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# In-Between Epistemic Paradigms of Disablement: A Reflective Journey

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# IN-BETWEEN EPISTEMIC PARADIGMS OF DISABLEMENT: A REFLECTIVE JOURNEY

by

DANIEL J. MCNAIR

(Under the Direction of Sabrina Ross)

## ABSTRACT

The author explores feelings of in-betweenness, hybridity, and dislocation (Aoki, 2005; Bhabha, 2007/1994; Saïd, 1994) as he contemplates the meaningfulness of a liminal placement between two epistemic worlds—that of his more recent experiences as a curriculum studies scholar and his previous training as a postpositivist practitioner of school psychology. This self-study engages pedagogical possibilities of in-between spaces (Aoki, 2005; He & Ross, 2012; Baszile, 2006) to construct a lived curriculum that challenges traditional stereotypes of autism and postsecondary disability services. To guide this critical self-reflective inquiry, the author applies the concepts of Joseph Schwab's (1973) curriculum commonplaces along with William Pinar's (1975) method of *currere* as organizational structures and metaphorical guideposts to look back upon previous educational experiences, to consider the present, and to envision a future praxis. In looking beyond the traditional-medico conceptions of disablement, the author seeks alternate understandings of the autism label that arise not from the epistemic landscape of prior training but rather are informed by postcolonial scholarship, critical disability studies, cultural studies, and the personal narratives of individuals with autism. By blending alternate understandings of autism and reimagining ways to recognize the personal agency and functional needs of college students with autism, the author reconceptualizes feelings of in-betweenness and dislocation as a potential position for hope, opportunity, and change.

In taking this approach, important findings of this project include a new recognition for the degree by which positivism has been embedded throughout most of the author's prior educational experiences, as well as how it continues to influence his thinking patterns and daily practice. The author also notes the difficulty experienced in the attempt to alter his writing style in a way that did not promote positivistic ideals, even while he was attempting to critique this philosophical worldview. Additionally, the author reaches a realization that initial feelings of in-betweenness and displacement, while uncomfortable, may actually signal a position of opportunity. Finally, the author concludes that the traditional-medico model of impairment does not do enough to promote the agency of those labeled with disability.

**INDEX WORDS:** Disability, Autism, Philosophy of psychology, Positivism, Critical disability studies, Cultural curriculum studies, Self study, School psychology

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IN-BETWEEN EPISTEMIC PARADIGMS OF DISABLEMENT: A REFLECTIVE JOURNEY

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## DEDICATION

This endeavor is dedicated to the memory of my father, Joe F. McNair, who is not here to share  
in the joy of this earthly accomplishment.

I love you Daddy.

## ACKNOWLEDGMENTS

I would first like to extend gratitude to all prior teachers, educators, and mentors who have helped me to reach this point in my academic life. For there were likely many of you who may have envisioned a different journey for me. Frankly, I remain surprised of how much I have grown to cherish the academic space. I would also like to offer an apology and a thanks to all of those who have endured my ramblings as I have been working on this project. For those who unintentionally broached the topic of this dissertation, I apologize for the litany of disorganized ideas that likely ensued. Whether you know it or not, you were helping me to conceptualize, rethink, and rework the ideas contained in this self-study. I will be ever thankful to each of my committee members, as you each contributed greatly in specific ways to my progress throughout this journey. Dr. Erevelles, your knowledge of alternate conceptions of the disability construct have been invaluable. Dr. He, you have not only been a motivating force, but were also the first to introduce concepts of in-betweenness and displacement that have been instrumental in this dissertation. Dr. Weaver, you have granted me the confidence to believe in myself and have faith that my work remains scholarly, even when I am disrupting the foundations of my past educational experiences. I want to extend my sincerest of appreciations to Dr. Ross, who has been my confidant, cheerleader, and guide as I have struggled throughout this project. There is no way that I would have made this journey without your expertise, care, and flexibility to keep me focused and on track. There can be no doubt that you were the perfect guide for this journey. I would also like to thank my mother, Donna W. McNair, for your never-ending love and support throughout my life. You have always prioritized education, but more importantly, have provided the model for a love of learning and personal growth. Finally, and most importantly, I wish to thank Katrina and Grace. You have each been willing to share the already limited time that we



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## CHAPTER 1

### INTRODUCTION

#### From Here to Where?: The Challenges and Possibilities of In-Between Spaces

I am clinically trained as a postpositivist school psychologist. I am becoming a cultural curriculum studies scholar. Cultural curriculum studies engages my imagination and encourages me to stretch beyond myself and the prior educational experiences of my past. Postpositivism roots me; my livelihood depends upon it. For the past two years, I have struggled to adequately convey my experiences of navigating the largely incompatible worlds of postpositivism and cultural curriculum studies - of being dislocated, disoriented, and lost. Of reading and writing my way into a new epistemological home, an in-between space where I can be both postpositivist psychologist and cultural curriculum studies scholar. While my experiences are personally educational, they also hold broader pedagogical significance. Through my self-examination of in-betweenness, I am highlighting the challenges and pedagogical possibilities of in-between spaces. My epistemological journey, and its pedagogical significance, are the foci of my dissertation.

My attempts to accurately convey this journey has required a combination of eclectic theories and methodologies that I detail in the following sections of this chapter. Below, I introduce the chapter with a discussion of a scene from a famous movie in order to highlight the connections between postpositivism and cultural curriculum studies that guide my lived curriculum.

Raymond is rocking in his chair while he mumbles to himself as he stares at the floor. He seems fascinated by the reflected light that is moving across the interior floor of the diner as a result of vehicles passing by the building. Just as the waitress approaches the table, Charlie tells

Raymond to “Stop That.” While the waitress is beginning to take their order, Raymond notices her nametag. He then states her name and telephone number. When she asks, almost in a startled manner, “how did you know my telephone number?” Charlie turns to Raymond, also asking “how did you know that? Raymond replies in a matter of fact way with, “you said to read the telephone book last night- Dibbs, Sally 4610192.”

The waitress shirks the encounter off with a smile and walks away. Charlie then inquires further and discovers that Raymond has memorized the phonebook entries through the letter “G.” A few moments later once they begin to discuss food, Raymond mechanically states, “yeah, Tuesday we have pancakes.” Charlie is responding to this statement about pancakes when Raymond then blurts “maple syrup.” Almost immediately Raymond realizes he does not have toothpicks. He becomes further agitated once he also realizes the maple syrup is not on the table.

Charlie tries to calm him by stating that the maple syrup will be provided once the pancakes arrive, but this does little to satisfy Raymond who insists “maple syrup is supposed to be on the table before the pancakes.” Charlie begins looking over his shoulder because he is obviously embarrassed by Raymond’s increasingly agitated behavior and insistence on the toothpicks and maple syrup. Charlie has tried to reason with Raymond to no avail and he loses his patience. He grabs Raymond by the back of the neck, pulls him in closer and forcefully whispers “don’t make a scene, stop acting like a fucking retard!”

Moments later the screen cuts to Charlie speaking on the telephone. He asks the waitress to take toothpicks over to Raymond, who had been eating at his table, but now appears to be aimlessly wandering around the diner. When Charlie has finished his telephone call, he walks over to the waitress and Raymond. The box of toothpicks have fallen onto the floor and

Raymond quickly mumbles a series of numbers. In a matter of moments, he has counted the 246 toothpicks that now lay across the floor.

The scene depicted above is from the critically acclaimed movie *Rain Man*. The film provides what is perhaps the best-known depiction of autism in a blockbuster production (Guber, Peters, & Levinson, 1988). The film has been so influential in painting people's perceptions that the phrase "Rain Man" is often used colloquially to refer to persons demonstrating either autistic behaviors or savant-type abilities. The film was well received by audiences and grossed over 172 million dollars. It also earned four Oscar awards including one for Best Actor in a Leading Role (i.e., Dustin Hoffman) for the portrayal of Raymond.

My experiences in the Curriculum Studies Ed.D. program have broadened my perspective to the pedagogical aspects of this popular film. To think critically about the film, I must consider what *Rain Man* teaches about the world, how the knowledge about autism as constructed through this film may impart understandings to an audience, whether those representations are of benefit to any particular individual or group, and how the film may construct a representation of difference and dis/ability. As a practicing school psychologist, I am also aware of the numerous diagnostic criteria and clinical representations of Autistic Spectrum Disorder (ASD) that Raymond embodies in the film. Such representations include variable eye contact, communication difficulties, poor social awareness, persistent patterns of repetitive behaviors, and difficulties in the management of sensory stimuli. As a result of my educative experiences in the Curriculum Studies program and my prior training as a school psychologist, I now wrestle with the competing paradigms of critical inquiry and postpositivism as I attempt to make sense of my professional practice.

These competing paradigms encourage me to simultaneously critique the power of normalizing discourses in *Rain Man* while also embracing the normalizing discourse of medicalization (Foucault, 1965/1961; 1973/1963) enacted in the film. Before entering the Curriculum Studies program, I had never given much thought to the epistemological orientation of my professional field of knowledge. As a clinician, I hang my hat (and pay my bills) by the basic tenets of empiricism and postpositivism. Through my experiences in the program, I have wrestled with questioning the foundations by which my previous learning experiences had been framed. Thus, my personal journey through the Curriculum Studies program has been an experience of isolation and blended boundaries. I have been confronted with alternate conceptions of knowledge and reality that have challenged my prior formal educational experiences.

It is through the competing paradigms of my clinical training and the understandings I have gained through the Curriculum Studies program that I now embody an epistemological in-between space. This space in-between paradigms of knowledge is difficult to inhabit. It is a space of incongruence, competing worldview, cognitive dissonance, and disorientation. The foundations of my professional training have been unsettled. While these feelings of an in-between space are of a turbulent nature, and not at all comfortable, I do realize that such a space can also be that of possibility and hope (Aoki, 2005; He & Ross, 2012; Baszile, 2006). This spatial possibility is the inspiration for this dissertation. I hope that through this project I may engage the seemingly contradictory practices of clinical diagnosis and critical reflection in a positive and productive way so as to improve my future work with autistic students in postsecondary settings. I wish to utilize these prior trainings and educational experiences to not only work through the feelings of epistemological alienation I currently experience, but to



ultimately become a better informed practitioner who recognizes the potentially negative effects of a medicalized discourse upon the students with which I work.

This dissertation is conceptualized as a critically reflective journey. At its most fundamental level, the dissertation is a self-study. I use a combination of scholarly writing, creative nonfiction, and a mix of postpositivist and critical perspectives to chronicle my epistemological origins and aspirations. Theoretically, this dissertation is guided by postcolonial theory and the concept of curriculum commonplaces (Schwab, 1973), though I also utilize postpositivism to explain my epistemological origins. Methodologically, I employ self-study as inquiry. My self-study utilizes the concept of *currere* (Pinar, 1975) and creative nonfiction. As metaphors, these guides are utilized broadly rather than specifically. They provide a framework for my journey of inquiry, preventing me from veering too far off course, but they do not overly dictate the movements of this inquiry. This freedom enables me to only utilize the aspects of these theoretical and methodological guides that are appropriate for this dissertation. The specific ways in which each of these theoretical and methodological guides inform this inquiry project is discussed below.

### **Theoretical Guideposts for the Journey**

#### **Curriculum Commonplaces**

I utilize the concept of curriculum commonplaces to organize this inquiry along a metaphorical landscape that locates my topic of study within the general contexts of curriculum making, educational experience, aspects of my own learning, epistemology, and environment to contextualize my experiences working with ASD college students. The curriculum commonplaces are used to analyze my thinking patterns prior to and in the midst of my experiences within the Curriculum Studies program.

Joseph Schwab first outlined the idea of curriculum commonplaces in one of a series of essays following his 1969 proclamation of the curriculum field as moribund. It is generally accepted that Schwab's assertion signaled the period known as the reconceptualization, in which the field moved away from matters of prescriptive planning for instruction toward an attempt to better understand the process of schooling from a wide variety of perspectives (Pinar, Reynolds, Slattery, & Taubman, 1995/2008; Schubert, Lopez Schubert, Thomas, & Carroll, 2002). In short, the curriculum field moved away from the traditional practice of curriculum development and guidance toward reflection and investigation upon the schooling process as a whole. However, this statement of a field near its death was not Schwab's grand conclusion, but rather a statement of what he perceived to be its current state when he first spoke these words in a speech in 1969. Through the writing of four practical essays, Schwab provided his view of a field that was in danger. He argued that the field of curriculum had become too reliant upon theory, and there needed to be a return to actual issues of education. His approach, termed the practical, provided a means to address specific problems and particular issues of education. Schwab was not arguing against theory completely, and neither was he suggesting that practical matters should overshadow the theoretical, but rather the two modes of inquiry should take equal footing in curriculum deliberation and educational decision-making.

Schwab referred to commonplaces as components of curriculum planning. More specifically, the commonplaces were representations of knowledge forms, or forms of experience, that he believed to be necessarily represented in any successful curriculum planning act. Schwab's essay, *The practical 3: Translation into curriculum* (1973) specifically addressed the importance of these commonplaces. In short, the commonplaces are defined as interrelated and fundamental components of any effective curriculum design, which comprise a

representation of four entities: subject matter, learners, milieu, and teachers. These groups could also be restated differently as content, learners, context, and teachers.

Schwab (1973) obviously recognized the need for a scholarly expert in the curriculum development process. The scholar, one who is well informed of a particular discipline, would constitute the commonplace of experience in subject matter. However, Schwab was careful to point out that the possession of disciplinary knowledge is not enough to construct a defensible curriculum. While knowledge of the subject matter is a necessary component, there should also be adequate representation of three other forms of experience/knowledge. Of these other forms of experience, the second commonplace would include representation of the prospective learners. This individual or group would need to be versed in not only general developmental knowledge about a particular age group of learners, but would also need expertise in other forms of knowledge regarding the particular learners. This would include considerations of what may be reasonably expected of students from a developmental perspective, what they already know, what they will be ready to learn, and how a particular group in question may differ from other children of the same developmental age.

The third commonplace, the milieu, refers not only to the situation in which the educational act is to occur, but also the larger context in which that learning will be applied. At the elemental level it could include classroom dynamics between students or the structural relationships of teachers to administrators within a school, but as Schwab (1973) states, “the relevant milieus are manifold, nesting one within another like Chinese boxes” (p. 503). In other words, the milieu does involve consideration of the immediate classroom or school environment, but it also includes an ever-expanding consideration of family dynamics, community, religious

beliefs, and considerations of class and ethnicity. These milieu may be further extended to a comparison of entire towns or communities, regional affiliations, and issues of national interest.

The fourth milieu includes a knowledge of the teachers who are to implement the curriculum. This representative commonplace would include a knowledge of the particular instructors, their current knowledge-base, their flexibility or readiness to change their teaching practices, their personalities, moods, and even professional motivations and goals. Each of these groups require representation. For example, Schwab (1973) suggested that the scholar alone cannot devise an effective curriculum because while this individual may have expert knowledge of a subject matter or discipline, the expertise and knowledge of other commonplaces must also be considered during the curriculum planning activity. For instance, without adequate representation of the learners or the potential instructors of a planned curriculum, the proposed model of instruction may be doomed to fail. In regard to students, amongst a host of considerations, effective curriculum planning must take into account where the learners are currently functioning, what prior knowledges they may hold, how receptive they may be to new instructional topics or techniques, and how they may benefit from such proposed instruction. In the same manner, the teachers of a proposed curriculum should also be considered, as well as the milieu or context in which the learning will take place. Schwab (1973) suggested that effective curriculum making occurs through a fluid interaction and consideration of these four commonplaces. He also identified a fifth commonplace, represented by the curriculum specialist, who acts as a moderator throughout the deliberative process and encourages the development of a curricular design that best represents the goals of the entire working group.

In addition to ensuring a recognition for the importance of each commonplace amongst the working group, the curriculum specialist also brings knowledge of the embodiments, or

material and concrete aspects of a curriculum, to the process. Whereas the curriculum specialist first works to ensure equal representation of all four commonplaces, this role evolves into that of technical support to ensure that a functioning curriculum may be realized. Schwab was very aware of the likelihood that a particular commonplace may overshadow the needs and interests of those representing other commonplaces. Accordingly, Schwab (1973) asserted:

Defensible educational thought must take account of four commonplaces of *equal* rank: the learner, the teacher, the milieu, and the subject matter. None of these can be omitted without omitting a vital factor in educational thought and practice. No one of them may be allowed to dominate the deliberation unless that domination is conscious and capable of defense in terms of the circumstances. . . . Coordination, not superordination-subordination is the proper relation of these four commonplaces. (p. 508-509)

The entire process is meant to be collaborative so as to best plan for the unique and situated needs of a particular educational group, situation, or context.

Schwab's curriculum commonplaces were conceived as a method for devising a defensible curriculum. However, the idea of curriculum commonplaces have also spurred a wealth of scholarly work in education. For example, Connelly and Clandinin (1988) employed the notion of curriculum commonplaces not as a process for curriculum development but as a useful analytic tool to be used by teachers as they construct their own notions of curricular understanding, experiential learning, and retelling of personal stories that embody a personally relevant knowledge of classroom practice. In the same way that Clandinin and Connelly drew upon the commonplaces to stimulate the self-reflection of teachers, I will employ the idea of commonplaces as a means to think through my complicated feelings of inhabiting an in-between or hybridized epistemological placement between paradigms of knowledge as well as to compare

how these feelings of in-betweenness may apply toward the issue of accommodating students with ASD in postsecondary settings.

### **Post-Positivism**

Postpositivism refers to a research methodology and philosophical approach in which knowledge is treated as external to the individual and based upon naturally occurring phenomena (Guba & Lincoln, 1994; Savin-Baden & Major, 2013). As such, this philosophical position holds that positive knowledge exists and may be empirically substantiated through scientific verification and logical reasoning. This approach promotes a singular view of reality in which knowledge is most often believed to be gained through a replication of the research practices employed within the natural sciences. The discovery of knowledge; therefore, must rely upon principles of objectivity, rationality, and replicability. Importantly, postpositivists retain the tenets of realism by positing that truth exists independent of the observer, but they recognize that research practices result in an imperfect understanding of truth. Therefore, assertions of research are open to falsification and a revisionary movement that enables the researcher to better approach understanding, but never fully in grasp of absolute truth. Key aspects of postpositivism include the empirical observation of phenomena, the scientific method, carefully designed experimentation, statistical analysis, and an emphasis upon validity (Savin-Badin & Major, 2013). I use postpositivism in this dissertation to frame the clinical representation of autism as subject matter as well as the philosophical framework from which I begin my inquiry.

### **Postcolonial Theory**

Postcolonial theory is used in this project to conceptualize the challenges and possibilities of in-between spaces. In a subsequent chapter of this dissertation, I utilize scholarship in postcolonial theory as part of the “data” for this self-study. I immerse myself in and reflect upon

postcolonial scholarship to break away mentally from the dominant theorizations about ASD that have so heavily influenced and framed my professional practice prior to entering the Curriculum Studies doctoral program.

Postcolonial theory refers to literature, research, cultural inquiry, criticism, and historical scholarship investigating the aftereffects of colonization of indigenous peoples, their geographic spaces, and their cultures by imperialist societies. (Bhabha 2007/1994; Said, 1978; Spivak, 1994). In short, postcolonial theory concerns itself with the study of how colonized societies reclaim, challenge, and resist the dominant ideologies, languages, and cultural representations that are imposed by colonizing forces. Postcolonial theory, while inclusive of the outright physical domination of the colonizer over the colonized, grants careful attention toward the ideological conflicts and power operations that ensue after a country or cultural group has been colonized. For example, this form of continued domination may include the distortion of the culture, history, language, or tradition of the colonized group. In this way, the imperializing society both imparts its own cultural ideals upon the people who have been colonized as a means of control and also justifies its colonization of other peoples. At best, this attempt to diminish the colonized way of life creates blended identities and cultural representations, and at worst results in the outright subjugation and domination of the colonized cultural identity. Postcolonial theory as a form of scholarly discourse provides analysis of the power operations at play in such cultural appropriation and domination as it is levied against a colonized society. Prominent theoretical constructs of postcolonial theory include notions of cultural hybridity, otherness, and in-betweenness as experiential factors at play in the cultures and social operations of those who have been colonized.

In addition to using postcolonial theory as data for my self-study, this perspective provides a useful conceptual tool to discuss my current feelings of in-betweenness because this form of scholarship, in addition to the incorporation of discursive and imperializing power, also provides a critical lens for the analysis of spaces in-between, or hybridized identities in which the subject experiences fluctuating and uncertain understandings of oneself. Furthermore, postcolonial theory also provides a critical view of totalizing stereotypes, a language for challenging fixed assumptions of otherness, and a method to disrupt the dominant narrative of subjugation. It is through the application of postcolonial theory that the opportunity for transitional and in-between spaces become sites of hope and possibility. This in-betweenness or hybridized state may seem hopeless, but it is in fact a site of struggle and opportunity.

### **Hybridity.**

I utilize the term hybridity as a direct reference to the postcolonial scholarship of Homi Bhabha. Through the course of this project, I will engage similar understandings of space and place as I recreate personal feelings and thinking patterns I have experienced as I have continued my work as a school psychologist while simultaneously studying the literature of curriculum theory. Bhabha (2007/1994) utilizes the concept of hybridity to refer to a liminal placement between two locations of a postcolonial and cultural landscape. I plan to adopt a similar notion of a placement in-between systems of knowledge or being, as I find myself in a liminal space that is “new, neither the one or the other,” and representative of a space of uncertainty, ambivalence, and fluctuation (Bhabha, 2007/1994, p. 37). While Bhabian concepts of hybridity provide much of the theoretical foundation for my journey to find a comfortable position between the competing discourses that characterize my life as either a student or clinician, it is also possible that similar sentiments of in-betweenness may be found in the expressed work of scholars



working from the discipline of education (Aoki, 2005; Baszile, 2006; Giroux, 1992; He, 2010; He & Ross, 2012).

Bhabha (2007/1994) defines the hybrid space as that of a liminal passage, or better explained, akin to a stairwell between two binary or fixed positions (i.e. two different floors of a building). In using this metaphor, the stairwell is neither the first floor or the second, but a middle space between the two that cannot be adequately defined by the characteristics of either floor. Bhabha (2007/1994) argues that the space of hybridity, while notable for ambivalence and uncertainty, is also a space in which the opportunity for agency arises. Whereas the position in-between is useful for challenging or contradicting the colonialist assumptions of fixity and essentializing stereotypes of a colonialist discourse, it does not resolve tensions between two cultures, but rather is a process in which the “other ‘denied’ knowledges enter upon the dominant discourse and estrange the basis of its authority—its rules of recognition” (Bhabha, 2007/1994, p. 162).

Importantly, I recognize the concerns of indigenous scholars who rightfully scrutinize and oppose the metaphorical usage of decolonization language. These authors highlight ways in which the adoption of such language in educational scholarship enables a perpetuation of settler colonialism (Tuck & Yang, 2012). However, this dissertation is not an attempt to “decolonize my mind;” rather I employ postcolonial themes of transition, in-betweenness, ambivalence, otherness, and hybridity in a self-examination of the feelings I have experienced as I have progressed through the Curriculum Studies program. Furthermore, I write from a position in my personal life that may be viewed as transitory, as a new parent and a burgeoning curriculum theorist. In adopting Bhabha’s construction, it is from within this liminal space of hybridity, that the subject can neither identify fully with the past or the future, with the one or the other.

Likewise, I feel myself pulled between the epistemological paradigms of my prior educational experiences. The contemporary education field now recognizes the importance of acknowledging, appreciating, and engaging diverse and subjugated viewpoints (Freire, 1970; He & Phillion, 2008; Sandoval, 2000), and post-colonial theory provides one such avenue for doing so.

### **Critical Disability Studies**

Disability studies is a field of scholarship that concerns itself with the representation of disability across social, cultural, historical, and political contexts. In many ways, similarities may be drawn between the project of disability studies and other social theories of human difference, such as gender studies or race/ethnicity studies (Ferguson & Nusbaum, 2012). Whereas disability studies originated following the period of deinstitutionalization, in which the severely impaired were transferred out of large-scale state-sponsored institutions, initial proponents emphasized political change, activism, and challenge to the traditional conceptions of the medical model of disablement (Meekosha & Shuttleworth, 2009). The field may be generally divided by two phases or philosophical approaches. First, early activists adopted what has come to be known as the social model. These early workers drew a hard line between conceptions of disablement and impairment. This stance argued that disabled persons are members of a socially oppressed group, who not unlike other minority groups, were oppressed by barriers and obstacles that were constructed and maintained by the greater society (Oliver, 1999, 2013; Shakespeare & Watson, 2002; Tremain, 2008; Watson, 2012). Accordingly, impairment was argued to represent the biological disruptions of bodily function, while disability was presented as the social oppression that individuals experienced as a result of such experience.

More recently, the field moved toward interdisciplinarity as it has evolved to include more diverse research approaches, greater concerns for self-reflexivity, a wider sociopolitical awareness, critiques of the impairment-disablement binary, and newer forms of theory borrowed from across the academy (Devlin & Pothier, 2006; Goodley, 2013; Meekosha and Shuttleworth, 2009; Watson, 2012). This newer phase of disability studies work, commonly referred to as Critical Disability Studies, now includes a greater variety of research methods emanating from the humanities and social sciences that are less reliant upon the traditional framework of the social model. In this self-study, critical disability studies scholarship comprises another source of data. By critically reflecting on this scholarship in a subsequent chapter, I attempt to stretch beyond the clinical training I received to understand autism differently.

### **Methodological Guideposts for the Journey**

#### **Self-Study as Method**

As a research method, self-study could be perceived as a form of narrative inquiry, or perhaps more precisely, a form of autobiography. In a sense, the final product stemming from such research does tell a story or convey the experience of an individual. However, within the realm of educational research, self-study refers to a specific form of introspective, and albeit narrative, form of scholarship in which teacher educators, practitioners, and preservice teachers alike focus upon the improvement of the personal and professional self. This critical turn inward toward one's own professional practice is used as a resource within self-study research. The resulting process of reflection and inquiry is undertaken with a goal of improving practice and reconceptualizing the professional role. I utilize the self-study method in this dissertation to explore the contested space I inhabit, and to envision alternate possibilities for my future practice as a school psychologist practitioner.

Self-study first gained traction as a recognizable area of research in the early 1990's (Samaras & Freese, 2009). Following an American Educational Research Association (AERA) session on self-study in 1992, an AERA special interest group for was created, which further contributed to the development of this method as a form of educational inquiry. (Bullough & Pinnegar, 2001; Samaras & Freese, 2009). With the development of this community of researchers, the method of self-study has gained acceptance as a viable form of educational research.

Importantly, self-study researchers have contended with issues of acceptability, just as other qualitative researchers have dealt with the problem of proving the value of their research to publishers and institutional administrators. As Feldman (2003) has explained, this problematic issue of validity was initially addressed by qualitative research pioneers through the development of alternate criteria, which included concepts of “believability, credibility, consensus, and coherence, to replace accuracy as a warrant for validity” (p. 26). In this respect, I draw attention to not only Feldman's (2003) discussion of validity in self-study, but also an earlier article by Bullough and Pinnegar (2001) which provided a set of guidelines that could be utilized to gauge the quality of self-study research.

In short, Bullough and Pinnegar (2001) proposed that quality in self-study could be substantiated through a series of questions and consideration of attributes found within self-study. First, they harken back to the sentiments of C. Wright Mills in 1959, who stated that personal problems within research cannot be approached as only personal problems, but must be framed and understood in the greater context of public issues and history. In this respect, they argue, “articulation of the personal trouble or issue never really becomes research until it is connected through evidence and analysis to the issues and troubles of a time and place”

(Bullough & Pinnegar, 2001, p. 15). They further proposed that quality research engages the reader, stirs the imagination, asks and provides answers to compelling questions, and transcends the personal. Following the publication of this article, Feldman (2003) provided additional criteria which he believed could be utilized to address the potential issue of validity when self-study research was purported to make knowledge claims or intended to sway the opinions and instructional techniques of others. These additional guidelines focus primarily upon the ways in which data is collected and how representations are constructed within self-study research. As such, Feldman (2003) suggested that researchers be very clear and detailed in their descriptions of how data is collected, what counts as data, clear descriptions of how that data is used to construct representations, explorations of how to present the self-study from different perspectives, and the provision of concrete examples of how the self-study has been of value to informing the praxis of the researcher. Each of the above criteria for self-study research are followed in this dissertation. Additionally, the concept of *currere* guides the introspective process of this dissertation. While I will not engage all aspects of this method, it is Pinar's emphasis upon bracketing experience and then reflecting upon those separate moments in time that informs this dissertation. *Currere* is used as a metaphorical guidepost for synthesizing my thoughts, feelings, and desires as I think through the stages of my educational training and seek to improve my future practice.

### **Currere.**

The method of *currere*, first proposed by Pinar in 1975, refers to a process of introspective inquiry which, “provides a strategy for students of curriculum to study the relations between academic knowledge and life history in the interests of self-understanding and social reconstruction” (Pinar, 2012, p. 44). The method itself, is comprised of four stages: the

regressive, progressive, analytical, and synthetical (Pinar, 1975; Pinar, Reynolds, Slattery, & Taubman, 2008). Briefly, the method of *currere* entails an evaluation of the self that is understood through a process of bracketing past experiences, future desires, and present understandings, in an attempt to gain a sense of interiority and presence for educational experiences, current issues at hand, and life history (Pinar, 1975; 2012).

The steps of this method are as follows. In the regressive, one enters into the past as an observer. Interpretation of past experience is withheld in this stage. The purpose is to observe the past, write it out, to take note. Pinar describes this as taking a photograph of one's life history. In the next step, the progressive, one focuses upon the future. Pinar recommends the enactment of this stage through a process of relaxation, self-meditation, and free association. One simply frees the mind of current and past concerns to allow oneself to construct ideas about future goals, research interests, nature of one's pedagogy, etc. Again, even though these ideas are to be written down, Pinar emphasizes that they should be done so through a loose and free association. This stage of the progressive is re-entered over multiple sessions on different days or weeks to promote the "likelihood that the photographs taken are reflective of more lasting anticipations" (Pinar, 1975 p. 10). In the analytical stage, the past and future photographs are set aside so as to allow one to focus upon the biographic present. This bracketing allows the individual to conceptualize the present in a way that is less constricted by the past and future. In the final stage, synthetical, all three pictures (past, future, and present) are analyzed to determine themes, similarities, incongruence, relations, and discontinuities. The methods of analysis should vary and cross disciplinary boundaries so as to promote a more thorough integration of ideas and themes. This final stage culminates in a consideration for the meaning of the present. Through

this process of self-reflection, the individual is able to blend the past, present, and future into a fully integrated whole.

The concept of *currere* has also been linked, in part, to the expansion of the curriculum field during the period of reconceptualization (He, 2010; Miller, 2005; Pinar et. al, 2008). There are a host of directions one could take in tracing the use of autobiography in contemporary curriculum studies scholarship, especially if connections were made to the use of storytelling, narrative, and intimacy (Clandinin & Connelly, 2000; He & Phillion, 2008; Phillion, He, & Connelly, 2005), personal voice (Grumet, 1990; Miller, 2005, 1990; Pinar & Pautz, 1998) or the significance of personal space and place (Kincheloe & Pinar, 1991; Reynolds 2013, 2014; Whitloch, 2007). Of course, even though *currere* begins with personal introspection, the process becomes more complicated by the scholar's interactions with past, present, and future, as well as the social-cultural landscape from which these remembrances and interactions are given rise.

While I will not engage the method of *currere* prescriptively, I will seek to reflect upon my past experience in working with a specific student with ASD. I will recollect and write-out a past experience, that will then be analyzed and looked back upon through a process of bracketing that considers my past ontological understandings as compared to any new constructions of reality that may arise once this past experience is considered through my learning in the Curriculum Studies program. Metaphorically, this dissertation will involve aspects of a bracketed past, present, and future, but it is the critical self-reflection and introspection of Pinar's method of *currere* that most inspires the approach I have taken in this project.

### **Creative non-fiction.**

Creative nonfiction has been utilized by researchers seeking to incorporate literary, artistic, and procedural differences between their work and traditionally positivistic and

quantitative research methodologies. As Richardson (1997) has suggested, attempts to create qualitative research along the same principles of quantitative research methodology are oftentimes burdensome and inappropriate. In addition to many other qualitative research approaches that have gained traction in the academy as scholars seek to incorporate greater awareness of subjectivity and contextualization to problems that may not be conducive to quantitative methodologies, creative nonfiction has become more widely utilized as an investigative tool.

Creative nonfiction may be utilized to promote a greater engagement for readers of qualitative research, and it often contains familiar literary characteristics such as plot, characters, storylines, scenes, dramatic events, and tension (Tedlock, 2018). Equally important to promoting a more interesting write up of research, other scholars have elected to utilize creative nonfiction as a means to increase the quality of how research findings are presented while also promoting truthfulness and credibility. Particularly, the use of creative nonfiction has been a valuable approach to communicating information about research participants when sensitivity and confidentiality are of concern. This approach to communicating private and personal details of the lives of others has been of distinct value for researchers working in the helping professions, which include medical professionals, sociologists, and psychologists to name a few, when participant confidentiality is of paramount concern yet sensitive issues are of importance to discuss and convey to the research consumer (Speedy & Wyatt, 2014).

I will employ creative writing/creative non-fiction as a tool to connect my daily work as a school psychologist to my work as a curriculum scholar. In consideration for the ethical guidelines of research and the profession of psychology, which include the imperative that I protect the confidentiality of research subjects and clients, I have elected to synthesize my



clinical experiences in working with many individuals with autism into a single fictionalized account. At the same time, it is only through using examples of my daily practice that I will be able to convey the embeddedness of positivism within my professional life. Through the use of creative non-fiction, I will be able to provide a rich recollection of my past personal experience of this curriculum topic (i.e., my prior experiences with autism in the postsecondary setting) while also honoring research and professional ethics.

### **Writing as process.**

Rather than relegating the writing process solely to presentation of a final product, or a communication of findings, Richardson (1997) argues that the process of writing is a valuable form of qualitative inquiry in and of itself. As the researcher grants attention toward the location of self, along with subjective and changing understandings of research, an emphasis upon the process of writing only serves to offer greater contextualization and meaning for one's academic work. In discussing this role of process in writing, Luidens (1997) states,

thinking is an elusive concept. We can't hold it, touch it, or smell it. Yet it is the heartbeat of writing. What we can hold, however, is the manifestation of our thinking -the written piece- the artifact that reveals the thinking. (p. 141)

The writing of creative non-fiction will be a process of thinking, recollecting, and also retelling. As such, the vignette will serve to replicate my thinking patterns as they relate to the positivistic paradigm from which I begin. The fictionalized vignette will be used to convey the typical interactions I may be expected to have in my professional work with ASD students.

The following chapter begins with a vignette that typifies my work with ASD college students. The vignette provides an opportunity to revisit my thought patterns from the alternate perspective of time and place that is the present. This same vignette, is reimagined through the

lens of cultural curriculum studies and critical disability studies at the conclusion of Chapter 3. This creative reimagining is one way in which I represent the “results” of my immersion in postcolonial and critical disability studies scholarship and works by ASD individuals and/or their parents.

