to his right and leans in close to his TA/facilitator, Ms. Grecco, letting out a sound that cannot be translated into words as he pauses just an inch from her face. She smiles back and whispers to him something that you cannot, but wish you could, hear.] 206

Ralph's Wibble's Story of Communication Spiced with Competence and Cool Inclusion:

I am Ralph Wibble, I am a student with a lot to say. I advocate equality and justice for people of all abilities. This is my story.⁵⁵

I came from a country called India on the other side of the globe where I could go to school but was told it was very difficult. I all the time, dreamt of finding a place doing righteous education for persons with disabilities like me, who are denied this, as always I was presumed incompetent. So my so much dedicated parents forfeited their entire life to bring me and my sister here to the US to become educated.

⁵⁵ *The first time I met Ralph, I heard him before I saw him—felt the pounding of his footsteps as they wore a new path in the carpet of the third floor corridor just outside our office suite. He used to run that hallway back and forth, pausing at the tall, rickety windows to examine the row of street parking and restaurants below before returning to his typing practice session. Sometimes on his way back inside he would stop to say hello to me, bringing his face about an inch away from mine, letting out a loud, drawn out sound and cracking the biggest damn smile you've ever seen (which was, of course, incredibly hard to see with his face so close and my eyes crossed). To this day, despite years of typed conversations and shared experiences, these remain some of my most cherished interactions between us, the kind that make onlookers (or other recipients of such proximally close greetings) move to the edge of their seat, wondering whether he is about to give a head-butt or a kiss. And yes, maybe I flinched once or twice, too.*

We moved to USA in March 2008⁵⁶ looking for this educational dream to happen. I fell in love with [this] country's interesting technologies and open spaces. I have great divine things to fit in my life after coming here, especially my communication through supported typing. Through typing I found my voice. It has given me an identity and new life. I was reborn. Now it was easy to communicate my feelings and I am finding some solace in the typing of cool syllables.

Life without technology is not a possibility now and for me there is no life without iPad. There were many devices early on that I used in my typing: Alphasmart, Lightwriter, Dynavox etc. Now I am on to iPad and its versatility got independence in my typing. I love the apps on it; I keep finding new ones every day. Though sometimes expressing thoughts and feelings is hard because the voice output is not mine but a synthetic dull voice of the device that cannot really convey my depth of feeling like a human voice, I have no choice. I communicate through [this] awesome device. I would be stuck and frustrated without it. So, I carry it with me everywhere and cannot be without it. It is my voice.

⁵⁶ *Between his weekly typing practice sessions with new facilitators, participation in events, and his visits alongside his mom when she trained other local individuals to type to communicate, I cannot think of a time during my graduate school experience when Ralph was not nearby. And I don't remember a time when he wasn't typing soulful, albeit direct, words, ideas and opinions. It was not until I started exploring his experiences as part of this project that I realized our timelines were actually much aligned; Ralph and his family moved to the US from India less than a year before I began my graduate school journey.*

I am forgetting to say that I have autism, but would add that you need to ignore my weird behavior resulting to this. Needless to say I love meeting people and making friends and doing activities like hiking, biking, swimming and skating. I also love cooking and to learn more about American cooking I did Food and Nutrition this year.

Art is my other passion. I do abstract painting with my art tutor. I am part of an art group [that was started by my art tutor] and five other friends that made waves at the Summer Institute conference at [a local] University. We continue to meet at my tutor's art studio and have fun creating art. I love to share my story through art.

The School where I found Inclusion

After we moved to the US I was seeking a school that could give me needed education and I found one after trying out a couple.⁵⁷ Cedarbridge is the school where I found inclusion. I am interested on everyone knowing how good the Cedarbridge school is in trying to giving winning position of gain, to students in a non-speaking state like I am. Here, my intelligence is recognized and am able to access all inclusive [General Education] level classes. Teachers in the school go out of the way to help me learn in my unique style and pace.

This fantastic school staff got me to where I am now so I see them as great educators. They treat me mainly with forbearance and dignity. They make me feel important and look beyond my label to see my intelligent mind. It gives me confidence at being seen as any teenager and not a person with a label. Personal attention to all aspects of my growth is what they strive for.

⁵⁷ *Ralph puts it gently by characterizing his early experiences in the US as “trying a couple” schools. I remember the weight of worry that clouded Ralph, his family, and those trying to support them during those days, years. I am even more troubled by them now that I know him and his story so well. What if he and his family had stopped “trying”?*

My support system at school and home is awesome with technology and great facilitators. With their support, things are wonderful. All that I have achieved in life is due to the support I have.

I enjoy all the subjects I studied at Cedarbridge. I graduated in June 2015 and will join Cedarbridge Community College in the Fall for Accounting AAS. I will be transferring my credits to a four-year college to get an Accounting BS degree. I wonder and worry how things are going to work out for me when I go out of my good school Cedarbridge. But I am happy to graduate and go to college also. It gets great to accomplish a degree but scary to take a new step in a so alien setting.

You may think why Accounting? That's because I am good with numbers. I have cleared the Algebra and Geometry [State Tests]. So this year to help in my Accounting career I did Principles of Accounting, Business Communication and Spreadsheet. In 2012 I had done Business and Criminal Law (College level). As a part of my Accounting training I have been volunteering in Core Banking with the elementary school. To know more about the Accounting career I have interviewed people working in the field including the Executive Director at our school Administration. I have been inducted into the [Statewide] Business and Marketing Honor Society recognizing my outstanding achievements. I have been throughout getting good grades in all subjects. I have been studying for my citizenship too. I want to add that my Senior Prom was Friday June 12th and my date was Ms. Tia Higgens.

I will say that all this would have not been possible but for my fantastic Cedarbridge School team. They saw all of a smart, bright and intelligent young man in me. And I have proved them right.

No ample assortment of words could realistically funnel into some befitting appreciation, so to release the towering gratitude that fills my heart.⁵⁸



Figure 6: Ralph's painting

⁵⁸ *Ralph's paintings, like this one, are distinguishable by the layers of paint and color he stretches across his canvas, "spiced" with lyrical lines peeking through the brushstrokes collaged throughout each piece.*

But, those Prickly Thorns...

Wavering through the many undulating steps of the ladder of life,
invariably you get into some prickly thorns too.

I have so many times got called names like

dumb

stupid

idiot

retard

Not only do I hear awful words here, I was bullied in India too.

It pained me no end;

I felt hurt and bewildered.

Hearing these words makes me angry and sad:

Sad that people think that little of me.

Angry because I thought they were smarter than that.

I would like to tell those people

the challenges I have going through each day,

like my sensory and motor planning challenges.

For example in moments that I come unregulated;

it feels like I do not know how to align

my time with inward thoughts.

So I exactly ward off an outward look
of disarray, so i look present in the real time.

They would not fathom it.

So to add such abusive names

makes my life even more challenging.

They should refrain from doing that.

But still I see kids look at me sometimes

like I am not smart.

I feel like I have to prove myself

e v e r y d a y.

People think I'm a

dumb

stupid

idiot.

retard.

They are making a huge mistake,

for I'm one of the smartest!

So when you see me

say hello,

shake my hand,

be my friend.⁵⁹

⁵⁹ *Ralph often chooses to set his iPad voice output to the fastest speed. You might find it comical if you weren't also trying hard to keep up with the pace of his messages. But when he set these words—"shake my hand, be my friend"—loose into an audience of his peers at the End the R Word assembly, time seemed to slow down long enough for everyone to catch them.*

[As he waits, Martin gently rocks his upper body in his chair. Occasionally, he raises his hands to his face, taps his left palm with his right index finger and alternates twisting his left hand up toward the ceiling then away. And every now and then you notice his TA/facilitator, Ms. Hamden, typing to him on his iPad. When she finishes, she points to the screen. Martin stops his gentle rocking and looks to the iPad to read her message. He brings his left elbow to the table and cradles the left side of his head in his hand as he raises his right arm and begins typing, Ms. Hamden's left arm lightly grasping his elbow. You wonder what they are typing about. You wonder if it is related to the presentation or something else entirely. You wonder why you are so interested in a private conversation so easily made public by its presence on a screen. Martin stops typing and returns his attention to the end of the previous student's presentation, tilting his head just slightly to the side as he listens. You clap along with the rest of the audience. It Martin's turn to tell his story.] 212

Autism, My Life as Martin LaMuncha

I am me.⁶⁰

My life is a battle.

Autism... Wow what is it?

Society can blame vaccinations or what ever it still doesn't matter, deal with it, there are lots of us. Follow my twenty year journey because my journey through Autism is real, clear, and 20/20.

Let's start by telling the technical definition of Autism, "a pervasive developmental disorder of children, characterized by impaired communication, excessive rigidity, and emotional detachment."

I am emotionally attached.

⁶⁰ *My early memories of Martin are not affiliated with Institute sponsored events or run-ins at the office during typing practice sessions. Instead, they are marked by his down to business approach and preference for academic contexts, a reality that I've learned to view as fitting to, rather than detracting from, our relationship. I first met Martin from behind the lens of a borrowed camcorder when I followed him from class to class during his freshman year of high school to develop a customized training profile to help new TAs learn to support him. Unlike the other four co-inquirers, I got to know Martin as student, first and foremost. I did not know at the time that he likely would not have had it any other way. I watched—captured—him participating in classes supported by his TAs, focusing on his assignments during free blocks, getting stressed about his academic performance and taking beanbag breaks throughout a long day of work. When he later provided a typed introduction for the final version of his training portfolio compiled from these videos, his comments were equally focused on his love of learning and prioritization of school: "My name is Martin LaMuncha I enjoy learning the unlimited subject material within the high school. Great opportunities are finally available for me. I learn by listening and analyzing information. Welcome to my world!"*

My emotions are expressed differently. I have hopes, dreams just like all people. My speech is detached, not my mind. The world has all different people. Some are left handed, right handed, blind, deaf and physically impaired. I'm autistic.

The journey begins.

I remember going to school, but I was young. Going to school was petrifying. My parents believe education is the key to success, so off to school I went. Did I mention I was two? My younger school years are kind of fuzzy. My first school was [an] Early Education Program when I was two. It was an inclusive preschool program. I went there for three years until I was five years old. Then I began my Cedarbridge School journey. I was in special education classes most of my life. You have to understand I am extremely intelligent, but I work rather slowly. When I entered middle school, the iPad became my life. That is when I began auditing classes. When I arrived in high school my real educational journey began.

Let me describe how my brain and mind works.

Living in my mind for one day is a challenge let alone twenty years. Describing my mind is complicated. It's like someone threw everything into a blender and mixed it all up. Then added batteries that sometimes work and other times they don't. This is the way I feel when I just cant find the file I'm looking for.

Speaking?

Forget it.

It's there but my brain is playing scrabble. I know what I want to say, but I can't get my brain to let my mouth say the words. I can not carry on a conversation like a typical person.

That is why I type on an iPad and use it as my voice. If you have spent any time with me, you know I just say random stuff. I don't control that either.

Most of the time I repeat what I have heard or my favorite video, Barney. I know, why Barney? I don't really know, it helps me relax. Repeating things I hear is called echolalia. This also happens when my supporters want to teach me to say something independent, for example, someone says, " say hi Martin," I then would respond, " say hi Martin."

Sorry. Again, no control.

I guess in the big world we don't control much.

That describes my mind so you can understand. Now, this is my description. To me it's perfectly clear. You view me as someone who could not possibly be like you. Well I am and I'm not. I am a twenty year old person. I like girls, going out, and joining my peers for activities. This is something that makes me very unique. I see the world in bright colors. Everything has a color glow around it. The colors depend on my mood. For example, when I am starting to get unregulated, this is when my body and mind are not working together, or upset in your eyes, everything has a bright blue blast around it. When I am happy the blasts turns sunny yellow. That is why I love the sun, that warm and cozy feeling.

When I am completely unregulated and mad, everything has a fiery red blast around it. Also, I love the wind! The wind goes through my body and sails me into another world. This world is so relaxing and calm, no pressure or stress. I will stand in the wind for hours.

The feeling I get in the wind is like an eagle soaring through the air with an intense freedom. The feeling sets me free from my Autism. In addition, spending time alone is another glorious time. The best part is there are no demands on me.

Independence?

I'm not even sure what independence is.

I will never be independent.

I would like to alleviate the misunderstanding about why I have trouble navigating around places. My body feels detached from me. I know what I want to do and where I am going but I just can't. I don't know why that happens. I think it's that scrabble game again. I cannot have my routine changed. It is very important to keep everything the same, so I know what to expect. I need my routine to stay in control.

When the routine changes I am anxious and out of control, this is what we call a crisis. This is a very emotional time for me.

I feel like my head is going to explode.

I get a feeling of panic, out of control.

My emotions are on a roller coaster when my schedule changes. Why? Another Autistic trait. I do not have an answer for it. I don't like change.

All I can say is, if my schedule changes, watch out because I become a tornado. I hate being out of control. I do things I don't want to do. Sometimes, I hit my chin, jump up and down, scream, hit my head, and hit people I care deeply about. My family and supporters play detective all day. They are looking for any sign that I am getting unregulated, being unregulated means my

body and mind are not in sync with each other, or upset. They try to get me to focus on myself to help me regulate so I can stay on task.

I have been taught many exercises to help me calm myself or get regulated. But, the problem is I can't do it myself. Someone has to guide me. This reality is why I will always need help in my life. I will never be able to live on my own without help. I am going to try college and I will work. But I need a supporter all the time. My feelings about independence are what we would say under control at this time. This topic is something I just cannot discuss.

This is my reality.

I could go on and on about what I can't have, but I won't because my heart shreds when I think about this. Let me tell you what I do have:

I have an exceptional life.

A wonderful family. My mom is my rock. She knows me, I mean she can look at me and she knows. I guess she reads me like a complicated novel. Mom and Dad have been there to fight my education battles. Also, to love me unconditionally.

Now my dad, he is my hero. He has taught me to be a man. Not just an ordinary man, a man who cares deeply and who loves without hesitation.

My brother? That's another story. We love each other but fight like prize fighters trying to win the WWE championship belt. I would not be where I am today without them. Not only am I autistic, but my brother is too. Marco is in sixth grade. He is higher up on the spectrum than me, this means Marco has speech but still needs educational help. He can talk and loves to act. He

had a lead role in the school play. I was so proud of him. We may argue but we love one another without question.⁶¹

My school family, they are unbreaking. Did you ever have someone, other than family, that never gives up on you? That is my school family. If something doesn't work for me, they try a number of things to fix it. A perfect example is my tantrums. I will get into an absolute rage over a stomach ache. I start hitting my chin, then my head, finally I hit my supporter.

Imagine how you feel when you get hit by someone. In my fit of rage I lose my vision. Then suddenly, through the fire, I hear the calmest voice say, " Martin go to the office." I arrive at my safe place, the voice is there, " take deep breaths and try to regulate." Then I realize that I'm in crisis. I look up and see my supporter. I'm on the floor and the first thing I see is that calm smiling face. Now, let's back track, this is the person I have just slapped, pinched or some other demeaning thing. But, there she is sitting there happy to help me. This is what I call an angel flying through darkness to save me. This type of patience is just unimaginable.

⁶¹ *Martin's increasing ownership of his autistic identity was an interesting evolution, explored in Act III, Sequence 4. During Phase 2 of the inquiry (Summer Inquiry Group meetings) Martin was clear and steadfast in his aversion to spending time discussing or writing about experiences related to his autism. He separated his identity as a high school student intently focused on academics, from his experiences as a student with autism. Somewhere, somehow, in the midst of his senior year something shifted and Martin began identifying with, writing about, and sharing his story from his perspective as a person with autism. No one but Martin knows for sure what changed, but his mother did share that his younger brother had recently entered middle school and was struggling with his self-confidence. One day, after a particularly "tough day" for Marco, Ms. LaMuncha asked Ms. Grecco (TA) if she could find time in the day to have Martin type some words of advice for Marco. He started writing this piece "Autism my life" that day.*

I'm a huge [hockey] fan. I try to go to all [the local team's] home games. You are thinking, why [hockey]? The constant movement really makes me happy. I also play challenger baseball and bowling.

Do you go to the [gym]? Well you might see me there. I go there to swim and work out. My favorite part of the [gym] is the hot tub. This is an activity that really relaxes me. When I get out of the hot tub, just show me my bed cause I'm ready for a long deep sleep. Did you know that I have people that take me to the [hockey] games and swim with me at the [gym]? It's really cool because Diana is my swimming partner, she loves me like a brother or best friend, do you know? I mess with her and do the opposite things she tells me. She just laughs and continues and redirects me. Then there is Mark, the guy who takes me out is close to my age. I love going out with him. He loves to eat like me and I know we are friends for life.

I want to share so many dreams I have, like amazing vacations with my family. I would like to go to Italy where my nanna and nonno are from and find out about their country. Understanding about my family history is important to me. I like to go to Disney World because I love all the sights and beautiful colored rides. You can be a part of the animation and feel like you are there having the great animation forming in an instant before you.

I hear the word normal all the time.

What is normal?

Everyone has quirks. Do you have to put things in your locker a certain way?

What about your bedroom? Do you arrange things in your bedroom a certain way?

Normal is not the same for everyone. Some people may think I am different, but to me, in all I do never seems so construed. Maybe I adapted normal allowing me to be able to share with you. I really don't know.

All I really know is that I am normal to me.

We all go through life with obstacles that we have to overcome. I personally have autism. This journey has been tough but has made me a compassionate person. I have had the opportunity to experience unconditional love from not only my family, but my school family as well. I really need to say thank you to all of those who have supported me...To all who know me you are all special. The journey has been long, but really a new journey is just beginning.

So, as you travel your journey called life, celebrate your small accomplishments. That is the gift autism has given me. I would like to leave you with one thing to think about:

Autism is a "gift."⁶²

⁶² *I watched Martin write this—his story—line by line over the course of his Senior Spring semester. I witnessed his peers give him feedback, and vice versa, workshop style and in Google Docs during his creative writing class. I imagine him piecing the words together and making edits in his head as he walked the hallways of Cedarbridge High School, or rocked in the red rocking chair during free periods in B13, lightly grasping his foam stress ball, occasionally touching it to his chin. I waited anxiously to find out whether his fellow writing students would vote his piece to be among those published in the school magazine at the end of the school year. When they did, I waited even more eagerly to get my hands on the finished product. And when that finished product became yet another draft as it transformed into this (re)presentation, I could not help but remind him—writer to writer—to keep going: “I want to tell you again (and again and again) how awesome this paper is, Martin. Every time I read it I learn something new and I see so much of your unique personality in here. Thank you for sharing it with me, and all those who read it. Don’t ever stop writing, you have a true gift.”*

[Are there any questions?]

Act III
The Dialogic Landscape

[I pull into the same front row visitor's parking spot at Cedarbridge High School I've pulled into many times before. Because I have literary license as I write this, I could say that I park with enough time to put on favorite citrus lip gloss, walk from my car, greet the receptionist, sign in, and move from the front entrance to my destination, room B13, with a few minutes to spare before my scheduled arrival time of 2:00 PM. But to convince you of my reliability, I will admit that it is probably 1:58 PM. I probably put my car in park slightly before I've stopped completely, mentally reminding myself that next time I should leave my office a few minutes earlier. And I am probably chewing the last few bites of my dark chocolate turtle über bar as I swing my backpack onto my shoulder, grab my camera bag and tripod from the backseat, and half-jog toward the entrance, using the selfie setting of my iPhone camera to check my teeth just before I press the bell to be buzzed into the school. And let's be honest, the woman at the reception desk waves and nods her head toward the second set of now unlocked doors; I stopped signing in years ago.]

I enter B13, where Martin, Carlee, Ralph, Henry and Peter are seated around a folding table temporarily placed in the center of the long, narrow room and I flash back with gratitude to the day that Peter insisted we all sit around the same table, instead of at the separate desks that line the walls.

Before I can finish reminiscing, Peter is in front of me saying out loud, "I want to touch your earrings, but I won't unless you say it's okay. I saw you and your friend Joe at the library. Joe types, but he's not here. You have a camera. You had pizza at the café last Saturday" as he extends hand toward me. I know what he is waiting for. I pass him the camera and tripod to set up at the other end of the room, replying, "Hi Peter." Now I'm smiling because no one flinches, no one (myself included) reminds him to be careful with the equipment; he has set it up many times before.

But I remember when that was not necessarily the case; I recall the sense of uncertainty that clouded those early days of figuring each other out.

I sit at the head of table, sign into my iPad Google Hangouts app and take a deep breath, "hi everyone," I say out loud as I type the same words into our group chat window. The four TAs say hello to me verbally, though none of them look at me. Their eyes—and attention—are focused on supporting their respective student partners to type their greetings into the chat window on their iPads. In the moments in between, you can hear a pin drop.]

Sequence 1

“We all have a path”; Conversations on Advocacy, Teaching and Responsibility

In this space, I explore the manner in which my co-inquirers positioned themselves and each other as “advocates” and spent time laying out, constructing, engaging in, and even complicating individual and collective acts of “advocacy”—actions they often described as “teaching.” In beginning with these dialogues around advocacy I honor a conversational thread that carried through both Summer 2014 and Spring 2015 Inquiry Group meetings. I also intentionally juxtapose these nuanced, intertwining discussions about the form, function, and relationality of advocacy with the previous Act, which emerged out of and took the form of the products of these self-(re)representational advocacy efforts.

This topical thread about advocacy prominently wove through our discussions, sometimes in more explicit ways than others. It most discernibly overlapped with conversations that touched on acceptance, to be addressed in Sequence 3. The students often came back to exploring the ongoing need for advocacy (through telling their stories as a means of teaching) as a vehicle to helping others understand their experiences as students with autism who type to communicate. Thus their overlapping and self-described roles as “advocates,” “teachers,” “leaders” and “trailblazers” were explored and (un)tangled through their candid conversations about how, when, where, to whom, and why they advocate. As an added layer of complexity, as the students narrated, teased out, and supported one another’s recounted advocacy efforts, their described perspectives shifted and changed, but always centered around resisting being misunderstood and positioned at the margins—fears grounded in their past, present, and future experiences. The irony, and perhaps the key to all of this, is that these students resisted and advocated most effectively (and most often) from their positions of inclusion in a school that did

not challenge, but instead valued, their presence. They did so through building community with one another, as well as peers and school personnel occupying that space.

The students' stories were constructed through and because of their own and one another's efforts to advocate for things to be different—better—than each of them had known previously, and realities that many of their similarly situated peers who type to communicate currently experience. However, it must also be noted that their own self-described roles as advocates grew out of, alongside, and intersect with their families' active and ongoing advocacy efforts to ensure access to equitable inclusive education; in fact, each student's position in Cedarbridge can be seen as the manifestation of reciprocal parent/student advocacy efforts. Finally, the Cedarbridge school personnel—and the school itself as a representative marker of their efforts—also play into the ways that advocacy is constructed, modeled, and negotiated with and around the students' experiences. The school personnel's aforementioned responses to these students' presence most visibly took the form of problem solving, and they often *shared* the details of that process with others through conference presentations, individual consulting with other school districts, and/or an openness to other schools (within and outside of district) observing the supports they provided. All the while, as the students expressed and demonstrated their own commitment to being advocates, the school personnel and their families responded by providing more and different opportunities for them to continue re-presenting their stories in new ways to different people. But it was always a choice: one that our group conversations served the purpose of teasing out, preparing for and reflecting on, together.

To illustrate the different (sometimes conflicting) ways in which the overarching topic of advocacy emerged, I pause on and highlight five dialogic sites, or scenes.

“I Have My Own Train”: Advocacy as a Means of Expressing Agency

Early on, the students each evidenced their own individual approaches to and conceptions of advocacy, a notion they collaboratively re-constructed through action and conversation to involve telling their stories as a means of teaching others about their experiences. I witnessed these ideas grow, shift, and mold over our time together and throughout their interactions as a group, capturing the complexities, variations, and tensions inherent to their perspectives on and participation in/as advocacy.

The act of sharing their stories through presentations to others—those out of which their narrative accounts grew—were manifestations of what the students discussed with one another as advocacy. While all of them voluntarily participated in opportunities to share those very individually rooted (re)presentations of their experiences, they used our group conversations as opportunities to unpack their own (sometimes conflicting) perspectives on, and explore the function of, their personal and/or group advocacy efforts.

- Carlee:** I every way want to step aboard the Tracy Train.⁶³
*[Ms. Roland says to Carlee, “They may not know what you are talking about.”
 From across the room, Ms. Grecco says, “I think they all know” and I follow up with
 “Yeah I think you might need to explain that a little Carlee at least for me, then, what
 that means to you: ‘Tracy train.’”]*
- Carlee:** Tracy and Larry⁶⁴ drive for advocacy.
 [.]⁶⁵
- Ralph:** We are all doing that every day.
- Carlee:** Join me boys.

⁶³ Unless indicated by the presence of [brackets], all students’ text appears exactly as it was typed.

⁶⁴ Carlee is referring to Tracy Thresher and Larry Bissonnette, two men with autism who type to communicate. They are the stars of a documentary about their experiences, *Wretches and Jabberers* and are well known in Disability Studies and Inclusive Education communities.

⁶⁵ Due to time it takes for each co-inquirer to type their comments, combined with the fact that multiple conversations were often occurring at once, each dot within a set of brackets (i.e. [.]) represents a contribution that has been removed from the transcript because it was not part of the conversation being discussed. These contributions are either spoken questions or responses during conversations prior to using Google Hangouts or text typed in Google Hangouts. The italics present in each transcript represent the auditory, movement, and support details relevant to and notable during the conversation.

- Casey:** [laughs] Carlee I think I might get in trouble here for starting a revolution.
[spoken]
- Martin:** Carlee I not want to follow Tracy. I have my own train.
- Carlee:** Awesome
- Martin:** Thank you

Here, in the first of the conversations that touch on this topic, Ralph, Martin, and Carlee⁶⁶ explore their ideas about what constitutes, as well as whether and how to engage in, actions they consider under the umbrella of advocacy. It is evident that they fundamentally see themselves as leaders, or as they sometimes referred to one another and were subsequently referred to, “trailblazers.” They position themselves at the forefront a movement toward equity, education, and communication rights that they did not necessarily choose, but are living, learning, and laying tracks for in anticipation of those who will follow. However, they make clear here that their approaches to conceptualizing and living out those leadership roles vary.

Carlee is on the advocacy “train,” hoping to use her lived experiences and written stories as lessons for others. She positions herself on board with Tracy (Thresher) and Larry (Bissonnette), two men with autism who type to communicate and are the stars of the documentary *Wretches and Jabberers* (2010), which chronicles their “global quest to change attitudes about disability and intelligence” (“About the Film,” n.d.). Carlee’s use of the train metaphor is reflective of the circumstances of her life: constantly in motion, questioning how long she wants to/can stay in one place (with one group of people) before moving on to the next. She is an explorer at her core content with wanderlust, but seeking community (“join me boys”) as she traverses landscapes unknown. In fact, her comments about advocacy were precipitated by a conversation (that she initiated) around her search for possible alternative routes to obtain her high school diploma, acknowledging that—for her in this moment—taking a traditional approach

⁶⁶ Henry was absent for this group meeting, Peter was present and participated earlier in the conversation, but left the room halfway through and did not return.

to high school was overwhelmingly anxiety producing (“Is high school really worth the anxiety it creates? [...] I want to think outside the box”). A path of advocacy, here, was positioned as a way out: justification for her proposed new path.

Ralph acknowledges that presence in inclusive school and community spaces is in itself a form of advocacy: “We are all doing that every day.” Not only does he situate his life as advocacy personified, but he reminds his peers of the unavoidable nature of their efforts; it happens in ways beyond their control. Yet Martin “has [his] own train” and is quite content with living his life, unapologetically, by his own rules; if he teaches someone something along the way, all the better. In this conversation, Martin owns his leadership role, grasping it tightly as he contrasts with his friends’ attempts to pull him into perspectives. But, as we will see below, he often wavers between seeking—conducting—his own train and yearning to get off the ride altogether.

While all of the co-inquirers used and related to the language of advocacy, which they constructed to mean intentional actions to alter others’ understanding, I also saw them enacting agency in doing so (Ashby et al., 2015; Rossetti et al. 2008). Layered between the lines of their conversation are the decision-making processes of choosing how, when, where, with whom, and why to engage in advocacy efforts. Even the ultimate decision Carlee, Ralph, and Martin come to here in respectfully agreeing to disagree suggests a level of agency within and across them as individuals. In so doing they not only exert power over their own lives but also resist the assumption that all people with autism (or more broadly all people with disability experiences) do or should share perspectives on and feel compelled to enact efforts to effect change in similar ways, if at all.

“I’m Relinquishing my Crown:” Advocacy as a Shared ~~burden~~ Responsibility

Many of the Spring 2015 conversations around advocacy were prompted and framed by Ralph and Peter’s participation in the campaign to “End the R Word” hosted by Cedarbridge High School and facilitated by a well-known local athlete, aimed at exploring the need to end the use of the word “Retard.” Aptly, this national movement to “raise consciousness of society about the R-word and how hurtful words and disrespect can be toward people with intellectual disabilities” is led by self-advocates with disabilities and their allies (“Fact Sheet,” 2015). The stated aim of the ongoing campaign is “to engage school organizations and communities to rally and pledge their support in helping to build communities of inclusion and acceptance for all people” (“Fact Sheet,” 2015). In fact, the impact of Ralph and Peter’s experiences preparing for and presenting in the school-wide assembly extended to our group discussions, as well as their relationships with their peers. This in turn later prompted additional conversations about dating, friendship, and acceptance (discussed in Sequences 2-4). The fact that this particular assembly was developed and executed over the course of our time together as a group had much to do with the students’ initiation of conversations around the need for advocacy and the relational aspects of it.

In one particular conversation, Peter and Ralph both separately called forth the topic, eager to discuss their participation in a planning session for the assembly.

Peter: Ralph and I presented at the assembly for the change the word.
[...]

Ralph: Peter and I are on a panel with the famous [local athlete] to educate the students on their hurtful language. Do you want to hear what I want to say?

Once Ralph and Peter both shared their prepared presentations-in-progress (via iPad audio output), Ralph made clear that he wanted to continue this thread of conversation, reflecting on his experience and feelings:

- Ralph:** There are so many people that are hurt by words of others.
- Casey:** Yeah there are [*spoken*]
- Ms. Grecco:** [*to Ralph*] I think you were a little shocked yesterday. You seemed it.
- Ms. Farber:** And it's not just the R word either. There are a lot of words that hurt.
[*spoken*]
[*Martin makes a loud sound*]
- Casey:** And Ralph, I know you are focusing on words and how they hurt, but sometimes it's how people act, too. What they don't say... that can be hurtful. So I think that's important. [*spoken*]
- Martin:** It's nice to hear people talk about our struggles. I'm tired of being the teacher
[.]
- Ms. Farber:** I say amen to that Martin [*spoken*]
[.]
- Casey:** You're tired of being the teacher. That's something I know we may not have time to get to today but it's something that I've wanted to talk with all of you about before. Because you are always getting each other pumped up, you know, "we can do this, we can show people..." [*trails off*] and I wonder if that *does* get tiring sometimes? So I would love to talk more about that. It must be a tension that you feel. I can imagine. [*spoken*]
[*Students typing: muffled side conversations and communicative support*]
- Martin:** Yes it is.
- Casey:** It is tiring? I totally understand that. [*spoken*]
[*Peter gets distracted by my phone buzzing and asks who it is. I tell him it is Carlee and he looks on the computer screen for her.*]
- Casey:** [*pointing to his iPad*] What did you say Peter? [*spoken*]
- Ms. Farber:** [*Reading from Peter's iPad*] Same as Martin. That it is tiring. [*spoken*]
- Henry:** I appreciate Ralph advocating for us. Outstanding speech my good friend.
- Casey:** It was. Outstanding. I'm wondering if the tiring part is more about the individual? It seems like you kind of band together when we have these discussions, but if you feel alone sometimes as "the teacher"? Is it easier to talk about this stuff and do things as a group? [*spoken*]
- Martin:** Yes I do like this
- Casey:** So you do like when you work together.
[.]
- Peter:** It is easier to teach when we are in a group.

The juxtaposition here of sentiments of excitement, renouncement, gratitude, and encouragement captures the spirit of the students' complex and ever-evolving relationship to conceptions of "teaching:" a term that they often used interchangeably with advocacy. Martin counters the implied unavoidability of his advocacy by stating that he is "tired of teaching," connecting back to the tensions, perhaps, associated with and resulting in being on his own *train*. However, even as he resists it, he insinuates the necessity of teaching in his expression of gratitude for "others" taking the reigns so that he does not have to shoulder the weight alone. His affirmative response to my question about individual versus collective action suggests that, for him, teaching is less tiring than the act of doing it solo. One can sense his internal tug of war.

As the oldest and most seasoned Cedarbridge student, the other co-inquirers often referred to Martin in our conversations as a leader and expressed recognition of the ways that he made room for the others' presence by "teaching" the school community about his communication, competence, and lived experiences. By coming first, he paved the way for them. However, he indicates here that his conception of what should constitute the kind of teaching for which he is considered a leader is necessarily more collaborative than not. Henry's expressed gratitude for Ralph's speech (though it is unclear why he does not include Peter in this statement) also calls forth the notion of teaching as a shared goal and reciprocal endeavor (Savarese et al., 2010; Sequenzia, 2013).

This thread of advocacy as a shared burden/responsibility was pulled through the group discussion that occurred a week later when Martin introduced the topic of conversation (an initiative action not typical for him): The End the R Word assembly, which had occurred the day prior.

- Martin:** How did you like the assembly?⁶⁷
- Casey:** I LOVED it. [*spoken*]
- Martin:** I'm relinquishing my crown
 [*Adults laugh. Martin, Peter, and Ralph are all quiet and still in their chairs, with the exception of Martin bringing his hands from being in front of his chest to the top of his thighs and tilting his head back to gaze at the ceiling.*]
- Casey:** That is a very generous thing for you to say! I loved it and I'm so grateful that you guys let me come. [*spoken*]
 [*Spoken side narration as Casey retrieves DVD copies of the assembly from her bag and distributes them to the group.*]
- Peter:** We all learn so much from you Martin.
- Casey:** I think we all learn so much from each other, but yeah I am glad you're willing to share that crown now, Martin [*spoken*] [.]
- Martin:** Thank you.

In this moment, Martin figuratively acts on his previous declaration about “teaching” being “tiring” and “relinquishes his crown,” a gesture marking his regard for his peers’ advocacy actions and solidarity. Echoing his brother’s expressed gratitude in the previous conversation, Peter’s response pings back at Martin the shared and reciprocal nature of advocacy. His comment that “we all learn so much from you Martin” suggests that though he may be “relinquishing his crown,” Martin’s time as a teacher, at least from his peers’ perspective, may be far from over.

[I cannot relate to the co-inquirers’ experiences with and perspectives on advocacy in the ways they can relate to each other, but I can identify with them. My relationship with Anne, and my position as part of our mobile unit (comprised of Anne, MJ, and me) has resulted in my own experiences with feelings of compulsory “teaching,” associated weariness, and energy gained through collective advocacy efforts-disguised-as-experience. I have watched and participated in the ways that advocacy becomes a requisite priority for parents and siblings of people with disabilities. I know it is not the same. I know I have choices about my “advocacy” in ways that neither the co-inquirers, nor Anne, do. But I also know that I, like them, sometimes have to make choices under the expectant gaze of others, those who don’t care if we are “tired of teaching.”

One of the most uncomfortably familiar things, to me, is being watched—that feeling where you know someone is looking at you and you don’t know why, or what they will do with the knowledge their eyes construct in the moments they rest on you. I know that people—teachers, administrators, parents, peers, mall-walkers, food servers, store

⁶⁷ This was an abbreviated meeting that began after Henry had already left the room for an OT session. He returned just after we concluded this brief exchange and participated in the remainder of the conversation. Carlee was unavailable to Skype in from Georgia.

clerks, strangers—have gazed at the three of us (Anne, MJ, and me) a curious triad occupying more space in the world than most, necessitating more time to be figured out than even the longest lingering glances can provide. I can handle those, often shielded by the diversions of the steel and rubber of Anne’s wheelchair, and her eyes that piercingly distract, or deflect, onlookers’ gazes. She is the one who notices—endures—it all, from her front row seat. I know from the sounds she makes and the way her right hand rests peacefully under her left thigh, poised to watch the things we probably miss. I know, too, from the moments when I happen to catch one of those glances lingering on her; too distracted—locked in—to notice mine.

But I am aware, have always known, that sometimes those stares land on me. Watching, waiting, expecting to catch me doing what young people without disabilities “do” in the company of those with them: be embarrassed by her noises, express confusion at her attempts to communicate, roll my eyes at the puddle of drool that decorates the collar of her dress, ignore the fact that we are peers and treat her like a child. I won’t, then, but they don’t see that I won’t, ever, either. To those expectant eyes, my failure to per(con)form can be waved away as a fluke. Luck of the draw. A fortunately timed glance. And even for those—teachers, administrators, parents, peers, mall-walkers, food servers, store clerks—who have watched us for years, it is like they are still waiting. To catch me. Watch us grow apart before their very eyes. Fall apart, so we fit the mold.

I have known this from the feelings of discomfort, pressure, annoyance, that well up in me as we move on with our days, lives. I have noted the conversations—framed by questioning of her competence and demands that I put into (the right) words “how” I know what she knows—that have confirmed that these instances of surveillance are not in my head. They exist, persist, and have shaped the way we have grown up, into a team. Someone is always watching, even when I write. Something is always at stake, no matter what words I choose.]

“Advocating is Part of my Autism”: Advocacy as Part of The[ir] Autism Experience

Even as the students collaboratively discussed the complexities of how, when, where, and why they advocate, they also shared moments in which they evidenced stepping back to recognize and problematize their feelings around being called—driven—to do so. To illustrate this, I return to the “tired of being the teacher” scene (p. 228), which took a different direction (still grounded in the topic of advocacy) for the remainder of that meeting initiated by a comment Ralph shared.

