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Neurodiversity in the Classroom: Pilot of a Training Resource for Teachers Educating Autistic Inclusion Students in a General Education Setting

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NEURODIVERSITY IN THE CLASSROOM:
PILOT OF A TRAINING RESOURCE FOR TEACHERS EDUCATING AUTISTIC INCLUSION STUDENTS IN A GENERAL EDUCATION SETTING

A Dissertation

Presented to the Faculty of
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Doctor of Psychology

By

Ariel Detzer

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NEURODIVERSITY IN THE CLASSROOM:

PILOT OF A TRAINING RESOURCE FOR TEACHERS EDUCATING AUTISTIC INCLUSION STUDENTS IN A GENERAL EDUCATION SETTING

This dissertation, by Ariel Detzer, has been approved by the committee members signed below who recommend that it be accepted by the faculty of the Antioch University Seattle at Seattle, WA in partial fulfillment of requirements for the degree of

DOCTOR OF PSYCHOLOGY

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Jane Harmon-Jacobs, PhD
Chairperson

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Steve Curtis, PhD

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Carrie Snow, PhD

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Date

ABSTRACT

NEURUODIVERSITY IN THE CLASSROOM:

PILOT OF A TRAINING RESOURCE FOR TEACHERS EDUCATING AUTISTIC INCLUSION STUDENTS IN A GENERAL EDUCATION SETTING

Ariel Detzer
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Autism spectrum disorder (ASD) is one of the most common neurodevelopmental differences in the United States, with estimates of prevalence as high as 1 in 68 (Centers for Disease Control and Prevention [CDC], 2016). Over recent decades, two trends have converged to bring autism to the fore as a challenge facing public education. First, changes in the conceptualization of autism have led to greater diagnostic capture of autistic individuals, and second, changes in special education practice regarding inclusion (emphasizing placement in Least Restrictive Environment) have increased the number of autistic students in mainstream classrooms. Meanwhile, autism research has largely been driven by a DSM definition based the behavioral and social deficits rather than the cognitive and sensory traits of autism. The legacy of this social functioning deficit lens is a lopsided emphasis in available educational interventions. A review of available educator resources online indicates that the majority of educational support has been developed to meet the *behavioral* challenges of autistic inclusion students, while differences in autistic ways of *perceiving*, *thinking, and learning* have gone largely unacknowledged and unsupported by standard available educational approaches. This Action Research project gathered input from a group of educators via a mixed methods approach (Likert-type survey and focus group) on their experiences and needs regarding effective support of autistic inclusion students. Drawing on educator input, author experience in the schools, and current psychological literature on autistic learning differences, a teacher training resource that emphasized greater support for autistic learning differences with awareness of sensory experiences and autistic cognition was developed. This dissertation is available in open access at AURA: Antioch University Repository and Archive, http://aura.antioch.edu/ and OhioLINK ETD Center, https://etd.ohiolink.edu

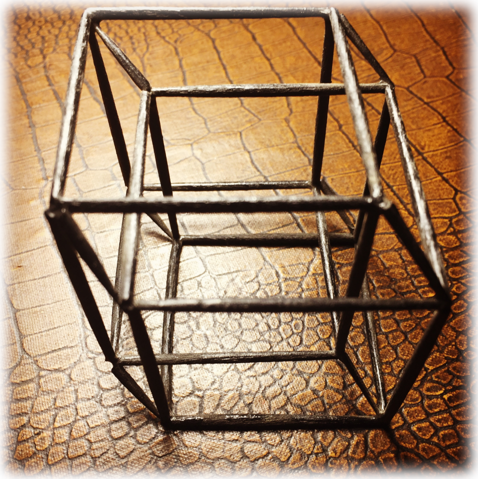
Keywords: autism, neurodiversity, pervasive developmental disorders, special education

Dedication

to my son Avi, whose sixth-grade research project became this dissertation

and also in memory of my father, his biggest fan

Eric Halsey (1945–2017)



Acknowledgements

Like all big projects, many people made this dissertation possible. First I would like to acknowledge the innovative program at Antioch University for providing the context of a scientist-practitioner approach that can support a somewhat unorthodox approach to a dissertation project such as action research. I would like to thank my first advisor Dr. Liang Tien for starting me on the path of qualitative research grounded in one's own community, and teaching me the importance of scrupulous attention to ethical practice. I would like to acknowledge the opportunities I had at my various internship sites, especially the Children's Institute for Learning Differences and the Northwest Neuropsychology Clinic for the opportunity to work with such a wide variety of young people. I would like to thank Dr. Fay, my internship supervisor, for her modeling of strong advocacy for young people with neurodevelopmental differences, and for the chance to get to get fluent with so many different psychometric instruments. I would like to thank Dr. Patricia Linn, who taught my first class in statistics, and who suggested the use of the pre- then post-test all-in-one measure.

I would like to thank my dissertation committee for their well-coordinate work—our meetings were always a pleasure and a learning experience—and for their suggestions on how to bridge between the demands of a community based action research project and the academic demands of a dissertation. I would especially like to thank Dr. Steve Curtis for his quietly reflective practice during the supervision walks we took during my work at CHILD institute, as well as his openness to identity-first language. I would like to thank Dr. Carrie Snow for her outside perspective from the field of education—I found her contributions from her experiences as a teacher to resonate very much with my own earlier teaching experiences and I really appreciated the sense of practical real-world knowledge that she brought to the committee, as well as her encouragement to take training materials developed in this dissertation to the next level. Finally, I want to thank Dr. Jane Harmon-Jacobs, who stepped up to chair this dissertation at time when she already had a great deal on her plate. Several aspects of her professional experience (too many to iterate here) made her the ideal chair, but what really needs acknowledgement more than any of her qualifications was her exceedingly kind patience and encouragement through a process with many setbacks. Years from now, when all the technical obstacles and frustrations have long faded from view, what I will always remember about Dr. Harmon-Jacobs is her profound kindness and faith in me at a time when that was more important than anything else. Finally, I would like to thank my advisor for my very last years at Antioch, Dr. Dana Waters, who encouraged me with great enthusiasm through the final stages of the dissertation process.

Last, and most of all, I would like to thank the members of my family who saw my start out on this dissertation process, and accompanied me through the various stages to the final pages of this particular chapter. I'd first like to thank my mom who began my interest in psychology when I was maybe six, when she read me *TA for Tots* (a book that introduced Transactional Analysis in appropriate language for kids) and got our family involved in the co-counseling movement. She and my step-dad, and my dad and step-mom have always been great supports for my kids and me as I've faced the challenges of graduate school. My father, Eric Halsey has been an especially strong supporter of my son Avi. With their mutual love of esoteric logic problems, museums, and science fiction, they shared a unique perspective on the world and a very meaningful closeness. My father died unexpectedly in the very final stages of the editing process of this dissertation, and it is one of my greatest regrets that he was waiting until the final public posting to look at it, and thus never got a chance to read it. As a mathematician, he would have enjoyed the statistics, and as a quirky and divergent thinker, I think he would have identified with the sense of seeing the world in unique and original ways.

It is the members of my immediate family who have provided the most support over the decade of this endeavor. I'd like to thank my ex-husband Martin Caspe, who, back in 2007, originally suggested that I return to graduate school. I appreciate his support for my career even at a time that our lives were splitting off in different directions. I'd like to thank my son Jacob Caspe, who basically has grown up with the reality of a mom in school as long as he can remember, and is starting out on his own university adventure just as I graduate. Jacob served as my official research assistant for the focus group qualitative research, running the recording equipment and tracking the order of the speakers by two-letter code. I'd like to give a huge thank you to my younger son Avi Caspe, without whom this dissertation, and indeed my whole career-focus as a child psychologist, would never have come to be. Avi's sixth grade project is the seed which eventually became this project. Avi helped create a presentation on autistic experience which we presented jointly at the Association for Autistic Community Conference in Pennsylvania in 2014. I included parts of that presentation as part of the teacher training tested in this dissertation, and in feedback I received from teachers, learned that his firsthand experiences were some of the most powerful material I shared. Avi also consented to have his story be included as an appendix in this dissertation write up. In all of these ways, Avi's developmental process and experience as a self-aware and developing autistic young person contributed directly and materially to this dissertation, and has very significantly shaped me into who I am as a psychologist.

My last thank you goes to my dear partner Erica, whose faith in me and determined ability to see me as the fully realized professional I am capable of becoming has made possible this final stretch to the finish line. Thank you to you all. Your support has made this dissertation what it is.

I close with the quote from I have printed on the back of my business cards:

Loneliness does not come from having no one around you, but from being unable to communicate the things that are important to you.

--Carl Jung

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Foreword: Constructing the Spectrum

A Brief Overview of the Project

Autism is a condition very much at the forefront of public concern and educational policy. Various lines of research have brought the field to a unique historical moment where several independent developments have come together to propel the autism diagnosis to a place of cultural and psychological prominence unprecedented in its brief history. These developments include theoretical changes in the conceptualization of autism symptomology, legal and educational policy shifts in the definition of the autism diagnosis, and evolutionary social change in the relative level of stigma attached to neurodevelopmental conditions. These shifts have important implications for autistic young people in the public education system. Widely varying approaches and remedies have been proposed for meeting the needs of autistic students, however, consensus seems farther off than ever as the voices of disparate stakeholders from causes as diverse as the disability rights movement, the neuroscience and neuropsychological research communities, families, schools, and the voices of autistic people themselves all converge to challenge basic understandings of autism and of the nature of disability itself.

The primary goal of this dissertation has been to initiate an Action Research process of collaboration with educators to better address the particular challenges and capacities of autistic students studying academic subjects in general education classrooms. The first chapter of this dissertation summarizes the history of autism and examines the autism diagnosis. The second chapter reviews the psychological literature on autism so as to provide background and rational for the development of teacher training materials. The applied portion of the dissertation focuses on creating informational resources for educators. Consistent with Action Research practice, initial input from the teacher study group was fed back into the project to inform design of training materials. The resulting training protocol, which was designed based on teacher interest and information from the literature review, was then piloted with the group of educator stakeholders driving the project. Quantitative and qualitative data were gathered and analyzed for the purpose of informing further revisions on the materials. Future plans include sharing the resulting resources with a wider group of educators in the form of teacher trainings and online resources.

Structure of the First Chapter

The introductory chapter of this dissertation focuses on the political and cultural context of autism with the purpose of outlining a theoretical framework for the dissertation project. The four sections of the first chapter include: a critique of current deficit-based conceptualizations of autism; a review of the theoretical tradition of constructivist thought within which that critique is located; a proposed alternative conceptualization in the form of a strengths-based understanding of autism; and an exploration of the practical implications for autism intervention informed by such a strengths-based perspective.

The first section of the introduction, What is Autism?, reviews the history of the diagnosis of autism, beginning with the initial identification of the syndrome and an exploration of Diagnostic and Statistical Manual (DSM) criteria and other diagnostic terminology. With the publication of the new DSM in May of 2013, the implementation of new diagnostic criteria has entered a state of active evolution and transformation which continues at the time of this writing. Changes in the DSM diagnosis of autism are therefore particularly salient at this time—both for mental health practitioners and for educators—and are explored in some depth in this dissertation. The first section of the dissertation also examines aspects of the autistic experience not well captured by current medically-informed diagnostic practice. Finally, this section steps back to take a broader view of the implicit deficit-based “medical model” stance of the DSM, along with the specific implications of medical model thinking for people who receive a DSM diagnosis of autism.

The second section of the introductory chapter, “Who Defines Autism?”, uses the theoretical lens of constructivist theory to examine the nature of autism as a culturally constructed phenomenon. The perspective of philosophical hermeneutics will be briefly invoked to dig deeper into the way notions of disability are constituted at particular points in history as manifestations of larger cultural meaning. The same hermeneutic lens will be used to examine the implications of those constructed meanings for autism intervention and treatment. This section will argue that cultural understandings of the location and nature of “disability” have very significant, often invisible impacts on the way educational interventions are conceptualized, and that unpacking those obscured meanings offers a shift in perspective critical to the design and implementation of more effective educational supports for autistic students. Specifically, this section explores the difference between medical model thinking and the social model of disability, as well as the types of educational practice informed by each. This theoretical background is included because it provides the framework for the “Social Model of Disability” concept which forms a central piece of the teacher training that constitutes the applied portion of this dissertation project.

The third section of the introductory chapter, “Who Speaks for Autism?”, explores the tension between academic research on the one hand, and the perspectives of autistic stakeholders operating largely outside of the academic tradition on the other. Building on the previously outlined constructivist understanding of the impact of culturally constructed notions of difference, the third section pays particular attention to the voices of autistic writers and activists who suggest that autistic students are being misunderstood and poorly served by current approaches to educational intervention.

The last section of the introduction, “Answering Autism,” makes the case that intervention at the general education level represents a critical and timely action at this point in the development of awareness and support for autistic students. That is, due to increasing diagnostic capture of autism as well as shifts in educational policy emphasis resulting in greater inclusion placement for special education students, general education teachers are more likely than ever to find themselves teaching autistic students in greater numbers than in the past. This final section outlines the Action Research project aspect of this dissertation including the attached teacher training for offering the developed resources to a wider audience. These resources have been created with an eye to organizing evidence-based information in a format that provides meaningful and practical support for general education teachers teaching autistic students in inclusion settings.

Chapter I: Introduction

What is Autism? Definition and History of the Diagnosis

Autism spectrum disorder (ASD) is a lifelong developmental condition that is one of the four most common categories of developmental differences in the United States tracked by the Centers for Disease Control (CDC). These four categories, in order of prevalence, include learning disabilities (LD; 7.66%), attention deficit hyperactivity disorder (ADHD, 6.69%), other developmental delays (3.65%), and autism (.47%), for the period 1997–2008 (CDC, 2016).

Autism Prevalence. The most recent information on current prevalence of autism diagnoses in the United States comes from the CDC National Health Interview Survey (NHIS). This effort yielded a prevalence of 1 in 45 in 3–17-year-olds, or 2.24% of the sampled population (n = 43,283; Zablotsky, Black, Maenner, Schieve, & Blumberg, 2015). The increase on this survey in ASD prevalence (up from 1.25% the previous year) was accompanied by an even bigger decrease in reporting of Developmental Disabilities (DD; down 4.84%). The ASD increase is speculated by the authors to be an artifact of "diagnostic substitution" arising from the fact that on the most recent version of the survey, the questions on ASD were placed earlier in the survey before the questions about DD. This survey was conducted with the intent to assess adequacy of available services and interventions rather than prevalence, and the CDC cautions that the results are not intended to replace the more in-depth analyses conducted on a four–year cycle by the CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network which continues to state a prevalence estimate of 1 in 68 (CDC, 2016), however, the higher prevalence estimates appear as an alarming footnote alongside other prevalence estimates on the color-coded national autism tracking map of the CDC website, and briefly made national headlines in newspapers across the country without accompanying explanation of the probable methodological reasons for the increase. This example is included here as just one illustration of the complexities of measurement that can complicate prevalence estimates and drive public concerns about an “autism epidemic” when such factors as a small change in methods such as the ordering of questions can create the illusion of a large increase in prevalence.