### **Significance of the Study**

Postsecondary school enrollment rates for all students with disabilities (Stroebe, Krieg, & Christian, 2008; U.S. Dept. of Education, 2013; Witte, 2008) and for students with ASD have increased (Chiang, Cheung, Hickson, Xiang, & Tsai, 2012). My goal in this project is to map out a more comfortable space of in-betweenness from which I may gain new understandings of the autism construct and better serve the autistic students with whom I work. This effort to embrace the disciplinary in-betweenness I experience, as well as my work with autistic students in postsecondary settings, represent important issues for curriculum theorizing. Additionally, my focus upon the formal and informal aspects of educational experience through a metaphorical application of the curriculum commonplaces to these issues will represent an important aspect of the big curriculum (Schubert, 2006) that holds significance for the overall project of curriculum studies.

### **Organization of the Dissertation**

#### **Chapter 1: From Here to Where?: The Challenges and Possibilities of In-Between Spaces**

Chapter 1 presented the conceptual framework for this dissertation and introduced the concept of in-betweenness to convey the cognitive dissonance I have experienced as a clinically trained practitioner and burgeoning curriculum studies scholar. As two epistemic worlds have collided, I have found myself in-between paradigms of knowledge. These feelings of unsettling were presented as both an alienating experience and a position of possibility and hope.

Chapter 1 represents my starting point and introduces the theoretical and methodological guideposts that have kept me grounded for this journey. These organizing principles have also been important to link my self-study to that of the broader pedagogical field. Rather than falling back upon the personally comfortable research format of scientific literature and study, I embrace the cultural curriculum studies field and the history of social science literature in education for this endeavor. As such, Chapter 1 introduced Schwab's curriculum commonplaces as a means to organize the topic of my study—students with autism in postsecondary settings. The role of self-study as research method, along with the prominence of Pinar's concept of *currenere* as a method of introspection serve to ground this project and perhaps grant generalizability to larger audiences. Additionally, Chapter 1 introduced diverse fields of study which serve to further organize this project. I utilize postcolonial theory to conceptualize feelings of otherness and in-betweenness, I call attention to the growing disability studies literature to present alternate conceptions of disablement, and reviewed the use of the writing process as a method of inquiry.

## **Chapter 2: Post-Positivist Origins**

This chapter details my experiences as a learner prior to entering the Curriculum Studies program. As such, the chapter reviews literature related to the postpositivist framework which has guided my clinical training experiences and everyday practice as a school psychologist. The chapter begins with a creative nonfiction vignette that was written to illustrate a typical experience I may have with an ASD student in the assessment clinic in which I work. Following the vignette, I explore the role of the postpositivist framework and how this paradigm informs the foundations of my training in psychology. The chapter follows a traditional literature review format to present the various milieu of my current practice as a school psychologist practitioner,

and includes information pertaining to postpositivism, the history of the profession, disability legislation, services within secondary and postsecondary school settings, and the psychological understandings of Autism Spectrum Disorder (ASD). This chapter concludes as I engage in a regressive exercise of currere to explore how my prior educational experiences have been informed by the postpositivist epistemology, as well as how this philosophical framework continues to shape my current practice.

### **Chapter 3: Imaginative Spaces**

In this chapter, I begin the progressive phase of currere to think about future possibilities of my practice. Rather than focusing upon myself as a past learner, in this chapter I explore new understandings gained as an emerging curriculum studies scholar. This involves consideration for alternate conceptions of disability that are influenced by perspectives beyond the traditionally postpositivist influence of my clinical training. These alternate perspectives are informed by postcolonial scholarship, critical disability studies scholarship, cultural studies, and personal narratives of individuals with ASD. Each of these perspectives may also demonstrate the lived experiences of in-between spaces, alienation, and otherness. While a literature review of these fields of inquiry is provided, I also incorporate personal reactions to convey the ways in which various milieu may alter my understanding of ASD. The discussion of these alternate perspectives is followed by a reflection of how my daily practice could be different if I were not constrained by the limitations of postpositivism. The creative nonfiction vignette that was presented at the start of Chapter 2 is reimagined and presented as a possible alteration to how I may reposition and prioritize the voice of persons with ASD in my daily practice.

#### **Chapter 4: Where Do I Go from Here?: Implications for Practice**

In the final chapter, I provide a review of the critical reflective journey that was undertaken during the process of writing this dissertation. I offer an explanation of the significant findings I have discovered through this self-study and contemplate how these new understandings have implication to my daily practice. Importantly, the findings presented in this final chapter are not meant to be conclusive, but rather as a tentative explanation of where I have ended up at the end of this formal dissertation. It would be a disservice to myself if I were to discontinue this process of self-discovery and questioning that was started at the beginning of this project.

Primary findings discussed in the final chapter include the pervasiveness of positivism, the challenge of writing about lived experiences in-between, understanding differences between abstract theories and lived experiences of in-between, and recognizing the agency of those labeled with disability. I also explore personal feelings of frustration as I have reworked ideas and encountered unexpected obstacles that arose during the writing of this dissertation. I utilize the final chapter as an opportunity to reconceptualize the creative nonfiction vignette of Samuel in a way that creates a space to better recognize alternate understandings of the autism construct while still maintaining standards of my professional practice. The chapter concludes by providing tentative ideas of how this self-study may inform my future practice in addition to the potential implications of these findings as they relate to the traditional methods of service delivery for postsecondary

## CHAPTER 2

### POST-POSITIVIST ORIGINS

This chapter reviews literature related to the postpositivist framework that guides my work as a school psychologist. A major goal in this dissertation is to authentically represent my struggles to push past the limitations of the postpositivist framework. With that goal in mind, this chapter begins with a creative nonfiction vignette that I wrote to capture my experiences working with ASD college students. The scholarly work of crafting the vignette is detailed in a section of this chapter titled “Theorizing the Vignette” in which I discuss the theoretical and psychological foundations of the vignette. A traditional review of literature related to postpositivism, school psychology, federal and state legislation, and Autism Spectrum Disorder (ASD) follows and is organized by the curriculum commonplace of milieu. Chapter 2 concludes with a section titled “Learner’s Perspective” that utilizes the regressive aspect of currere to reflect upon the ways in which my educational experiences with postpositivist epistemology has influenced my current practice. This reflective writing is distinguished in the dissertation by an italicized font.

#### **Creative Non-fiction Vignette** (session with ASD college student)

I am employed in a University-based psychoeducational assessment clinic. This center provides standardized assessments of cognitive abilities, learning characteristics, academic proficiency, and other psychological processing strengths and weaknesses by means of a variety of norm-reference and standardized assessment instruments. In addition to providing standardized assessments, the centers also review preexisting documentation of learning disorders or other impairments to determine whether a student’s documentation of disability already meets criteria for accommodation under provisions of the ADA. The decision-making in regard to eligibility for academic accommodations is based upon strictly defined psychological

criteria and legal mandates. To make diagnostic decisions of eligibility, there must be documented evidence of functional impairment that arises from the presence of a mental health or learning disorder. This documented evidence takes the form of test data and clinical observation.

### **Setting and Staff**

At the particular clinic in which I work, there are nine full-time staff. The assessment team consists of three school psychologists, a licensed clinical psychologist, and a liaison who acts as a point of contact between the center and the various institutions within our catchment area. Three administrative support staff and a Director provide assistance to the assessment team and manage the daily operations of the center. Additionally, the center employs two part-time graduate assistants and receives rotating practicum trainees on an annual basis. These persons also participate as members of the assessment team. Although the full-time staff may only comprise nine positions, the addition of student trainees and graduate assistants fluctuates throughout the academic year and most often adds an additional three to five persons to the working group.

This clinic is located on the campus of a large-sized postsecondary institution. However, the clinic is somewhat secluded from other academic and administrative buildings on this campus. The relative anonymity of the assessment clinic provides prospective clients a degree of privacy as they arrive and depart from evaluative sessions. The assessment center is located in the basement of a campus building that is located near the edge of campus. Our offices are not shared by any other campus group; thereby offering an extra layer of client confidentiality. With the exception of the booths that are utilized for testing, the physical attributes of the clinic are not unlike many other academic office settings. The area consists of multiple offices, a record room,

a room utilized for printing, a research lab, a lobby area, private bathrooms, and a break room. There is a doorway from the parking lot which leads directly into the center, thereby providing an extra level of discretion for prospective clients. The assessment room/testing booths are entered through a doorway of the clinic's only hallway. This door looks no different from the other doors of the building which lead to staff offices. The doorway to the assessment area leads to a small hallway/observation area. There are four smaller rooms connected to the observation area. These smaller rooms are 8 ft wide and 7 ft long, with 8 ft ceilings. Three walls of each smaller room are solid, while the wall and doorway facing the observation room are one-way mirrored glass. When in the smaller assessment room, one only sees their reflection through the glass. While in the observation area and looking into the smaller assessment room, the glass window and door are transparent. The individual rooms are wired for sound, and observers may listen through headphones to the interactions and dialogue occurring within the smaller assessment booths. Three of the four rooms contain a table that is centered within the area. Two chairs are located on opposite sides of each table. A bookshelf may be found to one side of the room, where the examiner sits, to provide an area to store testing materials such as easels, books, and manipulatives. The fourth room also contains a small table, but it is pushed against the far wall from the doorway. A computer is located on this table, and it is used to complete some of the assessment activities.

Clients of the center rotate between these assessment rooms during their evaluations. Specific standardized tests are completed in different rooms, and these materials are organized by day of evaluation. Typically, evaluations occur over two sequential days. With this form of organization, the center can see multiple clients at a time without needing to purchase additional copies of assessment instruments, which can be very expensive. Except for computer-based



activities and a few tasks that require the manipulation of common objects, the majority of activities are completed by either verbal exchanges or paper and pencil format.

In addition to the use of standardized testing instruments, the entire evaluation itself is rather regimented. Most clients engage in the same tasks, in the same order, and for the same amount of time unless there is a presenting issue that calls for the inclusion of some other activity that is typically not included in the routine battery of assessments. However, the testing protocol and specific assessment activities are rarely altered, so as to promote long-term collection of assessment data for research purposes. The typical routine of an evaluation is as follows: The client completes paperwork consisting of questionnaires and formal rating scales prior to arrival at the assessment clinic. They bring these forms with them on their designated appointment day. Upon entering the building at 8:30 a.m. on the first day of the assessment, that person is greeted by a receptionist. This staff member takes a photograph of the individual and instructs them to follow her to the assessment booth. At this point, the client completes additional rating scales, a confidentiality agreement, and other paperwork. This process usually takes about thirty minutes. At that point, the client is escorted across the hallway to meet with the licensed psychologist for a clinical interview. This interview usually lasts approximately one and a half hours. During the interview, a detailed psychosocial history is collected, and the student is allowed to discuss pertinent concerns or presenting complaints. At the conclusion of the interview, the client is offered a brief restroom break. By now, it is mid-morning and the client is introduced to the first evaluator. This person is either one of the school psychologists or a student trainee (graduate assistant/practicum student) employed by the center. From this point on, the client participates in the battery of standardized assessment tasks. These activities are designed to measure the person's skills in cognition, academic achievement, attention, or other executive

functions (e.g., organization, planning, self-correction, etc.). The individual is provided a one-hour lunchbreak around 12:00 p.m., with the specific timing being dependent upon progression through the testing protocol. The client is encouraged to take quick restroom or rest breaks at any point during the evaluation as a means of encouraging an optimal performance. Members of the assessment team take turns administering assessments. As each practitioner rotates throughout the assessment schedule, most encounters between an evaluator and student typically last approximately one to two hours before a new evaluator is introduced. A prospective client of the center may expect to meet anywhere from four to six evaluators during their two-day evaluation. The second day of assessment is much like the first, with the exclusion of the initial paperwork and interview that were completed on the morning of the first day. Clients take a lunch break on the second day and are again encouraged to take as many breaks as necessary to promote their best effort. Most people complete their assessments of each day around 4:00 p.m., but some may finish the scheduled activities either earlier or later. Completion times are primarily dependent upon a client's timely arrival to the center and the pace at which they are able to work.

The assessment team meets on a weekly basis to discuss the results of the prior week's assessments. After group discussion and deliberation, the group comes to a consensus to any diagnostic decision. The general findings of the evaluation are sent to the student by mail, and this brief letter informs the student as to whether they will be eligible to receive academic accommodations at a USG institution. Students are then re-contacted and invited to schedule either a face-to-face or telephone feedback session in which these results are discussed in greater detail.

**Samuel**

Samuel was an 18-year-old incoming freshman student when he scheduled an evaluation to update his documentation of disability. Samuel had been diagnosed with autism during early childhood, and as such he had received special education services throughout the majority of his educational career. During his early school years, Samuel received extensive intervention services that were primarily targeted toward behavioral problems, attentional difficulties, and social skills. While Samuel had exhibited significant difficulties in social functioning, he was by all accounts quite bright. His grades were exceptionally high and he was a very successful student throughout his school career. However, Samuel had also benefitted tremendously from the academic supports he had previously received. Samuel continued to experience some difficulties in independent living skills, and he seemed to be most comfortable when he was able to follow a strict routine. In the high school setting, he was granted time extensions, verbal reminders, and close attention by instructors to encourage on-task behaviors. Occasionally, he would become overwhelmed in the classroom due to noises or the presence of peers, and he was therefore granted opportunities to leave the room as a means of decreasing his overstimulation. Samuel's parents had been very involved in his prior academic planning, and they were strong advocates for his educational success throughout high school. His parents attended all special education meetings and were very involved in all aspects of special education decision making. As Samuel was a strong performing student, he rarely required modifications to the secondary school curriculum. He was often at the top of his class. However, he did require the opportunity to distance himself from peers from time to time, and he did benefit from the close lines of communication between his parents and the school. Perhaps the greatest benefit from this parent involvement was that his parents helped him to remain organized. The constant communication

between Samuel's parents and teachers safeguarded against the possibility that he would forget to turn in homework, complete long-term assignments, or study for upcoming exams. Samuel's parents requested an evaluation to ensure that he would receive all possible academic accommodations as a college student. They had taken a very active role in his learning thus far and planned to continue doing so once he entered college.

**Scene one.**

*SAMUEL arrives at the clinic during the summer months prior to the start of his freshman year at a large regional postsecondary institution served by the clinic. It is raining heavily at the time of SAMUEL's arrival. He is accompanied by his PARENTS. Although he is 18 years of age, he does not possess a driver's license. SAMUEL had never expressed an interest in driving, and his PARENTS had never pushed the issue. He is dressed in khaki shorts, a tucked in collared shirt, and wearing tennis shoes. SAMUEL is tall and of slender build. He appears healthy and with good hygiene. It was immediately apparent that SAMUEL experienced difficulties in social communication<sup>1</sup>. His PARENTS spoke on his behalf and appeared hesitant to leave him alone. SAMUEL was not very talkative with members of the assessment team, and his responses to conversational attempts were seldom more than a few words. He did not initiate conversation and exhibited limited eye contact and social reciprocity. As SAMUEL and each of his PARENTS enter the building, they are greeted by a RECEPTIONIST.*

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<sup>1</sup> Perhaps the most defining characteristic of ASD is that of abnormal or impaired social interaction with others. Communication deficits include both verbal and nonverbal forms of interaction. Social comprehension may be described as the ability to interpret social interactions between individuals by observing body language, facial expressions, speech tones, or use of pragmatic language (Rubin & Lennon, 2004). This knowledge of socially acceptable forms of communication has also been termed social intelligence or language pragmatics. These communication and social interaction impairments are not only significant but also sustained across environments and contexts for persons with ASD.

RECEPTIONIST: Good morning, welcome.

*(Turning her attention toward SAMUEL.)*

How are you this morning Samuel?

*(SAMUEL looks at the ground and is unresponsive to the RECEPTIONIST)*

MOTHER: Good morning, how are you?

FATHER: We are the Smiths. This is Samuel.

*(SAMUEL looks up and gives a slight smile toward the RECEPTIONIST.)*

RECEPTIONIST: I am doing well, thank you.

*(RECEPTIONIST again directs her attention toward SAMUEL as she prepares to begin the intake procedures.)*

RECEPTIONIST: I would like to take your photograph for record keeping purposes.

*(Walking from behind her desk to take a photograph of SAMUEL.)*

Great! We will go ahead and get started, Samuel, if you will follow me, I am going to walk you to another room so that you can complete some paperwork.

*(The RECEPTIONIST escorts SAMUEL from the lobby to the assessment booth while his PARENTS remain in the lobby. Upon the return of the RECEPTIONIST to the lobby moments later, the PARENTS ask about the day's activities.)*

FATHER: What types of things is Samuel going to be doing today?

RECEPTIONIST: He will complete some questionnaire forms, then he will complete an interview with the psychologist. After doing those two things, he will complete a variety of tests.

FATHER: Okay, we were planning to take Samuel to lunch today. Will he be free for lunch?

RECEPTIONIST: Oh yes. He should be available around noon. You can come back here at 12 to pick him up. He will have an hour for his lunchbreak.

FATHER: Great.

(PARENTS *remain standing in the lobby and the RECEPTIONIST senses their reluctance to leave the building.*)

RECEPTIONIST: Was there anything else I may help you with?

MOTHER: I guess we were just wondering about the types of activities Samuel would be completing and if you needed anything from us.

RECEPTIONIST: I can't say much about the specific test procedures, but can tell you that he will be completing a variety of activities designed to test his skills.

MOTHER: Is there anything you need to know from the two of us?

RECEPTIONIST: I don't believe so, we should have everything that we need between the paperwork you completing prior to arrival. If we develop questions or in the event that you are needed, we will be sure to call you.

MOTHER: So, you do have our telephone number?

RECEPTIONIST: Yes, I have it right here. (*holding paperwork*) This is your number, correct?

MOTHER: Yes, that is my phone number. Is that the only number you have for us? Let me give you my husband's cell phone number as well. We should be together, but let me give you that number just in case. Here is his number.

(MOTHER *writes a telephone number onto the document and hands back to the RECEPTIONIST*)

MOTHER: We are going to stay in town until lunch, and then we will go back home. Samuel is going to stay in the hotel across the street tonight, and we will drive back tomorrow to pick him back up at the end of the day's testing. Can we say good-bye to Samuel before we leave?

RECEPTIONIST: uh...yes ma'am.

*(The RECEPTIONIST goes to the booth to retrieve SAMUEL and returns to the lobby with him)*

MOTHER: *(compassionately.)* Good luck honey, remember to mind your manners and work hard.

FATHER: We will be back at lunch, and then we will go get you checked into the hotel.

SAMUEL: *(apathetically.)* Okay.....

*(SAMUEL leaves the lobby area to finish the paperwork he had been working on in the testing booth. FATHER then turns to RECEPTIONIST):*

FATHER: Are you sure we are not needed for anything?

RECEPTIONIST: Yes. You are free to leave, we will contact you by telephone if you are needed. We will see you back around lunch. If he gets done early, I will have him call you.

FATHER: Ok, well...I guess we will see you at lunch. Have a good morning.

*(Samuel's PARENTS leave the building)*

*(Samuel takes almost an entire hour to complete the paperwork. He comes out of the booth to ask questions about the documents twice. After finishing the paperwork, he meets with the licensed psychologist for the clinical interview. This interview only lasts 45 minutes, since Samuel provides simple responses and does not elaborate upon queries during this meeting. He is then introduced to the first examiner and escorted back into the assessment room to complete a computer activity.)*

EXAMINER: Good morning Samuel. How are you doing this morning?

SAMUEL: *(staring at the ground)* Good.

EXAMINER: (*in a chipper tone*) It is really raining cats and dogs outside this morning, isn't it?

SAMUEL: (*speaking in a monotone voice*) Yes, it is raining outside. If that is what you mean<sup>2</sup>.

(*There is a momentary silence between Samuel and the examiner*)

EXAMINER: Ok. (*Pausing further...*) Well, we are going to begin by completing some activities on the computer. Before we begin, do you have any questions about how the assessment will proceed?

SAMUEL: No.

EXAMINER: Would you like a restroom break before we get started?

SAMUEL: What time is it?

EXAMINER: It is 10:30.

SAMUEL: Okay, I'm ready to start.

(The EXAMINER directs SAMUEL to the assessment room with the computer and provides instructions for the computer task. SAMUEL sits at the computer table, stares at the computer, and limits eye contact while the EXAMINER is speaking.)

EXAMINER: Do you have any questions about this activity?

SAMUEL: No.

EXAMINER: Okay, then. If you are ready to begin, just click the mouse. I'm going to step out of

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<sup>2</sup> Individuals with ASD also may have difficulty recognizing sarcasm, irony, or humor when engaging in interactions with others (Baron-Cohen, 1992; Emerich, Creaghead, Grether, Murray, & Grasha, 2003; Happè, 1994). Deficits in reciprocal social interaction skills manifest through failure to utilize appropriate nonverbal behaviors such as eye-gaze, facial expressions, or hand gestures (APA, 2013). Additionally, there may be a lack of desire to spontaneously share enjoyable experiences or point out objects of interest to others. These deficits often result in the individual's difficulty in maintaining developmentally appropriate peer relationships (APA, 2013).



the room while you work on this. I will be back.

*(the EXAMINER leaves the room, and SAMUEL begins the computer task. The EXAMINER returns to the assessment room after approximately 30 minutes, just as SAMUEL is finishing up the computer activity.)*

EXAMINER: How was that? *(smiling.)* That activity didn't make your head spin, did it?

SAMUEL: *(seemingly annoyed.)* No, my head is still attached, thank you.<sup>3</sup>

EXAMINER *(pausing momentarily.)* No, I'm sorry, I was just commenting on the computer activity. Sometimes people have a lot to say about that activity once they are finished with it.

SAMUEL: *(seemingly impatient or insulted)* I know what you meant.

EXAMINER: Okay then, I apologize. We are going to switch booths and begin some other activities if that is alright with you?

SAMUEL: yes.

EXAMINER: Do you need a break, or do you have any questions?

SAMUEL: What time is it?

EXAMINER: It is 11:00. Are you ready to begin the next activity, or do you need a break?

SAMUEL: Let's begin. I will go to the bathroom at 12:00. Can I go to the bathroom at 12:00?

EXAMINER: Yes. You can wait and go then if you would like.

SAMUEL: Okay.

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<sup>3</sup> Individuals with higher functioning ASD may demonstrate extensive vocabulary knowledge and correct usage of grammatically correct language, but continue to experience significant difficulties in social communication. These difficulties are often the result of an inability to recognize the emotional cues of others (Klin, Jones, Schultz, & Volkmar, 2003). This lack of understanding of pragmatic language may result in perceptions of the individual as aloof, eccentric, or lacking in empathy (Landa, 2000; Rumsey, 1992).

*For the next 30 minutes SAMUEL and the EXAMINER begin other assessment activities, which included a combination of paper and pencil tasks, verbal exchanges, and the use of fine-motor movements to manipulate small objects<sup>4</sup>. SAMUEL did not initiate exchanges with the EXAMINER. When required to respond verbally, his speech was forced and occasionally pedantic. His eye-contact was very limited, and he most frequently focused his eye gaze downward towards the table. His affect was restricted, as he smiled infrequently and seemed distant. The EXAMINER frequently attempted to engage SAMUEL in small conversations during transitional periods with little success.*

SAMUEL: I need to go to the restroom.

EXAMINER: That's fine, you may go. The bathroom is on the left at the end of the hallway.

SAMUEL: Is it 12:00? (*Seemingly concerned that he will be using the restroom before 12:00*)<sup>5</sup>

EXAMINER: No, it is 11:30. We have about 30 more minutes before you will be able to take your lunchbreak.

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<sup>4</sup> Psychological assessment most often includes a multi-tiered approach in which a variety of informational sources are considered as the practitioner seeks to better understand the presenting problem of the client (Sattler, 2001). A standard evaluation is likely to include information taken from interviews, observational data, informal assessments (e.g. district tests, criterion-referenced tests), and norm-referenced tests. These norm-referenced tests, such as intelligence tests, are normatively referenced to clearly defined groups of individuals and administered in a standardized form to promote psychometrically sound (i.e. reliable and valid) instruments for measuring aspects of human learning and behavior (Sattler, 2001).

<sup>5</sup> Restricted or repetitive behaviors are characterized by high frequency, repetition, and invariability (Leekam, Prior, & Uljarevic, 2011). The individual may also demonstrate an inflexible adherence to specific nonfunctional routines or rituals (APA, 2013). Attempts to alter the individual's routine or ritual is often met with significant resistance or distress. For example, parents may be met with great opposition by the individual with ASD if they make a minor change to a morning routine, travel route, or other aspect of daily living (Leekam et al., 2011). These atypical behaviors are associated with the individual's insistence upon sameness. This inflexibility and opposition to changes in environment are defining features that may pose significant implication for adaptive behavior.

SAMUEL: I can't wait that long. I will go now.

*(SAMUEL leaves the room and returns a few minutes later. He then completes the remaining tests that were scheduled for him prior to his lunchbreak. He finishes these activities and goes back into the lobby to wait for his PARENTS to pick him up for lunch.)*

*(When SAMUEL returns from lunch one-hour later, his PARENTS also come back into the building.)*

MOTHER *(speaking to RECEPTIONIST in the lobby)* We are about to leave town. We helped Samuel get checked into his hotel room. He will be staying across the street, and he will walk over tomorrow morning.

RECEPTIONIST: Okay. Have a safe trip back, drive safe.

MOTHER: Are you sure that nothing is needed from us?

RECEPTIONIST: Yes, I am sure. The assessment team will contact you if any questions or concerns develop.

MOTHER: Okay, well we will see you tomorrow afternoon. Now Samuel, make sure you work hard and follow directions. Remember to use your manners. Give us a call tonight. Love you.

*(PARENTS leave the building.)*

*(A new clinician, EVALUATOR #2, walks into the lobby to introduce herself and take*

*SAMUEL back to the booth for afternoon testing.)*

EXAMINER 2: Good afternoon Samuel. How was your lunch?

SAMUEL: Okay.

EXAMINER 2: Well, if you are ready, we will go on back and get started.

SAMUEL: I'm ready.

(SAMUEL and EXAMINER 2 walk back to the booth.)

EXAMINER 2: (*attempting to make small talk.*) Where are you from? How did your morning go? Are you excited about college?

(SAMUEL responds with single word responses to each of these questions and does not make direct eye contact with the examiner when speaking to her.)

EXAMINER 2: Okay then, well we will go ahead and get started on the next activities.

SAMUEL: (*noticing a stopwatch that the examiner is holding*) What kind of stopwatch is that?

EXAMINER 2: This? I'm not sure, (*looking down at the stopwatch in her hand*) it is just a regular stopwatch that we keep here in the office."

SAMUEL: Are you going to time me? Does that stopwatch have a lap split function? Or does it just do a cumulative split?

EXAMINER 2: [*startled by Samuel's sudden talkativeness*] "Oh, I'm not sure, I just use it to record times from start to finish...."

SAMUEL: (*Interrupting*) Lap Splits are a more advanced function of stopwatches. Most don't have that ability. You only see that when the stopwatches are more advanced.

EXAMINER 2: You seem to know a lot about stopwatches. Are you collector?

SAMUEL: No. Not really, I'm just interested in time pieces. I have studied time keeping and have read a lot about how they work. I worked on my family's grandfather clock when it broke one time and have taken apart stopwatches and wall clocks since I was younger.<sup>6</sup>

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<sup>6</sup> The individual may demonstrate a restricted range or a single narrow area of interest (APA, 2013). These patterns of restricted or repetitive behaviors and interests, along with communication deficits, have long been recognized as the primary characteristics of ASD since Hans Asperger and Leo Kanner first documented the disorder in the 1930's and 1940's (Leekam et al., 2011). For example; the individual with ASD may become engrossed with numbers,

EXAMINER 2: Well, that's quite impressive! (*attempting to get the assessment tasks started.*)

SAMUEL: all of these digital clocks today are an abomination, I mean the real art of time-keeping is in horology-that's the study of mechanical time-keeping devices  
(*almost condescendingly.*)<sup>7</sup>

EXAMINER 2: Wow! I didn't know that. Let's get started on this next activity, shall we? I am going to have you complete the following page of problems as fast as you can...

(*SAMUEL and EXAMINER 2 work together for the next two hours. SAMUEL takes a five-minute break and then resumes testing with EXAMINER 3. He demonstrates the same mannerisms and limited verbal interaction with EXAMINER 3 as he exhibited with prior examiners. At one point, he begins to discuss calendars and astrology, but EXAMINER 3 curtails an extensive conversation about these topics so that the remainder of the day's activities may be completed. At the conclusion of this third segment of testing, SAMUEL leaves the center for the day to return the following morning. He was able to complete all tasks that were scheduled for this first day of evaluation.*)

### **Scene two.**

SAMUEL returns on time for the second day of testing. He is dressed in different clothes, with alternate colored shirt and shorts. Unlike his appearance on the first day of testing, he

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musical groups, vehicles, or space exploration. In the case of young children, a fascination with either dinosaurs or trains seems to be quite common. The focus of interest is often so great that the person may demonstrate no desire to learn about any topic that is unrelated to the area of interest. This lack of variability in areas of interest may even result in the person becoming somewhat of a pseudo-expert on whatever the preferred topic of interest may be.

<sup>7</sup> The speech patterns of some individuals with ASD may appear pedantic or stilted. Pedantic speech refers to a linguistic style characterized as overly formal, pompous, or ostentatious. Because of impairments in social awareness, persons with ASD who engage in pedantic speech patterns may be unaware that their communication style is offensive to others.

*appears disheveled. He does not appear to have bathed or perhaps even brushed his teeth, as the small confines of the testing booths make his body odor clearly apparent.*<sup>8</sup> SAMUEL enters the clinic building and is met by one of the evaluators.

EVALUATOR: Good morning Samuel. How was your night last night?

SAMUEL: Good. (*avoiding eye contact and appearing anxious.*)

EVALUATOR: Did you get enough rest?

SAMUEL: (*with distress*) My bed was not soft.<sup>9</sup>

EVALUATOR: I'm sorry to hear that. Sometimes I find it difficult to sleep in a new bed, or in unfamiliar places.

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<sup>8</sup> Adaptive skills refer to one's ability to perform normal day-to-day routine tasks and activities. Harrison & Raineri (2008) define adaptive behavior as an array of important competencies for coping with everyday environmental demands that include the performance of daily skills needed for self-care and relating to others. Deficits in adaptive skills may greatly influence personal independence and are therefore a very important consideration when working with individuals with disabilities (AAMR, 2002; Harrison & Raineri, 2008).

<sup>9</sup> Sensory processing refers to the physiological ability to receive, organize, and interpret sensations from one's own body or environment (Cheung & Siu, 2009; Schoen, Miller, Brett-Green, & Nielsen, 2009). Sensory processing, or sensory integration, is believed to be a neurologically based function that when impaired may have negative consequence to adaptive behavior and daily living activities (Cheung & Siu, 2009; Schoen et al., 2009). These processes include tactile, auditory, visual, olfactory, and gustatory functions of the body. These body faculties are also known as the five senses of touch, hearing, sight, smell, and taste. Rates of sensory processing impairments in individuals with ASD have been estimated to be as high as ninety percent by some researchers (Schoen et al., 2009). Manifestations of sensory processing impairment include hypersensitivity or increased levels of arousal to sensory stimulation. Individuals may demonstrate avoidance behaviors, under responsiveness, or seeking behaviors in attempts to organize or equalize unregulated sensory input (Dunn, Miles, & Orr, 2002). Some researchers believe that stereotypic or repetitive patterns of behavior, which are defining features of this disability group, are a result of the individual's attempts to regulate sensory functions (Dunn et al., 2002). Examples of observable behaviors commonly associated with sensory impairments include repetitive rocking, rubbing of objects or fingers, visual avoidance, inflexibility to change, and lower thresholds for sensory stimulation such as sounds or smells (Cheung & Siu, 2009; Schoen et al., 2009).

SAMUEL: Yeah.

EVALUATOR: Well, I hope you were able to at least get some sleep?

*(SAMUEL sits idly and unresponsive to the empathy of the EXAMINER.)*

EVALUATOR: We do have a full day of testing, so I would like to get started. Please remember that you can take a break if you feel yourself getting tired. Just let me know if you would like a break.

SAMUEL: "Okay."

*(the EVALUATOR and SAMUEL begin testing procedures. By mid-morning, SAMUEL has completed the block of standardized assessments that were scheduled to be completed by the first evaluator of the day. SAMUEL is offered a break during this transition while EVALUATOR 2 is preparing to administer the next block of tests.)*

EVALUATOR: Well, that's all that I have for you today Samuel. I am going to step out and get the next person to work with you. Would you like to take a bathroom break or get up to walk around for a minute?

SAMUEL: No. I don't think so...what time is it?

EVALUATOR: It is 10:30.

SAMUEL: No....I will wait.

EVALUATOR: Okay, then. Remember, if you would like a break...just let us know.

SAMUEL: Okay.

*(The EVALUATOR walks out of the testing booth, and EVALUATOR 2 comes into the booth approximately two to three minutes later. SAMUEL remains seated.)*

EVALUATOR 2: Good morning Samuel.

SAMUEL: Morning.

EVALUATOR 2: I don't have too much stuff for you to do, but we will try to get it done before lunch. That way, once you take your lunch you will not have as much to complete this afternoon....so maybe you will be able to leave a little earlier.

SAMUEL: *(looking down/away from EVALUATOR 2.)* Okay.

*(Testing procedures are begun for this next block of tests. SAMUEL responds to verbal prompts and questions, but he does not initiate conversation. By this point in the assessment, all evaluators have limited their attempts to initiate conversation or engage in extraneous dialogue with SAMUEL. He appears content to complete the assessment tasks and refrain from additional conversations with the examiners. By lunch time, SAMUEL has completed the second block of assessments. He is instructed to take a lunch break and return in one hour.*

*SAMUEL returns to the clinic approximately 1 ½ hours later. The third and final examiner of the day initiates testing with Samuel. While they are seating themselves in the testing booth, and EXAMINER 3 is readying test materials, she attempts to engage SAMUEL in small-talk.)*

EVALUATOR 3: How was your lunch?

SAMUEL: It was good. I walked over to Wendy's.

EVALUATOR 3: Oh, I like Wendy's hamburgers.

SAMUEL: Yeah, me too. I had a chicken sandwich.

EVALUATOR 3: Those are also good...the spicy chicke.....

SAMUEL: *(abruptly responds)* Yeah, how much do we have left to do?<sup>10</sup>

EVALUATOR 3: *(recognizing SAMUEL's discomfort in small-talk)* We should be done in

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<sup>10</sup> Samuel's interruption of the examiner in this instance may be representative of his weakness in social communication. His lack of desire to continue the reciprocal conversation initiated by the examiner, along with his abrupt interruption, may be reflective of difficulties understanding informal social rules, social etiquette, or the intentions of others.



about 2 hours. I'm the last person you will be working with. We can go ahead and begin if you would like.

SAMUEL: Yes.

(EXAMINER 3 *begins administration of the standardized tests.*)

**Scene three.**

(SAMUEL's PARENTS *arrive to the clinic to pick him up. They enter the lobby area.*)

FATHER: Good afternoon. We are here to pick Samuel up.

RECEPTIONIST: Okay, he is still working. He should be done within the next hour.