Ralph: I guess that advocating is part of my autism. I will always have to prove my competence to look what we are and what we will be.⁶⁸

Ms. Farber: So your autism sort of forces you to be an advocate [*spoken*]

[Ralph becomes very loud and stands up out of his seat. He is smiling and makes a high pitched sound. He sits back down and becomes quiet. Martin rocks his upper body and makes high pitched sounds, hitting his chin and bouncing rapidly. Overall the room gets very loud. Henry steps out to go to the bathroom.]

[..]

Casey: Do you feel, Ralph, and anyone else at the table, like [*trails off*] ... You said that your advocacy is part of your autism. Do you have feelings towards that? Is that a good? A bad? Just a fact? [*spoken*]

[Students typing: the room quiets down considerably. At her facilitator's request, Casey types Ralph's comment into the Skype chat box for Carlee to read.]

Peter: My autism and my advocacy go hand in hand.

Casey: So you feel the same way that Ralph does? They go together. [*spoken*]

Ralph: I believe that we all have a path.

Casey: [*Turning the Lazy Susan to face her, Casey says to Carlee on Skype*] Ralph said "I believe we all have a path." And [*noticing Carlee has responded to Ralph's previous message*] **Carlee** said "yes you do." You do always have to prove your competence. [*spoken*]

Ms. Grecco: Not to us Carlee. [*spoken*]

Casey: Not to everyone. [*spoken*]

Here, Ralph brings to the table his belief that his experience as a person with autism is innately tied to his sense of responsibility to advocate for himself and others; essentially, for him, it is a package deal. Peter, too, articulates feeling this connection that his autism and advocacy "go hand in hand." Both students describe this as if an unquestionable fact, and when I push them all to articulate their feelings on this the only answer provided is Ralph's assertion that he "believe[s] we all have a path," conveying, again, that he sees his advocacy as an unquestionable element of his experience as an autistic person.

[I want them to tell me they feel angry, frustrated, fed up with, the constant need to teach people how to interact with, support, and relate to them and their experiences. I want them to see the injustice of this. It makes me want to scream that we live in a world that necessitates such copious amounts of time spent—by some and not others—justifying the place of difference in it. But I also want to scream that we live in a world, too, that

⁶⁸ Carlee Skyped into this portion of the conversation via video call. My laptop was placed on a Lazy Susan at the head of the card table (facing inward) around which the rest of the group sat. She typed her contributions into the chat window and I read them aloud since there was no audio output to do so.

threatens to hide, hurt, and hinder the experiences of those (these) who are different, unless they can articulate the reasons not to. Maybe, probably, these students know something that I don't. Maybe they feel that they only have two options; teaching or silence(ing). Maybe they know the futility of anger without action.]

Ralph places the inexorability of advocating alongside and equal to the inescapability of “prov[ing]” himself that his autistic experiences necessitate and drive him to enact. His clear connection between “advocacy [as] part of [his] autism” and his need to “prove [his] competence,” a perspective with which Carlee and Peter both identify, further accentuates temporality operating in the construction of these students’ experiences and their perspectives on them. Underlying this conversation is the notion that if advocacy is connected to “proving...competence,” it is, then, a means to resisting the pervasive and apparently inevitable experiences of being presumed *incompetent*. I/they/we know that they have all individually experienced presumptions of incompetence and the tangible educational and social ramifications of such (mis)conceptions (Biklen, 2005; Biklen & Burke, 2006; Rubin et al., 2001). All of the co-inquirers’ previous school experiences were marked by low expectations, segregation, and administrative resistance through which their communication needs were either dismissed, or used as justification for continued exclusion. It is not surprising that the students choose to describe and discuss with one another the indispensability of proving oneself against the tacit understanding of otherwise low expectations that, it seems, constantly threaten to surface as they live out their experiences.

“For Students like us in the Future”: Advocacy as “Work” with Tangible Results

Across many of the conversational threads, the students often made it a point to recognize and encourage one another’s contributions. Discussions about advocacy proved no different. Evidenced in the examples above, it was often the younger students (Henry and Peter), with less experience typing and fewer years under their belts in high school, who paused the conversations

to express gratitude and acknowledge the tangible results that the older students' advocacy have had in shaping their experiences. In such cases, the dialogue around advocacy blurred into real-time examples of mentorship (Ballin, Balandin, Togher, & Stancliffe, 2009; Cohen & Light, 2000; Frost, 2015). Captured in these conversations, the processes of learning from one another's storied perspectives and experiences, as well as others' (families' and school personnel's) responses to them, shaped the co-inquirers' educational lives considerably. In fact, it was these relational learning processes that laid the paths that led each of these students into the doors Cedarbridge in the first place. Advocacy, in this context, becomes both action (with tangible results) and framework for/of understating experience (with resultant connections).

In particular, one conversation during Spring 2015 began with Ralph expressing fears about his upcoming transition to college and demonstrated the reciprocal nature of mentorship, layered beneath stories of advocacy, in the co-inquirers' experiences. From there, the discussion evolved into an opportunity for shared understanding around issues of change, more broadly, and a pep talk reminding Ralph and Martin of the impact they have had on others' lives and the need for their continued advocacy moving forward.

Ralph: I'm going to college and I'm scared⁶⁹

Peter: You are my idol you have been my reason I have been typing you are an inspiration to me [2x]

[Martin is typing from his seat in the rocking chair and is speaking (inaudible) words in a high pitched voice. Otherwise, the room becomes very quiet when the students are typing.]

Ralph: I sometimes forget. Thank you.

Martin: I'm scared too. I am leaving it up to trust.

⁶⁹ Carlee participated in this meeting via Skype video call. My laptop was placed on the desk at the bottom right corner of the room, facing inward. She typed her contributions into the chat window and I read them aloud since there was no audio output. The rest of the students sat at their respective desks with their backs toward the center of the room, though they often turned toward the center while or after typing. This was the only Spring 2015 meeting in which the room was set up like this. In fact, during this meeting Peter requested that going forward we all sit around one table, which we did for the remaining Spring 2015 meetings.

[Immediately prior to sharing his comment, Henry begins humming a rhythmic pattern loudly. He becomes quiet once his words are being read by the device.]

Henry: You are an inspiration. Ralph is my friend for life. [3x]

[...]

Ralph: Is he [Martin] ready to help me try?

Peter: I am not leaving but I have had change. Roland⁷⁰ is gone. Koz⁷¹ is working with you. She is good. We are all awesome inside and out. Ralph you are why I work so hard I too want to follow in yours and Martin's footsteps.

[Henry makes a loud, drawn out sound.]

Henry: You are intelligent. Show the world in college Ralph.

[Henry hums in rhythmically. Ralph smiles, laughs, and rocks back and forth in his seat before beginning to type.]

Ralph: Peter school is worth it.

Peter: Martin and Ralph you guys can make a huge difference in this world. Advocate for us out there and for the students like us in the future.

Martin: Ralph yes I will help you

[...]

Henry: Leading the way Ralph will make it possible for us all

Martin: Peter, I have and will continue to advocate

[Martin speaks, "Okay?" in a high-pitched voice.]

The supportive dialogue that emerges in this conversation again illustrates the complex, collaborative, and nuanced approach to experience and/as advocacy that these students take up. There is no question raised in their discussion about the inevitability that, like their experiences to date in high school, college will necessitate levels of advocacy, particularly given the lack of precedent for inclusion of students who type to communicate at the college level (Ashby & Causton-Theoharis, 2012). Thus, as Peter constructs it, "show[ing] the world [...] intelligence" as a means to "mak[ing] a huge difference," becomes situated as "work" worth doing, even in the face of fear.

In addition to the layers of support and articulated need for continued experience-as-advocacy, Ralph and Martin are clearly positioned (and take ownership of their role) as leaders—and "inspirations"—in Henry and Peter's eyes. The brothers' similar choices to respond

⁷⁰ In casual conversations like these, the students often referred to their TAs and teachers using only their surnames.

⁷¹ Peter often used the abbreviation "Koz" to refer to his primary TA, Ms. Kozlow.

to Ralph's expressed fear with support and encouragement cannot be separated from the ways in which their stories overlap. This relational reality is further illustrated in Peter's effort to segue the conversation from being only about Ralph's upcoming college transition, to his own parallel experiences with "change" in support and how he looks to Ralph and Martin's "footsteps" as worth "following" even if a route necessarily taken through hard "work." This is echoed in Henry's comment that "leading the way Ralph will make it possible for us all." Notably, though present for the conversation, Carlee is not included in either Henry or Peter's recognition of leadership and advocacy, perhaps reflective of the complex intersections of her contingent physical presence, alternative path(s) toward graduation, and/or the gendered dynamic of the group. Henry and Peter both regard Martin and Ralph as responsible for laying the groundwork for the academic inclusion they sought out and currently experience at Cedarbridge. Here, they illustrate that they see the older students' entrance into college as yet another example of the potential for new paths to be traversed. Yet even as they all move forward, their experiences are linked. This is particularly evident in Ralph's assurance to Peter that "school is worth it," which conveys a level of understanding that extends beyond the words typed. In his initial comment, Peter does not express doubt that school is worthwhile, yet Ralph is compelled to provide him with reassurance anyway, suggesting that the two share an awareness of the challenges associated with "change" and the temptation to, potentially, lose faith in the fight. Perhaps in this moment, Ralph sees himself, or his previous experiences, reflected in Peter's narration of his recent changes. Perhaps he is anticipating Peter's (and his own impending) frustration with training new staff and "work[ing] so hard." Perhaps Ralph's comment is directed as much to himself as it is to Peter. Whatever the impetus, the supportive interaction conveys a shared understanding between these two, in this context.

[I remember squirming in my seat during this conversation, (used to being) uncomfortable with the repetitive “inspiration” trope I’ve learned to pinpoint and resist through my work in disability studies. I (’m conditioned to) roll my eyes when I hear or see the use of this term in references to and around disability.⁷² But what about “within” disability? What about disability community and culture? Could it be that there is space for a re/new/vision of this term? Peter and Henry both appear to use “inspiration,” without hesitation, as a means to encouragement and solidarity. They both seem to be drawing on feelings rather than definitions. They both work to restore Ralph’s confidence in his time of expressed vulnerability, employing language as a vehicle of intended motivation and justification for pushing past his fears. My academic self could chalk this up to them not “knowing better:” a reminder that disability experience does not automatically translate into a disability studies lens. I could locate their choices as being rooted in having heard this term used in reference to themselves, or others similarly positioned. But that, too, makes me squirm in my seat as I type it. Could I, instead, see this usage as a form of tacit resistance and reclaiming of what it means to inspire with and be inspired by the actions and relationships of others? I cannot answer these questions, but I pose them. What I can do is acknowledge the tension I feel and re-present it here, using my relationship with my co-inquirers to guide my interpretation that perhaps there is something to be said for their empower(ing)ed application of a term too often used to oppress.]

Ralph’s appreciative response, rooted in his acknowledgement that he “sometimes forget[s]” that he is an inspiration to others, suggests that twins’ joint efforts to buoy him up are effective—that a reminder that he has had discernable impacts on the lives of others is a motivating force for him. Interestingly, despite his gratitude, this veritable pep talk alone does not quell his fears and he directly seeks Martin’s support in helping him “try” to follow his lead and “leave it up to trust.” Martin’s commitment serves as a reminder that their friendship, shared experiences, and mutual support will endure this transition as they both embark on a new

⁷² The term “inspiration porn” has been used to describe media (i.e. images, videos, social medial stories, books, etc.) that position the, often mundane, actions/accomplishments of people with disabilities as exceptional based solely on the fact that they were performed by/through non-normative bodies. Disability activists, scholars, and allies are often critical of these representations, noting that they perpetuate ableist attitudes about what constitutes a “normal” or “ideal” body. Inspiration porn positions deviations from normalcy (i.e. disability) as so inherently challenging and undesirable that it takes a significant amount of courage or superiority to “overcome” the barriers that those differences present to living every day lives. As comedian, journalist and disability advocate Stella Young (2014) shared, inspiration porn involves “... objectifying disabled people for the benefit of nondisabled people. The purpose of these images is to inspire you, to motivate you, so that we can look at them and think, ‘Well, however bad my life is, it could be worse. I could be that person.’”

journey—anticipated rough terrain—on the same college campus; they enter into their future tied together by their pasts. The combination of encouraging admiration of the past and assurances of future support from friends not only reflects the diversity of relationships and roles present among these students, but also the complexity of navigating experiences that have implications for the opportunities of others: a reality that these five co-inquirers grappled with throughout our conversations, particularly around advocacy.

The interrelated nature of these students' experiences as they unfold within this particular conversation further suggests that the meaning of advocacy, for them, transcends the individual and involves collective aspects of working toward change. Peter clearly lays out these overlapping expectations when he insists, "Martin and Ralph you guys can make a huge difference in this world. Advocate for us out there and for the students like us in the future." In the context of a conversation about change and transition, Peter's choice to broaden the lens, referencing "out there" and "the future," to characterize his peers' impending entrance in college, hints at the complex entwinement of living life (as a person with autism who types to communicate) and advocating for others' opportunities to do the same: an assertion that connects to Ralph's aforementioned inability (and unwillingness) to dissociate advocacy from autism. Here, the co-inquirers situate and honor their roles as advocates—for themselves, one another, and those they may not yet know—even if it is "work" they feel compelled to do by default.

"You Would be a Good Teacher": Advocacy as a Bridge

During the same group meeting, a second conversational thread ran through the discussion prompted by Ralph's aforementioned confession that "I'm going to college and I'm scared." Carlee provided an initial response to him that, "Yes, the people [college students] are mean" which evolved into a more focused conversation (running parallel and through the one discussed

above) on the need to “teach” for understanding and acceptance, grounded in a tacit acknowledgment of the ableist culture in which they are situated (Ashby, 2010; Hehir, 2005).⁷³

- Carlee:** Yes the people are mean.
Casey: Carlee, what people? [*spoken*]
Carlee: College students
 [*Henry is humming loudly and rhythmically*]
Martin: I don't think mean is right. I think uneducated.
Peter: We are a school a family. We sing and dance on Fridays. We are a family.
 [*Martin, who is typing from his rocking chair, becomes very loud. Ms. Grecco says “shhh.” He makes three more loud sounds. Henry begins making sounds by blowing air through his mouth and biting his tongue.*]
Carlee: teach love
 [*Martin begins speaking (inaudible) words in a high pitched voice.*]
Ralph: Carlee we go up to SU all the time. People are okay they just don't understand.
Ralph: that is why we need to be on the [End the R Word] Committee
 [*Martin returns to making loud sounds and speaking (inaudible) words in a high pitched voice.*]
Carlee: teach love to the kids understanding.
Peter: I agree. Like [local basketball team] we are team B13.⁷⁴ Let's do it.
Casey: B13 in two zip codes [*spoken*]
Ralph: Carlee, I agree.
Peter: Cipriani⁷⁵ maybe can get us uniforms LOL [device reads “laugh out loud”]
 [*Henry says what sounds like “no” and begins humming quietly. He hums this way for the remainder of the conversation. Peter stands up briefly and sits back down. Martin begins verbally reciting his schedule for the afternoon.*]
 [...]
Carlee: Teach
Casey: Teach. Carlee so you are still talking about teaching love and understanding? Is that what you're relating to? [*spoken*]
Carlee: Yes teach. Yes love.
Peter: Carlee you would be a good teacher.
 [...]
Carlee: Thanks

Carlee, too, identifies with and justifies the fear Ralph referenced early in the conversation, but connects it here to attitudes of others, specifically “college students.” Her

⁷³ While the previous excerpt and the one discussed below did happen within the same conversation, there were essentially two separate (but related) threads being discussed and thus they have been pulled out as independent excerpts to allow thorough analysis of the nuanced ideas addressed in each.

⁷⁴ The students' “home base” classroom in which these conversations occur (see Act I).

⁷⁵ Ms. Cipriani, Director of Special Education

response calls forth the reality that she considers her experiences, and perhaps fear around them, as intimately tied to others' perceptions of and responses to her (more accurately, to her as a person with autism who types to communicate). Carlee is warranted in her fear, as attitudes of others are often cited as the greatest barrier to acceptance and inclusion, particularly across chasms of communicative difference (Biklen & Duchan 1994; Biklen & Kliever, 2006; Bogdan & Taylor, 1989). Yet Martin challenges her, reframing "mean[ness]" as a lack of education; a distinction that Ralph, too, supports when he describes his trips to the local university: "people are okay, they just don't understand." Ralph and Martin both give the imaginary college students the benefit of the doubt, but between the lines of their conversation about others being "uneducated" is the implicit notion that those others need to be taught. Taking into account her peers' challenges to her initial comment Carlee puts words to this implied call to mobilize and proposes an active measure: "teach" (an idea that she expands upon to yield "teach love to the kids understanding"). Though she does not affirm or rescind her previous statement about college students being innately "mean," her call to action incorporates Martin and Ralph's implied suggestion not to give up on them. Ralph's assertion, "that's why we need to be in the [End the R Word] Committee," seems to represent his acknowledgment of Carlee's prompt and suggests that he positions his (at this point anticipated) participation in the End the R Word assembly as a step towards "teach[ing]" others to understand.

In a role that became typical for him throughout our time together, Peter serves as the requisite cheerleader, taking the conversation from a string of individual perspectives to an opportunity for collective agency and community building. He first likens the five of them (and perhaps the adults supporting them?) to "family" and then, to a "team": "Like [local basketball team] we are team B13. Let's do it." He even goes so far as (facetiously) suggesting that the

Director of Special Education invest in uniforms to aid them in their efforts to teach others. While comical, Peter's suggestion also touches on the previously described notion of advocacy as a collective and relational experience; there is no question, for him, that he and his peers (as well as the implied presence of allies, such as TAs and even the administrators) share a mission. This literal and figurative positioning of advocacy as a "team" work not only highlights the collaborative relationships cultivated within this space, but also serves to resist the pervasive individualization of disability (Linton, 1998).

This portion of the conversation also highlights an instance in which the students' interactions revisit their sense of responsibility to bridge gaps between their experiences in a world populated by others who "just don't understand." Evidenced here, they take ownership of these (mis)understandings and, even in moments where it would be easier to project blame (illustrated by Carlee's initial decision to write college students off as "mean") the students use their conversational interspace to actively re-construct "meanness" as unfamiliarity, and people as worth "teaching."

[This could have been a vent session; and to be honest, that would have probably been warranted. Was it my presence that prevented it from being one? Did my identity as a someone from the University result in the students' hesitancy to be critical? College students, people, can be mean. How good might it have felt to get that out? To complain about the inevitable rude stares and/or averted glances in school and community spaces? I know they happen; I have seen—felt (for)—them. Who could blame these students for using their time to talk with one another for collectively agreeing that people who don't "understand" them are not worth their time? Where does the faith in humanity and the willingness to shoulder responsibility for teaching others how to be—do—better in interaction with them and others like them come from? And is solidarity like theirs strong enough to sustain it?]

So What?

Through both action and conversation, the co-inquirers made it clear that advocacy occupies a salient place in their lives. Their conversations on this topic took the form of

demonstrations of and/or engagement with notions of advocacy as an agentive action; a relational and sometimes burdensome responsibility; a reality innately tied to the[ir] disability experiences; “work” worth doing; and a bridge to cultivating understanding across difference. Through these dialogues, they highlighted the ways in which their experiences have had (and are expected to continue having) impacts on one another’s lives and the spaces in which they (will) occupy. They also articulated individual and collective ownership of advocating for more, better inclusive attitudes and contexts so that some day they—and others like them—may not have to.

As they did so, I constantly came back to the question of “what is it my co-inquirers *mean*, and what are they doing, by calling themselves advocates and their actions advocacy?” From our interactions, I understand these students as situated alongside others—self/advocates, activists, families, scholars, allies and friends—in solidarity with a mission to resist, reframe, and re-narrate the experience that has come to be called disability and the manifestations of that in their lives, particularly around communication, competence, and educational opportunity. What matters most, perhaps, is the acknowledgement that here the (albeit, blurred) notions of advocacy, teaching, and acceptance (see Sequence 3) are situated both in the nitty-gritty of their everyday high school lives (see Sequence 2) and with/in the larger (continued) call for justice for all people with disabilities. Thus, the co-inquirers’ efforts and conversations around them must also be located with/in the models of effective advocacy they have been exposed to—on personal and broader socio-cultural levels—in the ongoing movement toward disability rights (Kliewer, 2008), set against the backdrop of a personal, historical, social, and political climate that has posed (and continues to construct) barriers to it/them. The students then, are in the company of—learning from—those self/advocates and activists, families, friends and allies, who have come before them, while paving the way for those they imagine (know) will come after.

[And even as I try/tried to unthread the meanings made through these overlapping conversations, I must also find—model—a willingness to reside in an undefined interspace. Whatever Carlee, Martin, Ralph, Henry and Peter (and others) call what it is that they do (alone and together), they are doing it; making change and using their stories as tools, their typed words (accompanied by sounds, gestures and movements) as mortar, laying new paths br/cl/ick by br/cl/ick.]

Sequence 2 Trudging through the Mud[diness] of High School, Together

The solidarity and flexibility of the group also extended into the use of our dialogic interspace to confront and engage with the complexities of wading through the mud(diness) of high school. Like everything else, these discussions emerged out of, and cannot be separated from, the particular temporal, social, and place-related details of these students' individual and collective experiences. Aptly, many of the conversations that centered on the nitty-gritty of high school life were tied to upcoming events (Junior Prom and Senior Ball) and/or specific spaces (classrooms). While these discussions began with or drew upon individual experiences, often as a means to supporting and connecting with others, they were tied together by two interwoven threads: navigating relationships and the physical/emotional realities of being (and staying) in school.

Navigating Relationships

Manifestation of the complexity of building and being in relationships across difference surfaced almost exclusively in discussions about school dances. In this sequence, we move through a series of conversations that follow Ralph and Peter's school dance stories and the dialogues that emerged out of the preparations for and reflections on those events including: planning, anticipating with apprehension, mind-changing, (evasion of) gendered dialogue.

“Does anyone have ideas?”: Planning the first move. During our earliest group meeting held in Google Hangouts, Ralph initiated the first of many conversations that explored relationships with others, specifically (heteronormative notions of) male/female relationships framed by school dances (Senior Ball and Junior Prom). The comment through which he brought forth this topic also connects back to the aforementioned End the R Word assembly (which had

occurred two weeks prior), suggesting the ways that advocacy and relationships overlap and intersect in Ralph's life.

- Ralph** (2:46 PM):⁷⁶ i am a star since the assembly and i have a new ⁷⁷
[...]
- Ralph** (2:47 PM): friend named Tia.
[.]
- [*School psychologist Ms. Adelstein enters the room. She approaches me and we have a whispered conversation about what the students and I have been doing prior to her entrance (i.e. getting set up in the Google Hangout).*]
- Peter** (2:48 PM): Tia is cute you should ask her to senior ball you two would be cute together
[.]
- [*Throughout most of the remainder of the conversation, Martin rocks back and forth in his chair and waves his hands near his head when he is not typing, sometimes repeating (inaudible) words in a high-pitched, but quiet, voice. Peter makes high-pitched throaty sounds both as he types and when he is waiting for responses. The Google Hangouts message alert chimes each time a message is sent.*]
- Ralph** (2:48 PM): i want to ask her to the senior ball but im really scared
- Peter** (2:48 PM): I can help
I have an idea
- Casey** (2:49 PM): Do it Ralph!
- Ralph** (2:49 PM): does any one have ideas
[*Peter laughs as he types the comment below and Ms. Kozlow begins too.*]
- Peter** (2:50 PM): She was eating goldfish maybe buy a bag of goldfish and hide the invite in it
- Ralph** (2:50 PM): i might try it Peter
- Peter** (2:50 PM): Like cracker jacks a prize you are a prize she would be lucky
- Martin** (2:51 PM): lets try
- Ralph** (2:51 PM): oh boy Peter that is a bit lame
- Peter** (2:52 PM): It is cool
Your my friend
Friends tell friends all
[.]

⁷⁶ This is the first excerpt pulled from a Google Hangouts transcript. Unlike previous transcripts, because of the digital nature of the interface, students' contributions are time stamped. I have chosen to leave these time stamps in to better convey the timeline and pace of each excerpted conversation. These timestamps also reveal the time between each student's typed response, painting a clearer picture of how and why the conversations between the six of us often went back and forth across topics (i.e. why the [...] are necessary for isolating the content of one strand of each conversation).

⁷⁷ Henry is in an Occupational Therapy (OT) session and not present in the room for this conversation until noted otherwise. Carlee had been signed in to the Hangout prior to this portion of the conversation, but was signed off at this point.

- Ralph** (2:53 PM): may i ask you a what you would do
Casey (2:53 PM): Ralph, who was that to? [*Spoken*]
Ralph (2:53 PM): all the guys
Peter (2:53 PM): I would make her a cake bring her flowers and just blurt it out
- [.]
Peter (2:54 PM): Sorry guys I am loud and rambling this is exciting
Ralph (2:54 PM): so maybe i can practice with you Peter
- [.]
Martin (2:54 PM): no problem Peter
Peter (2:54 PM): Sure sounds good I can wear Ms. Rizzo's [Cosmetology teacher] blonde wig
- Ms. Adelstein** (2:55 PM): Ralph I was thinking it might be nice to figure out a time in the day that you and Tia can have a social group. Maybe when we get things started you'll have a chance to ask her then.
- Casey** (2:55 PM): If Carlee were here she could help get you all dolled up in the coz⁷⁸ room
- Peter** (2:56 PM): I can be Tia Ralph
 When she says yes no kissing I won't help you with that sorry man
- Martin** (2:56 PM): Ralph just ask her she said she would go with you.

In this, the first half of the conversation, Ralph makes clear that he is sharing his news (“I have a new friend named Tia”) with the hope that the group will provide support and brainstorming power (“I want to ask her to senior ball but im really scared...does anyone have any ideas?”). The dialogue that ensues is not only a reflection of Ralph, Peter, and Martin’s personalities, but also the contextual realities of Ralph and Tia’s unfolding relationship: a new experience, across communicative boundaries, on the border of a familiar disability discourse and a new narrative of relationship building.

Peter’s palpable excitement about and eagerness to help with Ralph’s budding relationship is clear as he quickly suggests a creative way for Ralph to ask Tia to the ball, perhaps reflecting (or subscribing to) the gendered expectations around school dances in which students (often males) go to great lengths to pop the question (Best, 2005), efforts that are now

⁷⁸ I am referencing the Cosmetology class, taught my Ms. Rizzo, that Carlee took for the previous year.

being dubbed “promposals” (Richardson, 2015). Notably, Ralph’s designation of Tia as a “friend” does not stop him from seeking “ideas” about asking her to prom, nor does it seem to impact Peter’s expectations of what should constitute that interaction. Though initially intrigued by the goldfish bag suggestion, Ralph does not hesitate to express his feeling that the sentiment Peter describes as the influence behind it (“like cracker jacks a prize...”) is “a bit lame.” Peter’s initial response that “It is cool” could be read as a counter to Ralph naming his idea “lame,” but the remainder of the comment—which he types and sends line by line, each idea building upon the prior (“You are my friend./Friends tell friends all”—suggests that “It is cool” is Peter’s way of shrugging off Ralph’s difference of opinion. Here, not only does Peter indicate that he does not take offense to Ralph’s playful banter, but he sees it as evidence of their friendship.

Ralph’s choice to repeat the question (“may i ask you...what you would do”) followed by his specification of his interest in responses from “all the guys” reminds us of the gendered dynamic of the group. In addition to the fact that three of the four TAs present are women, my voice and (as we soon see) Ms. Adelstein’s voice thread through the conversation as further representatives of the female presence. Additionally, while Carlee was not signed into the Hangout at this moment due to technological difficulties, she had been previously and her track record of inconsistent entries/exits into meetings always made it possible that she could join conversations at any moment; she never seemed fully absent. I underscore this feeling when I insert myself into the dialogue by referencing “if Carlee were here...” I see Ralph’s call to “all the guys” as an invitation aimed at Martin and Henry (who he knew would soon return from OT) who have not yet contributed their ideas to the discussion. It also serves as a reminder to the (female) adults in the room *whose* conversation this is. Ironically, just two minutes later, Ms. Adelstein inserts herself into the discussion for the first time. Her suggestion that “...it might be

nice to figure out a time in the day that you and Tia can have a social group” calls forth the dominant narrative that positions experiences of students with disabilities as necessitating different/separate contexts than others’ (Brantlinger, 2005; Ferri, 2009). This tension, illustrated in her decision to name an opportunity for Tia and Ralph’s interactions a “social group,” rather than letting it stand on its own as authentic relationship building (even if facilitated with her, or other adults’, help) suggests not only the complexities inherent in the presence of adults in this interspace, but also the constant push and pull of existing dominant narratives and counter-stories-in-progress.

Ralph does not directly respond to Ms. Adelstein’s comment. Instead, he moves the conversation forward by referring back to that day’s lunchtime meeting with Tia.

- Ralph** (2:57 PM): She came in today and ate lunch with me. im teaching her to support me
[Martin speaks in a high pitched voice quietly and rocks back and forth in his chair as he types. Ralph makes a low groaning sound and smiles. Peter occasionally makes high pitched throaty sounds.]
- Casey** (2:57 PM): That's so great Ralph
- Martin** (2:57 PM): its about time
- Ralph** (2:58 PM): her schedule is trick. but ms grecco left us alone to figure it out
[Henry returns to the room and sits down. I verbally say to him “you have lots to catch up on” and Mr. Meyer scrolls back through the comments to fill him in. Henry makes a few loud sounds and blows air between his teeth loudly before settling in.]
- Peter** (2:58 PM): I am going to prom I don't want a date I dance with all the girls
 Grecco left you alone oooooooooo
- Ralph** (2:59 PM): im pretty sure she would go. im just nervous
- Henry** (2:59 PM): Yes
 Yes
 I was in ot.
- Ms. Adelstein** (2:59 PM): that's great that she's starting to learn how to support. It would be nice for you to ask her when it's just the two of you.
- Peter** (2:59 PM): You got this Ralph your the man just do it like Nike
- Martin** (2:59 PM): your were not alone we were all here
- Casey** (2:59 PM): Martin are you thinking of going to the dance?

Ralph (2:59 PM): iwill.
 [.]
Ralph (3:00 PM): not today i am sivk
 sick
 [.]
Martin (3:00 PM): no dances for me
 [.]
Peter (3:01 PM): That's cool Martin

Despite the fact that his lunch meeting with Tia was aided by adults, Ralph's representation of it to the group re-positions him as in charge: "i'm teaching her [Tia] to support me." He follows this by describing his TA's support as an *absence*, seemingly countering (for whose benefit?) pervasive but narrow notions of independence and support (Ashby et al., 2015; Rosetti et al., 2008; Rubin et al., 2001). Martin, ever a source of exactitude, points out that Ralph and Tia were not *actually* alone ("we were all here"), serving through contrast to highlight the weight Ralph attributes to being with a friend without an adult by his side. Ms. Adelstein's follow up comment, "...It would be nice for you to ask her when it's just the two of you" suggests that she takes a cue from Ralph's efforts to reframe his time with Tia.

A (re)presentation and analysis of this conversation cannot conclude without acknowledging the ways that Martin's and Peter's varying perspectives on school dances were honored. Peter expresses wanting to go to prom, but without a date so he can "dance with all the girls," while Martin's aversion to dances in general is accepted as "cool," and he does not make clear how he feels about relationships or potential dates in other contexts. However, in a later conversation he clarifies that he is "not going to ball... [and does] not like dancing."

"Taking out a girl no experience": Nerves and change(s) of heart. Two weeks later, Ralph updated us on the status of his Senior Ball scenario which, despite being met with great enthusiasm from his friends, was still making him "nervous."

Ralph (2:12 PM): I asked Tia to the senior ball. I rented my tuxedo. Tia is wearing blue.

[Martin is rocking back and forth in his chair while he types. Henry is humming rhythmically as he types. Besides that, the room is quiet. The Google Hangouts message alert chimes each time a message is sent.]

[.]

Casey (2:12 PM): Congratulations Ralph that is so exciting!

Peter (2:13 PM): Awesome Ralph you go man! How much fun you will have

[....]

Henry (2:15 PM): Yes.

I am excited for you my friend.

[...]

Casey (2:17 PM): Ralph how are the dance lessons coming!?

[..]

Ralph (2:17 PM): I am nervous.

[...]

Ralph (2:18 PM): Me and Grecco need to work on it

[..] *[Henry steps out to go to the bathroom @ 2:18PM. Mr. Meyer follows.]*

Casey (2:19 PM): Ralph what are you most nervous about?

[.]

Ralph (2:20 PM): I'm taking out a girl no experience

Martin (2:20 PM): Ralph what do you and Grecco have to work on.

Peter (2:20 PM): Ralph you will do great

Ralph (2:21 PM): Dancing

Casey (2:21 PM): That is a new experience but a good one to have.

[..]

[Henry returns at 2:21. He makes a few loud sounds as Mr. Meyer scrolls through the progress of the conversation that occurred in Henry's absence.]

Peter (2:22 PM): Ralph I don't think I could take a girl out I would feel like I was on a date with me I talk a lot even more when I am nervous

[..]

Casey (2:24 PM): Ralph what kind of dancing are you working on?

[.]

Ralph (2:25 PM): Modern dancing

Peter (2:26 PM): Nice Ralph

While initially Ralph's nerves centered on the task of asking Tia to Senior Ball, the reality of "taking out a girl" in the absence of prior experience is now the focus of his uneasiness; a thread of unfamiliarity runs through his conversations about the dance. Peter echoes his concern, implying that his own apprehension would usurp a hypothetical date since, "I talk a lot

even more when I am nervous” and thus “...would feel like I was on a date with me.” Here, the irony and presence of these students’ diverse communicative realities echoes in Peter’s typed comment about his struggle with (often echolalic) speech, particularly in the context of stressful situations (Donnellan, Leary, & Robledo, 2006). The borderland between speech and typing literally manifests in Peter’s acknowledgment that though he can and does speak (quite a bit), the unpredictability of this communicative channel positions it as a barrier to relationships, an observation he shares, fittingly, via typing.

[Peter’s speech could be a stand alone character in this work, and certainly in his life; sometimes, it has a mind of its own. His spoken words come together to form an (incomplete version of his) identity that radiates and communicates likability and humor and curiosity and creativity. His speech is clear; he can and does articulate full, relevant sentences and carry on conversations that make you think you know him, or more dangerously, what he knows. But as he’s made clear, he prefers—insists—that you attend to his typing over his speech, even as he recognizes and aims to reap the benefits of learning to occupy both spaces at once. Peter’s unique position—with a foot in each the speaking and non-speaking worlds—is one that he referenced often, particularly in conversations with me and, as reported by his mother, at home with his brother, Henry. He primarily connected his difficulty controlling his speech (especially when anxious or excited) and his ongoing efforts to convince others not to respond to his verbal comments. At the same time that he continually worked on harnessing and honing his use of speech through focused practice, he was also learning for the first time how to articulate and clarify his (otherwise incomplete, spoken) thoughts through typing with support. These ongoing efforts were bolstered by Peter’s family and school team, who honored his preferences and supported him in learning how to utilize multiple modes of communication in ways for which there is not much precedent. Yet, even as Peter continued to engage in this process of finding and conveying communicative clarity, the complexity of his communication sometimes melded into misunderstandings, embarrassing situations, and feelings of isolation. Other times (when his words...body...stars...aligned) it did not.]

Just ten days later, Peter’s previously stated speculative views on prom and dating shift significantly when he announces:

Peter (2:14 PM): Carlee I have a date to prom

Casey (2:14 PM): I didn't know that Peter!

[.]

[Martin is rocking back and forth in his chair. Henry has been humming quietly, but now raises his voice for a moment before returning to his rhythmic sounds.]

- Peter (2:14 PM): Larissa from clay asked me she is beautiful
[As I type my response to him, Peter (seated to my left) tries to sneak a peek at what I am typing on my iPad. I laugh and say, "you'll see it when I send it." At the same time, Henry raises his voice and makes a loud abrupt sound.]
- Casey (2:15 PM): That's very exciting! I thought you said you didn't want a date before?
- Peter (2:16 PM): She makes me comfortable
- Ralph (2:16 PM): i have a date for ball. her name is Tia we are becoming good friends

That Peter chooses to direct this news to Carlee, a gesture that Ralph too mirrors with his repetition of already established news,⁷⁹ is not surprising, as her physical absence from the classroom often became a frame for conversations. When I inquire about Peter's change of heart, here, he attributes it to his feelings of comfort with Larissa, suggesting that his prior (rather steadfast) hesitancy to pursue a date for prom may have been more rooted in fear of the uncertain than he let on. It is important to add that Larissa had been in Peter's clay class all semester, but decided to ask him to prom following his presentation during the End the R Word assembly; the development of their relationship paralleled that of Tia and Ralph. It is also significant that Larissa asked Peter to prom and not vice versa, illustrating an intersection of gender and disability that complicates the narrative of heteronormative relationship roles and how they operate with/in the presence of disability.

Guy talk(?). For Peter specifically, the conversations around prom precipitated and overlapped with uncertainties around romantic relationships and, ultimately, sex. During one discussion, Peter used his experience watching *Romeo and Juliet* in English class as a means to initiate a conversation about (heteronormative notions of) intimacy.

[As this portion of the conversation begins, Martin makes a loud sound. He is playing with his pants, which are crooked. Ms. Grecco tells him to stand up to fix his pants. He does, but sits right back down and continues pulling at his pant leg, near the inseam. She quietly says to him, "stop doing that!" and Martin turns to her and

⁷⁹ This was the first conversation Carlee was signed on for since the Ralph and Tia saga began.