The most recent broad-based ADDM estimate for autism prevalence in the United States population (1 in 68) was based on 2010 data derived from sampling 8-year-olds at 11 sites around the United States to create population-based estimates in those communities. The ADDM uses a surveillance method that has remained largely stable since it was created by the Children’s Health Care Act in 2000 (2000)—ten sites in the original act and one more site, Atlanta, added for the upcoming cycle (Interagency Autism Coordinating Committee, 2014). Under their sampling protocol, ADDM staff members use a multiple-records-based approach (e.g., both educational and health records), to achieve as complete a count as possible of all 8-year-olds diagnosed with ASD in 11 study counties that are distributed across the nation. Although the 1 in 68 number is often touted in the general press as straightforward fact, the CDC warns that their estimates cannot be accurately generalized to all 8-year-olds. This is for two reasons: first, the 11 sites do not constitute a representative sample of American children (for example, no West Coast states or New England states are included); second, the samples indicate significant variations in ASD prevalence by geographic area, sex, race/ethnicity, and level of intellectual ability. For example, the ADDM surveillance estimate for ASD is 1 in 175 children in Alabama, while it is 1 in 45 in New Jersey. All sites report higher prevalence among White children (15.8 per 1,000 combined prevalence) than among Black (12.3 per 1,000) and Hispanic (10.8 per 1,000). In addition, the male-to-female ratio varies greatly between sites, from 3.6 to 1 in Alabama and Colorado, to 5.1 to 1 in North Carolina.

> The extent to which this variation might be attributable to diagnostic practices, under recognition of ASD symptoms in some racial/ethnic groups, socioeconomic disparities in access to services, and regional differences in clinical or school-based practices that might influence the findings in this report is unclear. (Baio, 2015, para. 3)

These statistical challenges and variations are documented here to demonstrate that the determination of autism prevalence is a complex matter influenced by a range of socioeconomic factors rendering truly accurate representation very difficult. An analysis of these factors is outside the scope this paper. For the purposes of this project, it is enough to recognize that autism prevalence is not the unitary or static construct often implied.

Rather than focusing on the factors affecting the prevalence statistics, this project is concerned with an analysis of the *manner* in which the social construct of autism is manifested in American culture today, and more specifically, the impacts of that construct on ideas about treatment and intervention. Such constructed meanings have their roots in the original perceptions and definitions of the condition. Any meaningful consideration of autism conceptualization must therefore begin with a history of the syndrome—specifically the history of the official diagnostic criteria. Accordingly, the first section of the introduction below outlines the history of the disorder from initial descriptions to today, as well as some of the implications of these historical definitions.

History of the autism diagnosis. Autism spectrum disorder (ASD) is a diagnostic label for a spectrum of neurodevelopmental differences. For the past four decades of psychological research, the disorder has been characterized in diagnostic and research literature by the so-called a triad of qualitative impairments in three domains: social interaction; communication; and restricted, repetitive, or stereotypic patterns of behavior (Stefanatos & Joe, 2008). Core features of the classic syndrome were initially described in 1943 by Leo Kanner, an Austrian doctor working in the United States (Grinker, 2007). Kanner is known for being the physician that wrote the 1943 seminal article that was the first in the literature to describe the “disturbances of affective contact” which Kanner identified as characteristic of a syndrome he named “autism,” thus differentiating the profile from schizophrenia or mental retardation (Silberman, 2015). At virtually the same time, another Austrian psychiatrist, Hans Asperger, independently documented symptoms of what he described as “autistic psychopathy in childhood.” Similar to Kanner, Asperger argued that “the autistic personality is neither biologically nor genetically related to schizophrenia” (Asperger, 1944, as cited in Grinker, 2007, p. 57). Asperger’s article remained unknown to English-speaking researchers until Lorna Wing at the UK’s Institute of Psychiatry in London published a translation in the early eighties (Wing, 1981).

The two psychiatrists, Kanner and Aspgerger, never met, and until very recently (2015 in fact) it was believed that they were unaware of one another’s work. With the publication of his book *Neurotribes*, journalist Steve Silberman (2015) has, for the first time, documented evidence that Kanner was very likely acquainted with Asperger’s work due to the fact that Georg Frankl, Asperger’s chief diagnostician, escaped the Nazi occupation of Vienna in 1938 and came to work for Kanner at Johns Hopkins University School of Medicine. Such a relationship makes it very likely that Frankl passed on concepts learned during the time he was employed in Asperger’s lab and that Kanner was aware of the origin of the ideas.

Kanner, being a pioneer (sometimes referred to as the “founding father” of the field of child psychiatry) set the stage for the long-standing focus in the literature on autism as almost exclusively a condition of childhood (Baron-Cohen, 2015) rather than the life-long difference in neurologic functioning and sensory processing as it is more commonly thought of today

(Silberman, 2015). Silberman (2015) speculates that Kanner pushed for the more severe definition because it was more academically prestigious to be the discoverer of a syndrome that was distinct and rare. Although the specifics are obscured by time and war, the evidence strongly suggests that ideas about autism came into being in a context fraught with competition and drive for individual recognition. Whatever the influences surrounding the early conceptualization of the syndrome, the most salient factor is that the extremely narrow way in which Kanner structured early definition of the diagnosis influenced understanding of the syndrome in the direction of the most severe symptomology for the first four decades of research.

Meanwhile, at the same time as Kanner was forging his narrow profile, Hans Asperger was seeing and documenting patients with a wide range of abilities and impairments in his clinic. In fact, Asperger was lecturing as early as 1938 on this group of clients whom he sometimes described as “little professors,” known for being highly verbal and having highly focused specific interests. At that time, Asperger was already speaking in terms of a spectrum of abilities (Silberman, 2015).

The work of these two groundbreaking researchers and clinicians has come to demarcate the two ends of what is now widely and indeed officially conceptualized as a spectrum of neurodevelopmental impairments—a spectrum which ranges from the severely impaired “classic” Kanner’s autism to the difficulties in social, emotional, and sensory processing that characterize the syndrome named after Asperger (Grinker, 2007). As indicated above, Kanner’s work much more than Asperger’s, came to shape early understandings of autism in the psychiatric literature due to the fact that Asperger published only in German and did little research beyond his initial publication after his lab was destroyed in World War II. Lorna Wing and Judy Gould, responsible for the 1981 translation and publication of Asperger’s 1944 landmark article, began to popularize the idea of a spectrum in the 1970s, and also began to demonstrate through their research that given changes in diagnostic criteria, the prevalence of the syndrome was much higher than that accounted for by Kanner's limited category (Silberman, 2015).

It is one of the ironies of history that it was Asperger far more than Kanner, who believed autism to be a spectrum of deficits caused by a complex interplay of biological and environmental factors. Asperger's more nuanced characterization sounds surprisingly modern in contrast to Kanner's criterion, which conceptualized autism as a single discrete syndrome (Grinker, 2007). Over the decades, there has come to be greater and greater overlap between the more verbal end of the autism spectrum on the one hand, and Asperger's syndrome on the other. For a long time, the basic differentiating symptom between the two was late onset of language—specifically, an autism diagnosis was specifically based on a delay of attaining single word speech at age two or later and phrase speech at age three or later (Jolliffe & Baron-Cohen, 1997). In 2013, the fifth edition of the *Diagnostic and Statistical Manual* (DSM-5; American Psychiatric Association) made questions of differential diagnosis irrelevant by collapsing Asperger's and Kanner's versions of autism into a single diagnosis, now labeled "Autism Spectrum Disorder" (ASD). Whatever the philosophical differences between these two contributors to the original conceptualization of the autism diagnosis, it is a safe bet that neither psychiatrist could have predicted the incredible momentum the phenomenon would take on at the turn of the third millennium.

Autism in the DSM IV-TR. Although a new edition of the DSM was released in May of 2013, the vast majority of autism diagnoses at the time of this writing, including all those included in the latest CDC sampling in 2010 (CDC, 2016) were made under the *The Diagnostic* *and Statistical Manual IV-TR, DSM IV-TR*, (American Psychiatric Association, 2000). Despite the implementation of the new manual in 2013, the DSM IV-TR categories remain extremely influential, both for psychologists and for members of the autism community themselves, who often strongly identify with the label they first received. Additionally, many school personnel, especially those outside of the specializations of special education and school psychology, remain relatively unaware of the significant changes to diagnostic categories related to autism that came about with the implementation of the DSM-5, not to mention the meanings and implications of these diagnostic categories for the students who may be placed in their general education classrooms. Finally, because the DSM IV-TR categories are frequently used in the research reviewed in this paper, a brief overview of autistic diagnoses in the DSM-IV-TR is salient.

The DSM IV-TR contained five separate diagnostic labels for autism-type disorders including Autistic Disorder (299.00), Rett's Disorder (299.80), Childhood Disintegrative Disorder (299.10), Asperger's Disorder (299.80) and Pervasive Developmental Disorder Not Otherwise Specified (299.80). The DSM-IV-TR diagnostic criteria for Autistic Disorder included separate criterion categories for each of the three "triadic symptom" areas mentioned above. In Asperger's Disorder, however, the criteria included only two of the three triadic core symptoms—the categories of "impaired social interaction" and "stereotypic behavior," while the Pervasive Developmental Disorder (PDD-NOS) category required that individuals demonstrate difficulties in social interaction combined with *either* communication impairment *or* stereotypic behaviors, interests, and activities. Clearly much intertwined, these various disorders were often difficult to distinguish from one another, despite small differences in definition. (The other two categories—Rett's and Disintegrative—had such low prevalence that they rarely appeared in the research).

Given the range of definitions for disorders associated with autism, confusion and contradiction were perhaps inevitable. The variety of possible criteria for autistic syndromes in the DSM-IV-TR, and the surging popularity over recent decades of the two least-restrictive diagnostic labels—Asperger's and PDD-NOS (Grinker, 2007), have contributed to a state of affairs where autism-type diagnoses meant vastly different things to different stakeholders. Under the DSM IV-TR, the multiple labels in use by the diagnostic community did nothing to reign in a national debate about autism—a debate based more on personal fears and highly charged emotion than solid research-based evidence. The resulting confusion amplified a sense of capriciousness and unpredictability in national policy decisions, research priorities, and educational practice. The lack of clarity about the meaning of terms may even, in fact, have been a significant contributor to the skyrocketing increase in prevalence of diagnoses, which has been labeled an "epidemic" in the popular press (Grinker, 2007).

Under the diagnostic system in use at the time of the DSM-IV-TR, even the most popular definitional terms lacked basic differentiation. For example, "high-functioning autism" (a non-DSM term frequently used in research)[1] and "Asperger's Disorder," a differential diagnosis ostensibly based on age of acquisition of expressive language,[2] appear, in practice, to be used either interchangeably or simply lumped together as one group (in fact, studies often include both descriptors in a single experimental group, treating the label "high-functioning autism" as a *de facto* diagnostic category, even though it does not appear in the DSM (e.g., Ashwin, C.,

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[1] "High-functioning autism" is generally taken to mean those with "normal" IQ or above—generally taken to mean an IQ of 70 or higher (Jaarsma & Welin, 2011).

[2] At age two or later to meet threshold for autism under the DSM IV-TR (Jolliffe & Baron-Cohen, 1997).

Ashwin, E., Rhydderch, Howells, J., & Baron-Cohen 2008; Edgin & Pennington, 2005; Jolliffe & Baron-Cohen, 1997; Robinson, Goddard, Dritschel, Wisley, & Howlin, 2009; and Williams, Happe, & Jarrold, 2007). Complicating this confusion of diagnostic category definition, many researchers sidestep the whole DSM diagnostic complexity problem by using the International Classification of Disease (ICD) criteria to define autism. While the ICD criteria for autism are very similar to the DSM-IV-TR, the ICD-10 diagnosis requires fewer symptoms to meet threshold, potentially leading to different rates of diagnostic capture (World Health Organization, 1992). Meanwhile, among diagnosticians, the Autism Diagnostic Interview-Revised (ADI-R; Rutter, LeCouter, & Lord, 2008)—a set of criteria which is not only far more comprehensive but also fairly different from any version of the DSM[3]—is considered to be the gold standard for diagnosis. The ADI-R is an instrument that is used frequently not only by clinicians, but is a highly-respected research tool as well. Its emphasis on sensory modes of processing and differences in cognition could be speculated to lead to the selection of notably different populations than autistic populations selected on the basis of DSM diagnostic criteria alone. Finally, despite the fact that researchers using DSM-IV-TR categories have frequently conflated autism and Asperger's in study populations (especially now that these two categories have been collapsed into one in the DSM-5), socially, these labels have carried very different associations and for many continue to do so. For all of these reasons, any consumer of research on autistic populations should be aware of this history and should approach the research with a healthy

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[3] For example, the ADI-R pays a great deal of attention to differences in sensory processing and sensory sensitivities, a sub-criterion that barely receives mention in the DSM-IV-TR, the DSM-5, or the ICD-10. In addition, the way the ADI-R is scored, the two criteria listed in the DSM-5 definition of autism receive very differential emphasis, with approximately four times the points recorded in the areas of language and social-interaction abilities as for restricted and repetitive behaviors (APA, 2013; Rutter et al., 2008).

skepticism as well as careful consideration of the actual demographics of the population under study.

Autism in the DSM-5. The DSM-5, released in May of 2013, attempted to remedy some of this divergence and confusion by consolidating the five autism diagnoses into a single diagnostic label: Autism Spectrum Disorder (ASD; 299.00; American Psychiatric Association, 2013).[4] Specifically, the three most common diagnoses were collapsed into one, while the two least common were essentially eliminated. Rett's was eliminated as a disorder because, since autism is defined as a specific set of behaviors, Rett's is already included (although it can still be specifically designated with the qualifier "with known genetic or medical condition;" APA, 2013). Childhood Disintegrative Disorder was eliminated on the grounds that, while it is so rare that systemic analysis is difficult, new research suggests that regression is a continuous variable in ASD generally, and that when specific and severe physiologic symptoms such as loss of bladder control are present, the patient should be assessed for neurological disorders distinct from autism (Kauffman, 2012).

The other three diagnoses, as noted above, have been collapsed under the new ASD label. Within this new singular diagnosis, the criteria have also been collapsed, from three areas (the so-called "triadic symptoms") to two. Specifically, the DSM-5 condenses the social and communication aspects of autistic disorders into a single criterion with emphasis on the *social* functions of language rather than on language development itself. The instruction is added in the DSM-5 that individuals whose primary difficulties fall into the language domain should be

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[4] Please note that for the sake of simplicity and compliance with current DSM-5 terminology, the word "autism" or the abbreviation ASD will be used to refer to all of the five autism spectrum diagnoses for the remainder of this review, even though the majority of research included in this review was conducted under DSM-IV-TR definitions.

evaluated instead for the newly created Social (Pragmatic) Communication Disorder (SCD) 315.39 (APA, 2013).[5] Effectively, the new DSM has reduced the long-standing “triad of impairments” to two: *Criterion A*—social communication and interaction, and *Criterion B*—restricted, repetitive patterns of behavior. This consolidation, while it simplifies the process of diagnosis, leaves two interesting legacies in the research literature: First, it creates an almost invisible incompatibility between studies that use the DSM-IV-TR definition of autism (a definition more aligned with classic or “Kanner's” autism) and studies which use the DSM-5 definition of autism (the whole spectrum). Despite using exactly the same language to describe their research populations, these studies cannot meaningfully be compared, a detail of dates which will likely be completely overlooked by non-academic consumers of research (and even by many academic ones). This shift also creates a significantly increased pool of diagnostic capture post–DSM–5—an artifact of definitional change which is again very likely to be misinterpreted as evidence of increases in prevalence by those not well versed in the history of the autism diagnosis. The second legacy of this consolidation of criteria is that the preeminent diagnostic tools of the field—the ADI-R and the Autism Diagnostic Observation Schedule (ADOS)—which were designed to evaluate the triadic symptoms with more or less equal emphasis (although even under DSM-IV-TR criteria, these instruments gave more attention to the first two criteria), now have become very unbalanced (Lord et al., 2012). That said, as the

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[5] Anecdotally, this disorder is the subject of a great deal of confusion as diagnosticians and special education providers struggle under various misconceptions relating to SCD, such as the idea that SCD is a straight-across replacement for the Asperger's Syndrome diagnosis, or the idea that SCD is best characterized as a speech pathology (and therefore best treated by speech pathologists) rather than a disorder of social communication. Similarly, because SCD is a brand-new diagnosis, there are few mechanisms and little knowledge of how to *serve* students with this diagnosis in the special education system. In practical terms, anecdotal evidence suggests that diagnosticians remain very reluctant to use this diagnostic label, which, after all, describes a set of impairments so similar to autism as to be again, difficult to distinguish.