FATHER: No problem. We came on in to town so that we could get Samuel's luggage and take care of the hotel checkout.

MOTHER: We are in no rush. We just wanted to make sure that we were here when Samuel was finished. This was a big step for both him and us. He hasn't spent many nights away from us before. This was kind of a warm-up for him going off to school next year.

RECEPTIONIST: Oh, that was a big step for each of you then, wasn't it?

FATHER: We were a little worried that he wouldn't make it in on time this morning.

RECEPTIONIST: Well, I can tell you that he did arrive right on time.

MOTHER: Good. We even called him to make sure. (*smiling*) Is there any way that we could meet with the PSYCHOLOGIST?

RECEPTIONIST: Yes, let me check to see if she is available.

(RECEPTIONIST *walks down hallway and returns with the LICENSED*

PSYCHOLOGIST. *The PARENTS are then escorted to the PSYCHOLOGIST's office.*)

PSYCHOLOGIST: How are each of you doing? I'm told that you each wanted to speak with me. How can I help you?

FATHER: We are doing well, thanks. Samuel's mother and I would like to make sure that you are aware of Samuel's difficulties. We have tried to be encouraging and supportive of Samuel, but are worried that he may become lost once he leaves our home.

PSYCHOLOGIST: What do you mean by lost?

FATHER: Well, we have always been very involved in Samuel's life and have worked really hard to ensure that he receives the best opportunities in his schooling.

MOTHER: We are worried about how he is going to manage on his own. We have always provided Samuel with reminders and have made sure that he doesn't forget about upcoming assignments and tests.

FATHER: Yes, we are not sure how we are going to be able to continue to provide Samuel the reminders that he has grown to depend upon to perform his best in his coursework.

PSYCHOLOGIST: Oh...you are saying that you worry that he will not be able to manage the new responsibilities of being a college student, is that right?

FATHER: Yes.

PSYCHOLOGIST: Well, I can see in some of the paperwork that was completed prior to Samuel's arrival here at the center that you each feel that the extra supports you provided at home were beneficial for Samuel. Samuel also shared some information about that with me, and he seems to agree that the extra reminders for upcoming projects, assignments, and homework that have been provided by you were helpful to him in high school.

FATHER: Yes, we believe that he would not have had as much success without our support.

MOTHER: We have always been involved with Samuel's education, and we have kept close

contact with his teachers so that we know what is going on. How are we going to do that at the college?

PSYCHOLOGIST: The transition to college is difficult for many students, and given Samuel's situation, he is probably going to need some extra help to perform to the best of his abilities. However, due to the differences in the legislative requirements and the ways that disability services are implemented in the high school and college settings, this is going to be a learning experience for Samuel in more ways than one. You are probably already aware of this, but the close lines of communication and frequent interactions you have had with Samuel's teachers are probably not going to be possible with Samuel's college instructors.

MOTHER: Oh yes, we certainly don't want to be *those parents*, but we are very concerned that without our help Samuel is going to fall back into his old routine of forgetting to turn in homework or not make it to class on time. It all seems so scary to think of Samuel all by himself at the college.

PSYCHOLOGIST: Yes, it's probably going to be a major transition for all of you. The good news is that Samuel has the prerequisite academic skills to be successful. This is obvious. We could tell that right away when working with Samuel. (*hesitation.*) But, like other students, he is going to have to learn to manage his time and not be dependent upon other persons as he makes this transition.

FATHER: That's really what we are worried about. I mean, we have always made sure that Samuel wakes up and gets ready for school on time. We have to remind him to brush his teeth sometimes or help him pick out clothes that match or ...

MOTHER: We are concerned about how he is going to do outside of the classroom. What can

we do to help him prepare for living on campus?<sup>11</sup>

FATHER: We are not really concerned with his academic performance, it's the other stuff-like being on his own and interacting with new people that we are most concerned about.

PSYCHOLOGIST: I think you have each already provided Samuel with excellent levels of support. He is going to have to learn some new skills, and he may have some difficulties initially, but that is something that many new college students experience. I have some documents that I would like to share with you, these are handouts that explain the major differences between the delivery of disability services in the high school and postsecondary settings. Due to the nature of how the laws governing the provision of services are different between these settings, there are going to be some major changes in the ways that you have been helping Samuel. You probably are not going to be able to have conferences with Samuel's instructors, and you are not going to be aware of upcoming assignments or deadlines, unless he shares that information with you.

*(PARENTS are looking over documents as they have been handed to them.)*

FATHER: Oh my, we figured there would certainly be some differences. We knew that much by just thinking about what it was like going to college ourselves, but these are some pretty big differences here.

PSYCHOLOGIST: Yes, there are some fairly significant differences between the two pieces of

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<sup>11</sup> Traditional postsecondary accommodations for learning disabilities or ADHD may not be sufficient in meeting the needs of students with autism (Jurecic, 2007). In fact, primary issues facing the transition to postsecondary settings by students with ASD include unique needs such as increased attention toward the fostering of independence, adaptive skills, self-advocacy, higher order problem solving, communication challenges, and social engagement (Glennon, 2001; Hewitt, 2011; McKeon, Alpern, & Zager, 2013; Roberts, 2010).

legislation. Were you not informed of these differences during transition planning conferences or when Samuel was preparing to leave high school.<sup>12</sup>

FATHER: No we weren't, or I guess maybe we just never saw them laid out like this.

MOTHER: What can we do? Samuel will be leaving for college in a few months. Since he has a disability, that will give him some additional protections and resources, right? I mean, we were thinking that we would still be able to interact with his instructors.

PSYCHOLOGIST: No, you most likely are not going to be able to have the same hands-on-contact in Samuel's education that you have had in K-12. Since Samuel is an adult, he will be expected to advocate for himself now, and professors may be unlikely to interact with you as the parents. Again, I don't mean to sound the alarm. Samuel has many strengths and I believe he is going to have success. He may struggle with the interpersonal aspects of college life, and he is probably going to have a steeper learning curve than other students given his unique needs. I can also share some other informational sources with you that you may find helpful while thinking about this information over the rest of the summer. The most important thing you can do is ensure that Samuel maintains contact with the disability services office on his campus.

FATHER: That's the office we went to before being directed here, right?

PSYCHOLOGIST: Yes, the office of disability services on Samuel's campus is going to serve as his point of contact for ensuring that he is receiving his accommodations.

FATHER: Well... can't we just have conferences with that office?

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<sup>12</sup> Research suggests transitioning students with autism may not have received appropriate transition services before leaving high school (Chiang et al., 2012).

PSYCHOLOGIST: I can't speak directly to that question. I do know that the disability services staff encourage the student to be their own advocate. Your best course of action now is to re-contact that campus department and they will be better able to inform you about these concerns you have.

(RECEPTIONIST *knocks on the door to the PSYCHOLOGIST'S office*)

RECEPTIONIST: Sorry to interrupt, but I just wanted to let Mr. and Mrs. Smith know that Samuel is done.

MOTHER: Okay. I guess it's time for use to go. Samuel's father and I would like to thank everyone for their help.

PSYCHOLOGIST: You are welcome, we have enjoyed working with Samuel over the past two days.

(ALL THREE *step into hallway as SAMUEL has also just exited the testing booth*)

FATHER: (*enthusiastically*) All ready to go Samuel?

SAMUEL: (*looking at floor*) yeah.

MOTHER: (*nervous laughter*) Okay then, we want to thank everyone again. We greatly appreciate everyone's help, and we have been very pleased with your understanding and desire to help Samuel.

(PARENTS *are exiting building with SAMUEL walking behind them*)

FATHER to RECEPTIONIST in lobby: Goodbye, thanks for your help

RECEPTIONIST: Goodbye, drive safe. Goodbye Samuel.

FATHER to SAMUEL: Say bye, Samuel.

SAMUEL: (*eyes forward, not looking at receptionist*) Bye.

(*Parents and Samuel leave the building*).

## **Results of the Evaluation**

Samuel performed exceptionally well across most of the formal assessment tasks. His scores were above average on the majority of the assessment instruments included in his evaluation. He demonstrated strong vocabulary and oral language skills on these tests, even though he failed to demonstrate such abilities in conversation with examiners. He demonstrated exceptionally strong skills on nonverbal reasoning and visual spatial tasks. Samuel's academic performance was above the average range across activities of math, written expression, and reading. However, assessment instruments measuring adaptive skills, social communication, social awareness, and executive function resulted in estimated weaknesses. The overall findings of his evaluation reconfirmed a diagnosis of autism. Specifically, he was diagnosed with DSM-5 299.00 Autism Spectrum Disorder, Severity Level 1 (requiring support), without accompanying language impairment. This diagnostic specification indicates a level of functional impairment requiring the least amount of support. Individuals demonstrating this level of functioning are generally able to function effectively with limited supports, but without such minimal assistance, they may experience noticeable impairments in social communication and independence. Samuel demonstrated some difficulties with social interaction and inflexibility of behavior, along with weaknesses in organization, planning, and independent living skills. Samuel's form of autism is sometimes referred to High Functioning Autism and was previously referred to as Asperger's disorder in previous iterations of the DSM. The recommended classroom accommodations for Samuel included: extended time, a reduced distraction testing environment, and note-taking assistance.

### **Theorizing/ Diagnosing the Vignette**

First and foremost, the results of the standardized assessment instruments utilized to evaluate Samuel's functioning indicated that he did not experience any significant functional impairments in cognitive ability or academic performance. His scores across cognitive and academic tasks were generally above average and greater than most other students his age. While research suggests that the more severe forms of autism have been long recognized to be accompanied by gross intellectual impairment (Bailey, Phillips, & Rutter, 1996; Rutter, 1979; 1983), those cases of "high functioning" autism and Asperger's disorder have not included this same cognitive deficit, and persons demonstrating these higher functioning forms of ASD may possess average or above average cognitive abilities while also exhibiting other symptoms of autism, namely difficulties with social awareness and a pattern of restricted or repetitive behaviors (Lincoln, Courchesne, Kilman, Elmasian, & Allen, 1988; Rubin & Lennon, 2004; Siegel, Minshew, & Goldenstein, 1996).

### **Communication**

However, other aspects of Samuel's formal evaluation did suggest areas of weakness. Samuel demonstrated deficits in social communication. While his language skills and verbal reasoning abilities were not of concern, he experienced difficulties in the interpretation of social cues, reportedly had difficulties forming friendships, and misinterpreted the intentions and thoughts of others. These weaknesses in social awareness are sometimes referred to within the literature as theory of mind. Theory of mind is closely associated with social intelligence and refers to the ability of an individual to understand the thoughts, desires, or intents of others while also recognizing that those mental states of other persons are different from one's own mental state (Baron-Cohen, 2000). Theory of Mind impairment is also referred to as "mind blindness"



and has been alternatively described by Baron-Cohen (2001) as an inability to reflect upon the content of the thoughts, beliefs, or feelings of one's on mind as well as the minds of others. Researchers also forewarn that deficits in social comprehension and theory of mind may make persons with ASD particularly susceptible to deception by others (Baron-Cohen, 1992; Sodian & Frith, 1992; Yirmiya, Solomonica-Levi, & Shulman, 1996). Failure to comprehend the intentions of other persons may increase the likelihood of an individual with ASD in becoming a victim of manipulation, pranks, or bullying (Baron-Cohen, 1997).

Examples of Samuel's difficulties in these areas were apparent during the evaluation when he misunderstood when one of the examiners utilized figurative language in a joking way. Samuel also failed to recognize the intention of one of the examiners as this individual encouraged him to end his conversation about timepieces so that additional testing procedures could begin. Samuel's interruption while one of the examiners was speaking mid-sentence could also be considered an aspect of theory of mind, as the examiner was actually attempting to make a connection with him through small-talk. Instances in which Samuel appeared to act rudely, or to not respond in socially acceptable ways (e.g., eye contact, reciprocal conversation, etc.) could also be related to this weakness in theory of mind and social communication.

### **Repetitious/Stereotyped Behaviors and Interests**

While he did not express significant repetitious behaviors (e.g., rocking, hand-flapping, tics, etc.) during his evaluation, Samuel's parents did report presence of significant sensory issues during early childhood. As a child, Samuel had a considerable aversion to loud sounds and rough textures in his clothing. However, as he grew older he had become more desensitized to these forms of hypersensitivity. Sensory processing refers to the physiological ability to receive, organize, and interpret sensations from one's own body or environment (Cheung & Siu, 2009;

Schoen, Miller, Brett-Green, & Nielsen, 2009). Sensory processing, or sensory integration, is believed to be a neurologically based function that when impaired may have negative consequence to adaptive behavior and daily living activities (Cheung & Siu, 2009; Schoen et al., 2009). These processes include tactile, auditory, visual, olfactory, and gustatory functions of the body. These body faculties are also known as the five senses of touch, hearing, sight, smell, and taste. Rates of sensory processing impairments in individuals with ASD have been estimated to be as high as ninety percent by some researchers (Schoen et al., 2009). Manifestations of sensory processing impairment include hypersensitivity or increased levels of arousal to sensory stimulation. Individuals may demonstrate avoidance behaviors, under responsiveness, or seeking behaviors in attempts to organize or equalize unregulated sensory input (Dunn, Miles, & Orr, 2002). Some researchers believe that stereotypic or repetitive patterns of behavior, which are defining features of this disability group, are a result of the individual's attempts to regulate sensory functions (Dunn et al., 2002).

Again, even though Samuel did not engage in overt physical movements such as rocking or hand-flapping, some evidence of his continued sensory processing difficulties were apparent in his report of sleeping poorly during his overnight stay in the hotel. He apparently had significant aversion to the feel of his bedding, and therefore did not sleep comfortably.

Samuel's parents did suggest that he was overly infatuated with the measurement of time, and was exceptionally interested in anything about clocks or other measurement devices. Samuel enjoyed tinkering with watches and would disassemble clocks in his spare time. As a child, he reportedly spent excessive periods in solitude, he frequently lined up or arranged his toys, and insisted on sameness. The presence of restricted, repetitive patterns of behavior, interests, or activities is a core diagnostic feature of ASD (APA, 2013). These restricted behaviors or interests

typically involve aspects of the immediate environment during early childhood, but more often include specific subject matter and are intensely studied in adolescence or adulthood.

Importantly, these highly fixated or restricted interests and behaviors tend to be abnormal in intensity or focus (APA, 2013) and are beyond that which is typically observed in similarly aged peers.

Samuel's intense interest in time keeping and the tools utilized to measure time was unintentionally broached by one of the examiners during the evaluation. Whereas Samuel had been very quiet and refrained for most of his assessment, once he found an opportunity to express his knowledge and understanding for this special area of interest, he became animated and excessively talkative. Of course, Samuel did not recognize that the evaluator did not share this similar interest. However, this instance during the evaluation demonstrated the degree to which Samuel had focused his energy and time in learning about this area of restricted interest. The fact that he disassembled and fixed mechanical clocks should illustrate the level of knowledge and skill he had achieved in this area.

### **Adaptive Functioning**

Samuel continued to experience significant weaknesses in adaptive functioning. He did not possess the independent living skills that would be typically associated with other 18-year-old persons. He obviously experienced some difficulties in social skills and communication, but his parents also reported that he often struggled to complete typical household chores (e.g., cleaning room, washing his own clothes, etc.). Samuel also reportedly failed to recognize how to seek assistance from others. Given that these types of activities may be taken for granted by many normally developing people, one could argue that Samuel's parents limited the

development of these skills by their constant over-parenting. However, these routine chores and activities of daily living were often difficult for Samuel to complete without reminders.

The American Association on Intellectual and Developmental Disabilities classifies adaptive behavior into three broad categories, which include conceptual skills, social skills, and practical skills (AAMR, 2002).

Conceptual: communication, functional academics, self-direction, health and safety

Social: interpersonal and leisure skills

Practical: skills in community use, self-care, home living, health and safety, work

Research has consistently illustrated adaptive skill impairments, particularly in social domains, in persons with ASD (Gilotty, Kenworthy, Sirian, Black, & Wagner, 2002; Lord, 1993). While normal developing individuals demonstrate strengths and weaknesses in adaptive functions, the individual with a disability will exhibit more severe marked impairments in one or more of the areas listed above. From a practitioner's standpoint, deficits in social domains are oftentimes the focus of evaluation when determining the likelihood of an ASD diagnosis; however, persons with ASD may also experience difficulties in each of the primary domains of adaptive behavior (Gilotty et al., 1993; Lord, 1993).

The drastic difference between Samuel's dress and grooming between the two days of evaluation suggested that he does continue to have some difficulties with activities of independent living and self-care. By the admission of Samuel's parents, he had not spent many nights away from them, which could be perceived as unusual for an 18-year-old. He also evidently failed to adequately bath or brush his teeth before his arrival on the second day. His general appearance was very different on each of these days. Also, his parents were sure to handle the registration and check-out procedures for him at the hotel. They stated that they

telephoned him to ensure he wouldn't be late and shared their previous efforts to ensure that he did not forget to complete school assignments in high school. Each of these actions on the part of the parents demonstrate the degree to which he continued to require forms of support for activities of daily living.

### **Awareness of Legislative Changes**

Finally, the misunderstanding of Samuel's parents for the forms of services he would be likely to receive in the college setting was a major revelation. Samuel's parents were not well informed of how the regulations and laws guiding disability services between the high school and postsecondary settings would be different. Despite their high levels of involvement and desire to provide the best opportunities for their son, this aspect of the transition to college was unbeknownst to them. This was likely due to poor transitional planning services by Samuel's high school special education team. Despite the requirements of IDEA (2004) that specify components of effective transition planning activities, research has highlighted how these preparations may at times fall short of meeting the needs of students with disability (Chiang et al., 2012; Hetherington et al., 2010; Janiga and Costenbader, 2002; Shaw & Dukes, 2013). As witnessed in their interactions with the licensed psychologist, Samuel's parents were unaware of the differences to be expected in their ability to participate in Samuel's education.

### **The Postpositivist Foundation of Psychological Assessment**

The reader may have noticed that these descriptions of Samuel were presented in concrete and encompassing terms. Furthermore, most of the assessment instruments compared Samuel's performance to that of a similarly aged normative sample. Many of these comparisons are premised upon well-accepted and conventionally agreed upon developmental progressions and conceptions of normalcy. There is little room to consider individuality when thinking in this

way. If a performance is different, or out of sync, with the normative sampling, then there is a tendency to then equate it with deviance or atypicality. These aspects of the formal evaluation process are deeply rooted in the philosophical framework of postpositivism. For instance, a test score is not questioned in terms of truthfulness, and a perceived weakness on an instrument is often interpreted at face value as representative of an individual's true level of functioning. The test instruments themselves are highly valued as knowledge forms within themselves. The clinician's role is to interpret these test results and make decisions based upon patterns of functioning as they are represented in disability legislation and diagnostic criteria for mental health conditions. To make decisions without the use of such data would be considered unethical and reckless. Psychological assessment retains multiple inheritances of the postpositivist worldview. For instance, newly developed instruments and methodologies are usually embraced as potential solutions to perceived shortcomings of the current approach to assessment. It is also quite acceptable for individuals to be re-evaluated across their lifetimes in an attempt to better understand a person's functioning over time, and with the benefit of new testing instrumentation. This acceptance of new instrumentation, and a strong emphasis upon re-evaluation, should remind the reader of the postpositivist view of research as working to approach the truth through a process of revisionary and conjectural understanding (Phillips & Burbules, 2000). The information obtained from assessment instruments is believed to be accurate and unflinching because they were meticulously designed through empirical research practice and developed in accordance with scientific understandings of human behavior. Assessment instruments are developed so as to quantify, predict, and identify the cause and effect relationships of human behavior. These quantifications of behavior are then utilized to support decision-making and are considered valid forms of evidence. Finally, that quantification of behavior is most often

depicted in terms of descriptive statistics and samplings of the general population. Inherent within this framework, of course, is the implicit assumption of a normal—abnormal binary.

Furthermore, the diagnostic decision-making process that was deployed to confirm Samuel's continued diagnosis of autism also follows principles of the postpositivist framework. The diagnostic criteria of ASD were first accepted without question as the definitive or absolute standard by which Samuel's functioning would be compared. In this respect, the latest iteration of the *Diagnostic and statistical manual of mental health disorders* (APA, 2013) served as the indisputable source of truth. The tests and formal assessment procedures utilized were also deployed as a form of evidence gathering that was deemed acceptable because they were determined to be valid and reliable instruments of measurement. The resulting data from these instruments and procedures was then systematically compared to the standard as outlined in the diagnostic criteria for autism. As illustrated by the vignette, Samuel's patterns of behavior, prior history, clinical presentation, and test performances were unproblematically analyzed and determined to provide hard and fast evidence for the presence of his continued diagnosis of autism.

### **Literature Review: The Milieus of Positivism/ Postpositivism**

Postpositivism refers to a particular research methodology that evolved from the earlier principles of positivism, and despite the generic usage of the singular term of positivism, each of these research approaches present distinct philosophical implications. In general terms, positivism refers to a paradigm in which the researcher accepts the premise that positive knowledge is based upon naturally occurring phenomena, and is discoverable through emulation of “natural” science procedures, such as the scientific method (Guba & Lincoln, 1994; Savin-Baden & Major, 2013). However, this generality may be misleading and not representative of the

long history of positivism and its developments. There appears to be general agreement that the origins of positivism may be attributable to the work of the 19<sup>th</sup> century theorist Auguste Comte (Creswell, 2009; Howell, 2013; Phillips & Burbules, 2000), but the field of positivism holds a long and complex history that includes a variety of dynamic voices and traditions. Most notably, disagreements have primarily circulated around the specific procedures for identifying and verifying knowledge claims. The most notable permeations of these disagreements may be illustrated through the works of the two doctrines of logical positivism and postpositivism. Whereas logical positivists are most often characterized by their outright rejection of knowledge claims that may not be validated through empirical observation (Caldwell, 1994; Phillips & Burbules, 2000; Savin-Baden & Major, 2013) the postpositivists promote a view of knowledge that is assumed to be tenable, imperfectly known, and open to revision (Creswell, 2009; Guba & Lincoln, 1994; Howell, 2013). Given this altered philosophical position, postpositivists perceive knowledge to be conjectural, with all research conceived as a process of revisionary movement that approaches the truth, yet will never fully obtain complete understanding (Phillips & Burbules, 2000). In summarizing the primary difference between these forms of positivism, Howell (2013) states, “positivists consider an external reality exists that can be understood completely whereas postpositivists argue that even though such a reality can be discerned it may only be understood probabilistically” (p. 32). The field of school psychology, that in which my daily work occurs, is fundamentally organized by the principles of postpositivism. These connections between school psychology and the philosophical position of positivism are discussed below.



## **School Psychology**

The broader field of psychology, while emerging from the theories of early philosophical pioneers such as Wilhelm Wundt, William James, and Sigmund Freud, to name only a few, would rather quickly move away from matters of philosophy to become shaped by principles of positivism (Slife & Williams, 1997). At the turn of the 20<sup>th</sup> century, practitioners sought to legitimize the profession, much like other social science disciplines, and therefore the psychology field began to incorporate the methodological and philosophical assumptions of the so-called hard sciences (Robinson, 2000). This early adoption of positivistic methods, along with an overreliance upon the scientific method and emphasis for measurement of observable behaviors, was a way to elevate the prescientific discipline to a respectable form of scientific practice (Slife & Williams, 1997). As Breen and Darlaston-Jones (2010) have offered, “almost since its inception, the dominant narrative of modern psychology has embraced the positivist orientation of the natural sciences and has been slow to adopt alternate epistemological and methodological approaches” (p. 67). With the logical positivist conception of the verification principle in hand, psychology quickly adopted experimental design practices that emphasized the use of empirical evidence to describe, predict, and identify cause and effect relationships for human behaviors (Breen & Darlaston-Jones, 2010). This emphasis upon objectivity and the positivist’s criteria of cognitive significance further positioned the field into a model of description and measurement of observable phenomena (Breen & Darlaston-Jones, 2010; Robinson, 2000). Additionally, the rise in popularity of behaviorism as a paradigm of psychological practice in the 20<sup>th</sup> century only further capitulated the discipline into the arms of positivism (Breen & Darlaston-Jones, 2010). To worsen the issue, the advent of cognitive psychology in the later part of the 20<sup>th</sup> century, which could have offered an opportunity to

consider alternate methodological approaches, was met with a doubling down for the positivist paradigm. Rather than considering alternate methodologies to facilitate the measurement of nonobservable phenomena, the empirical problem of cognitive psychology was addressed through the creation of complicated operational definitions that could replace the measurement of observable behavior while still allowing an engagement with the positivist paradigm (Breen & Darlaston-Jones, 2010).

### **School Psychology in Practice**

The development of the school psychology field followed the philosophical progression of its parent discipline, as the earliest school practitioners were simply applying their methods of practice to younger student populations. Fagan (1992) traces the emergence of psychological services in educational settings to the various educational reform movements of the late 19<sup>th</sup> and early 20<sup>th</sup> century period. As new legislative measures for compulsory schooling, juvenile courts, child labor laws, and a host of other social service endeavors were initiated, school attendance increased dramatically. According to Fagan (1992), “the preeminent force behind the need for school psychological services was compulsory schooling. The increasing enactment and enforcement of compulsory attendance laws between 1890 and 1930 dramatically changed public education” (p. 236). As student populations grew, a variety of new supportive personnel were required to maintain order within educational structures. These personnel included a diverse array of professionals who had not previously been imbedded in school settings, such as school nurses, doctors, attendance monitors, psychologists, guidance counselors, and school social workers (Fagan, 1992). These new workers found themselves to be instrumental in the newly identified need to segment and segregate student populations into selective groupings (Fagan, 1992; Kliebard, 2004).

The prominent models of psychological service delivery of this period may be illustrated by the very different approaches of two figures, namely Lightner Witmer and G. Stanley Hall. Whereas the former focused his efforts upon individual students, the later focused his efforts upon systemic problems affecting all students. Lightner Witmer, largely considered to be the forefather of school psychology, advocated for the training of clinical practitioners to evaluate and treat individually referred students for concerns of atypicality (Fagan, 1992). G. Stanley Hall, on the other hand, worked to disseminate information to administrators, teachers, and parents to bring attention toward the correction of broad educational issues (Fagan, 1992; Kliebard, 2004). The divergent approaches of these individuals constituted a dualism that continues to present-day, as debates persist in whether practitioners' efforts should be focused upon individual or systemic concern. Fagan (1992) surmises,

Whereas Hall helped to establish the concept of the normal child, Witmer helped to define the abnormal and the subnormal. The descendants of Hall and Witmer carried their ideas to greater and more scientifically acceptable ends and bridged the approaches of child study and clinical psychology. Although Hallian and Witmerian orientations are discernible throughout the history of school psychology, the clinical orientation has tended to be the dominant form; and the most common recipients of services have been school-aged children suspected of being eligible for special education. (pp. 241-242)

As the clinical approach to service delivery has dominated the practice of school psychologists, the role of formal assessment has been both a positive development for the growth of the field, while also a limiting factor to the practitioner's ability to engage in activities beyond the traditional assessment role (Farrell, 2010). The requirement for specially trained clinicians has spurred a need for these individuals, thus creating job opportunities for school psychologists, yet

this has created a double-edged sword in which practitioners became imprisoned and unable to move beyond the clinical model of IQ testing and formal assessment (Fagan, 1992; Farrell, 2010; Kehle & Bray, 2005). According to Farrell (2010) the historical development of IQ tests, along with the continued emphasis upon their use, have promoted a perspective on the part of educational administrators, teachers, parents, and legislative bodies for their need in the identification of students with learning problems. Since school psychologists have historically claimed expertise and a distinctive role in the use of these instruments, this singular aspect of professional practice has come to symbolize a key role of the profession in the eyes of these stakeholders. While beneficial for promoting the profession, this dependence upon formal assessment as an identifying privilege and primary responsibility of the school psychologist has, unfortunately, further entrenched the principles of positivism within the field.

### **The Cultural and Legislative Milieus of Disability Services**

#### **Cultural Milieu**

The cultural milieu of contemporary disability services in America can be traced to three distinct moments. The first moment developed in response to the educational reform movements occurring around the turn of the 20<sup>th</sup> century. Perhaps most noteworthy, the advent of compulsory education laws necessitated the support of social and medical service practitioners, who began working within schools to assist in controlling, segregating, and segmenting the dramatic influx of new students (Fagan, 1992; Kliebard, 2004).

The second moment of growth in public school disability services occurred during the period of deinstitutionalization. Briefly, deinstitutionalization refers to the period of time and the accompanying policies in which the severely mentally ill and impaired were transferred out of large-scale state-sponsored institutions. Prior to this period, persons with severe physical and

mental impairment were generally placed into state-run asylums. While these settings may have been constructed as places of care, they devolved into warehouses for the separation, experimentation, and mistreatment of persons with disabilities (Blatt, 1969; Dorn, Fuchs, & Fuchs, 1996; Grossberg, 2011; Salend & Garrick-Duhaney, 2011). As individuals were transferred out of these institutions, school-aged individuals joined their non-disabled counterparts in public schools.

Reasons for the policy shift of deinstitutionalization are multiple, but aside from the issue of the rising costs associated with state-sponsored institutions, there were advancements in healthcare which included the development of new antipsychotic drugs (Torrey, 1997), and even some changes in attitude as injured veterans returned from WWII (Meisels & Shonkoff, 2000). The grassroots advocacy of persons with disability further altered the public's perception of otherness, and these efforts soon culminated in initial legislative reforms and public support for deinstitutionalization. Community based services quickly grew to serve disabled populations and primarily operated upon the principles of normalization and social valorization (Flynn & Lemay, 1999; Hamlin & Oakes, 2008; Wolfensberger & Tullman, 1982), which posited that the goal of integration should be to assist persons with significant impairments in leading lives that are as socially and culturally relevant and acceptable as their non-disabled counterparts.

The third moment of significant change is represented by the enactment of federal protections for persons with disability. With the success of the Civil Rights Movement, disability advocates utilized court rulings declaring equal educational opportunities for African Americans as a legal basis for the establishment of rights for persons with disability (Ashbaker, 2011). In a similar fashion to the civil rights laws of the 1960's, Section 504 of the Rehabilitation Act (1973) banned discrimination against persons with disabilities, offered protection of civil liberties, and

provided for legal minority group status. The Americans with Disabilities Act of 1990 would later provide additional protections against discrimination. A separate entitlement law was also passed in 1975 for the protection and support of students with disabilities within PreK-12 settings, and now guides the various tenets of contemporary special education services in the United States (IDEA, 2004).

Within these three moments, we can see a clear evolution in the way that disability has been treated in the public sphere, and particularly within the educational setting. Whereas disablement may have first been a thing to hide away, or set aside, as within the asylums, it would later become prominently displayed as a valued form of human experience within the grassroots movement. Today, the construct is a federally protected status that ensures the civil liberty and educational opportunity of persons with physical, cognitive, and psychological impairment.

### **Legal Milieu**

Within postsecondary settings, the provision of disability services is guided by mandates set forth by the Americans with Disabilities Act (ADA) of 1990 and Section 504 of the Rehabilitation Act of 1973. These two federal laws protect students with disabilities from discrimination or other unfair treatment. While there are differences between these two pieces of legislation, the application of these laws in higher education settings is essentially the same (Simon, 2000). For this reason, the mandates of Section 504 and ADA (1990) are often spoken of interchangeably in postsecondary education settings. The other paradigm of service delivery, that which occurs in PreK-12, is significantly different from the ADA (1990) and Section 504. The Individuals with Disabilities Education Act (IDEA) of 2004 ensures a free and appropriate education within PreK-12 school systems, and this is the system of service delivery that students

and parents will be most familiar and possibly expecting upon entrance to the postsecondary setting.

Although postsecondary students are guaranteed reasonable accommodations for access to the curriculum, they do not receive the same specialized services that are afforded in the PreK-12 setting (Shaw, 2009; U.S. Dept. of Education, 2002). While reasonable accommodations such as note-takers, extended time, or reduced distraction environments are common, students are rarely granted curriculum modifications or afforded a decrease in academic expectations (Geller & Greenberg, 2009; Gordon & Keiser, 1998; Koch, 2014; Shaw, 2009; U.S. Dept. of Education, 2002). Additionally, many students experience difficulty understanding their role as self-advocate under ADA (1990). Whereas IDEA (2004) requires PreK-12 school districts to identify and provide special education services for students with disabilities, there is no provision under ADA (1990) that requires institutions to identify or evaluate students with disabilities (Shaw, 2009; U.S. Dept. of Education, 2002). If a student wishes to be considered for accommodations, ADA (1990) stipulates that it is the student's responsibility to disclose their disability status and provide adequate documentation of a disabling condition to the Disability Service Provider (DSP) at their respective campus, of which specific requirements may vary between states and institutions (Gordon & Keiser, 1998; Shaw, 2009; U.S. Dept. of Education, 2002).

Federal regulations set forth the guiding principles for postsecondary educational institutions in the provision of services to college students with disabilities. While individual colleges and universities may enact additional policies and procedures, every institution must meet the minimal requirements for services that are mandated by the federal law.

The three primary pieces of legislation that protect the rights of all students with disabilities within the American educational system are: 1) The Individuals with Disabilities

Education Improvement Act (IDEIA) of 2004, 2) the Americans with Disabilities Act (ADA), and 3) Section 504 of the Rehabilitation Act of 1973. The legal rights of students in secondary school are protected by the IDEIA, while the ADA and Section 504 guard an optional, appropriate education for students in higher education institutions. Abbreviated summaries of these laws are provided in Figure 1, followed by further explanation of these laws and the impact they have upon the delivery of services in secondary and postsecondary settings.

Figure 1.

### **Federal Regulations Concerning Disabilities and Public Education**

<b>IDEIA</b>	<b>ADA and Section 504</b>
Free and appropriate education is guaranteed and mandatory	Appropriate educational supports, educational pursuits are optional
Entitlement Law	Civil Rights Law
Special Education and Remediation	Accommodations and aids
Success in the classroom	Equal Access to classroom
Federal Funding for services and evaluations	Evaluations are not publicly funded

#### **PreK-12 learning environments (IDEIA).**

The Individuals with Disabilities Education Improvement Act (IDEIA) of 2004 ensures a free and appropriate education to students with disabilities within PreK-12 school settings. The total scope of this federal law ensures appropriate educational services for students from birth to 21 years of age. This law, was first passed in 1975 and originally titled the Individuals with Disabilities Education Act, but has undergone numerous amendments since that time. As the law has been strengthened through the years, these revisions have come to include additional



protections for the rights of children and their families. Such alterations have included additional requirements of educational agencies to provide appropriate intervention services, legal protections for families during litigation, adoption of research-based procedures, age range extensions for qualified candidates of services, funding mandates, incorporating the use of transition planning services, and requirements for least restrictive educational environments. Whereas the acronym IDEIA has been utilized to some degree to refer to this legislation, it would appear that most researchers, educators, advocacy groups, and political organizations have reverted to the traditionally utilized acronym IDEA to refer to the latest iterations of the law. To reduce confusion, I have elected to refer to this special education law, in all of its configurations and amended versions, by the single term IDEA (2004).