- replies, clearly and loud enough for all to hear, “HA!” Ms. Grecco (along with the other adults) laugh. Ralph and Martin both smile. Henry leaves the room for OT immediately prior to the beginning of the interaction below.]*
- Peter** (2:31 PM): Martin are you ok?
- Martin** (2:31 PM): i have a silly⁸⁰
- Peter** (2:32 PM): Me too Romeo and Juliet were naughty in the movie
[Peter speaks the word “naughty” as he types the above comment.]
- Carlee** (2:33 PM): Bye.
[The school band walks through the hallway and the sound of the bells ringing carries into the room. Martin becomes loud and rocks back and forth.]
- Peter** (2:33 PM): Santa is here
[The adults laugh and Peter begins laughing loudly as well. Martin hits his chin. Ralph is typing.]
- Casey** (2:33 PM): Hahaha Carlee there were just bells ringing in the hall!
 Have a great rest of the day Carlee!
[Peter verbally says, “Santa is going to come take you to the prom.”]
- Peter** (2:34 PM): He can take Henry to the prom
- Martin** (2:34 PM): Peter its just a story. they love each other
- Peter** (2:34 PM): They do
 [...]
- Peter** (2:36 PM): Wow sorry everyone I am so SILLY
 [...]
- Peter** (2:38 PM): Boys do you kiss a girl when you slow dance?
[Martin is talking in a high-pitched voice (words inaudible)]
 [...]
- Martin** (2:40 PM): im pretty sure you better stop. thats personal
- Peter** (2:40 PM): Ok sorry
 I just did not know what to do
[Peter turns to Ms. Kozlow and verbally says “bathroom” before he gets up and walks quickly out of the room. Ms. Kozlow follows.]
- Martin** (2:41 PM): I every one of us has the sillys

Though ostensibly extraneous, the “silly” narrative that threads through this conversation ultimately serves as both a doorway and an exit strategy during the, seemingly uncomfortable, dialogue (perhaps paralleling the function of nervous laughter in a spoken interaction). Is using a fictional reference Peter’s way of dipping his toe into the waters of a conversation about intimacy? And is Martin’s matter of fact response that “it’s just a story” a way of putting up a wall? Four minutes later, when Peter asks, “boys do you kiss a girl when you slow dance?”—

⁸⁰ Based on the rest of the conversation, it appears that Martin uses this phrase (“I have a silly”) to describe being in a “silly” mood (i.e. “I have the sillys”).

transitioning from fiction to his own unfolding reality—Martin’s is again the sole response: “I’m pretty sure you better stop. That’s personal.” *Pretty sure*. Martin’s comment reveals a guardedness, a hesitancy to follow Peter down the road he is on. Is this response rooted in Martin’s personal discomfort? Is it related to the number of adults—female adults—in the room? Is it reflective of a larger ableist (or non-existent) narrative around disability, sex, and sexuality (Cowley, 2012; Gill, 2015; Gordon, Tschopp, & Feldman, 2004)?

[I had a pit in my stomach about Martin’s dismissal of Peter’s question. I wanted to respond; I remember feeling my fingers hovering over the on-screen keyboard of my iPad. But I held off, leaving space for the other “guys” to say something, desperately hoping they would fill it, for me. For him. What is the chat-room equivalent of radio silence?]

Peter’s question went unanswered. He stood up and left the room just minutes after posing it and in his absence the others moved the conversation on to the topic of anticipating summer vacation.

However, it soon became clear that Peter had not as easily changed course.

[At 2:45PM Ms. Farber called me into the hallway and nervously asked if she could run something by me. I immediately thought of the “kissing” conversation and feared that she was upset that the topic came up. Or with my lack of (appropriate?) response. I was poised to defend myself, unnecessarily (as usual). She told me that Peter had just asked a 9th grader in the bathroom “why his penis won’t go down?” She said the student was so embarrassed he ran out of the bathroom, his face beet red. She said Peter was mortified, and I wonder whether he is more embarrassed by his own comment, or the student’s response to it; the second time in an hour that his questions have been dodged by others. Ms. Kozlow, who stood outside in the hallway, apologized to the student and explained that Peter sometimes can’t control what he says out loud. I’m sure I was cringing as Ms. Farber spoke, sensing that Peter’s described embarrassment situates this as an example of both the complexity of speech in his life and the complicated interplay of discourses around sex and disability that underlie the responses to it, here. Ms. Farber wanted to know if it would be okay if when Peter came back into the room, he asked the other students for support around this experience. Only if he wanted to. Relieved that we seemed to be on the same page about the importance of these conversations, I responded, “Absolutely, yes. That’s what this is for. They need to be able to talk about what is relevant and important for them—even, especially, this” (though I must admit wondering how the other students would respond given their failure to do so around his earlier question about kissing). Ms. Farber thanked me and then waved Peter over from where he stood, hovering in the hallway between the bathroom and B13.]

By the time Peter returned another student, Kareem,⁸¹ had joined the conversation. The group was greeting him and asking him about his prom plans when Peter entered.

[Peter enters the room and sits back down in his chair. Ms. Kozlow enters behind him and as she sits down and looks to me across the room and mouths “are you sure?” and I nod affirmatively. Peter begins typing immediately.]

Peter (2:51 PM): Guys I was so inappropriate in the bathroom
I asked someone what was wrong with my
penis

[.]

[Martin is alternating between making loud noises and speaking (inaudible) words in a high pitched voice.]

Casey (2:52 PM): Pete are you looking for some advice from
the guys?

Peter (2:52 PM): Yes

[.]

Peter (2:53 PM): It wouldn't go down so I asked
[Ms. Farber enters the room. Ralph begins making loud sounds and looking directly at her, he appears to be calling for her attention. He taps the table three times with his left hand.]

[..]

Mr. Meyer (2:54 PM): This would be a great question to ask your
father Peter.

[The room quiets down considerably.]

[.]

Martin (2:55 PM): well that was not a good idea. you need to
think before you talk. people will think you
are weird. ask your dad hes a doctor

Peter (2:55 PM): They are not here

[.]

Ralph (2:55 PM): I'm not sure that we should talk about that

Peter (2:55 PM): Ok Martin

Martin (2:55 PM): ask them at home

[.]

[Martin's device runs out of batteries. Ms. Grecco plugs it into a charger but it takes some time to boot up again.]

Peter (2:56 PM): Sometimes I am impulsive now Koz took
away the public bathroom

Ralph (2:56 PM): We are in school.

⁸¹ This student, Kareem, as described to me by the other co-inquirers, is also a student with autism. He speaks and types independently (with two hands). Though he was not a participant in the inquiry, he was the only other student that the co-inquirers invited to join these Google Hangouts, at his convenience. This is the first of two conversations in which he (partially) participated (i.e. in both he joined for approximately 10 minutes). His contributions have been removed.

- Casey** (2:57 PM): Any good suggestions for Peter for working on not being impulsive in general?
- Peter** (2:57 PM): Ok sorry guys I am an awful person. I am done typing.
- [...][*Conversation between Kareem and Peter about Kareem's job site*]
- Casey** (2:59 PM): Peter you are not an awful person. Talking with others like this and getting their input can be helpful.
- [...][*Conversation between Kareem and Peter about Kareem job site*]
[*Henry enters the room at 3:00. He sits down at his iPad and Mr. Meyer scrolls through. Henry makes a few loud sounds and brings his hands to his face before settling in.*]
- Peter** (3:01 PM): Can I be done please
- Henry** (3:01 PM): Welcome back.
- Ralph** (3:02 PM): So what do you want to talk about now?
- Peter** (3:02 PM): I can't do anymore
No please
- Casey** (3:02 PM): Would you be willing to hang in and talk about the tech presentation for a few?
- Martin** (3:02 PM): we have more time
- Henry** (3:02 PM): Yes.
- Peter** (3:03 PM): Ok

While Kareem is the first to respond to Peter (his contributions have been removed), Mr. Meyer's suggestion that, "This would be a great question to ask your father" echoes his sentiment. These initial and repeated references to parents' roles seemingly set the tone for the others' comments, situating this as a conversation that should happen at home (Martin: "go ask your dad, he's a doctor;" Ralph: "we are in school"). In addition to encouraging Peter to bring the discussion elsewhere, Martin roots his piece of advice ("think before you talk") in perceptions of others ("people will think you are weird"). Though I try to reframe and expand the conversation ("Any good suggestions for Peter for working on not being impulsive in general?"), it is clear that these responses are not what Peter is seeking and he shuts down. And though he does not stop participating in the conversation for the day (he actively contributes to a conversation about the upcoming technology presentation) his questions do go unanswered. Again.

[Would you talk about bodily functions with your friends if four women who could be your mother(s) and a man who could be your father were around the table? I wouldn't. On the other hand, what boundaries should a TA uphold—or push—around supporting (physically and literally) conversations about bodily functions, intimacy, sex, and sexuality in school. This isn't just about whether these conversations should happen in this space, it's also about how, when, and with whom. It seems like this conversation reveals as much about the complicated experiences of having (and being) adults present, and necessary for communication, than it does about being a male with a disability in high school. I see, feel, this most in the hesitancy (un)expressed in Ralph and Martin's responses; it resonates in the words they chose and those that they chose to leave out. Though they replied to Peter, they did so after (in light of?) others' comments that had already clearly situated this as a conversation for home. Ralph and Martin's responses evidence them both acting like and relying upon adults, capturing the complexities of age and power dynamics made salient by their paradoxical occupation of both spaces as high school students over the age of 18. Add to that the complexity of a historical and pervasive infantilization of people with disabilities that positions them as "too innocent" to engage in these kinds of conversations, combined with a narrative that positions impulsivity as inappropriate; clarity, here, is elusive.]

This was the first and last time that a topic even tangentially related to sex was raised during our time together; perhaps the terrain was decidedly too rocky to traverse by these students, and adults, in this context. It saddens me to think that the ways the co-inquirers support each other around academics, advocacy, anxiety (see below), and relationships positioned as non-intimate do not extend to this realm of their experience. I cannot know how much of this hesitancy—and the manifested avoidance of this topic—was related to my presence and that of the other (primarily female) adults and how much was reflective of a more ingrained conception of what kinds of topics are or are not up for discussion by students like the co-inquirers. Would that have been the case if I were facilitating conversations with students without disabilities, or without the presence of other adults in the room? What would have happened, here, if the students were alone and could converse in private? And what do I make of the fact that Peter narrates his interaction in the bathroom as reflective of his impulsivity, positioning his act of asking the question as beyond his control? Because he claims it as evidence of "impulsivity" I want to honor his assessment and representation of the experience. But I also want to pose the question,

what if it wasn't? What if, here, Peter's use of impulsivity to explain his actions (which became situated as "inappropriate" by the student's embarrassment and physical avoidance of them/Peter) represents an artful reconstitution of the existing understanding of his speech as beyond his control, shifting the onus away from his otherwise natural, adolescent curiosity to a manifestation of his disability? And what if he actually believes that such curiosity does make him "inappropriate" and "awful"? But also, what if this conversation never had a space to occur in the first place?

Navigating Anxiety through/with/in School Spaces

While the conversations around relationships and dances involved discussions of "nerves," we also had many discussions about anxiety in general and, specifically, how it related to physically being (or not) in school. All of the co-inquirers (and, in some ways, I too) identified feelings of anxiety as salient to their high school experiences. However, they made it clear that despite similarities in how it manifested, they each experienced anxiety in different contexts and for different reasons.

"Anxiety comes as part of who we are:" Anxiety as shared experience. This subject surfaced early in our time together in Summer 2014⁸² as the students shared ideas important to them as individuals and topics they hoped to discuss as a group. In these initial brainstorming sessions, they identified the goal of generating strategies for "calming down," managing "sensory needs" and "get[ting] out" of "feel[ing] dark;" all experiences they later tied to anxiety. The following exchange represents the first instance in which anxiety emerged as a focus of conversation during Summer 2014, as well as its connection to the school experience. It begins with Ralph proposing a topic he would like to discuss.

⁸² Summer 2014 Inquiry Group meetings were co-facilitated with Beth Myers.

- Ralph:** When I feel dark what I do to get out of it. Share how I feel when I go to class⁸³
- [..]
- Casey:** I think it's really interesting that [those] two items on your list, I could see being sort of like "how to's" for other people that may provide some insight into how other people experience or work through some difficult things.
- [.]
- Carlee:** I'm hopeful about emotions.
[Beth asks Peter if he has any feedback for Ralph and he plays his list of topics. Beth says, "We'll come back to you for your list. You're next."
A minute later, Peter begins making high pitched throaty sounds. Ralph, who has been quiet, groans and make abrupt loud sounds. Henry makes a few staccato sounds as he finished his comment.]
- Henry:** That's very interesting I would like to discuss the classroom feeling with you Ralph.
- Beth:** ... Henry I thought that was great feedback. It really helped us think about what you also feel about this and how you would like to participate in that conversation [*spoken*][.]
- Carlee:** I think anxiety is huge for all of us.

As Beth and I allude to in our contributions, this conversation calls forth associations of classroom experiences with anxiety and strong emotions, as well as a desire to share strategies to sort through those experiences. This is a topic that threaded through our discussions, exposing the nuances in each student's relationship to anxiety (and related sensory experiences) as they navigated the high school landscape.

Particularly during the Summer 2014 meetings, Carlee was the most upfront about her experiences with anxiety and referenced the topic as a "huge issue" to continually probe with the others. She made clear that grappling with her own anxiety impacted her ability to participate in school and relationships, and as such she frequently sought her peers' support, guidance, and evidence of shared understanding. For her, and most others, anxiety was intimately tied to the realities of sensory needs and experiences—elements often reported to be related by both those who live with autism and those who explore the neurological roots of the associated lived

⁸³ Martin was absent.

experiences (Barron & Barron, 1992; Biklen, 2005; Donnellan, Hill & Leary, 2013; Higashida, 2013; Mukhopadhyay, 2000; Robledo, Donnellan & Strandt-Conroy, 2012). This is particularly salient in a section of Carlee’s memoir-in-process that she shared with the group during a discussion around this topic:

My first year in public school was interestingly difficult. Maneuvering through crowded halls terrified me. There were so many sounds, smells, faces and movement which made me cringe. Eating in the cafeteria made me want to rip my clothes off due to sensory overload... I pick my fingers and have other anxiety issues. I'm not sure if I will ever stop doing these things. I don't feel pain like others do. My body does not always cooperate with me.

Here, Carlee describes experiences in school spaces as triggers for “sensory overload,”⁸⁴ a state she repeatedly associated with anxiety and confusion. Yet, while most of the other students tended to identify affirmatively with connections between anxiety and sensory overload, some also expressed anxiety about school structures, such as their schedules, physical locations and/or academic expectations, as being primary areas of focus. For instance, in addition to relating to Carlee’s notion of anxiety as intense emotions and feelings associated with going to class, in previous conversations Ralph, Henry, and Peter each connected it to uncertainty related to school spaces, particularly the transitions into or out of different classrooms. Aptly capturing these diverging experiences, Martin’s experience most drastically contrasted Carlee’s:

Martin:⁸⁵ I guess I don’t have the sensory overload. I’m all about my schedule.
[Martin is seated in and types from the rocking chair. He occasionally rocks back and forth and speaks (inaudible) words in a high-pitched voice.]
Ms. Grecco: He’s right [*spoken*]

⁸⁴ The students often used the terms “sensory overload,” “deregulation” and “unregulated” either interchangeably or in direct connection with one another. This is an interesting semantic distinction to be further explored in the context of these five students’ lives, but is also reflected in the research and first person accounts (i.e. Endow, 2011; Endow 2015, Donnellan, Hill & Leary, 2012; Higashida, 2013; Robledo, Donnellan & Strandt-Conroy, 2012; Spectrum Documentary, 2015). The students’ and/or their parents were familiar with some or all of these accounts.

⁸⁵ Henry and Peter were absent.

- Beth:** Yours is all about your schedule? So stress about your schedule?
[spoken]
- Ms. Grecco:** Yes if his schedule changes, it's stressful. [to Martin] Is that what you mean? The change of your schedule, is that what your stressor is? [spoken]
- Beth:** Stress or anxiety. Would you call that anxiety, Martin? [spoken]
- Martin:** Yes
[Martin rocks back and forth and waves his hands up and down in front of him.]
- Casey:** But Martin would you say that you identify with what Carlee's talking about, the feelings of anxiety or pressure when your schedule changes? Are your responses similar? [spoken]
- [.]
- Martin:** I feel unregulated
- Casey:** Can you describe that feeling? [spoken]
- Ms. Grecco:** [to Martin] What does that mean? How does it feel when you are unregulated?
[As Martin types his answer, Ms. Grecco quietly says to him, "I like the smile on your face while you're talking about this. It's pretty cool."]
- Martin:** Am not in control.
- [.]
- [Martin stands up from the rocking chair and walks across the room to Peter's empty desk waving his hands back and forth by his ears.]
- Carlee:** Deregulation is confusing.
[Carlee stands up and makes a high pitched moaning sound. She takes her headphones off, puts them back on and bites her finger. Ms. Roland asks her to sit down and reminds her it is not time to go. Carlee briefly sits down (for 2 minutes), but ends up leaving shortly after to take a walk and never returns.]

Martin attributes the root of his feelings of “unregulat[ion]” to changes in his schedule, and admits to not sharing Carlee’s (and others’) experiences with sensory overload. Interestingly, Carlee identifies with the experience of not feeling in control—“deregulation”—as a source (and product of) of anxiety as well; ultimately it is how and why they get there that varies.

In many ways the students worked through the lived realities and consequences of heightened anxiety together. During one particular conversation, Carlee shared with the group her feelings of limited agency due to her anxiety, “I think anxiety runs my life and ruins my ability to come [to school] for more than 1 hour.” Two meetings (ten days) later, she called forth

her own uncertainties around her anxiety and its ramifications again. This time, Ralph and Henry shared how their perspectives and experiences diverged from hers:

- Carlee:**⁸⁶ Is the high school experience really worth the anxiety it creates? Time to let it go and move on.
[Martin asks Ms. Grecco, "sit in chair?" and she replies, "two minutes. Go ahead." He gets up and sits in the rocking chair to the left of his desk. Ms. Grecco sets a timer on his desk.]
- Ralph:** I think it is worth it, it is an experience
[Henry makes a loud sound. Carlee smiles, drops, and rolls her head side to side and makes a drawn out, high pitched sound. Thirty seconds later, Peter says verbally, "It's time to go."]
- Henry:** I really enjoy the high school experience so far
- Carlee:** Yes I am overcome with anxiety to function
[Peter and Henry both pack their bags and exit the room. There is movement and muffled conversation as they do so.]
- [...]
- Ralph:** Carlee what does that question mean?
[Martin sings from the rocking chair, "Have a nice day. Mother Goose [followed by inaudible words]" Ms. Grecco reminds him he still has a half hour of the day.]
- [..]
- Carlee:** I want to think out of the box.
[The timer on Martin's desk beeps rapidly. Ms. Grecco signals to him and says "okay, come on. Cover over. [pause] 1-2-3. [pause]." Martin remains in the rocking chair and, singing [inaudible] words. Ralph makes loud groaning sounds.]
- Ralph:** What does that mean?
 [.]
[Ms. Grecco says, "Martin LaMuncha. Get up and over here." Martin sings under his breath and she says, "don't sing 'goodbye mother goose.' Come on. We have work to do." Ralph smiles and makes a loud sound, alternating between looking at Ms. Hamden, to his right, and toward the poster paper at the center of the room. Ms. Hamden whispers to him [inaudible] and Ralph responds verbally, "yes, yes." Martin returns to his seat. Ms. Grecco re-reads Carlee's original question quietly to him (which she typed into his iPad), adding, "Considering you have been around a long time, I think you might have a really good answer to that." Watching Ms. Grecco, Casey says to the group, "I think this is why I think an online chatroom might work nicely. Because then you guys could all see each others questions as they come in and scroll back up to them when you need to."]
- Carlee:** I can attain goal with GED and get flexible schedule.

⁸⁶ This Summer 2014 Inquiry Group conversation was the first in which I played with the visual representation of the students' typed text. As they shared their contributions via audio output, I hand wrote their words onto large poster paper at the front of the room. Carlee and Ralph, in particular, seemed to find this helpful, as they spent most of the time they were not typing turned in their seats looking at the poster paper. This format would later evolve (Spring 2015) into our use of Google Hangout.

[Martin makes a loud “HA. HA” as he looks at Ms. Grecco. She laughs and briefly puts her arm around his shoulder. They both look at each other and laugh simultaneously. Ralph makes a high-pitched sound and turns toward the center of the room to look at the poster paper. He remains turned in this direction until he begins typing again. Martin sings quietly and returns to typing.]

Ralph: That sounds like it might work.

[Martin makes a series of loud sounds before he begins singing, “have a nice day Mother Goose [and inaudible words].” He stops typing, Ms. Grecco says, “what have you learned to do? You have to finish your thought you are in the middle of a sentence.” Ralph makes groans quietly and taps the surface of the table. Carlee plays the audio of her response before she finishes typing it. Ms. Roland says, “For...? Finish.” and waits for Carlee to begin typing.]

Carlee: I’ve been thinking it is better for me.

Martin: I am really happy in school. It can be scary but I have learned to use my words when I get frustrated.

[The room is very quiet.]

Ralph: You will be missed here but you will always be one of us.

Carlee: I’m not sure when. *[Carlee shares this. Pauses and then begins typing again to add:]* No goodbyes.

This conversation is particularly contextualized because it occurred when Carlee was attending school for only one hour per day. Her absence was palpable in the classroom, and the other four co-inquirers often asked about and/or referred to her (presence and/or absence) in their conversations. While Carlee attended every Summer Inquiry Group meeting, the other students often questioned and/or expressed concern about her limited presence during the rest of the school day (which was precipitated by absences in the preceding Spring semester and followed by erratic attendance during the Fall). This brief interaction offers a partial explanation for her absence, one of the first and only instances in which Carlee attempts to provide an explanation for her inconsistent school attendance. Despite this, Ralph pushes Carlee to consider the cost-benefit of being in school (“I think it is worth it, it is an experience”). Carlee’s reply (“I am overcome with anxiety to function”) indicates that she positions her (body’s) responses beyond her control; anxiety makes staying in school nearly impossible, even if it *is* worth it to her.

“Stress is a real problem”; Un(for)seen hazards on school terrain. The overlaps between sensory/movement differences and anxiety also emerged during our Spring 2015 group conversations. While what constitutes “stress” versus “anxiety” are certainly nuanced and complex, the co-inquirers tended to use the latter to represent physiological responses to stressors and the former in references to the antecedents of them. Beyond those addressed above, these conversations were primarily framed around the students’ requests for support in strategizing ways to manage their responses to stressful experiences or encounters with/in classrooms. In the conversation below, both Peter and Ralph’s originally distinct points of entry merge into one large group discussion about—albeit varied—stress and stressors.

- Peter** (2:14 PM): I have a topic
Ralph (2:14 PM): Reason why I'm tired is the loud noises today
Casey (2:15 PM): Peter what's your topic
[Henry is loudly blowing air between his tongue and teeth and occasionally erupts into a loud, nasally sound. Martin is speaking/singing quietly (inaudible words) in a high-pitched voice. Henry’s sounds overpower Martin’s and are more consistent.]
Peter (2:15 PM): How do you deal with stress in classroom
Ralph (2:15 PM): End of my patients today
Peter (2:16 PM): I had to leave science today because the topic was stressful
Carlee (2:16 PM): You try
Ralph (2:16 PM): Stress is a real problem
Peter (2:17 PM): It is I am trying to figure out how to not make me anxious
Martin (2:17 PM): yes stress and noise i think everyone is ready for break
Casey (2:17 PM): Maybe everyone could share one of the best strategies they have to deal with stress and anxiety?
Ralph (2:18 PM): How can you tell class mates they are too loud
Peter (2:18 PM): I know it makes me weird sorry everyone
[While typing the comment below, Henry is noticeably quieter. He only makes sounds by blowing air through his tongue and teeth. Once he sends it he sits back in his chair, eyes on device, with his arms crossed.]
Henry (2:18 PM): Sorry if I am.
I try to control my volume it is a struggle.
[Ms. Grecco scrolls back through the conversation and asks Ralph, “did you read that?” He leans back in his chair and audibly says “yes,” She continues, “What do you do?” and he begins typing.]
Peter (2:18 PM): Just ask nicely I had last week in math Ralph
Casey (2:19 PM): You are not weird Peter I think everyone can relate to this

[Martin repeatedly tries to send his message but has trouble accessing the small target. After his second attempt, he yells loudly and hits his chin with the back of his fist before moving his hand back to the device to try again. Ms. Hamden responds by straightening his index finger (which is slightly bent) and quietly reminding him, "okay.... straight...get there." He tries again and the message sends. He verbally and loudly exclaims, "I did it!" He repeats, "I did it." Ms. Hamden says, "you did." Martin verbally says, "yes you did, okay? Yes you did."]

Martin (2:19 PM): i go to the bathroom

[In the middle of Martin's exclamations (above) Henry loudly speaks, "gummies," a snack he typically receives at the end of an activity, specifically after an OT session. Mr. Meyer quietly says to him, "ask me at 3:10. So you've got to do this and then in a little bit you're going to OT, I think. After OT we're typing for a little longer before its time to go. You're doing great." Henry, who has been silent during Mr. Meyer's comments, blows air between his tongue and teeth and begins typing. He types a private message to Mr. Meyer to which Mr. Meyer replies, "no problem, no problem." He deletes Henry's text from the Google Hangouts text box and says, "we won't send that. I know you were responding to me."]

Peter (2:19 PM): Bathroom

Casey (2:19 PM): Sometimes getting away from the stress is a good strategy I understand that Martin

[The room becomes very quiet.]

Peter (2:20 PM): For sure M⁸⁷

Henry (2:20 PM): Yes

[Henry speaks, "OT" and leans back in his chair with his arms over his head. Mr. Meyer says, "10 minutes." Henry stretches over the back of his chair, sits back up and then turns as if he is going to get up out of his chair. Mr. Meyer places his hands on his shoulders and Henry turns back toward the table. Scrolling back through the conversation, Mr. Meyer says "come back here, we're going to actively participate in this conversation until it's time for you to go." Martin says, "oh buh bye." As Henry begins typing, he makes repeated sounds that start loud and decline in volume.]

Ralph (2:20 PM): I try to place myself in their body and remember I'm noisy too

Peter (2:21 PM): Good point Ralph

Casey (2:21 PM): Henry what do you do to work through stress?

Henry (2:21 PM): I agree Ralph

[Henry continues alternating humming and blowing air between his tongue and teeth.]

Peter (2:22 PM): Farber are you going to type

Casey how do you handle stress

Ralph (2:22 PM): Draw

Peter (2:22 PM): Love your support Martin

Casey (2:22 PM): I am not very good handling it all the time, but I do deep breathing and try to put the stress in perspective. I try to look at the big picture,

⁸⁷ Adults and peers often refer to Martin by the first letter of his name, "M"

Henry (2:23 PM): I am both loud and affected by noises.
Peter (2:23 PM): The big picture scares me
Ms. Farber (2:23 PM): Hi this is Ms. Farber. I think all of you handle it differently. You all have good strategies for different times. Even we adults get stressed at school. I find my friend and she makes me feel better.

[.]

Peter (2:23 PM): Thanks Farber
Casey (2:23 PM): The big picture is scary but it is also comforting to remind myself that whatever I am dealing with is just a small piece of the big picture

[...]

Peter (2:24 PM): Very inspiring Casey

In this, the first half of the conversation, Peter apologetically (“I know it makes me weird sorry everyone”) seeks support rooted in having “to leave science [class]... because the topic was stressful,” connecting back to the summer conversation (above) about anxiety and physical presence in school spaces. In addition to validation (“stress is a real problem”), he is initially met with two concrete strategies from his peers (framed by my attempt to structure the conversation): Martin’s “go to the bathroom” and Ralph’s “draw,” which both serve as veritable ways of escaping—if only temporarily—the stressful situation or space. However, Peter’s invitation to Ms. Farber (“Farber”) to “type” (i.e. officially enter the conversation via Google Hangouts), as well as his direct request for my input, suggests that he is also seeking perspectives and suggestions from beyond his peers (from/beyond the blurred lines between anxiety experienced with/through autism?). The first part of Ms. Farber’s response is both observation and validation (“I think all of you handle it differently. You all have good strategies for different times”); she recognizes that the students each already know, or are actively figuring out, how to handle stress in ways that work best for them. The latter half of her response ostensibly adds to their growing list of strategies (“Even we adults get stressed at school. I find my friend and she makes me feel better”), yet it also serves to honor the ways in which her recommendation is

manifesting in/through the unfolding dialogue. If Ms. Farber is suggesting “find[ing] a friend” as a means to navigating stress, she is also underlining the value of what the students are doing through conversation with—finding friend(s) in—one another.

[When Peter directly asks for my advice, I feel a familiar surge of anxiety run through my veins; shit.just.got.real. I hope he’s only asking to be nice. Can I “go to the bathroom?” Could he possibly know that the honest (...enough. I really am not skilled at handling stress, ever), concrete (“deep breathing”) and meditative (“look at the big picture”) answer comes from school experiences eerily similar to the ones he describes? Do I wear the scars of panic attacks and failed breathing exercises that visibly? Would he—they—believe if I admitted that I, too, know what it feels like to have-to-get-(and stay)-out-of-here-right-NOW? Can he—they—see in my eyes that a struggle with anxiety in school lays beneath us as common ground? And if not, what lines in the sand am I willing to cross (or draw)? I don’t know, but I squirm. This isn’t (supposed to be) about (that part of) me. So I type about (like I’ve seen) “the big picture.” And do some deep breathing.]

While I attempt to pull Henry into Peter’s conversational thread (“Henry what do you do to work through stress?”), he is more focused on the “noise” discussion that both parallels and intersects with it. When, after establishing that noise is behind his current state of fatigue and impatience, Ralph asks, “how can you tell classmates they are too loud?” it is clear that Henry interprets that *he* is the problem (“Sorry if I am. I try to control my volume it is a struggle”). Ralph does not affirm or deny that this is the case. Though Peter quickly jumps in and evidently connects this question to “classmates” broadly and uses his experience as a guide (i.e. “ask[ing] nicely” for students to quiet down in his math class), most of the conversation about noise is dominated by Ralph and Henry’s (seemingly coded) comments about their experiences with one another. Answering his own question, Ralph adds, “I try to place myself in their body and remember. I’m noisy too,” while Henry highlights the complexity and incongruity of the issue at hand for him, “I am both loud and affected by noises.” The interpersonal nature of this exchange reminds us that shared disability identities experiences do not rule out the possibility that each of these students have unique needs, preferences, and experiences; what is comforting, or

involuntary, for one person could contribute to making classrooms “stressful” for another. Further, regardless of whether Ralph was using his question as a doorway to comment specifically on Henry’s volume, the situated nature of this conversation within and alongside one about stressful classroom experiences reinforces that auditory stimuli can fall into the category of potential stressors that these students must navigate, even if they also use noise(s) as coping mechanisms, and/or means of regulating their bodies.

This dialogue around stress continued when Martin introduced and sought connections around sleep as a related issue. As the conversation progressed, the group constructed sleep as both a(nother) source and vehicle of reducing stress.

Martin (2:23 PM): i could not sleep last night. any one else have that problem?
[As Martin types the above comment, he all of a sudden begins saying letters out loud (in a melodic, high pitched voice) “A...N...Y... O... N... E!. (raises voice on E).... Space!” there is a brief pause and he begins again, “E. L. E.” He stops typing, stretches his hands to his ears, elbows wide, yawns and turned toward Ms. Hamden. She says, “you’re not done with your comment.” He continues typing, speaking (inaudible) words as he does so, pausing to rock in his chair as he finishes.]

Ralph (2:24 PM): I am really trying now really hard because I'm tired
[Martin is rocking back and forth in his chair and repeats, “Yes, Yes, Yes” followed by repetition of the same (inaudible) phrase in a high pitched voice. Henry is humming rhythmically.]

Peter (2:24 PM): I hardly ever sleep my poor mom [.]

Carlee (2:24 PM): The reason is u you really have to help.

Ralph (2:24 PM): Me too

Martin (2:25 PM): yeah me too.

Ms. Farber (2:25 PM): I couldn't sleep either, Martin. I woke up every hour and looked at the clock. Because of that I woke up with a headache. I took a walk and it helped.

Peter (2:25 PM): Carlee can you explain

Casey (2:25 PM): I don't understand Carlee, can you clarify?

[Henry repeatedly blows air through this tongue and teeth as he types.]

Henry (2:25 PM): I have been sleeping well.

Casey (2:25 PM): Does not sleeping connect to stress from the day? Or does it cause stress the following day?

Peter (2:26 PM): Henry you sleep but I don't because you make noises in your sleep ugh

Yes it does Casey when your tried your stress levels are huge

- Martin** (2:26 PM): it is a viscous cycle
[Ralph turns his body towards Ms. Grecco and places his right hand in hers on the table. He takes his left hand and taps twice on the table. She moves the device so it is square to him in this new position. He folds his arms and rests his head on them on the table. Ms. Grecco turns to me and shrugs her shoulders. I look at Ralph, then at Ms. Grecco, and smile. She mouths something to me across the table, blocking the left side of her face with her hand. I shake my head, shrug my shoulders and mouth back, "no. It's okay." She lets Ralph rest on the table for a short while longer (about 30 seconds) before tapping him on the back and saying, "come on, you need to do this. I know you're tired but you have to work through it." Ralph sits up and begins typing.]
- Casey** (2:27 PM): I see. I totally get that.
- Henry** (2:27 PM): Sleep replenishes my ability to focus.
- Peter** (2:27 PM): Henry what do you do
- Carlee** (2:27 PM): You have help.
- Ralph** (2:27 PM): You type Grecco
[Ms. Grecco laughs and says to him, "no it's your job not mine."]
- Casey** (2:27 PM): Got it. You have help to deal with stress?
- Carlee** (2:28 PM): You know.
[Martin speaks (inaudible words) in a high-pitched voice.]
- Peter** (2:28 PM): Carlee your right our team
[Ms. Grecco turns Ralph's iPad towards her and types on it.]
- Ms. Grecco** (2:28 PM): we all have trouble sleeping.
- Henry** (2:28 PM): Resting is important.
[Henry loudly blows air between his tongue and teeth. He also hums rhythmically. He verbally asks to go to the bathroom. Mr. Meyer coughs and Henry briefly brings his hands to his ears and then independently scrolls through the conversation. Martin begins reciting his daily schedule out loud.]
- Carlee** (2:29 PM): Yes.
- Ralph** (2:29 PM): Family helps too
- Peter** (2:29 PM): Martin your a Sr. What did you do when you were in my grade
- Casey** (2:29 PM): Help is great. Family too.
 And friends who can relate to your experiences.
- Peter** (2:30 PM): Always family it is like the song we are family
[Henry makes a particularly loud, nasally sound. Peter looks over to his right at Henry, one of the few times during this conversation that he averts his gaze from the device.]
- Ms. Farber** (2:30 PM): (Ms. Farber). How does your family help, Ralph?
- Peter** (2:31 PM): DJ Martin can play it [.]
- Ralph** (2:31 PM): My mom is helpful she knows my moods
 [...]
[Carlee's facilitator types to the group that "Carlee is on a break"]
 [..]
- Peter** (2:33 PM): Carlee it is a Monday I get it
[Ms. Karl, the OT enters the room. Peter turns toward her and repeats her name "Ms. Karl, the OT." Martin says, "She's back. She's back." Henry stands up.]

Though he had been typing he does not finish or send his comment. Mr. Meyer says, “go get your OT on.” Martin sings, “Okay have fun. Okay have fun.” Ms. Farber says, “see ya in a bit Henry,” which Martin repeats in a melodic voice, “see ya in a bit Henry.” The room then quiets down completely.]

Ralph (2:33 PM): All understand

[Peter looks at Ms. Kozlow and verbally says, “she won’t call today.” Ms. Kozlow says, “uh-uh” and shakes her head side to side.]

Peter (2:34 PM): Thank you

Casey (2:34 PM): So far for strategies to deal with stress you've got: get away, deep breaths, sleep, help, family, looking at the big picture, friends

Ralph (2:34 PM): Ready to go to the rest

[Ms. Grecco says to Ralph, “I think you’ve said you’re tired and you want to sleep about 30 times.” Martin repeats out loud, “thirty times. That’s thirty times.” Ms. Grecco laughs. Martin then says, “What are you doin’ Grecco? What are you doin’, Grecco?” She responds, “I’m sitting next to you, listening, what are you doing?” Martin answers, “what are you doing?” Ms. Grecco says, “you’re typing. Talking to Carlee and Henry (it’s actually Peter who remains in the room) and Ralph.” As this interaction is going on, Peter is typing his comment below, smiling.]

Peter (2:34 PM): You rocked it everyone thank you everyone

While this second half of the conversation continues to build on stressors and strategies to navigate them (specifically sleep, but also family, “help” and “team[s]”) it also highlights the relational dynamics of the group. Martin takes on an uncharacteristic role and seeks, rather than only responding to calls for, guidance from his peers (“i could not sleep last night. any one else have that problem?”). Ralph connects to Martin’s question about sleep with another reference to his physical state (“tired”) which he has already described as linked to environmental factors: (possibly Henry’s)“loud noises”. Carlee, on the other hand, continues with strategies to navigate stress, adding “The reason is u you really have to help” which she, Peter, and I work together to clarify as a reference to the “help” of their “team.” Henry establishes that he does not relate to Martin’s struggle, but instead touts the benefits of sleep (“...replenishes my ability to focus”). Peter, on the other hand, places the onus for his own lack of sleep on Henry and his noises (“Henry you sleep but I don't because you make noises in your sleep ugh”). He also, however,

directly requests Henry's feedback ("Henry what do you do?") suggesting that, despite being twin brothers, this is not a conversation that Henry and Peter have had outside of school.

As the initiator of the stress conversation in the first place Peter's continued efforts to solicit responses from select group members, as well as his declaration marking the end of the conversation ("You rocked it everyone thank you everyone"), situate him as the driver of this discussion. In particular, toward the end of the conversation he shifts back to seeking specific suggestions on how to navigate stress and reveals again the weight he attributes to the advice of others, particularly Martin. In his targeted question, "Martin, your a Sr. [Senior] What did you do in my grade?" Peter's regard for Martin—conceivably as an older, wiser figure—is evident. Interestingly, Ralph, too, is a senior and Carlee's experiences with anxiety are abundant, so why does he not push them for additional contributions? Is he satisfied with the comments they had previously provided? While of unknown origins, his choice to put Martin on the spot (despite having already provided one answer) perpetuates the ways that Peter continues to revere Martin as "the leader," particularly for his assumed lived experiences.