ADOS/ADI-R diagnostic instrument duo is widely described as the "gold standard" of autism diagnosis, it would appear that leading diagnosticians in the field tend to agree in practice that this uneven distribution of symptom evaluation (even though it is not really in line with the DSM-5 symptom profile) is nevertheless, appropriate. Ironically, the literature is silent on this basic tension between applied clinical practice and DSM criteria, and this subtle but significant divergence in diagnostic practice remains as a serious future challenge to be resolved between the research and clinical communities.

With the shift to a spectrum formulation in the DSM–5, all autism diagnoses now fall under one umbrella, and variations in the presentation of the syndrome are denoted with specifiers in each of several domains. For example, language impairment may still be diagnostically noted, but only as secondary to the main diagnosis (that is, it may be denoted in the diagnosis as "Autism Spectrum disorder *with language impairment"* emphasis added; APA, 2013). Similarly, "with or without intellectual impairment" is offered as a specifier to designate differences in intellectual functioning (APA, 2013, p. 51).

This latter specifier appears to represent an effort to disentangle level of intellectual functioning from the social and behavioral traits of autism. This means that giving a diagnosis of intellectual impairment secondary to autism requires a deliberate choice on the part of the diagnostician, rather than a defaulting to a norm of assuming both—a common practice influenced by co-morbidity prevalence figures first appearing in the DSM III (3rd ed. rev.; American Psychiatric Association, 1987). This default conflation of intellectual disability with autism continues to cast a shadow over formulations of autism today (Biklen & Burke, 2006) despite growing evidence to the contrary. Evidence suggests that, in fact, a majority of individuals with autism evince no co-morbid intellectual impairment. For example, when the

U.S. Centers for Disease Control conducted a prevalence study in 2006 (*Autism Surveillance Summary*; CDC, 2009), they concluded that in that year, only 41% of eight-year-old children diagnosed with autism also had intellectual impairment (referred to as Intellectual Disability, ID, in the *DSM 5* when given as a stand-alone diagnosis).[6] The 41% figure takes on even more significance when it is taken into account that the CDC used a strict definition of autism and included only children with the DSM-IV-TR diagnosis of autism in this study, excluding those with an Asperger's diagnosis (a diagnosis which carries no particular associations with ID).

Diagnosis à la carte. As noted above, in condensing the five diagnoses into one, the new DSM-5 places far more emphasis on using specifiers (rather than different diagnoses) to delineate areas of difficulty and levels of severity. In a departure from previous practice, the DSM-5 also encourages diagnosticians to evaluate the level of need for support of the ASD client, from mild (level 1) to severe (level 3), providing the caution that severity may fluctuate over time and that such evaluations of need "should not be used to determine eligibility for and provision of services" (2013, p. 51). This striking specificity in description of symptom severity occurs in only two other places in the DSM-5—the section overview for Intellectual Disability (pp. 34–36) and the section overview for Neurocognitive Disorders (pp. 593–595). The DSM-5 autism severity level table goes into great detail concerning deficits in functioning and clinically significant impacts on social, occupational, or other important areas of current functioning for clinical reference. These specific and salient examples provide a meaningful, real-world guide

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[6] It is worth speculating that even this number may be a significant over-representation of ID among ASD individuals, given that a majority of the intellectual performance measured by IQ testing relies on factors mediated by oral language production and quick processing speed—both areas of relative weakness for autistic individuals. The Weschler intelligence tests, for example, are composed of a variety of sub-tests, of which more than half are timed, and most of which are measured by verbally delivered performance.

for care and treatment planning, and the addition of these three tables to the DSM represent perhaps the most significant change in philosophy of diagnosis and care in the entire current revision.

To round out the procedure for making a diagnosis of autism, other medical or genetic conditions, or environmental factors (e.g., organic brain trauma), including neurodevelopmental, mental, or behavioral disorders (such as chromosomal abnormalities or Rett's), may be mentioned in the diagnosis as associated factors (e.g., "autism spectrum disorder associated with Rett syndrome"; DSM-5, p. 51). Finally, other previously used labels for autism from popular culture, earlier research, or other countries (including early infantile autism, childhood autism, Kanner's autism, high-functioning autism, or atypical autism) are mentioned as encompassed by the diagnosis, but not approved to be used as specifiers (p. 53).

A place at the table: Sensory aspects of autism. One more change in the DSM-5 autism diagnosis bears comment. Due to the efforts of the Sensory Processing Disorder Foundation (see spdfoundation.net), a sub-criterion for "hyper- or hyporeactivity to sensory inputs or unusual interests in sensory aspects of the environment" has been added to Criterion-B (APA, 2013, p. 50). Although not recognized as a disorder by the American Psychiatric Association, Sensory Processing Disorder (SPD) appears as a recognized disorder in the *Diagnostic Classification: Zero to Three: Diagnostic Classification of Mental Health in Developmental Disorders in Infancy* and *Early Childhood and the Diagnostic Manual for Infancy and Early Childhood* (DC:0-3R, 2005), however, due to lack of empirical support for SPD as a unique and specific disorder, it was not included in the DSM-5. Despite this, the atypical sensory processing aspects of ASD have been well studied (e.g., Gerrard & Rugg, 2009; Leekam, Nieto, Libby, Wing, & Gould, 2007; Reed & Gibson, 2005). According to many autistic self-advocates, the area of sensory functioning represents the most clinically significant aspect of the syndrome in terms of the internal experience of autistic people (Biklen & Burke, 2006; Jackson, 2002; Savarese, 2013; Singer, 1999). In fact, the sensory and motor differences in autism are identified as the core feature of the condition in one of the recently emergent models of autism—the Sensorimotor Perspective Model (Donnellan, Hill & Leary, 2010. See Chapter II for a more detailed discussion of this model of autistic functioning).

Deficit definitions embedded in the medical model. Finally, in considering the new DSM-5 diagnostic framework, it is worth noting what does *not* appear in the ASD diagnosis. However, before commenting on specific diagnostic silences, a brief discussion of the essential nature of the DSM itself is salient. This discussion is necessary because the DSM and documents like it form the foundation of a worldview that permeates not only psychological diagnosis and treatment, but a wide spectrum of social and educational interventions based on medicalized understandings of human functioning represented by the DSM approach. An understanding of this worldview is important because one of the major goals of the action research project (the teacher training module) that forms the project portion of this dissertation is to help educators make a shift in their understanding of how disability is understood in our culture and how that change in understanding of disability fundamentally shifts academic intervention in the direction of teacher empowerment. In order to make that change, it is critical first to understand how notions of disability are culturally constituted and contextually dependent.

To unpack the assumptions inherent in medical model thinking, it is worth taking a moment to do a close reading of the presentation style of the DSM, sometimes called the “bible” of the psychiatric profession. Despite the well-rehearsed signifiers of medical science omnipresent in that volume, it can be argued that the DSM, while it represents a broad professional consensus, may make no real claim to objective truth. In its opening pages, even the manual itself cautions against uncritical application by warning against use of the DSM in forensic settings (APA, 2013, p. 25). Despite the minutely parsed definitions of disorder that lend "scientific" authority to the more than 300 diagnoses found within its pages, the DSM-5 remains a cultural artifact—a product of the sensibilities of our time and place—and one which, moreover, is firmly rooted in the medical model thinking which produced it.

The DSM, as a product of this worldview, is implicitly coded with a number of profound and mostly invisible assumptions. Disorders and syndromes are described in the DSM solely in terms of deficits and symptoms, thereby imperceptibly shading the experience of difference with value judgments related to illness, corruption, and disintegration, as informed by the sensibilities of our highly systematized and optimized society. Because the DSM is a descriptive reference, relying on classifications of clusters of symptoms and observable behaviors, rather than analysis of biologic, genetic, or social etiology, the categories it creates often encompass highly heterogeneous syndromes, varying greatly in severity, and including a range of observable behaviors from motor functioning to perceptual phenomena to quality of social interaction. Autism, more than many disorders, represents a very broad diversity of experiences indeed.

Finally, the DSM is a document framed to conceptualize disorders within a Cartesian worldview—that is to say, it conceptualizes disorders as occurring intrapsychically, within individuals, as opposed to occurring both intrapsychically and interpersonally—as experienced in the interface between individuals and their family, community, society, and culture. In contrast, in a post-Cartesian or constructivist worldview, disorders are experienced as disordered *both* because of the internal discontinuities of experience *and* because they manifest within a social context which constructs those experiences as abnormal or discordant with context.

Disorders are only disabilities when they appear in a context which constructs them as factors which cause an inability to function adequately or comfortably within the parameters of that context.[7]

Despite the Cartesian focus on isolated individual experience implied in the scientific stance of the DSM, in *practice*, the document actually (though invisibly) references social context a great deal. It does so in its repeated acknowledgement that experiences are only symptoms if they cause *distress* (and only "clinically significant distress" at that—that is, distress that is impactful enough in the judgment of a clinician to disrupt the patient's ability to function effectively within the expectations of that patient's culture). The salience of this distress lens as a cultural yardstick is most obvious when the quality of the distress itself is designated as the DSM cut-off criterion determining whether an experience rises to the level of disorder (as was famously the case with Gender Identity Disorder—now Gender Dysphoria—and is likewise the case for nearly half the disorders overall; APA, 2013).

Embedded in the "clinically significant distress" criterion is the understanding that distress is uniquely a socially experienced phenomenon—one that is encountered in the context of relating to others when behavior or experience is deemed abnormal in light of socially agreed upon notions of normal. Yet no such distress criterion appears in the autism diagnosis. This is particularly surprising for two reasons: first, the above discussed reliance of the DSM on the

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[7] In the teacher training module, the example given to help illustrate this point is that of a society in which all but a few people are non-hearing. The society would have developed with no concern for mitigating loud noises. In this culture, being a hearing person would be a disability because you would be at risk for pain or even damage to your sensitive hearing due to loud noises that no one would think to mitigate, while most people would be unaffected and unconcerned. It is the context alone that makes being a hearing person a disability. People might accuse you of being "too sensitive" for worrying about noises they can't even hear. They might not even believe that those noises exist. Your disability is constructed by the norms of your culture which constitute a non-hearing status as normal.

subjective experience of distress as a criterion for defining "illness" in a majority of diagnostic profiles, and second (and perhaps more importantly), the centrality of *social* interaction differences as a defining feature of autism.

Instead, the DSM-5 diagnosis of severity for autism relies solely on a criterion that can be designated without any reference to an individual's internal experience but rather are objectively observable by outside observers—that symptoms must "limit and impair everyday functioning" (APA, 2013, p. 53). This criterion begs the question—limit for whom? As Bumiller (2008) points out in her feminist critique of diagnostic practice, one of the greatest flaws with the diagnostic criteria for autism is that they emphasize experiences which cannot straightforwardly be classed as disabling: "The symptoms that satisfy the diagnostic criteria are not necessarily the source of difficulties in functioning, nor does their amelioration change the constraints that arise from living with autism" (p. 971). In other words, there is a mismatch between what the DSM defines as disabling from an outwardly observable perspective on the one hand, and the evidence of limitations arising from the lived experience of autistic people on the other.

The implications of the DSM's heavy reliance on externally observable and independently defined criteria for autism is discussed at greater length in the third section of this introduction. Meanwhile, suffice it to say that while the changes, inclusions, and omissions of the DSM-5 may be imperfect and rooted within a narrow, empirical worldview, they are still hugely influential and cannot be ignored or minimized in their importance to defining current policy and practice in regard to ASD.

Who Defines Autism? The Construction of Difference

Impacts of definition on conceptualization and treatment. Unpacking the constructed nature of "disease" as it is embedded in a medical model of diagnosis is critical to any interrogation of constructs such as disability and deficit. Building on the idea of an embedded Cartesian stance within the DSM-5 approach to diagnosis, this section examines the implications of a deficit-based medical model not only for treatment of autism, but for the wider cultural attitudes toward disability that inform the construction of difference and the treatment of disorders in general. Based on the premise that notions of disability are culturally constructed, this section will briefly borrow the lens of philosophical hermeneutics to further elucidate autism as a socially constructed phenomenon.

A hermeneutic stance, like a constructivist one, proposes that society's perception of what is normal and what is disorder are not biological fact, but rather culturally constructed understandings in which illness can be viewed as a particular confluence of meaning and experience informed as much by the available technologies of healing as by the underlying constructs of "normal" and "dysfunctional" (see Cushman, 1995, for an extended discussion of the construction of mental illness vis-à-vis historical evolution of favored technologies of healing, throughout the history of psychology in America). Generally stated, a hermeneutic stance argues that cultural ideas of dysfunction and repair emerge together as interlocking systems of metaphor for human functioning. Simply put, Cushman proposes (1995), that in symbolic terms, the cure creates the disease as much as the other way around. And while human dysfunction and treatment operate on a literal level as valid medical processes, a hermeneutic inquiry asks also how they may serve at a symbolic level as cultural expression of the particular anxieties and technologies of repair unique to that era.

A hermeneutic stance goes one step beyond constructivist stance to ask: how does the manifestation of any given phenomena—in this case autism—operate not only as a product of the culture from which it emerges, but more curiously, how does it serve as a reflection of the cultural moment and touchstone innovations for that culture? That is to say, how do the particular preoccupations of our time reveal themselves in the way our culture constitutes divergence from the norm? Observing twenty-first century American culture through this lens, it is perhaps unsurprising that a syndrome like autism, concerned with social isolation, idiosyncratic patterns of thought, and barriers to communication, should so vividly come to light as illness in society where communal meaning and civic engagement are at their lowest ebb in generations (Howe & Strauss, 1991). From a hermeneutic stance, autism can be viewed as a powerful metaphor for the culturally relevant manner in which a particular way of experiencing the world “shows up” as a biologically constituted deficit in twenty-first century developed nations.

This is not to say that viewing illness as a function of location in history and culture makes the suffering of those impacted any less real, but rather to argue that an analysis which takes into account the constructed and cultural-bound nature of disorder opens up two important possibilities: first, a hermeneutically-informed constructivist lens makes possible the examination of mechanisms by which cultural constructions of “normal,” and moral understandings of difference *contribute* to the suffering of individuals in the affected group (a topic that will be explored in greater depth below) and second, hermeneutic analysis allows a reexamination of otherwise puzzling or inexplicable cultural phenomena as products of, rather than contributors to, their socio-historical context.