IDEA (2004) not only guides the delivery of services for students, but also sets forth requirements and responsibilities of PreK-12 educational agencies to identify those students in need of such specialized services. The IDEA (2004) provides diagnostic guidelines for service categories, specific procedures of evaluation and treatment, as well as a variety of other stipulations designed to protect and guarantee the educational rights of secondary students with special needs. In their description of IDEA, Geller and Greenberg (2009) provide explanation of the terms “guarantee” and “right” as they relate to a free and appropriate education. If an individual has a documented disability, then that person is ensured special education services that are monitored and reviewed for appropriateness. The responsibilities of identification and service delivery are placed upon the school and the Individualized Education Plan team members associated with that educational agency (Shaw, 2009). An Individualized Education Plan (IEP) team is likely to consist of at least one regular education instructor, one special education instructor, a representative of the educational agency, an individual qualified to interpret

evaluation results, the parent, and the student whenever appropriate (IDEA, 2004). IEP team members work collaboratively to create a strategic plan for meeting the educational needs of identified students (IDEA, 2004). Special education services guide interventions and curriculum modifications to meet the needs of a student with disability, and are required for federally funded PreK-12 school systems (Shaw, 2009).

Included in this model of services is a requirement for ongoing progress monitoring, planning, adaptation, revision, and re-evaluations of learning ability. Parents are included in every aspect of educational decision-making, planning, and implementation of services within the PreK-12 setting (Geller & Greenberg, 2009; IDEA, 2004; Shaw, 2009; Stroebe, Krieg, & Christian, 2008). Until the age of 18 years, the parent maintains the power of consent, or informed approval, which is required before any type of decision-making is to occur. Within this framework, parents are an integral component since educational decisions have the potential to affect a child's life greatly. This is the system of services that students and parents will be most familiar and possibly expecting upon entrance into a postsecondary educational setting.

***Transition planning requirements of IDEA (2004).***

Effective transition planning should provide students with information about community resources that may be utilized after graduation, but should also include the identification of appropriate goals and objectives for the student after high school graduation, the exploration of career opportunities, assessment of personal strengths and weaknesses, increasing self-advocacy skills, an introduction to available technologies of support, and the determination of reasonable accommodations that could be useful if the student plans to enter a postsecondary educational setting. In the least, effective transition planning as defined by IDEA (2004), should identify appropriate goals and objectives for the student to seek after high school graduation. These

transition plans should identify potential sources, such as individuals or agencies, for future service supports as the student seeks to achieve these goals.

While these types of skills and future plans should be promoted through PreK-12 transition planning activities, research suggests transitioning students with autism may not receive the appropriate transition services they require before leaving high school (Chiang et al., 2012). However, this issue of unsatisfactory transition planning is not exclusive to students with ASD, as other researchers have suggested this to be an issue for all student disability groups. For example, one qualitative study of parent and student experiences through the transition planning process revealed significant dissatisfaction (Hetherington et al., 2010). These students and parents were critical of their transition experiences due to perceptions of limited support from school staff, feelings of being devalued, and a lack of opportunities for both parental and student involvement in transition planning activities.

The failures of transition planning mandates have also been voiced by professionals at the postsecondary level, as Janiga and Costenbader (2002) illustrated through their survey of New York state disability service providers. According to these researchers, DSPs overwhelmingly reported that transitioning students were unprepared to take a proactive role as self-advocates for their own learning needs. Likewise, one of the outcomes of a nationwide survey of DSPs included advocacy assistance as one of the most commonly utilized supports extended to students with disabilities (Stodden, Whelley, Chang, & Harding, 2001). This change in responsibility to act as one's own advocate should be a fundamental component of any legitimate preparation for transition to postsecondary education.

### **Postsecondary environments (ADA and Section 504).**

The Americans with Disabilities Act (ADA) of 1990 and Section 504 of the Rehabilitation Act of 1973 are two federal laws that guide disability services in postsecondary settings (Lissner, 1997; Mangrum & Strichart, 1988). Both the ADA and Section 504 are similar in that they guarantee civil rights protections to individuals with disabilities. These civil rights are similar to those provided to individuals that protect against discrimination on the basis of race, color, sex, nationality, age, or religion (Lissner, 1997; Mangrum & Strichart, 1988). While there are differences between these two pieces of legislation, the application of these laws in higher education settings is essentially the same (Simon, 2000). For this reason, the mandates of Section 504 and ADA are often spoken of interchangeably in postsecondary education settings. Section 504 (1973) was designed to protect the civil rights of individuals with disabilities in programs and activities receiving federal funding. Section 504 is widely recognized as the first civil rights statute for individuals with disabilities, and this legislation ensures that persons are not excluded from participation or denied benefits of public services based solely upon reason of a disability (Lissner, 1997).

ADA (1990), while similar to Section 504, expands upon the previous federal law by broadening the agencies and businesses that must adhere to nondiscriminatory operations. Furthermore, in 2008, the Americans with Disabilities Act Amendment Act (ADAAA) was adopted as a means of clarifying the term “disability.” Given a series of controversial court rulings in which the definitional attributes of the term disability were believed to have been construed too narrowly, the ADA was amended. The ADAAA (2008) broadens the definition of disability in an attempt to relieve the burden of proof that had been placed upon individuals seeking protection under the ADA. Since the revisions of the ADAAA apply to all sections of

the previously signed ADA (1990), unless otherwise noted, the Americans with Disabilities Act (ADA) will be used to refer to both the original act of 1990 and its 2008 amendment in subsequent sections of this paper.

ADA guarantees equal opportunity for individuals with disabilities in accommodations, employment, transportation, state and local government services, and telecommunications. This landmark piece of legislation provides guidelines for everything from minimum size requirements for doorways, wheelchair accessible buildings, employment opportunities, and accessibility to services. The Americans with Disabilities Act is divided into five title areas. Title I prohibits employment discrimination. Title II prohibits service and program discrimination against disabled persons by state and local governments, which also includes public educational agencies. Title III addresses regulations for private entities such as corporations, businesses, restaurants, retail stores, hotels, etc. Title IV includes telecommunications regulations and minimum standards for meeting the needs of individuals with hearing or speech impairments. Title V provides additional information pertaining to implementation of regulations and grievance procedures.

Title II is most likely applicable to a student's postsecondary needs, as it sets forth direct mandates for such settings. Therefore, this area is the most often the focus for disability service providers and administrators of higher learning institutions. However, that does not mean that the other sections of ADA are not applicable to colleges and universities. For example, persons with disabilities may seek employment in such environments, and telecommunications devices such as telephones or televisions are obviously found in these settings.

*Postsecondary disability services.*

Since public postsecondary institutions are required by law to provide reasonable accommodations to students with disabilities (Gordon & Keiser, 1998; Shaw, 2009; Simon, 2000; U.S. Dept. of Education, 2002; Wilson, Getzel, & Brown, 2000), many colleges and universities have created Offices of Disability Services (ODS) on their campuses to remain in compliance with federal regulations and facilitate the provision of accommodations to students with disabilities. Postsecondary disability services is recognized as the established profession in which practitioners organize services, implement procedures, and ensure equal access for students with disabilities in these settings (Madaus, 2011). At the very least these professionals, termed Disability Service Providers (DSPs), are tasked with the duty of preventing violations to federal regulations by ensuring students with disabilities are afforded appropriate accommodations, but DSPs are also oftentimes involved in a host of other activities such as the development of campus policies, providing consultation to faculty, offering training opportunities to the campus community, collaborating with other campus departments, and acting as an informational resource for students and parents (AHEAD, 2016).

While some institutions may offer greater programming opportunities and academic supports than others, these variations of support are largely attributed to philosophical differences of educational stakeholders, allotment of financial resources, personnel resources, and associated limitations arising from programming or administrative guidelines of individual institutions (Wilson et al., 2000). In fact, the amount of support for students with disabilities across postsecondary settings is very diverse. For instance, some smaller institutions may employ a single individual who works tirelessly to coordinate services for students that include accommodations, tutoring, and counseling support. Despite the positive attitude and optimistic

goals of the professional, these situations of limited resources often result in minimum levels of regulatory adherence.

Larger schools allotting greater funding towards disability programming may offer specialized services that are much more individually tailored. Many schools have developed comprehensive service plans and employ specialized staff members (e.g. sign-language interpreters, behavioral therapists, tutors, counselors, etc.) who are skilled in meeting the needs of their population of students with disabilities (Wilson et al., 2000). These institutions may go beyond what is required in federal regulations, and the student of these types of institutions may have a markedly different experience than those students attending schools with fewer allocations of support. It is also worth reiterating that this variation in student experiences is unlikely to be a consequence of a particular DSPs work ethic or dedication to students, but rather a manifestation of the specific institutional resources made available to said providers. Disability service professionals must work within the constraints of fiscal responsibilities and program limitations, which unfortunately results in a variation of services between institutions.

#### **Georgia's unified model of postsecondary services.**

In 1993, Georgia's public postsecondary institutions embarked upon a unique effort, with the support of the Georgia Board of Regents (BOR), to ensure that support to students with disabilities was consistent across each of its USG member institutions. Given the climate of the time, with nationwide concerns of ensuring appropriate service delivery to students with disabilities and the questions revolving around the mandates of the ADA (1990), the Georgia BOR acted upon a previously conceived plan to establish three state-funded centers for learning disorders (Gregg, Heggoy, Stapleton, Jackson, & Morris, 1996). These centers, known as the Georgia Regents Centers for Learning Disorders (RCLDs), were established to provide

comprehensive reduced-cost assessments to college students with suspected learning disabilities, offer consistency in the review of pre-existing disability documentation submitted to institutional disability services staff, provide technical assistance to regional DSPs throughout the state and assist with the development of institutional policies, conduct research on issues facing students with disabilities in postsecondary settings, and offer support to private and PreK-12 practitioners preparing documentation for transitioning students (Gregg et al., 1996).

Today, these RCLDs continue to offer consultative services to USG school disability services staff, collaborate with community agencies, and provide comprehensive state-subsidized psychoeducational evaluations to USG students seeking evaluations for suspected learning disabilities, AD/HD, psychological conditions, or other disorders covered by the Diagnostic and Statistical Manual of Mental Disorders warranting accommodations as outlined by the reauthorization of the ADA. The Georgia RCLDs not only provide a state-level resource for DSPs, but these centers have promoted ongoing educational workshops and routinely offer consultative services pertaining to appropriate accommodations for students with disabilities. Given the existing research that speaks to the variability that has existed in the experience levels, training, and resources available to DSPs, the RCLDs were promoted as a means to offer a unified system of support to these practitioners whether they worked in settings with or without extensive institutional resources. While today's practitioners benefit from guidance set forth by groups such as AHEAD, this unique model of state-level guidance for services was instituted during a period in which fewer resources existed for DSPs working across the nation.

### **Autism Spectrum Disorder as Subject Matter**

Autism Spectrum Disorder (ASD) is defined as a persistent pattern of deficits in social communication and interaction, with an accompanying pattern of restricted or repetitive interests



and activities (American Psychiatric Association, 2013). Persons with ASD may experience difficulties in both verbal and nonverbal communication, as well as demonstrate a strong insistence upon routine due to poor coping skills for environmental changes, each of which may be of negative consequence to learning. (APA, 2013). Importantly, the varied manifestations of the condition hinder any single best approach to providing supportive services to this student population (Hewitt, 2011). According to the U.S. Department of Education's National Center for Education Statistics (2013), rates of autism and developmental delays have increased significantly over the past decade. For example, percentages of total school enrollment for autism increased from 0.3% to 0.8% between 2003 and 2010. These data are supported by prevalence rates reported by the Centers for Disease Control (2015), which suggest an increase in prevalence from about 1 in 150 children in 2002 to 1 in 68 at the time of last sampling in 2010. In a recent study utilizing National Longitudinal Transition Study-2 (NLTS2) data, researchers identified a nationally representative sample of students with ASD who had left high school and found that approximately 43% of these individuals had attended some form of postsecondary school (Chiang et al., 2012). As the number of students with ASD entering colleges and universities is increasing, the need for additional supports have become more apparent (McKeon et al., 2013 Taylor, 2005; VanBergeijk, Klin, & Volkmar, 2008).

Autism, or at least the looming threat of ASD, has been brought to the forefront of the public's consciousness in recent years. This is due, in part, to the efforts of advocacy groups, educators, and members of medical communities to inform the public of the need for intervention. Unlike other neurodevelopmental disorders (e.g. specific learning disability, intellectual disability, AD/HD) Autism Spectrum Disorders seem to have captured and maintained the collective consciousness of parents, educators, medical experts, media figures,

corporate groups, scholars, politicians, and a host of special interest groups, alike. At the heart of this awareness is the variety of media that have promulgated public information campaigns to include television, radio, literary, and other popular media in the interest of informing the general public of a dire need to identify and treat autism. In fact, McGuire (2016) characterizes such calls for action as a strategy that intentionally causes distress so that the phenomena of ASD will be represented as a pending crisis that must be confronted with immediate action.

### **A Brief History of Autism Spectrum Disorders**

As recently as the last five to ten years, the term Pervasive Developmental Delay (PDD) was more commonly used to refer to the broad range of behaviors and symptoms associated with autism spectrum disorders and other medical conditions sharing similar features. To better understand how these changes in dialogue and reference have occurred, a quick explanation of the Diagnostic and Statistical Manual of Mental Disorders (DSM) is necessary. This manual, published by the American Psychiatric Association, provides a system of nomenclature and classification for mental health practitioners. The manual serves to categorize mental disorders and provide a standard method for diagnosis, clinical treatment, and further research into these psychological domains. The DSM is periodically revised to reflect the most current empirical literature and beliefs regarding mental health conditions. With each revision, changes may occur in not only the classification or nomenclature for specific disorders, but also in methods or requirements for diagnosis. Some disorders may be amended, added, dropped altogether, or in the case of closely related disorders they may be combined into broader disability categories. In the case of ASD, this is what occurred as an effect of the reorganization the DSM-5. Whereas the term PDD had been previously used in the DSM-IV to refer to a group of diagnoses sharing similar features (e.g. Autism, Asperger's Syndrome, Childhood Disintegrative Disorder, Rett's

Disorder and Pervasive Developmental Delay, not otherwise specified), in the DSM-5 these specific conditions have been regrouped under the umbrella of Autism Spectrum Disorders. Commentary at the time of the DSM-5 publication suggests that the workgroups involved in the revision of the text felt it best to focus upon specifications for the levels of care and support individuals may require (hence the current use of severity ratings) as opposed to distinguishing between the particular form of developmental delay that was expected. As a result of this change in classification, the term PDD has fallen out of favor amongst clinicians. While this distinction is less important for the purpose of this writing, readers should be aware of the potential interchangeability of these terms, especially when reading research that was published before the 2013 release of the DSM-5.

With these definitional, and likely politically motivated, alterations to the system by which practitioners communicate with one another, it is also important to realize that psychological diagnosis is often a dynamic and fluid construct that tends to change over time or between the personal opinions and experiences of individual practitioners. The process of diagnosing mental health conditions, just as it is with physical health, is often an evolving process in which hypotheses are formed and revised as new information becomes available. In an attempt to reflect the most current nomenclature, I have not elected to utilize the term Pervasive Developmental Delay in my writing. However, the two terms Pervasive Developmental Delay and Autism Spectrum Disorders, when used formally in the context of psychological literature, actually refer to the same group of medical diagnoses.

Of the several conditions now included under the umbrella of Autism Spectrum Disorders, the two previous diagnostic terms of Asperger's Syndrome and autism are likely to be the most recognizable to most persons. While it is true that rates of ASD appear to be on the rise

(Taylor, 2005; VanBergeijk et al., 2008), it is not insignificant that the group of symptoms and diagnostic characteristics commonly associated with ASD have only more recently been documented and acknowledged as a particular type of mental health condition.

The term “autism” first appeared in 1910 in the symptom definitions of schizophrenia by Swiss psychologist Eugen Bleuler (Kuhn, 2004). But it was the work completed by two individuals operating independently of one another that would form the basis of the contemporary meaning of the term.

While working at Johns Hopkins University School of Medicine, Leo Kanner, meticulously detailed the characteristics of severe developmental delays in young children. Kanner is credited with the introduction of the early infantile autism label in 1943, and his descriptions would lead to the very first formal diagnostic descriptions of autistic disorder, or “classic autism,” as it would be colloquially referred. Shared features of the population described by Kanner included social difficulties, repetitive behaviors, unusually narrow interests, language delays, and low cognitive functioning.

Almost simultaneously, yet independently, Hans Asperger also adopted the concept in 1944 to describe a set of shared features or symptomatology he observed while directing a children’s clinic in Austria. Asperger’s descriptions would include similar characteristics to those described by Kanner, yet he did not include the premise of either language impairment or low cognitive functioning. This collection of behaviors described by Asperger would eventually become known as Asperger’s Syndrome, but his work would remain relatively unknown to the English speaking medical community until the 1980’s (Baron-Cohen & Klin, 2006). Since Asperger published his work in German, the worldwide community remained largely unaware of his findings until pieces of his work were first translated by Wing (1981) in a professional

journal intended for English speaking audiences. Subsequently, Frith (1991) translated Asperger's original paper for publication as a book, which resulted in a wider availability of information pertaining to Asperger's Syndrome.

As western medical practitioners learned of this "new" diagnostic category, there was a sudden rise in both clinical and research interests for the condition. Resulting from this unexpected discovery of a new subgroup of ASD in which individuals did not necessarily exhibit severe cognitive or language deficits (i.e. Asperger's Syndrome), the overall prevalence rates of diagnosed ASD dramatically increased. Aside from the excitement for Asperger's work when it was first introduced to English speakers, a notable explanation for why his descriptions appear to have had such a sudden impact in the psychological and medical communities is that Kanner's descriptions were focused upon more severe behaviors and symptoms on the so-called spectrum, whereas Asperger had effectively opened-up a whole new population of potential candidates for the disorder by not including the diagnostic requirement of low cognitive function or language impairment to his descriptions. If desired, one could envision Asperger's descriptions to refer to a milder form of autism, thus prevalence rates of Asperger Syndrome could conceivably include individuals not meeting all criteria for a diagnosis of "classical autism," yet exhibiting some features of the disorder.

Today, controversy continues to exist in the available literature as to the legitimacy of Asperger's Syndrome, or High Functioning Autism as some may call it, and this continued debate is likely to explain the DSM-5 editorial committee's decision to move away from drawing lines in the sand as to the particular subgroup of ASD when making formal diagnoses. Obviously, this is a very simplified history for the two most widely recognized "types" of Autism Spectrum Disorders, but I wish to make two important points through this historical

review. First, it is important to acknowledge that the medical community's understanding of ASD remains limited. In relation to other mental health disorders, the widespread recognition, research, and awareness of ASD is a relatively new phenomenon. Truthfully, worldwide attention toward ASD has only occurred within the past two to three decades. In relation to the understanding and historical awareness of other mental health conditions, ASD is a new construct. Secondly, the debate remains ongoing as to whether actual cases of ASD are on the rise, or whether the increasing rates of diagnosis are better explained by the medical community's recent acceptance of the ASD construct as a spectrum of both mild and severe symptomatology.

### **Diagnostic Criteria of ASD**

To speak broadly, the DSM-5 diagnostic criteria include the following:

- A. Persistent deficits in social communication and social interaction across multiple contexts
- B. Restricted, repetitive patterns of behavior, interests, or activities
- C. Symptoms must be present in the early developmental period
- D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of functioning.
- E. Disturbances are not better explained by intellectual disability or global developmental delay.

These five major criteria may seem overly simplified, as they are presented in list form and condensed to represent the core tenets for diagnosis. In the most generic sense, ASD may be described as a lifelong condition in which a person experiences significant difficulties in social-

interaction and communication, along with restricted or repetitive patterns of behavior. However, these core attributes of ASD fail to adequately represent the complex nature of this condition.

### **Learner's Perspective**

*In reflecting upon my prior experiences of school psychology training, I have tried to follow Pinar's (1975) instruction. I began this regressive step by first thinking about my prior educational program, my location, age, interests, friends, professors, and colleagues. I entered graduate school at the same institution in which I had completed my undergraduate coursework. I lived with the same group of friends as in years past. My hobbies included sports, videogames, hunting, fishing, and of course, a continuation of the stereotypical "extracurricular activities" of a free-spirited undergraduate student.*

*To begin this regressive exercise, I simply thought about these years of my life as a student and jotted down ideas specific to my training experiences. The words I wrote are as follows:*

*Graduate school-at night, 4 hour seminars, small classes-a close cohort, statistics, theory of human development, developmental progression, text books, cramming for tests, exams, theories of intelligence and theories of human learning (loved these classes), psychometrics and test standardization, rigidity, all components of evaluation are standardized, learning test instruments, being scared I would make an error, 2 mistakes in administering a test resulted in automatic failure of course, report writing, federal regulations, laws, forms of measurement, normative assessment, validity and reliability of instruments, evaluating a test's usefulness for an assessment question, more statistics, multiculturalism, diversity, ethics, crisis intervention, counseling/therapy, psychological consultation, behavior modification/functional behavior assessment, intervention planning, practicum/internship, DONE!*

*Now, after writing these seemingly random statements down, I spent an evening thinking about this list of words. In some instances, these words refer to actual courses, while other words are personal feelings or simply major concepts presented through my program of study. Given their prevalence and the emphasis of some concepts, there are words appearing on the list that should have been repeated multiple times. I tried my best not to make interpretations about these memories, but admittedly this task was difficult to achieve. Memories of my prior training are strongly connected to emotion.*

*Allow me to offer additional explanation of this list that has just been provided. My graduate courses were in the evenings. Oftentimes, courses were presented in a seminar fashion and usually lasted no more than four hours. So for any given course, I would attend twice a week for approximately three or four hours. The program of study was approximately 78 credits, and included a comprehensive exam midway through the course progression as well as an applied research project. The program culminated with one semester of practicum field experience and then a year-long internship experience/field placement. I recall feeling lost and disconnected during the progression of coursework. I did enjoy courses in which we learned how to administer assessment instruments, as well as the psychological report writing courses. I really enjoyed these applied courses, but also remember being very scared that I would make errors in test administration. There was a rule in test administration courses that a certain number of errors would result in an automatic failing grade. We would administer tests to children, who we had to find on our own. We were also not to practice these administrations with family members, which I thought unreasonable. I remember thinking to myself that it would have been weird for a 20-something year old male to have access to upwards of a dozen school-aged children. I don't*



know how other classmates abided by this rule. I simply tested kids in my family who had a different last name!

I was one of two males in my classes. Our cohort was small, approximately 10 students. The classes that I recall with the fondest memories were **Theories of intelligence and Theories of human learning**. These courses were more abstract and philosophical in nature. Most other courses emphasized standardization, with concepts such as normative sampling, validity, reliability, and psychometrics. Of course, there were multiple courses that emphasized legal mandates and legislation, along with the application of ethical guidelines and issues of confidentiality. For the most part, most courses emphasized standardization and adherence to legal rules, along with a steady sampling of warnings about unethical procedures. Classes closely followed an assigned textbook. There were periodic examinations which were comprised of multiple choice and short answer questions. My practicum and internship experiences were where I was able to apply these various classroom skills. I enjoyed internship very much and it was not until this time that I was sure that I had chosen the right profession. Working with the school children was fun, and I never knew what to expect from them. This was the point in which I realized the assessment process was similar to that of investigative work, or the process of solving a puzzle. I enjoyed putting the puzzle pieces together and then presenting my assessment findings to school teachers and parents. Every aspect of my internship activities was guided by local school district rules and the **Georgia Department of Education Special Education Implementation Manual**. This manual provided direct requirements for special education decision making and was constructed in accordance with the IDEA (2004).

In his explanation of this first regressive step Pinar (1975) instructs his audience to write out the past so that “the words coalesce to form a photograph. Holding the photograph in front

*of oneself, one studies the detail, the literal holding the picture and one's response to it suggestive of the relation of past to present" (p. 9). In holding my photograph of past experience, my first response would be to think of words such as rigid, naïve, and one-sided. Of course, this perception is only possible because of my more recent educative experiences in the field of curriculum theory, which promotes alternate conceptions of knowledge and educational praxis.*

*When I think about my current practice within a University-based assessment clinic, I can easily identify direct correlations between my psychological training and my daily professional practice. I engage in the application and practice of school psychology every day that I am at work. This means that I employ a variety of strategies learned in formal evaluation courses such as standardization and descriptive statistics. I also apply my knowledge base to identify and describe symptoms and characteristics in clinical terms. I provide instruction and supervision to student trainees. In a way, I am not only abiding by the rules and guidelines of my formal training experiences, but I am also passing along those understandings and encouraging a similar adherence by those under my supervision. This passing of knowledge to others is carefully planned so as to emphasize the very aspects of my prior training that I at times found rigid and unnecessarily structured. Aside from my role in forwarding professional knowledge to trainees, my clinical work experiences provide ample opportunity to apply these previously learned concepts during the psychoeducational evaluations of postsecondary students.*

## CHAPTER 3

### IMAGINATIVE SPACES

In prior sections, I took a regressive step backward to consider the commonplaces of my prior training and current professional practice. In these aforementioned sections, I utilized aspects of Schwab's curriculum commonplaces as an organizational structure to discuss the content and situational factors of my prior learning experiences, as well as to present the disciplinary knowledge gained through my prior training as a school psychologist. This was a regressive step backward, as I recollected those prior educative experiences and considered how they have shaped my professional practice.

In this chapter, I seek to think progressively in an attempt to consider possibilities of future practice. As I have identified the various milieu present in my understandings for the subject matter of ASD and disability services as promoted through the traditional disability paradigm, I now turn toward alternate conceptions of disability that are informed by postcolonial scholarship, critical disability studies scholarship, cultural studies, and personal narratives of individuals with ASD. In this chapter, these alternate conceptions of disability illustrate lived experiences of in-between spaces, otherness, and difference that comprise the "data" for a reimagining of the creative nonfiction vignette presented in Chapter 2. Whereas that vignette served as the introduction to Chapter 2, the reimagined vignette concludes Chapter 3 and serves as a representation of what my work with ASD college students could be without present day limitations. Chapter 3 begins with a discussion of in-between spaces and curriculum, followed by a literature review of scholarship in postcolonial theory and critical disability studies. My reflection on this work and the implications it holds for understanding autism is presented in a section titled "Subject Matter: Critical Perspectives of Autism." Portions of this section appear in

italicized text to indicate my revisions and my rethinking of issues related to ASD. My Learner's Perspective in Chapter 3 reveals yet another layer of analysis in this self-study; it represents my attempts to bracket out my postpositivist training to more fully receive the themes that emerged from the scholarship reviewed in this chapter. The reimagined vignette concludes this chapter.

### **Curricular Possibilities of In-Between Spaces**

While the feeling of being in-between epistemological paradigms may be unsettling, I rely upon the prior work of others to embrace this in-betweenness as a space of possibility and potential resistance to the dominant narrative of disablement. That dominant narrative is informed by postpositivistic conceptions of the world and those who inhabit it. I build upon scholarship of the theoretical and physical locations of space and place (Bhabha, 2007/1994; Saïd, 1994) to consider how these positionings provide unique opportunities for conscious reflection, epistemological curiosity, resistance, fluctuation between paradigms of knowledge, a personal space of belonging within disparate conditions, and a recognition of contradictions between theory and practice (Aoki, 2005; Baszile, 2006; Collins, 2000; Giroux, 1992; He, 2010; He & Ross, 2012; Solorzano & Yosso, 2002). According to Homi Bhabha (2007/1994):

the postcolonial perspective resists the attempt at holistic forms of social explanation. It forces a recognition of the more complex cultural and political boundaries that exist on the cusp of these often opposed political spheres. It is from this hybrid location of cultural value – the transnational as the translational – that the postcolonial intellectual attempts to elaborate a historical and literary project. (p. 248)

Bhabha (2007/1994) encourages challenge to the false assumptions of cultural dualities and totalizing stereotype. He forwards the concept of hybridity not as a resolution to cultural difference but a process by which subjugated or the “other ‘denied’ knowledges enter upon the

dominant discourse and estrange the basis of its authority – its rules of recognition” (p. 162). Importantly, Bhabha does not argue for a total replacement of dominant cultural ideology, but rather identifies ways in which a displacement of colonialist discourse results in a hybridization of culture, or a space that is liminal, in-between, and evasive of fixed or binary definition or assumption. It is this space between that provides a grounds for new epistemic understanding.

Edward Saïd (1994) also touches upon a similar space of contradiction and in-betweenness in his arguments that intellectuals should live as metaphorical migrants or exiles. He argues that this displacement and unfamiliarity is necessary to remain critical of conventional truths and to gain:

a double perspective that never sees things in isolation. Every scene or situation in the new country necessarily draws on its counterpart in the old country. Intellectually this means that an idea or experience is always counter-posed with another, therefore making them both appear in a sometimes new and unpredictable light: from that juxtaposition one gets a better, perhaps even more universal idea of how to think. (p. 60)

He further describes this state of exile as a position of discomfort, restlessness, and constant unsettlement. However, it is through this self-imposed isolation that scholars and intellectuals are able to set themselves apart, work from the margins, question authority, and remain critically conscious of not only the pressures imposed by allegiances to institutional structures and relationships to others, but also one’s vision to speak truth to power (Saïd, 1994).

Curriculum theorist Ted Aoki (2005) also identifies the same type of living in contradiction and tension faced by teachers as they struggle to inhabit the space between the official or sanctioned curriculum-as-plan and that of the lived-curriculum of experience, which occurs within the daily interactions and spaces of the classroom itself. Aoki (2005) identifies this

tensionality as a space of being, or “a mode that could be oppressive and depressive, marked by despair and hopelessness, and at other times, challenging and stimulating, evoking hopefulness for venturing forth” (p. 162). Rather than focusing upon the negative, Aoki (2005) suggests teachers should not attempt to overcome tensions but rather learn to dwell within this zone-between as a way to facilitate the personal growth of both students and teacher. By embracing the tensionality of the zone-between, instructors are able to satisfy sanctioned requirements of the planned curriculum while simultaneously promoting relationships with students—taking the time to relate to students as individuals and providing a safer space for them to simply be themselves.

These understanding of hybridity, in-betweenness, or even voluntary exile, are foundational elements to this undertaking in which I seek to disrupt or challenge the master narrative of prior training that emphasized the role of the experimental method in the formation of new knowledge. Just as He and Ross (2012) identify the power of counternarratives to disrupt dominant narratives of oppression for disenfranchised groups, I too will seek to find sources of understanding that run counter to the dominant scientific-medico narrative of autism. These alternate epistemological sources do not arise from sanctioned researchers within the typical disciplinary boundaries of my prior training, but are rather told by marginalized individuals themselves who defy the master narratives which promote deficiency (He & Ross, 2012). In addition, there are other forms of counternarrative to be found within the cultural sphere. Although these representations may portray stereotypes of disablement or fail to adequately challenge the master narrative of the scientific-medico framework of ASD, these representations within the cultural sphere also serve as a viable source of understanding.

### **Milieu: Cultural Curriculum, Critical Disability Studies, Postcolonial Hybridity**

To expand the epistemic possibilities of ASD calls for a consideration of alternate forms of knowing. While challenges to the master narratives of disablement arise from a wide variety of perspectives, I have elected to focus my efforts upon counter stories presented through the fields of critical disability studies, cultural curriculum studies, and postcolonial theory. Given my concentration of interests during the Curriculum Studies program, I believe that I began this research project with a fair understanding for the cultural studies field. However, I will admit that I have had to devote a considerable amount of time to learn more about critical disability studies and postcolonial theory.

After many hours of reading, I have concluded that similarities and interconnections exist between the common approaches deployed by both critical disability and cultural curriculum scholars. For example, critical disability scholars have frequently utilized analytical approaches that incorporate ideas of normativity, which are culturally constructed and ideologically coded into the popular consciousness. In many ways, the work upon disability has taken on the theoretical and philosophical approaches typically found in cultural study. However, as we shall see, I have not been able to substantiate such a relationship between the fields of disability studies and postcolonialism.

#### **Critical Disability Studies**

Scholars working within disability studies have employed a variety of techniques and adopted theoretical methodologies from across the disciplines to forward their project of challenging the traditional scientific-medico model of impairment. As an interdisciplinary field, one that has witnessed dramatic and rapid growth, many approaches have been used to disrupt the able/disabled binary to the medical model of deficiency. The task I set for myself has been to

provide a survey of this field, and this simple goal has been much harder than I originally envisioned. Perhaps due to my complete unfamiliarity to the field beforehand, or maybe because of how quickly it has evolved over recent decades, the process of understanding the who, what, and when of this discipline has been demanding. With each new insight, or research article reviewed, I have had to revise my working synopsis. I believe it easiest to present this section through somewhat of a historical tracing of the field's development, and in doing so, I will describe the use of the primary analytical methods that have characterized each of these periods.

### **The social model of disability.**

As a field of scholarship, critical disability studies evolved from the initial field of advocacy that arose after the period of deinstitutionalization<sup>13</sup>. Early disability studies scholarship was closely aligned with the disability rights movements, and the social model<sup>14</sup> was prominently deployed from the start as a means of gaining political traction and drawing attention to disability topics. Within the social model, impairment was viewed as the biological

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<sup>13</sup> Briefly, deinstitutionalization refers to the period of time and the accompanying policies in which the severely mentally ill and impaired were transferred out of large-scale state-sponsored institutions. The governmental policy took shape in the 1960's in both the European and American contexts. While beneficial for some, the policy has been poorly managed and resulted in dire consequence for many of the severely impaired, with the prison system now serving as a stand-in for contemporary long-term mental health facilities (Torry, 1997; Hamlin & Oakes, 2008).

<sup>14</sup> The social model arose as the dominant framework of disability scholarship in the late 1970's, and was particularly visible in Europe. Most scholars recognize the 1976 publication of the *Fundamental Principles of Disability* to signify the outset of disability studies as a formal field of inquiry (Oliver, 1999, 2013; Shakespeare & Watson, 2002; Tremain, 2008; Watson, 2012). The Union of the Physically Impaired Against Segregation (UPIAS) organization argued in this highly influential statement that disabled persons are a socially oppressed group, who were not unlike other social groups, and were not really disabled by impairments but rather by the barriers and obstacles that were constructed and maintained by the greater society. This statement was revolutionary in the sense that these self-advocates were distinguishing between the notions of disablement and impairment.



or environmental disruptions to bodily function, while disability was argued to be the social oppression that individuals experienced as a result of such impairment.

These early rumblings of the field, particularly within the U.K., were highly influential in reshaping public perceptions of disablement away from the traditionally medicalized view of deficiency toward a more powerful form of support to shape public policy, dismantle barriers, and address civil rights issues of the day (Oliver, 1999; Shakespeare & Watson, 2002). While it is true that the UPIAS document and the social model were instrumental in affecting initial changes to public policy, the true benefit of this approach may have been in the widespread engagement and subsequent transformations of personal identities resulting from new articulations of the impairment experience (Oliver, 1999; Shakespeare & Watson, 2002). Dissemination of the UPIAS document led to both individual and collective empowerments for advocacy campaigns to increase public services, break down barriers, and reposition the disability construct into the public consciousness.