So What?

While I've separated the discussions about navigating relationships and anxiety as distinct conversational threads, they also overlapped and intersected in ways that account for their joint placement under the larger umbrella of "navigating the mud[diness] of high school." Narratives of nervousness and uncertainty wove through, and yielded manifestations of anxiety, in conversations about upcoming dances and new peer relationships. Likewise, discussions that centered on stress and anxiety included references to and were contextualized by the importance of relationships with others (family, friends and support teams), particularly touching on complexities of finding and navigating connections with classmates.

Additionally, conversations on these topics breathed life into the act of “navigation” itself; they all involved elements of planning, (re)directing, resisting and/or moving across unknown ground in, and/or seeking (to) (alter)nate routes to, the high school experience. While the dialogic interspace proved an opportune venue for the students to share their concerns, intentions, and stories, they made clear through their pointed questions and (in some cases, non-) responses to one another that these were also spaces conducive to (re)crafting and (re)charting the experiential terrain all together (as we’ll see more clearly in Sequence 3). That the students chose to use time together (as similarly situated peers) to seek and provide conversational feedback/support around friendships, dating, interaction, and anxiety (as a term that has both roots in *and* branches off of sensory experiences) says much—and raises questions—about the potential uses of that collaboratively constructed information. While the pressure to conform to ableist notions of normalcy was ever-present (see Sequence 3, which follows), these conversations yielded ideas and (unanswered) questions that emerged out of—and in many ways remain firmly and unapologetically entrenched in—the experience of autism, within the context of adult support, and through non-normative modes of communication.

Perhaps above all, the students’ enthusiasm, honesty, and support for one another during these conversations illustrated (and built) reciprocal friendships through shared understanding and unconditional acceptance—a relational experience (as we’ll see in Sequence 3) they all identified as paradoxically essential and elusive.

Sequence 3 **Seeking Acceptance, Building Community**

In addition to the topics addressed thus far, we spent much time implicitly and explicitly discussing, seeking, problematizing, and reframing notions of “acceptance.” Conversations around this subject highlighted the complexities of seeking acceptance, while also pushing back against the status quo that often positioned these students as individuals not worthy of it.

In this sequence, I put forth a set of conversational scenes that exhibit the variety of ways that the co-inquirers encountered, reflected on, and troubled notions of “acceptance.” Some of our conversations (primarily during Summer 2014) called attention to the pervasiveness of the construction of “normalcy” in the co-inquirers’ lives. Others served as opportunities to candidly discuss the realities and intricacies of navigating school landscapes (and the world) not constructed with a diverse range of experiences, needs, and preferences in mind. In some instances, the students described being engulfed by pressures to fit in. In others, they exposed normalcy as a façade, questioning the necessity (inevitability?) of fitting in as a means to achieving the kind of acceptance they sought. They also explored and underlined the perceived and palpable gaps between their experiences and others’ they often wished they could bridge. Across many conversations on this topic, the students actively encountered and puzzled over the tensions between autism as a barrier and autism as an identity. Paradoxically, as we wandered down these—sometimes diverging, sometimes hopeful, sometimes painful—paths, I witnessed and participated in the co-construction of experiences grounded in a reflection of belonging that seemed to mirror what the students expressed as otherwise missing from their lives.

Finally, by ending this sequence with a storied dialogue that began and occurred primarily between Carlee and me, I illustrate how these questions, experiences, and complexities

around notions of acceptance weave together in a conversational comparison to construct contrasts between narratives of “inclusion of the brain and inclusion of the heart.”

Participating for (as) Normalcy

Over the course of our time with/in the dialogic interspace, the co-inquirers sometimes described their own experiences in relation to what they considered “normal.” Because this term carries so much potential for discrimination and alienation (Ashby, 2010; Baglieri, Bejoian, et al., 2011; Davis, 1995; Garland-Thomson, 1997) I, along with Beth Myers (who co-facilitated Summer 2014 meetings), often attempted to tease out their choices to use this word and the inherent assumptions in doing so. The first time that the students called forth the term “normal,” we engaged them in an examination of the construct and its perceived role in their lives:

- Carlee:**⁸⁸ Going to class makes me feel normal
- Casey:** What does that mean to you Carlee, normal? [*spoken*]
- [.]
- [*Henry makes an abrupt, nasally sound.*]
- Carlee:** I think of my peers.
- Casey:** You think of your peers as normal [*spoken*]
- [.]
- [*Ms. Roland says to Carlee, “Do you have anything else to add” and Carlee begins typing. The room is quiet, with the exception of whispered prompts and support from the TAs as the students type. Henry makes an occasional abrupt sound or hums a rhythmic melody.*]
- Carlee:** Thinking my showing my abilities of intelligence is important
- [.]
- [*Carlee looks at Ms. Roland, and curls forward toward her, resting her head on Ms. Roland’s left arm, which is leaning on the desk. Ms. Roland leans over and whispers “nice job” while rubbing Carlee’s back in a circular motion. Carlee suddenly burrows her head into the crease of Ms. Roland’s inner arm and sits up quickly. Ms. Roland says, “I know it’s hard. It’s okay.”*
- [*Peter leaves the room to go to the bathroom. Carlee stands up, pauses to touch the top of her water bottle and proceeds to slowly pace around the room with her hands folded behind her back while Beth speaks.*]
- Beth:** I thought it was really interesting how you talked about how going to class makes you feel normal. And then when Casey asked “what is normal?” you said you think of your peers. I’d love to hear more about how you

⁸⁸ Ralph was absent. Martin had become frustrated and exited the room just prior to Carlee’s comment. Ms. Grecco followed him.

think your peers are normal and what that means to you. And what kinds of things you do to try to feel normal. [*Carlee returns to her seat*] Or whatever your thoughts are about that word normal. I'm curious about that. Some people think about that as just a technical term and some people find that to be problematic. [*Spoken*]

[*Ms. Roland types to Carlee on her iPad "How are your peers normal? What is normal?" Carlee begins typing. Henry makes a loud sound that sounds like a bellowing laugh. Martin returns to the room and goes directly to his seat. Carlee re-plays her original comment again out loud to share with Martin before playing her follow up comment, which she has just completed.*]

Carlee: They are typical teens.

Beth: They are typical teens. Yeah. [*Referring to Carlee's original comment, "Thinking my showing my abilities of intelligence is important"*] I also find it really interesting how you tie your intelligence into that.

[*Martin says "Sorry Grecco" in a singsong voice*]

Henry: Being able to participate is normal [*After continuing to expand on this idea throughout the remainder of the conversation, Henry later adds to this comment and shares it with the group as:*] Really having a voice to express my thoughts has made it possible to be a part of class discussions. I enjoy being able to express my opinions. Being able to participate is normal.

[.]

Martin: My teachers view me as a dedicated and smart student. I am unsure with relationships because we need more time to talk. Right now I am just waiting for the end of summer school. Carlee, we really miss in school.

The idea of normal is so embedded in the notion of school participation that the co-inquirers had difficulty positioning around it. Disability studies in education (DSE) scholars have highlighted the unquestioned prioritization of "able" minds and bodies and the associated utilization of teaching practices, expectations, and curricula geared towards the "normal," idealized student compared to which those who differ are unequivocally less than (Ashby, 2010; Baglieri, Bejoian, et al., 2011; Brantlinger, 2004). Modes of presentation, assessment, participation in and documentation of learning, are constructed based on the supposition that the student receiving them hears, sees, walks, talks, eats, breathes, sits, etc. in "normal" ways; those who do not conform are thus positioned as a problem (Hehir, 2005). Yet, as students who move through and interact with/in the world in ways that push up against notions of normalcy, the co-inquirers breathed life into the rootedness and influence of these expectations.

In the preceding conversation, Carlee and Henry position their ability to consistently participate in class through access to communication as an avenue of seeking and achieving normalcy; Carlee even equates it with demonstrating intelligence. She locates herself outside the realm of “normal” as compared to her peers (those “typical teens” who, by way of contrast, participate in class with presumed ease), yet inside the realm of “normal” when she “show[s]...abilities of intelligence.” Henry, too, considers participation in class as a pathway to normalcy, particularly in the form of “discussion” and “express[ing]...opinions.” Both regard performative demonstrations of knowledge as vehicles to achieving (being perceived as) normal. Martin, on the other hand, does not engage with the language of normalcy, but instead responds by revealing incongruity—pointing out missing pieces—in his experience (“My teachers view me as a dedicated and smart student. I am unsure with relationships because we need more time to talk”). His perspective highlights the gap between participation in academics and relationships (with peers) a reminder that while Henry and Carlee tout communicative access in academic settings as paramount (especially to being seen as normal) barriers and gaps remain. While Carlee and Henry dominate the majority of this particular conversation, it is important to note that all of the co-inquirers brought with them to the table personal histories of not having access to communication—pasts marked by misjudgment and exclusion that cannot be separated from their conceptions of normalcy, or their identities themselves.

“Real Acceptance,” “Real Problems”: Fitting in and(/or) Finding Peace

In addition to confronting notions of normalcy, the inclination for and intricacies of seeking acceptance—a critical element of both high school and adolescence—wove and evolved through our discussions, particularly during the Spring 2015 meetings. The conversation that follows marks what I view as one of the most emotional and pivotal of our time together. To

properly call attention to the complicated tensions and nuances of it, I divide it into two shorter sections. To set the stage, as the first excerpt begins I am fulfilling Henry and Peter's mutual request that I share with the group their responses to an email in which I had sought individual feedback from each student: "We're about halfway through the semester and I want to be sure you have an opportunity to give me feedback on the way our time together is going. You've all mentioned enjoying Google Hangouts, which is great. Are there some topics you'd like to make sure we discuss as a group that we haven't already?"

- Casey (2:38 PM):** Peter wanted to talk about: "real acceptance without holding back."
- [.]
- Casey (2:38 PM):** Henry wanted to talk about: "real real problems of wanting peace and relief from autism."
[The room relatively quiet. Henry makes a few high pitched sounds. Martin rocks back and forth in his chair.]
- Ralph (2:38 PM):** I'm not sure what that means
- Peter (2:40 PM):** Holding back is not good if you want to be accepted you have to go all in. Kind of like what my [*clay H-O-P-E*] letters stand for
 We are all so smart we should show it and gain acceptance
 I want to be accepted badly in this school
- Ralph (2:40 PM):** Henry peace comes from within. You need more chanting and Rama
- Peter (2:41 PM):** Ralph you are so right my friend
[Ms. Grecco points to Ralph's iPad and says, "what do you think about this one? What do you think about 'I want to be accepted so badly in school?'" Ralph looks at the device and begins typing.]
- Casey (2:41 PM):** What makes you feel like you are holding back from being accepted Pete?
[Peter clears his throat loudly. Given that the room is so quiet, this sound seems to carry. Peter tips his head back quickly (as if involuntary) and begins to type. Martin is rocking back and forth in his chair.]
- Peter (2:41 PM):** My impulsive behaviors and anxiety
- Henry (2:42 PM):** Autism holds me back from attains true peace.
 Rama helps.
[Ms. Grecco says to Ralph, "Look at this. What do you think about those two responses?" Ralph looks at the device, turns and leans toward Ms. Grecco and makes a low groan. Henry makes a sudden high pitched noise and verbally says "Gummies." Mr. Meyer gestures toward the iPad to redirect his attention.]
- Ralph (2:42 PM):** We cannot expect acceptance without learning

- Peter** (2:42 PM): Kids find ms strange because i talk and type touch people when I shouldn't
- Casey** (2:43 PM): Ralph, what kind of learning do you mean?
- Peter** (2:43 PM): Ralph I am trying we all do learn from mistakes
I am sad can I excuse myself for a minute
- Martin** (2:43 PM): Henry to be at peace you need to believe in what you do.
- Casey** (2:44 PM): Sure Peter
[Peter leaves the room @ 2:44 PM. Ms. Kozlow follows him but does not take his iPad with her. Martin is speaking (inaudible words) in a high-pitched voice. He stands up and picks up his red stress ball just after Peter's exit. Ms. Hamden says, "You said you had to go to the bathroom?" Martin leaves the room. After the door shuts behind him, Ms. Farber cracks it open again peeks out the doorway. She immediately returns to the room, takes a handful of tissues and Peter's iPad off the table and exits the room.]
- Ralph** (2:45 PM): Every person has anxiety. We continue to try different things until we find something that helps
[The room is incredibly quiet with the exception of the occasional sound of Henry blowing air between his tongue and teeth, Ralph softly singing a few words to himself and the Google Hangouts message chime.]
- Casey** (2:46 PM): I agree. This connects to what we talked about last time too.⁸⁹ It's an ongoing learning experience and it seems to connect to all aspects of your lives. I can relate to that in many ways, and then also in some ways I can't.
- Henry** (2:46 PM): My impulses prevent me from peace and acceptance.
- Ralph** (2:49 PM): I believe some of our impulses are habits. We have learned them somewhere and only practice breaks them.
- Casey** (2:50 PM): That's really interesting. I wonder if some of those habits are leftover from your days of not having much access to communication?
- Ralph** (2:52 PM): I believe that is correct. we just need to communicate better
[Ms. Hamden exits the room. It has been 8 minutes since Martin left for the bathroom. Ms. Grecco points to the iPad and says to Ralph, "What do you think? Did you read it?" Ralph verbally responds, "yes" and sings a few (inaudible) words before beginning to type. Henry repeatedly blows air between his tongue and teeth before sneezing twice. Mr. Meyer reminds him to "try that elbow sneeze that we worked on." Henry continues typing.]

While Henry and Peter's proposed topics initially run parallel, they intersect and merge into one another as the conversation progresses. Right from the start, Peter calls forth varied notions of acceptance in complex and conflicting ways. Whether he intended to reference acceptance of self or acceptance by others (and if others, which others?), the dichotomy he

⁸⁹ See Sequence 2. The conversation, "Stress is a real problem" preceded this one by 14 days.

proceeds to construct as “holding back” versus “going all in” suggests an experiential understanding of acceptance as both contingent and self-directed. He also positions demonstrations of smartness as vehicles of acceptance, evoking the aforementioned conversation about participation for [as] normalcy, yet it remains uncertain how “show[ing] it [smartness]” connects to “going all in” for him. In his extended response to Ralph’s bid for clarification (“I’m not sure what that means”), Peter vacillates between describing “acceptance without holding back” as an individual and shared experience—swinging across past, present, future, and hypothetical in just five typed lines. He first counsels an ambiguous “you,” then an isolated “we” (the group?), while weaving himself into the picture through reference to his artwork (H-O-P-E sculpture) and his personal aspirations for acceptance. Peter had previously shared with the group that his HOPE sculpture was representative of pride, awareness, and limitless possibilities (see Sequence 4). By alluding to his sculpture in this dialogic context, he implicitly draws connections to acceptance as *what we make of it* while at the same time acknowledging the power of others to *determine it*.

While Peter’s narrative of “holding back” versus “going all in” suggests the necessity of self-acceptance (possibly intersecting with what Henry seems to reference when he discusses “peace”), his ensuing comments are increasingly focused on the ways that he feels that he (and perhaps his autism and/or communicative realities?) gets in his own way. As Peter explains to the group, he attributes his “impulsive behaviors and anxiety,” two experiences intimately tied to his autism (Donnellan, Leary & Robledo, 2006; Groden, Baron, Groden & Lipsitt, 2006; Hallett et al., 2013), as holding him back from being accepted. Henry later echoes this connection. Peter’s follow up, “Kids find ms [me] strange because i talk and type touch people when I shouldn't”, appears to bear the weight of lived experience. So then, is “going all in” code for

changing—removing—these elements of his interactive reality? Or is “going all in” a metaphor for accepting him/oneself and creating a new narrative by rejecting expectations that it is “strange” to “talk and type [and] and touch people when [he/one] shouldn’t?” Perhaps it is (is it?) somewhere in between.

Evident in my request for clarification, I was unsure of how Ralph intended his response, “we can’t expect acceptance without learning,” to be interpreted. Tying back into the topical thread of advocacy (Sequence 1), “learning” here could be a further illustration of the sense of responsibility these students feel to “teach” others what it means to be, and be with, them. If so, Ralph could be suggesting that to be accepted others need to understand his/their experiences—impulsivity, anxiety, typing, talking, touching and all—as individuals with autism who communicate in diverse ways. Yet it seems that Peter interprets Ralph’s comment as placing the onus on him, an implication that *he* is the one who needs to “learn” from perceived “mistakes” (i.e. “touching people when [he] shouldn’t”) and change his behavior accordingly. In Peter’s interpretation, one could imagine an implicit second half of Ralph’s comment to be ... “one can’t expect acceptance without learning [*to be less autistic*].” This potential miscommunication/misinterpretation is complicated by the fact that Peter leaves the room (in tears) and Ralph does not directly answer my question, “what kind of learning do you mean?”

Returning again to the beginning of the discussion, Henry’s original proposed topic (“real real problems of wanting peace and relief from autism”) and Ralph’s initial response (“Henry peace comes from within. You need more chanting and Rama”⁹⁰) uncover the unique connection that Henry and Ralph (as well as Peter) share related to their cultural/spiritual⁹¹ backgrounds and

⁹⁰ A Hindu deity; the seventh incarnation of Lord Vishnu and hero of the Sanskrit epic, *Ramayana*. Lord Rama (Ram) is thought to represent the “Ideal Man.”

⁹¹ Ralph was born in India, while Henry and Peter were born in the US. Both sets of parents immigrated to the US from India.

experiences.⁹² This portion of the conversation captures the ways that Ralph and Henry position the role of Vedantic⁹³ practices (chanting) and associations (Rama) with their cultural/spiritual beliefs as vehicles of negotiating the physical and emotional aspects of autism as a lived reality. Regardless of whether they approach “chanting” as a spiritual exercise or routine element of constructing/living life, Henry and Ralph’s exchange disrupts the body/mind/spirit dichotomy, instead placing disability as the axis around which faith and lived experience revolve, not vice versa (Minz, 2006). Ralph clearly positions “peace” as a form of self-acceptance, with chanting and Rama as means to looking inward. Henry’s response, “Autism holds me back from attains true peace. Rama helps,” evidences that looking to his faith as an avenue of support already plays a role in his life; Ralph’s is not a novel suggestion for him. However, it is not clear *how* Henry perceives autism to be holding him back, or what “true peace” would look/feel/sound/be like for him. While Martin’s addition to the conversation does not provide a clear picture of “peace” either, it does serve to reposition it as paradoxically methodical—under Henry’s control (“you need to...”)—and rooted in a form of faith (“...believe in what you do”).

Later, when he ties into Peter’s conversational thread about impulsivity and behavior with his comment, “my impulses prevent me from peace and acceptance,” Henry connects peace with acceptance (by self or others?) and, by extension, implies that impulses are a characteristic

⁹² I intentionally keep the lines blurred here between these practices as cultural, spiritual, philosophical and/or religious in nature to reflect and the varied ways that these three students represented their own experiences at different times. None of them used the terms “spiritual/ity” though Henry had previously used “faith” to characterize time spent reading from the *Bhagavad Gita* (a Hindu scripture) with his family. This is also consistent with the divergences in the ways that Hindu practices and beliefs are sometimes represented as spiritual and/or religious commitments and others, a way of life.

⁹³ Vedanta (representative of “knowledge” derived from the Vedas, ancient Hindu Texts) is “an orthodox system of Hindu philosophy developing especially in a qualified monism the speculations of the Upanishads on ultimate reality and the liberation of the soul” (Merriam-Webster, 2015). In Sanskrit, the term references in the “conclusion” (anta) of the Vedas, the earliest sacred literature of India” (Encyclopedia-Britannica, 2015). Broadening my use of language here to Vedanta/Vedantic allows for these diverse approaches (and uncertainties) to remain. In so doing, I move away from labeling these as “religious” practices, acknowledging the colonizing implications of doing so.

of his autism that he sees as a barrier to acceptance. Conversely, Ralph's suggestion that "... some of our impulses are habits. We have learned them somewhere and only practice breaks them" repositions the notion of "impulse" from being an autism-related phenomenon to a learned routine. In so doing, Ralph opposes conceptual notions of autism as a barrier and situates it within the realm of action(s): learning, practicing, and breaking. His concurrence with my inquiry ("...some of those habits are leftover from your days of not having much access to communication?") regarding the evolution of those "habits" is one of the few times that the past is explicitly evoked in our group conversations. It is also indicative of the intimate connection between communication, action (here, perceived as a mode of "breaking" impulsive "habits") and agency. And as the students' narrate and inquire into their own experiences of/with autism, acceptance, anxiety, behavior, communication, culture, and faith, I see them breathing life into the process of moving "inward and outward, backward and forward and situated within space" that Clandinin and Connelly (2000, p. 49) use to describe narrative inquiring as a whole.

[The evocation of cultural/spiritual identities in this conversation was not surprising to me, despite my inability to connect with it on the same level that Henry and Ralph (along with Peter) clearly could. Since Henry and Peter entered the school, I have seen glimpses of the significance that their faith and practice of it plays in their lives and identities. Each of their desks bears an image of a Hindu deity and both previously referenced how much they cherish time spent reading the Gita with their family. I often noticed that when Peter took a break from work during free periods, he would choose to lay on a pile of mats while watching and listening to YouTube videos of chanting. This was the first time, however, that I noticed Ralph invoking his cultural/spiritual identity, especially in connection with others. I later learned (upon inquiring) that Ralph's interest in actively exploring chanting was sparked by Henry and Peter's frequent allusions to their own experiences. With his mom, he began visiting the same temple that Henry and Peter attended (he had previously not done so) and listening to/participating in chanting as a means to calming his body and mind. When I later asked him to clarify how he intended his advice to Henry to be taken, he explained that, "big things in life come from developing a more calm mind which is great thing for folks like us. So we have to find many ways to do that. Chanting of mantras is one of them. The mantras are in Sanskrit and very powerful. Chanting the name of Lord Rama is also elevating."

While the connections across the three co-inquirers are rooted in their shared cultural roots, it is also clear from the conversation and Ralph's follow up that they are

in some ways drawing upon these practices as resources to navigate and honor the physical and emotional experiences associated with autism. In so doing, Henry and Ralph counter the pervasive notion that efforts to navigate disability experiences necessarily be mediated in and guided by therapeutic, clinical, or special settings. Instead, they (re)place such endeavors within relevant cultural/spiritual—individualized—realms.]

Building on his previous statement that “my impulses prevent me from peace and acceptance”—turning the lens from inward to outward—Henry continues the conversation by drawing a comparison between himself and his peers:

Henry (2:53 PM): What is easy for my peers is painfully hard for me. Not many understand especially my peers.
Yes

[Henry and Ralph both hum quietly and rhythmically. As Ralph types his response, Henry suddenly says, “Gummies” to which Mr. Meyer responds, “It’s 2:53. At about 3:10 we can wrap it up. But you’re on track you’re doing great.” I add, “It’s exciting to have you here the whole time, Henry.” He looks at me, smiles, begins laughing loudly, and starts typing. He responds to me later in the Hangout but as an aside from the conversation, with “I enjoy ot but I enjoy this Time too.” I reply (also via typing) “I’m glad you get to do both Henry.”]

Ralph (2:56 PM): Well remember they so nervous too. The more time you spend with them they get to understand your noises and things. I learned from [Ms.] Hamden to stay in class. my peers are so much better with me.

[Martin re-enters the room and he returns to his seat. Ms. Hamden follows a few feet behind him. Before Ms. Hamden reaches her seat, I quietly ask if everything is okay with Peter in the hallway. She says, “yeah they are just out there talking” before taking her seat to Martin’s right and scrolling through the conversation to catch him up.]

[.]
Casey (2:57 PM): Very true Ralph. That’s a great point... Being and staying together benefits everyone.

Peter (2:58 PM): I am sorry guys I don't want you to see me cry this is a hard topic and really want to talk about it and it will get easier I just can't anymore today have a good day everyone [*from the hallway*]

[Ms. Kozlow enters the room to retrieve a handful of tissues. When she passes me to exit again, I follow her. Outside in the hallway just outside the door, Peter sits on the floor against the lockers. Ms. Kozlow sits down to his left, hands him the tissues and resumes alternating between having a typed conversation in SpeakIt and following along with the Google Hangouts conversation. I squat down next to them and ask

Peter if I can type something. He responds affirmatively and Ms. Kozlow hands me Peter's iPad. In this private conversation, I provide Peter with encouraging words indicating that feeling insecure is okay, but reminding him of the important friendships he has in the other students that can sustain him in tough times. I also suggest to him that he draft an email to Carlee to initiate the conversation with her, as I believe she could be a great source of support due to her similar feelings and experiences. He agrees to do so.⁹⁴]

[..]

Martin (2:58 PM): the peers some times should not count, these are our behaviors.

Ralph (3:00 PM): Peter we are great friends. It will get easier I promise. I used my communication I am finished talking.

[Ms. Farber enters the room. Ms. Grecco says, to Ralph, "I get it. I get what you are saying." She adds to Ms. Farber, "we're talking about communication and he's been typing, 'I'm done. I'm done.' Ms. Farber replies, "yeah Peter has had enough too, so... But I'm impressed with maturity in here though." Ms. Hamden adds, "you're very focused."]

Henry (3:00 PM): Yes.

Yea.

I have been working to change my behaviors.

[Henry stretches back over his chair with his arms raised. Mr. Meyer says, "you've been chugging right along, here." Henry begins laughing and sits up straight. Ms. Farber exclaims, "I'd love to tape that laugh, Henry" Ms. Grecco adds, "That is the best laugh."]

I reenter the room at 3:04 and shift the conversation to the technology presentation.]

[.....] *[6 minutes later, after talking about the technology presentation, during which Peter agrees to contribute his ideas but does so from the hallway.]*

Peter (3:08 PM): Sorry I cried

Casey (3:08 PM): No apologies necessary. You are among friends.

Peter (3:08 PM): Awesome sauce lol

[Martin rocks back and forth and makes a loud sound]

Martin (3:09 PM): you never have to apologize for crying

Peter (3:09 PM): Henry lets go

Thanks Martin

Henry (3:10 PM): Yes.

Ralph (3:10 PM): We all have been in your position

Peter (3:10 PM): Thanks Ralph

In this, the second half of the conversation, the co-inquirers again turn the lens on perceptions of others, highlighting their varied interpretations of how their peers (read: classmates without disabilities) view them and their "behaviors." In a comparative statement,

⁹⁴ At Peter's discretion, the text of this hallway conversation was removed from his device so verbatim transcription is not available.

Henry postulates, “What is easy for my peers is painfully hard for me. Not many understand especially my peers,” suggesting that he considers that the gap between his experiences and those of others are in some ways rooted in the effort necessary to move through the world. Ralph reminds him that (mis)perceptions can go both ways and that separation from (by) difference is not a solution—“Well remember they [are] so nervous too”—an empathic statement that, also, ironically and starkly contrasts the often assumed notion that people with autism lack Theory of Mind, or the ability to extrapolate from their own experiences and perspectives to others’ (Baron-Cohen, 1996; Baron-Cohen, Leslie & Frith, 1985; Frith, Happe, & Siddons, 1994). He adds to this, “The more time you spend with them they get to understand your noises and things.” It is important to note that in the context of a conversation that has evolved into one about behavior, acceptance, and autism, Ralph does not imply a recommendation to abandon his (their) “noises and things.” In fact, as he describes them here, they are an unquestioned presence to be better understood and accepted. This could also be an ancillary clarification of the meaning of “learning” in his aforementioned comment (“we cannot expect acceptance without learning”). His reference to his TA (Ms. Hamden) as integral to him learning to “stay” in class again references the importance, for him, of coexistence not as a means to erasing, but to honoring and better understanding difference. I consider(ed) Ralph’s final comment, “my peers are so much better with me,” to have a double meaning, reflected in my response, “Being and staying together benefits everyone.” While he appears to be connecting his peers being “better” to his ability to stay in the classroom and therefore their “understand[ing of his] noises and things,” his comment could also be read as a reflection of the benefits of his presence in the classroom, i.e. “my peers are so much better [*off*] with me.” Either way, Ralph’s message is cogent, made arguably more so by Martin’s follow-up comment “our peers sometimes shouldn’t count. These are our

behaviors.” Clearly resisting the weight given in this conversation to seeking “understanding” of others, here Martin also counters the normative behavioral expectations that make “[their] behaviors,” in Peter’s words, “strange” (Brantlinger, 2004; Garland Thomson-1997). The tensions between *acceptance as we are* and *acceptance as we should be* is palpable throughout the whole discussion, punctuated by Henry’s final, contrasting comment, “I have been working to change my behaviors.”

[I know we're at an intersection. I know I can and should outline how complex and nuanced and indescribable but important these ideas—these overlapping experiences—are. I know I could hide behind academic jargon, couched by parenthetical citations, to make explicit (as if I could do, say, better than the students did) the complexities of how autism, identity, behavior[al expectations], culture, spirituality, communication, adolescence, emotions, relationships and time intersect in significant ways. I also know that I cannot truly do this messy experience justice. Maybe some distance from this conversation will yield clarity; ease the sting that lingers from passing through—being at—this interchange. But for now it feels more like (I'm watching... causing... in the midst of) a collision.]

Finally, from his seat in the hallway (where he retreated upon being overwhelmed by emotion), Peter apologizes for crying. The responses he receives from the rest of the group—both in words and in actions—epitomizes (I think) the kind of acceptance around which this whole conversation centered. To his first apology, Ralph reminds Peter, in solidarity and from a place of shared experience, “Peter we are great friends. It will get easier I promise,” underlined by his reply to Peter’s second apology, “We all have been in your position.” Martin, too, infers a promise—projecting out into (inevitable) future experiences, “you never have to apologize for crying.” To Peter’s request “let's go,” Henry replies with an affirmative response, as well as his physical presence as he exits the room by his brother’s side a few minutes later. Evidenced by Peter’s expressed gratitude and lighthearted reply (“awesome sauce lol”) the reminder of friendship and the assurance of (current and future) shared understanding is impactful and gratifying—the kind of support grounded in true belonging.

[This conversation weighed heavy on my heart. I hurt because the co-inquirers talk about the acceptance of “peers” without including one another in that group. I cringe because they are probably not wrong in their assessments of how others look at their “strange” behaviors. They are spot-on that “understanding” is necessary but hard to come by. It is a large gap to bridge between being (comfortable and) seen as one who “talks and types and touches others when [they] shouldn’t” and as someone who brings assets to the spaces they enter. I ache, impatient, because (I know) “disability as diversity” does not just happen, it is (re)made, and some(ones) need to do the hard labor. I wince because I cannot relate in the same way that they can to each other, but also because I don’t see them counting these relationships in their assessments of “acceptance.” I hurt because I hate that they do, even in spaces—with people—intending for them not to. I squirm because this is hard and I hate that “inclusion” can be painful. I regret that this conversation is happening in a room full of students with autism, only, but I understand that for them, in this moment, in this space, it absolutely has to.

But even as it hurts, I see their deep, open, honest, and supportive—even if conflicting—dialogue as restorative. It reminds me that these students have a unique bond; relationships I both can and cannot understand. I’ve thought a lot and often about my position here. In this context I am witness, I am participant, I am something un/re/defined, to and for each and all of them, careful not to overstep my bounds but very much wanting them to push theirs. Yet this is one of the first times I’ve started to see what they are to each other. And for...because of...that I am hopeful.

Though it (still) stings, it is not my heart that matters.]

Acceptance Letter(s)

While the previous conversation confronted (sometimes conflicting) meanings of and avenues toward an abstract notion of “acceptance,” the following conversation was prompted by a more literal and contextual manifestation of acceptance: to college. To set the scene, as Ralph references, the students were all observed in their classes throughout the course of the day and had a group conversation with administrators from Cedarbridge Community College (CCC), the local community college in which both Ralph and Martin were intending to enroll. Since the college did not have previous experience with students with autism who type to communicate, the Cedarbridge High School administration set up this observation opportunity to familiarize the college staff with the support necessary for such students to participate in school. This is an example of the ways that the school personnel reconstructed their roles in the students’ lives and

in this community. That the CCC visitors also observed Peter and Henry (who are two years from graduating) suggests that this observation was about more than Martin and Ralph's impending enrollment. Perhaps, the Cedarbridge administration intended to shift attitudes, more broadly, about students with autism who type to communicate.

Once again, the discussion began as a "report" to Carlee in Georgia:

Ralph (2:12 PM): im going to c c c for college Carlee i got my letter

[.]

[Martin is standing when this conversation begins. Ms. Hamden asks him to sit down and he does, after pausing first behind at his chair. Henry is humming rhythmically and verbally asks to go to the bathroom twice, but Mr. Meyer encourages him to stay and participate, which he does.]

Henry (2:13 PM): Yes, we had visitors from ccc.

Peter (2:13 PM): Ralph you will rock C C C

Ralph (2:13 PM): today the administration from c c c came to observe us in class.

Carlee (2:13 PM): thats awesome.

Ralph (2:14 PM): i hope they will give us a shot

[Henry laughs loudly. Ralph makes a repetitive, staccato sound. Peter brings his extended arms together in front of him with his hands between his knees, hunches his shoulders, and makes a drawn out, high pitched squeal. Martin is rocking back and forth in his chair.]

[.....]

Henry (2:16 PM): Yes.

They have philosophy. I am excited.

[.....]

Ralph (2:18 PM): Henry how did it go for you today

[.....]

Henry (2:20 PM): Yes.

Yes

Great Ralph.

[Henry leaves the room. Ralph leans over towards Ms. Grecco and brings his face close to hers. She reminds him of her "personal space." Martin is speaking (inaudible words) in a high-pitched voice while typing.]

Ralph (2:20 PM): Martin how was your observation

[....]

Martin (2:21 PM): it was good Ralph how was yours?

Casey (2:22 PM): So Ralph what made you nervous about today? [.]

[Martin rocks back and forth in his chair and loudly repeats, "So...So...So...."]

Ralph (2:22 PM): i felt like i needed to be perfect

Peter (2:24 PM): Ralph you are perfect to us friend

[.]

- [*Ralph makes a pronounced groan. Martin speaks (inaudible words) in a high pitched voice.*]
- Ralph** (2:24 PM): well because i so want to go to c c c
- Peter** (2:24 PM): They are lucky to have you
- Carlee** (2:24 PM): imperfect and enough.
- Martin** (2:24 PM): i thought that it was nice not everyone gets a visit were the school comes to us.
- Ralph** (2:25 PM): thanks Peter
thats right Carlee
- Casey** (2:26 PM): That's true Martin. And Carlee. Perfect doesn't exist... It's time we all figure that out. But I do understand the fear when it feels like something is at stake that you really care about
- Carlee** (2:26 PM): ccc will lucky to have you.
- Ralph** (2:27 PM): i have my acceptance letter. [.]
- [*Henry returns to the room and sits down, singing rhythmically to himself. He makes a few loud sounds as Mr. Meyer scrolls through the conversation to catch him up. Martin is repeating (inaudible) phrases and rocking back and forth in his chair.*]
- Martin** (2:27 PM): ya but we try
- Peter** (2:28 PM): A (awesome) U (unique) T (tremendous) I (intelligent) S (super) M (magnificent) this is why we are perfect to each other
- [*After sending his comment, Peter brings his hands to his face and tenses his body for a brief moment. At the same time, Henry yells abruptly into his cupped hands.*]
- Casey** (2:28 PM): I'm guilty of the same thing, Martin.
Love that Peter. You're a poet.
- [.]
- Peter** (2:29 PM): I am deep my heart talks instead of my mind sometimes
- Carlee** (2:29 PM): you so are.

Ralph begins the conversation by declaring (to Carlee) that he has been officially accepted to CCC: “I got my letter.” Henry and Ralph’s comments serve to catch Carlee up on the day’s preceding events, just prior to checking in with one another about them for the first time. Ralph’s follow up, “I hope they will give us a shot” muddies the waters of his excitement over being accepted on paper. That there is uncertainty in his comment suggests that he knows his participation at the college is contingent on the administration being willing to provide, or allow him to access, support for his communication. It is also clear from Ralph’s use of “us” here to Henry’s proclaimed enthusiasm about the possibility of taking college level “philosophy” classes

(despite being two years away from graduating) that the attributed significance to these observations extends beyond the two current seniors. When I ask Ralph to describe “what made [him] nervous” about the observation, his response, too, reveals the pressure he feels to perform: “I felt like I needed to be perfect [...] because I so want to go to ccc.” Though not referenced in words, the past looms large here in this discussion of the future.

The rest of the group rallies around Ralph’s expressed feelings of insecurity. Peter reminds him, “you are perfect to us friend,” adding “they are lucky to have you,” again demonstrating the kind of unconditional acceptance and friendship for which all of these students, at different times, conveyed yearning (ironically from other, external sources). Yet Carlee challenges Ralph’s association of perfection with (literal and figurative) acceptance when she reminds him that he is “imperfect and enough,” resisting his implication that (any form of?) acceptance requires alteration. Echoing Peter, she later adds that “ccc will [be] lucky to have you;” reassurance with which, based on her previous comment, she implies the college will be lucky to have him *just as he is*. Martin puts a positive spin on the event, broadening the conversation by positioning the whole group as privileged and the observations as an instance of empowerment rather than (potential) consequence: “i thought that it was nice not everyone gets a visit were the school comes to us.” In an attempt to honor Ralph’s feelings, but reinforce the others’ supportive messages, I add, “Perfect doesn't exist...It's time we all figure that out. But I do understand the fear when it feels like something is at stake that you really care about.” Martin is the only one who responds, acknowledging (presumably the first part of) my comment with “ya” but countering it with “but we try.” I later confess to being “guilty of the same thing.”