The increase in prevalence of the autism diagnosis in the last half-century is one such inexplicable anomaly. In the United States, for example, autism has gone from one of the rarest and least used diagnoses in the DSM as recently as 1994 (approximately 3 in 10,000 live births; Grinker, 2007) to an “epidemic” of cases estimated by some to be as high as 1 in 45 in the

United States (Zablotsky, Black, Maenner, Schieve, & Blumberg, 2015). As has already been discussed, this dramatic increase is likely an artifact of a complex intersection of political pressures and cultural meanings rather than an actual rise in prevalence. That the current reporting rates represent stabilization at a more realistic and valid capture rate is now supported by data both from the CDC, which has reported the same rate—1 in 68 school aged children—for the years 2014 and 2016 (CDC, 2016), as well as data from the UK, which is reporting stabilization of autism rates beginning in the early 2000s (Taylor, Jick, & MacLaughlin, 2013).

Some of the factors affecting the increase in autism diagnosis reporting rates are caused by easily identified influences, and none have anything to do with contagion (as is implied by the loose use of the word "epidemic" to describe the increase in autism prevalence). Grinker (2007) summarizes seven major contributors to the rise in diagnostic capture that arise from factors other than actual increase: (1) better awareness and recognition of the symptoms of autism among parents and diagnosticians; (2) earlier diagnosis (meaning that more cases show up in "snap-shot" type prevalence studies that often single out eight-year-olds); (3) an end to the practice of diagnostically conflating autism and schizophrenia; (4) a broadening of the concept of autism (traceable in the shifting diagnostic definitions used to select study populations); (5) greater use of the label "autism" instead of "mental retardation" (MR) or other learning disability labels, ADHD diagnoses, and even Bipolar Personality Disorder (BPD); (6) changes in the methods used by epidemiological studies (e.g., more sensitive screening tools); and (7) a shift in diagnostic policy leading to the inclusion within the category of autism certain individuals with clearly identifiable medical disorders (for example, Down Syndrome, fragile X syndrome, congenital rubella, and other chromosomal abnormalities).[8]

Although the factors affecting change in prevalence are due to changes in epidemiologic and methodological practices, the first category—shifts in awareness—hints at the magnitude of underlying cultural change in attitudes which created the conditions for all of the "scientific" factors to fall into place just in time to "discover" this emerging "epidemic." A hermeneutic stance begs the question—did science uncover more autism (e.g., autistics were "always here," though poorly recognized) or did perceptions of autism create a science that simply confirmed shifting cultural understandings (e.g., the cultural need for a category drove the expansion of diagnostic capture)? When it comes to a phenomenon that is as much cultural as it is biological, it is salient to consider in which direction shifts occurred.

Take for example, the trend of studies with either "autism" or "autism spectrum disorder" in the title or keyword list: over the years, although the ostensible focus of the studies has remained unchanged—autism—there has been a slow but marked shift in the characteristics of individuals included in such studies. It is easy to make the case that researchers did not base their shifts in participant selection on newly discovered genetic evidence because *no such discoveries occurred*—case closed. However, over the years, the demographics of those included in study populations have slowly drifted from a general research practice tending to focus on individuals with "classic"-type autism (e.g., Shah & Frith, 1993) to research including on those with "high-functioning" autism (e.g., Plaisted, O'Riordan, & Baron-Cohen, 1998), and more recently, to

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[8] To this list, I would propose another addition: a category of symptom-expression which in the past might have been labeled as Reactive Attachment Disorder (RAD) but which I now see in my practice as being labeled as autism. A search of the literature identifies a similar phenomenon—the plight of Romanian orphans demonstrating severe failure to thrive—which includes a constellation of traits that has been dubbed "Post Institutional Autistic Syndrome (PIAS)" (Hoksbergen, ter Laak, Rijk, van Dijkum, & Stoutjesdijk, 2005).

research trends including Asperger's (e.g., Robinson et al. 2009) and PDD-NOS individuals (e.g., Edgin & Pennington, 2005). This handful of studies offers just a few representative examples of a larger trend occurring across the field. It also mirrors the shift that occurred in the diagnostic practice as the DSM moved from a structure which conceptualized "severe" autism as a separate category, to a structure which included all types of autism in one more fluid category.

As Grinker (2007) points out, "The DSM's description has nothing to do with genetics, so the descriptive psychiatrists really don't care if all sorts of different illnesses are lumped together as autism" (p. 162). Because of the inconvenient fact that autism diagnoses are based on descriptions of externally observed symptoms rather than genetic profile through blood test or some other more deterministic method, the consistency of research is not only highly vulnerable to shifts in diagnostic practice that occur beyond the control of the researchers, but the practices of researchers themselves (as sketched above), who appear to be contributing as a community to the shift in population focus. In light of the lack of clear genetic markers, it seems very plausible that disorder definitions in the literature have shifted in response to changing cultural understandings of the syndrome as opposed to shifts in biological or psychological knowledge.

And really, on greater reflection, this is as it should be—research *should* reflect the current understanding of what it studies—to do anything else would be to fall out of step with the most salient state of cultural understanding of a given category, and even to fail to serve the very individuals such research purports to help. On the other hand, the invisibility of shifts in meaning is a hallmark of the kind of change that is generally unquestioned as "scientific truth" but which, on more careful examination, is both responsive to and iteratively contributing to larger cultural shifts in the understanding of the diagnosis. The key, in such cases, is not to try to resist such change but to acknowledge and document the shift, rather than to let it go unremarked upon (thus subtly endorsing the idea that it is not the definition of autism that has changed, but the actual incidence).

Part of the problem with documenting large shifts in the landscape such as these is that, with the exception of anthropologists like Grinker (2007) and journalists like Silberman (2015), researchers tend to write articles with very narrow scope, including in their reviews just enough context to locate the particular experiment they are documenting within a conversation of very similar investigations. By focusing on the minutia of neurological functioning, and spending little ink on these very significant changes in the diagnosis over the decades, the academic community has contributed through silence and unintentional myopia to the emotional and distorted rhetoric surrounding autism on the public stage. If the world of academia (in concert with the journalists and social scientists) were to call more attention to the step-wise and logical progression of changes in the way autism is viewed and defined, this might go some way toward calming some of the fears and reactivity surrounding this controversial diagnosis.

It is worth re-emphasizing here that highlighting the constructed and mutable nature of the autism diagnosis is in no way intended to undermine the idea that autism *exists* as an important category. Rather, this discussion intends to make the case that deconstructing the way in which understandings of disorder emerge from a socio-cultural context makes it easier to avoid falling under the sway of unexamined ideologies and the circumscribed remedies such ideologies prescribe.

The tyranny of ideology. Two of the most influential unexamined ideologies currently ascendant in the American culture of autism awareness are that autism is a disease in need of cure (suggesting that individuals with autism are medically damaged, flawed, or “less than”), and that autism is an epidemic (propelling research toward investigation of vectors of contagion or environmental toxins). While aspects of these ideologies may eventually be shown to have some truth to them, the risk of taking either as an overriding mandate is first that many, many other research avenues will be excluded and neglected, and second, that each ideology does a particular kind of harm to individuals identified as having autism, their intimate and social relationships, and their families. A discussion of the pitfalls of the ideology of autism as an epidemic is beyond the scope of this paper and shall be left to the capable hands of social historians and cultural critics such as Bumiller (2008), Frith (2003), Grinker (2007), and Silberman (2015). However, the notion that the construct of autism as a disease in need of a cure may cause harm to the very individuals it seeks to help, is thus central to this endeavor.

Deficit verses difference: Why does it matter? The "social model of disability," a phrase coined in the 1980s by disabled academic Michael Oliver (Oliver & Sapey, 2006), proposes an alternative conceptualization to the paradigm of autism-as-disease. This alternative conceptualization has two major ideological components, each of which have significant implications for educational policy and practice. The first component has been outlined above in the proposed shift away from the paradigm of autism-as-deficit to a conceptualization of autism-as-difference—that is, viewing autism as a set of neurologic differences and behavioral sequella which include both areas of challenge and areas of strength that are not stigmatized as inherently disordered.[9] The second, and perhaps more profound shift is from a conceptualization of the problem as one which is located *within* individuals (a Cartesian worldview) to viewing the

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[9] Viewing autism as a difference and not a disability in-and-of-itself should not be taken to negate the important fact that aspects of autism are, in fact, disabling, or that there are not many specific disabilities (such as processing deficits, sensory sensitivities, executive functioning difficulties, etc.) that are associated with autism. Operating from an autism-as-difference stance allows for the possibility that autism as a whole can be seen as a way of being or identity, which is an example of the spectrum of human diversity, though it may also include aspects of disability.

problem as one which is located in the *interaction* between individuals and the contexts which constitute them (to borrow a phrase from relational psychoanalysis).

The manner in which neurologic difference is conceptualized has obvious and very significant implications for educational and psychological practice, especially in the fundamental differences between the approach represented by *remediation* (treatment/cure approaches) verses the approach represented by *accommodation* (universal design to support differences in learning that occur across the spectrum of student learners—not just autistic learners). Shifting away from a Cartesian view and towards a constructivist one informs a conceptualization of autism that recognizes problems as arising from a *mismatch* between individual and environment, which in turn suggests environmental remedies rather than attempts focused solely on efforts to change the patient.

A significant impact of this re-conceptualization is the effect it has on provider empowerment. Consider: an educator managing the "disordered behaviors" of a disabled student has only a limited repertoire of consequences and behavioral modification tools with which to attempt to alter the student's behavior; a medical practitioner treating "symptoms" within a medical model automatically turns to therapies and medication that attempt to alter the patient. These interventions flow directly from a conceptualization that locates the problem within the autistic individual.

On the other hand, educators, therapists, and medical practitioners working from the paradigm of a social model of disability are influenced by that worldview to evaluate a much wider range of environmental factors—physical and social setting, group culture, expectations both obvious and invisible, the legitimacy of rationales behind those expectations, and even their own behaviors and unaware assumptions as providers. When those interacting with autistic people expand the scope of intervention to include this wide range of factors (many of which are far more within their control than the internal workings of another person's mind and body), they are likely to feel far more collaborative and empowered, and by the same token, are likely to meet with significantly more success in effecting desired outcomes for their students and patients.

As has been mentioned already, the philosophical exploration of the manner in which disability is constructed is a concept of central important to the project portion of this dissertation. Specifically, the teacher training associated with this project was designed based on the principle that training can be most effective when, rather than focusing primarily on the minutiae of tools and techniques, it operates at the meta-level of conceptual understanding. A primary goal of the attached training is to offer educators the opportunity to make a paradigm shift that involves moving from medical model thinking to an understanding of the social model of disability and the implications of that model of curricular design. The primary goal of this shift is to empower teachers as change agents.

Put another way, status quo medical model thinking locates "the problem" within the individual student, which results in a mindset in which educators, as an outsider attempting to influence the internal life of an individual, have relatively low power and few, relatively ineffectual tools to bring about change for that student. The goal of the training introduced by this action research project is to empower educators through training them in the social model of disability. The social model of disability approach conceptualizes the issue as a mismatch between student functioning and environmental context. As designers of the educational environment, teachers have much greater agency and efficacy to implement interventions that create effective academic experiences for a wide range of learners.

Baby with the bathwater: Where is the line between difference and distress? The deficit verses difference question warrants very careful parsing as it is clear that, while some of the neurologic differences found in autism can be adaptive and successful in a supportive educational or occupational context, somewhere along the continuum of difference, the neurologic traits of autism begin to impact quality of life and contribute to a subjective sense of distress for autistic individuals, sometimes very severely. The degree to which these experiences are a product of the cultural construction of deficit rather than an experience of innate distress, however, is very much up for debate.

Given the very significant aspect of autism conceptualization that is culturally constructed, what then lies in the future of autism diagnosis and educational approach? While there is evidence of multiple biological differences between typical and autistic brains (see Herbert, 2011, for a review of the literature of the neuroanatomy of ASD), the demarcation of "dysfunction" has not been clearly delineated being as it is, such a highly socially-referent category. In many ways, any biological basis of autism must be left for future generations of neurological researchers to delineate more conclusively (if even then). That is to say, even if clear neurobiological markers are discovered, a very real portion of the subjective distress of autism will remain culturally constructed, based as it is on prevailing views of expected behaviors and culture-bound moral understandings of suffering.[10]

Given the biological evidence of difference, the latter seems possible—that is, that some category of organic differences in functioning comprising core autistic traits will ultimately

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[10] In one classroom, hand flapping and rocking are viewed as a totally acceptable way to express joy, indications of intense concentration, and are uncritically accepted and even adopted by neurotypical peers, while in another such movements are regarded as a pathological symptoms, indications of lack of concentration, or even evidence of unfitness for participation in "normal society," and are therefore targeted in the IEP for extinction. This is just one example of how widely divergent the definition of "dysfunction" in autism can be.

remain after potentially adaptive differences now conceptualized as deficit are deconstructed and re-envisioned. However, given the culturally constructed signification of that difference, the internal and embodied experience of living as an autistic person in a potential future that does not automatically pathologize the atypical cannot yet be predicted. For the time being, at any rate, it is worth asking if the current culturally normative boundary between potentially functional and adaptive neurologic difference on the one hand, and impaired or compromised neurologic function on the other, is located too far toward the side of deficit rather than difference.

Accordingly, an overarching purpose of this dissertation is to examine the effects on education intervention and practice of educational policy driven by deficit narratives that conceptualize autism solely in terms of a disease model, thereby necessarily framing interventions in cure-based or eradication terms. The following review of the literature suggests that a significant weakness of the deficit-based model (often called "medical model" thinking) is that it frames the conceptualization of intervention in certain limiting ways before discussion of specific interventions can even begin. If Medical model thinking operates by treating individual "symptoms" with the aim of bringing those individuals in line with dominant narratives of neurological "normal," the social model of disability provides an alternative perspective by endorsing the idea that difference can be supported more effectively by system level change in concert with individual support rather than by individually-targeted change-goals only. (An example of this would be creating a classroom culture that intentionally honors the diverse learning styles of all students rather than pulling out only the autistic student and attempting to teach that student to conform to traditional learning expectations). Such an approach to educating autistic students would seek to valorize the contributions of all kinds of "neurodiverse" ways of being, while "treating" or "remediating" only those aspects of disability that cause significant distress for the individual, or which are exacerbated by other variables such as poverty, poor access to medical care and supportive therapies, or ill health.

Models of cognitive functioning in autism. As noted in the previous section, a constructivist stance allows two powerful cultural critiques. The section above explored one of them—that is, it examined how larger cultural patterns create the conditions that allow certain "scientific truths" to emerge and be "discovered" when cultural conditions create the ideal conditions for such a discovery. Such are the mechanisms by which unquestioned "facts" such as an "epidemic" of autism are seen as the outcome of sinister and unknown causes rather than a culmination of readily observable (and non-contagious) cultural forces. Let us now return to the second constructivist critique to examine how cultural constructions of "normal" and moral understandings of difference *contribute* to, as well as describe the suffering of individuals in the affected group.