These earliest analyses of disability using the social model approach primarily followed a materialist critique (Erevelles, 2000; Meekosha & Shuttleworth, 2009; Oliver, 1999; Watson, 2012). This type of analysis was particularly useful for not only identifying and calling attention to oppressive circumstance, but also in eliciting the advocacy and personal empowerment necessary for persons to collectively call for change. This historical materialist or classical Marxist approach represented disability as a form of socially imposed oppression that served to position individuals according to the economic relations of production (Erevelles, 2000; Meekosha & Shuttleworth, 2009; Oliver, 1999; Watson, 2012).

The materialist approach to autism may be considered a more traditional method to theorizing within disability studies. In taking this perspective, scholars focus upon the capitalist

economy and means of production as a starting point to theorize disability. As Goodley (2013) explains, the traditionally Marxist approach was most helpful to social model advocates for gaining political attention. When thinking of the Marxist political economy, those who were less able to participate in the means of production were either oppressed or altogether excluded from the labor market (Goodley, 2013; Meekosha & Shuttleworth, 2009). Early social model scholars viewed disability as a form of societal oppression that was prefaced upon differences in productive capacity rather than any other factor, such as intrinsic worth, humanity, or personal desire. In her criticism for the lack of consideration of the disabled subject by educational theorists, Erevelles (2000) also explains this perspective of disability from the materialist perspective to be an issue of the productivity of the disabled body. However, she also highlights extensions of this approach to consider the consumptive practices necessary within the capitalist economy to theorize the value of the disabled subject as consumer. Nevertheless, unlike the bourgeois consumer whose separation from the production process is celebrated, the disabled subject as consumer could also be viewed negatively because unlike the elite bourgeois who facilitate and organize production, the disabled consumer is likely to have neither the labor capital or the propensity of production to be viewed as anything more than a parasite upon the capitalist system—reaping the benefits of production without first contributing labor value.

In addition to considerations of the disabled subject as lacking value as a productive worker under the tenets of classical Marxism, we may also question the conditions in which those who could work under this economic paradigm may have been exploited<sup>15</sup> for their lack of independence, social awareness, or special talents.

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<sup>15</sup> Exploitation of able-bodied workers is a common criticism of early capitalism, and such treatments of those who were viewed as deviant or abnormal, if they were able to work, would have been likely.

Also within the historical materialist perspective, as Oliver (1999) points out, the various social agencies and institutional services provided to persons with disability could be viewed as a form of production. Social agencies and rehabilitation services employ persons who erect ideological mechanisms of control and produce a product, or service, that support an entire industry of workers. The health and rehabilitation industry produce the concept of disability to be consumed, not unlike other sets of goods to be consumed in the capitalistic economy. From this perspective, the helping professions may not be seen as benevolent endeavors but rather as extensions of control or surveillance over the less productive members of society. Examples of such disability commodities might include the resources that are sold to parents and families for treatment, professional services such as behavior training, therapy, speech services, and medical treatment which each emphasize the need to correct deficiencies and abnormalities of the disabled individual.

If we expand this theoretical stance beyond the strict tenets of historical materialism/classical Marxism to also consider the cultural processes and social values of a consumer culture, such as those that were first brought to light by the later works of Frankfurt School scholars who termed their work as critical theory, then the autistic construct takes on a different form. Rather than emphasizing the productive act, these scholars<sup>16</sup> focused upon the

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<sup>16</sup> Analyses that focused upon commodification and the perceived infatuation of the western capitalist populous to acquire possessions or to crave consumption (Fromm, 1955) illustrate different ways in which the citizenry could retain their social value simply through engagement in the consumptive act. Additionally, the accompanying analyses of culture, and particularly mass media's role in promoting conformity and consumerism, also may hold importance for considerations of the disabled subject to retain social value through a culture that emphasized consumerism over production of goods (Adorno, 1954; 1963). Within a culture in which the landscape of labor was altered by technological advancements, an increased bureaucracy, and separation from certain forms of labor value, this system of consumerism served to grant

ways in which consumerism worked as a byproduct of capitalism that was promoted through the popular culture and mass media (Kellner, 1992). In other words, attention was moved away from the process of production and toward an emphasis upon the consumption of goods and services. For persons with severe disabilities who were not considered productive citizens within classical Marxism, these same persons who held purchasing power could be valued within this later permeation of the consumer society.

### **The critical turn in disability studies.**

While the social model must be recognized for its importance in transforming the issue of impairment into an issue of civil rights and social justice, as well as in supporting the development of a liberating mindset amongst the disabled community, the approach has not been without controversy as scholars have sought to progress the field toward more postmodern interests. Criticisms of the social model included attention toward the rigid dichotomy between impairment and disability, which potentially failed to recognize all forms of impairment or representations of disability (Shakespeare & Watson, 2002). Furthermore, the all or nothing thinking of the social model was also criticized for its incorrect treatment of disabled persons as a homogenous group, which did not provide a space to consider the intersectional dimensions of other social constructs such as gender or cultural group (Watson, 2012).

As new ideas and methodological approaches have been introduced to the traditional frameworks of disability studies work, the field has evolved from the strict binary that once established the separation between the constructs of impairment and disability. In part, this progression of thought has been due to the interdisciplinary nature of disability studies, with

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comfort, reinforce conformity, and offer a sense of belongingness to the alienated worker (Aronowitz, 1982; Fromm, 1955).

scholars bringing their own preferred methodologies and areas of knowledge into the conversation. At the time of their writing in 2009, Meekosha and Shuttleworth recognized an increasing use of the term critical disability studies (CDS). It has also been noted that the influx of workers from the humanities and social sciences<sup>17</sup> in the 1990's likely contributed, in part, to the progression of terminology as these scholars brought a willingness to move beyond materialism as a means of analysis into their work on disability (Goodley, 2013; Meekosha & Shuttleworth, 2009). In this respect, Meekosha & Shuttleworth state “the use of CDS signifies an implicit understanding that the terms of engagement in disability studies have changed; that the struggle for social justice and diversity continues but on another plane of development –one that is not simply social, economic, and political, but also psychological, cultural, discursive, and carnal” (p. 50).

Furthermore, the noted divisions amongst social model theorists have been well noted by a variety of scholars seeking to explain the need for change in theoretical approach (Goodley, 2013; Meekosha & Shuttleworth, 2009; Oliver, 2013; Shakespeare & Watson, 2002; Shakespeare, 2006). The apparent distancing from the doctrine of the social model may serve to not only open the field to new possibilities, but it may also serve to bridge the divide between American and British disability studies as well as encourage international participation by non-western theorists who may have been excluded by the restricted interpretations of the social model<sup>18</sup>.

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<sup>17</sup> Given that these newcomers promoted the adoption of postmodern approaches such as participatory methods or psychoanalysis that would have likely been rejected by traditional theorists on the grounds that these alternative techniques reinforced the medical or individual model of disability, the convergence of these ideas clearly signaled a paradigm shift.

<sup>18</sup> Whereas the social model was a clear organizing principle of disability rights work in the European context, the North American model had developed independently and had not made

Another reason for the adoption of new language and strategies of analysis may have been due to a perceived need to better define the scholarship of the field, as Meekosha and Shuttleworth (2009) noted growth in “the cooption of the language of disability studies by the institutions of government, along with the professional areas of rehabilitation and special education taught within higher educational institutions” (p. 50). Given the re-badging or re-branding of these traditional structures, which oftentimes fall short of truly addressing the sociopolitical concerns of the disability studies field, the adoption of the term CDS may also be perceived by some as a means of distinguishing between traditional establishments and the focus of a contemporary disability studies agenda.

Dan Goodley, writing in 2013, identified key features of CDS that distinguish this newer form of theorizing from the traditional disability studies research field. Foremost, he communicates that self-reflexivity and a willingness to acknowledge past insights of the field while simultaneously thinking toward the future is a very important feature of the contemporary field. As we now inhabit a postmodern world, the strategies of the past may no longer serve all persons. For instance, identity politics, globalization, and technology have reshaped our society. Therefore, theory also needs to evolve to meet the new needs of a changing society. This sentiment was previously noted by Meekosha & Shuttleworth (2009) as they argued that the history of the Frankfurt school suggests that even the originators of the Critical Theory paradigm had themselves demonstrated a willingness to move beyond classical Marxism toward a stronger emphasis upon power operations, ideology, and culture as changes in society signaled a need for newer approaches of analysis.

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such a clear distinction between the constructs of biological impairment and socially imposed (disabling) conditions (Shakespeare & Watson, 2002).

Goodley (2013) also notes that CDS may continue to engage discourses of materialism, but scholars should be willing to move beyond these forms of analysis. The realist interpretation of impairment (i.e., the bodily effects of impairment), while sometimes glossed over in the social model, is often engaged more directly within CDS as a means of communicating actual lived experiences. Given strict adherence to the social model, the intersectionality of other social identities (e.g., gender, age, race, etc.) were oftentimes disavowed in traditional approaches. Critical disability studies recognizes that individuals are not defined by a single identifying trait, and it seeks to confirm, explore, and better understand the ways in which an individual's socio-cultural identities interact or coincide (Goodley, 2013; Meekosha & Shuttleworth, 2009). Of course, the growth of the field has led to interpretations beyond the traditionally western conceptions of impairment, given that disablement is a universal concept; therefore, these theorists envisioned that postcolonial or indigenous concepts of disability may be incorporated into future CDS work (Goodley, 2013; Meekosha & Shuttleworth, 2009). Watson (2012) also explained that CDS seeks to analyze disability in terms of power and knowledge to better understand how our notions of disability have been constructed. In introducing a collection of essays on the subject, Devlin & Pothier (2006) clearly state that the construct of disability with critical disability studies is not an issue of medicine, health, or interpersonal relations, but rather a clear issue of politics and powerlessness. They further identify core assumptions of this newer theoretical approach to disability, which include the operations of language, a recognition and acceptance of difference, and a politics of transformation.

### ***Critical autism studies.***

Within the last decade, a new form of critical disability studies work has emerged in the field of autism research. Critical autism studies as a specialized field of inquiry has gained

traction since the publication of Davidson and Orsini's (2013) *Worlds of autism: Across the spectrum of neurological difference*. This newer field of scholarship is closely aligned with that of critical disability studies by way of core elements, research focus, and theoretical frameworks, but critical autism theorists keep their focus upon the topic of autism, and do not venture far into topics concerning other issues of disability (O'Dell, Bertilsdotter, Ortega, Brownlow, & Orsini (2016). Critical autism studies has been described as complementary to critical disability studies, with primary elements to include: attention to power relations; a desire to advance enabling narratives of autism and challenge to the deficit-focused and medicalized narratives that dominate contemporary autism research; a commitment to better understanding autism from multiple perspectives, which involves working from an abilities oriented and inclusive framework; and to provide a space for action and resistance to dominant narratives of autism. (O'Dell et al., 2016; Orsini & Davidson, 2013; Woods, Milton, Arnold, & Graby, 2018). Furthermore, critical autism studies demonstrate careful attention to the role of neuroscience in pathologizing difference, while advocates embrace this difference, or abnormality, as a form of neurodiversity that should be appreciated and celebrated. (Brownlow & O'Dell, 2013; O'Dell et al., 2016; Ortega, 2013).

***Foucauldian analyses of disability.***

While critical disability scholars engage a variety of theoretical approaches to conceptualize disability, the work of the French philosopher and social theorist Michel Foucault has provided a particularly fertile ground for theorizing disability. Although Foucault worked across a wide variety of subject matter, his method in historical analysis of social systems reveals operations of power and knowledge that have been used to either position or exclude persons and groups from society. Whether through his analyses of prison systems and punishment (Foucault,



1975/1977), mental illness (Foucault, 1961/1965), or the ascendancy of the medical field (Foucault, 1963/1973), Foucault's conceptualization of power and knowledge were a common thread uniting his diverse interests throughout his career. In the late 1990's Disability Studies scholars began using Foucault's theories as a way to engage the construct of disability in new ways (Meekosha & Shuttleworth, 2009). The adoption of Foucault's approach also served to further distance those CDS scholars seeking to disrupt the prominence of the social model (Tremain, 2008). Most social model theorists took a traditional view of power, in that it was an oppressive entity that only served to subjugate. The Foucauldian method opened the opportunity to view power operations<sup>19</sup> differently. From Foucault's perspective, power may be seen as a productive force in which social systems of control were erected to meet societal needs of a particular time period. Therefore, these dominant power operations served to identify, regulate, and control (often through physical force) persons and groups for the betterment of the greater society. While it is important to note the presence of other models and theoretical approaches for conceptualizing power<sup>20</sup>, Foucault's work has been popular within CDS because it not only

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<sup>19</sup> A primary emphasis of Foucault's theory of power involved the creation of knowledge for the control of "docile bodies." Given his attention toward the physical treatment, placement, or exclusion of persons through the use of force (e.g., prisons, mental asylums, hospitals, etc.), it seems that disability theorists would naturally gravitate toward his viewpoints, which emphasized treatment or exclusion of bodily differences.

<sup>20</sup> Foucault's concept of power, while popular within CDS is not the only way to view this construct. Perhaps it is my background in cultural studies, but I actually prefer to think of power in terms of the model proposed by John Fiske, which acknowledges the roles of Althusser's (1971/2001) ideas of ideology and Gramsci's ideas of cultural hegemony (Hoare & Smith, 1971) to identify a space and opportunity for resistance of dominant power operations by subordinate groups. Fiske's model of power breaks away from Foucault's primary perception of control through the use of force to situate power operations within a realm of ideology, meaning-making, symbolism, representation, and consent. Fiske's theory of power seems to be more comprehensive to me, as it provides a theoretical space for local agency. Furthermore, the socially contested space has been utilized by critical researchers, cultural theorists, and politically minded curriculum workers to identify and expand possibilities of change, personal

lessens the relevance of the social model approach, but also provides avenue for investigations on a wide range of social issues.

Shelley Tremain's (2008) edited book *Foucault and the government of disability* is perhaps one of the better known comprehensive treatments of disability from a Foucauldian approach. In introducing the collection of essays contained in this book, Tremain (2008) outlines Foucault's concept of biopower, as a new technology of control that emerged in the 1700's. This biopower was unlike prior systems of localized control because this new framework focused upon initiating change and regulation of the masses through newly developed normalizing technologies that were made possible through the tracking of demographic information such as birth-death rates, the mechanization of health care, developments in sanitation, increased focus upon safety from accidents, and even the beginning of the insurance industry (Tremain, 2008). Such regulatory structures of biopower also promoted new methods of statistical analysis, forecasting, and other methods of interpreting data to improve the life expectancies of the general population. These various developments in the regulation of groups on a mass level are examples of a host of activities that represented a shift toward what Foucault termed a biopolitics of society (Tremain, 2008). The practices of biopower served to classify, group, and individuate the aberrant or abnormal from the rest of society. These normalizing technologies facilitated the surveillance, identification, objectification, and regulation of the populous.

Hughes (2008), writing within Tremain's book, states that disability could be seen as a product of biopower. She also acknowledges that a Foucauldian approach, unlike traditional materialist discourses, may also involve greater opportunity to consider the roles of language and

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freedom, and social justice. I simply do not envision the existence of such a space from a purely Foucauldian perspective.

symbolism in constituting the construct of disability. Also writing in the same text, Yates (2008) explores the ways in which knowledge is created as a way by which power operations could be enacted. As an example, Yates (2008) cites Foucault's analysis of punishment systems and how the concept of criminality as a knowledge form led to new ways in which power could operate to control persons and groups. In this same respect, knowledge and discourse of disability from the medical perspective may also be conceptualized as the grounds in which power works to exclude persons with disability from society.

More recently, McGuire (2016) utilized a Foucauldian approach to trace the history of autism. Her intentions of this exercise were to defamiliarize her readers with the structure of knowledge concerning autism, or better stated to make the familiar strange so as to understand our contemporary assumptions about the disorder. McGuire's (2016) application of Foucault's method to the concept of autism through distinct historical periods serves the purpose of demonstrating how it has operated to signify deviance and normality. First, McGuire (2016) discusses the period in which Kanner and Asperger, those researchers associated with the earliest descriptions the condition, may have been influenced by the desire to differentiate between normal and abnormal attributes of persons, which was characteristic of the eugenic period in which they worked. Following the eugenic period, McGuire (2016) cites the rise in popularity of psychoanalysis within the psychiatric field. This gave renewed attention toward the debate over nurture, and within this scenario the detachment of children was seen as a reflection of the mother's availability to her children. As women entered the workforce following WWII, autism became associated with the changing role of the mother within the home environment. Interestingly with the subsequent periods in which paradigms shifted to discourses of behaviorism, cognitive psychology, and eventually neuroscience, the mother's role would

change from the focus of surveillance to the primary surveyor of the child. This newer responsibility of the mother in bringing attention to the aberrant behavior of her children signaled a dramatic shift in which warning signs and early identification have not only altered the role of the mother but also the discursive knowledge we hold about autism. McGuire (2016) concludes that whether one approaches the construct of autism through any of these distinct periods, the constant has been a perception of the condition as a disorderly threat to the normative individual and social body. She contends that contemporary autism advocacy represents a call to action against this perceived disruption, therefore justifying the need to classify, label, organize, treat, and intervene whenever ASD is suspected. Importantly McGuire (2016) also notes the recent rise in autism self-advocacy, promoted through the use of technology and the internet, as a new discourse that has the potential to disrupt normative understandings of autism once more. This self-agency of the autistic community to challenge and disrupt conventional representations of disability is a form of localizing power (Fiske, 1993) in which the autistic community seeks to take back control of the immediate relations and conditions of their everyday lives. It is this aspect of the self-advocacy movement that defies the imperializing power that is so often forwarded through Foucauldian analyses of power.

### **Cultural Curriculum Studies**

While it may not be necessary to go into great detail explaining the connections between cultural studies and curriculum theory, I will only briefly describe how the field of cultural studies has been beneficial to the work of curriculum theorists. These connections, as I will soon describe, are also transferrable to the work of disability scholarship.

According to the curriculum theorists Stuart Hall (1997):

Culture, it is argued, is not so much a set of *things*—novels and paintings or TV programmes and comics—as a process, a set of *practices*. Primarily, culture is concerned with the production and the exchange of meanings—the “giving and taking of meaning”—between the members of a society or group. (p. 2)

Hall (1997) goes further to explain that the meanings we assign to objects, artifacts, texts, and behaviors constitute a shared symbolic representation that, if agreed upon by a group of persons, could then be said to represent a cultural representation. It is this shared representation and system of understandings for interpreting the world around us that may also be termed a cultural code. John Storey (1996) explains the foundation of cultural studies to have been shaped by Marxism. In this regard, cultural studies scholars tend to view the circulation of cultural representations in terms of the process of production and consumption, and the field generally recognizes that culture is a principal site for the contestation of social and economic inequalities as dominant groups seek to impose meanings upon subordinate groups. Therefore, cultural studies scholars often think in terms of symbolism, hegemony, and power operations to identify the shared understandings and interactive processes by which ideological meanings are either constructed or contested in the public sphere (Storey, 2010).

It is with this attention toward the notions of ideology, operations of power, and cultural significations, or shared systems of representation, that we can draw a connection between matters of the cultural studies discipline and educational theory, as well as work in the field of critical disability studies. In the words of Henry Giroux (2004), a theorist who blurs the lines between cultural studies and curriculum theory, “culture now plays a central role in producing narratives, metaphors, and images that exercise a powerful pedagogical force over how people think of themselves and their relationship to others” (p. 62). Likewise, the curriculum scholar

Marla Morris (2016) emphasizes the role played by social and cultural operations upon the lives of children, and states “one of the major points made by many curriculum studies scholars is youth learn outside the traditional boundaries of the school” (p. 174). This understanding of learning as occurring outside the confines of formal educational structures is not a new idea, as we may find aspects of such broadening in even the earliest of curriculum scholarship. For example, J. Franklin Bobbitt’s 1918 publication of *The curriculum*, which has been touted as a representative start of the formalized field of curriculum study, includes an acknowledgement for learning that occurs outside the experiences of the school setting (Pinar et al., 1995/2008). Additionally, in the decades following Bobbitt’s proclamation, new terms such as the hidden, null, or unstudied curriculum would emerge from scholars seeking to better delineate forms of learning that occurred outside of schools or outside of the official curriculum (Apple, 1975; Jackson, 1968, 1992; Pinar et al., 1995/2008; Schubert, 1981). Similar sentiments for a broadened definition of curriculum include understandings of a BIG CURRICULUM (Schubert, 2006), and public pedagogy (Sandlin, Schultz, & Burdick, 2010).

These arguments for an expanded conceptualization of teaching to include the cultural sphere, power operations, and ideological forces is also found in the work of critical disability theorists who argue that disablement is a socio-culturally constructed phenomena that is value-laden and inscribed with power and ideological representation (Devlin & Pothier, 2006; Tremain, 2005; Watson, 2012). As Devlin and Pothier (2006) explain:

Two key political insights undergird critical disability theory: power(lessness) and context. . . issues of disability are not just questions of impairment, functional limitations, or enfeeblement; they are issues of social values, institutional priorities, and

political will. They are questions of power: of who and what gets valued, and who and what gets marginalized. (p.9)

If we were to again consider popular culture as a site of learning, films such as *Rain Man* would certainly provide evidence to the sociocultural representation of otherness within the construct of disability. While it is all too easy to pick apart a film such as this, the themes of abnormality, deviance, and dependence abound in the representation of Raymond as being detached from the social-relational world and reliant upon the care of others.

The field of critical disability studies routinely employs the same theoretical concepts of cultural study to disentangle the ideological inscriptions and discursive practices of culture upon the concept of disability. For example, McGuire (2016) analyzes cultural artifacts found in advertising and advocacy campaigns to reveal themes portraying autism as a problem of pathology within the individual that must be fervently addressed and even engaged as a form of battle or response to a terrorizing force, hence her aptly titled work *War on autism*. McGuire's (2016) analysis includes cultural artifacts ranging from charitable giving advertisements on consumer goods to graphic ransom note billboards that portray autism as kidnapping children from their families.

The link between autism and culture is multi-layered, and not reliant upon discreet analyses of cultural artifacts that forward some ideological construction of the condition. As noted by Grinker (2007) an anthropologist writing about his experiences parenting a child with autism, the field of psychiatry is, at its core, a subjective undertaking that is influenced by not only the individual perspectives of practitioners but also the cultural values of a society. In comparing the construct of autism across cultures, Grinker (2007) finds that the symptoms we associate with ASD may not even be perceived as abnormal in other cultural landscapes.

Furthermore, through his travels as an academic he observed that although the presentation of autistic symptoms remain similar across different places in the world, he concluded “autism, like all disorders, does not exist outside of culture. It is culture that sees something as abnormal or wrong, names it, and does something about it, and all cultures respond to illness differently” (p. 11-12).

Orsini and Davidson (2013), foundational scholars in the developing field of critical autism studies, expand upon this relation to culture to state that ASD only exists within the confines of culture, and it is through culture that ASD is understood. This role of culture in constituting autism abounds within critical disability studies literature, whether one is considering the different ways in which autism is perceived amongst diverse cultural groups (Grinker, 2007; O’Dell, et al., 2016), the appearance of autism representations within culture (McGuire, 2016; Straus, 2013), or the cultural constructions of autism advocacy campaigns (McGuire, 2016).

Importantly, Straus (2013) posits that autism was likely to have always existed as a form of being, but the remaking and labeling of autism has constituted our modern-day perception of it as a natural category. Furthermore, the category of autism has been contingent upon the cultural and social pressures that shaped its development. There are clearly connections here between Foucault’s understanding of discourse, ideological practices, and the medical field because the construct of autism has been dramatically publicized and brought into the public consciousness since it was first incorporated into medical practice as a recognized form of disability.

Furthermore, critical autism scholars have also employed the concept of “looping” forwarded by philosopher Ian Hacking to illustrate ways in which the labels or categories placed upon persons and groups not only has influence upon those persons being labelled, but also upon



the very categories themselves. (O'Dell, et al., 2016; Orsini & Davidson, 2013; Ortega, 2013). In other words, the use of these labels to classify persons also has the consequence of contributing to the discourse and stories of autism, which in turn signify what autism is and influences the potential for what autism may become (McGuire, 2016).

Disability scholars, and specifically those working within critical autism studies, have called attention to the recently developed neurobiological perspectives of autism which frame the condition in terms of neurological deficiency (Brownlow & O'Dell, 2013; O'Dell et al., 2016; Ortega, 2013). This dominant construction of autism presents the concept in terms of abnormality and deviance from neurotypical or normative ways of being, and critical autism scholars contend that the authoritarian emphasis upon genetic testing and neuroimaging conjure images of a new form of eugenics (Orsini & Davidson, 2013). Furthermore, critical autism scholars and advocates cast aside the preoccupation of autism experts and clinicians in treating or curing autism to advance alternate narratives from an abilities framework that re-envision the construct of autism through the lens of neurodiversity, difference, and a potential identity of pride (Brownlow & O'Dell, 2013; Orsini & Davidson, 2013; Ortega, 2013).

McGuire (2016) suggests that this growth in the self-advocacy of newly formed cultural communities of autistics has been made possible by advancements in internet technologies. Online communities not only provide a logistical solution to the geographical problem, but such venues are also helpful because the online format provides a way to connect with others without the added stresses that often accompany face-to-face interactions (Prince-Hughes, 2002). This newly developing community of persons who identify as autistic has led to the development of distinct voices in areas of literature, art, and music (Straus, 2013). Within this social group, and culture of autism, individuals collectively navigate the landscape of negative representation to

reformulate their identity in their own terms and have even adopted the language of medical experts and neuroscientific theory to de-pathologize the construct of autism. (Brownlow & O'Dell, 2013; O'Dell et al., 2016; Ortega, 2013).

### **Postcolonialism**

It would appear that most treatments of disability within the field of postcolonial theory only present the construct in decontextualized or under theorized and uncritical terms that simply serve the purpose of illustrating the negative effects of colonization while failing to adequately consider the construct as a politicized subject position (Barker, 2014; Barker & Murray, 2013; Erevelles, 2006; Sherry, 2007). This same criticism also appears to hold true for disability scholars who have sought to incorporate postcolonial concepts into their work as well. Multiple scholars have noted that although transdisciplinary efforts between the two fields may hold new insights for each respective discipline, most of these attempts have either not been substantial or have simply relied upon metaphors that serve the purpose of rhetorically portraying oppression (Erevelles, 2006; Grech & Soldatic, 2015; Meekosha & Shuttleworth, 2009; Sherry, 2007). Sherry (2007) highlights interconnections between the fields of postcolonialism and disability studies, but noted that most of these connections are of a rhetorical nature insofar that they do not fully engage the theoretical models of the disciplines from which they make these comparisons. For example, the use of postcolonial metaphors in disability work has included characterizations of the relations between patients and doctors as a form of medical colonialism, disability has been characterized as exile, and psychiatric treatment has been compared to a metaphorical form of slavery (Sherry, 2007). Likewise, disability has been treated as a metaphor by postcolonial scholars to signify the efforts and outcomes present in the imperializing operations of colonialism, whether disability is used as a justification of domination through forwarding of the

stereotyped other or to symbolize the negative effects of colonialism upon indigenous populations (Sherry, 2007). However, despite these perceived shortcomings, Sherry (2007) does identify intersections of racism and disablism as potential sites for more productive interactions between these two fields.

Rather than relying upon metaphor, Sherry (2007) notes that interactions between racism and disablism through history may provide fertile grounds to engage in more productive interactions between the two fields. He offers racist themes of contamination during the AIDS epidemic, the presence of the exotic in carnival freakshows, and racist and normative goals of the eugenics movement as examples. Other scholars have noted the historical interrelation of race and disability within educational structures, such as the historically conflated placement of African Americans into special education, suggesting that both critical race theorists and disability scholars often draw upon the same philosophical arguments to reject biological difference and retheorize the position of the other in historical, political, and socio-economic terms (Erevelles, Kacknga, & Middleton, 2006). However, such scholarship may remain reluctant to fully embrace a fusion of critical race theory and disability studies due to concerns for the likely extrapolation of these concepts into themes of postcolonialism.

While a rich and meaningful blending of postcolonialism and disability studies may have not yet materialized, I can only add a few more metaphorical relations between the two fields. These may include additional comparisons between the medical field and colonialism, especially if we consider Foucault's history of modern medicine. Also, treatments of autism as a metaphorical subaltern other that becomes more layered if we think in terms of cultural capital or any arguments that place ASD outside the realm of participation in popular culture, as well as considerations for the commodification/exploitation of autism for commercial gain, which is

seen is advertising for the latest self-help styled treatments. Perhaps the most relevant to my work here, I would also offer the metaphor of the postcolonial concept of a liminal or in-between space in which the person labeled as autistic neither identifies fully with social constructions of the typical-atypical or the normal-abnormal division.

### **Subject Matter: Critical Perspectives of Autism**

*The various milieu of alternate autism representations do not come from the traditional-medico model of disability, but rather from critical perspectives that are to be found within the cultural and social sphere, as well as newer forms of academic work. This next step has not been without difficulty. I am seeking to draw connections between alternate theories of disability while thinking through ways in which the autism construct is culturally produced. My inclination is to engage these ideas from a more academic writing style, as much of this and preceding chapters have been written. However, to do so would be counterproductive to my goal since my “normal” writing style is so firmly rooted in the positivistic tradition. Even if I am thinking differently, and even if I am able to break away from the tradition of my prior educative experiences and achieve personal growth, how do I show that through my writing? How do I write differently? This attempt to break away from the style of my writing, which is undoubtedly influenced by my prior educative experiences and positivistic influence, has been the hardest part of this dissertation project. I might as well have been asked to finish this project in another language. But yet, in a way, that is what I am attempting to do. The rules of writing and communication are being changed here. This has been very problematic for me. It continues to be problematic. It will probably always be problematic. To stop writing a certain way is such an incomprehensible task for me personally that it disrupts all aspects and foundations of my identity. I would not have thought this was going to be a problem, but so it is. I worry that writing differently won't*

*“count” as academic writing, or that decreasing the formality of my writing may make it less important, acceptable, enviable, truthful, correct, etc. My committee would likely not know the difficulty that I have experienced in this aspect of the dissertation, if I don’t bring it to light, so that is why I am being so straightforward here. The rendition you are currently reading has been rewritten multiple times. My committee may question if I have achieved a goal of writing differently. I probably have failed to live up to each of their expectations but I hope they may, in the least, appreciate the degree to which this has been a struggle.*

*The following passages are somewhat split. You may read the rest of this chapter in two ways. The chapter was first written out and submitted to my chair. That first rendition appears in the same type font as the rest of this project. The italicized font represents my attempt to go back and alter my writing, whether through inserting more of myself into the text, or by really attempting to incorporate alternate milieu into the cultural concept of autism. This exercise in alternating typeface was also deemed necessary by myself to break away from my typical writing style. As I conveyed to my chair, this was first done so that I could almost trick myself into thinking in a different mode to write this section. While the plan was not to leave these sections separated by different font, I decided that it may be helpful to see the process of switching gears, so to speak.*

As a middle aged cultural consumer, and as best I can recall, the first two depictions of autism I encountered in popular cinema were presented through the films *Rain Man* (Guber, Peters, & Levinson, 1988). and *What’s Eating Gilbert Grape* (Blomquist & Hallstrom, 1993). In thinking about these two films and the potential understandings communicated through the main characters, I am immediately confronted with the shared theme of dependence upon others. Each character is reliant upon either family support or institutional services and the provision of such

support often results in either strained family relations or undue burden. Furthermore, the autistic characters are presented as very atypical, abnormal, and different from all other persons appearing within each film. These autistic characters are outcasts, and their differences are pathologized as a problem and not simply a form of individual difference. *These characters are produced to signify the aberrance of autism. Every aspect of these autistic characters promote a negative stereotype.* There are of course many other examples of film depictions of the autism construct, but I argue that the majority of these representations do not break significantly away from the traditional-medico-deficiency trope that first appeared within these two films.

Even when autism is presented in film in a way that does not appropriate stereotypes of the condition, such depictions are likely to be strongly influenced by the direction and perspective of neurotypical adults. For example, while appearing benevolent at first glance, even the public information campaigns disseminated through television, radio, and print advertisement (Autism Speaks, 2018) and children's programming efforts (Sesame Street Workshop, 2018) to convey the autistic experience to youth are influenced by the perspectives of the neurotypical community. Whether intentional or not, these influences appear as a side effect of the production process, where in the very least the decisions of directors and editors impact what is eventually represented. *I have watched a particular Autism Speaks (2018) television advertisement multiple times. This commercial describes the experience of a boy named Jacob. As a narrator describes Jacob's symptoms, viewers are presented with an animated visual depicting a boy in a rowboat who takes an unexpected turn in the river, goes into dark woods, is confronted by strange creatures, and appears to be lost, overwhelmed, and scared by his surroundings. On one hand, I watch this video and think to myself that the advertisement is good because it communicates the symptoms of autism to an audience in an accessible and nonconfrontational manner. On the*

*other hand, if I think more deeply about the commercial, the traditional-medico emphasis of this tv spot becomes more apparent. All we really know about Jacob, is that he has symptoms of autism. The symptoms, those organizing principles of otherness, define him. That's all the audience is to know. We are told that he "got help," which we can only assume is by the medical establishment, hence we are lead to believe that he benefits from treatment. What about the animation itself? The animated boy is seemingly scared or overwhelmed. What may be considered a pleasant experience, rowing in a boat on a bright sunny day, quickly turns into a terrifying and potentially dangerous scenario. This graphic perpetuates concepts of alienation, dependence, and otherness. As symptoms are described, the graphic turns dark, creatures emerge from the shadows, and the boy wraps his arms around himself as if to turn inward or to be protected from his environment. If I think about it, this television commercial presents a stereotype of a young child who is in need of rescue. He is lost. He is scared. He has something wrong with him. Never mind the landscape of the animation, the problem is with the boy. We as the audience are instructed to seek help for children like Jacob by learning the warning signs of autism and visiting the website of [autismspeaks.org](http://autismspeaks.org).*

*Rather than continuing with other visual media, I turn the focus of my analysis toward the representations of autism within literature. While book editors and publishing houses certainly retain a degree of decision-making as to what should be included in a text, I agree with the sentiments of Dawn Prince-Hughes (2002) who argues that the writing of autistic individuals, as a form of communication, provides what is perhaps the best opportunity to better understand the experience of autism. This is not to say that valuable contributions to the conversation of autism only exist in autobiographical writings of autistics, but this form of subject matter is likely to provide the best opportunity for understanding that has been unaltered by neurotypical*

perspectives. With this being said, there are numerous examples of neurotypical persons sharing their experiences of autism, but these stories often take the form of an outside's perspective.

Two excellent examples of such writing include books by Grinker (2007) and Nolan (2004), who reflect upon their role as parents of autistic children. Grinker (2007), an anthropologist and social scientist, takes on a scholarly approach to consider the meanings of autism as it is experienced through culture. This work encourages the reader to think more critically about the cultural representations of autism, and therefore it takes on a more objective format. Nolan (2004) on the other hand, is a retired journalist in the United Kingdom who does not make any concerted effort to align his writing with any specific scholarly discipline, rather this book is a memoir of his experience as a father of a child with severe autism.