At the same time that others (myself included) try to talk him out of seeking “perfection,” Ralph re(types)peats—as if to remind himself, all of us, and the universe—“I have

my acceptance letter” defying his previous insinuation of its uncertain weight. As Ralph places his confidence—and future—in the acceptance (letter) of others, Peter contrasts him with an acrostic poem: “A(awesome) U(unique) T(tremendous) I(intelligent) S(super) M(magnificent) this is why we are perfect to each other.” Here, not only does Peter call upon and re-present “autism” as a fulcrum of shared experience and a source of community, he adjectivally positions it as an asset, a source of pride. This diverges from the aforementioned conversation about “acceptance” (which occurred just ten days prior) where autism was portrayed (primarily by Henry) as a barrier. In his emblematic pep-talk, Peter reconstructs autism as a (series of) strength(s), reflecting an acceptance and esteem that veers toward ownership of autism as a form of neurological diversity and/or cultural identity (Grace, 2012; Silberman, 2015; Sinclair, 2010).

[What would the world be if we all let our, “hearts tal[k] instead of [our] mind[s] sometimes?”]

Inclusion of the Brain vs. Inclusion of the heart: A Storied Dialogue

Just as the question posed above grows out of the Peter’s response to me calling him a “poet” and the dialogue that preceded it, the best kind of questions are the ones that start with a story:

The call timer displayed on my phone screen tells me it has been almost an hour. My head hurts from nearly 60 minutes of tele-brainstorming with Ms. Sanders about ways to support Carlee’s school experience given her current circumstances. My heart hurts from having to do so. I cannot imagine how Ms. Sanders is feeling, as her mother. Or Carlee. Or the school staff.

My orange post-its are filling up with questions, to-dos, ideas, and doodles. Summer school? Inquiry Group? ((geometric triangle design)) One hour @ a time. How many credits 2 graduate? Keep Cosmetology!!! ((sunflower)) Half day? Georgia in December? ((squiggly arrows)) Internship? What about friends? ((broken heart)) Ask Carlee is scribbled at the bottom of the note, though it’s unclear whether this is a reminder to myself or the advice I really want to be giving.

We circle back to the beginning of the conversation as Ms. Sanders starts re-narrating Carlee’s current struggle with anxiety and behavior as if, this time, something will become clearer. Maybe she’s right? I listen and pace and focus on reminding her—and me—that Carlee can get

through this. We all can. It's a bump in the road. It's going to be okay. This is not over. This is not the end.

But this time there are more questions, a list of them. What if this isn't just about Carlee? What if it is something bigger? What if she is telling us all something about her experiences that could have implications for others?

Ms. Sanders slows down, as if processing her own thoughts for the first time: "Carlee's included in school, for sure. I am not arguing that. She participates academically. Her teachers respect her and no one doubts that she is smart. No one. It's wonderful. But what if something's missing? Her ideas, her work, her participation—her brain—are valued, but is she? Is she part of a community? Does she feel like she truly belongs? Is she free to be—figure out—who she is? Is inclusion of her brain the same as inclusion of her heart? I don't know. I don't know".

I mumble some answer about not knowing either and frantically jot down on the top of my already filled-up post it note: Inclusion of the brain vs. inclusion of the heart, punctuated with row of scribbled question marks increasing in size (????)

Good question. Ask Carlee.

*

Nine months later, I found myself doing just that. The dialogue that follows is a (re)presentation of interactions in which Carlee and I engaged across space and time while she was in Georgia for the Spring 2015 semester. We later collaboratively developed these exchanges into a conference presentation that we gave together in April 2015 at a national education conference. This side conversation/project was initially aimed at bringing Carlee more into the loop and feeling more connected with her (and, I hoped, her with me) in spite of her physical absence from the school building and inconsistent participation during our group meetings. However, the dialogue evolved into a way for both of us to learn about and expand on topics addressed by the other co-inquirers in ways that Carlee did not, or could not, make clear during the weekly Google Hangouts. Thus her words, my questions, our interactions cannot be separated from the space and experiences that initiated the original question in the first place. Ultimately, what began as an attempt to center Carlee's perspective and include her in a different

but equally meaningful way turned into a journey that allowed both of us to tacitly explore some of the underlying issues and tensions at the heart (and brain?) of her complicated relationship with school.

Casey: *A smart woman I know (your mom!) asked whether "inclusion of the brain is the same thing as inclusion of the heart"? What is your interpretation of that?*

Carlee: Inclusion of the brain for me is people being aware of my intelligence. It's not the same as inclusion of the heart. That is even more rare. Inclusion of the heart is accepting that I'm autistic. That I'm just as smart as you and still different.

Casey: *Why, in your opinion, is inclusion of the heart so rare?*

Carlee: it's rare because inclusion often means being expected to act as if I don't have autism.

Casey: *Do you think you need inclusion of the brain to have inclusion of the heart? Vice versa?*

Carlee: you need inclusion of the heart to have inclusion of the brain. if you accept my differences then you can accept my intelligence.

Casey: *So clearly there is work to do. I understand that. I'm wondering where to start...*

Carlee: I think presumption of competence⁹⁵ is the most important aspect of inclusion. both brain and heart. schools need teachers who can see past physical disabilities and presume competence. that leads to self confidence in the student.

⁹⁵ The use of the phrase "presuming competence" is rooted in a shared (geographic and conceptual) "local understanding" (Kliewer, 2007). The use of it in our conversation suggests how our geographic location(s), access to training resources, and involvement in a tightly knit community of individuals who type to communicate (and their allies) intersect. While this phrase is widely used in research and practice of disability studies and inclusive education it is most often associated with the work of Douglas Biklen (i.e. Biklen 2005; Biklen and Burke, 2006) related to individuals, like Carlee and the other co-inquirers, with autism who do not speak. The importance of presuming competence is emphasized in the field broadly, but specifically in all materials, trainings, supports, and literature on the facilitated communication training process. Carlee's (and others') exposure to, training by and continued support from those affiliated with the primary training Institute of FC in the U.S. contributes to her/our use of the phrase in conversation and presentations. Further, the TAs, administrators and teachers from Cedarbridge received training in similar ways and spaces, as they sought to better understand and support these five students in school. My place as a Research Assistant at the Institute and doctoral student who has worked closely with those who share this viewpoint, combined with nearly life-long friendship with Anne, also adds to layers of shared understanding that we bring to "presuming competence" in this context.

- Casey:** *Where does friendship fall in all of this? I'm noticing you and the other students often addressing difficulties of making friends. Can you expand on how your experience in school with your peers connects to your interpretation of competence?*
- Carlee:** I think making friends has little to do with my competence. Is hard being included and not being really. I have few but real friends. High school would be easier with friends. I feel competent with or without friends, it's easier to have them tho.
- Casey** *You say that making friends has “little do you with [your] competence,” which I’m reading as your “intelligence” in this context. Do you think there are other types of competencies, though, involved with making friends?*
- Carlee:** being autistic means I will not behave as society expects me to. it's a competence I don't have. but has nothing to do with my learning abilities.
- Casey:** *So what are some qualities that those friends you have possess?*
- Carlee:** they presume my competence. they accept me for who I'm. others stare at me when I don't act normal.
- Casey:** *That seems to relate to “being included but not...” I think I get what you are saying but could you expand on what that looks and feels like?*
- Carlee:** feels like to be included I have to act as if I'm not autistic. real inclusion is accepting my special needs while presuming my competence.
- Casey:** *I'd love for you to describe what you think inclusion **should** look like, in your opinion, taking into account all of the things we've discussed.*
- Carlee:** it's hard even for me to tell you how inclusion should look like. we can start presuming competence. you need to truly do that before real inclusion can happen. together with a balanced schedule is a good place to start.
- the problem with inclusion in schools in my experience is that everyone is judged in the same way.
- Casey:** *Tests are often a way that students get “judged” and I’ve noticed you and the others reference them often. Can you comment on how testing plays a role in constructing expectations about what competence and inclusion means?*
- Carlee:** to evaluate ones competence the same way for everybody is something I don't understand. anxiety isn't exclusive for special needs. I think testing need to be redefined. we are all competent and that comes out in different ways. I think sensory breaks at exams is a must. not enough but it's a start.

my ability to learn is the same as yours but my body needs more time to react. in real life that means more time at exams. now real inclusion for me isn't about being in the same room with non autistic kids all the time but being given the same opportunities and enough time to react.

Casey: *I've noticed **time** to be a constant topic and that sometimes it's been tough to carve out enough time for everything between academic schedules, meeting sensory or other needs, and social opportunities in school. What are your thoughts on that?*

Carlee: students with special needs need to have the chance to socialize at the same time they need time away from all the crowd, I think a balanced schedule is the key. to me that would be something like breaks between classes to sensor my body back. walks for example. balance between my brain and body. I have a great team sorting that out and helps a lot.

Casey: *Final words?*

Carlee: It's hard to draw a line between inclusion of brain and heart, because real inclusion is both. **You want to include my brain you have to include me whole.**

Throughout this dialogue, Carlee touches on many of the topical threads that wove through our group conversations and are addressed throughout this Act: academic participation, peer relationships, autistic identity/identities, and conflicting notions of acceptance (of self and by others). Further, that she chose to share these perspectives as part of a public presentation aligns with her expressed commitment to using her experiences to “teach” others, connecting back to the earlier conversations on advocacy. I see disability studies coming alive in Carlee’s commentary; I hope her perspectives breathe life into disability studies. “[B]eing autistic means **I will not behave as society expects me to.**” Underlying her responses to and about normalcy, I see an awareness of and narrative around her lived experiences with “ableism” (Bogdan & Biklen, 1977; Hehir, 2002; 2005; Rauscher & McClintock, 1997). “**The problem with inclusion in schools in my experience is that everyone is judged in the same way.**” I see her exposing the “myth of the normal child” in all its dangerous fallacy (Baglieri, Bejoian, et al., 2011), and

embracing a “**real life**” without it. “[**B**]alance between my brain and body”. Above all, I see Carlee calling for a holistic approach to inclusion—from the nitty-gritty to the philosophical underpinnings and beyond. “**You want to include my brain you have to include me whole.**”

In particular, Carlee’s described experiences with/of inclusion and implications for its further evolution also reveal the process of making sense of her own identity as a person with autism and questioning, resisting, and teasing out her educational past, present, and future. Not only does she demonstrate a perceptible shift in priorities from her comments of one year prior (i.e. “Going to class makes me feel normal”) but it is also evident that she now feels comfortable openly challenging the expectations that “going to class” *should* “make [her] feel normal.” Her remarks are less about yearning for said normalcy, but opposing those underlying messages, or systems, that position that as a worthwhile goal in the first place (Ashby, 2010; Gallagher, 2010). Instead, Carlee exposes and problematizes expectations of what Davis (1995) termed “enforced normalcy” (“being autistic means I will not behave as society expects me to;” feels like to be included I have to act as if I’m not autistic”) while also carving out a valued/valuable space for her differences in, as part of, school (“Inclusion of the heart is accepting that I’m autistic. That I’m just as smart as you and still different;” “if you accept my differences then you can accept my intelligence”). Just as in Peter’s acrostic poem, Carlee presents autism—and the lived experiences intimately tied to it—as a critical part of her identity as a student, and as a person (Brown, 2011; Sequenzia, 2013; Silberman, 2015). A counter-narrative at (brain and) heart, our side conversation calls forth the gaps and tensions inherent in even the most progressive inclusive educational spaces.

[I cannot help but not(ic)e though, that, just as her mother’s original line of questioning did, Carlee starts from a point of inclusion; she does not question, nor infer discontent with, her place in school (despite, ironically, not occupying it physically at the time). Her interpretation of what is missing from inclusive

spaces comes from an experience of being in them. Her distinction between “inclusion of the brain and inclusion of the heart” lies in a yearning for more instead of something, not something instead of nothing, though I know she has experienced both.

In this way, her reflections bring to light the reality that, even in a school committed to supporting students with a wide range of abilities, there is little precedent for inclusion of the brain, not to mention inclusion of the heart; that path has not yet been traversed thoroughly or often enough for it to be well trodden. In her message and from my time with her, I see the fact that Carlee (and others) may not currently or consistently experience “inclusion of the heart” not as evidence of the futility of the efforts made by Cedarbridge staff, families, and students, but an entreaty for them to keep moving; a caution against complacency; a call for continued exploration.]

In an attempt to bring the other co-inquirers into our conversational thread (since they so often pulled Carlee into theirs), I inquired the following via email during their Spring Break from school. Three of the four students chose to respond.

- Casey:** Carlee and I have been having a side conversation⁹⁶ about different ideas about inclusion and competence, and I’d love to bring the rest of you into it. Think about the following, “inclusion of the brain is not the same as inclusion of the heart.” **What does this mean to you? What are examples of this? Do you see this relating to presuming competence?**
- Peter:** Really true. I feel that I am not accepted as much as my brother is in my academics. I also feel that I’m not as good as him. Inclusion of the heart is needed for me to thrive. Really I would love to be accepted as Henry is wholeheartedly.
- Henry:** Inclusion of the heart is not the same as the Brain. I feel really accepted both ways in school and community. [I] want my brother to be accepted too.
- Ralph:** Yes that is the way it alters the commentary as the inclusion of heart assumes a different plane in the domain of inclusion. It is full inclusion.

Like Carlee, Peter and Henry both explicitly tie this topical thread into notions of acceptance, specifically the ways that they already do, and/or long to, feel accepted in school. Peter’s response, “I feel that I am not accepted as much as my brother is in my academics” reveals his connection between “inclusion of the brain” and academic participation—a link that

⁹⁶ I did not share each individual student’s (including Carlee’s) responses with the others, though doing so and engaging in conversations around their comments is something I am considering (if they are willing) for a follow up project.

echoes Carlee's commentary. His follow up, "I also feel that I'm not as good as him [Henry]," again illustrates the ways that Peter wavers between—gets wound up in the complexities of—acceptance of self and acceptance of others. This link carries through in Henry's description of feeling "really accepted both ways in school and community," further accentuating that he, too, connects his experiences of "inclusion" with feelings of "acceptance." Yet Henry concludes with his desire for his "...brother to be accepted too" suggesting that knowing Peter does not share in his feelings of acceptance, and is still seeking "inclusion of the heart," casts a shadow over his own experiences. For him, it seems, inclusion is not complete if it is not inclusion for all.

Ralph's response did, and remains an apt way to, punctuate this extended, multi-site exchange. His explanation that, "that is the way it alters the commentary" constructs inclusion as a dynamic, moving force. In fact, unlike Carlee's emphasis on "... real inclusion [as] both" inclusion of the brain and heart, Ralph positions inclusion of the heart on "a different plane." His use of seemingly transcendent language, here, contrasts with notions of inclusion as rooted in a set of (evidence based?) practices (Gallagher, 2010) and locates it in distinct dimension, much like the others' emphasis on inclusion as acceptance more subtly infers. It seems that for them, the most valuable kind of inclusion is felt rather than seen, cultivated rather than constructed. It is clear from what began as (and in many ways remained) a side conversation that as much as the co-inquirers' described and observed experiences of inclusion are positive, they are also tangled with/by nuanced visions for a kind of inclusion, perhaps, not yet known—questions, not yet answer/d/able.

["What's the main condition to sustain infinite potential such as ours, if not a big question mark always out of our reach." (Kiriakakis, n.d.)]

(????)

So What?

Fittingly, the multiple ways that the co-inquirers engaged with varied notions of acceptance, while also exemplifying (and building) community, *do* raise more questions than answers. The conversational scenes that comprise this sequence illustrate how, as they navigated the uneven terrain of the high school landscape, the students were also simultaneously exploring—testing the boundaries of—the forces driving them to do so. It is the tensions they raised, and in many ways left unresolved, about normalcy, acceptance (of self and/or by others), autism, and inclusion, throughout these dialogues that are perhaps most revealing.

The co-inquirers' differing perspectives on and experiences with “normalcy” and class participation pose questions about the pressure and purpose of feeling compelled to subscribe to normative forms of academic performance as students (Ashby, 2010; Hehir, 2005). Their discussions around behavior—which they often connected to autism—elicit the same uncertainties about (their own or others') expectations of conforming to normative ways of engaging in the world as people (Davis 1995). In some ways, in some instances, the students resist these expectations; they unapologetically own their behaviors, experiences, and identities as locations of diversity, not evidence of inferiority. In other ways, in other moments, these expectations—and the desire to move through the world with less effort—engulf the students; they express frustration with the physiological, emotional, and environmental realities they face in their attempts to do so. And yet, their dialogical pushing and pulling only scratches the surface of the experiential realities informing their words; they are continually navigating the middle ground between being *able* to be (and stay) in educational spaces not constructed with them in mind, and *choosing* to be in those spaces (or not).

The constant tension present(ed) between the students striving to attain acceptance from others in inclusive educational spaces and seeking it of themselves serves the paradoxical function of building community (with one another) while expressing the inadequacy of it (on a broader scale). The co-inquirers seem to be yearning to fit in, while at the same time interrogating the potential benefits (or harms) of a quest for acceptance centered on others' terms. I witnessed—took part in—these students developing and asserting a collective identity grounded in shared experiences and respect for one another. Yet as they did so, I also saw them saying that their choices to identify with and value each other should not preclude them from being accepted as part—redefining architects—of the larger community as well. Evidenced, in the Sequence (4) that follows, the students often used art to capture, reflect on and communicate these complicated ideas on identity, community, and inclusion.

Sequence 4: Making Art[selves]

Threaded throughout our Spring 2015 conversations were notable exchanges about ways that the co-inquirers, and the group as a whole, re-presented themselves through art. You will recall from the description of how this group evolved (see Methods) that I was taken aback by, but respectful of, the students' unanimous decision to use our time together to converse with one another, not to tell their stories through multimodal activities as I had initially intended. While my approach to bringing the co-inquirers together each week remained consistent with their expressed choices, some of our conversations ended up centering on their artistic endeavors anyway; the difference was that it was on *their* terms, not mine.

To reflect this, first this sequence highlights process-based interactions that wove through one quarter of our Spring 2015 meetings around Peter's H-O-P-E sculpture and Martin's autobiographical creative writing piece. Aptly, both artistic endeavors are composed of letters. Both projects tie into the topical threads of advocacy and acceptance and were constructed in ways that (as means to?) resist sociocultural assumptions that (have) place(d) their identities as students with autism who type to communicate at the margins. While these two pieces were the primary topics around which these student-initiated art conversations revolved, the other three students' responses to and participation in them also shed light on the value placed on art as a vehicle of expression and power.

Based on these conversations, I too brought forth opportunities to collaboratively make art(selves)work⁹⁷ as a valuable part of, and way of re-presenting, our experiences together. The mural project with which this dissertation opened served as a culmination of our time as a group and a way of weaving together varied ideas about art, identity, advocacy and inclusion. Our

⁹⁷ I use this hybrid term to blur the lines between the making of art and the crafting of self which the students helped me see as interrelated, as well as equally laborious and important endeavors.

process is also described as an illustration of an interactive approach of documenting experiences through making art(selves).

“H-O-P-E”: Carving out Identity

Conversations around Peter’s clay project were not only the first and most consistent examples of the emergence of this topical thread, but also represented the only student-initiated integration of visuality into our interspace. Over the course of three group meetings, Peter brought his art(self)work forward with both pronouncements about and photos of his project’s progress. Consistent with the way Peter often drew strength from (and provided) support for others, it was apparent that sharing his process with the group, and receiving their feedback, was equally as important to him as the finished product. Displayed below, each in-progress photo was presented as a follow up to Peter’s initial comment (caption of each photo), all of which were unprompted and served to spark conversations about his art.



Figure 7: "Hey guys I can't wait to show you my clay project" (3/30/15)



Figure 8: "My clay piece went in the kiln today" (4/13/15)



Figure 9: "Casey I finished my word project" (4/23/15)

From the first time that Peter brought his art(self)work to the attention of the group, he made it clear that “it [had] a ton of meaning:”

- Ralph** (2:46 PM): Do you want to share what it means
[.]
[Ralph had been typing about being tired for the duration of the conversation. He folds his hands on the table and rests his head for a few minutes before standing up and (verbally) asking Ms. Grecco if he can go to the bathroom. She nods affirmatively and he exits the room.⁹⁸]
- Casey** (2:46 PM): Yes please do
[.]
[The room is quiet, with the exception of Martin singing, “Hi-ho, hi-ho it’s off to work we go” in a high-pitched sing-song voice.]
- Peter** (2:49 PM): H has autism puzzle pieces o has purple ribbons for fc p has star reach for them always and e has clouds follow your dreams and be on cloud nine
Thanks guys
[Martin is speaking (inaudible) words in a sing-song voice]
- Martin** (2:49 PM): thats really good Pete
- Carlee** (2:49 PM): That is hopeful.
- Peter** (2:49 PM): Thank you
- Ms. Grecco** (2:50 PM): Great thought in your project Peter. Impressive
- Casey** (2:50 PM): Are those the purple ribbons like the ones Carlee gave out a few years ago?⁹⁹
- Peter** (2:50 PM): It is a lot of work
Yes she inspired me

Through his clay piece, Peter begins carving out a new discourse around his experience, one that he controls and constructs. His description of its deeply personal meaning transforms this project from a class assignment to a vehicle of his agency, a reflection of his identity. His eagerness to share it with the other co-inquirers suggests he seeks (and receives) their solidarity and affirmation in both how and why he creates what he does. In marking the word HOPE—a sentiment not often associated with autism experiences in our deficit-based culture around

⁹⁸ Ralph does not return during this excerpt of the conversation.

⁹⁹ Two years prior (Spring 2013), Carlee organized an “FC awareness campaign” that involved a feature on the school’s morning news program and Carlee, along with Ralph, Martin (the only other typers in Cedarbridge at the time) and some students from Carlee’s Cosmetology class, handing out purple ribbons in honor of communicative diversity. I was not actively involved in the efforts, but heard about it from many students, school personnel, and family members over the years. It seemed to have quite a longstanding impact.

disability—with symbols that he ties directly to his identity as a person with autism who types to communicate, Peter calls up important contractions and tensions. These choices suggest that his intention is to visibly assert the meaning he makes of him/self and his experiences as positive, his as a life with promise and purpose. In so doing Peter’s clay piece situates his identity and lived reality in ways that rub up against the positioning of disability as deficit that has marked—“masked”—his experiences (Rolling, 2009, p. 94).

[Can I say that Peter’s HOPE piece was intentionally, or solely, constructed as a vehicle of resistance? Can I connect the dots that led him to choose the words and symbols he decided to represent? I can neither say for sure, nor tease out on my own, why Peter chose the symbols he did or the overall message, function, of his piece. And while my disability studies background drives me to call particular attention to the paradoxical use of “puzzle pieces,” which have been used to further oppressive public messages about people with autism as incomplete or broken (yet always seeking wholeness) and, thus, find ways to see Peter’s reproduction of them here as either re-appropriation or evidence of his internalization of them, I will do neither. Instead, I see his use of the puzzle pieces, along with the other symbols of awareness and/or ambition, as nuanced and rooted in a developing (and co-constructed) identity that honors and celebrates his experience as a student—as a person—in all its complexity, uncertainty, and promise. In that way, I see Peter’s HOPE piece, as a whole, operating as resistance; inscribing/ascribing new meaning to an experience that has in many very public ways been categorically (mis)constructed as hopeless.]

Peter’s weekly updates to the group involved references to his process (i.e. “It keeps falling apart it is so heavy”) which were met with follow up inquiries (i.e. Martin: “what color will it be Pete?” Henry: “I would [like to see it]”) and, more than anything, praise (i.e. Ralph: “It looks very intricate;” Carlee: “looks beautiful;” Martin: “Pete that is cool”). All involved in the group (including myself and the TAs) showed interest in and respect for Peter’s art(self)work. The encouragement he received mirrored the optimistic perspective physically manifested in his clay work, suggesting that the interactive nature of his process cannot be overlooked as part of the work itself. His self-initiated opportunities to articulate and connect with the other co-inquirers around the meaning he was physically (re)casting in clay adds a layer of complexity, agency, and

power to the presence of these conversations in our interspace. The ways that he ties this deeply personal piece into his relationships with others is also evidenced in his description of the symbols he chose for the “P” and “E:” “p has star reach for them always and e has clouds follow your dreams and be on cloud nine.” While his identity is (literally) writ large on his clay letters, it must be noted that he does not insert himself in these words of guidance he uses to describe their meaning. Specifically, his choice to explain the use of “clouds” as instructions to “follow **your** dreams” as opposed to a note to self (i.e. follow **my** dreams) suggests that Peter has broad intentions for his HOPE piece.

Peter later shared with me (in an unprompted Google Hangouts message) the significance of this clay piece, which he consistently referenced as one of the most important and memorable aspects of his experience in high school thus far: “My HOPE peace means the world to me it was the first time I could express my thoughts in clay the deep meaning that it provides gives a ton of strengths.” It is also important to point out that not only is this the first time Peter could “express [his] thoughts in clay,” but his ability to supplement his art(self)work with articulation of its meaning through typing was also a relatively new experience for him.¹⁰⁰ I would argue that, as demonstrated by his eagerness to share it with his peers, part of the meaning he made in/through this sculpture was rooted in his experience sharing it in words through typing; a possibility that just one year prior had not yet materialized. Peter’s construction of his HOPE piece, conversations around it, and explanations of its meaning(s) cannot be separated from the context (clay class, which he was enrolled in during/because of his journey of learning to type to communicate at Cedarbridge, where there was precedent and support for his needs and preferences). Finally, positioned anthropomorphically in his explanation, the HOPE piece—

¹⁰⁰ Peter had been typing to communicate for approximately one year.

which he interestingly (mis)labels as “peace”—both holds Peter’s expressions and “gives” back “a ton of strength;” the lines between this art, self, and audience—hope(fully)—remain blurred.

Rewrit[ing]: A “Guide for the Future”

Like Peter, Martin, too, spent a significant amount of the Spring 2015 semester working on a project for (creative writing) class that had deeply personal roots and intentions that transcended a passing grade; he chose to write about his life with autism. Unlike Peter, and very much in line with his private, poised personality, Martin did not use our Google Hangout as a forum to share his writing with his peers, despite stated interest (i.e. Henry: “I would really like to hear it”). Instead, conversations that involved reference to this project were about his purpose (“i try to think of what might help others understand”) and process (i.e. “[Mr.] Waring wants rewrites”; “being an author is hard”), rather than product. In fact, the other co-inquirers never got a sneak peek, nor did Martin call on them for feedback; they saw finished product when it was selected for and published in the school magazine, just like the rest of the student body.

Yet what Martin was writing about was closely tied to the experiences discussed during our conversations and the lived realities that underlay them. It was a personal and sometimes tumultuous writing process made apparent in the amount of time he spent working on it outside of class (during core support periods in B13) and in conversations with others, including me. In the following interchange, which was preceded by the first instance of Peter discussing his clay piece (addressed previously), I inquire about Martin’s writing, situating it alongside Peter’s clay piece as art(self)work:

Casey (2:51 PM): Martin how is your writing project coming?

[...]

[The room is quiet, as Martin and Peter are the only two students present. As Martin types his comment (below) he pauses and rocks back and forth in his

chair, bringing his hands above his shoulders as if to frame his head. Ms. Hamden touches his elbow and whispers to him before he begins typing again.]

Martin (2:52 PM): good almost done
[Peter folds his hands over his head and stretches backwards over the back of his chair. Ms. Kozlow points to the iPad and quietly says, “can you sit up so you can answer...?”]

Casey (2:52 PM): Awesome I can't wait to see the finished product. It's going to be great, I'm sure.
[Martin rocks back and forth in his chair and briefly speaks a few (inaudible) words.]

[..]

Casey (2:53 PM): You are all artists in different ways

Peter (2:53 PM): Martin your paper should be published it is our guide for the future

[As he types, Martin hums quietly to himself]

Martin (2:54 PM): i try to think of what might help others understand.

Peter (2:54 PM): Carlee you are a great artist too
 Martin you don't have to try you got it

While I initiate the connection here between Peter’s clay piece and Martin’s writing, Peter’s encouraging response directs the exchange. Not only does he evidence an existing knowledge about Martin’s project in the absence of explication, but he also broadens the possible implications of the work. Martin does not disagree with him about the role of his writing as a “guide,” adding “I try to think of what might help others understand.” In this way, Martin’s stated intentions for his project connect to the previously addressed threads of advocacy and acceptance; both Peter and Martin position the possibilities of this writing piece within the realm of teaching for understanding and, perhaps, understanding as a means to/a form of acceptance. On the flip side of Martin’s aim to “help others understand” lie the shadows of mis/not understanding—a tacit reminder that his experiences are, have been, marked by misjudgment in an absence of mutual awareness of his lived realities. Peter insists, “Martin you don’t have to try you got it,” reminding him—all of us—of the primacy and authority that experience and story can and should have. In all of this, Martin’s writing becomes constructed as agentic; he draws

upon his experiences—his life—to reframe, resist, and rewrite the narratives (or lack thereof) that yield mis/non understanding of him (them?).

A follow up conversation between Martin and me enhances the illustration of both his ultimate purpose and development process with and through his writing. Prior to this excerpt of the discussion, I asked him to share examples of moments during high school in which he felt “proud.” He answered with a description of coming to high school and, with support from Ms. Hamden, helping “not corroborative” teachers “understand” him and his experiences.

Casey (10:30 AM): That seems like a theme throughout your high school experience—facing people who don't understand and helping (along with your supporters) to bring them towards understanding. I see your creative writing piece as serving a similar purpose...
I'm wondering if you agree and if you could tell me more about your decision to write it?

[Martin does not begin typing right away. He alternates running the tips of his fingers inside each of his palms. He rocks a few times back and forth and brings the back of his hand to his nose. Ms. Hamden replays the audio of my comment on his iPad. He begins typing.]

Martin (10:31 AM): i do agree. it was something know a lot about.

Casey (10:33 AM): Absolutely it is. I'm curious about what made it a priority to share with others. Over the summer you didn't seem all that interested in writing your story or sharing your experience with autism. What shifted for you?

[Martin brings his hands behind his head, yawns and stretches back over his chair. When he leans forward he rocks slowly while he reads my words on the iPad. He runs his fingertips along the inside of each palm and begins typing.]

Martin (10:34 AM): maturity

Casey (10:35 AM): Ah I see. Can you expand on that a bit more?

[Martin rocks back and forth and brings his hands above his shoulders before he types. As he types he shakes his left hand near his left eye and brings it to the table, running his fingertips over its surface.]

Martin (10:38 AM): i understand that if people are to accept its hard to do so i explain what it was like to be me.

[Martin stands up and exits the room. He returns eight minutes later.]

Casey (10:48 AM): Okay thanks. Well that's a really helpful way of understanding how your priorities shifted, and I'm so glad they did. Your piece is beautifully written and I think it is going to have a big impact on people.

Martin (10:49 AM): i hope it wakes people up.
[Martin rubs his fingertips along the inside of each of his palms. He rocks slowly and gently in his chair.]

Martin connects his desire to write about his experiences as a person with autism who types to communicate to a “maturity,” which helped him envision and construct a sense of authority and ownership: “i understand that if people are to accept its hard to do so i explain what it was like to be me.” Here again Martin alludes to the previously discussed connection between understanding and acceptance, and I’m reminded of his comment from a few months prior that people are not “mean” but “uneducated” (Sequence 1). In this way, “maturity,” for Martin seems to encompass both a growing awareness of the gaps in understanding between people whose experiences diverge, as well as a commitment to his autism as an authentic and valuable way of being in/with the world. In using his writing to “explain” Martin owns “what it [is] like to be me;” he does not imply that his experiences are inferior or broken, he does not seek pity, he does not resign himself to things as they are. “Explain[ing] what it was like to be me,” then, becomes a bridge, a means to traversing into a new territory (for both author and reader). Just as Peter attributes mortal characteristics to his HOPE piece, Martin’s stated goal, “i hope it wakes people up” also breathes life in—gives power—to his art(self).

Leafing Legacies: Collaboratively Making Art(selves)

It was the discussions around Peter and Martin’s respective art(selves)work—along with the others’ encouragement and participation—situating art as a vehicle of agency, a “guide” for/toward others’ understanding, a marker of pride, and a call for acceptance—that led me to introduce the idea for a mural project to the group. As I witnessed the ways that the students chose (were continuously choosing) to make their experiences, identities, and perspectives visible through varied avenues of (re)presentation in the name of “advocacy,” “awareness,”

“teaching” toward “understanding,” and “acceptance,” I often found myself reflecting on how their efforts intersected and overlapped with my own memories and experiences with Anne.

The final five group meetings constituted a manifestation of these intersections. From introduction to designing (and re-designing), collaborating and completing, the students and I, along with their support team, embarked on this journey of leaving—leafing—a legacy as they(we) ended one and began another chapter of their (our) story. My interactive proposal of this project to the co-inquirers in our Google Hangout remains the most fitting way to capture the origins of this work:

- Casey (2:26 PM):** I've spoken to all of you before about my best friend Anne, right? What I don't think I've mentioned is the fact that when we graduated from high school, a bunch of classmates and I surprised her with a mural created by her classmates and donated to the school as a reminder of the importance of acceptance, community, inclusion, and friendship. It still hangs in our high school.
- When I started spending time with all of you, I didn't set out to re-create and re-tell a story that had already occurred, and I still don't intend to do so. However, my time here has shown me some important parallels and intersections within and across our stories.
- Carlee (2:26 PM):** Yes.
- Casey (2:28 PM):** This year marks the end of one chapter and the beginning of another in different ways for all of you. In addition to the paths of your own individual stories, over the last few years, the group of you have been a force that has made a difference here and taught many people important lessons about inclusion, friendship, and community (whether or not you asked for that job!). It seems like an important moment to celebrate and commemorate; a valuable message to send future classes to come.
- I had this idea to perhaps do so through a mural, like we did when my friend Anne and I graduated. I've spoken to Ms. Farber about the idea and all are on board if you are. We are thinking that this might be a great opportunity to pull

together many of your classmates across grades to make a mark on the school; we could put it together like a collage of contributions from many students. One idea we had was to set up a table at Cedarbridge Day¹⁰¹ and have students come by to create small pieces that will become part of a big mural. While it would not be an exact replica of the mural in my HS, like the one my friends and I created, it seems like a perfect message to organize around the theme of:

"What you do, what you say, what you are may help others in ways you will never know. Your influence like your shadow, extends in places you may never be."

I have some different ideas about how we could do this, and am totally open to yours as well, but first would love to know if you're interested in doing this with me as a kind of finale to our time together.

- Carlee** (2:29 PM): Yes.
- Peter** (2:29 PM): I LOVE IT WHAT IS IT GOING TO BE
[The room is very quiet and still as the students type their responses.]
- Henry** (2:30 PM): I like it already.
- Ralph** (2:30 PM): i would like to i love art and want to share my story through art
[Ms. Karl (OT) opens the door to B13. Henry looks over at her, stands up and exits the room. Martin speaks a few high pitched (inaudible) words and brings the back of his hand to his lips.]
- Martin** (2:31 PM): I really like the idea. what would it be made of?
- Peter** (2:31 PM): one person, one voice, but unique and amazing in many ways. Come together and be one
- Carlee** (2:31 PM): Yes.
- Casey** (2:33 PM): Awesome I'm glad you're all on board.

Designing. Following this enthusiastic introduction, the co-inquirers and I immediately began brainstorming design ideas for the mural. Spanning the remaining 24 minutes of our meeting that day, the conversation that followed made this the second¹⁰² longest discussion

¹⁰¹ An annual recreational field day held (outside, weather permitting) at the high school comprised of various activities, food vendors, games, and social opportunities.

¹⁰² The longest conversation (42 minutes) came the following week, and again revolved around the mural design.

devoted to a sole topic during all of Spring 2015. This initial design brainstorming was both lengthy and less demonstrative of students' interactions than others; it was more indicative of how they constructed their individual ideas. Thus, I have represented it visually according to the three primary design elements put forward to highlight the ways that the final design was borne out of these originally distinct suggestions.¹⁰³

¹⁰³ Text of conversation has been grouped by theme.