As mentioned above, autism is typically characterized by and diagnosed according to what are known as the "triadic symptoms"—difficulties in social interaction, impairments in communication, and restriction of interests or repetitive, stereotypic behaviors. As noted in the first section of this chapter, these symptoms have been consolidated into two criterion in the DSM-5—social communication and restricted repetitive behaviors. However, despite being grouped into fewer categories, the core features (especially as reflected in the ADOS and the ADI-R) remain essentially unchanged.

These symptom clusters include both negative symptoms (impaired or absent abilities) and positive symptoms (observable behaviors which depart from socially desired categories). As has been discussed above, the DSM-5, as a diagnostic tool, concerns itself only with dysfunction and makes no mention of the strengths or remarkable abilities which, even in the popular cultural imagination, have come to be associated with autism (e.g., the savant abilities demonstrated by the eponymous character in the 1988 movie *Rainman*; the idiosyncratic and creative grieving of the narrator coming to terms with the death of his father in the World Trade Center in *Extremely Loud and Incredibly Close,* Foer, 2011; or the resourceful “detection” and tenacious problem solving demonstrated by Christopher in *The Curious Incident of the Dog in the Night-time*, Haddon, 2004).

Contrary to notions of exceptionality alluded to in these narratives, the disease paradigm of autism propagated by DSM criteria frames an international and cross-disciplinary discussion in which autism is invisibly and unquestioningly constituted as a disorder. The fields of Disability Studies (e.g., Broderick & Ne’eman, 2008) and Critical Race Theory (e.g., Solorzano & Yosso, 2002) have led the way in bringing to light such assumptions and their implications for policy and research. In the case of autism, for example, the lens of autism-as-disease leads logically to the premise that a solution to “the problem” can be found by untangling a complex array of biological and genetic factors contributing to the syndrome, thereby determining the underlying cause or causes of the disorder. This belief can be said to be at the heart of much of the autism research project of the last few decades.

Beyond the obvious influence on selection of research focus, a disease conceptualization has far reaching social and political effects. *Autism Speaks*, a powerful national organization, is one of the loudest proponents of this disease model (see autismspeaks.org). Autism Speaks uses these pervasive fears to effectively motivate its fund-raising efforts through controversial tactics such as the recent film *I Am Autism.* The film has been vehemently criticized for its manipulatively negative characterization of the condition and its rhetorical strategies akin to the visuals in children’s food-aid commercials, with narration such as “I am Autism . . . I know where you live...I live there too...I work faster than pediatric AIDS, cancer, and diabetes combined...And if you are happily married, I will make sure that your marriage fails" (as cited in Wallis, 2009). Fundraising appeals such as these, which seem to be attempting to evoke every possible hot-button anxiety, from stalking to homophobia, demonstrate the pervasive impact of a disease conceptualization taken to its most irrational extreme.

The impassioned rhetoric of the autism crusade begs the question of motivation and representation—who is asking for this approach and for whom? Perhaps not surprisingly, advocacy organizations such as Autism Speaks and others active on the national stage are led almost exclusively by neurotypicals (non-autistics), in contrast to organizations such as the Autistic Self-Advocacy Network (ASAN; see http://autisticadvocacy.org), a policy and advocacy network that asserts their core value upfront with the byline "Nothing About Us Without Us." More than 60 disability advocacy groups including the ASAN have signed a petition "condemning Autism Speaks for their negative advertisement and sponsorship" (Krcek, 2013, p.16). Recently, in response to criticism such as this, Autism Speaks has brought two well-qualified autistic individuals to serve on its board (Autism Speaks, 2015). This move has been met with guarded optimism in the autistic community, but substantive change has yet to be seen (Autism Self-Advocacy Network, 2015).

In spite of the growing resistance of politically active autistic people, Autism Speaks has staunchly defended the disease view of autism with all of the associated stigma that stance implies, repeatedly calling for a "cure," and lobbying the federal government for research into the genetic and environmental roots of autism (Snow, 2015). According to publically available annual reports, less than four percent of the substantial budget of Autism Speaks goes to services for autistic people (Autism Society, 2012). Because Autism Speaks is by far the largest recipient of donations for autism, autistic activists charge that this single-minded focus on cure research siphons money away from local communities and support for quality of life and accessibility interventions that would be of greater benefit to autistic people (Brown, 2013). In alliance with the priorities of this leader in the autism fundraising field, a great deal of scientific energy and funding over recent decades has gone into the effort to capture the elusive root causes of the syndrome in order that it may be better mapped, treated, and in the hopes of some, eliminated. This includes $693 million in federal funding authorized by the Combating Autism Reauthorization Act, 2011 (Krcek, 2013).

An obvious concern relating to "cure"-motivated efforts is that if autism is found to be predominantly due to genetic etiology, the only currently available remedy would be selective termination of pregnancies, as is the case with prevention efforts aimed at Down Syndrome and other genetic disorders. For comparison, a meta-analysis by the National Institute of Health estimates termination rates at 91-93% after a pre-natal diagnosis of Down Syndrome (Mansfield, Hopfer, & Marteau, 1999). Given that research to date suggests that autism is due to a complex interaction of genetic and environmental influences, with a probable diathesis-stress component, a finding of exclusively genetic etiology appears unlikely (Krcek, 2013). However, the concerns of autistic people that trends in autism research carry within them sinister suggestions of a eugenic agenda are well-taken, and critiques of research priorities from all stakeholders should be seriously considered.[11]

For much of the course of autism research fundraising, the political conversation has been rather one-sided, dominated by politically-oriented fundraising and advocacy groups such as

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[11] Hints of this type of selective approach to genetics can be seen in the recent action of Britain's largest sperm bank, which among other disqualifying "neurologic conditions" has banned autistic men from donating (Borland, 2015).

Autism Speaks and Cure Autism Now (which merged with Autism Speaks in 2007; Roithmayr, 2007). However, with the rise of disability rights movements and the blossoming of web-based forums as a method of community-building particularly suited to autistic communication, recent years have seen the emergence of several organizations run by and for autistic people.

Who Speaks for Autism? Presuming Competence and The Politics of Representation

The examination of the phenomenon of autism in this chapter began with an analysis of the history of the deficit-based DSM diagnostic criteria. In section two, a constructivist lens was used to highlight the culturally constructed nature of the autism diagnosis, and the manner in which understandings of disability inform attitudes toward treatment and intervention. A larger step back using the framework of philosophical hermeneutics allowed an investigation of how "scientific truths" (such as the "discovery" of autism as a common condition) emerged as a function of larger social forces and have resulted in largely unquestioned assumptions, such as the conceptualization of autism-as-disease and autism-as-epidemic—assumptions which in turn drive highly-politicized and divisive efforts at finding a cure and/or eradicating autism through pre-natal selection. These critiques of the disease model of autism imply the obvious question—what other perspectives are possible? This third section will examine alternative ways of conceptualizing autism that depart from disease-model thinking and instead emphasize the unique and quirky aspects of difference that characterize the autistic experience. Foremost among these alternative conceptualizations is the stance put forward by the Neurodiversity Movement.

The Neurodiversity movement. "Neurodiversity" is a recently emergent cultural and political movement that promotes the idea that individuals with neurologically variant functioning should be understood as being part of a spectrum of the infinite variety of human functioning rather than viewed as aberrant or damaged versions of some culturally sanctioned norm. Inherent in this conceptualization is the idea that people with all varieties of neural functioning deserve to be valued, treated with dignity, and to have their civil rights respected as self-determining individuals—even when such individuals communicate through methods other than verbal speech or need high levels of support to navigate activities of daily living.

The rapid growth of the Neurodiversity Movement is a phenomenon of which academia has appeared to take very little notice. (The search term “neurodiversity” pulls up only 34 hits on 2015 PsychINFO search.) However, with over 15 years of organized programming and over 50 related websites (Bumiller, 2008), the movement is big news in autistic culture, and has stirred up controversy through promoting a critical stance toward attempts by neurotypical people to represent the needs of autistic people (to speak for autistics) as well as engaging in acts of resistance toward dominant culture “cure” narratives (this resistance includes political action—for example, one sign at a 2014 Seattle protest read “Don’t cure my identity”; ASAN of Washington State, 2014).

The term “neurodiversity” was coined by Judy Singer (1999) in a book chapter titled “Why Can’t You Be Normal for Once in Your Life: From a ‘problem with no name’ to the emergence of a new category of difference.” The Neurodiversity Movement began as a collection of web-based communities and organizations providing space for personal expression and promoting the needs of autistic individuals and those with Asperger’s syndrome. The movement has now expanded its umbrella to include a broader definition of neurodivergent identities including individuals with Attention Deficit-Hyperactivity Disorder, Bipolar Disorder, developmental dyspraxia, dyslexia, epilepsy and Tourette’s syndrome (Jaarsma & Welin, 2012). The autistic community, however, remains the central cultural focus of the movement. This focus has been especially powerful in the way that the tools of the internet (social media, blogs, and other forms of web-based written communication) appear to be uniquely adapted to autistic communication styles (Jaarsma & Welin, 2012). For example, autistic people often prefer to use a single channel of communication (e.g., written only), as opposed to both visual and verbal at once (as happens in face-to-face communication), where the built-in delay in exchanges of written communication allows time for reflection and regulation, avoiding the potentially activating features of fast-paced interpersonal interaction.

These aspects of the growth of the Neurodiversity Movement have contributed to the development of a unique and distinct sense of cultural identity among its members. As a movement emerging in the 1990s in tandem with other disability rights movements such as Deaf activism, members of the Neurodiversity Movement see themselves as creating a similar community—one that is united by difference, made up of members dispersed among a majority population of neurotypical people, marked by ways of communicating that fall outside the cultural norm, and united in common cause through proud identification with a sometimes stigmatized category of difference (much as is the case with deaf culture and queer culture).

What's in a name? The politics of self-labeling. An issue of language needs to be addressed before going any further in the discussion of neurological differences. With an effort similar to other civil rights struggles, the Neurodiversity Movement has countered the well-meaning attempts of allies to speak for autistics by moving to claim space so that autistic voices may be better heard. One way the movement has done this is to challenge the long-standing "politically correct" language of labels such as "person with autism" or even "person labeled with autism." These phrases, and "politically correct" language like them, have been promoted for at least the last decade as usages intended to keep the disability from obscuring the person (often called “person-first” language). Recently, however, those active with the Neurodiversity Movement have advocated for the idea that if autism is, in fact, an essential trait and not, in and of itself a disability, efforts to de-emphasize the term in fact belittle a central and formative aspect of their personalities. Using “autistic” as an adjective that describes identity underlines the parallel with other proudly owned identities such as gay or Hispanic.

To illustrate with a parallel example, “person with gayness” sounds ridiculous because being gay is a widely-accepted identity that the gay community has worked hard to normalize as inborn, inherently part of the person, and worthy of pride. Further, the grammatical construction “with gayness” would seem to imply that the quality of being gay exists is somehow separate from the person, or represents a negative quality that shouldn’t “obscure” the person. In the United States, autistic activists have reclaimed the adjective “autistic” as both adjective and stand-alone label, while in some commonwealth countries (and some academic communities), the label “autist” is gaining traction. Out of respect for the expressed wishes of autistics active in the Neurodiversity Movement, “identity-first” language has been used throughout this dissertation.

The language surrounding autism points up a difficult tension between a disability rights stance on autism (one which advocates for a language valuing strengths and diversity), and advocacy for access to treatment—access to which is currently reliant on formal diagnosis as a necessary threshold to enable utilization of services (Krcek, 2013). The paradox is reminiscent of the dilemmas faced by transgender patients who must simultaneously advocate for rights and self-respect based on pride in identity while at the same time negotiating a medical system grounded in disease-based diagnosis in order to access medical services which inherently pathologize them. Both dilemmas underline the way that current deficit-based systems of healthcare place power to define not only health but core aspects of identity in the hands of diagnosticians and mental health workers rather than with the affected individuals. This power imbalance represents an imbedded challenge to autistic self-determination and full adoption of a contextually constructed rather than deficit/medical model of disability.

In the eye of the beholder. Central to the tenets of the Neurodiversity Movement is a basic re-envisioning of the *causes* of difficulties experienced by autistics and others who are neurologically different. The paradigm of neurodiversity questions the assumption that the condition of having a neurologic disorder is, in and of itself, what causes suffering. Neurodiversity as a worldview instead interrogates the assumptions of dominant cultural ways of being that are not, in the words of activist Joyce Davidson, “autism-compatible”—especially in expectations of social behavior (as cited in Jaarsma & Welin, 2012, p. 26). Much of the effort of the Neurodiversity Movement is aimed at deconstructing the way that the DSM pathologizes autism. These critiques have taken as the model for political action the depathologizing of homosexuality in the DSM-IV (American Psychiatric Association, 1987). This process of decoupling disabling aspects of autism from the core identity of being autistic has highlighted the impact of cultural beliefs on individual experience of distress in a way that is highly reminiscent of the historical struggle for the recognition of gay rights, as understandings of homosexuality moved from unquestioned pathology to fully contextualized and proudly-claimed identity over the past four decades: “In a society with a strong prejudice of homosexuality the lives of homosexuals will be troubled…In homophobic society nearly all homosexuals will appear pathological. The cure for these problems has simply been a wider acceptance of homosexuality” (Jaarsma & Welin, 2012, p. 25).

Likewise, a dominant cultural view that devalues the typical autistic preference for nondirect communication (e.g., preferring conditions in which sensory stimulus can be carefully titrated, such as email) or which interprets limited (or no) ability to speak using verbalized language as indicative of a *preference* for avoiding human interaction, (or equally inaccurately, as a sign of low IQ), will perceive autistics as disabled and will pathologize their ways of being. When, on the other hand, the pathology is conceptualized as operating at the level of worldview as well as the individual, effective remedies must address both individual needs and cultural beliefs and institutions.

Changing the level at which the problem is conceptualized changes intervention in two ways: First, when autistic challenges are seen as partly a function of environment, providers have many more options, because their toolkit expands to include interventions which change the context (for example, through greater scope of accommodation or simply through changes in expectations), as well as supports intended to help the person function better (for example, through skills training or conceptual learning). Second, when autistic behaviors are understood as part of a diverse range of "normal," many behaviors that are pathologized as symptoms under a medical model can be understood as functional variations that may wall cause no distress to the individual—especially when the environment is expanded to meet common autistic traits with greater tolerance.[12] Under this worldview, autistic differences are not automatically assumed to need treatment, but are targeted for intervention only if they result in *symptoms that cause distress to the individual* or make it difficult for that individual to function in certain contexts (e.g., sensory sensitivities that contribute to a proclivity to sensory overwhelm, auditory

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[12] An example of expanding expectations rather than changing individual behavior is when educators shift from seeing lack of eye contact from being a problem to simply being an example of a neurodivergent way of paying attention—that is, when an educator can understand looking away while listening as a more effective way to manage attention because the energy required to maintain distracting eye contact actually interferes with ability to process auditory information on the part of the autistic person.

processing deficits that undermine ability to follow oral instructions, mucosa sensitivity that results in gastrointestinal distress). One simple touchstone to evaluate appropriate intervention is *treat symptoms and accommodate traits*.