Within each of these books, we have educated and professional fathers who are sharing their story of having a child with autism. Each of these fathers is looking back upon the past, as their children are now grown. These writings are revealing of the environment decades prior in which little was understood by the scientific community about autism, and even less understanding was held by the general public. Additionally, these two works—and especially that of Nolan (2004)—are rife with assumptions of the traditionally conceived deficiency-based mindset, but these personal accounts do serve to convey the potential ramifications or disruptions to not only the daily lives of these parents but also their previously held aspirations of parenthood. Each father provides insight into their feelings of helplessness and loneliness as they sought the best opportunities for their children, but it is Nolan's (2004) descriptive details, made possible through a review of previously written journal entries that takes on a relational tone that is likely to be more identifiable and accessible to readers.



Nolan's (2004) graphic recollection of spending a week with his son while he was on break from a residential facility is both heartbreaking and overwhelming. The book is filled with themes of parental angst and feelings of helplessness. As Nolan details the daily activities of this single week, the reader is left feeling drained of energy by the constant requirement that his son, Liam, be supervised at all times. Even the simplest of activities, such as going into town or driving down the highway, are fraught with potential dangers. Nolan's account is full of themes that revolve around feelings of parental guilt and excessive worry. However, despite the somber account of hardships, Nolan does highlight a persistent feeling of hope that his son will someday improve.

*The insert of this book alluded to heartwarming moments, but I had difficulty identifying the moments of hope or the lighter moments, because I was overwhelmed by feelings of sadness and discomfort while reading this book. I could not help but to think of my role as a father while reading, and in doing so, the thought of being so helpless as to place my child into an institution was almost more than I could handle. The only positive feelings I took away from Nolan's story was a thankfulness that my own child was not like this boy. Of course, that only made me feel guilty for thinking in this manner. While Nolan only describes one week, the whole account seems to be nothing short of torture. Speaking of guilt, there are several moments when Nolan loses his temper with his son, only to describe feeling guilty afterward because he is certain that his son did not understand what was going on, or why his father had lashed out. In each of these instances, I could only think of those times in which I have lost my temper with my own daughter. It can be an easy thing to do during stressful times, but at least I can apologize for my actions and have a heart to heart with my daughter later on. It was agonizing to think of the blank stare and unresponsiveness Nolan received while he was giving these apologies to his autistic son. I*

*also was stricken by Nolan's continuous efforts to avoid mishaps while in public with his son. He had to be on alert constantly and frequently seemed to worry about what others would think of his son. These trips outside the home were even anxiety provoking for me, as I found myself worrying about what was going to happen. Again, I could not help but to think of my daughter and what this would be like if she suffered from such a severe impairment. What would it be like to not have the close relationship we enjoy? What would it be like if she no longer surprised me with inquisitive statements, demonstrated her strength of faith during times of grief, or simply showed care and compassion to others in her daily interactions? What would it be like to not really know my own child? My daughter, as an only child, often accompanies my wife and I to social events and public gatherings. Since our families live far away, we don't have stand-in babysitters. We usually just take her along with us to events, or simply don't go at all. To be in a situation like Nolan, I couldn't join friends for social gatherings, go out to eat, or simply run errands around town with my daughter in tow. It really seems to be a form of imprisonment for the parents. The entire family just seems so isolated from the outside world. These accounts forward the stereotype of severe disablement. When I think only of this story, I am left with two principles. The severely disabled child is a burden upon the family, and this burden results in a necessary decision to either completely alter the entire existence of the family, or to completely disavow themselves of the child in favor of institutionalized full-time care by medical professionals.*

While it should be noted that these narratives portray severe forms of the autism construct, in which individuals experience significant symptoms, these forms of discourse contribute to the negative stereotypes of otherness, dependence, and limited self-expression of autistics. There are of course other collections of parental accounts of raising a child with autism

(Shopler & Mesibov, 1992; Meredith Women's Network, 2019) that present a more optimistic discourse, but many of these accounts remain rooted in the treatment-care paradigm.

Recently, a book authored by neurotypical adults and produced in conjunction with the Autism Speaks organization has addressed the issue of students with autism in college and seeks to inform parents and educators of potential approaches to helping these students in their pursuit of advanced degrees. While the representation of autism appearing within *Educating college students with autism spectrum disorders* (2013) may not be as problematic as those portrayals of severe disablement, the book remains characteristic of the treatment-cure approach appearing in most mainstream autism literature that presents the autism construct as a pathological deficiency. Within this text, authors deploy terminology of the scientific-medico-positivist framework to present potential strategies that are “scientifically-based” and “proven” to be beneficial for college students with autism. While I find the use of scientific terminology and descriptions of common symptoms to be very familiar, it is the recommended techniques for providing services to students with autism in the college setting that are of interest. These researchers, through the provision of two case studies, suggest that students are best supported through an individualized and specially tailored form of services that are reminiscent of the types of individual attention often forwarded by K-12 special education service delivery (Zager, Alpern, McKeon, Maxam, & Mulvey, 2013). For example, students are afforded consultation with a team of practitioners who identify critical goals for each student's success. From these identified goals, specific strategies are developed to assist the student in meeting these goals. In the case of David, a freshman college student experiencing difficulties recognizing when he was monopolizing classroom discussions and occasionally not speaking clearly, his service team suggested a system of nonverbal cues or phrases spoken by the professor that would redirect David, along with some

additional speech assistance as a means of behavioral correction and support. In the case of Max, a freshman student experiencing difficulties with tardiness/attendance and assignment deadlines, the support team recommended the use of technology resources for organization, color coded file folders for different courses, and a consistent method of posting assignments across each of his classes. While the strategies recommended in each of these cases were not all that unique, they are perhaps unique to the setting of a college classroom where professors working in different departments do not meet regularly or work collectively to adapt their instruction for consistency. Furthermore, the approach of individually tailoring goals and objectives to meet the unique needs of specific students is not a common occurrence in the postsecondary setting. Although there is perhaps value in the recommended approaches outlined in this text, the potential benefits of these practices are obscured by the authors' allegiance to the treatment-care and scientific-medico paradigm. *As I read this text, I had a difficult time looking beyond the scientific language and psychological jargon. That I had trouble with this language may be difficult to fully appreciate, unless we remember that I am attempting here to step outside of my prior training. The format of the book thwarted the already difficult task of considering possibilities beyond the treatment-cure approach. Of course, that would be the whole point of this chapter. If I were reading the book for any other reason, the language would have been preferred, but since I was trying to look at the content differently, the format of the book was a hindrance. Tried as I may, it was just hard to look beyond the scientific language.*

*What I eventually took from this text was that although the ideas are presented as novel and powerful, the approach still remains firmly squared in a medical and health-rehabilitation model. All interventions and forms of assistance are targeted at the individual. Again, this presents the person as the problem. Mainstream assumptions of disability are not challenged*

*through this text. To delve a little further, this book was written by neurotypical experts, and was endorsed by the Autism Speaks foundation. Is this not a perpetuation of the dominant health and rehabilitation industry? This book purportedly seeks to inform educational stakeholders of the empirically tested strategies for meeting the needs of students with autism. While it may do this to a degree, I would say that it also preserves the power dynamic of expert and subordinate, along with the authority of the medical establishment. Since this text failed to show a critical perspective of autism, I reviewed another book that seemed to have more promise.*

Attwood and Santomauro (2012) present an edited collection of essays for the expressed purpose of countering the sad stories that prevail in autism research communities. *Since the sleeve of this book stated that it would counter the typical stories of autism, I figured it might fit the bill.* Santomauro, the mother of a child with autism, is an author of autism resources and books about autism, while Attwood is a well-known British psychologist. *Realizing the status of the book's authors was my first sign that this book would not present autism much differently.*

While the stories contained in this book are first-hand accounts of persons with autism, the book itself is a production of two neurotypical individuals who have collected, edited, organized, and framed these personal accounts through a neurotypical lens. The book is broken into sections organized around topics of postsecondary education, relationships, creativity, and areas of special interest. The section concerning education includes the stories of three individuals, and although these brief essays do problematize experiences of youth and adolescence, the reported experiences from the college environment are presented favorably as liberating, unproblematic, and even as a solution in some instances to feelings of isolation. Granted, the aim of Attwood and Santomauro (2012) was to present uplifting and encouraging accounts, but I believe the

inclusion of these three stories does not adequately convey the potential pitfalls inherent within postsecondary educational experiences.

*Yet again, this book is another example of experts speaking on behalf of those with disability. The heavy editing and organization of the text may be similar to the appropriation that is discussed by postcolonial scholars. The authors are speaking for their subjects. They are presenting the lived experiences of others as unproblematized. The situations presented are pie-in-the-sky, and perhaps sanitized beyond a point of authenticity.*

The shortcoming of these previously discussed works is that the voice of the autistic individual is dominated and silenced by the neurotypical perspective. Critical autism scholars demonstrate a strong commitment to the voice of persons with autism (Brownlow & O'Dell, 2013; O'Dell et al., 2016; Orsini & Davidson, 2013). Such commitment is evidenced through not only the contribution of critical autistic perspectives and alternate methodological frameworks (O'Dell et al., 2016; Orsini & Davidson, 2013), but also the inclusion of scholarship produced by academics who identify with the autistic label (Milton, 2014; Woods, Milton, Arnold, & Graby, 2014) and the voices of self-advocacy figures and groups such as the Autism Self Advocacy Network and Autism Network International. *Furthermore, most of these examples only sustain the status quo of the expert's authority over the meaning of autism.*

Perhaps the most widely known autistic figure in the academy is Temple Grandin, a successful professor of animal science at Colorado State University and notorious spokesperson for the autism community. Although she revolutionized livestock handling practices and is an expert within her professional field, she has used this platform to also engage in autism research and advocacy (Grandin, 2019a; 2019b). However, Grandin may also at times embrace the traditional paradigm as her work vacillates between the language of self-advocacy and scientific

discourse (Grandin, 2009, 2013a, 2013b; Grandin & Panek, 2013). *Given her training in the sciences, and the widespread appreciation for her work as an animal scientist and behaviorist, I just can't go much beyond this mention of her as an advocate. After all, she is firmly entrenched in the very paradigm I seek to move beyond. While she does speak from the first person perspective of an individual with autism, her advocacy is mired in the traditionally positivist-medico model.*

A better example of autistic memoir that prioritizes the voice of persons with autism is provided by Dawn Prince-Hughes (2002), an anthropologist who identifies as autistic. Prince-Hughes's (2002) *Aquamarine blue 5: Personal stories of college students with autism* is a collection of short essays written by postsecondary students with autism. First, these autobiographical accounts provide straightforward and oftentimes blunt representation of autism, and Prince-Hughes (2002) states that the collection of essays represents the first time that an autistic person has collaborated with other persons on the spectrum to explore personal accounts of the autism experience for publication. Secondly, the motivation for the work is stated to have been due to a desire to improve the accommodation and service of college students with autism. Most importantly, Prince-Hughes (2002) did not edit these writings heavily, as she maintains that such endeavors would have altered the meaningfulness of the book. Rather than attempt to reformat and potentially alter the words and meanings of her contributors, Prince-Hughes (2002) embraces the writing styles of these individuals due to a personal belief that such unaltered accounts provide a more accurate depiction of the autistic mind. This collection of essays not only communicates the real lived experience of ASD but it does so without altering the voice of its autistic authors. Of equal importance, in speaking of the potential benefits of academic experience, Prince-Hughes (2002) states that students with autism do seek to make meaningful

connections to others and “...intellectual activity and a place in the academy are indispensable lifelines that give them the connections they need while providing an outlet for their unique intelligence” (p. xvii). The individual essays are broad, with shared stories of isolation and acceptance, misunderstandings of self and social interaction with others, and examples of how students have navigated the postsecondary environment, but the essays do not gloss over the failures experienced by some of the contributors who obviously did not have positive experiences in the academy.

There are twelve personal accounts included in the book (Prince-Hughes, 2002), all of which except three, are provided by persons who received a diagnosis of autism while in college. These three individuals were either not informed of their diagnosis until adulthood or not provided a definitive diagnosis until that time. While the stories told by these individuals do discuss symptoms that are commonly forward by the scientific-medico discourse (e.g., social difficulties, habitual behaviors, special interests, etc.), these discussions are presented in more relational terms that reveal not only personal perceptions about these attributes but oftentimes they are presented to the reader simply as forms of difference rather than hardship. This is not to say that these stories are unproblematic though, as the contributors detail ways they have learned to self-accommodate for these differences of experience. *The first thing I noticed while reading Aquamarine blue 5 was the diversity of essays within the book. Yes, each writer talked about aspects of their personal lives, and the writing styles were qualitatively different within each section, but since each author was asked to write about their pressing concerns, the individual topics were very diverse. The variety of topics contained within these essays should convey the individualized and localized experience of autism. For each writer, their experience of autism, or what it meant to their daily lives, is presented in individual terms. For example, whereas one*



*writer appears to have used her essay to criticize the medical specialists and naysayers throughout her lifetime, another writer used his space in the book to advocate for better job training opportunities since he was experiencing difficulties finding post-graduation employment at the time of his writing.*

The breadth of topics within the book include the story of Michelle, who shares her history of peculiar eating habits. For Michelle, her eating routine was influenced by sensory issues with the texture, color, and presentation of her food. Michelle shares with her readers that during her adolescence and young adulthood, this quirkiness in her eating habits had resulted in the suspicions of others that she may have an eating disorder. While Michelle may not have been at risk for malnutrition, she explains the ways in which she adapted her eating routine to appear typical in the eyes of others while also maintaining her food references. *It does not appear that Michelle's friends knew of her ASD diagnosis, so differences in eating habits were perceived as abnormal. Of course, the only explanation from the perspectives of others was that something was flawed with Michelle. As we know from the Foucauldian perspective, this abnormal behavior was to be seen as deviant and a sign of something inherently wrong. Therefore, her friends jumped to the conclusion that she was anorexic, "like the girls in the made-for-TV movies" (Prince-Hughes, 2002, p. 46). Aside from this conflation with popular media, Michelle recounts her discussion with the school counselor, who was called upon to address Michelle's eating issue. Here, we can really equate her story with that of Foucault's medical gaze, as she writes, "...it was a matter of shape up or ship out. I was told I had a couple weeks to start eating 'normally,' and warned that she had people watching me all over campus. If I didn't 'improve' by the deadline, I'd be sent to the locked psychiatric ward of the hospital across town" (p. 46). With this revelation, I immediately think of the medical gaze and the power of the counselor to*

*exert disciplinary control over Michelle. This poor girl went from demonstrating different eating habits to being identified by the medical gaze and threatened through disciplinary control that her body would be ordered further into the domain of medical power if she did not change her behaviors. This is not to mention the fact that from the perspective of the counselor, the appropriate response would be to send Michelle off involuntarily to a psychiatric ward. This seemingly automatic response of the counselor brings in a whole other host of notions about the positioning of the medical establishment as being the ultimate and all powerful or absolute solution to a person's problem—or better yet, as one could frame it—a problem person.*

The story of Jim, who did not learn of his autism diagnosis until age 19, begins with a strong argument for why he believes his parents were at fault for hiding his diagnosis from him, stating “the trauma of knowing does not even approach the trauma of growing up not knowing why the world is so difficult to comprehend” (p. 69). He then describes his feelings of despair and failed attempts to correct his behaviors, until finally adopting an approach that he compares to a metaphorical tool kit. Within this tool kit he devised individual modules of rules and default behaviors that he determined to be socially acceptable. He has since developed many modules that he uses to navigate the social world. *I can't help but to think of the postcolonial themes in Jim's essay. He is navigating an unknown landscape. He utilizes strategies to avoid the detection of his subaltern status. He has to be cunning, creative, and vigilant to avoid being identified as different from those around him. As he matures and gains increasing skills of mimicry, he only further positions himself into a state of ambivalence or in-betweenness.*

Darius, a middle-aged student who self-referred himself for evaluation as an adult, discusses the various ways he has sought to self-accommodate so that he is not viewed differently by others. For example, he explains that he began intentionally leaving items out of

place in his bedroom so as to not appear abnormally organized or tidy—which would be considered off or unusual as compared to similarly aged peers. He also explains how his time spent doing volunteer work in other countries was freeing because his social awkwardness would simply be viewed as a natural cultural difference rather than an inherent character flaw or trait. Darius provides that this time spent in foreign lands helped him to engage socially and gain confidence in his interactions with others. *In reading Darius's essay, I was really amazed at his ingenuity. Obviously, the postcolonial themes are present here as well, as Darius embarks on physical journeys to other countries, but many of his efforts seem to be motivated by a desire to avoid the surveillance of others, to go undetected by hiding his natural tendencies. Although he does not explicitly mention medical professionals, these attempts to avoid detection by others may be seen as a precursor to avoiding the medical gaze as described by Foucault, since community members, family, and friends serve as proxies for the identification of subjects by the medical establishment.* He describes other strategies of self-accommodation, such as selecting to take classes in the evening or utilizing computers for writing. Darius closes his essay by sharing his perspective of how his autistic traits may be seen as positive attributes. *This aspect of Darius's essay also makes me think of critical disability themes, and the critical autism/neurodiversity movement, since he is taking a stance of empowerment.* For example, he argues that with the exception of social interactions, where there are a host of variables to consider such as nonverbal gestures, inflections, and sarcasm, which often result in the communication of unintended or misrepresented messages, he believes himself to be a very strong communicator. He is unbridled by constraints of social rules and is therefore able to communicate his ideas in a concise and objective manner. He also states that he is most often able to remain calm in emergency situations because he is not overcome by emotions and is able

to focus upon the situations at hand. *Unlike other people, Darius likely has confidence and clear thinking in such situations. I would certainly want someone who can step outside of the emotional mindset and think in more logistical and pragmatic ways if I were involved in a future emergency situation.*

*On a personal note, I could have used these skills recently. In the past year, I lost my father through a traumatic emergency event, and while I believe my response was the best I could have mustered at the time, my emotions were out of check. Last summer, my father got into an accident while we were fishing alone. We were far off the beaten path—out in the countryside—when I called 911. I could not provide an address to the dispatcher or explain my location. In my emotional mindset all I could do is repeat unhelpful information to the dispatcher while simultaneously conducting CPR. This resulted in a delayed response time of the paramedics, and it would be thirty minutes before anyone arrived. While it is impossible to know whether this delay had any real impact, I did lose my father that evening. My emotions were clouding my pragmatic and logical thinking. Perhaps someone with the abilities of Darius to think more clearly would have been of benefit in this situation. I know what I would have done differently had my mind been clear. I could have asked the dispatcher to text message my cell phone. I could have then sent a google maps pin location back to him. Sitting here now, that occurs to be the most logical way to have relayed my precise location; however, in that emotional moment—the thought never occurred to me.*

There are other stories within the book, which include essays supplied by Douglass and Susan, that provide example of how areas of special interest have contributed to professional or academic careers. Each of these writers portray their special interests as yet another positive attribute of their autistic behaviors. *We may pull themes of critical disability, critical autism, and*

*neurodiversity from these stories. Douglass and Susan have taken pride in their special interests. Unlike the cultural stereotype in which such interests are seen as a shortcoming, quirk, or source of humor, they have each embraced these interests which have led to professional success. Susan also explains how her autistic tendencies provide her with an almost superpower to sort through the minutiae of manuscripts and archival records. Susan recognizes this personal strength, and I think anyone who has attempted to sift through archival documents can appreciate what a benefit Susan's skill in this area would provide.*

However, the stories of Angie and Chris provide example of failure and despair as they describe ways in which they believe their atypical traits have hindered their ability to participate in the workplace environment. *Angie's story epitomizes the alienation and casting aside of those who are different. Her essay is brief and heartbreaking. I feel her despair and isolation within her essay as she appears to have given up on life. But it was the essay from Chris that really struck a chord with me because I have witnessed his experience in my professional work firsthand. Chris writes to express his disillusionment and despair he has experienced in the job market after college graduation. He describes the economic system and structural obstacles that he believes to have worked against him. Chris had completed college and graduate school with a future expectation that he would be employed in his selected field. He did well in school, but had difficulty with the social aspects of the job interviews and potential work environments he found after graduation, which resulted in a lack of employment. There are clearly themes in his article of discrimination but the biggest thing that stuck out to me was his perspective of how his college education came at a monetary cost to both him and the state. He argues that this financial cost was being wasted because job placement services were attempting to train him for an unrelated field of employment, hence the wasted time, effort, and resources put into his college education.*

*He also describes how he has become dependent upon social services to meet his current living needs, further costing the state additional resources. In reading Chris's essay, I view him as disgruntled. I think he probably has a right to feel that way though, since the promise of a college education appears to have been nothing short of a bill of goods. Chris was supported and encouraged in his academic pursuits, but no one ever had a real discussion with him about his options after school. This is a problem that I see all too often in my own field. Students are encouraged and supported to pursue advanced degrees, usually racking up enormous debt, and feeding the business of the academy, but often times no one is really considering the best interests of the student.*

*I cannot count the times that students have come into the clinic under these circumstances. Whatever the diagnosed condition or professional goals of the student, the situation repeats itself. These scenarios play out in a rather expected way. I meet a student seeking disability accommodations, there is a long history of academic struggle, and the student expresses a goal of working in some specified field. However, the student seems oblivious to the fact that he or she is unlikely to be able to perform academically or practically in their chosen field. The student has never been informed of the difficulty that may lay ahead since all educational stakeholders have encouraged the student on his or her path. Rather than having a difficult discussion, educators just pass the buck along to the next teacher or advisor. Don't get me wrong, I fully support any student's wishes to work toward their dreams, but someone should inform the student and parents that some career choices may be incompatible with the skills of some people. Educational loans provide great opportunity to many students, but when young adults rack up large amounts of debt with no foreseeable way to pay back monies because they*

*are unable to achieve gainful employment, this promise of success in the pursuit of an often-unattainable degree or employment in a field for which the student is mismatched is just wrong.*

*These students are being hurt by the educational system. There is plenty of blame to go around here. In my experience, transition specialists and K-12 instructors rarely get down to brass tacks on this issue with their lower performing students. There seems to be a failure to have realistic discussions about future prospects after high school graduation. Postsecondary instructors, by way of the organizational structures of the college setting, may be limited in their opportunities to invest in individual students, or may fail to really get to know students beyond the space of the classroom lecture hall. In the same way that false promises are afforded in K-12, this cycle continues into the college setting. There also seems to be an expectation today that just because nearly everyone can go to college—that everyone should go to college. I try my best in the limited interactive time I have with students to help them recognize when their skills are incompatible with their goals, and to identify alternative options and goals. But my time with individual students is limited to only a few days. Also, it can be extremely hard to help students understand these things when no one has ever come out and made such obvious statements to them before. When a student only receives praise and encouragement, with no pragmatic discussion for the realities of employment prospects, we end up with students who are in positions like that of Chris. Again, it's great to have dreams and it's great to pursue those dreams. The problem is that students with disabilities are often blindsided with the reality of the real world once they get to that point where those dreams are suddenly shattered. Then, the student has accumulated debt, spent years in classrooms, and has no formal training for reasonable employment beyond their self-determined goal. It is as if the student only serves the economic purpose of bringing dollars into the university, but is then discarded by the very same*

*academic entity once the money source has dried up. I'm beginning to ask myself more and more, whether it is the students who are using education to better themselves, or if our educational structures are simply just using these students?*

### **Thematic Analysis of Subject Matter**

As I have sifted through autism research, the immediate impulse has been to set aside any and all forms of representation that were not created by persons with autism. This strategy; however, results in fewer examples that may be considered for my analysis. Obviously, I have elected not to completely discard works by persons who do not identify as autistic.

I've established two primary themes through readings of artifacts produced by typically developing persons. The first, as demonstrated through parental writings (Grinker (2007; Nolan, 2004) and popular media portrayals (Autism Speaks, 2018; Guber, Peters, & Levinson, 1988; Blomquist & Hallstrom, 1993) is of the immense impact a child with autism may have upon his/her family. In these depictions of severe autism, the family members are burdened with the care for their child and/or sibling. Aside from the emotional stress of parenting a child with special needs, there are also obstacles to everyday life that would be otherwise inconsequential for the parents of typical children. In short, the construct of autism is represented as a trauma that is inflicted upon the loved ones who are tasked with caring for the autistic family member. Importantly, these depictions do not suggest that parents love their children with autism any less, but the difficulties are clearly portrayed as overwhelming. These depictions also demonstrate a willingness to try nearly any treatment strategy that may offer relief or support to these families. In the same vein, there also appears to be a skepticism that develops as frustrated parents eventually recognize the latest treatment approaches as ineffective. Along with this skepticism, is an underlying theme of decreased confidence or even distrust of the medical establishment.



The second major theme that I have formulated in the cultural artifacts produced by persons without autism is the focus upon treatment and alteration of the individual with autism. Whether through public advocacy campaigns (Autism Speaks, 2018) or writing aimed at providing assistance to persons with autism (Attwood & Santomauro, 2012; Zager et al., 2013), these discourses primarily adopt the deficiency language of the scientific-medico paradigm of disability. In these forms of discourse, there is an emphasis upon relieving the burden of caretakers and supporting persons with autism to integrate into society. However, despite the generous intentions of the individuals and groups producing these cultural artifacts, autism is routinely represented with a pretense of othering that dehumanizes the subject and pathologizes an inherent problem in the individual that requires treatment or cure.

These problematic representation of autism, while well-intended perhaps, stand in stark contrast to the autobiographical reflections and representations of the autism construct by persons who identify as autistic. Whether these works are formally associated with the discourse of critical autism studies (Milton, 2014; Woods et al., 2014), or are forwarded as unadulterated examples of autistic writing (Prince-Hughes, 2002), these works share the common themes of individuality, personal expression, identity, and pride. The writings of persons with autism juxtapose the objective descriptions of the dominant medical framework to describe lived experience in relational terms that do not overshadow the personhood of each individual author. There is also an obvious presence of challenge to the dominant narrative of autism, as the identity of autistic persons is framed as a form of personal difference to be valued and appreciated rather than deficiency or flaw. While there may be drawbacks and difficulties to living with the autistic identity, which autistic authors seem to admit, these are also reshaped into positive attributes and are not portrayed with the same negativity of those representations

forwarded by non-autistics. In short, the assumption that autism is a problem is denied in the cultural constructions of the autistic community. Autistic culture also appears to be a vibrant and growing community of individuals who seek to disrupt and challenge the narrative of disablement that has been placed upon it by outsiders who neither fully understand or recognize the lived experiences or desires of its members.

*Within the first-hand accounts of autism experience, I can also view critical disability, postcolonial, and cultural themes that help to conceptualize these challenges to the medical establishment. Whether individuals are describing their attempts to appear normal and go unnoticed, or if they choose to embrace their difference as a point of pride and individuality, these critical perspectives provide an alternate framework to think about the social construct of autism.*

### **Learner's Perspective: Reflecting Upon the Progressive**

*While it is difficult to set aside the experience of my prior training, I've attempted to focus upon progressive themes and contemporary understandings of autism that may be found in these contemporary milieu and subject matter. First and foremost, I recognize how language functions to organize and limit the construct of autism within a traditionally medicalized discourse. Such approach also functions to dehumanize and pathologize human differences. I also must recognize that when I utilize scientific language and think in diagnostic terms that I am complicit with this symbolic system. As opposed to the ableist narratives of contemporary autism self-advocacy, the deficiency-based language and positivistic research methodologies of my prior training further separate the subject/person from the autism construct. The notable absence of these operations within the critical perspectives of autistic autobiography, self-advocacy, critical disability studies, and critical autism studies signal the importance of breaking away from*

the scientific-medico paradigm if one is to better understand the lived experience of autism. This strategic split from the authority of professional voices results in opportunity to consider the autism construct not as an othered position, but from a place of shared experience, relation, and humanity.

The voices of the autistic community are not defined by objective symptomatology or medicalized narrative, but by relational explanation. What this alternate understanding implies, is that services for students with disability should not be determined by preconceived assumptions of symptom related functional impairments—but by individualized needs. Stated differently, a relational understanding of autism would lead one to make accommodation decisions *through a more personal and interactive process than the result of impersonal formal measurement tools*. Rather than basing support services and academic accommodations upon archaic beliefs in the naturally occurring deficiencies that are portrayed as valid through the use of normative assessments, the better approach may be to simply ask or observe the student to identify areas of difficulty. After all, who better to understand personal learning difficulties or areas of significant stress in the college environment than students themselves?

If I were able to completely disregard requirements of formal documentation in my daily work, I could then rely fully upon the voice of the student who seeks assistance in obtaining learning supports. Through a decreased emphasis upon objectification and documentation, new methods of accommodation may also be revealed. The critical perspectives I have reviewed seem not only to prioritize the voices of persons with autism, but also suggest presence of needs that are unlikely to be mitigated by standardized testing accommodations alone. This revelation suggests a shortcoming *to the current framework of postsecondary disability services*, which most often only includes a limited range of easily deployed testing supports. While not excluding

the opportunity to receive these standardized supports, *breaking away from the current emphasis upon empirical evidence may provide clearer understanding of what a student may really need to be successful*. Why can't disability specialists, instructors, and students collaborate to identify ways that the student could gain better access? Rather than simply providing a list of classroom accommodations, and then taking a hands-off approach to disability services, it seems more appropriate that students, parents, and school personnel should identify problems and work collaboratively to first meet presenting needs but to also continue these interactions so that adjustments may be made to provided supports as individual needs arise.

In the book *Educating college students with autism spectrum disorders*, postsecondary professionals share the successes of such collaborations that go well beyond the standardized practice of providing test accommodations (Zager et al., 2013). While the requirement of the ADA is to provide equal access, why not initiate procedures that will support the success of students with autism? *Although resources are obviously varied across institutional settings, there are students who need something more than the standard testing supports. These students may excel in the classroom, but require assistance navigating the social spaces of a college campus*. Why is there a separation between the accommodation of classroom access and that of college experience? The communicated difficulties of persons with autism seem to be much more prevalent in regards to the latter. The provision of support groups, peer mentors, individualized coaching, and alterations to instructional delivery seem to be far less prevalent than the traditionally conceived and finite testing accommodations that are most frequently provided to students. Despite the scientific-medico approach forwarded within *Educating college students with autism spectrum disorders* (2013), the intent to provide individually tailored supports to students with autism recognizes the individual differences between this population of students

and seems to be a more appropriate method of ensuring the positive learning experiences of postsecondary students with autism. *Such a dramatically different approach to postsecondary disability services would not be easy to achieve. There would be the issue of institutional resources, and there would likely be a resistance to change by campus communities. However, unless this issue becomes a priority of administrators and governing boards, these circumstances are likely to remain.*

Even my professional role as an evaluator becomes less important if we break away from the traditional model of postsecondary disability services. Rather than relying upon standardized evaluation results *and empirical evidence when determining accommodations*, it would be much more preferable to engage in a dialogue with students to first identify areas of potential need and then engage in *a process of problem solving*. Such conversations could shift power to the student so that he/she may express better control of their own educational experiences.

**Progressive Vignette: Considering the Possible (reimagined scene with ASD student)**

My professional practice would be altered significantly if I were able to engage in the contemporary milieu and subject matter of autism from a critical framework that deemphasized current requirements of standardized assessment, documentation, and legal access. I envision that this alternate approach would likely involve more relational interactions with students and parents, as well as increased collaboration with campus professionals and instructors. Rather than serving primarily as a gatekeeper by way of my assessment role, I imagine that my interactions with a student such as Samuel, who was introduced in the creative nonfiction vignette of an earlier chapter, would likely proceed as follows.

**Scene 1.**

*It is the summer after SAMUEL's high school graduation and he will be coming to the university in a few months. SAMUEL and his PARENTS have been invited to come into the office for a brief meeting to determine what forms of support SAMUEL may need, and to establish a working relationship for the future.*

(SAMUEL enters building with his PARENTS)

DANIEL: Good morning Samuel. How are you today?

SAMUEL: Good. (*looking down/away*)

DANIEL: I assume these are your parents? It's nice to meet each of you.

MOTHER and FATHER: Good morning.

DANIEL: Let's all step into my office so that we can begin our meeting.

(EVERYONE leaves lobby area and enters office)

DANIEL: Please have a seat and make yourselves comfortable. The purpose of our meeting today is first of all for me to get to know each of you better, and then for us to brainstorm ways that we can support Samuel's college experience. Do you have any immediate questions?

MOTHER: Yes, did you receive the paperwork we submitted to you already?

DANIEL: We did receive it, and I can tell you right off the bat that given Samuel's history of prior services, there is plenty of documentation to justify his reception of basic academic supports.

MOTHER: Basic supports?

DANIEL: Yes, all students with documented disabilities are provided access to basic levels of support which include things like extended time for testing, reduced distraction test

environments, and notetaking assistance. Samuel will be provided those accommodations whenever he feels that they are needed. That has already been determined. The purpose of our meeting today is to figure out whether Samuel may benefit from other forms of support that are more individualized to his specific needs, if he has any. There is no requirement that a comprehensive psychoeducational evaluation be conducted, because Samuel's history clearly demonstrates a prior reception of special education services. We can provide such an evaluation if desired, but it will not be necessary to document Samuel's need for additional learning supports.

FATHER: That sounds great! While Samuel could probably use extended time occasionally, we are really more concerned about how he is going to remain organized and not miss deadlines in his classes.

DANIEL: Good. It seems that you already have a fair idea of what Samuel may need. In looking back over the types of accommodation that were provided in high school, it does appear, (*turns toward SAMUEL*) that you rarely needed traditional academic accommodations. However, your past instructors report that you experienced problems with organization, planning for assignments, and remembering project deadlines. Does that seem accurate?

SAMUEL: (*looking down/away*) yes.

FATHER: Oh yes, we have no concerns with Samuel's ability to complete the work but do worry whether he is going to have difficulties with new responsibilities of keeping up with his assignments in college.

DANIEL: Okay, we have a couple of strategies that we can utilize from the start. First of all, Samuel, you and I are going to meet on a weekly basis to review events of the past week, discuss any concerns you may have, and plan for the upcoming week. These meetings are

where we are probably going to begin thinking more specifically about things that we can do to address issues as they arise. How does this sound?

SAMUEL: (*looking down/away*). Okay.

DANIEL: (*turning attention toward PARENTS*) Mom and Dad, you can check in with me from time to time if you wish, but this process is going to work best if you can try to step back and be more hands off.

MOTHER: Oh? (*with surprise*)

DANIEL: Don't worry, please don't think of this as taking your support away from Samuel, but rather as a handoff to me for the responsibility of the daily stuff. It's going to be much easier for me to address issues, if they arise, here on campus than you will be able to address from home. As Samuel and I meet weekly, he will be able to keep me updated and informed about what is going on with him. I will eventually have copies of his assignments so that I can remind him of upcoming events, and I will also likely have contact with his professors.

MOTHER: Okay, that doesn't sound quite as bad (*nervously*).

DANIEL: I know it can be difficult to relinquish control, but that is going to be part of this transition to college for Samuel. While he is going to be confronted with new responsibilities, I am going to serve as a safety net as he gets started with his college experience. Given the changes in legislation that guide disability services in high school and college, you are no longer going to have as much access to Samuel's teachers. I will serve that role for Samuel and will interact with his instructors as much as needed to ensure he isn't falling behind. My goal is going to be for Samuel to learn better ways to



self-accommodate and advocate for himself, and ideally he will not depend as much upon my help as we progress through semesters, but I will always be here if needed.