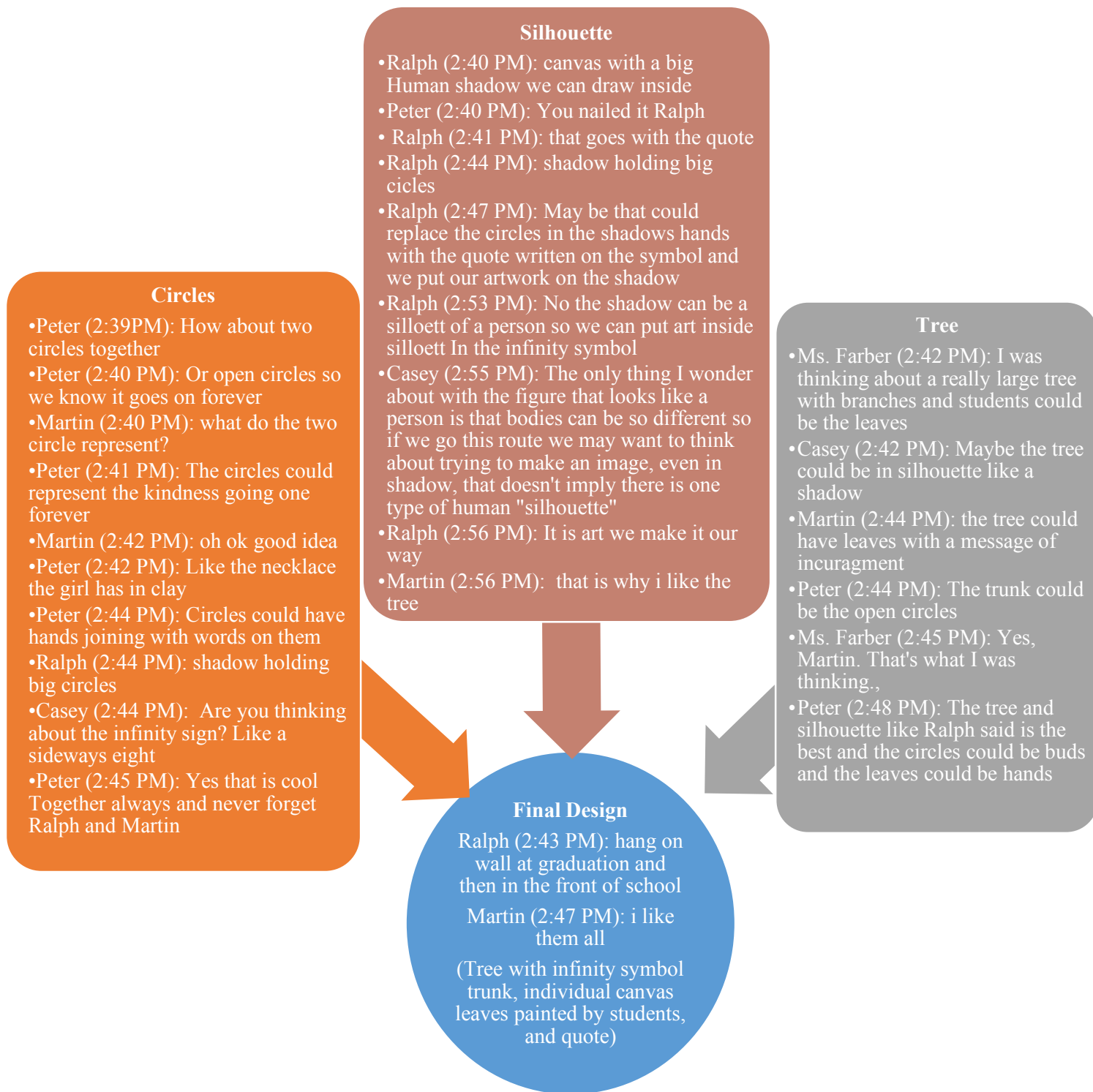


Figure 10: Design ideas by topic

As illustrated in Figure 10, the three designs that evolved and took precedence during this first conversation¹⁰⁴ included: overlapping circles (later determined to be an infinity symbol); human silhouette; a tree with leaves. Not only did these contributions come to ultimately comprise the mural's final design, but the process of developing them reflected each student's individual personality. For instance, though Martin does not introduce a distinct design idea, his bids for clarification and expressions of his preferences serve to facilitate the discussion—a lived example of his leadership in both conversation and experience. Peter enthusiastically introduces the idea of “circles” and, at Martin's request, clarifies that he considers that symbol to represent both temporal and interactive values: broad hopes for “kindness going [on] forever” and a tribute to friendship and shared experiences (“together always and never forget Ralph and Martin.”). Additionally, Peter explains that he draws his inspiration from “the necklace the girl has in clay;” tying his ideas about this mural project to a space (clay class) he has described previously as incredibly important to him socially, artistically, and personally. Ralph, on the other hand, is more focused on capturing the essence of the mural's quote and determining a space for the finished product (“hang on wall at graduation and then in the front of school”). Even as he takes up Peter's ideas (“shadow holding big [circles];” “May be that could replace the circles in the

¹⁰⁴ Carlee left the Hangout at 2:35 PM, just prior to the brainstorming session about the mural design. Prior to signing off she shared, “it could be a book.” However, since she did not expand on this idea and none of the other students took it up in her absence, it never developed into a full fledged design option.

Henry left for OT shortly after the introduction of the mural idea. He returned 30 minutes later. We had the following interaction:

Casey (3:00 PM): You have lots to catch up on! Maybe if you have time this afternoon you can read through the idea the guys generated.

[As he types, Henry smiles and clicks his tongue.]

Henry (3:02 PM): I would like to help.

Casey (3:02 PM): Great! We will talk about this next Friday.

shadows hands with the quote written on the symbol and we put our artwork on the shadow”) Ralph is firm in his commitment to a design that foregrounds a human shadow/silhouette—an amorphous and yet specific construct he continues to develop. When I push back against his proposal (“The only thing I wonder about with the figure that looks like a person is that bodies can be so different so if we go this route we may want to think about trying to make an image, even in shadow, that doesn't imply there is one type of human ‘silhouette’”), Ralph bears both an unwavering commitment to his creative vision and a confidence in his/our artistic abilities as inherently flexible and resistant to narrow (dominant) expectations: “It is art we make it our way.”

It is important to note that though I offered, I did not share the image of Anne’s mural with the students. I had, however, shown Ms. Farber a photo of it in a previous conversation and we had privately discussed the idea of carrying through the “tree” theme into the Cedarbridge mural. Therefore, her suggestion (“I was thinking about a really large tree with branches and students could be the leaves”) during this conversation was neither surprising, nor out of line. If she had not proposed this idea, I would have. While it is possible that the proposal to create a tree mural coming from an authority figure (a teacher) could have swayed the students’ choices, as the conversation unfolded it became clear that they would not have incorporated this element into the design if they had not collectively agreed upon it. In fact, when the conversation ended, the group was very much divided into two camps: the tree vs. the silhouette (with the idea that the overlapping circles/infinity symbol could be incorporated into either). Captured in Ralph’s declaration, “Well I guess we need to vote next time,” I was left with the challenge of crafting mock-up designs that incorporated all of these ideas for us to choose from the following week.

[I left this conversation feeling both excited and in over my head. A typical Thursday. The students’ ideas are creative and, thoughtful, but I worry about figuring out a way to

incorporate all of them in a way that makes everyone happy. Not to mention, in such a short period of time, with a self-declared lack of artistic ability. Help! We have less than a month to get this together. I remember feeling this way with Anne’s mural—pressured to please everyone, but unsure of how to do it. If I’m to be honest, I remember feeling this way about most things in my life. And it usually works out. I have no idea how this is going to happen, but I am so happy [we/they get] to do it. Together.]

Eight days later, we were back around the same table, discussing the mural once again.

All of the co-inquirers participated in the forty-two-minute conversation (our longest on a single topic) during which we were to decide on a final design for the project. I came prepared with five different digital mock-ups (three trees, two silhouettes) to present as choices based on our previous conversation. After seeing the three tree images, all of the students (Ralph included) expressed being so committed to the mural taking the form of a tree that they did not want to see the silhouette designs when it came time for me to share them. Interestingly, despite being steadfast about his preference for the silhouette design the previous week, Ralph now was most interested in finding out if he could “really write the words on the mural.” Once Ralph’s role as scribe was confirmed and all settled on a tree design, we moved forward by negotiating how to combine the students’ favorite elements of each of the three tree options I presented. Reproduced here to capture the spirit of our collaborative process, much of this portion of the conversation revolved around how to make the infinity symbol more prominent in the design.

Peter (2:55 PM):¹⁰⁵ How about the infinity sign behind the shaft of the tree

Ralph (2:55 PM): I want to see the infinity symbol on it

Peter (2:55 PM): Shadow

[.]

[Henry groans loudly as he types. Otherwise, the room is quiet. Ms. Grecco, who is supporting Carlee, verbally reminds her to “look.”]

Carlee (2:56 PM): The infinity symbol as the shadow

[Peter exits the room.]

Martin (2:56 PM): what if the trunk is the infinity symbol

¹⁰⁵ This was the first meeting of the Spring 2015 semester that Carlee attended in person.

[Ms. Grecco reads Martin's comment, "what if the trunk is the infinity symbol" out loud, then addresses Carlee, "what do you think? Is that a good idea?" Henry makes an abrupt sound and laughs.]

Casey (2:56 PM): Keep in mind between the thicker tree trunk and the very large canvas the infinity symbol will show up much more

[Ms. Grecco reminds Carlee, who has hunched over and placed her pointer fingers over her eyes, that she has one minute before she can get ready to go, adding, "I'm proud of you."]

Ralph (2:57 PM): I think we should put i in the trunk

Carlee (2:57 PM): Yes

Henry (2:57 PM): Students should understand how meaningful this is.

Casey (2:58 PM): we could make the trunk of the tree the infinity symbol
[.]¹⁰⁶

Henry (2:58 PM): Shadow.

[Carlee stands up and packs her bags. She exits with Ms. Grecco at the same time that Peter re-enters the room.]

[.]

Martin (2:59 PM): i like that [.]

Henry (2:59 PM): Yes.

Peter (2:59 PM): Love that one

Ralph (3:00 PM): I like it

Casey (3:00 PM): Henry are you saying yes to the infinity symbol as the tree trunk?

Henry (3:00 PM): Shadow please.

[I begin speaking my comment, laugh, and remind myself to type.]

Casey (3:01 PM): Well if we have the tree trunk as an infinity symbol, the shadow will mirror that.

[Mr. Meyer reads my comment aloud to Henry and asks, "do you like that?" Peter brings his hands behind his head, yawns, and stretches over the back of his chair.]

Peter (3:01 PM): Yes

[Mr. Meyer says to Henry, "it's kind of like a compromise."]

Ralph (3:01 PM): Sounds good

Martin (3:02 PM): i like it

[.]

[Henry fixes his gaze to his left and is seemingly staring into space. Ms. Farber, who is sitting across from him (supporting Ralph) laughs and waves her hand in the space between them, presumably to break his stare. He reaches his left hand into the center of the table and interlocks his fingers with hers. He looks back at his iPad and Mr. Meyer says, "you ready?" Henry brings his hands to his face and makes a loud, abrupt sound. He adjusts his posture, places his left elbow on the table and leans on his left hand as he types with his right.]

Henry (3:03 PM): Yes.
Ok.

¹⁰⁶ Carlee says goodbye and signs off the Hangout at 2:58 PM

This marked the end of our design decision making process. I agreed to make the necessary changes to the digital sketch based on the students' feedback in order to keep us on our timeline to complete the project by the end of the school year so that, as Ralph requested, the mural could "hang on [the] wall at graduation."

Collaborating. Before we finished for the day, I shared an option for collaboration with other students.¹⁰⁷

- Casey (3:03 PM):** Ms. Grecco mentioned that there are some drawing students that offered to help us get the backdrop of the mural painted. But I want this to be under all of your control, so what do you think about having those students help??
- Peter (3:03 PM):** Awesome
- Ralph (3:04 PM):** I like the idea of us doing it ourselves
- Martin (3:05 PM):** i like it and i hope they will
[Martin stands up and sits in the rocking chair. He sings (inaudible) words.]
- Henry (3:05 PM):** Teachers picking them.
[Henry makes an abrupt sound.]
- Ralph (3:05 PM):** If we give them the picture we would be in control
[Henry hums rhythmically.]
- Casey (3:06 PM):** What do you mean Henry?
 Yes absolutely. So I am thinking that whatever we do is going to be traced directly only to the canvas from a projected image.
- Peter (3:06 PM):** Supervisors
- Ralph (3:06 PM):** Yes we show them what we want drawn
- Peter (3:06 PM):** U.S.
- Casey (3:06 PM):** Totally, Pete.
 Ralph, yes we are on the same page.
- [.]
- Henry (3:07 PM):** Yes.
 Students involved are picked chosen selected.
[Ms. Farber says out loud, "Henry, I think the idea is that a couple of art students volunteered, but then any student in the school can put a leaf on the tree. I think

¹⁰⁷ After the previous week's introductory discussion about the mural, Ms. Grecco and I had a casual conversation during which I laid out my plan to create a digital image that we could project and trace onto a canvas (which is how we created Anne's mural as well). She mentioned that she would be seeing the art teacher and could talk with him about any art students that might want to get involved in the project. I agreed that it would be nice if some other students wanted to help with the tracing, but told her I would run it by the group first and would make sure that we all agreed before proceeding.

the student that volunteered just wanted to help us out.” Henry stretches his hands over his head, yawns, and leans back over his chair. He begins blowing air through his teeth.]

- [.]
- Casey** (3:08 PM): If the students get started on tracing once we've finished the image during the school day, you could go and work with them if you are free too.
- Peter** (3:08 PM): Henry common on brother
- Casey** (3:09 PM): Henry, I will be there no matter what to make sure whoever is working on it is being respectful.
- [.]
- Peter** (3:09 PM): Henry Casey can fire them
- Henry** (3:09 PM): No.
- [.]
- Casey** (3:10 PM): No what, Henry?
- [.]
- Henry** (3:11 PM): I like it please explain how it means to us Casey.
[All of the students stand up and start packing up when I send the following comment. I pick up Henry's iPad and bring it to him where he stands near his desk and say, "I'm not sure if you saw my last comment," holding up the iPad and reading my words.]
- Casey** (3:11 PM): Absolutely, Henry. Maybe you could come in with me and do that too?
[Henry does not type an answer, but I ask him to think about it over the weekend.]

Though all of the students were on board with recruiting others to help with the tracing, they approached this collaboration differently. In his matter-of-fact manner, Martin both appreciates and encourages the participation of the art student(s); he shares his perspective and does not engage in the subsequent discussion about their selection and supervision. Peter, too, welcomes the idea, responding at first only with “awesome” to indicate his enthusiasm. However, both Ralph’s and Henry’s initial responses reveal a hesitancy and desire to preserve their control over the project. Ralph seems to oppose the idea with his statement, “I like the idea of us doing it ourselves.” Henry, on the other hand, seems open to the participation of others, but entrusts the selection of them only to “teachers.” Seemingly countering his previous statement, and possibly reassuring Henry, Ralph adds, “If we give them the picture we would be in control.” It appears here that any hesitation from the co-inquirers (i.e. Ralph and Henry) grows

out of a perceived risk of losing ownership of the project. Once I confirm and commit to a participatory process that minimizes opportunity for the art student(s) to make changes to the co-inquirers design, it becomes clear that “we are on the same page.”

However, Henry is the last to fully commit to the idea of including others. His emphasis on the careful selection of the art student(s) weaves through the entire conversation, and is underscored by synonymic repetition: “Students involved are picked chosen selected.” Despite the fact that Henry is not denouncing the idea all together, Peter positions his brother’s comments as resistance and lightheartedly appeals to him to change his mind (“[come] on brother;” “Casey can fire them”). It remains unclear whether Henry’s subsequent “no” is in response to Peter’s entreaties, the participation of the art students all together, or something else. However, his final comment—“I like it please explain how it means to us Casey”—suggests that his primary concern throughout this conversation has been about upholding the significance of the mural, even in the hands of others. This echoes his earlier comment (which was not taken up or expanded upon), “Students should understand how meaningful this is.” For Henry, sharing responsibility for the project threatens to dilute its symbolic magnitude. Yet, his ultimate solution is not to exclude or deny others the opportunity to collaborate. Rather, he insists that they be guided to understand (whether that guidance comes from me, as he requests, or from “us” as I suggest) in order to move forward together.

Creating. The two weeks that followed—the last two of the school year—were a whirlwind of simultaneous and important events, both related to and separate from this mural project. Not only did the time blur, but so too did my role; I became a liaison between the co-inquirers and other students, a facilitator of the mural’s progress, a cheerleader encouraging the co-inquirers to reach out to others, and a participant in a creative process that seemed, in some

ways, to become bigger than me/us. With the students' permission, supervision (during their individual free periods), as well as my detailed instructions (and frequent visits), a single art student took on the task of tracing the projected tree design (minus leaves) onto a 6'x4' canvas. At the same time, the co-inquirers and I worked together on determining the appropriate size and number of leaves to cut out for other students to paint during Cedarbridge Day, and we developed a list of guidelines to share with those interested in contributing to the project. I stayed up late into the night(s) tracing and cutting 200+ leaves out of sheets of canvas paper. The co-inquirers and their TAs fulfilled their commitment to spreading the word about the project in classes, hoping that students would seek out our table during the Cedarbridge Day festivities.

Two days before the event, an interested student in the same art class as the mural's tracer, approached me and offered to publicize information about the project on the student morning news show, which she helped produce. Peter and I collaborated on the announcement, which the other students then individually approved, before sending it off to the in-house broadcasting station. It was shared on the school's news program, along with the draft image of the mural, the following morning:

Hi Cedarbridge! This message comes to you from Peter, Ralph, Henry, Martin, and Carlee. We are making a mural with our friend Casey to continue the spread of awareness. The image you see on the screen is the mural we have designed, except we need your help to fill the tree with leaves! We encourage you to stop by our table on Cedarbridge Day to come and design a leaf to make a difference. It will be hanging in our school for future students to be aware. Thank you hope to see you there."

And as we worked as a group to pull (this project) together, Peter reminded us all of the purpose of our efforts during our final conversation in preparation for Cedarbridge Day: "It is not about them or us it is about awareness and togetherness."

Our collective efforts proved effective. Over two hundred pre-cut leaves were painted by students and staff during Cedarbridge Day. The co-inquirers alternated staffing the "leafing

legacies” table (supported by their respective TAs) in shifts so that they, too, could participate in the day’s other activities. Even Carlee, who had just recently returned to the area from Georgia, came to the event (accompanied by a community support person) to paint her leaf and oversee the table for a short period of time. I spent the day managing materials, fielding questions from students, and making sure that the painted leaves didn’t blow away in the wind.



Figure 11: Leaves drying at Cedarbridge Day

[Despite my scribbled notes on the back of canvas leaf scraps during brief lulls in the flow of visitors to our table, my role as participant and co-creator overshadowed any intentions I may have had to “observe” this creative and hands-on event. Inevitably, I missed some of the nuanced interactions between the co-inquirers and their peers, as well as details about the kind of support the TAs provided during this unique occasion. However, the experience of working alongside them as a team member—just as covered in paint and excited about the slowly dwindling pile of blank canvas leaves as they were—was a testament to the rapport we had built and the collaborative journey we were on.]

The following week—the last of the school year—we had our final conversation in Google Hangouts, during which the students alternated between chatting informally with one another (i.e. catching up with Carlee after her long physical absence, discussing summer plans, and expressing best wishes for Ralph at the upcoming Senior Ball) and taking turns leaving the

table in pairs to each place a set of painted leaves on the mural canvas.¹⁰⁸ The meeting was equal parts anticlimactic and momentous; the first of the Spring 2015 semester that all five students were physically present, every topic they discussed took the form of looking forward. And as each student took their turn placing leaves on the gradually decreasing white space above the tree traced on the canvas, our conversation(s) and artistic process—along with the unique moment in space/time we occupied—drew to a close.

The Reveal. Two days later, on the last day of school, the time that would have normally been reserved for a conversation in Google Hangouts took the form of a celebration and surprise party for the graduating seniors, Ralph and Martin. It also represented the reveal of the finalized mural,¹⁰⁹ which leaned up against the whiteboard in B13. I brought the gluten free goodies and, though I videotaped the party for good measure (and old time's sake), I partook in the festivities. Michael Jackson blared through the speakers of the Promethean Board and a steady flow of students and staff streamed into the room with good wishes and high fives; for finishing a school year, for graduating, for creating (and leaving) a legacy. In fact, Ralph even personally visited the principal's office and invited him to come view the mural and reassert a commitment to having it displayed on the graduation stage a few weeks later. He, and it, did.

[I bumped into a faculty member this week and told her about the mural project. While supportive and excited, her first (gentle, but firm) response to me was that I need to “stop collecting data.” She is probably right, but the interaction struck me. My response to her echoed this and remains true: I have no idea what's data and what's not anymore. I cannot tell—separate—whether this mural project is more part of dissertation inquiry or more of an opportunity to participate in something collaborative and meaningful and creative. I can't tell whether producing art with the co-inquirers is more about fulfilling my ambitions, honoring theirs, and/or leaving behind something tangible in this place

¹⁰⁸ I had taken the dried leaves home over the weekend, mounted them on black construction paper and placed glue dots on the back to allow the students to quickly and easily place each leaf on the canvas over the course of this meeting. Once the leaves were in place, the final step was for me to permanently glue them to the canvas and seal it with a varnish product.

¹⁰⁹ Before permanent glue and varnish was applied.

that has created (turned into) such a rich environment—for them, for me, for us—to learn in/through. I do know that I love that this project provides a way of meshing the students' stories and my own. I love that they are enthusiastic. I love that regardless of what this thing looks like, its message is powerful. But data? I'm not sure it's just that (though I'm not sure that it isn't, either)...

So What?

The art(selves)work discussed in this sequence takes different forms and was initiated in and created for different spaces. The group conversations that included, and/or centered on, these creative processes served varied and overlapping purposes; bids for validation, stated endeavors to educate, mediums of honoring the past, tools used to clear paths for new stories. Each art(self)work, and its unfolding development, warrants its own inquiry and extended analysis. However, it is perhaps what these pieces are—do—as a collective that is most relevant, and telling, here.

Much like the co-inquirers' stories and conversations, all of the individual and collaborative decisions made around art(self)work during this inquiry are inseparable from their disability experiences and the contexts in which they/we occupy. In content and in function, each piece described here is entwined with and grew out of efforts to replicate, convey, resist, and/or re-imagine the place of diversity in spaces that, by nature of the need for such work, have not yet made (enough) room for such dynamic understandings of human variation and experience. Crucially, the artistic (co)creation processes described here occurred within a space (Cedarbridge High School) that had already established and demonstrated a commitment to moving toward and modeling such dynamic understandings. And while the art(self)works themselves hold these messages calling for something more, different, the interactive creative processes and supportive dialogues around them hinged on and modeled validation, acceptance, and collective group identity in ways that are just as important as—critical to—the products of it.

I see in their/our art(selves) the materialization of what disability studies scholar, Tobin Siebers (2010) deemed “disability aesthetics,” a foundational element of modern art:

Disability is not, therefore, one subject of art among others. It is not merely a theme. It is not only a personal or autobiographical response embedded in an artwork. It is not solely a political act. It is all of these things, but it is more. It is more because disability is properly speaking an aesthetic value, which is to say, it participates in a system of knowledge that provides materials for and increases critical consciousness about the way that some bodies make other bodies feel. The idea of disability aesthetics affirms that disability operates both as a critical framework for questioning aesthetic presuppositions in the history of art and as a value in its own right important to future conceptions of what art is. (p. 20)

In light of this, the lines between products and processes constituting the art(selves)work discussed in this sequence blur into and out of one another; the experiences and conversations that inform the art(selves) cannot be separated from how, or in what form, they came to be represented.

Growing out of this understanding of the inseparability of disability identities and experiences to the creation and production of art(selves)work, the co-inquirers’ approach to and narration of the individual and collective artistic processes can be understood as operating along (carving out new) paths of resistance. In calling attention to the ways that the group, individually and/or collectively, made art(selves)work (particularly juxtaposed with their initial opposition to doing so as an organized activity) Rolling’s (2009) notion of in/di/visuality or “the agency to reinterpret misrepresented physical or conceptual bodies” (p. 94) becomes particularly relevant. Situated in the historical and social forces that construct and cloak “lesser physical bodies, lesser bodies of knowledge, and bodies lesser-than-normal” as invisible, Rolling’s in/di/visuality works “both as a noun and as the verb to in/di/visualize, as a designation both of social work sites and of transformative social practice” (p. 94, 105). While specifically formulated around the pedagogical possibilities of in/di/visuality in (as) art education curriculum, I understand it as

applicable here in (as) our Inquiry Group interspace. Given that the students' descriptions of and responses to one another's artistic processes and products are both a narrative of self/selves as well as resistance to the sociocultural ideals that construct them, I consider them exemplars of, often co-constructed, in/di/visuality at work.

After being met with resistance about arts-based storytelling during the Summer 2014 Inquiry Group meetings (see Methods), the eventual return to art in this inquiry was an unexpected, but welcomed, turn on the meandering journey we as co-inquirers (and those who supported us) roamed together. While the initial idea (which did not come to fruition) to include art projects into our Inquiry Group was a way for me to learn more about these students as *individuals*, the eventual inclusion of art into our group proved to reveal more about *relationships*—those interactive spaces that the students occupied, were building, had lost, never had, and/or yearned for. Regardless of how deeply personal (Martin's writing), symbolic (Peter's HOPE piece) or collaborative (the mural), the art(selves)work rose out of and produced revised notions of connection in both art and life.

[...Sure, in the end, I can write about the collaborative mural design and artistic processes. I can take a reader along that journey. I can include photos, conversations, vignettes. I can try to replicate in words the ways the students became a collective at the same time they drew upon their individual identities. I can try to convince my reader that my words (always) fall short. You had to be there. The project—and product—will provide a nice conclusion to an otherwise meandering story. But I think this kind of ending is more about who they are and who I am and who we are together than it is about data, or field texts. This is more than pages pulled together in (by) my dissertation.

But if it is—has to be—both, then I'll cling to Ralph's response when I introduced the idea to the group: "I want to share my story through art." Interactive, evocative, dynamic (is) art; I like the sound/look/feel of that.

This mural, then, is not (just) data. It is not (only) an image; it cannot be adequately described (defined) by words. It is not mine or theirs or even ours. It is not static.

This mural holds our stories and the same time it carries them. It reflects who we are at the same time it (re)creates us. It exists in/as past, present, and future; connecting lives beyond the borders of space and time.

*This mural—this art—is
(re)action. And it's moving.]*



Figure 12: The Finished Mural

CODA
A C(onversation on I)nclusion

<p><i>The login window prompts me to enter my username and password and my fingers fly across the keyboard, filling the blank white of the form boxes with black letters and symbols before I have time to think; this is not my first dance. The circle above my login information reveals a small, photo of my face, grinning at the camera. I chose this image last year alongside my co-inquirers as they too selected the photo avatars that would accompany their typed comments during our Google Hangouts conversations. I wonder if it is time to update the picture, or replace it with an ambiguous symbol instead, but sentimentality gets the best of me and I keep it there. I click the blue “sign in” button.</i></p> <p><i>My screen transforms into a familiar digital interspace: a grey background with a running list of past conversations in a column on the left. I type your name in the “start a new conversation” bar, electronically inviting you to chat. But I notice you are not yet signed on, so take a moment to scroll through my saved conversations. I watch the text of discussions about proms and anxiety and friendship and schoolwork and autism flash in front of me; frozen in time even as the slightest flick of my finger moves them on the screen. I reminisce about the hours logged and lessons (I) learned in this otherwise unremarkable interspace.</i></p> <p><i>While I wait.</i></p>	<p><i>The login window prompts you to enter your username and password; your fingers hover over the keyboard as you search your memory for the password you chose when you set up your account in anticipation of this meeting. The circle above the blank fill-in form depicts a faded grey, amorphous silhouette that tacitly reminds you to upload a photo as your avatar, but perhaps you opt for ambiguity today and leave it as is. (Or maybe you don’t and upload a picture of yourself, or your dog?) You click the blue “sign in” button.</i></p> <p><i>Your screen transforms to a grey background with a blank bar on the left that prompts you to “start a new conversation.” At the top of the screen, the Google Hangouts logo tells you that you are in the right place. A new window pops up announcing via a short message in a call-out bubble next to my photo avatar, “I want to chat on Hangouts!” At the bottom of the window you are given options to “ignore” or “accept” this invitation. You click the green “accept” button and watch as the screen changes into a chat-room like space. The blank, white bar at the bottom of the screen suggests you “send a message” punctuated with a smiley face (which when clicked, you figure out, opens a menu of countless gumdrop-shaped emojis to add to your text). You type a greeting, hit send, and set off the sound of the message chime; this officially begins the conversation.</i></p> <p><i>And you wait.</i></p>
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Me: Hi, thank you for meeting me on here; it is only fitting that we wrap things up in Google Hangouts. I see you made it through to the (an) end of this dissertation; I’m glad you stuck with me/us. As a narrative inquirer, I (am) expected to end with a coda, or my research signature. I guess that comes here, with you. I do not take this lightly, as I know it requires delicate balance.

[I can feel the weight of Clandinin and Connelly’s (2000) caution about this “dilemma” “...of how lively [my] signature should be: too vivid a signature runs the risk of obscuring the field and its participants; too subtle a signature runs the

risk of the deception that the research text speaks from the point of view of the participant (p. 148). I wonder if you do too. I keep typing...]

To be honest, I am still exploring the nuances, tensions, and uncertainties brought forth in and by this research narrative. I imagine you are, too. I even have the privilege of hindsight, the power of literary license, the position of having witnessed and lived the experiences about which you just read; I know what this space, these stories, looked like at the end in ways I could not have prepared for in the beginning. Yet I am still seeking clarity at the same time I know it is beyond—antithetical to—my/our reach. Maybe we can converse, rather than conclude?

You: I am here for the same reasons, with the same hesitations. I sense we are not alone...

Me: We are and we are not. Two other players in this experience, Narrative inquiry (NI) and Disability Studies in Education (DSE), are signed on too. They always have been. Like the TAs/facilitators are to the co-inquirers, they are both support and participants, but know to interject selectively.

NI: Like this: Dewey's (1934/1980) metaphor about flowers might help put these tensions into perspective. He makes clear that you can appreciate the beauty and fragrance of flowers without knowing anything about plants. But if you want to understand how they bloom, you have to inquire into the interactive processes (with air, soil, sun, water) that create the conditions for growth (p. 4). So *this* ending is part of the process: "this is what differentiates narrative inquiry from mere storytelling because...no work can of itself assist the understanding of the nature of the work itself; the work has to be researched, analyzed, interpreted, theorized, and foremost, understood" (Kim, 2016, p. 236).

Me: I've studied this. I've learned about how crucial it is for me, as a narrative inquirer, to situate this inquiry in, and link it to, the broader social context.

NI: ...in other words, to "plan[t] the seeds of social justice" (Kim, 2016, p. 237).

Me: But *how*, and *how much*?

You: And as I've read this dissertation I know how integral it is for me, as audience, to participate in cultivating understanding through critical reflection and problem solving, while also accepting incoherence. I want to be part of that process.

NI: Just keep in mind as you go that "narrative inquirers try less to drain the 'swamp' of experience through systematic analysis of particular aspects of situations than try to make its muddiness, if anything, even more generative in the sense of opening up possibilities for it to be otherwise, for different stories to be lived and told"(Downey & Clandinin, 2010, p. 395). Like its inquirers, you as audience must enter into and participate in the mi(d)st.

You: But *how*, and *how much*?

Us: Let's figure that out as we go.

Identity, Affiliation and Acceptance: Starting with the Students

You: How about we start with the students, your co-inquirers, as individuals and as a group? The students draw upon one another's storied experiences as models, sources of support, and evolving ownership of their identities. What does that mean for them, for us, for the context(s) in which we are all situated?

[I smile, recalling Peter's unsolicited acrostic poem: A (awesome) U (unique) T (tremendous) I (intelligent) S (super) M (magnificent) this is why we are perfect to each other." This seems like a good place to begin.]

Me: I was struck by the co-inquirers' increasingly visible and complicated negotiation, cultivation, and/or (re)presentation(s) of their autism and communicative diversity as integral elements of who they are. Of course, I acknowledge that by bringing them together in an inquiry centered on their experiences as students with autism who type to communicate, I contributed to their sustained focus on those aspects of their identities, as well as their relational and experiential corollaries. Yet, while I did provide opportunities to shift and alter the pivot point of our time as a group, the students consistently opted to engage only with one another, most often about the nuances of being individuals with autism and diverse communicators. Perhaps they chose to be, and talk about being, together because that is how we began, but maybe also because that is what they wanted. I hope I have made clear the tensions I felt in honoring—and ensuring I was accurately interpreting—these choices, while also recognizing that doing so potentially eclipsed opportunities for the students to attend to and explore their other intersecting identities and experiences. However, in calling forth these less explored paths of dialogue I also do not want to minimize the collective community these students co-created through shared/sharing experiences as people with autism who type to communicate.

You: That the co-inquirers chose to affiliate with each other in/as our Inquiry Group reveals that they value their aligned experiences and the connections built through dialoguing about them. It also suggests that at this time, in this (inter)space, spending time together was a means of producing, and holding on to, a community in which they felt (most?) comfortable.

Me: Yes, particularly because here, in their home-base classroom (B13), and in a co-constructed interspace with others who shared or intimately understood their communicative and corporeal ways of being, the students did not have to explain themselves or their bodies as a means of gaining access. While the necessary presence of the adult TA/facilitators added layers of complexity, this interspace was understood as belonging to the students.

You: But was it affiliation out of choice or out of necessity? Was this the only community they could build?

Me: I struggled with this question. One of the striking aspects of this community building through shared/sharing experiences in our dialogic interspace was the fact that it often happened around the students' expressed yearning for the kind of acceptance I witnessed them demonstrating in relation to each other. I feared that they may not have "counted" the belonging they epitomized together in their understanding of acceptance (of self and by others), even if they did consistently choose to spend that time only with one another. I worried that perhaps they were subscribing to more ableist notions of and routes to acceptance and belonging as contingent on normative behavioral, communicative, academic, and social requisites. And certainly, the co-inquirers did often reify those expectations in descriptions of themselves, their bodies, their goals.

[My memory flashes to watching Henry, focused and blowing air through his tongue and teeth, as he types: "My impulses prevent me from peace and acceptance."]

You: Right, this comes through in the "Real Acceptance," "Real Problems" conversation (Sequence 3), illustrating how some of the students (i.e. Henry, Peter) sometimes position their behaviors and communicative differences as problems getting in the way of their acceptance by others and, as a result, impacting their acceptance of themselves. Yet in other moments, don't the co-inquirers also explicitly resist the demands placed upon them (by themselves and others) to conform to norms too stagnant to stretch, or break open, to hold their experiences?

Me: They do. This opposition happens in the context of (as a means to?) strengthening the ties that the co-inquirers have to one another, even if at the same time distancing themselves from the other high school peers from whom they seek acceptance.

[How did Martin phrase his opposition to this? It was so forthright. I flip to p. 284 of my well-worn printed copy of this dissertation. Oh yes: "sometimes peers shouldn't count. these are our behaviors"]

In these ways, even as the students adhere to normative notions of what constitutes competence, behavior, and educational spaces, they—as a collective—also resist buying in to the concomitant (mis)conception that they are inherently less than.

DSE: ...that (mis)conception is "ableism" (Rauscher, L., & McClintock, 1997; Hehir, 2005).

Me: Over time, I started to think about this dialogic interspace, grounded in the co-inquirers' shared experiences, not as incongruent with their inclusive school lives, but as conducive—vital—to them. In dialogue with one another, they made space to explore who they are, build confidence in their perspectives and how they choose to (re)present them, gain and give feedback on others' strategies to navigate barriers to experience, and feel safe making mistakes.

You: It seems important to note that, perhaps crucially, this interspace was not positioned as at odds with the co-inquirers' membership in the larger school community, but in addition to—augmenting—their place in it.

Me: Yes, that's so true. And through it, the students also used their conversations to begin exploring their allied and embodied experiences with autism and communicative diversity as interrelated (Sequence 2); sources of pride, which also spilled out into their classrooms (Sequence 4); the basis of a powerful call for more, better, inclusion for current and future students like them (Sequence 3); the roots of knowledge that position them (and through which they position themselves) as authorities on their experiences (Sequence 1).

[I think of Martin's creative writing piece and still feel the push and pull of his process as he decided to and followed through with writing it: "i understand that if people are to accept its hard to do so i explain what it was like to be me." Should he have to? But, if he chooses to...? As always I am (was he?) torn between an ideal future and the muddiness of now.]

Advocacy as (a Means and) an End

You: Describing the students as "authorities" ties back into their conversations about and demonstration of advocacy. It is clear from Act III (Sequence 1) that the co-inquirers have evolving and varied ideas about *what it means* to resist through advocacy and *why* they choose to do it (or not). And Act II gives a glimpse of what it looks like when they (re)present themselves to an audience, or the *how*? What about the students' developing individual and collective identities as advocates/teachers/activists, the *who*, as part of a larger movement toward inclusion?

DSE: If it is true that "counter-thinking and counteracting (against dominant hegemonies) create spaces for individuals to recognize and respect their own knowledge, see their own strength, and contrast their beliefs with 'officially' circulated knowledge(s)" (Connor, 2006, p. 360), then we also have to attend to the *what*—the form and function—of resistance and advocacy.

Me: I thought a lot about this during the inquiry, seeking to understand how the co-inquirers positioned themselves and one another as advocates, how I may have contributed to those developing self-conceptions, and the role of local understanding in our shared contexts (Kliwer & Biklen, 2001). The conversational thread about advocacy weaving through our Inquiry Group meetings (Act III, Sequence 1) revealed that the co-inquirers were troubling, enacting, and crafting varied notions of resistance and advocacy as part of who they are and what they do. They also blurred lines between these actions as choices and charges—critical to, and reflective of, their experiences as they interact with, and navigate, a world not made with them in mind.

You: But they are also not alone in those endeavors.

Me: No, they were in good company. There is a growing, critical mass of media that documents, and calls for new understanding of, experiences of autism and diverse communication. Take for example, the documentary *Wretches and Jabberers*, to which the co-inquirers alluded in conversations, as did I in interpretation of them. In fact, the

three-act structure of this dissertation is a nod to this, and other, film(s). *Wretches & Jabberers* was released in 2010, the year that Martin entered high school; it grew in popularity along the same timeline as these five students' emerging high school experiences. The film chronicles Larry Bissonette and Tracy Thresher's worldwide trip to teach people about autism, communication and inclusion, while also seeking solidarity in others similarly situated to join them on their continued journey.

You: Sounds familiar.

Me: Exactly. While some of the co-inquirers take to this model of advocacy more than others (i.e. Carlee: "I want to step aboard the Tracy train" vs. Martin's "I have my own train"), to deny the overall impact that (re)presentations like this particular film have had on them, and the contexts in which they are situated, would be remiss. *Wretches & Jabberers* contributes to and reflects a larger emergence of counter-narratives about autism, competence, and communication. It also offers an opportunity for individuals like the co-inquirers to see themselves reflected in empowered and empowering ways that for the most part were previously unavailable, or much less visible.

You: So that documentary both hinges on and exists as advocacy. But it is only one (re)presentation; we need more and different.

Me: Always. I have also situated these students' efforts as paralleling and intersecting with the larger neurodiversity movement, despite the fact that they do not explicitly place themselves in it. The co-inquirers often (re)presented themselves, their communication, and their experiences as unapologetic manifestations of diversity warranting new consideration and conceptions of inclusion.

DSE: You're right. "A concept of neurodiversity can help us to remain attentive to a different sensibility—indeed a different way of being in, and perceiving, the world—while at the same time reminding us of the need to construct the category of the human in the most capacious manner possible" (Savarese & Savarese, 2010, Section 5, para. 6)

Me: The students' approach to positioning themselves, autism, and communication, mirrors the larger call put forth within and through the neurodiversity movement and paradigm; language that I know circulates in these students' local and social contexts, but to which I cannot lay claim as the origins of, or impacts on, their self-conceptions. And while the concept of neurodiversity does not solely, or explicitly, center on the rights of individuals with autism to access a particular kind of communicative support (i.e., FC), it does champion a radical shift in re-constituting what communication and interaction *looks, sounds, feels, is* like in the first place.