This paradigm shift in treatment approach has significant real world impacts. For example, much time and expense is spent on teaching autistic non-speaking children to verbalize. A cure-based autism website, in their section on Alternative and Augmentative Communication (AAC) begins their discussion by stating up front that, "Speech will always be the goal for people with autism" (Borfield, 2015, para 7). Activists charge that this emphasis, especially in public schools, promotes ableism by privileging verbal speech over all other kinds of communication, a stance which directly and proportionally reduces educational focus on support for other alternative methods of communication without a solid basis in research showing that speech is better for autistics than other kinds of communication. Kerima Çevik (2015), contributing editor at Ollibean (an online social justice community and resource hub which seeks to connect "thought leaders in the disability community" with "families seeking support for neurodiversity"), charges that even when schools support AAC instruction, they do not pursue it vigorously enough. She recommends annual reevaluations of student needs until an AAC system is found that is a good match for the student, with intensive services continued until students truly master the medium:

> This means mastery sufficient to use [the system] to communicate effectively with their teaching team in an *inclusive classroom setting*. Establishing a solid communication foundation between nonspeaking students and all teaching teams that will facilitate their educational lives both now and in the future is critical. (Cevik, 2015, para. 5, *emphasis added*)

When intervention is shifted from focus on the medium (speech verses non-speaking communication accommodations) to focus on the goal (effective communication), the intervention can be better targeted to meet functional needs of autistic individuals rather than invisibly privileging the needs of the neurotypical majority.

One reason the example of communication intervention is particularly salient to the discussion of intervention design is that functional level of communication ability is often conflated with intelligence. Another front for political action from the Neurodiversity Movement pertains to the division between "high" and "low" functioning autistics (often defined by IQ score). Many in the disability community oppose these "functional" labels as arising from a false dichotomy created by medical model thinking—effectively such labels represent an externally imposed division that does not track accurately with the lived experience of autistic people. In practice, functional labels often fail to be accurate because autism is a highly heterogeneous condition characterized by a great deal of functional variation in response to factors outside of individual control (and indeed outside the awareness of most neurotypicals). Most obviously, perhaps, the use of a functional label provides an inaccurate representation of autistic functioning because such a label condenses many different domains of functioning under one category label. In reality, humans of all neurotypes have many domains of achievement and ability, with wide variation possible between domains that vary widely from not only from setting to setting and domain to domain, but from day to day and even hour to hour, depending on a wide range of internal and external variables—and the same is true of autistics: an autistic person can be an eloquent writer, for example, while still needing significant assistance with activities of daily living. Amy Sequenzia, a leader in autism activism, describes in a blog post her experience of the limitations and potential harm imposed by functioning labels:

> I am one of those autistics who were said to be hopeless. Doctors and "experts" were convinced that I would never make any progress in life, that my parents were better off sending me away so they could have one. The "experts" said I was "too low-functioning to learn." Of course, they were wrong. I am here, I have an independent mind, a fairly independent life. I taught myself to read and I am a writer. But I am still non-speaking and I look very disabled. I also need a lot of help with things that are considered simple by most people. Maybe that's why the "low-functioning" label stuck. It happens to a lot of autistics like me. The assessment is incomplete and based on parameters that were created for non-autistics, by non-autistics, not taking into consideration the neurological differences of autistics." (Sequenzia, 2013)

Functional labels in the psychological literature. Though few academics have weighed in on the issue of functioning labels, some of those that have, seem to be contributing to divisiveness. The construction of categories such as high and low functioning carry a veneer of scientific categorization, but may actually obscure a kind of subtle ableism or embedded bias against certain stereotypes or categories of autism. An example of this is the resistance that arose in some parts of the academic community to the combining of autistic diagnoses into one spectrum in the process of finalizing the DSM-5.

Researchers such as Baron-Cohen (2002), a leader in autism research for three decades and the head of the Autism Research Center, as well as the Cambridge Lifespan Asperger Syndrome Service in Cambridge, or Swedish researchers Jaarsma & Welin (2012), urged that Asperger's and PDD *not* be subsumed into Autism in the DSM-5 for the reason that doing so might impact the chances for "high-functioning" autistics to gain recognition for being neurologically different rather than disabled. This rather politicized discussion among well-established autism researchers employed some alarmist tactics, especially when proponents speculated that if the efforts to combine the categories gained traction, it could result in the declassification of autism as a disability altogether, impacting the ability of "low-functioning autistics" to access needed services. This is presumably because, from the perspective of a worldview which depends on parsing severity of disability, being accepted into the mainstream directly implies "normalcy" which, by the same token, would potentially negate the perception of being deserving of assistance. In other words, under this worldview, functional labels force a kind of either-or assessment where it is not possible to be both a self-determining autonomous adult and at the same time dependent on support services.

The stances of these researchers seem reductionist at best and prejudiced at worst. First, both the above referenced articles unquestioningly cite the 75% figure for intellectual disability in autistics rather than the more recent 41% CDC estimate (which as stated already, may well also be a significant overestimate, due to the reliance of IQ testing on verbalized responses and timed tests). When the clear intelligence of non-speaking autistics is considered (e.g., as demonstrated through the typed communication of autistics such as Amy Sequenzia and others[13]), it seems likely that estimates of intellectual level are worth holding lightly, no matter what the presumed level of "functioning." Given that the goal of the Neurodiversity Movement is simply to have autistic traits respected as neurologic difference, and not at all the rejection of specifically-targeted therapeutic or pharmaceutical interventions when helpful, conflating efforts towards a less pathologized view of autism with a rejection of treatment (as these researchers

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[13] There has been a recent spate of publications of book length written narratives by non-speaking or low-verbal autistic individuals, (e.g., see autobiographical works by Biklen & Burke, 2006; Fleischmann & Fleischmann, 2012; Higashida, 2013; Kadar, 2012; Mukhopadhyay, 2003, 2011; Savarese, 2010; and Williams, 1998).

seem to) seems disingenuous. (By similar logic, no one would argue that respecting the full personhood of an individual who cannot walk would equate to denying them a wheelchair.)

In point of fact, the solution to this impasse seems rather obvious: separate the overall conceptualization of autism as an identity from the specific neurologic capacities within autism that impair functioning. When one views autism as a set of traits or a way of being that includes potential strengths and challenges like any other, there is no reason not to conceptualize such impairments as intellectual delay, executive functioning issues, or sensory regulation challenges as capacity- and skill-based deficits as with any other learning challenge and to offer support and education accordingly. Such an approach leaves practitioners free to treat and support the disabling *aspects* of autism while conceptualizing autism overall as identity rather than disability.

Doing the least harm: Presuming competence. When it comes to appropriate educational interventions, there is mounting evidence to suggest that despite the best intentions of caregivers and educators, the abilities of autistics (well beyond the domain of IQ) have frequently been underestimated or mischaracterized. Krcek (2013) argues that the dual focus in autism research on social impairment on the one hand, and islands of ability on the other, has led to a combined trend of underestimation and mystification of autistics wherein both extremes of autism stereotypes (as socially disconnected, but with savant-type skills) have been used to justify exclusionary educational practices:

> Popular opinions of autism (e.g., lacking of empathy or inability to love) give the impression that the social impairments of individuals with the autism (sic) cause them to function at the boundaries of what is characteristically human, therefore justifying inhumane exclusionary treatment. (Krcek, 2013, p. 18)

In the popular culture realm, notions of the "confusion, complexity, and unsolvable mystery of ASD (Krcek, 2013, p. 18) have come to be symbolized by the puzzle piece emblem used by many ASD organizations. The autism self-advocacy community feels that this symbol goes too far in the direction of the trend of othering autistics—that is, it errs in the direction of representing autistics as unknowable, perplexing, and outside the realm of ordinary and human. Hence the emergence of a counter-slogan: "I'm not a puzzle piece, I'm a person," (Bumiller, 2008, p. 981). One adult autistic blogger put it this way in a blog post describing a feeling of lack of respect from "curebies" (i.e., autism activists promoting cure research):

> I'm *different*, I'll admit, but I'm not a missing piece of a puzzle that needs to be completed. I am not the piece that doesn't fit. I am not a lost piece or mistakenly put in the box of the wrong set. If that's what you think, I don't want to talk to you. It's that simple. (Au, 2013, para. 9)

To advocate for a cure, these autistics feel, is to subscribe to the idea that a core aspect of their identity—autism—is inherently undesirable and stigmatized. More significantly, cure rhetoric constructs autism as something foreign to, or external to the person, as if it were an independent disease process that could be excised. Autistic blogger Zoe explained in her post titled*, Disability first: Autism is not an Accessory*, "why do I use identity-first language to describe myself? Because I like my disability, but more importantly, because it is a part of me that can never be separated from my personhood" (Zoe, 2012, para. 9). Autistic activist and founder of the Autistic Self-Advocacy Network Ari Ne'eman recently quipped, "If I'm on a flight and the airline loses my luggage, I don't arrive without my autism." (Ne'eman, as cited by Zoe, 2012, para. 8).

Responses like these are based on the belief that autism itself is a trait so basic to way of being that it cannot be cured or removed, and moreover, that, as a valued part of identity, it does not need to be. These self-descriptors align solidly with the stance that autism falls into the category of identity, and as such, deserves the typical English adjective-noun construction as discussed above: autistic person. Finally, it should be clearly stated that these sentiments are not reserved to autistics who can “pass” in neurotypical contexts, but have been expressed by a range of autistic activists from highly verbal autistics like Ari Ne’eman, to completely non-speaking activists like Amy Sequenzia, who describes herself as looking “highly disabled” (Sequenzia, 2013).

Doing the least harm: Assessing competence. As has been discussed already, one contributing factor to widespread misconceptions about autistic functioning arises from the limited ability of current IQ measures to capture intelligence in individuals with atypical verbal abilities. When poor ability to communicate verbally is taken to indicate impaired cognitive functioning, the result is the inflated figure of 75% co-morbidity between ASD and intellectual disability (APA, 1987). Similarly, when underdeveloped ability (or opportunity) to form human connections is interpreted as either lack of desire for relationship (Saverese, 2013), or greater interest in machines than people (Baron-Cohen, 2002), a whole series of related assumptions undermining the full personhood of autistics follows. One of the most demoralizing assumptions for autistics is the tendency of caregivers to take expressive ability as representative of overall intelligence. Such assumptions tend to result in neurotypical ways of communicating with autistics that fall far below the receptive ability of non-speaking autistics (e.g., the tendency on behalf of neurotypicals to speak to non-speaking autistics in baby talk), or in teaching interventions that inappropriately focus on basic level functional skills (e.g., a focus on activities of daily living rather than on higher level cognitive skills).

As Biklen and Burke (2006) have pointed out, diagnostic criteria for intellectual abilities are circular:

> The very student who has difficulties with performance, including speech, will often be caught in the diagnostic category of severely retarded, not because of any proof about thinking ability, but because of an *absence of evidence* about his or her thinking ability. Hence the student may be defined as unable to benefit from inclusion. (p. 167, *emphasis added*)

Jamie Burke (2006), a previously non-speaking autistic, was able to provide vivid examples of this experience once he learned to type through the process of assisted communication.[14] He first described his early experiences in education, almost from the perspective of a "shut-in" patient—being fully aware of what was said to him, but unable to respond:

> What made me feel angry was that I knew exactly what I was to say and my brain was retreating in defeat. I felt so mad as teachers spoke in their childish voices to me, mothering me, but not educating me. (Burke, 2006, p. 170)

Like many autistics, Burke's education included a large focus on functional skills, especially in the motor realm. He specifically criticized the amount of time spent teaching him to tie his shoes (which he finally mastered at age fifteen):

> I now think it was so foolish to ask me to learn to tie my shoes. My brain moved into hiding the reason for not being able to do it, but yet my school believed it important mostly as a way to tell you that you are now just greatly smart…. I screamed silently,

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[14] The controversy surrounding questions of the true independence of certain types of assisted communication will not be addressed here except to say that Burke learned to type through this method, but now types completely independently and is able to speak if he speaks as he types or reads what he has written. He still requires the presence of a supportive mentor in order to help him organize and focus his physical body on the task of communicating his ideas, however, he no longer needs any physical support for the motor task of typing.

> “make my mouth work as my hands; can you idiots not see my struggle to tell you I have so many answers to the questions you place before my face? Isn’t tying the speech to my mouth from my brain more critical to life than making a piece of cotton secure?” (Burke, 2006, p. 171)

The experience of Burke and others like him demonstrate the profound importance of presuming the underlying competence of even totally non-speaking autistics. Bicklen & Burke (2006) promoted the “presuming competence” approach as the conservative choice: “It refuses to limit opportunity; by presuming competence, it casts the teachers, parents, and others in the role of finding ways to support the person to demonstrate his or her agency” (p. 167). As Bumiller (2008) has pointed out, assuming unknown capacity is conservative because no one is harmed by presuming competence.

This glimpse into the view from inside autistic experience also calls into question the extreme educational focus on basic functional and motoric skills for people whose perceptual experience of the world, as well as their cognitive and sensory processing is profoundly different. As mentioned already, one of the unintended side effects of decades of research focused on the triadic symptoms delineated by several DSM editions has been that the investigation of atypical sensory processing and motoric functioning of autism have represented a small minority of research endeavors. Bumiller (2008) pointed out that, by specifically excluding sensory symptoms, the DSM-IV-TR diagnosis did not even seem to acknowledge this experience that is so significant a part of the experience of autism. Although this gap has been somewhat ameliorated in the DSM-5 with the addition of criterion B-4 and the intellectual and language impairment specifiers, it could be argued that Bumiller’s main point—which is that the diagnosis for the most part fails to describe the core features of the condition—still holds true: “Any attempt to delineate autism by naming particular deficits such as poor social skills or language disorder fails to adequately describe how profoundly it is linked to atypical mind/body communication" (p. 971).

When it comes to fostering an ability to communicate, sensory differences leap to the fore. Burke (Biklen & Burke, 2006) wrote of how his occupational therapy teacher used targeted rhythmic interventions: "Listening therapy is a joy. It gives your ears the feeling of reaching the bridge over the missing meaning of sounds" (p. 170), as well as motor interventions that helped him connect to the use of his body:

> She has me blow darts through a small tube from a distance to a target on the window. This seems to help my lips form better with more accuracy… Before I would lose certain sounds and the words seemed as garbage to be thrown out with no use to them. You might say I felt I am training my brain to hear better. It helps me to begin to speak better. Also it sends needed rhythm to my speech. (p. 170)

Differences in perceptual understanding do not affect just the mechanics of communication, for many autistics, but the very perception of being-in-the-world, which, in turn, affects what can be communicated. Savarese (2010) related the experience of Tito Mukhopadhyay, another previously non-speaking autistic and author of several landmark books on autism. Savarese (2010) illustrated how perceptual differences inform the autistic experience by exploring Mukhopadhyay's use of the preposition "in" and its implications for an alternative understanding of containment and boundaries:

> "I sat *in* the chair," we say, but what if the preposition *in* makes no sense because our proprioception is so different from that of most people?...What if we have significant body boundary challenges—if we flap (a common form of autistic perseveration) to know

> that we have arms? Some of the strangeness of autistic writing, but also its beauty, originates in different operational metaphors that spatially situate (or fail to situate) the person. (p. 279)

Biklen and Burke (2006) described this commitment to perspective shifting by challenging caregivers and teachers to decenter the majoritarian[15] narrative: “The observer’s obligation is not to project an ableist interpretation on something another person does, but rather to presume there must be a rational or sympathetic explanation for what someone does and then try to discover it, always from the other person’s own perspective” (p. 168).