FATHER: That sounds like a great plan, we were really worried how this was going to work with us living apart. We certainly have concerns for Samuel's organization and planning, but we are also somewhat worried that he is going to have difficulties meeting new people and finding a place to fit in on campus.

DANIEL: (*speaking directly to PARENTS*) Well, those are exactly the types of things we are going to be focusing upon. Do the two of you have any other major concerns?

MOTHER: No, not really.

DANIEL: Great! I am going to ask each of you to wait in the lobby while Samuel and I have a quick discussion and try to lay out a tentative plan for how the semester will begin.

FATHER: Okay. We'll be right outside Samuel.

[PARENTS leave office and sit down in lobby]

DANIEL to SAMUEL: Okay Samuel. I've noticed that you haven't really offered very much in our discussion thus far. Do you have any major concerns?

SAMUEL: (*looks down/away*). No, I usually just let my parents do the talking. I like the idea of having the extra help.

DANIEL: Okay, I just wanted to have a few moments with you so that I could explain how this process is going to work.

SAMUEL: (*looks up*) Okay.

DANIEL: I am going to do as much as I can to help you, but you need to first understand that you are going to be responsible for all of your coursework, this isn't going to be a way for you to get around that.

SAMUEL: I don't mind the work, especially if it is interesting.

DANIEL: Good. Do you have any pressing concerns about the start of college?

SAMUEL: No, once I get started I think I will be fine. I don't even know what classes I am going to be taking yet. I'm mostly just nervous, but also excited. I'm ready to try being more on my own.

DANIEL: That's all to be expected. We are going to set up weekly meetings so that we may stay in contact with one another and you can keep me updated on any issues you may be having. I imagine these meetings may occur less frequently over time, but you may feel a need to meet more regularly at the start of the semester. After the first week of school, I want you to come see me. We will set up a time then for the future meetings. In the meantime, I want to share a few resources with you that I want you to just be aware of. You don't have to do any of these things if you don't want to. I just want to give you an idea of the types of things we can do as the semester progresses.

SAMUEL: Okay.

DANIEL: First, our weekly communications don't always have to be face to face, if you find it more comfortable, we can talk online. Secondly, with your permission, I am open to meeting with your professors if you ever need me to. There are many campus organizations and groups that I can help you find once you get to campus so that you can find a group of people that share similar interests. We also have a support group comprised of students with autism that meet on a biweekly basis. These students usually get together and hang out, and they often help one another whenever needed. It's mostly a social group, and people tell me that it is really just a safe place where folks can be themselves and not worry about what other people are thinking about them.

SAMUEL: That sounds good. I don't really have any friends coming here and I've never spent much time with other autistic people.

DANIEL: I'm going to help you get plugged in to campus life.

SAMUEL: I think I would like that, but meeting new people is scary. I'm mostly concerned with making it to my classes on time and feeling safe and happy on campus. I also believe I am ready to be more independent from my parents.

DANIEL: I hear other students say that a lot. I want you to be independent, but I also want you to remember that I am here for backup. You may still mess up, and your school performance is still going to be your responsibility. However, I am going to help you to navigate campus and figure out what types of activities and instructional supports work best for you. If situations arise with your classes, or if you are having difficulties in the dorm, or are seeking help with anything else, we will be able to work together to find a solution to those problems. The main thing will be for you to figure out what works best for you. As far as classroom accommodations go, we will devise plans once you determine what your needs may be in individual classes. You might find that you need more or less than you originally imagined. We will keep in contact and revise our plans on an as needed basis. Do you have any other concerns?

SAMUEL: No, not really.

DANIEL: Ok then, it was great meeting with you, and I am looking forward to the fall semester.

Remember to come meet with me after your first week of classes. Goodbye.

SAMUEL: Goodbye. (*meeting is concluded, SAMUEL and his PARENTS leave the building*)

**Scene 2.**

*A few weeks into the semester, SAMUEL begins having problems organizing his work. During one of his weekly meetings, he expresses that with the exception of going to class, he rarely leaves his dorm room. SAMUEL does not appear to have made many social connections on campus.*

DANIEL: Hey Samuel, how has it been going this past week?

SAMUEL: I missed another homework assignment in economics. I don't know why I wasn't aware of it. It wasn't in my syllabus. Everyone else in the class seemed to know about the assignment but me.

*(SAMUEL has become much more comfortable and confident in these one-on-one meetings)*

DANIEL: Sometimes professors will assign additional work during class meetings that is not included in the syllabus. I will work touch base with your professor to try and determine how you may have missed the assignment. Are you still using the daily calendar that we talked about?

SAMUEL: Yes. I just never put the assignment into the calendar so I never did it when I was going through my checklist for the day.

DANIEL: That's okay. It is still early enough in the semester that we can probably make up for the assignment. Hopefully by next week we will also have a better plan for putting things into your calendar and perhaps we can figure out a way for you to better recognize announcements for new assignments. You have done so well maintaining your calendar and completing the tasks you outline each week that I believe the best route to take will be to focus upon the ways you put new information into your to-do-list. I also would like for you to join me for lunch tomorrow outside the cafeteria. Don't worry about bringing

anything, I will take care of the food. I am meeting with two or three sophomore students who I have also been helping. I think they may be able to help you with some of the issues you have been having outside the classroom. These students could help with navigating campus and finding fun things to do in your spare time.

SAMUEL: That is fine. What time should I meet you?

DANIEL: Meet me in front of the cafeteria at 12 noon. Feel free to call or text me if you can't find me. I will probably be sitting on a bench outside.

SAMUEL: Okay. See you tomorrow. (SAMUEL *leaves the office*)

### **Vignette Analysis**

This alternate scenario in which my professional practice is guided less by documentation and a standardized delivery of services should reveal a drastically different form of interaction with Samuel and his parents. Rather than emphasizing the role of formal assessment to determine appropriate supports, this vignette reveals how taking a more relational approach could result in a more personalized and individually tailored form of service delivery. Additionally, the decreased role of formal documentation also positions Samuel as the primary resource for decision making. It is through the development of trust, and perhaps even trial-and-error, that Samuel may receive more refined forms of support that directly address his unique needs. Importantly, this approach places value upon Samuel as the primary information resource. Although the disability services professional acts as a guide and facilitates access, this professional also grants attention to the student's experiences outside the classroom as equally as those from within the classroom.

## CHAPTER 4

### ACCEPTING THE (UN)COMFORTABLE, EMBRACING THE PATH IN-BETWEEN, AND MOVING FORWARD

This chapter provides a candid review of the critical reflective journey I have undertaken for this dissertation project. Chapter 1 outlined the theoretical and methodological guideposts for my critical reflective journey. The theoretical guideposts included the curriculum commonplaces, post-positivism, postcolonial theory, and critical disability studies. The methodological guideposts included self-study, currere, and the use of creative non-fiction as both a product and process. Chapter 2 provided information about my past educational experiences, along with a conscious effort to present information about the autism construct from the perspective of my professional training. I utilized the Chapter 2 vignette to present a typical encounter I may have with an ASD student in my daily practice. I also provided a historical account of positivism and explored ways in which this paradigm has not only shaped the traditional-medico understanding of the autism construct, but also the typical activities of my professional field. Within Chapter 3, I sought to consider the possible. I looked beyond the positivistic and traditional framework of disability scholarship to identify alternate understandings of the autism construct as a way to conceptualize a reimagined possibility for my future practice. These alternate understandings were informed by postcolonial scholarship, critical disability studies scholarship, cultural studies, and personal narratives of individuals with ASD. I utilized the Chapter 3 vignette to reimagine ways in which my interactions with ASD students could be different if I were able to move beyond the present day positivistic influences, legal and ethical guidelines, and emphasis upon normative assessment that organize the daily practice of my profession.

The goal of this dissertation project was to map out a more comfortable space of in-betweenness as a first step in determining my own role as a practitioner. As I have gained a better understanding of this space in-between, I have also gained better understanding of the autism construct and have identified a way that I may utilize my hybrid location as a place of hope and possibility so that I may better serve students with autism in the postsecondary setting. These efforts to embrace the disciplinary in-betweenness have illustrated a practical application of curriculum theorizing to reconceptualize and reinvigorate the daily practice of those who find themselves uncomfortably placed between paradigms of theory and practice.

In the sections below, I review the process of undertaking this critical self-reflection and discuss four significant findings related to the following themes. I first describe the pervasive and insidious operations of positivism to shape and construct contemporary educational practice. I share the difficulties that I have experienced in writing about my lived experience of in-betweenness. I discuss the inherent difficulty in understanding differences between abstract theories and lived experiences of in-betweenness, along with the recognition of how this position of in-betweenness should not be conceived as a feeling to resolve but rather a position of hope and possibility. Finally, this study has resulted in a greater understanding for the importance of recognizing the voice and personal agency of those persons labeled with disability. The chapter concludes with my offering of thoughts on the theoretical and practical implications of my self-study and some tentative considerations of where I may go from here. This chapter makes no attempt to be conclusive but rather chronicles and reflects upon the tentative understandings with which I have arrived thus far. In describing the process of *currere*, William Pinar (2012) states:

The method of *currere*-the Latin infinitive form of curriculum meaning to run the course, or, in the gerund form, the running of the course-provides a strategy for students of

curriculum to study the relations between academic knowledge and life history in the interest of self-understanding and social reconstruction. (p.44)

In this respect, I have not completed my “running of the course” and will continue working to better understand how my prior educational experiences have influenced the ways in which I interact within the world.

### **Process: False Starts and Discontinuous Progress**

The process of constructing this dissertation has been lengthy and not without obstacle. Whereas I began this project by describing the difficulty of inhabiting a space in-between philosophical paradigms, perhaps I was naïve to believe that such a critical exploration would not be too difficult. Even though I have been thinking about this epistemological space between my experiences and understandings of curriculum studies and school psychology for quite some time, the actual endeavor of writing through these contradictions has been frustrating.

From a practical standpoint, the dissertation writing process has been one of repeated revisions and rewriting. There should be nothing unexpected about that; however, it has been the reworking of ideas and abstract concepts that have given me more trouble than I would have anticipated. Rather than dealing with quantitative data or clearly defined empirical observation, my goal has been to challenge myself by engaging in a form of inquiry that would be different from my past research experiences. I have certainly achieved the goal of challenging myself. This project has been different for me, because both my experience and process of writing this dissertation have been fluid, cyclical, and constant. Even when I am away from my computer or notepad, I am continuously thinking through and sitting with these ideas. This is a different form of academic work for me, because I have not been able to ‘shut off’ or ‘step away’ from the concepts I have been exploring within this project. Perhaps it is because of the personal



relevance that is inherent in a self-study, or the fact that I have really tried to focus upon the philosophical implications of my daily work, but I have never before wrestled with ideas and concepts to the degree that I have over the past two years.

Likewise, I am also confronted with these contradictions in my daily work as I am expected to rely upon formal measurement and quantitative data to make decisions; however, my readings of critical autism perspectives encourage greater emphasis upon the personal voice of those I evaluate. I feel myself caught between two paradigms, one in which assessment consists of normative measurement, and the other that consists of relational understanding and even a degree of faith in a client's truthfulness when they do make a request.

However, this ongoing internal debate that at times has felt inescapable has not been without merit. By intentionally utilizing the writing process as a strategy to explore my feelings of in-betweenness, I believe that I have discovered aspects of my thinking of which I was previously less aware. First, the act of writing through my feelings and understandings of a complex issue has forced me to reflect upon ideas over a period of time while revisiting different aspects of my daily practice. This cyclical process of thinking and returning to previous thoughts and feelings has resulted in new ideas. In utilizing components of currere to reflect upon my past and synthesize my future, I have probably given more direct consideration to my own educational experiences. This process has also given me the opportunity to envision how my interaction with students could be different if I were not as hindered by the rules and regulations that guide my professional practice. For example, I utilized the writing process while constructing the progressive vignette (in Chapter 3) to envision a totally different way of determining the types of services and supports that a student may receive. The process of sitting down to write out such possibility has provided a vessel by which I have traversed between

modes of thinking. The decision to employ the writing process, and currere, as a method of inquiry has without a doubt resulted in better personal understanding.

Aside from this process of thinking through and grappling with philosophical and paradigmatic notions of subject matter throughout this project, my election to focus upon the writing process as a form of inquiry has also resulted in another unexpected challenge. Along the way, as I have worked tirelessly on this dissertation, I have been made aware of an unexpected manifestation of my previous experiences of positivism which involves my writing style and the ways in which I present ideas to others. This was an unexpected discovery of this self-study endeavor that has been accompanied by a wholly different form of unsettling. Honestly, this may have been my greatest personal revelation of this entire project and I discuss this revelation in greater detail in the findings section of this chapter.

### **Significant Findings**

**Finding One: Positivism has been embedded through most of my prior educational experiences, and it continues to influence my thinking and daily practice.**

From the start, a primary objective of this dissertation has been to critique the role of positivism in the development of my professional identity. While I already understood that postpositivism was likely to be the primary organizing principle of my professional field, I was unprepared to discover the degree to which it has framed the majority of my entire educational experience. The organization and positivistic foundations of our educational practices serve to indoctrinate students into the singular philosophical worldview of positivism. I will first discuss some of these attributes within school psychology, before broadening the discussion to more general educational matters.

**School psychology.**

The field of school psychology emphasizes a single, external reality. As an example of this treatment of knowledge and truth, we need look no further than the Diagnostic and Statistical Manual of Mental Health Disorders (DSM). As previously discussed, this manual provides definitions and diagnostic criteria for mental health conditions. It is the standard by which the individual is compared to determine deviance from the norm. The form of knowledge espoused in the DSM is accepted as indisputable truth. While the manual does undergo revisions from time to time, this is not to suggest that the old versions were necessarily wrong, but rather incomplete. In true postpositivistic fashion, diagnostic clarification is viewed as a byproduct of a closer movement toward truth that is gained over time as practitioners and researchers achieve better understanding and knowledge of the world through carefully designed experimentation and demographic tracking. In addition to the organizing worldview expressed by this manual, the philosophical emphasis upon scientific procedures extends down to the daily practice of clinicians in the field. This would include everything from the accepted conventions of normalcy to the emphasis upon measurement of behavior. As comparisons are made between individuals and the larger population, deviance from the norm is viewed as something that is inherently wrong or flawed. The fallacy of such an approach has been addressed by the French philosopher Michel Serres (1982/1995) as he has criticized ways in which a singular philosophy of science limits understanding and knowledge accumulation through the self-regulative processes of the scientific community. As new ideas emerge, they must first be vetted from within the field to ensure that such ideas are not a threat to the status of the field itself. Serres (1982/1995) contends:

The sciences amongst themselves perform a surveillance, a monitoring that is both conceptual and social, and which defines the validity of a learned procedure. Consensus is the ensemble of these monitorings. At a given time, the community knows, as though instinctively, what is admissible. To be learned is to have this knowledge, often without knowing it. This regulation, this self-regulation, this set of feedbacks in the network of relations, makes up the main constraint for anyone wishing to enter the community in question. . . . The dominant theories at present say that no such scale exists, since competition is the driving force of discovery. These hypotheses are too favorable to those currently in power to have any hope of being plausible. . . . The monitoring in question works only for monitoring, only for selecting, the maintenance and perseverance in existence of a group that lays itself open to becoming a pressure group, slowly ceasing to be fruitful. In other words, the scientific community is in danger of arming itself less to ensure discovery or invention, than interventions are advertised in order to ensure the status of the scientific community. . . . Free thinking is put in danger through the working of the strategies of fine thinking. (p. 104-105)

The scientific field has doubled down on the epistemology of positivism. As Serres (1982/1995) explains, this determination to maintain rules of an ordered, and predictable world may not be due to any true belief in the validity or appropriateness of a particular research methodology, but rather provide example of a field's attempt to maintain its position of power.

Returning to the topic of normalcy in the field of psychology, it is deviance from the norm that may be viewed as an unfavorable threat to the reign of positivism. This difference of bodies and minds represents a disruption to the predictability of a perfectly ordered world, which once again finds its foundation within the positivistic worldview. The focus upon quantification of behavior

and the identification of cause and effect relationships that characterizes much of the psychology field is a manifestation of the positivist's metaphysical worldview, which is that of a single-apprehendable reality.

The positivist view of reality assumes that it is not only apprehendable, but predictable, measurable, and understood through an exacting application of research methodologies, controlled scientific experimentation, and empirically observed phenomena (Lavery, 2003). The instruments commonly utilized in clinical settings are touted by the positivistic ideals of validity, reliability, and objectivity; therefore, they are also accepted without question as providing insight into what is true, certain, or real. Whenever a measurement tool fails to provide answers to questions of human behavior, the field does not step back to consider the philosophical approaches of instrumentation but rather refocuses its efforts to update these instruments to move closer to truth. In other words, a doubling down occurs for more predictive and causal experimentation and research. Rather than rethinking the approach altogether, clinicians address shortcomings of instrumentation by the development of more instrumentation.

In my experience, the field of school psychology does not move beyond positivism. Perhaps it is because of the emphasis upon normative assessment and cognitive testing that have positioned the field into its current status within educational settings, but it is also partly due to a limited exposure of trainees to the general field of philosophy within the classroom. I believe there is meaning to be taken, with the perspective of hindsight, that I do not recollect any direct engagement with philosophical matters as a school psychologist trainee. Furthermore, when I think about my lifetime of formal educative experiences, I do not recall any demarcation from the single philosophical approach of positivism. Of course, I also recognize that without my

recent experiences as a student of curriculum theory, that I may not have realized that these experiences were so influenced by this singular philosophical paradigm.

**General education.**

It is because of these covert operations of positivism that I believe a statement made by George Steinmetz (2005a) may have particular meaning to me. In introducing a book of collected essays that deal with the epistemological developments of the contemporary human sciences, he writes,

One of the guiding threads in this volume concerns the surprising longevity of positivism—especially in latent, unexamined, or unconscious forms—in the human sciences. Despite repeated attempts by social theorists and researchers to drive a stake through the heart of the vampire, the disciplines continue to experience a positivistic haunting. (Steinmetz, 2005a, p. 3)

Steinmetz goes so far as to portray positivism as a monster that is worthy of violence. I read his statement and immediately think of a nefarious creature, lurking in the shadows, engaging in some form of diabolic act to bring harm upon the world. I think this metaphor, particularly as it pertains to a lack of awareness, is likely to be a fair depiction of my educational experiences. I have been haunted by a monster of positivism my entire life. I have lived with Steinmetz's proverbial vampire, yet had not been alarmed or scared, because I did not know to question this monster from the shadows. Simply put, positivism has been the status quo.

Today, I can claim an awareness of the "positivistic haunting" Steinmetz speaks of, yet I have only begun to bring this figurative monster from the shadows and into the light. Despite my lifetime of experience in formal education, it was not until I began studying curriculum theory that this role of positivism was exposed.

As a curriculum studies student, I undertook my first formal study of philosophy. While these explorations were admittedly cursory, it should be noted that it was not until I entered the doctoral program that these matters were ever addressed as a part of a formal curriculum. Within the first year of classroom experiences in the Curriculum Studies program, I was beginning to question these prior learning experiences. I can fondly recollect a course in educational philosophy in which I was introduced to the basic tenets and three major branches of philosophy. I remember working very hard to understand these abstract concepts, and truthfully, I enjoyed it very much. I was especially fond, like most newcomers to a directed study of philosophy, of picking out which paradigm best fit my personal views. Of course, this was also the point in which I began to realize the breadth and depth of western philosophy. I remember being awestruck when I first realized that there were so many “other” ways to do research. I also recognized that the manner in which I envisioned the world was not necessarily consistent with the inherent assumptions of positivism. Rather, I choose to view the world as individualized, with reality being constituted by an individual’s perceptions. In this relation, I would argue that knowledge, or truth, is a construction of one’s perceptions and beliefs of reality. This is very different from the positivist’s stance. This cognitive dissonance between the philosophical assumptions of my profession and the manner in which I choose to see the world was one of the reasons why I chose this topic of study for my dissertation.

My introduction to philosophy as a curriculum studies student was also the moment in which I realized that I had been conditioned for my entire student career to define legitimate research by positivistic standards. However, this revelation extended much further than the confines of formal research or my practice as a school psychologist. As a curriculum studies student I discovered that the positivistic haunting had been present throughout my educational

career. From even my earliest experiences of grade school, every aspect of my schooling—from science fair projects and end of course tests to textbook instruction and grade-level standards—had been influenced by positivism. My educational career, like that of most American students, has been dominated by high-stakes tests, a revolving door of standards and objectives, repetition, regimented learning, performance outcomes, and accountability. I emphasize testing as a part of my own experience in public education because of the notable role it played in the day to day activities of the classroom; however, by all accounts it does appear that the prominence of this activity has only increased since the time of my grade school years.

It took Curriculum Studies for me to fully realize that these activities were actually an encroachment upon the classroom space by outside forces, namely politicians and administrative overseers. The regimented and standardized teaching practices of my youth were not devised by my instructors but rather handed down by governmental groups in response to socio-political concerns that culminated in the 1960's (Pinar, 2012). This mechanization of classrooms, or “school deform,” has promoted tenets of positivism by an overreliance upon standardized testing, regulatory control, surveillance, and learning objectives that have fractured our educational experience (Pinar, 2012).

Steinmetz (2005b) also links the political developments of Fordism, namely the mass production, consumption, and materialistic practices occurring between the second world war and the cold war period in the West as a precursor to the entrenchment of positivism within sociology and other social sciences. As governmental contracts and funding were offered to researchers, these often came along with strings attached in the prioritization of particular methodologies that emulated the scientific method. When we consider Steinmetz's argument along with Pinar's explanation, then there appears to have been a clear assault upon teaching and



research practices at both the secondary school and university levels. While he is specifically addressing his own field of study, the following statements provided by Steinmetz (2005b) certainly have credence for many other social science disciplines, and especially that of psychology. He writes

Methodological positivism in sociology has also privileged specific ways of representing social reality. Articles have been preferred to books; statistical and tabular forms to textual ones; analytic genres of writing to narrative or experimental forms; and written forms of inscription to visual ones. Authorial voice is disdained as subjective and the voiceless style felt to be more scientific. Multiple rather than single authorships is the norm, providing a synecdoche of the “scientific community” of peers. (Steinmetz, 2005b, p. 285)

I would argue that these implications of methodological positivism have become the norm across the academy. Those fields of study that emphasize textual interpretation, written narratives, and author subjectivity are rare occurrences in the modern-day academy. For a teacher to gain upward mobility in the university setting, they most often have to abide by these structures. They must play the game in order to advance, whether they accept the worldview as their own or not. The ability to advance as a scholar in the academy seems to be directly tied to the metrics of scholarship, which again resemble the administrative oversight and bean-counting behavior taking place in secondary school settings.

### **Finding Two: It Was Challenging to Write about my Lived Experiences and New Understandings of In-Betweenness.**

While I began this project with a clear goal of critiquing positivism, and I believed early on that the content of my arguments would be effective, it was not until I was engaged in the revision

process of prior chapters that the issue of my writing style was brought to my attention. Despite my best intentions and unbeknownst to me, my writing style throughout this project continuously reflected the tenets of a positivist's worldview. As my committee was quick to point out, I tend to write in a formal and objective style. In my mind, this style of writing is the preferred method of academic discourse. It also comes most naturally to me as formal style has been emphasized throughout my educational life. Placing myself into academic writing, speaking in the first-person, and loosening the restrictions that I unconsciously place upon personal voice while writing are all effects of my prior positivistic training experiences. Even when I was made aware of these issues of writing style by my advisor and committee, I have continued to struggle greatly to alter the format of my writing.

Even though it is hard to convey the difficulties I have experienced while attempting to alter my writing approach, there are two byproducts of this struggle that are readily visible within this final written product. The first piece of evidence can be found in the appearance of alternating voices of objective and subjective, or the formal and informal, that is found in the italicized sections of Chapter 3. These alternating fonts were not so much of an artistic decision for my final product but a strategy I utilized to trick myself into thinking and writing differently. Secondly, my use of footnotes throughout prior chapters has also been a strategy to lessen the burden of objectivity that I felt must appear within the narrative of this project. Undoubtedly, the most difficult aspect of this project has been in loosening the constraints of formality. My perception of what counts in academic discourse, specifically my subconscious expectation of writing style and format, or what legitimate scholarly work should look like, continues to be influenced by the specter of positivism. My grappling with this issue has been labored, and this may or may not even be apparent to the readers of this final document; however, suffice to say,

the simple task of changing my writing style has been exceptionally challenging. This will forever be a struggle for me.

**Finding Three: Feelings of In-Betweenness and Displacement, while Uncomfortable, may Signal a Position of Opportunity.**

When I began this project, I thought of in-betweenness as a difficult place to reside. I have recognized that alternative views existed that stood in contrast to my professional training and I have felt discomfort throughout my time in the Curriculum Studies program as a result of this recognition. When I meet students who are obviously not being granted supports that they require, I am now more prone to question the standards and practices of my daily work. As I work alongside other professionals who ascribe to the technicality of formal training, I now feel different. I have these new ideas and sometimes do not feel able to express these concepts for fear of ridicule or exposure as a rogue practitioner. When I am alongside my curriculum theory cohort, I feel more at ease. While I am no longer taking classes, the opportunity to engage in scholarship and attend conferences with other curriculum scholars has felt like a homecoming of sorts. Perhaps this is like the displaced traveler who returns home to be reminded and rejuvenated before leaving once again? I no longer feel completely at home within my professional setting. Unlike the traveler who departs from a physical space, I continue to inhabit the same physical location as a professional. Those around me remain unchanged, yet I am new. In some way, I am now different. At this point in my doctoral journey, with the completion of coursework, I am no longer surrounded by other curriculum students and professors. The influence of my cohort has become more distant, both physically and mentally. The lines of communication have been strained. There is no longer an ideological resetting that once took place every time I set aside my professional practice to meet with my classmates and engage in

the work of curriculum. In short, I now feel more alone. I have reentered the confines of my professional setting without the scheduled class meetings that once provided an escape from the positivistic paradigm and the traditional view of disability. Along with feelings of loneliness and displacement, I also hold fears that I may revert back to prior thinking patterns. Without the continued interactions afforded by class meetings, there is a worry in the back of my mind that I will forego this work and simply go back to my old ways. Each of these factors have contributed to feelings of uneasiness and uncertainty. The typical response to these feelings, like any other aversive experience, is to seek a change. As humans, we seek to fix problems that cause discomfort.

While I was fairly certain that I would not be able to find a resolution to these feelings of hybridity, as I have read more throughout this project, I can now see that this is not a position I should seek escape from, but a placement from which I should learn to dwell (Aoki, 2005) as a way to maintain a degree of discomfort and unfamiliarity that will promote a critical eye toward conventional truths and assumption (Saïd, 1994). As Bhabha (2007/1994) reminds, hybridity is not a resolution to cultural difference or false assumptions of an either-or-dualism, but a way in which alternate understandings enter into the dominant paradigm of knowledge. In this same sense, my feelings of in-betweenness do not signify a need to choose between critical understandings of autism and the epistemology of my prior training but instead it suggests that my awareness of critical autism perspectives should reside alongside and offer challenge to the assumptions that are inherent in my daily practice. What I take this to mean is that results of this study are to be incorporated into my daily practice as a way to provide alternate ways of envisioning the autism construct. Obviously, I can't throw away my training as a practitioner, to do so would threaten my professional credentials and ability to perform my duties as a school

psychologist. However, by embracing this hybridized epistemology, I can work within the field to question the positivistic assumptions of what it means to have autism and how that may impact students in the college setting.

Rather than assuming that the system of postsecondary disability services adequately addresses the needs of all students, I am more inclined to consider perspectives that arise outside of the traditional-medico model. This willingness to work from the margins of the positivist's framework of assessment provides an opening to consider ways in which I may help students that may have otherwise been overlooked. This form of work would also entail a responsibility of retelling counterstories to promote others' awareness of subjugated knowledge and experience (Baszile, 2006; Collins, 2000; He & Ross, 2012; Solorzano & Yosso, 2002). The stories of ASD are a form of counter knowledge that illuminate critical perspectives of the autism construct. These counterstories can be used to disrupt the status quo and support others in considering things from a different perspective. If I want to change the system, perhaps the best way to do this is through sharing counterstories at the grass-roots level. I cannot simply start working from outside the boundaries of my profession, but I can share counterstories with other professionals that may hopefully begin a future movement for change. I can also rely upon the work of other scholars as a reminder that feelings of uneasiness and discomfort are not altogether a bad thing, but rather an indication that I continue to inhabit this unique space from which I am able to see things differently or in new ways (Aoki, 2005; Bhabha, 2007/1994; He, 2010; Saïd, 1994).

As Aoki (2005) describes the zone-between the experiential and planned curriculums, I too must reside within a space-between that satisfies my professional and ethical responsibilities as a practitioner. However, that does not mean that I must blindly follow prescribed rules without question. I am allowed to seek personal and relational understandings of my clients. These are

not achieved through objective measurement, but rather through dialogue, an ethic of care, and a desire to connect with students I evaluate. While I must follow the dominant procedures of my profession, that does not mean that I may not also incorporate tenets of narrative, personal understanding, or a relational tone to those I evaluate. There are multiple ways that I could begin this process, but this begins with a consideration of Samuel's voice. Rather than emphasizing objectivity, a relationally oriented approach would prioritize the voice of Samuel.

**Finding Four: The Traditional-Medico Model Fails to Adequately Promote the Agency of Those Labeled with Disability.**

I hope that this exploration of alternate forms of disability scholarship, which stands in contrast to the traditional-medico model of impairment, can help others begin to question and disrupt the assumptions and connotations of disablement as it is represented in mainstream culture. Such views include the work of social model theorists who separated the idea of disability from that of impairment to portray the disability construct as a form of social oppression. It includes the materialist interpretations of both disability and the rehabilitative structures and programs that have been promoted, with arguably negligible result, in recent decades. These alternate views also include the more recent recognition of how power operates to construct identities, position persons, and reinforce mainstream assumptions of the disability construct. But most importantly, each of these alternate approaches to disability have also highlighted the work that has arisen from within disabled communities to challenge public perceptions and policies that have been placed upon and shaped the lives of persons labelled with disability.

My primary finding after spending considerable time immersed in alternate forms of disability scholarship has been a realization that the traditional model of disability differs from

all other forms of disability studies scholarship by one important factor, which is an acknowledgement for the voice and agency of those identified and labeled as having a disability. Whereas the traditional-medico model prioritizes the voice of the expert, which promotes a view of disablement in terms of otherness and deficiency, all other forms of disability studies scholarship challenge this assumption of otherness by prioritizing the personal voice and agency of people with impairment(s). Rather than blindly following recommendations of professionals who likely act in lock-step fashion with the traditional-rehabilitative model of disability, alternate forms of disability scholarship promote the unique and personal ideals of the very persons who will be most affected by disability decision-making. When an individual is able to express their own personal agency, they take ownership of voice, express their own identity, and are better able to identify goals that are relevant to their own lives. At its core, the traditional model of disability assessment seeks to identify deviance and is not organized as a method in which one sets out to identify unique qualities that are considered to be inherently positive.

If I step back and think about this single difference between the traditional and alternate forms of disability scholarship then I should be able to easily recognize that there is a need to deprioritize any emphasis I may place upon the rigidity and objectivity that is emphasized in my role as a formal evaluator in favor of acknowledging the voice(s) of students like Samuel. First, this acknowledgement of Samuel's agency should make sense to me because my desire to help others is why I chose to work within this profession from the start. It is not a very dramatic shift to remember that there is a need to recognize the wishes of clients. How can I be of help if I am not acknowledging the wishes of those I encounter professionally?

Secondly, such acknowledgement is also outlined in ethical and legal responsibilities of my practice. My first priority should always be to do no harm to those I encounter as a school

psychologist, which necessitates that I grant consideration to the wishes of clients. However, tied up within that determination are the accompanying stipulations that I follow best practices of the field, as endorsed by governing boards, organizations, and state credentialing agencies. What this means, is that there are rules to follow so that I am acting in accordance with ethical and research-based guidelines, and not risking my credentials in the unfortunate event of litigation.

My gut reaction as to whether it is difficult to let Samuel's voice guide my practice, would be a definitive "no." However, such a response is also dependent upon whether Samuel's wishes are achievable by the means I have to work with. For instance, if Samuel were to request the need for some form of accommodation that I could not justify by the principles of psychological assessment, then I may be opening myself up to the surveillance of my professional credentialing agency. I need to be able to justify the decisions and recommendations that I make while maintaining the practices of my field. I need to help students in any way I can, but I also must protect myself while doing so. Truthfully, unless students such as Samuel are requesting something outlandish then it is quite easy to let his voice guide my practice. The dilemma of acknowledging a student's voice only appears in those instances in which requests are without merit.

Even in those instances when a student requests something that is unorthodox or unlikely to be possible, then I can still acknowledge the student's desire and express understanding of the student's situation. Perhaps I could engage in dialogue to educate the student as to why such a request is likely to be unjustified, or I could work with the student to identify alternate ways of addressing the said issue. I can let Samuel's voice guide me, but I also must simultaneously grant consideration to the legal and ethical voice(es) of my profession.



Despite the balancing act I may need to follow when working with students who make requests or express desires that challenge my professional ethics, I should always recognize the importance of connecting with those I encounter. My desire to help is likely my strongest ally in such scenarios. It is only through a relational understanding of the lived experience of autism that I may recognize the true needs of students such as Samuel. Sometimes needs are outright stated by students, and at other times they are observed or estimated. While it is possible that my hands may be tied in those instances when extreme requests of accommodation are made, I am not prohibited in any shape or form in my ability to acknowledge when a student is struggling. In this same vein, I am not limited in the ways in which I may choose to approach understanding of a person's lived experience. Although I may be required to substantiate accommodation requests with data or research-based evidence, there is no such requirement when it comes to relationship building, an ethic of care, or a desire to identify with another. The ability to honor the wishes of a student, whether it is in fact a possibility or not, is not the real issue here. The real objective that guides my practice, one that I am willing to risk my career for, is a recognition for a person's agency. I should never abuse my power and role as an evaluator to mandate services or supports that a student does not wish to receive. Yes, I can encourage the availability of supports that a student may ultimately decide not to use, and it is true that I can't grant all requests, but I can draw a line in the sand when it comes to honoring the wishes and personal agency of clients.

For instance, consider the issues brought up throughout the previous vignettes. While two very different approaches to the assessment scenario were presented, within each of these vignettes we were presented with the story of Samuel. While the regimented and standardized approach of the Chapter 2 vignette did reveal some of Samuel's difficulties, the Chapter 3 vignette is likely to have brought these areas of need into sharper focus. Samuel exhibited

weaknesses in social communication. He misinterpreted idioms and common expressions and behaved in a way that could potentially be misinterpreted as either rude or disinterested. He engaged in some unconventional behaviors and expressed high levels of interest in topics that may be considered unusual. He also demonstrated significant problems with organization and planning, as well as a limited understanding of how services may be different between the secondary and postsecondary learning environments. Acting as the evaluator, I can identify areas of need and make recommendations for services based upon these various understandings of Samuel. I can help students like Samuel to gain access to resources and supports, but I could never require these students to comply with recommended treatments or services. As a more generalized example, let us say that I meet a student who does not appear capable of completing the requirements of a very difficult program of study. Who am I to stop a student from chasing that dream? Yes, I believe it would be my duty to ensure that the student fully understood the difficult road they may have ahead, but I can never force a student's hand in planning their own life. It is only in those rare instances in which students may pose a harm to themselves or others that I may act so decidedly. For the majority of my interactions with college students, my primary objective is merely to help identify ways to provide assistance and to promote their own self-awareness of their personal strengths and weaknesses.