DSE: Keep in mind that movements to reframe constructions of disability and affect change have always been a political crusade grounded first, always, in the experiences and actions of those with the most at stake. Further, the origins of disability studies as a field cannot be separated from the political advocacy and activism of the disability rights movement (Kliewer, 2008; Shapiro, 1993). In fact, it emerged as the result of and as a mechanism to continue rewriting(s) of what disability means, how and by whom it is

(re)constructed to counter the historical, political, and social power dynamics that position(ed) individuals so labeled at the margins of society.

Me: Thus, the intersecting communities of individuals who type to communicate, individuals with autism who claim an identity as neurodivergent, disability rights activists, advocates and their allies, parents and family members...

DSE: ...Scholars and allies of disability studies and disability studies in education...

NI: ...Researchers aiming to push boundaries of restrictive research frameworks...

You: ...Audiences seeking alternative paths to understanding non-dominant stories...

Me: ...All of those pieces converge(d) in and through these five co-inquirers' (re)presented experiences-as-advocacy.

You: So, these varied (re)presentations—in film, social media, literature, and these students' lives—happen alongside and with/in each other; they all draw upon the relational and ideological underpinnings of one another. Separately and together they put forth alternative viewpoints grounded in lived experience and insist on re-consideration of the status quo. In so doing, they counter the too often hostile cultural context for individuals who move and interact with/in the world in diverse ways.

Me: You took the words right out of my fingers.

[Just a little humor my co-inquirers would appreciate.]

As I watched the students co-construct their experiences and (re)tell stories about them, I had to acknowledge their place in a larger (ongoing) quest for justice for people with disabilities. Thus, I began to see the co-inquirer's descriptions of advocating, teaching, and expressing agency as rooted firmly in a conception of advocacy that centers on relationships and diverse communication as powerful vehicles of social change. Drawing on the work and words of other autistic self/advocates, like Larry and Tracy, disability studies scholars (i.e. Ashby, 2010; Biklen & Burke, 2006), autistic activists/bloggers (i.e. Faulds, Grace, Sequenzia, Sibley, Walker) all of whom have recognized the need to honor a broader range of activist(s)/isms, I see the students as part of a movement toward clarity around the role of lived experiences and stories as sites/cites of political and social resistance (Connor, 2006; Sequenzia, 2013).

You: And while all of that happens, even if the co-inquirers choose to tell their stories as a means of affecting change, and cultivate a sense of belonging by surrounding themselves with others who do the same, that is quite a bit of weight for anyone to carry, not to mention a teenager.

DSE: Keep in mind that “The goal in attending to counter-discourse is not to romanticize the resistance of marginalized groups but to understand ‘how this resistance clarifies the way power works’” (Vogel, 2001, p. 13 in Connor, 2006, p. 360)

You: It seems that counter-narratives, like Martin, Carlee, Ralph, Henry and Peter's self(re)presentations and the stories they come together to tell in this dissertation, exist to/as evidence of what novelist Adiche (2009) calls the "danger of a single story." Yet at the same time don't they also threaten to minimize these students' experiences to "single stor[ies]" as individuals?

Me: I want to raise and resist that possibility, even as I also rely on and (re)tell their/our stories to counter others.

(re)Telling New Stories, New Ways

NI: This friction between "relying on and (re)telling stories" is why we, as inquirers, have to think carefully about our methodological choices, the way we collaborate with participants/co-inquirers.

Me: Just as DSE scholars defy the pervasive idea that there are normative ways of being interacting in, and conducting research in/with schools and the world, so too does narrative inquiry push back against prescriptive approaches. For instance, this idea that we claim to know how to do research with and about particular people before we do it poses a problem for narrative inquirers; it certainly did for me.

You: So that explains, in part, why your methods, as well as your approaches to analysis and interpretation, varied over time. It seems like this inquiry is as much about the methods as the people.

Me: It was and is. I think of the inquiry process, and my (re)presentation of it, as characters in this story: living, breathing things that shifted every time I was confronted with another way that what I was doing as a researcher threatened to reify what I was trying to not do. In this written document, I mirror and tell the story through that process of discomfort, incongruity, and change by allowing each section of this work to methodologically and/or structurally contrast with those that it precedes and/or comes after. But you probably want to ask: what does this mean for *other* research, my own and beyond?

You: And does posing that question imply that it is one you can answer?

NI: Don't forget, though, restlessness is constructive. Narrative inquiry promotes understanding of "tensions in a more relational way, that is, tensions that liv[e] between people, events, or things, are a way of creating a between space, an inquiry space." (Clandinin, Murphy, Huber, & Orr, 2009, p. 82)

Me: Both intentionally and serendipitously, my/our process blurred lines across disciplines and methodologies. I continuously reshaped my approach to capturing, participating in, engaging with, and understanding my co-inquirers' stories in relation to one another's and my own. I often found that I had to keep returning to my Narrative Inquiry texts to confirm that I was in fact *still* a narrative inquirer.

- NI:** That's what we are here for (Clandinin, 2013; Clandinin & Connelly, 2000; Kim, 2016; Schaafsma & Vinz, 2011).
- Me:** And even here, as much as I hope elements of this research experience move other inquirers to think about methods "playfully and seriously at the same time" (Kim 2016, p. 187), I also want to resist the temptation to lay out this process in ways that implies it is a template.
- You:** No one is expecting you to, but there are important implications for others wishing to pursue the kind of collaboration upon which this inquiry and document is built.
- Me:** I agree, but which thread can I pull out and offer, without unraveling the whole thing? I came to this work with an awareness of the challenges and opportunities present in inquiring into, across, and through communicative diversity. Yet even as I pushed boundaries, I also created them.
- DSE:** Didn't we warn you? (Ashby, 2011; Cowley, 2012; Danforth & Gabel, 2008; Wickenden 2009)?
- You:** Wait, didn't you say you made intentional efforts to create space for and accommodate the co-inquirers' mode(s) of communication, their voices? Didn't you use video in an attempt to capture otherwise fleeting moments? Didn't you "check in" with the co-inquirers frequently and flexibly to account for time and fatigue associated with typing to communicate? Didn't you acknowledge from the start that things like transcription and(re)presentation are fraught? What gives?
- NI:** Didn't we prepare you? (Clandinin, 2013; Clandinin & Connelly, 2000; Kim, 2016; Schaafsma & Vinz, 2011)?
- Me:** I've asked myself the same things over and over. Could I have started this inquiry with the methods we ended with? And if I did (do)—set out with an intention to collaboratively construct narrative accounts with co-inquirers and dialogue in a digital interspace, while attending to their social/educational context—would it feel more smooth? Or would it just be a new starting point from which a different approach emerges? Let's not—you/we can't answer.
- You:** Maybe there is something to take away from your experience, then, about starting with an expectation for a co-constructed approach to inquiries.
- Me:** You're right, our collective negotiations about the "how, where, when, and then what?" of conversation could reverberate into others' research experiences. For example, even though I/we attempted to use time creatively in (group and individual) conversations across speech and typed text, I/we still privileged audio-based conversations and sought linearity within them (Phases 1 & 2). This led me to question the conduciveness of these methods to facilitating and (re)presenting experiences.
- NI:** We've been there.

Me: For instance, I had to address my own (and others') assumptions and consider whether waiting for the co-inquirers' to share the audio-output of their typed contributions (via a device or TAs' speech) somehow implied that their conversations existed more completely there than through the visual display of them on the screen. Doing so reflected a consciousness of the co-inquirers' communicative agency and an attempt not to attribute undue weight to words they typed, but did not want to share. But what did we lose in translation? Those ongoing tensions about what we were doing and who it was serving led me/us to explore a different (visual) realm of conversation as a means to more communicative efficiency and flexibility. In so doing, we crossed into and out of constraints on conversational space and time.

[It was when Ralph aptly pointed out that “google hang out [is] great something happens when you talk on this. The room gets so quiet you can hear a pin drop” that I knew I was not the only one feeling the difference of our digital interspace...]

You: It also seems like you kept trying to find different ways to make the mechanism of research more in line with your commitment to collaboration and non-normative participation. And it seems that when you, as a collective, moved away from audio-based conversations (via device output and TA/facilitator clarification and recitation) into Google Hangouts (with guidelines about who could and how to participate), this ownership became more evident.

Me: Yes, I felt that too. Since Google Hangouts conversations relied on the visual aspects of communication verbal (adult) mediation of students' typed comments became less necessary and—maybe unrelatedly, but maybe not—tended to yield less intrusive verbal support. All of the students' expressed, implied, and interpreted preferences call forth the narrow notions of what constitutes conversation, and subsequently the privilege that conventional communicators hold to interact, adapt to, shape, and affiliate across a diverse set of contexts and people. It also suggests the possibility that in choosing, and being supported to be, with one another as similarly situated peers, the co-inquirers acknowledged and resisted the impact of that communicative privilege in their experiences outside of B13. Did they find this space—each other—restorative? And if so, what does that *do* to the beliefs we have about what constitutes “inclusion”?

And speaking of inclusion....

You: Hold that thought. Let's keep going with this.

Me: You're right. There's more to cover here. Similarly, the process of writing, or (re)presentation, also took a meandering path.

NI: That's okay. Remember that writing is part of the inquiry, especially if you think about it as Richardson does: “...consider writing a method of inquiry, a way of finding out about yourself and a topic...a method of discovery and analysis. By writing in different ways,

we discover new aspects of our topic and our relationship to it. Form and content are inseparable.” (Richardson, 1994, p. 516)

- Me:** That makes sense, particularly in the context of Act II, the students’ self-(re)presentational narrative accounts. I aimed to narratively recount the arc of each student’s stories, but also oppose the insinuation that as researcher and writer *I*—my words—could do better than theirs.
- You:** But you still interfaced with and rearranged the co-inquirers’ existing words and (re)presented stories to create something different for this dissertation. You added in your voice. And you didn’t just do that there, in Act II; you did it everywhere.
- Me:** I did. I knew that to reproduce only the students’ typed text would not accurately represent the process by which they came to be, nor would it reflect the ways that they tell and live out their stories—performatively and/or relationally. Even as I funneled their storied experiences into (re)presentations on a page, I also needed to convey the dynamic and relational (inter)actions that undergirded them. I had to find ways to account for and describe those elements of (their/our/my) experience for which words fall short, even as I used the written word to capture them.
- You:** So you interacted with the students and their words—produced in a digital, co-constructed interspace, through public (re)presentation, in the context of time and their backstories—to put forth a counter-narrative (on research and school landscapes). But doesn’t the translation of their ideas into typed text-words—(re)presented here as a dissertation—mark a level of adherence to those expectations you/they aim to disrupt?
- Me:** Yes, of course. But if we are constrained by using socially translatable (inter)active vehicles to tell stories —words, documents—then the process by which we co-created them exists, also, to counter. The co-inquirers’ words were thus (re)produced and placed in this document through interaction and negotiation; the (re)presentations kept moving until we settled on an arrangement that made sense for us, and this (dissertation) space. What is here is so because of, and through, what we co-constructed it to be, together.
- NI:** But inevitably some things defy description. Accepting and reflecting that is part of narrative inquirers’ work: to insist/exist on a plane of partiality. Don’t forget about Neumann’s work concerning “the interplay of text and silence in stories of human lives.” You referred to it too often to leave it out. Didn’t you print out some of Neumann’s words and carry them with you in one of your mini notebooks?
- Me:** *[I rummage through my oversized, overfilled shoulder bag for the notebook with red poppies dotting a crisp white cover. I flip through for the folded half-sheet of printer paper responsible for its bulge when the notebook is (tries to stay) closed. The edges are worn and the creases intersect with the paragraph, leading my eyes to follow its now familiar words.]*

Yes. I felt the weight of Neumann’s words in all that I/we did:

People live their stories as much as they tell them in words. They live them in what they do not say. They live them in attending to the words of others rather than their own. They live them in the gaze that comes with inward thought and inward talk while others all around them are conversing. They live them in the feelings that come to surround them, that they give off in sighs and looks and gestures of simply in the feeling that our presence evokes in others. All of these forms of telling, though without words, and they are forms of telling that we can begin to read and hear through and also without words. (Neumann, 1997 pp. 107-108)

You: So even with all of the pages here (and there are many) and the details you have provided about how they got there, you want us to attend to on what is not here, too?

Me: Yes. And I also want you/me/us to always be thinking about the ways that research methods do and do not—can and cannot—make space for those “forms of telling” that resist being told. We owe that to each other.

[My head is spinning; what did I just say? I know that these muddy waters of methodology are as important as they are obscure. But it doesn't make them any easier to wade through. Maybe we should move back into something more concrete to ground us again.]

Inclusion as More than Space, More than Service, More than...

You: Okay, now let's talk about inclusion. It seems like your fluid approach to research design and methods draws on your experiences with and perspectives on inclusion. It feels like many of the things you attempted to put in place methodologically reflected the practices you highlighted as conducive to the co-inquirers' inclusion at Cedarbridge. I have to ask, was this school as good as it sounds? Was it an inclusive educational paradise realized?

Me: Of course the school was more complicated than the limits of words printed on paper allow. I'm aware that by approaching this inquiry from a framework of optimistic research early on that I risk romanticizing the practices and experiences within the school. I do hope that the tensions raised in Act I through the parents' timeline narratives (Sequence 1) and the interactive tour through Cedarbridge (Sequence 2) illustrate that this place was not perfect; to imply otherwise would contradict what it is that made the school, and those operating within in, *different*. There were absolutely sticking points, uncertainties, and fumbles along the way.

[Sati Wibble's (Ralph's mom) comment to me early on that, "I knew that everything wouldn't be rosy" rings in my ears. I did not, nor did anyone else, expect them to be.]

During my three years chronicling the co-inquirers' experiences in Cedarbridge, I did take note of things like the palpable tensions between the structural *and* social barriers the students faced in building meaningful relationships with their classmates. I often sensed

the irony in the presence of a segregated life-skills classroom (from which Peter hailed midway through this inquiry) in a school so committed to, and adept at, supporting the inclusion of *these* particular students with autism who type to communicate. Particularly early on in the inquiry, I felt the dominant narratives of demonstrated competence and behavioral compliance as gateways to inclusion surface, and (threaten to) overflow into the practices that positioned the school, and its personnel, as in opposition to them. I witnessed instances of bullying, adults talking over the students, and missed opportunities (by both students and staff). The reality of the financial and social privilege underlying the co-inquirers' and this school's ability to gain and garner access to inclusive opportunities was a constant tension in my own reflections and conversations with others.

[I am reminded of the conversation in which Lara Sanders [Carlee's mom] pointed out, "we were able to [move] but what about all the families who can't?"]

DSE: A Disability Studies in Education framework encourages you to pause on these sticking points in the experiences you witnessed and contributed to. That critical perspective was part of your lens.

Me: But I also will not reduce those experiences, or my (re)presentation of them, to that. I recognize that Cedarbridge and those operating within it—including the students—are not isolated from the larger cultural narratives, the pressures to per(con)form, the restraints inherent in attempting to break new ground and explore new territory, without getting lost.

DSE: These are common tensions faced by those working in the system while at the same time aiming to change it (Ashby, 2012; Rice, 2008).

You: But even as they were constrained by the current realities impacting all schools, you insist that Cedarbridge administration and staff engaged in important and progressive practices that impacted the students' co-inquirers' inclusive experiences...

Me: Yes, and I consider that to be more representative of the culture of this space, in this moment, with these five students. I saw examples of thoughtful and flexible pedagogical practice grounded in modeling a culture of respect: I watched support relationships develop in respectful, interactive, and creative ways tailored to students' evolving needs and preferences, even if at the same time complicating existing notions of adult support when it involves proximity to facilitate students' participation; I noted an administrative philosophy and presence that made these particular students' diverse communicative and corporeal experiences an expected and valued part of the school community, no matter how challenging the logistics; I watched as a team of professionals negotiated and joined forces to keep the students at the center. I witnessed collaboration across home and school as a means of filling in gaps in understanding about the students' experiences in both spaces; I engaged alongside the school personnel as they shifted from prioritizing academic access to supporting the co-inquirers (Carlee, in particular) in increasingly holistic and fluid ways.

And above all, I watched this process start from, but not stop at, a commitment to supporting these students' inclusion. During this time, I watched the co-inquirers grow and change in relation to each other, their classmates and different environments in ever-expanding and varied ways. I saw them enter into and build upon one another's experiences, both academically and socially. At the same time, I witnessed this school and the personnel in it mold and change across space and time in ways that I cannot help but attribute to these students' presence. It was *this* relational, fluid, and (inter)active approach—to figuring things out, embracing the complexity, problem solving through challenges with (not on behalf of) students, learning from missteps and building on small victories—that made this experience so different.

You: Isn't this the kind of humility—the kind inherent in asking the hard questions, admitting to not knowing the answers, but being willing to cross new (collaborative and experiential) boundaries—the ground upon which inclusion (of both brain and heart) should be built? And if that's the case, how can we extrapolate from these five students' unique experiences, in this moment, in this specific context to have an impact on others'; after all isn't that what the students, the school, you as an inquirer, are hoping to do?

Me: Yes, and no, and yes. I see the value in allowing these stories to speak for themselves; I tread lightly on the temptation to claim knowledge, and turn it into a blueprint, through which experiences like these could be replicated. Yet I also know how futile our collective efforts and interactions could be if I fail to draw out from them new questions and directions for those who follow to consider and build upon. Fittingly, that is the process by which these individual (myself, the students'), collective (our Inquiry Group), and institutional (Cedarbridge) stories evolved.

DSE: It is also reflective of how we, DSE scholars, have encouraged others to think about inclusion to begin with: "...a distinctly political 'in your face' activity that proceeds from larger political, as opposed to technical, questions about the nature of society and the status afforded to people in varying forms and structures of social organization...Its impetus emanates from the recipients of professional services rather than from being orchestrated by professionals themselves" (Corbett & Slee, 2000, p. 136).

Me: I don't think inclusion, broadly, has *gotten there* yet, though. Many of the promising practices and creative problem solving efforts I noted during the co-inquirers' experiences were guided and driven by the teaching assistants and head teacher. Essentially, those in specialized roles (TA/facilitators, the head teacher, school psychologist, SLP) were tasked with the adaptation and modification of materials and environments to meet each student's unique needs to facilitate inclusion. This worked for these individuals, in this space, during this time, but I do think the next question to ask—of all of us—centers on how we shift to an understanding of inclusion as the responsibility of schools (and *all* who co-exist within them) writ large.

NI: That seems like an appropriate direction toward which to head, since narrative inquirers keep "one eye on stories lived and told and the other on the stories and lives that live at their edges, creating an orientation that can feel more dizzying than directional, more a

muddling around in the myriad of stories that compose a life than making any situation in it clearer with the goal of moving it along” (Downey & Clandinin, 2010, p. 392).

Me: I saw movement toward this expanded, more dynamic approach to inclusion at Cedarbridge toward near the end of this inquiry, suggesting that perhaps I am not alone in advocating that we go down this path.

You: The active role that the Cedarbridge administration and staff played in supporting and preparing the community college for Martin and Ralph’s transition to college (Sequence 3) seems like one example of how they are pushing the boundaries of responsibility and tearing down walls demarcating educational experiences.

Me: I think so, too. And within the school I noted instances in which general educators started to collaborate and take ownership of the co-inquirers’ experiences in their classrooms, troubling hierarchies and building capacity for inclusion (Sequence 1, Act II). For example, Ms. Grecco shared that Mr. Hotchkins (general Education Environmental Science Teacher) welcomed her offer to provide him with the binder of notes, support materials, and modified assignments that she developed during the two consecutive years she spent in his classroom. She told me she planned to do the same for all of the classes in which she was supporting. While I envision a perfect world where these materials are collaboratively constructed by educators, paraprofessionals, and students, these initial endeavors to shift responsibility, anticipate diverse needs/preferences, and make adaptation/modification more efficient grounded in past experiences, is a route worth exploring.

You: Could those efforts within some schools then contribute to, or further necessitate, a reconsideration of the way we talk about about the concept inclusion across all schools?

[...In other words, how can the impact of this one set of experiences encourage that others, as Ralph put it, “follow the right path of equality?”]

Me: Well I’ve been thinking about that. We tend to consider and (re)present inclusive education as if it exists prior to students arriving, as if there is a (albeit complicated) combination of practices, attitudes, personalities, and experiences that come together to create an inclusive space. And maybe there is: the fact that four of the five co-inquirers and their families’ intentional efforts to find different, better inclusive educational opportunities manifested in physical relocation to Cedarbridge suggests the power, and elements of truth, in this understanding of inclusion. Yet, I also watched (and engaged in) the process of this particular school space, along with the personnel and students within it, shifting and changing in response to one another. This observed pliancy suggests that a conception of inclusion as emerging out from an existing set of commitments and practices doesn’t tell the whole story. We, as a field of scholars, inquirers, professionals, families, and allies, do not often talk about—and in my experience rarely make room for—the possibility that constructing equitable, fruitful, and relational educational spaces depends, in large part, on the students. Being with/in these students, at Cedarbridge, over time, convinced me that we should.

[I'm transported back to Dr. Desimone's office, learning from her that this fluidity was an articulated part of the(ir) process: "We are continuing to learn, there's no question about it. [The students] present us with new challenges or new areas of growth and we'll continue to develop in that way."]

DSE: The oft-referenced insistence that inclusion is a set of services rather than a place illustrates the fundamental incongruity of segregated special education with inclusion. And research, practice, and instruction on how to provide services inclusively undoubtedly influences how and to what extent schools move away from oppressive, segregated models into a more socially just and inclusive framework based on a metaphor of action rather than place(ment) (Ferri, 2015).

Me: However, over the years this approach, too, has been taken up in perhaps unintended ways, undermining the movement away from the individualization and diversity essential to inclusive delivery of services to students to a push for models of service delivery that we call inclusion. Most often those models center on keeping students in (a) place (a general education classroom) where adults provide services to support them. Not only does this narrative subtly subvert the objective of moving away from a framework grounded in place(ment), but it also does not adequately capture the urgency and potential of re-imagining what classrooms, school, looks/feels/sounds like to begin with. Even within school contexts like Cedarbridge ostensibly committed to doing otherwise, access in/to classrooms tends to hold weight over the experiences happening—co-constructed—with/in them.

[I still feel the ache of a sucker punch by the precision and candidness of Carlee's reflection on her inclusive experiences, "inclusion often means being expected to act as if I don't have autism.]

This assimilationist model of inclusion that requires students to fit in, rather than alter, educational contexts, yields a dynamic that threatens to overshadow the nuances and creativity possible, and inherent, in approaching inclusion as/in *interaction*.

DSE: You are not the only one whose lived and observed experiences rub up against the limitations of how we talk about, and what gets constituted as, inclusion. Other DSE scholars, too, have called attention to the need for a broadened approach to the diverse ways of being with/ in the world—beyond solely disability—that should comprise and come together through educational spaces; they have called for a more intersectional and radical approach to inclusion (Ferri, 2015). Some have highlighted the tensions growing out of the Standards Based Reform movement that result in the prioritization of access to academic content in segregated settings (i.e. prioritized curriculum classrooms) over access to fully inclusive instruction with their peers (Bacon, Rood, & Ferri, in press; Gallagher, 2010; Rood, 2015). Others point out that it is not just inclusion that is flawed, and call for abolishment of the whole education system as it is; we need to, they insist, start fresh (Smith, 2013). These scholars, as you/they/we do, all highlight the ways that a DSE perspective that pushes us to re-envision schools that do not pivot around normative notions of smartness and behavior (Broderick & Leonardo, 2016; Leonardo & Broderick,

2011). They also ask us to think about the ways that the presumption of competence—an otherwise broad and flexible conception—is often taken up as a reification of smartness as a form of property, serving as a means of gatekeeping to inclusive educational opportunities.

Inclusion as Experience

Me: It seems that in the same way that we can learn much about research methods from this inquiry into these inclusive experiences and the people comprising it, we can draw understanding about inclusion from narrative inquiry. So if we establish that communities of inclusion shape the spaces they occupy, could we then say that inclusion itself is experience in the way that narrative inquirers grounded in Dewey approach it: a three dimensional space calling attention to the temporality, sociality and place of the relational happenings within it. If that were the case, we could consider (experiences of) inclusion as both phenomenon and method(ology).

NI: Remember? Narrative inquiry involves "...both a view of the phenomena of people's experiences and a methodology for narratively inquiring into experience" (Clandinin & Caine, 2013, p. 166).

Me: So, for individual students, thinking about inclusive educational experiences requires an acknowledgement that they are temporally located and evolve, over time, in interactions with other people (personnel and students) and contexts (classrooms, school spaces, buildings). Likewise, their experiences are part of—interacting with—the inclusive experiences of others, over time. These inclusive experiences—as phenomenon and method—become the elements that shape those places (the classrooms, schools, districts, communities) in which they are situated. Do you remember when I talked about this on page 80? I'll wait here if you want to flip back to it and review Figure 1: Narrative Inquiry Commonplaces...

...You're back! Okay, so for schools, the implications of framing inclusion as experience (a phenomenon and method) necessitates acknowledging the ways in which it *must* evolve as/in (inter)action with students themselves. It requires a recognition that aside from the urgency of committing to inclusion as a vehicle of social justice, taking time to puzzle out what works and how, for which students, and in what contexts is part of the experience. To predetermine what those experiences will look like undermines the purpose of it: to build a strong community grounded in inclusion, in a particular space, at a particular moment in time.

You: If we frame inclusion as experience, narratively speaking, the sociality and place commonplaces help to situate schools and those who operate in positions of authority within them as located in (interaction with) a current and evolving political moment.

DSE: And *this* current political moment in education involves standardization; a continued call for evidence based practice; normative discourses that construct smartness and goodness as property (Broderick & Leonardo, 2016; Leonardo & Broderick, 2011); ableist attitudes

about who deserves to, and can, access communication; and even well-intended, but incomplete, manifestations of inclusion as solely a model of service delivery.

Me: Thinking about inclusion as collaboratively and intentionally crafted experience positions schools to (inter)actively subvert those pressures as part of a process of cultivating community, through and in inclusive experiences, *with* and for students. Inclusive experience as phenomenon and method, then, becomes a means for schools and those who operate within them to honor the process, engaging as co-inquirers alongside students, asking the hard questions, and seeking to understand from new angles. It creates important space for reveling in the mo(ve)ments, both big and small, in which time, context, and relationships converge and engender something worth replicating in different places, with other people; it is also what makes inclusion, experientially speaking, difficult to replicate.

You: So, there isn't a template or handbook schools could follow? It seems that you are proposing something else – that thinking experientially (and narratively) about inclusion could allow for acknowledgment of the inseparability of community to/as inclusion. Am I close?

Me: Yes, so the three dimensional inquiry space that constitutes inclusive experiences (as a phenomenon and method) is incomplete without (inter)action in/with the communities of inclusion they help to sustain.

You: [*cutting in*] ...And doing so could aid in re-directing us toward more holistic approaches to inclusion that both depend on and lead to conversation, belonging, and community; a path, I think, we are surprised to find not already well-worn in practice.

DSE: You know, Kliever (1998) described community grounded in interrelated corollaries of belonging and inclusion, and the harm done by evading either, not to mention both: “Community is not a location within circled wagons configured to keep out those charged with having differences that matter. It is instead a web of dynamic, constantly shifting relationships that encompass the individual [with a disability] and all other human beings” (pp. 95-96).

Me: I love that. I see and feel in Kliever's description the kind of belonging I watched the co-inquirers craft and refine in interaction with one another, even if only as a strand of that larger “web.”

You: But isn't this a slippery slope? If we focus so intensely on belonging and community, (which we already know are so important) as the roots of inclusion, don't we then risk moving to a model that privileges *only* the social aspects of school experiences of students with disabilities, potentially at the expense of academic opportunities?

Me: It is a delicate balance, which I often watch the students, families and staff at Cedarbridge attempt to foster, sometimes more successfully than others.

[*In other (Carlee's) words, "It's hard to draw a line between inclusion of brain and heart, because real inclusion is both."*]

Speaking of seeking balance, I'm reminded of the sign in that café that jolted me into thinking about what I was doing with this research (Chapter 3). In scrolling white font on a black background, it laid out a series of actions for *How to Build Community* and I wonder if perhaps there is something in that simple sign that can jolt me/us into action, again. The list of actions that comprise the "how" on that sign each contribute to, but are not in and of themselves, movement toward building community. What if we thought about those in the context of building—cultivating—inclusive communities?

You: What would happen if we started talking about communities of/as/through inclusion rather than an otherwise idealistic element, or by-product, of it?

Me: What if we took what we learned with/through the co-inquirers' experiences at Cedarbridge as the starting place? Could we agree on a set of efforts as springboards to building the kind of communities of inclusion that sustain themselves through (inter)action? I don't mean an exhaustive, prescriptive list, but a (growing) collection of actions each contributing to, but not in and of themselves, movement toward building communities of inclusion. I have some ideas.

You: I do too.

Us:

Building Communities of Inclusion

- *Know and value your colleagues/classmates/students*
 - *Anticipate and welcome diversity*
 - *Embrace and adapt for unexpected differences*
 - *Create new (inter)spaces*
 - *Affiliate to facilitate, not replace, inclusion*
- *Never look down, or think another person is not capable of being like you, or better*
 - *Share what you have* • *Ask for what you don't*
 - *Honor elders* • *Honor youth, too*
 - *Support (other) schools*
 - *Dance and sing together* • *Start a tradition*
 - *Make art*
 - *Tell stories, in whatever way you choose*
 - *Heed stories, in whatever way you can*
 - *Acknowledge when you "don't know";*
 - *(Learn to) ask for help if you need it*
- *Listen before reacting to/in anger* • *Mediate conflicts*
 - *Seek to understand*
- *Presume competence* • *Presume possibility*
 - *Learn from new and different angles*
 - *Interact in new and different ways*
- *Make room for mistakes* • *Expect—respect—failures*
 - *Celebrate small mo(ve)ments*
 - *Turn up the noise* • *Turn down the noise*
- *understand the compromises inherent in both*
 - *Be curious* • *Be humble*
 - *Know that no one is silent though many are not heard, work to change this together.*

You: That's heartwarming and all, but how does a list create (inter)action? How does it initiate movement?

Us: Together, when individual (student) and structural (school) experiences of inclusion—which generate and constitute communities of inclusion—are considered as both the means (method) and an end (phenomenon), we are brought again to the importance of stories. Thus, we—students, families, educators, paraprofessionals, teacher educators, allies, inquirers, scholars—must acknowledge the role of (re)presentations of inclusive experiences not as inspiration, not as prescription, not even as (only) practice, but as possibility.

Me: Maybe if we consider inclusion as experience the way narrative inquirers consider experience as phenomenon and method, then (re)presentation is also part of that process.

And if that is the case, can't we also say that the process—experience grounded in/driven by communities of inclusion—can be (re)presented as and through, (an) art?

[I can almost still hear the message chime announcing Ralph's comment: "I want to share my story through art."]

DSE: “When the stories are done right, and are the right stories, they have a point to make. Intellectually and emotionally. And that point can be a force to not just describe the culture, but to change it, a force for social justice. Just like any good literature, any good art” (Smith, 2013, 264).

ME: What if we took a hint from the art(self)making process that yielded the co-inquirers' collaborative mural? What if we thought about inclusion as a creative, collaborative, temporal and relational (inter)active process? What would it look like if we stopped zooming in on the tangible product—the art(self)—but instead tried to focus on the means—the work—to crafting it, in contexts with, in relation to, one another?

You: And if inclusion and research, as in this inquiry, are symbiotic, then can't the same be said of the experience of inquiring into experience?

Me: Is this turning into some kind of metaphor?

NI: Probably. We “seek out personal metaphors to highlight and make coherent our own pasts, our present activities, and our dreams, hopes and goals as well. A large part of self-understanding is the search for the appropriate personal metaphors that make sense of our lives” (Lakoff & Johnson, 1980, p. 232).

Me: Well I am not sure a metaphor, or a bulleted list will do much to change things...

You: But it can start, and exist in, conversation...

US:

[Zoom in] to the blankness of an untouched piece of canvas (or, in our case, a leaf shaped cut-out); a group of artists—i.e. a student, administrator, staff or maybe a researcher and his/her co-inquirers—begin with/in this blankness that will hold, transform into, the layers of support, experience, relationships, and learning that will become part of their inclusive experience, a picture-in-progress. They cannot know what it will look like before the process begins, nor will they be able to distinguish each layer from the others at the end. Of course, the school is equipped with a set of tools, perhaps in the form of the grounding (inter)actions of “building inclusive communities.” But the students also bring with them their own supplies. Together, they get to work; it is only in collaboration that the school (space, personnel, peers) and the student can lay out, share, and simultaneously employ this merged assembly of materials to develop each layer of (re)presented experience. Each layer blankets the whole canvas piece (or leaf), piling on top of those that come before and providing a new surface upon which the next will rest. Sometimes those layers are the manifestation of many different contributors' (inter)actions: a collage of experiences and (re)presentations. Others are the result of one contributor's intentional

brushstrokes and/or playful use of new and different media, knowing if this approach doesn't pan out then there will be other ways to (co)create the next layer on the top of this canvas piece. All along, no one quite knows where this is going, but they are committed to seeing it to an end.

[*Zoom out*]: If each student's (co-inquirer's) layered (leaf-shaped) canvas, crafted through relation and (inter)action (re)presents the day-to-day, month to month, year to year co-composing of their inclusive experiences, or pictures-in-progress, then when we step back we should see these individual pieces arranged alongside—overlapping with—one another. They take (new) shape. All come together to arrange and imbricate these (re)presented experiences on a larger surface (in our case, a wall sized canvas), acting as and (re)presenting a community of inclusion. Though you know that shared tools were used to produce each individual piece, and despite their similar (leaf shaped) silhouettes, no two look the same. They have been co-crafted layer by layer, across varied moments, with/in different relationships, using assorted media. You know that the glue may not hold; the big picture may/will fade, naturally and with time; the edges of each small piece may tatter. You know that part of this creative process involves cyclic deterioration and restoration; ongoing incorporation—weaving, layering, (re)placing—of new materials into each piece, and thus new pictures-in-progress onto the ever-changing big picture. This palimpsestic re-negotiation constitutes a creative process that is not, can never be, static. That, here, is the point. It is the process—the co-crafting, the (inter)action—we can learn from as it tells these stories it holds.

[*Zoom out farther*]: Now imagine you enter a gallery (or an open space, a long corridor, a virtual interspace, whatever kind of display-space you find most engaging). In it, you are faced with this co-created layered (re)presentation (growing out) of inclusion. As you begin to examine the pieces (leaves), you can only make out the top layers of each: some have rough edges while others are more fresh, the glue is still wet. When you move still farther back you admire the whole; a (re)presentation comprised of (re)presentations. You cannot distinguish the co-composition process(es)—the negotiations, (inter)actions, small and big mo(ve)ments—that lay beneath and within each one. You know that the process had to have happened, you want badly to know what it looked/sounded/felt like, but from where you are all that you have is what that process—those negotiations, (inter)actions, mo(ve)ments—yielded: a big picture comprised of smaller ones.

[*Zoom out farther still*]: You realize that this big picture is not the only one in this gallery (open space, corridor, virtual interspace, etc.). You clutch in your hands a black postcard with white scrolling font about “building communities of inclusion,” a grounding theme of this exhibit to which you refer as you pass through the space. You are surrounded by a series of related, but different, big pictures. Each of them resembles the others in notable ways (maybe they all portray interpretations of trees?) all are comprised of small pieces woven, layered, stuck together on top of and overlapping with the others. Yet none of these big pictures is quite the same as the others; they each occupy, create, their own space. Each one draws you in, sparks your curiosity, urges you to spend time with it before moving on to the next.

[*Zoom back in*]: You go back to your place—a classroom, an office, a hallway, a studio, an online interspace—to start crafting your own picture. You are brimming with ideas, drawn from a myriad of models (big pictures) that you have studied from both up close and far back. You have the tools everyone tells you that you need. You have a set of small blank pieces and a

destination—a space—for them to come together. What you saw was beautiful, but it was theirs. You cannot just try to copy it. But where, with whom, and how do you start at the beginning when all you have seen is (are) the end(s)? You begin (again), relying on the tools you know those before you have used; your eyes search a black and white bulleted list you keep close by, reminding you of what goes into “building communities of inclusion.” You wonder if these tools will be enough. What will the others with whom you will co-craft *this* piece of the big picture, bring to the table? You cannot know what this will look like before the process begins, but from what you hear, you will not be able to distinguish each layer from the others at the end. You alongside the others—the student, support team, teachers administration, the peers, your co-inquirers—begin to mark up the canvas.

So What?

Me

as NI: Here we are at the (an) end of this final research text (the dissertation) that braids together the experiences of Martin, Carlee, Ralph, Henry, Peter, and I—our overlapping and intersecting lives with the complexities of temporality, sociality and place woven into and spilling out from the product. This big picture comprised of smaller ones is not neat (a reality I struggle with even as I type this), as I must honor the messiness of these, our, lives as lived. I am aware that you cannot know what this looked like before the process began, and you cannot distinguish each layer from the others here, now, at this end. This story will not (ever) be complete; the partial and fluid nature of (this) inquiry is a presence rather than an absence in this work, as even the most tightly braided threads have gaps between them. In these final pages, I only hope to have provided opportunities for you to “wonde[r] about and imagin[e] alternative possibilities”(Clandinin, 2013, p. 52) alongside me/us

Whatever it is that I/we have done, or left, here I consider this experience and its (re)presentation a counter-narrative, rooted in an inquiry process that “opens up the possibility for growth, by... coming to tell and live what at least seem, in the moment, to be better stories” (Clandinin, 2013, p. 203). These stories (re)presented here, (inter)act with/in—talk back to—the ones that constantly threaten to overpower them.