Whether from the perspective of “presuming competence,” or from radical re-imaginings of the situatedness of parties in a communicative exchange, these researchers and writers have brought much-needed new perspectives to the discussion of the education of autistics. Saverese (2010), a professor of English, adoptive father and biographer, and Neurodiversity ally, described his stance as calling for a “postcolonial neurology” using the metaphor of nationalistic oppression to interrogate the centering of certain types of neurological functioning as normal and privileged, while certain other types of functioning are marginalized and pathologized. At the heart of the neurodiversity project, then, is a challenge to the dominant narrative of autism as medicalized deficit functioning, and the offering of an alternate vision celebrating autism as a condition of neurologic, social, and perceptual difference. In a world where “difference does not equate with deficit” (Biklen & Burke, 2006, p. 172), autism can be seen as a normal variation in human genetics (Bumiller, 2008; Jaarsma & Welin, 2012) as well as developmental variation in cognitive style (Baron-Cohen, 2002). In a context that destigmatizes difference, specialized

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[15] The term “majoritarian,” referring to the hegemony of “master narratives” sustained and invisiblized by privilege, is borrowed from Critical Race Theory as outlined by Solorzano & Yosso (2002).

support for specific skills may then be offered without pathologizing the neurological differences central to autism (Biklen & Burke, 2006).

***De*constructing the spectrum.** When essentialist descriptions of autism are deconstructed through autistic-centered understandings of perception and communication, other assumptions begin to unravel in their wake. As with all research, much depends upon how questions are posed. For example, the widespread assumption that autistics have impaired "theory of mind" is based on rather mechanical point-of-view measures rather than qualitative information about real and emotionally important interactions. Many of these common "perspective taking" tests are problematic because they are rife with unexamined assumptions about the meaning of the activities measured by the tests. For example, the "Sally-Ann Test" (which can also be found as a subtest of the NEPSY-II—a standard neuropsychological assessment for children) purports to measure ability to postulate the mental content of other people's thoughts. People who do not pass such Theory of Mind (ToM) tests are said to have difficulty mentally representing a state of mind different from their own, demonstrating this impairment by responding in a way that suggests they believe Sally will know what they know.

Let us ignore for a moment the large assumptions made in equating these two abilities in order to consider the other weaknesses inherent in this assessment and the related assumptions made about autistic people. In addition to the fact that ToM test findings are fairly inconsistent (see discussion in section one of the introduction), ToM deficits have not been significantly or consistently linked to the core autistic symptoms of reciprocal social interaction impairment or repetitive behavior symptoms (Joseph & Tager-Flusberg, 2004). Put another way, what these researchers have proposed is that while ToM tests seem to be measuring something, they do not appear to be directly measuring symptoms of autism; and second, although ToM tests are designed to capture ability to "put yourself in another's shoes," the parallel between a mechanical or hypothetical exercise with little affective valence, and a real situation concerning the emotions of significant others may not seem as parallel to actual life situations from the very different perceptual perspective of an autistic person as neurotypical people assume (in other words, a neurotypical person may automatically intuit the implied social construct underlying the test demand—that is, they may realize, "oh, I'm supposed to show that I understand how the world works by demonstrating that I can perform on this test," while an autistic individual may not initially see the point of the test, and may not care to engage in an obviously meaningless exercise).

By the same token, improvement in ToM abilities over time does *not* seem to translate to changes in other areas of challenge in autistic functioning: Based on the extremely mixed findings in the ToM literature, Begeer et al. (2011) designed an intervention to teach ToM skills to autistic children. While the children showed significant improvement in ToM abilities, their self-reported empathetic skills and parent reported behaviors showed no change, suggesting that ToM skills bear little relation to applied social abilities.[16]

The most important issue, however, is that poor ability to communicate about the internal states of others does not equate to poor ability to mentalize[17] or empathize with such states. Although, compared to neurotypicals, autistics may tend to place a different distribution of emphasis on how they direct their attention between internal and external events (or at least how they *appear* to be directing their attention based on their verbal expression), this should not be

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[16] Anecdotally, from my own experience working with autistic children, I have found that ToM concepts are often fairly easily learned by autistic clients once they understand the task as relevant. This would imply that ability to accurately interpret and pass a ToM test seems to represent an isolated cognitive ability with little bearing on real world ability to perspective-take.

[17] Mentalize: Create an internal mental representation of externally observed information

taken as evidence that they *cannot* understand the internal states of others. (For further discussion of the literature on assessments of Theory of Mind, see Chapter II.)

Naoki Higashida (2013), the 13-year-old autistic author of the recently translated, *The Reason I Jump*, illustrates the impact of incorrect assumptions about the capacities of autistic people. He describes being acutely aware of how others perceive him:

> For people with autism, what we're anxious about is that we're causing trouble for the rest of you, even getting on your nerves. *This* is why it is hard for us to be around other people. This is why we often end up being left alone. (p. 27, *emphasis original*)

Higashida (2013) reiterates repeatedly that the barriers to communication which sometimes lead to a tendency to leave autistics alone should *not* be interpreted as a *preference* on the part of autistics for things rather than objects (as the Empathizing-Systemetizing model would have it, Baron-Cohen, 2005) or worse yet, a *preference* for avoiding human relationships (Savarese, 2013). "Whenever I overhear someone remarking on how I prefer to be alone, it makes me feel desperately lonely" (Higashida, 2013, p. 27).

My autistic son Avi[18] has expressed a similar concern. He often interrupts the flow of his own conversational contributions, even right in the middle of a sentence, to say, "Mom, mom?" I used to attribute this habit to poor sensory perception of his surroundings—I assumed he was losing his sense of my presence and needed some auditory input from me to assure himself that I was indeed there—an auditory variation of "we flap to know that we have arms." I thought that perhaps his awareness of me was poor enough that it faltered when he became absorbed in his own areas of interest. In working on writing this section, it finally occurred to me to ask him why he so frequently says "mom" while talking to me. His answer surprised me (though it bears a

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[18] See appendix E for a personal account of my son's story.

poignant resemblance to Higashida's account): "Well, I know that the things I say are really interesting to me, but they might not be so interesting to you, but I still really want to share them with you because they are important to me. I'm worried that when I see you looking away or something, you might be getting bored, and I really want you to keep listening." In other words, he says "mom" because he is acutely aware of my fading attention and is prompting me to keep listening. Although only one anecdotal example, this answer seems to support the idea that autistics are frequently hyper-aware of, even distractingly aware of, rather than disconnected from the internal states of others.

Another assumption commonly applied to autistics concerns affective connection to others. Barriers to communication for autistics are often interpreted to indicate that autistics are inwardly-focused to an extreme degree, and lack empathy for others. Empathy in this context, like Theory of Mind above, is a construct often evaluated through third-person observations that cannot, by definition, give a complete picture, especially in cases where the observed individuals cannot verbally represent their own internal states.

An issue of semantics further complicates attempts to accurately assess empathy. The English word "empathy" actually represents two very distinct skill sets—first, the ability to perceive or mentally represent a projection of the internal states of another, and second, the ability to generate a verbal response that maps to typical and socially accepted ways of expressing care for another. Writers like Savarese and autistics themselves point out that it is entirely possible to be able to perceive the internal states of others without being able to verbally communicate that understanding in a way that is meaningful to others. As Savarese (2013) pointed out, "Describing autism as a difficulty attaching words to emotional states and motorically executing an expected response is very different from describing it as a lack of feeling for other people" (para. 3). If empathy is understood to be an ability to identify with and experience the suffering of others, many examples of radical identification can be found in the writings of autistic authors who relate experiences possible only when mainstream understandings of boundaries do not exist and sensory representations blur across perceptual categories. Mukhopadhyay (2008) describes an intense experience of empathy in response to a news segment concerning people who were strangers to him:

> I see these stories, sometimes in vermillion or indigo, the richness depending upon the intensity of the stories. Sometimes they smell like vitriol and sometimes they smell like boiling starch in a pot of clay. And sometimes they have the essence of the twilight sky.
>
> As I feel my worries for the trapped coal miners, I can smell the boiling starch, frothing on the brim of the clay pot, then spilling out with the smell of burning rice. My worries grow as the voice of the newsreader continues to say that the miners are still trapped. I smell burning rice spread across the room as more starch spills out.
>
> My body begins to itch as though tiny black tickle ants have been set free from a box. They can smell the burning rice from the spilling starch, and they rush around to find the source with a collective ant hunger. My worry now accumulates in and across my itching skin, as the voice of the newsreader comes from far away, like a blue floating balloon. I have no hold on it because it floats away, leaving me with itchy skin. (Mukhopadhaya, 2008, as cited in Savarese, 2013, para. 4–6)

Accounts like this, demonstrating an experience of identification made perhaps more intense by lack of verbal ability to express it, radically challenge assumptions about autistic capacity for empathy. By interrogating these notions of disability, the very binaries of normalcy/difference and typical/impaired may be unlinked, and along with them, the standards by which the education and treatment of autistics are evaluated. At the heart of this debate is the essential question: whom do the interventions serve?

Critiques of frequently used interventions for treating autism. As noted above, current educational practice places great emphasis on bringing the behaviors of autistics closer to mainstream presentations. Dr. Ivar Lovaas, famous for strongly promoting behavioral approaches to treating autism declared that the goal of his therapy was to make autistic children "indistinguishable" from their peers (Dawson, 2004). This type of intervention bears within it embedded values justifying the modification of autistic behaviors in a way that privileges neurotypical behavior as standard, for the convenience and comfort of the dominant culture systems within which they exist.[19]

The most well-known and intensive form of behavior modification for autism (as well as the mostly widely reimbursed by insurance)—the Lovaas Method, also known as Applied Behavioral Analysis (ABA) therapy—aims to teach functional skills to autistic children through one-on-one interventions at an intense level of up to forty hours per week. Lovass' original claims are based on a relatively small study group (n = 19; Lovaas, 1987) that has been criticized for methodological errors (Gresham & MacMillar, 1998), and faulty conclusions—specifically, that the improvements documented were due to normal maturation rather than the ABA intervention (Morris, 2009). The method involves very intensive interactions including use of aversives, and has been criticized by some for practices bordering on abusive (Bumiller, 2008).

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[19] It should not pass without comment that Dr. Lovaas is also the originator of reparative therapy, a therapy designed to alter the behavior of boys thought to be acting in sexually deviant ways, that later evolved into therapies designed to change the sexual orientation of gay people (Silberman, 2015). Reparative therapy (called Sexual Orientation Change Efforts by task force researchers) was declared, based on evidentiary findings, to be ineffective, harmful, and therefore unethical by the American Psychological Association in a Resolution issued in 2008 (www.apa.org).

As a process wherein effectiveness is measured only by outward, observable behavior change, this approach yields little data about the internal experience or aims of autistics, and may be successful mostly in fostering externally evident adaptations rather than internal changes: “Since autism is a form of bodily difference that interferes with the person’s ability to process information (sensory, language, tactile, and visual) in typical fashion, children learn to cope by either imitating norms of behavior or making sense of the world within their unique perceptual systems” (Bumiller, 2008, p. 976). A comment on the blog Queering Autism responds to Lovaas’s claims by stating, “No visible signs of autism does not! = not being autistic. It just means that the autistic person has better learned how to fake ‘normal,’ which I know from experience to be hugely stressful and exhausting. How wonderful” (Queering Autism, n.d.).

The real danger in a normalization strategy, as this comment highlights, is not in *whether* it is successful, but in *what* it is successful at achieving. Bumiller (2008) argues that the harmful subtext of efforts to alter autistic behavior is not only that atypical behavior is thereby stigmatized as disordered (rather than probed for meaning), but that, by the same token, typical behavior is valorized in the service of the implicit goal of creating good workers and consumers in harmony with the capitalist values of industrialist Western cultures. This effort is not unique to autistics but reverberates throughout critiques of normalization models from disability activism initiated in the 1990s.

The tendency to pin remediation efforts on conformity to a socially constructed notion of normal is particularly strong in the case of autism, a “disability” that is “medically defined by an inability to understand social convention” (Bumiller, 2008, p. 976). Bumiller (2008) chronicles the “enormous pressure” on parents to modify children’s behavior in a world where “even relatively minor differences in social behavior are met with disapproval and rejection, and are sometimes grounds for exclusion" (p. 977). Nowhere is this potential for exclusion played out more fiercely than in the label-generating and life-course altering bureaucracies of special education policy and practice.

Answering Autism: Implications for Educational Interventions

Using a constructivist framework, the first two sections of this introduction set out to make the case that the deficit model of autism is a culturally constructed understanding originating in a Cartesian notion of disability as located within affected individuals, rather than at the level of individual-context interaction. This Cartesian worldview, whitewashed with a veneer of scientific classification (for example, into "high" and "low" functioning) has been reinforced by the medical model assumptions promulgated by successive editions of the DSM. This medical model construction of autism emphasizes the syndrome as a collection of behavioral departures from social norms (e.g., social impairment and repetitive behaviors), while ignoring important neurological aspects of the experience of autism related to sensory perception and processing and motor differences. A behaviorally-defined deficit-based construction of autism leads necessarily to treatment approaches that focus on externally observable behaviors, targeting such behaviors for extinction through feedback and behavioral conditioning. Within this deficit-based paradigm, a related assumption is that the ideal treatment outcome is a change in the behavioral presentation of individuals that is as "normal" as possible.

The Neurodiversity Movement described in the third section of this chapter proposed an alternative conceptualization of autism. This conceptualization uses a disability studies perspective to interrogate socially construction notions of difference and to critique conceptualizations that locate the challenges of autism within individuals. A neurodiversity-based stance regards autism as a neurologically different way of being rather than a condition of disablement (while maintaining the idea that autism may include aspects of disability). A neurodiversity stance proposes that the challenges of the autistic experience lie both within individuals *and* in the interactions between autistics in contrast to medical model culture which attempts to define autism solely from a deficit-based framework. A neurodiversity-based stance proposes that autism interventions should be based in a worldview which values and respects autism as a way of being rather than a disability, and should place primary emphasis on the voices of the most important stakeholders—autistics themselves. Such a stance addresses the autistic experience at the systemic and structural level as well as attending to the expressed desires of autistics in supporting those aspects of their experience in which they most need intervention. One of the most salient examples of an area of need for intervention that is largely ignored within a deficit-model DSM-informed stance are the differences in sensory perception and processing (and by the same token, the interactional and motoric outputs that flow from those differences in processing) which can contribute so significantly to challenges in functioning in all other domains.

The third section of this introduction concluded with a discussion of current practices in the field of autism treatment and the potential for harm represented by behaviorist models based in a deficit worldview. One of the arenas in which the large differences between a neurodiversity stance and a deficit conceptualization play out in practical terms is the general education classroom. The final section of this introductory chapter will outline the impact that the changes in autism prevalence reporting and federal law have had on the U.S. educational system, with particular attention to requests for greater support from general education teachers in meeting the challenges of autism inclusion. This section will suggest that the types of educational interventions that can best meet the needs of both teachers and autistic students operate from a conceptualization of autism as a neurological difference rather than a deficit based medical model conceptualization.

The literature review in Chapter II will expand the foundation for a paradigm shift in educational interventions for autistic students by documenting the current state of strengths-based research into autism. This analysis of the literature will make the case that few resources were found that incorporate both current neuroscientific understandings of autistic functioning and a neurodiversity-informed worldview into practical and applied teaching guidance. To begin to meet this need, this project-based dissertation has designed and piloted a teacher training resource created with the dual purpose of providing (1) research-based information on autistic functioning from a neurodiversity perspective to support a paradigm shift in educational approach and (2) practical and concrete guidelines for applying a neurodiversity paradigm in the classroom.