As I have become more aware of the ways in which persons with disability have been historically subjugated and oppressed by technologies of the traditional-medico model, then I have also become more open to consider alternate possibilities and conceptions of the disability construct in my daily practice. The realization that the emphasis of my formal training has the potential to be harmful to others can be a bitter pill to swallow, but once I am able to move past this initial discomfort, it becomes quite easy to admit that I have been conditioned to blindly

accept the traditional-medico model without question. The intentional decision to accept alternate views of disability is a way in which I may exercise my own determination to recognize the voices of people with disability. It is through the conscientious and intentional acceptance and prioritization of the disabled subject's agency and voice that I may offer challenge to the historical mistreatment and continued practices of subjugation that occur within the traditional-medico model.

### **Practical Implications**

As I have begun to unravel new meanings and interpretations for my field of work and my interaction with students in the postsecondary setting, this progress has elicited additional questions about the traditional model of disability services and my place within the academy. This entails considerations for the aforementioned primary findings of this study. I would hope that this may highlight the pervasiveness of positivism within educational discourse and the need for practitioners to grant more consideration for the personal agency and individuality of those encountered during formal assessment. I also hope that this self-study demonstrates that despite the challenges of writing through feelings of in-betweenness and discomfort, when such an endeavor combines the theoretical with the practical, the end result can be of great reward and personal meaning to the researcher. I believe that these are practical implications for others working within my field. However, in addition to providing insight to people without disabilities, it is also possible that this self-study may offer some form of support to the transition of students with autism to the postsecondary setting. In my experience, many students with disability, as well as their families, are unprepared for this transition. Such changes include environmental differences, but also new expectations of independence and personal responsibility. While these differences may be expected to a degree, I continue to be surprised by how few of these

incoming students understand how legislative differences will impact the types of services they may receive. Perhaps this study could provide some cursory explanation of how these services may differ in the college setting. While these implications may be discernable within the review of literature that has been presented in previous chapters, it is also possible that the story of Samuel may have been the most illustrative means of communicating these issues to readers of this dissertation. Whether that is the case or not, I can say without question that the process of constructing these vignettes has been of enormous benefit to my own understanding of these issues.

### **Samuel's Story**

The vignettes presented in chapters two and three hopefully illustrated two very different approaches. Whereas Samuel's voice was muted in the Chapter 2 vignette, his voice was given prominence in the Chapter 3 vignette. When emphasis is given to the positivistic methods of formal assessment, Samuel's agency was overshadowed by the perspectives of evaluators. Decision-making and recommendations were explicitly tied to the results of formal tests and the perceptions of examiners. As positivistic principles guided the decision-making process, the focus was upon the quantification of functional impairments, with attention toward how those weaknesses could then be related to the organization of the DSM, and how those areas of need could be addressed by the existing structures of postsecondary disability services.

In comparison, the progressive vignette of Chapter 3 was envisioned as a wish for how I could have interacted with Samuel if I could fully adopt the contemporary milieu and subject matter of the autism construct without restraint. This fanciful vignette was imagined as a way that I could engage an alternate approach that de-emphasized the role of documentation, formal assessment, and the constraints of fiscal and administrative resources at my disposal. Within the

progressive vignette, Samuel was given access to traditional forms of academic support almost automatically. There was no need to subject him to additional testing because of his history of prior services in K-12. In essence, what he stated he would need was arranged and provided. He was even offered some forms of assistance, by way of interpersonal support and guidance, that he did not request.

While there are aspects of the progressive vignette that I may be able to incorporate into my future praxis, this approach in which formal assessment was completely replaced by an emphasis upon an interactive process of dialogue and relational understanding is not a realistic possibility if I wish to maintain my employment. Given the guidelines by which I am bound to work, I cannot completely absolve myself of the responsibility to engage in formal evaluation (i.e. testing). Furthermore, I envisioned that I was going to be the person who would provide Samuel with ongoing guidance and support throughout the upcoming semester. While it would not be an impossibility that some of these services could be arranged, it is highly unlikely that I would be able to effectively act in this role. The center I work within serves numerous colleges, spanning a large geographic area, and comprised of many students receiving disability accommodations. It would be impractical for me to be the point of contact for Samuel as he begins college. Therefore, I must seek a way to incorporate aspects of the progressive vignette into the daily practice of testing and evaluation that were described in the initial vignette of Chapter 2. Since I can't fully adopt the techniques that I envisioned in the progressive vignette (namely the minimization of testing), then I must ask, what are the things that I could do right now, in this moment? I present this third and final vignette as a potential middle ground that will allow for the recognition of Samuel's voice and agency while also maintaining the ethical standards and required guidelines of formal testing that I must maintain.

### Vignette 3

SAMUEL *comes to the clinic with his PARENTS. SAMUEL participates in the 2-day evaluation process. His PARENTS express concern with the evaluation team, and they are reassured, as before. The overall process of the evaluation remains the same as that in the first vignette because these formal procedures must be completed to satisfy the documentation criteria for services as set forth by the University System of Georgia. While the administration of standardized tests must follow prescribed formats, there are opportunities throughout the evaluation to engage SAMUEL in conversation, to seek a relational connection, and attempt to understand his perspective. Such conversations could occur between the administration of tests or during rest breaks. Such a conversation could proceed as follows.*

#### Scene one.

DANIEL: Okay Samuel, that is the end of the test (*shuffling papers and rearranging test materials*). We do have one more activity to complete before your lunchbreak.

SAMUEL: Okay, what time is it?

DANIEL: It is 11:00.

SAMUEL: Yeah, (*seemingly uncomfortable*) I'm supposed to eat lunch at 12:00.

DANIEL: You should be able to take your lunch at 12. If it gets too close, we can just stop where we are at. Do you like to keep a schedule? I've noticed that you seem occupied with concepts of time and scheduling....

SAMUEL: What do you mean?

DANIEL: Like how you have an interest in clocks, and how you seem uncomfortable if scheduled activities get messed up.

SAMUEL: Yeah, I usually have a schedule that I follow. It helps me to get all of my work done

and I feel more comfortable when I know what to expect and when I have a plan.

DANIEL: I understand that. That makes sense. How do you make your schedule?

SAMUEL: Well my homeroom teacher, Ms. Smith, helps me. My parents also help. Ms. Smith makes sure that I have the stuff I need at school and my parents help at home. They work together to create daily schedules.

DANIEL: I think everybody can benefit from a schedule. How are you feeling about coming to college and losing that type of help from your parents and Ms. Smith?

SAMUEL: Really, I'm nervous and also excited. I know I do better with a schedule, and I know I need to use one, but I am not sure if I am going to be able to keep up with stuff as good when it's all up to me. This is going to sound bad, but...I'm used to having them made for me.

DANIEL: Like anything, it's something that you will get better at with practice. Have you ever tried making the schedules yourself?

SAMUEL: Well, no...not really. I'm pretty sure I can do it. I've just never really had to do it myself before because my parents were always right there.

DANIEL: That is probably going to be one of the most important things you can work on from the start. I have some resources I can email you that might be of help. Perhaps you should start practicing with a weekly planner before the semester starts? You could write down your schedule of activities and practice the planning aspect of your week for the rest of the summer. How does that sound?

SAMUEL: It sounds just like everything else you've said (*straightforwardly*). It's the same...it's your voice.

DANIEL: (*realizing the miscommunication and SAMUEL's literal interpretation of the idiom*)

I'm sorry, what I should have asked was... *(pausing briefly)* do you believe that practicing with a daily planner before the start of classes will be beneficial?

SAMUEL: Oh, yea...it probably would help.

DANIEL: Okay. I encourage you to try it out for the rest of the semester. I am also going to contact the service provider at your school, the person who is going to help you on campus and let her know that you may need some extra assistance with creating a schedule for the first few weeks. She will not make your schedule for you but will be there to help you figure out the important assignments and stuff.

SAMUEL: Okay. *(unemotionally)*

DANIEL: I know that your parents are concerned about your skills in organization and they may be worried that you could miss assignments. I will also talk with them to let them know about our plan.

SAMUEL: Alright.

DANIEL: Okay then, lets get back started on this next activity. We should be able to finish it up in time for you to go to lunch.

*(Shuffles test materials and readies to begin the next section of formal assessment tasks.)*

*SAMUEL completes the remaining activity quickly and efficiently. His PARENTS are waiting for him in the lobby when he leaves the test booth. He then leaves the building to eat lunch.)*

### **Scene two.**

*(SAMUEL returns to the assessment clinic one hour later and re-joins DANIEL in the testing booth. DANIEL once again takes the opportunity to interact with SAMUEL informally, before the standardized testing resumes.)*

DANIEL: Welcome back. How was your lunch?



SAMUEL: Good. *(Looking down/away)*

DANIEL: *(Attempting to elicit spontaneous conversation)* Did you go somewhere with your parents?

SAMUEL: Yeah.

DANIEL: Okay, where did you go? There are lots of choices nearby.

SAMUEL: *(now making eye contact)*. Yeah, too many. I wanted chicken though.

*(DANIEL pauses as if to provide Samuel time to complete his statement. However, it seems that SAMUEL was finished with his response. He sat idle, as if DANIEL would have understood the implications of his wanting chicken.)*

DANIEL: *(with almost a knee-jerk response)*. Oh, well uh...were you able to get chicken?

SAMUEL: yeah.

DANIEL: I'm guessing that you must have had either Wendy's or KFC then...

SAMUEL: I had Wendy's.

DANIEL: Okay *(with more enthusiasm in an attempt to encourage SAMUEL's interaction)*

I really like Wendy...

SAMUEL: *(Interrupting.)* Can we get back started. I want to get finished with today's stuff. I don't want to get behind.

DANIEL: *(quickly shifting back into a mode of formality)* Yes, of course! Let's get started.

*(DANIEL and SAMUEL complete the next section of testing activities with very little extraneous dialogue. SAMUEL's interactions are restricted, matter-of-factly, and succinct. He expresses no desire to engage in small-talk. His performance on the subsequent measures is very strong, but DANIEL can't help but to notice his own discomfort as he has difficulty engaging SAMUEL in relational small-talk for the rest of the afternoon.)*

*(At the conclusion of the afternoon's testing, DANIEL escorts SAMUEL back to the lobby area to meet his parents. Despite his best efforts to get to know SAMUEL better through informal dialogue, SAMUEL expressed little interest in talking about himself. DANIEL concludes after this encounter that SAMUEL may benefit from some additional assistance with social interactions. DANIEL makes a note of this observation, which may be incorporated into the psychological report. DANIEL also makes a plan to inform the Service Provider at SAMUEL's school of this potential area of weakness in addition to a potential need for organizational assistance.)*

### **Analysis of Vignette**

Within this reconceptualized interaction with Samuel, I still did all of the things I am expected to do by following the positivistic traditions of a formal assessment. However, I also moved beyond the objective data to try and get to know Samuel better. In doing so, I recognized areas of need that Samuel could potentially use some help with. While I would not force Samuel to utilize my recommendations for obtaining help with his organizational weaknesses or the development of his social functioning, I could help him to obtain these supports if he wished. I could encourage their availability. That way I am attempting to understand the relational experience of Samuel, listening to his voice, and also moving beyond the standardization of an objective evaluation.

Within the Chapter 3 vignette, I envisioned a situation in which I would be the primary contact for Samuel as he matriculated through coursework. I would be there to help Samuel when he encountered obstacles. In reality, Samuel's primary advocate would need to be a professional at his school, possibly the disability services professional who arranges the implementation of traditional academic supports for his classes. The logistics of acting in the

capacity of personal advocate or advisor for every student I meet who has been diagnosed with autism are far too great. I am too busy fulfilling my current obligations as an evaluator to take on the additional responsibilities of acting as Samuel's primary source of support in his daily campus interactions and activities. What I could potentially do is provide assistance to the disability service provider who would be interacting with Samuel on his campus. This could be achieved in multiple ways, such as the provision of additional training opportunities to disability service professionals, acting administratively to set up programs to be implemented by others, or simply communicating more openly with service providers so that they may be better informed about the functional needs of students with autism.

This process of incorporating alternate forms of support to students such a Samuel would begin with the assessment process itself. I must use formal assessment, those activities that are founded in positivistic ideals of objectivity, measurement, and prediction, that stipulation will not and cannot change. However, this does not mean that I could not also consciously grant more consideration to the voice of Samuel during this process. What I mean by this, is that I will continue to use formal assessment techniques but can simultaneously pay more attention to the subjective components of my interactions with Samuel to better understand his wishes and concerns. As I interpret test results and data, keeping Samuel's voice in mind would serve as a way to ensure that his personal needs do not become overshadowed by the objectivity and depersonalizing aspects of formal assessment. In the same sense, as I contemplate appropriate forms of services for Samuel, my subjective and relational understandings of his real needs would be more likely to be met.

A second way that I may encourage Samuel's voice to shine through the assessment encounter would be to change the way in which I write up the results of psychological reports.

Currently, these reports are written with a formal tone, third-person language, and objectivity. There is an emphasis upon actual test data, rather than how data support observations and interactions with the students. By taking a more client-centered approach to report writing, I could decrease the emphasis that is placed upon test scores. I could frame results within a greater context of the individual's overall functioning as well as those needs that are communicated during informal and relationally minded interactions. When the product of a formal assessment, the written report, adheres to a positivistic writing method that deemphasizes the personal, then this only promotes a continuation of standardized responses and traditional strategies of support. Furthermore, such a report writing style would grant power to the student, as opposed to other professionals, because the report would be envisioned as serving the student as primary audience. Rather than the use of formal language and technical jargon, the narrative of a report could be written in plain language. Findings from an evaluation could be better explained by attempting to link test data and results to practical implications to the student. In other words, what these results may mean for the student's daily academic and social life. While I already provide recommendations to students, these could also be more tailored to individual needs and operate to introduce potential tips and strategies that were derived as a result of the assessment. In short, my knowledge base and understanding of assessment can still serve the student but the assessment report should be written in such a way as to make it meaningful and accessible for the actual persons who are discussed in these reports. If approaching the assessment process more relationally, the traditionally objective, standardized, and technical reports that are created to communicate assessment findings are to be viewed unfavorably.

### **Examples of daily practice in the present**

My findings have meaning to my current daily practice. I began this project with a recognition that students with ASD may not be receiving the necessary supports for college success. These assumptions were based solely upon prior experiences as I have witnessed students continue to struggle academically and socially even though they participated in a formal assessment and received academic accommodations after receiving a diagnosis. The types of disability supports are limited to what amounts to a standard list of accommodations. As previously mentioned in Chapter 2, federal regulations only mandate equal access to the postsecondary educational setting and do not guarantee services to ensure the success of students with disabilities. Therefore, students entering the college setting may not be afforded the same levels of support that they may have received in K-12. The decision to provide services beyond the legal requirements is up to individual institutions; however, such determinations are often times driven by financial resources and administrative objectives. All institutions must comply with the minimal requirements set forth by federal law, but these minimal requirements most often result in the deployment of standardized accommodations that fail to address the specific needs of some students. This tendency to act in a standardized fashion limits consideration to the unique needs of students with ASD.

Returning to the story of Samuel, he often performed well in the classroom, and although he did at times benefit from the use of extended time—a commonly arranged support for college students—he was also likely to struggle with other aspects of the college experience. Samuel's weaknesses in social awareness, limited independent living skills, and poor organization would be unlikely to be addressed by the standardized forms of accommodation that are typically provided to other students with disability. Samuel really needed other forms of assistance. He

needed individualized support to meet his unique needs, many of which may not be realized until specific situations were to arise. The accommodation of these needs would not be burdensome or expensive necessarily, but they would be different. However, it is only through a willingness to look beyond formal assessment data and to seek a fuller understanding of Samuel's academic experiences that one would be more able to identify methods to address his real needs.

### **Relating critical perspectives to daily practice**

The fact remains that the traditional supports that are typically offered to postsecondary students with disability have the potential to not accommodate the functional needs of students with autism. These classroom accommodations such as extended time, notetaking assistance, or technology are only applicable to classroom spaces. Although these forms of accommodations may meet the needs of most students with disability, and they can be helpful to students with ASD, these forms of support were not conceptualized with the autism experience in mind. Yes, they may be easy to implement with the service structures that are already in place, but ease of implementation should not be the primary consideration when determining appropriate services. My readings of firsthand accounts of autism have made these prior assumptions clearer.

I can even relate examples of my practice to some of the accounts that were provided through my readings. For example, in Dawn Prince-Hughes's (2002) collection of stories, I discovered a few recognizable scenarios. In Chapter 3, I discussed at length my identification with the story of Chris, who had difficulty finding a job after graduation. In short, he appeared disillusioned and seemed to feel that he had been taken advantage of because even though he had been a good student, no one prepared him for the obstacles he would face after leaving the university. Chris would have likely benefitted from assistance with his social functioning. Although he did obtain a degree, this training had not adequately prepared him for the job

market. While Chris's story resulted in my strongest reaction, I also found other stories within *Aquamarine blue 5* to be relatable to students I have known.

Within the account of Michelle, we learned of a girl with ASD who had been targeted by peers and administrators because of her peculiar eating habits. Michelle was suspected of having an eating disorder when she had actually just been sensitive to particular types of food.

Michelle's story was personally relevant to me, because it reminded me of a student I encountered in my practice. This student had recently dropped 20 pounds of weight in a single semester because she had avoided eating in her school's cafeteria. The student did not have the same sensitivities to food as Michelle, but she found the cafeteria to be overstimulating. The noise of the bustling cafeteria was simply more than this student could manage. So instead of finding an alternate way to obtain her meals, she just went without. Had someone been aware of this issue, the student's situation could have been easily addressed. However, she did not have any friends or a system of support to recognize the issue that was occurring. Certainly, there were other options for the student to obtain her meals, but she failed to recognize these on her own.

The stories of both Jim and Darius were similar to some students I have seen in the clinic. Since I work with college students, I do encounter persons who have either not been previously diagnosed or may not have been aware of a previous diagnosis. Some students seek evaluation because they sense they are different from others, or they want to understand why they have difficulty with activities that seem so easy for others. In most instances these scenarios play out with the student gaining better understanding or awareness, which then seems to offer relief because they finally have an explanation for how they have felt different. Many of these students seem to be grateful because they no longer feel to be broken. The act of offering a label in these

instances seems to be more liberating than hurtful because the students often obtain a better understanding of their past experiences and begin to move toward the development of a more positive self-identity.

I have also found myself seeking to help students such as Douglass and Susan find a career path in which they may experience joy and success. Likewise, I have attempted to help students with ASD to consider why certain career paths may not be a great fit given their areas of weakness. The point I wish to make here, is that the stories within *Aquamarine blue 5* are not uncommon. These are issues that most college students may face at some time. While the clinical component of my work will not cease, I must recognize that it is only through relationship building and a concern for the personal stories of others that I will recognize when students need assistance in areas that do not fit the mold of traditional academic accommodations.

### **Where I Want to Go**

#### **Viewing assessment tools differently**

Beyond the experience of working with Samuel, this self-study has influenced other aspects of my daily practice. The simple act of taking a step back to consider the philosophical foundations of psychological assessment has served as a reminder to interpret test data more cautiously. These formal measures are already well understood to be imperfect tools of measurement amongst practitioners of the field, but I now feel more at ease when questioning these instruments. While normative measurement and objectivity remain gold standards of diagnostic decision-making, I have greater confidence to move beyond these forms of data in an attempt to better understand the persons I encounter professionally.

I will never be able to stop the use of these assessment tools completely, but I hope that I may gain greater confidence in my abilities to engage with students relationally, to be more



present as a caring person, and to view the overall assessment process as an ongoing dialogue for understanding. By altering my thinking about assessment, the statistical representations and scores derived from normative measures are no longer viewed as the defining features of time spent with a student but may be perceived as components of the greater interactive process that occurs during an assessment. The test data serves to support assertions, but not to make them.

I have become more aware of the tendency I have had to view formal assessment tools as the foundation of assessment. I no longer see that to be the case. Recently, while writing this chapter, I worked with a student for whom English was not a native language. As the clinical team prepared to evaluate this student, we engaged in long conversations about potential test validity since this student's educational history and prior experiences were assumed to fall outside of the normative samplings of our test battery. Aside from the obvious continuation of positivistic ideals from which this conversation started, this energetic discussion morphed into broader philosophical discussions of assessment. For instance, we began contemplating the roles of language as a representation of knowledge. We discussed the degree to which potential cultural differences or prior educational experiences would invalidate our assessment measures, and we delved into the roles of cultural experience in shaping personal values and aspirations. Throughout this discussion, all participants seemed invigorated and open to considerations of new ideas. It was at this point that I realized that the unspoken theme of our dialogue was really about the positivistic foundation of assessment rather than the logistics of working with this particular student. At that moment I was aware that these forms of questioning and inquiry are rare occurrences in my daily practice. We were excited and lively in our debate because this line of thinking was somehow novel to our typical work. I was then left to wonder, why are these modes of thinking not always present?

### **Critical Disability Studies and Alternate Understandings**

One of the greatest things I have learned through this research process has been the depth and breadth of alternate perspectives of the disability construct. The entire disability studies field, in its many permeations, provides a different way to conceptualize the knowledges of the traditional-medico-rehabilitation model of disability. These understandings are often times in direct contention with the knowledge base of my prior training. Whereas the assumptions of positivism are certainly a major aspect of these differences, there are also other frameworks, histories, and worldviews that shape divergent interpretations of bodily difference. When I think about my daily practice in comparison to these newfound understandings of the disability studies framework, I am more aware of how I inhabit the scientific-medico model. Nearly every aspect of my daily practice may be viewed negatively from the disability studies framework.

Unfortunately, this assertion holds true whether one ascribes to nearly any variation of disability studies work. For example, from the perspective of traditional Marxism/historical materialism, I must ask whether my provision of services constitutes a commodity in which capital is transferred for a rendered product? Is the knowledge base of my field not commodified through recommended treatment practices or forms of support? Furthermore, aspects of historical materialism as well as the work of Foucault may also be seen in the identification and labeling of deviance as an extension of surveillance or control to manage the productive capacities of the larger economic operations of a society. The normalizing technologies of assessment and tracking of individuals is also a concern.

A common theme to many iterations of contemporary disability studies is to consider the power operations at play in the traditional model of disability services. The role of the examiner as expert represents one aspect of this power differential, but the use of a medicalized discourse

further objectifies the individual—it takes away the humanity of those it describes, and it depersonalizes the entire interactive of disability assessment. When the primary objective of psychological assessment is to identify deviance, this incorrectly shifts attention toward deficiency and aberrance as opposed to difference and individuality. The emphasis upon identifying and describing the things that a person can't do is flawed. Whether intentional or not, this approach to assessment emphasizes normalcy and limits the appreciation of individuality. Standards of human behavior do not encourage individuality but rather condemn those who do not fit into the preconceived mold of normality.

I have learned that the scientific-medico model of disability is so pervasive that nearly all popular media portrayals of disability are framed within a model of deficiency and aberrance. The popular media portrayals of ASD perhaps best characterize this dominance of the scientific-medico model, as most depictions of ASD promote conceptions of abnormality, deviance, plight, and a need for correction. I actually experienced a fair amount of difficulty while conducting my research to even find portrayals of ASD that were not inspired by the scientific-medico model of disability. I do recognize that perhaps some of my difficulty in finding alternate representations of ASD may have been due to my prior training and research experiences, but I would also argue that it is also in part due to the sheer volume of cultural artifacts that emphasize aberrance, deficiency, and a need for treatment. As McGuire (2016) illustrates, many popular media representations convey ASD as a phenomenon to be feared, attacked, battled, treated, and combated. From this perspective, the ramifications of not seeking treatment of ASD seem to be catastrophic.

As I have explored alternate conceptions of the ASD construct, I have become more aware of ways the traditional-medico model of disability prioritizes the voice of the practitioner

over that of the individual. Alternate understandings of disablement recognize this disparity and grant prominence to the voices of those with disability. The traditional model and neurotypical perspectives silence the voice of the autistic individual. All too commonly, experts speak on behalf of the person with disability. The various personal accounts of ASD I have reviewed demonstrate the problems of assuming the needs of persons with ASD. Each of these accounts illustrate that despite their carrying of the ASD label, each person experiences very different problems. They encounter different barriers to access and success. These individuals are just like the rest of society. They have unique aspirations, desires, and goals. They are confronted with both unique and common obstacles, with associated responses that are also individually specific.

I want to be careful not to emphasize a dualism here, but we can generally construct two frameworks between the implications of my prior training within the traditional model and that of the expanded understandings of disability as promoted within disability studies. Whereas the traditional model of disability emphasizes the expertise and sovereign power of the practitioner to identify, define, and speak on behalf of the disabled subject, a critical disability perspective recognizes the othering of the disabled identity and redirects the power of the medical expert to the personal agency of the disabled subject.

When experts speak on behalf of the ASD person, the personal agency of these individuals is silenced and portrayed through lenses of the neurotypical perspective. The traditional-medico model, in its attempt to provide treatment, defines disability as deviance. That difference is automatically assumed to be socially undesirable, hence the need for treatment and correction. As opposed to the traditional-medico conception of disability, alternate perspectives of disability celebrate difference as a source of pride and appreciation. As such, the voice of the disabled subject is prioritized. The role of the expert is decreased and the individual with a

disability is afforded more freedom to express their own needs and values. When lived experiences are communicated in more relational terms, the disabled subject is less objectified. The relational depictions of disability do not adopt the positivistic language of the traditional-medico model, further humanizing these conditions of difference.

Common themes emerging from Critical Disability Studies and autobiographical accounts of disabled persons suggest a reclaiming of personal agency to demonstrate pride, personal expression, a valued identity, and the celebration of difference. Such personal expressions grant value to bodily difference and present conditions of experience in ways that are positive rather than negative. Instead of being presented as flaws or shortcomings as in the traditional model of rehabilitation, these alternate ways of perceiving difference are celebrated.

My investigation of critical autism studies suggests that a more relational understanding of the autism construct leads one not to focus upon symptom related functional impairments but rather to engage in an interactive process in which the individual communicates their own needs. The impersonal formal assessment process does not provide such opportunity to better understand the holistic person, it only emphasizes these differences in behavior and/or ability that differentiate the person from a standard of normalcy. The critical perspective also seems to be more about needs that arise outside of the classroom space than specific classroom scenarios. This leads to the likelihood that supports may be more individually tailored to each specific individual.

### **Moving forward**

The findings of this study may be used in my future practice to better serve students with autism in the college setting. Through this research I have learned how much of my prior educational experiences have been shaped by positivism. Whereas I may envision myself as

thinking in different terms, my daily practice only reinforces the tenets of positivism. When left unexamined, this positivistic leaning does impact my ability to identify, understand, and acknowledge the lived experience of persons with autism. Most importantly, an overreliance upon positivism has the potential to limit my ability to recognize individuality. The alternate epistemologies and situated knowledges revealed through readings of critical autism perspectives clearly demonstrates that a more relational approach is needed. Objectivity is not the answer. Within the traditional model of assessment and disability services, standardized assessments and uniform forms of accommodation are likely to fail in meeting the unique needs of students with ASD. When delivery of services follows a prescribed homogeneity, then it becomes more likely that students with uncommon needs may not receive appropriate supports for their learning.

In Chapter 3, I was critical of the book *Educating college students with autism spectrum disorders* which was published in conjunction with the Autism Speaks organization (Zager et al., 2013) because of its adherence to the scientific-medico-positivist framework, which I argued served to perpetuate the treatment-cure approach of the traditional model of disability services. However, despite this caveat, the procedures outlined in this text do hold promise because they move beyond the standardized way that postsecondary disability services are typically deployed. Primarily, I viewed the concerted effort of multiple professionals, advisors, and instructors as perhaps a better way to address the real needs of students with ASD. Rather than simply setting up academic supports and never meeting with or checking in on the student, this method involved frequent interactions, planning, revision of supports, and proactive problem solving.

The ongoing dialogue between the student and the support team ensured that the student was granted a voice. As new needs developed, the team of practitioners was able to work with each student to develop new plans of solution. I do believe this would be a more appropriate way

to provide postsecondary disability services to students, such as those with ASD, who require additional assistance beyond the traditional supports that are typically provided to students with disabilities. Given that the approach has been conceptualized and promoted from within the traditional structures of the disability-rehabilitation model and endorsed by a prominent organization (e.g., Autism Speaks), this form of approval may provide a sense of legitimacy to those who blindly follow the authority of the traditional-deficit based approach. I have to reiterate that the scientific jargon and objectification that I identified within this book would be an issue to address, and the adoption of such a methodology would need to emphasize student centeredness and the voice of the student as opposed to a domination by the perspectives of the practitioners involved, but the approach may be a way to move forward and alter the landscape of college services for students with autism.

Whereas I began this project feeling that my position was hopeless, I now see that my position in-between paradigms of knowledge may be of benefit. As I move between forms of knowledge and understanding of ASD, I recognize that I may have a unique agency to affect changes. Given that many of these problems are systemic, my position as a practitioner within the dominant perspective of disability may grant opportunity to cultivate situated knowledges and approaches that may otherwise be discarded if proposed from outsiders to the field. My position as a professional may offer legitimacy to arguments for change. I now envision my hybridized location not as someone who has been left out, or someone who is striving to regain his sense of self, but as a position of opportunity in which I may disrupt or offer challenge to the dominant socio-cultural assumptions of the ASD construct.

Through this study, I have learned that this disruption must be internal as well as external. I have written in detail about the incompleteness of my critical reflective journey, as I

have sought a more comfortable position between my roles and personal identities as a school psychologist and an emerging curriculum studies scholar. While much of my focus through this writing has been toward an inward examination of myself, I now must apply these epistemic transformations outward and to my interactions with others. In this sense, the work of this project remains incomplete. During my final defense of this dissertation, I was confronted with the lived reality of this incompleteness. When members of my committee posed questions to me about disabled futures, the privileging of verbal versus nonverbal communication in my dissertation, and ways that disabled bodies (and particularly the bodies of disabled psychologists) could challenge notions of disability within the discipline of school psychology, I admittedly had no answers, only additional questions. Such examinations of my own perceptions of possibility for students with significant disablement were mostly left unexamined in this dissertation. If I honestly examine this exclusion, then I am also confronted with a need to question my own relationship with disability. As I do not identify as being disabled, then a host of other questions are also formulated. What does it mean for a normative body to assume understanding of a disabled subject? How can such an understanding be assumed to be realistic? Do I hold unconscious assumptions of those I see in a clinical relationship?

First, I must recognize that throughout this project I have enjoyed a privileged position that has been made possible through language and verbal expression. As I have been able to not only communicate my ideas through writing, I have also been able to interact with my committee members without restraint. When speaking with others, I have not been confronted with the need to prove that my thoughts or experiences were truthful, trustworthy, or even my own. This issue, while seemingly unrelated at first, does have implications for the ways in which I interact with others who may experience communication difficulties. Our society does privilege the oral word



over other forms of communication and interaction. When individuals do not communicate verbally, whether by choice or impairment, questions of competency or validity of experience may arise. In their edited book *Typed words, loud voices*, Amy Sequenzia and Elizabeth Grace explore these very issues. The collection of essays challenge this assumed hierarchy of verbal speech as being greater than other forms of communication. Sequenzia and Grace (2015) encourage their readers to resist the trap of assuming that those who utilize technology or engage in alternate forms of communication behavior are without value or independent thought processes. This recognition for the value of alternate communication forms will need to be kept in mind as I move forward in my interactions with autistic individuals who may not exhibit the same types of oral language behaviors that I may take for granted.

If I really take the time to think about my own relationship with the autism construct, then the majority of examples I could provide reside within the practitioner-client relationship. One in which I am acting not from a position of true understanding but rather from a position of clinical interaction, which entails, to some degree, an amount of objectification, ordering, and identification of difference. When I sit and think about my personal relationship to the autism construct, then I am forced to admit that I actually hold a degree of fear, and dare I say, guilt—for feeling relieved to not have the same experience of those I encounter professionally. I certainly recall the fear that I held for the prospect of my daughter having autism when she was first born. Aside from physical deformity upon birth, (yes, I did count those fingers and toes) I was keenly aware of her behaviors during the first months of her life as I watched intently to see whether she focused upon people's faces or responded to environmental stimuli in ways that I deemed to be "appropriate." I can also admit that I feel sadness for persons who, for no understandable reason, are faced with obstacles in the everyday activities of life that most people

will take for granted. Given the tendency that most people have to avoid thinking about their own mortality, I think that we as humans are hesitant to deeply consider the uncomfortable possibility of one day no longer being able to live with independence and the full range of our current aptitudes and abilities. As such a proposition is uncomfortable, we tend to overlook the prospect of disabled futures. Samuel, the subject of my vignettes, has a future. As does every other person we encounter in our daily lives. The difficulty of envisioning a future for other persons who have disabling conditions is complicated, at least in my opinion, by a fear of personal tragedy. We avoid such considerations because it is too easy to move into thinking patterns that involve ourselves. It is simply safer to avoid the thought experiment altogether than to risk devolving into considerations of one's own vitality. The issue of guilt comes into play when feelings of thankfulness emerge after considering what it may be like to have a disabling condition. When thinking, "I am glad that did not happen to me," I would imagine that a sense of guilt may soon follow. This has been my experience at least. This relationship with disability, once I turn the tables back onto myself, are complicated.

### **Significance of the Study**

This effort to embrace the disciplinary in-betweenness I have experienced as a student of curriculum theory has importance to the project of curriculum studies and the broader field of education because these issues of contemporary educational practice, namely the organization of the disability construct and an overreliance upon the positivistic approach to instruction, will continue to be important topics of curriculum theorizing.

This project holds significance for the field of curriculum studies because it illustrates the potential effects that arise from the compartmentalization of knowledge that is all too frequent an occurrence in traditional educative practice. Whether intentional or not, a strict adherence to

sanctioned philosophical and methodological teaching practices tends to construct a limited view of the world. If it were not for my sudden awakening, promoted through a pedagogy that moved beyond the standardized curriculum practices of my previous experiences, I may not have realized how such arrangements serve to organize and position some forms of knowledge above others. The ways in which students with disability, and specifically those with autism, are conceptualized and positioned into a location of difference, should clearly illustrate the consequences of such a limited philosophical focus.

My attempt to find a comfortable position in-between paradigms of knowledge contributes to the existing body of literature and the work of other scholars who have engaged in this process before me. In addition, through my use of a metaphorical application of the curriculum commonplaces and the concept of *currere*, I have demonstrated ways in which previous developments of the curriculum studies field continue to be applicable for understanding contemporary educational issues. Furthermore, my recognition of both formal and informal learning experiences as presented within this dissertation contribute to the longstanding recognition that learning does, in fact, occur outside of formal educational structures and procedures. In this respect, I believe that my work further positions the role of cultural studies and other nontraditional disciplines to the forefront of curriculum theorizing as the field collectively seeks to consider alternate conceptions of educational practice.

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