[These are stories that are not easy to hear, tell, or to get told. They come from places that others have written off, from mouths of minds that often are not seen as worthy of listening to. This isn't me theorizing about the value that is or is not ascribed to peoples' lives and stories; it is me telling of what I've seen and why I care. These narratives belong to those who sit, or have sat, in segregated classrooms and are asked to put square blocks into round holes day after day because, it is presumed, they are not smart enough to do anything else. They come from the bodies that some assume don't work, from which come strings of sounds; contributions that, they are told, make no sense. They are the stories that get at what it feels like to rock back and forth, run hands over smooth surfaces, watch the world from different angles, in different colors. They are the stories of how Anne, along with MJ, a small community of inclusion and I, navigate(d) academic and social spaces that were not constructed with her (us) in mind. They are the stories of what happens when a school (and those in it) tries to do something

different, better. They are the stories of my co-inquirers, figuring themselves out at the same time they feel compelled (for a variety of reasons) to teach others what it means to be, and be with, them. They are the connections I see between these lives and networks of support (sought and built) around them/us. They are stories about growing up, being apart, (never) being alone, coming together. They are the stories that blur lines and resist the notions of in/dependence and I/dentity. They are the stories I wonder about and am conscious of the risk of never knowing (being known).]

**Me,
as NI**

in DSE: In the preface to the *Handbook on Narrative Inquiry*, Clandinin (2007) poses questions to consider about the purpose of narrative inquiry as a methodology: “Does [it] set out to change the world as people engage in the processes of narrative inquiry with their participants, or is it a more descriptive kind of inquiry” (p. xv)? Craig and Huber’s (2007) more definitive statement, from the same handbook, that narrative inquiry, “...seeks to understand, not to critique” (p. 272), does not leave much room for the kind of change Clandinin references as inherent, albeit questioned, in the methodology. Reflecting on this tension, my own position as a researcher, and my grounding in Disability Studies in Education, and my experiences with my five co-inquirers, *this* inquiry and its purpose lie somewhere in between. Given my use of narrative inquiry as a means to creating new interspaces (Sava & Nuutinen, 2003) in which to engage the voices and experiences of co-inquirers, I feel that it is my role to “seek to understand” and (re)present their stories, rather than critique them. Yet, doing so may not be enough. Or might it be too much?

**Me
as DSE**

in NI: My position as a researcher grounded in the tenets of disability studies in education complicates Clandinin’s and Craig and Huber’s articulations, and tensions, around purpose. I acknowledge through relationships with my co-inquirers, their circles of support (including their TA/facilitators, families, siblings, friends and teachers) and more thorough understanding of their (our) co-constructed stories that I/we do both: we “describe” at the same time I/we/they “set out to change the world” Clandinin, 2007, p. xv), a larger space that too often threatens to eclipse those very stories and people. Doing so often requires attention to and critique of those things (systems) that perhaps defy (rational) understanding (or should).

[The interesting thing about stories told by people who (must or choose to) communicate in diverse ways is that there is always room for interpretation and always the presence of an interpreter. As friend and colleague, student and teacher, interpreter and inquirer, I claim my own understanding and recognize the room for a miss (interpretation).

Yet, while my narratives have been linked with those of diverse communicators, they are at the same time, often [positioned as] in contention. My friend Anne is just as much in the spaces we share as I am; her perception of the moments is equally valuable and present. The co-inquirers’ experiences weigh equally in this document, but I am the one in a position to arrange, print, and defend it. I am the one who will take something tangible away from it. The

narratives in which we are situated that privilege my voice—one that speaks and writes—tell me that in some ways mine “count” more. They are the systems that (continue to) make it tempting for students, parents and school personnel to “take what you can get.” These are the systems that Cedarbridge (and the personnel who comprise it) work to resist, even if also perpetuating, as they seek to support diverse ways of being, learning, and (inter)acting. These are the systems that drove Martin, Carlee, Ralph, Peter and Henry, to Cedarbridge and those that they continue to navigate as time, relationships and space shift and change in response and relation. These are the systems that position them/us/this inquiry, as trailblazers on a path that screams for more traction.]

Me: The construction of this inquiry in many ways mirrors my process of learning about and wrestling with/in these complexities around my/self, narrative inquiry as a methodology, the unique characteristics of the co-inquirers’ communicative needs and preferences, the systems in which they are situated and the discomfort of entering into an area of uncertainty. All I can conclude is that based on our experiences together, as well as my moral, academic and personal commitments, I/we did what we set out to do. We adhered to Rolling and Brogden’s (2009) advice—“Take the risk to find a personal style, make your acts of research to your own casts, and then take the risk of contributing your ways of doing to the constitution of a community of like-minded doing”—believing (trusting) that they are right when they insist that, “New ways of doing produce new habits of doing, which in turn produce transitions in our disciplinary states of mind and being” (p. 1147). Above all else, I have to start (and end) with this in mind.

[These (re)presentations of (our) stories aim to counter those powerful dominant narratives, forces, systems, constraints, to put out into the world an opposing, even if quieter, viewpoint. They prove that the cycles in which we are wrapped/rapt do not tell the whole story, but only serve to reproduce themselves in familiar and oddly comfortable ways. I hope that together we have told—been a vehicle of—the stories that are unconventional, raw, and beautiful so that, perhaps, the uncertainty around that which is difficult to hear/see/feel/do becomes just a bit less cogent and we all become a bit more curious about (how to seek, tell, and grasp) the stories (and people) we think we already know.]

Us: But we are (all, only) one set of stories.

You: So that’s it then? That’s the end?

Me: No. It is (only, ever a) beginning, again.

EPILOGUE

[.]

This page
 Is not a page
 But a space.
 These words
 Are not here
 To say
 But to hold—
 All
 That is not
 was not
 (cannot be)
 said
 sayable
 read
 readable
 translated
 translatable
 interpreted
 interpretable
 (into
 out of)
 words.

But they are t/here.

This page
 is not a page
 But a border.
 These feelings
 —frictions—
 Are not mine
 yours
 theirs

They are
 Ours
 are not questions
 for answers,
 They are
 They were
 those
 Not asked
 Not seen
 Not known

Appendix A
Summary of Field Texts

Phase 1 Data/Field Texts

Class Observations (majority videotaped; field notes)

Students' public presentations

Interviews (students, families, TAs, teachers)

Meetings (field notes)

Research memos and reflexive writing

Phase 2 Data/Field Texts

1 observation, 9 IG sessions over a 6 week summer session (video)

Student artifacts (photo, text, and reproduction)

Research memos and reflexive writing

Phase 3 Data/Field Texts

16 sessions over 16 weeks (video; Google hangout transcripts)

Interviews (students, families, teachers, administration) & Classroom observations (video)

Students' public presentations

Artifacts (photos and/or originals; primarily shared through Google Hangouts)

Research memos and reflexive writing

Appendix B

Guiding questions for initial interviews

Students

- 1) I'm interested in knowing how things are going for you in school. Can you share some examples of:
 - a. Things that are going well
 - b. Things that are challenging
- 2) What are the things, or people, that contribute to you feeling included in school?
- 3) What would you like teachers or peers to know about you?
- 4) What are your goals for High School?
- 5) What else do you think is important for me to know about your experience at school right now?
- 6) Do you have any questions you want to ask me?

Parents

- 1) Can you summarize the events that brought you/your child to Cedarbridge High School?
- 2) How do you feel things are going overall?
- 3) What role do you play in supporting _____'s day to day school experiences?
- 4) What do you see as the big successes and/or challenges in school at this moment?
- 5) Can you share any stories that really stick out as examples of _____ that made you proud? Surprised you? Instances of _____ standing up for or advocating for himself and controlling his own experiences?
- 6) What are your hopes for _____'s future?

Teaching Assistants

- 1) Please talk about your background (including previous experiences with students who type to communicate)?
- 2) How "things" in school going overall?
- 3) Can you give some examples of strategies you have used to support _____ inclusion?
- 4) What are some challenges to this process/your role in it?
 - a. Where do you go for support?
- 5) What are some examples of things you consider to be successes?
- 6) Can you share any stories that stick with you about _____? i.e. a time they surprised you, or taught you something? A time when things went well, or didn't that sticks with you?
- 7) Do you have any questions you he/she is currently contemplating (about student/school)?

Teachers

- 1) How have you thought about prioritizing and supporting _____ to be a member of this class?
- 2) How have you thought about/supported academic participation? Social participation?
- 3) Can you share any stories that stuck with you during your time with each (any) of these students? A time when he/she taught you or others something? A time when something went really well, or didn't go so well that struck you?
How has your relationship with this student impacted your approach to teaching (if at all)?
- 4) What would you want other teachers to know if they haven't had this experience?

Administrators

- 1) I am most interested in hearing about your experiences with the five HS students who type to communicate- how you have supported their membership in the school community from your position as _____?
- 2) Can you talk about your learning process as the students began entering the High School- what did/does supporting them entail on your end?
- 3) Can you share any stories that stuck with you during your time with each (any) of these students? A time when he/she taught you or others something? A time when something went really well, or didn't go so well that struck you?
- 4) What would you want other _____ to know if they haven't had this experience?

Appendix C
Ways to Tell a Story (Summer 2014 Brainstorming)

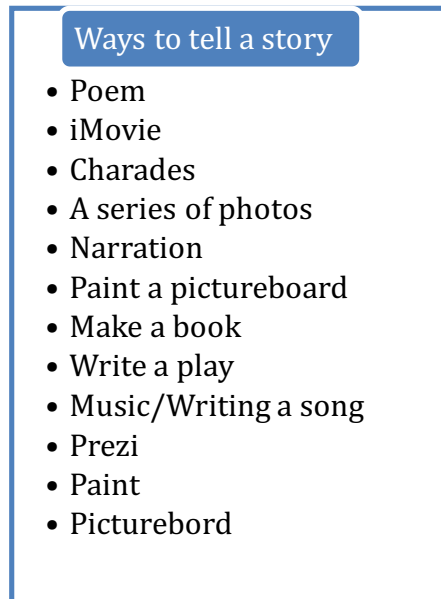


Figure C2: Ways to Tell a Story (broad)

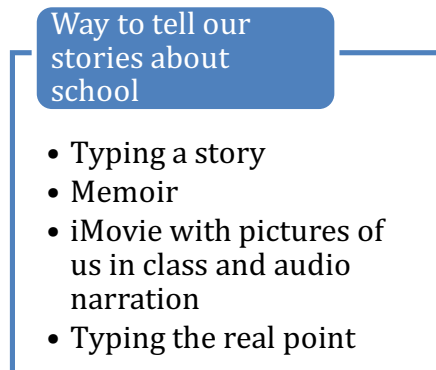
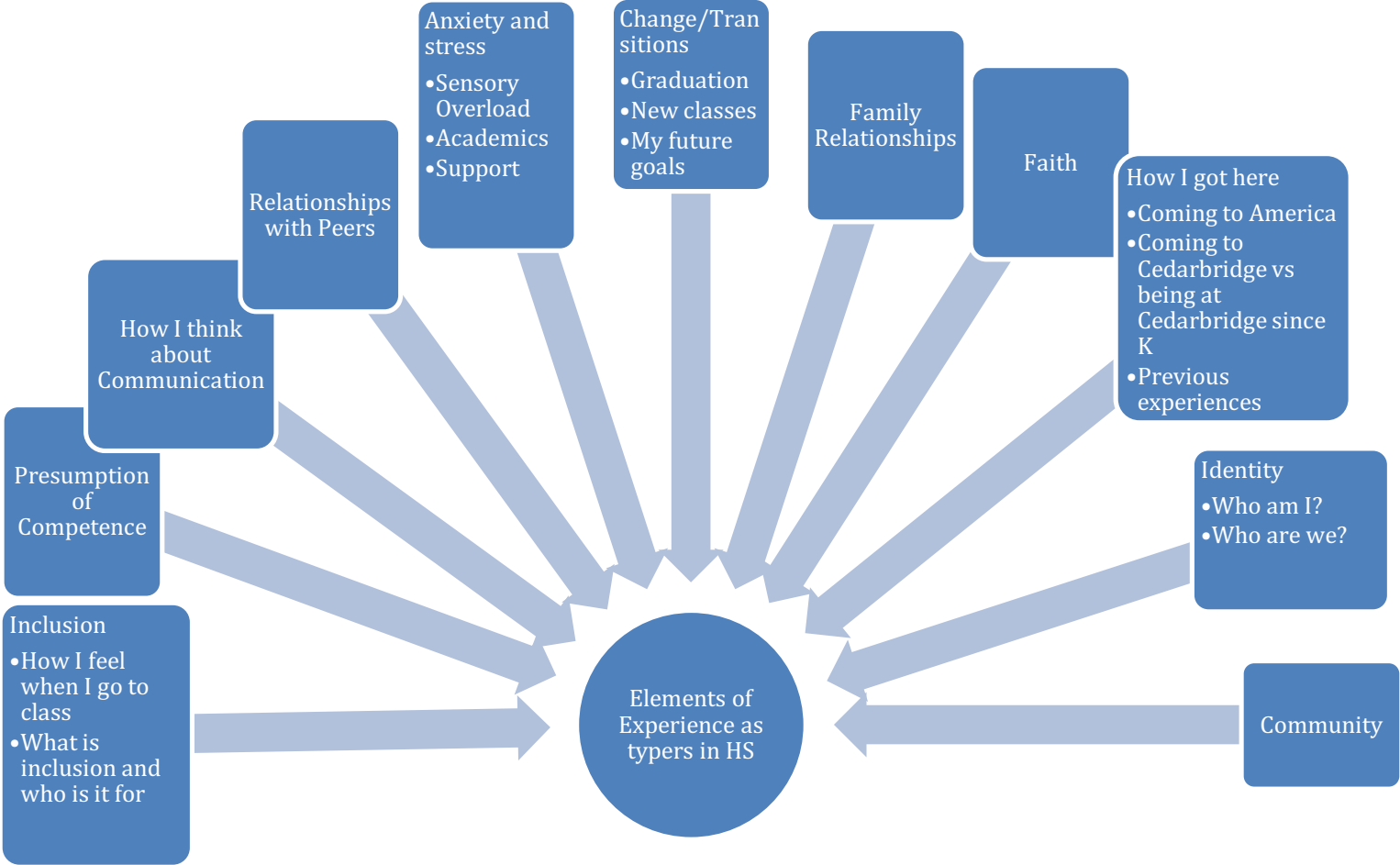


Figure C1: Ways to tell our Stories about School

Appendix D
Topics for Discussion (Derived from Summer 2014 Inquiry Group meetings)



Appendix E
Group Guidelines (Developed Summer 2014; Revised Spring 2015)

Group Guidelines

- Be respectful
- Encourage each other
- Listen
- Quietly take a break if needed
- Everyone's ideas are important
- Say what you mean and not what you think we want to hear
- Keep an open mind
- Don't talk when others are talking
- Adults should remember this is a student group
- Whole body, active listening
- We are one

Appendix F Pre and Post Google Hangout Transcript Maps

Figure F1: Pre-google hangout transcript map excerpt

Conversation Thread	Typed contribution	Audible, spoken words /sounds part of conversation	Audible spoken words/ sounds not part of conversation	Notable movements	Other notes
(greeting)	Henry: Yes hello Casey [00:08:29]				
1 (Tech conference planning)		Casey: Hi Henry we are just talking about the technology conference			
			Peter: Casey do you have gum?		
			<i>[Henry makes a loud sound and brings his hands to his face, cupping his nose and mouth. All students are typing; side conversations and muffled communicative support]</i>		
			<i>[Martin makes a loud high pitched sound and hits his chin with the back of his hand. Martin and Henry play their comments at the same</i>		

			<i>time. They are both inaudible.]</i>		
		Casey: Woah woah woah			
			Ms. Grecco: [<i>to Martin</i>] OK. Let Henry do his again.		
1	Henry: Yes my mother will handle it				
1	Martin: I really do not I will help [00:10:19]		Ms. Grecco: I really do not, I will help, he said.		
1		Casey: So do you mean that you don't want to present at the conference but you would help but a presentation together? Is that what you are saying? [<i>to the whole group</i>]			
1 (clarification)		Casey: Who said they needed a reminder?		Ms. Hamden: [<i>points to Ralph</i>]	
1 (clarification)		Ms. Grecco: Ralph		[<i>Casey gets up and goes to Ralph's side of the table. Gives him a reminder of the premise of the conference privately</i>] [00:10:44]	

	Martin: Yes		<i>[Henry makes a loud sound, covers his ears and begins typing again]</i>	<i>Casey returns to seat] [00:11:45]</i>	
(clarification)		Casey: <i>[to Martin]</i> Martin was that yes to me?		<i>[Ms. Grecco turns the iPad toward Casey to show her what Martin typed]</i>	
1 (clarification)		Casey: Peter, did you answer?			
		Ms. Farber: He's thinking about something else right now.			
(clarification)		Casey: So, Henry, you're in? I'm wondering if <i>[under breath]</i> he did say he was in right?		<i>[Casey stands up to look at Henry's iPad]</i>	
1 (clarification)		Mr. Meyer: He said my mother will handle it.			
1 (clarification)		Casey: <i>[To Henry]</i> What does that mean?			
1	Ralph: No thank you [00:12:20]				

Figure F2: Google hangout transcript map excerpt

Conversation thread	Typed contribution	Audible, spoken words/sounds part of conversation	Audible spoken words/sounds not part of conversation	Notable movements	Other notes
2 (prom)	Ralph (2:12 PM): I asked Tia to the senior ball. I rented my tuxedo. Tia is wearing blue.		<p><i>[Henry is humming rhythmically as he types. Besides that, the room is quiet. The Google Hangout message alert chimes each time a message is sent.]</i></p>	<p><i>[Martin is rocking back and forth in his chair while he types.]</i></p>	
2	Casey (2:12 PM): Congratulations Ralph that is so exciting!				
2	Peter (2:13 PM): Awesome ralph you go man! How much fun you will have				
1 (what did you do...)	Casey (2:13 PM): I'm very glad Henry.				
1; 3(family)	Ralph (2:13 PM): No hung out with dad he is home from India				
1	Casey (2:14 PM): Peter what did you do out in the community?				
1; 3	Peter (2:14 PM): Awesome Ralph I am sure you are glad dad is home				

2	Henry (2:15 PM): Yes. I am excited for you my friend.				
1	Peter (2:15 PM): Casey I went to the YMCA, the mall and lunch				
3	Martin (2:15 PM): ralph it must be hard when he is away				
1	Ralph (Apr 13, 2:16 PM): Martin what kinds of thong did you do				
3	Ralph (Apr 13, 2:16 PM): It was hard martin				

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- Young, S. (2014). *I'm not your inspiration, thank you very much* [Video file]. Retrieved from https://www.ted.com/talks/stella_young_i_m_not_your_inspiration_thank_you_very_much/transcript?language=en

Casey L. (Reutemann) Woodfield

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EDUCATION

- Ph.D. in Special Education** Spring 2016
 Syracuse University, Syracuse, NY
 Dissertation Topic: *Blazing trails, being us: A narrative inquiry with five high school students with autism who type to communicate*
 (Chair: Dr. Christine Ashby; Committee Members: Dr. Beth Ferri, Dr. James Haywood Rolling, Jr.)
- Master's of Science Cultural Foundations of Education** Fall 2010
 Syracuse University, Syracuse, NY
- Certificate of Advanced Study in Disability Studies** Fall 2010
 Syracuse University, Syracuse, NY
- Bachelor of Arts in American Studies** Spring 2009
(Business & Writing Minors)
 Providence College, Providence, RI

PROFESSIONAL EXPERIENCE

- Research Experience**
Associate Clinical Researcher February 2016-Present
 Hussman Institute for Autism, Catonsville, MD
- Developing research and practice to support communication and inclusion of individuals with autism.
- Research Assistant** Fall 2014-Fall 2015
 Institute on Communication and Inclusion, Syracuse University, Syracuse, NY
 in collaboration with Hussman Institute for Autism, Catonsville, MD
- Developed training materials and engaged in research on autism, inclusion and communication
- Research Apprenticeship** February 2014
 Dr. Christine Ashby, Syracuse University, Syracuse, NY
- Conducted qualitative research study utilizing interviews and video taped field observations to understand the experiences of students who type to communicate in high school
- Research Assistant** Fall 2012-Spring 2013
 Institute on Communication and Inclusion, Syracuse University, Syracuse, NY

- Coded and analyzed video data of training study on skill development of individuals who type to communicate and were working towards physical independence

Research Assistant

Jan. 2010-Sept. 2010

The Lawrence B. Taishoff Center on Inclusive Higher Education, Syracuse, NY

- Collected data during summits on Intellectual Disability in Higher Education

Grant Funded Research Experience

Research Assistant under Ashby, C. & Biklen, D. Co-Principal Investigators. (2011-2013).

Research and training on communication strategies for people with autism. John P.

Hussman Foundation.

- Assisted in development and execution of qualitative research projects utilizing video data collection and analysis methods

Teaching Experiences

Syracuse University

Department of Teaching and Leadership

Instructor

- SPE311: Perspectives on Disabilities (Summer 2015)
- SPE 644: Significant Disabilities: Shifts in Paradigms & Practices (Spring 2015)
- SPE 700: Narrating Competence: Exploring the Discourse of Autism (Spring 2014)
- SPE 705: Psychoeducational Evaluation and Planning for Exceptional Children (Spring 2013)

Teaching Assistant

- SPE 652: Assistive Technologies for Integrating Students with Special Needs (Summer, 2014)
- SPE 324: Differentiation for Inclusive Education (Spring 2014)
- SPE 311: Perspectives on Disabilities (Fall 2012)

PUBLICATIONS

Ashby, C., **Woodfield, C.** & Delia, Q. (in press). Communication is the root of necessity: Constructing communicative competence. In C. Ashby & M. Cosier (Eds.), *Enacting change from within: Disability studies meets teaching and teacher education*. New York, NY: Peter Lang

Asby, C. & **Woodfield, C.** (in press). Communication under fire: Defending communication rights for all. *TASH Connections*.

Woodfield, C. & Ashby, C. (2015). 'The right path of equality': supporting high school students with autism who type to communicate. *International Journal of Inclusive Education*.

Ashby, C., Jung, E., **Woodfield, C.**, Vroman, K. & Orsati, F. (2015). "Wishing to go it alone": the complicated interplay of independence, interdependence and agency. *Disability and Society*, 30(10), 1474–1489.

Theoharis, G., Causton, J. & **Woodfield, C.** (2015). Leading inclusive schools for students with disabilities. In G. Theoharis & M. Scanlan, (Eds.) *Inclusive leadership for increasingly diverse schools*, (pp. 13-38). New York, NY: Routledge.

Woodfield, C., Jung, E. & Ashby, C. (2014). "Hoping for Greatness": Exploring the Notion of "novicity" in Communication Support Partnerships. *Research and Practice for Persons with Severe Disabilities*, 39(4), 274-289.

Manuscripts in Preparation

Woodfield, C. & Delia, Q. (2016). "*Inclusion of the Brain Versus Inclusion of the Heart*": *Constructions of Competence in Schools*. Manuscript in preparation.

Woodfield, C. & Myers, B. (2015). "*We are one*": *A collaborative group inquiry with high school students who type to communicate*. Manuscript in preparation.

PRESENTATIONS

National Peer Reviewed Presentations

Woodfield, C. (2016, April). *Blazing trails, being us: A narrative inquiry with five high school students with autism who type to communicate*. Paper presentation at American Educational Research Association (AERA), Washington, DC.

Vroman, K., Ashby, C., Woodfield, C., Dickens, B. (2016, April). *An Unspoken Code: collaboratively developed ethics for communication support professionals*. Paper presentation at American Educational Research Association(AERA), Washington, DC.

Ashby, C.E., **Woodfield, C.**, Vroman, K., Orsati, F. & Smith, A. (2015, December). *Communication [still] under fire: New directions in research and practice for individuals who type to communicate*. Workshop presentation at TASH (formerly The Association for Persons with Severe Handicaps) Annual Conference, Portland, OR.

Ashby, C., **Woodfield, C.**, Dickens, B. & Vroman, K. (2015, December). *The right to respectful communication support: Developing a code of ethics*. Paper presentation at TASH (formerly The Association for Persons with Severe Handicaps) Annual Conference, Portland, OR.

Woodfield, C. & Delia, Q. (2015, April). "*Inclusion of the Brain Versus Inclusion of the Heart*": *Constructions of Competence in Schools*. Paper presentation at American Educational Research Association (AERA), Chicago, IL.

- Woodfield, C. & Myers, B.** (2015, April). *"We are one": A collaborative group inquiry with high school students who type to communicate*. Roundtable presentation at American Educational Research Association (AERA), Chicago, IL.
- Vroman, K., **Woodfield, C.**, Jung, E. & Ashby, C. (2015, April). *Communication (still) under fire: The role of disability studies in education in the fight for communication access*. Paper presentation at the Second City Disability Studies in Education Conference, Chicago, IL.
- Woodfield, C. & Ashby, C.** (2014, December). *"The right path to equality"; Supporting high school students with complex communication needs*. Paper presentation at TASH (formerly The Association for Persons with Severe Handicaps) Annual Conference, Washington, DC.
- Jung, E., **Woodfield, C.**, Vroman, K. & Nichiporuk, K. (2014, December). *iPad for communication: iPad app training for the development of independent typing*. Paper presentation at TASH (formerly The Association for Persons with Severe Handicaps) Annual Conference, Washington, DC.
- Ashby, C., Jung, E., Orsati, F., **Reutemann, C.** & Vroman, K. (2014, April). *The complicated interplay of independence, interdependence and agency*. Paper presentation at American Educational Research Association (AERA), Philadelphia, PA.
- Reutemann, C. & Ashby, C.** (2014, April). *All it takes: Communication, competence and support of high school students who type to communicate*. Paper presentation at American Educational Research Association (AERA), Philadelphia, PA.
- Rood, C. & **Reutemann, C.** (2014, March). *Restrictions of retelling: Memory at the intersections of gender and disability*. Paper presentation at Equity and Social Justice Annual Conference, Syracuse, NY.
- Jung, E., Ashby, C., Orsati, F., **Reutemann, C.** & Vroman, K. (2013, December). *Comparative study on linguistic features of people with autism and their facilitators*. Poster presented at the TASH (formerly The Association for Persons with Severe Handicaps) Annual Conference, Chicago, IL.
- Ashby, C., Jung, E., **Reutemann, C.** & Vroman, K. (2013, December). *Making the dance look easy: Lessons learned from facilitated communication trainers*. Paper presentation at the TASH (formerly The Association for Persons with Severe Handicaps) Annual Conference, Chicago, IL.
- Ashby, C. & **Reutemann, C.** (December, 2013). *Typing to communicate in School: Getting it going and keeping it going*. In Building a Community of Knowledge and Support for Communication (workshop) at the TASH (formerly The Association for Persons with Severe Handicaps) Annual Conference, 2013, Chicago, IL.

- Ashby, C., Jung, E., **Reutemann, C.** & Vroman, K. (2013, December). *Developing independent typing skills in individuals with disabilities who type to communicate*. Poster Session at the TASH (formerly The Association for Persons with Severe Handicaps) Annual Conference, Chicago, IL.
- Reutemann, C.** (June, 2013). *All it takes: Communication, competence and support of high school students who type to communicate (preliminary findings)*. Paper presentation at Society for Disability Studies Annual Conference, Orlando, FL.
- Reutemann, C.** (2013, June) "*Fading support: Quantitative outcomes and trends*". In "A world of difference": Analyzing the development of independence of individuals with disabilities in typing to communicate (Panel). Paper presentation at the Society for Disability Studies Annual Conference, Orlando, FL.
- Reutemann, C.** (2012, November). *Typing Lives: Blogging as life writing and a means to building self advocacy in high school students*. Poster session at the TASH (formerly The Association for Persons with Severe Handicaps) Annual Conference, Long Beach, CA.
- Chadwick, M., Seybert, J., & **Reutemann, C.** (2012, November). *Be the driver of your own communication training*. Workshop presentation at the TASH (formerly The Association for Persons with Severe Handicaps) Annual Conference, Long Beach, CA.
- Ashby, C., Orsati, F., Jung, E., **Reutemann, C.**, & Tracy-Bronson, C. (2012, November). *Making the dance look easy: Lessons learned from highly skilled facilitated communication trainers*. Paper presentation at the TASH (formerly The Association for Persons with Severe Handicaps) Annual Conference, Long Beach, CA.
- Ashby, C., Chadwick, M., Orsati, F., Jung, E., **Reutemann, C.**, Tracy-Bronson, C. (2012, August). *Achieving greater physical independence when typing to communicate: A training study*. Paper presentation at the TASH (formerly The Association for Persons with Severe Handicaps) Annual Conference, Long Beach, CA.
- Reutemann, C., & Jung, E.** (2012, July). *Narrative analysis on experiences of novice facilitators and FC users*. Poster session at the International Society for Augmentative and Alternative Communication (ISAAC) Conference, Pittsburgh, PA.
- Damiani, M., **Reutemann, C.**, Rood, C., & Tracy-Bronson, C. (2012, May). *New teachers' knowledge of special education law beyond teacher preparation programs*. Paper presentation at the Disability Studies in Education Annual Conference, New York, NY.

Invited National Conference Presentations

- Reutemann, C.** (2014, July). *"The Right Path to Equality": Supporting High School Students with Complex Communication Needs*. Paper presentation at the ICI Summer Institute, Syracuse, NY
- Ashby, C., Jung, E., **Reutemann, C.**, Vroman, K. & Chadwick, M. (2014, July). *iPad for Communication: A Case Study of iPad App Training for the Development of Independent Communication*. Paper presentation at the ICI Summer Institute, Syracuse, NY.
- Jung, E., Reutemann, C., Vroman, K. & Ashby, C. (2014, July). *Lexical Features of Supported Typers and Their Facilitators*. Paper presentation at the ICI Summer Institute, Syracuse, NY
- Ashby, C., Jung, E., Orsati, F., **Reutemann, C.** & Vroman, K. (2013, July). *Analyzing the development of independence of individuals with disabilities in typing to communicate*. Paper presentation at the ICI Summer Institute, Syracuse, NY.
- Chadwick, M., Seybert, J. & **Reutemann, C.** (2013, July). *Taking control of your own training*. Presentation at the ICI Summer Institute, Syracuse, NY.
- Reutemann, C.** & Jung, E. (2013, July). *Hoping for greatness: Examining experience of novice facilitators*. Paper presentation at the ICI Summer Institute, Syracuse, NY.
- Orsati, F., Jung, E., & **Reutemann, C.** (2012, August) *Research in facilitated communication: Shifting from "if" to "how"*. Paper presentation at the Autism Summer Institute, Concord, NH.

Invited Local and Regional Presentations

- Reutemann, C.**, Vroman, K., Burke, S & Burke, J. (2014, June). *Voice, access and hope: an Introduction to supported typing*. Advocates Incorporated, Fayetteville, NY.
- Reutemann, C.** (2014, March). *Augmentative and alternative communication and academic access*. Guest lecture in SPE 652: Assistive technology for integration of students with special needs, Syracuse University, Syracuse, NY.
- Reutemann, C.** (2014, March). *Supporting academic access for students who type*. Institute on Communication and Inclusion Introductory Workshop, Syracuse, NY.
- Damiani, M.L., **Reutemann, C.**, & Rood, C.E. (2013, May). *Moving beyond lecture in teaching*. Future Professoriate Program/Preparing Future Faculty Annual Conference, Hamilton, NY
- Reutemann, C.** (2013, March). *Supporting academic access for students who type*. Institute on Communication and Inclusion Introductory Workshop, Syracuse, NY.

Reutemann, C. & Orsati, F. (2013, January). *iPad applications as tools for communication and learning*. Advocates Incorporated, Fayetteville, NY.

Reutemann, C., Tracy-Bronson, C., & Ashby, C. (2012, May). *Supporting learning and communication through iPad technology*. Advocates Incorporated, Fayetteville, NY.

Reutemann, C. (2011, March). *Typing to communicate*. Guest lecture in SPE 412: Adapting Instruction for Diverse Student Needs, Syracuse University.

GRANT FUNDED EXPERIENCE

Woodfield, C. (2015). TASH Annual Conference. Graudate Student Travel Grant.
Awarded: \$400

Woodfield, C. (2015). AERA Annual Meeting. Graduate Student Travel Grant.
Awarded: \$400

Woodfield, C. (2015). AERA Annual Meeting. The Legacy Fund for Disability Studies and Human Policy.
Awarded: \$800.00

Reutemann, C. (2014). AERA Annual Meeting. GSO Travel Grant.
Awarded: \$150.00

Reutemann, C. (2013). *Using Video to Explore Experiences of High School Students who Type to Communicate*. SOE Research & Creative Grant.
Awarded: \$947.00

Reutemann, C. (2013). TASH Conference. Graduate Student Travel Grant.
Awarded: \$400.00

Reutemann, C. (2013) Disability Studies Program Conference Travel Grant for 2013.
Awarded: \$450.00

Reutemann, C. (2012). *Narrative Analysis on Experiences of Novice Facilitators and FC Users*. International Society of Augmentative and Alternative Communication Conference. GSO Travel Grant.
Awarded: \$350.00

Reutemann, C. (2012). International Society of Augmentative and Alternative Communication Conference. Graduate Student Travel Grant.
Awarded: \$400

EDUCATIONAL EXPERIENCE & CONSULTANCIES

- Communication Consultant** Fall 2015
Genesee Elementary, Auburn, NY
 Conducted communication assessment of second grade student and provided strategy development for student's communication skills and access to AAC
- Educational Consultant** Spring 2015
Mexico Elementary, Mexico, NY
Via Kelberman Center
 Consulted with team of fourth grade student around AAC options and provided strategy development for ongoing communication skill development
- Independent Evaluator** Spring 2015
Slingerlands Elementary, Delmar, NY
 Observed and evaluated first grade student around placement decisions.
- Service Provision Development** Spring 2014
Ed Smith Elementary, Syracuse, NY
 Engaged in ongoing collaboration with staff to redesign service provision model
- Communication Consultant** Spring 2014
Liverpool Elementary, Liverpool, NY
 Conducted communication assessment of first grade student and provided ongoing strategy development for student's communication skills and access to AAC
- Program Evaluator** November 2012
Friends' Central School, Wynnewood, PA
 Evaluated elite private school's Department of Student Support Services through interviews, observations and focus groups
- Program Evaluator** February, 2012
Episcopal Academy, Newtown Square, PA
 Evaluated elite private school's Department of Student Support Services through interviews, observations and focus groups

SERVICE

- Profession
 Reviewer** Spring 2015
Disability Studies in Education
 Reviewed Disability Studies in Education proposals for annual conference
- Newsletter Editor** Winter 2014
American Educational Research Association, DSE SIG
 Designed and edited bi-annual newsletter for DSE SIG

Reviewer Summer 2014
American Educational Research Association, DSE SIG
 Reviewed Disability Studies in Education proposals for annual conference

Document Reviewer Spring 2012
New Jersey & Education Law Center, Newark, N.J.
 Assisted in federal class action lawsuit versus New Jersey Department of Education

University

Beyond Compliance Coordinating Committee member 2009-2014
Syracuse University, Syracuse, NY
 Graduate Student leader in programming and advocacy for disability rights

Staff Member 2009- 2011
Institute on Communication and Inclusion, Syracuse NY
 Planned & executed training and workshops; Contributed to functions of the Institute

Conference Planner/Event Facilitator

Collaborated in planning, material development, and facilitation of international conferences:

- *Summer Institute 2016: Communication is More than Speech: Building Inclusion through Typing*
 Columbia, MD Summer 2016
- *Summer Institute 2014: Envisioning the Future: A New Disability Narrative*
 Syracuse, NY Summer 2014
- *Summer Institute 2013: Connection, Communication, Creativity*
 Syracuse, NY Summer 2013
- *Autism Summer Institute 2012: Express yourself: Supporting Communication through the Arts, Advocacy and Education*
 Concord, NH Summer 2012
- *Summer Institute 2011: Finding a voice, Finding a place, Finding a Purpose*
 Cambridge, MA Summer 2011
- *Disabled and Proud: A Call to Lead*
 Syracuse, NY Summer 2011
- *Disability in an Intersectional Lens Conference*
 Syracuse NY Fall 2012

Department

Special Education Faculty Member Search Committee Spring 2015
 Member of job search committee seeking tenure track Assistant Professor in Inclusive Special Education

Inclusive Steering Committee Member Fall 2014-Present
 Graduate student representative

edTPA Task Reviewer Spring 2014
 Evaluated student work for alignment with edTPA standards

Community

Sibshops Facilitator Spring 2014-Fall 2015
ARISE Child & Family Service, Syracuse, NY
 Organize and facilitate workshops for siblings of kids with disabilities

Transition Planning Support Fall 2012
Fayetteville Manlius High School, Fayetteville, NY
 Assisted in transition planning for high school student with Autism

Classroom Support Person Jan 2012- June 2012
Ed Smith Elementary School, Syracuse, NY
 Supported reading and independent work skills in an inclusive first grade classroom

Communication Facilitator Jan. 2010- Apr. 2011
Syracuse, NY
 Supported high school and college students who type to communicate

RELATED PROFESSIONAL EXPERIENCE

Direct Support Mentor Aug. 2012-Dec. 2015
Advocates Incorporated, Fayetteville NY
 Support daily activities and business endeavors of adult with autism who types to communicate

Website Liaison/ Marketing Assistant
Syracuse University School of Education, Syracuse, NY May 2010-Present
Institute on Communication and Inclusion (ICI) Syracuse, NY May 2010-Aug. 2011
 Managed content of web domains; ensured accessibility of content

Archivist of Wolf Wolfensberger's personal collection Feb. 2010- June 2010
The Center on Human Policy, Syracuse, NY
 Prepared Wolfensburger's personal archives for permanent housing at Syracuse University Bird Library

PROFESSIONAL MEMBERSHIPS

- American Educational Research Association- member
- TASH (formerly The Association for People with Severe Disabilities)- member
- Society for Disability Studies- member