Autism in the American education system. This final section of the introductory chapter makes the case that the general education classroom in the American public school setting represents an area of critical need in terms of supports for autistic students. Whatever the social and cultural mechanisms at play in the recent rapid increase in autism diagnoses, there is no question that the rise in documented prevalence is having enormous impact on educational systems, not only in industrialized nations but increasingly around the world (Grinker, 2007). Part of the increasing demands on United States public educational services have been driven by changes to federal law such as the Americans With Disabilities Act, section 504 (1973), which states:

> No otherwise qualified individual with a disability…shall solely by reason of his or her disability be excluded from the participation in, be denied the benefits of, or be subjected

> to discrimination under any program or activity receiving Federal financial assistance.
> (http://www.ldonline.org/article/6108)

More specifically, the 1975 Individuals with Disabilities Education Act (IDEA) mandated that students with disabilities receive the opportunity for a "free and appropriate public education in the least restrictive environment" (U.S. GPO). The emphasis on "least restrictive environment" has fueled an increasing push toward inclusion in general education settings for all special education students including those with autism.

The statistics on autism in general education settings can be surprising even to those familiar with the issue: in 1994–1995, the first year to list autism as a separate category, 10.8% of students with an autism diagnosis received some or all of their educational services in a general education setting. 15 years later, in 2010–2011, that number was 90.7%, with the largest service delivery group in fully mainstreamed placements (U.S. Department of Education Institute of Education Sciences, 2010). While this increase was due in part to a greater number of highly verbal autistic students being diagnosed and included in special education (Grinker, 2007), those in the upper end of the bell curve tail alone cannot begin to account for an 80% increase in inclusion, which has been driven more by change in law and policy than by diagnostic shifts.

Increased understanding and diagnosis of autism made possible by active research focus, combined with the profound shifts in educational approach initiated by such laws as the IDEA, have created a perfect storm of converging needs and limited resources in which it is increasingly clear that Western educational systems are not keeping pace. Calls for action have appeared not only in academic publishing (e.g., Batten, 2005; Connor, 1999; Sansosti & Sansosti, 2012), but also in the mainstream press.

In 2011, for example, *Education Week* called for general education teaching competencies for teaching students with autism, citing the "severe shortage of teachers qualified to teach students on the autism spectrum" (McCulloch & Martin, para. 7). An in-depth report in the Atlantic citing the exact demographic trends identified in the opening sections of this dissertation highlights lack of teacher training for general education teachers as one of the greatest obstacles to learning for special needs students, and reports that most teacher trainees receive one or fewer classes in the teaching of special needs in their teaching preparation programs (Mader, 2017). Academics document similar findings (Robertson, Chamberlain, & Kasari, 2003). Even the U.S. Congress has gotten into the act, with Virginia Representative Jim Moran (D) introducing a bill—the "Autism Understanding and Training In School Methodologies for Educators Act of 2012" (or the "AUTISM educators act," H.R. 5195; *Govtrack*, 2012—as of this writing, this bill has not passed out of committee).

Teacher training: A critical need. While education programs for pre-service teachers have the ability to adjust to the changing enrollment landscape and are showing signs of doing so (Mader, 2017), perhaps the greatest training need is experienced by currently practicing general education teachers who, with the exception of occasional continuing education workshops, are beyond their active training years. In a recent survey of educators in Virginia, for example, educators expressed a need for help in increasing their ability to meet the needs of students with autism—on that survey, 90% endorsed a desire to utilize more training through their schools (McCulloch & Martin, 2011).

Delivery of training to currently serving educators is not without challenges, however. Experiments with the creation of training programs for currently serving teachers have been documented in the psychological and education literature, including approaches such as intensive on-site training programs (Jones & Howley, 2010), blended instruction (online and in person), continuing education credits in Applied Behavior Analysis (Roll-Pettersson & Ala'i-Rosales, 2009), and distance education for special education teachers and parents (Wainer & Ingersoll, 2013). Money for special training programs such as these has tended to be focused on the needs of students with more severe behavioral symptoms and the needs of teachers who work with them (e.g., special education teachers). Many of these programs require a significant investment of time, and frequently (especially in the United States), personal financial investment on the part of teachers. What has not been documented in the literature is attempts to provide distributed (e.g., location-independent, technology-based) training resources for general education teachers serving mainstreamed autistic students, that can be accessed online for minimal investment of time and funds. The review in the next chapter includes a section that investigates possible platforms for resource distribution, including teacher trainings and distributed (online) resources.

A new approach to teacher training. As has been demonstrated in the foregoing sections, the current American approach to educational services for autism is grounded in a medical model deficit-based view that pervasively colors curricular planning, classroom dynamics, and student assessment. That stance has generated approaches to intervention that almost exclusively attend to providing instruction for managing the behavioral challenges of autism, rather than creating improved educational supports for the cognitive development and academic learning of autistic students—to put it bluntly, the academic resources available on the web are nearly all behavior plan and hardly any lesson plan.

The existing available curricular approaches have three prominent weaknesses: First, these approaches seem to rest on a largely unquestioned but highly suspect assumptions that autistics learn just like typical students. Second, they channel educational interventions toward an area of autistic weakness (behavioral regulation), ignoring areas of cognitive strength (see review in Chapter II), thereby tacitly reinforcing a deficit view of the syndrome and failing to support areas of cognitive strength. Finally, a behavior-before-content approach contradicts the educational truism that exciting and motivating curriculum content is an essential component of effective classroom management. What is needed, this dissertation argues, is not more behavioral management techniques (plenty of those exist already), but rather a redesign of the theoretical framework from which those techniques are delivered—a redesign informed by a more complete understanding of autistic perception and cognition. The foundation of such an alternate view must rest upon a deconstruction and re-envisioning of the deficit model of autistic functioning.

Grounded in the alternative theoretical framework put forward by advocates for a neurodiversity worldview, the teacher training resource developed as part of this project is informed by an autism-as-difference conceptualization and is organized with respect for the strengths of characteristically autistic modes of thinking (rather than assuming that autistic students learn just like neurotypical students). In addition, the teacher training module suggests structural supports and pedagogical approaches to address autistic vulnerabilities through increased awareness of sensory processing issues (change the context), rather than primarily a behavioral management approach (change the child). As mentioned above, because available web resources for educators of autistic students are strongly focused on behavioral aspects of autism, the teacher training materials developed for this project provide a much-needed focus on autistic perception and cognition and how these create a context for understanding autistic behaviors as meaningful and functional targets for instruction rather than simply as undesired behaviors to be targeted for extinction.

Finally, this dissertation project is based on the belief that web-based resources and teacher training materials should meet the needs of educators in a manner that is immediately applicable, easily digestible, and grounded in the real experiences of teachers in their classrooms. The training materials promote a pedagogical philosophy for autism inclusion students grounded in the constructivist framework elucidated in this Introduction chapter. The materials offer explorations of divergent neurological functioning and related curricular intervention guidelines grounded in the empirically-supported, strengths-based conceptualization of autism that will be further explored in the literature review in the next chapter. In order to better meet teacher needs, the training materials were developed through an action research process in consultation with a group of end-users—currently teaching classroom educators.

Process of developing the training materials. As an Action Research project, this project was designed to be responsive to teacher needs by being flexible in format. Originally, the primary product of this project-based dissertation was envisioned to be a web-site based collection of online resources and a platform for professional sharing and collaboration (e.g., a lesson plan sharing platform). As a result of early negotiations with the on-site stakeholders (the educational staff of a small independent school), the project evolved from a primary emphasis on web-based materials to a focus on in-person teacher training materials and discussion. As detailed in the Results and Discussion chapters (Chapters IV and V), the collaborative discussion portion of the teacher training intervention appeared to be as important and influential for the participants in terms of crystalizing new understanding, as the two-hour informational presentation that preceded it. The collaborative experience of creating and participating in this type of experientially-linked training and discussion with a group of highly invested stakeholders suggests not only that there is a hunger for strengths-based, cognition-focused interventions for autism, but that interpersonal interaction remains a powerful and preferred method of learning for educators. That said, participants eagerly welcomed the idea of online web-based resources based in a neurodivergent understanding of autism.

Chapter II: Review of the Autism Literature

As one of the most common neurodevelopmental disabilities and a focus of a great deal of social and political energy, autism research has become one of the best funded and active areas of psychological and educational investigation. In the decade preceding the publication of the *Textbook of Clinical Neuropsychology* in 2008, Stefanatos and Joe estimate that nearly 4000 articles concerned with understanding autism had appeared in scientific journals—a volume representing an iterative doubling of output over each of the four consecutive decades documented. At the time of the writing of this dissertation, an informal perusal of the search term "autism" in the PsychINFO database suggests that the half decade or so since the estimate made by Stefanatos and Joe has seen easily another doubling. With this intensity of research attention, autism has become far too extensive a topic for even the most ambitious review to address in any kind of comprehensive way. Any useful inquiry, therefore, must be narrowly and specifically focused; the current review takes as its area of inquiry the strengths of autistic neurology[20] and the implications of a strengths-based approach for creating effective educational interventions.

Most psychological research in the past has operated from a deficit-based perspective informed by the DSM definition. A huge portion of the autism literature, for example, has been focused on elucidating the core pathology of autism by investigating the various observed symptoms and traits of the disorder, rather than focusing on the strengths of autistic functioning. The first half of this chapter therefore situates research on autistic strengths within the core deficit conversation by summarizing the three leading theories of autism etiology. These three theories are, the "Theory of Mind" deficit hypothesis, the Executive Functioning deficit

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[20] "Autistic neurology" is used here because of its common usage in the autistic community as an identity term. For example, autistics sometimes speak of "feeling discriminated against due to my neurology."

hypothesis, and the Weak Central Coherence hypothesis. The psychological research community has not reached consensus on any of these three theories as being the single "core deficit" underlying autism because each hypothesis has generated disconfirmatory evidence.

Given the lack of consensus and the increasing sense of urgency surrounding autism, innovative new researchers from both inside and outside the psychological research community have suggested revolutionary new ways of understanding both the causes and manifestations of autism. The second half of this chapter explores four recent theories for the etiology of autism, all influenced to a greater or lesser degree by the recent strengths-based perspectives that have emerged to counter the deficit-informed accounts of older DSM-based conceptualizations.

Finally, because this dissertation proposes that web based resources offer one possible route for making available improved education for autistic students to general education teachers, and because the internet is a useful and frequently used platform for offering resources to educators, a brief review of web resources was conducted. As it was impossible to review resources on the web according to the conventions of academic research standard for academic papers, the web review is not included in this literature review chapter but rather appended at the end of the dissertation (see Appendix A[21]).

The main purpose of the web review should not be thought of as a review of current web literature, so much as an impressionistic snapshot of availability of web-based resources in a specific area of autism resources for general education teachers at one moment in time. The "web review" makes the case for a need for educator resources by documenting the general paucity of online resources designed specifically to address the domains of autistic perception and cognition

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[21] Note: Because the citation of resources on the web represents a non-standard use of citations for an academic paper, and because information on the web is subject to rapid change and evolution, it should be noted that those citations are not included in standard "literature review" format but rather included more as a kind of data in and of themselves.

and their implications for practical application (specifically, the web review demonstrates a general lack of resources that instruct educators how to use neurologically-informed understandings of differences in autistic cognition and learning to support effective lesson planning and instruction).

Parameters of the Review

As noted already, the field of autism research is far too vast to cover in any one summary. Because the overarching goal of this review is to promote a paradigm-shifting understanding of autism, this review primarily focuses on one particular aspect of autism: the phenomenon of exceptional strengths frequently called "islets of ability" or "slinter skills." Exceptional abilities in autism are increasingly understood to be not only associated with, or emblematic of autism, but more fundamentally, to be a core defining feature of the syndrome (Happe, 1999; Mottron et al., 2012). The study of exceptional strengths is fascinating in and of itself, but ultimately the study of disparate strengths across the spectrum[22] may serve a larger function in contributing to a case for an entirely new understanding of autism.

Accordingly, the first half of this review chapter begins by examining individual findings of exceptional strengths that offer disconfirming evidence for the historically proposed theories of autistic "core deficits." The second half of this chapter follows the implications of these anomalous findings into the new territory of some of the most exciting new proposals for theories of autistic functioning. The Introduction chapter of this dissertation built a historical and

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[22] One of the hallmarks of autism that diagnosticians look for is the so-called "sawtoothed profile" of abilities—that is, larger than typical difference in abilities in various domains, especially a difference between verbal abilities and perceptual abilities. Analysis of IQ results at the level of comparing performance on individual subtests using tables that indicate the frequency of atypically large disparities. Such analysis can help bring to light, on the one hand, unusual degrees of impairments such as slow processing speed or delays in motor development, in the presence of otherwise high performance, especially on perceptual or pattern recognition tasks.

political case for the need to re-envision autism through a lens of difference rather than deficit. This chapter examines trends in the literature to demonstrate that some specific threads in the field of empirical research, for different reasons and along different paths, are coming to very much the same conclusion.

Before diving into this very specific subset of the literature, however, it is worth pausing for a moment to remember the intended stakeholders in this training resource project—teachers in general education classrooms, and ultimately autistic students such educational interventions are intended to serve. The previous chapter detailed how a strengths-based perspective answers the needs of autistics, but it remains relevant to ask: is a strengths-based perspective on autism one that will best serve general education teachers? Might it be the case that such educators would benefit more from training in the vulnerabilities and areas of impaired functioning in autistic students? This review proposes that there are three compelling reasons, from a pedagogical perspective, to frame an investigation of autism from a strengths-based perspective:

First, an appreciation for strengths counters stigma. Any poorly understood syndrome brings with it a stigma of difference and challenge, and autism certainly falls into that category. General education teachers fill an educational role that already demands a great deal from its practitioners. Increases in inclusion mean such teachers are now faced with challenges of which they may have little understanding and for which they have few institutional supports. Depending on when they were trained, mainstream inclusion of atypical learners may not have been a teaching demand that teachers prepared for or even considered during their pre-service training (Mader, 2017). Due to the deficit focus of the DSM, information about autistic deficits currently dominates available resources on autism, not to mention popular media, and likely constitutes the majority of what general education teachers have encountered. A strengths-based understanding of autism can help reframe the profile of autistic students to an understanding of autistic functioning that brings assets and strengths as well as challenges—a perception that may foster more positive attitudes toward autistic inclusion among general education teachers.

Second, teaching to student strengths powerfully engages learners. An understanding of the unique and characteristic strengths of autistic students may help inform generative pedagogical practices that take as their target the fostering of aptitudes as well as the remediation of deficits. While remediation is the dominant focus of most special education interventions, there is broad consensus among educators that engaging students where they are most motivated and capable is a better way to help them thrive academically. In a syndrome that is poorly understood in general, autistic strengths are one of the least understood and least studied aspects of the condition. A better understanding of what autistic people do well can not only help educators to design better, more targeted curriculum, but can help peers learn greater respect for autistic students, and help autistic students increase their self-knowledge and enhance their resilience.

Finally, when better understood from a neurologic foundation, autistic deficits can actually be understood as strengths. From a psychological research perspective, some of the most exciting work on neurological functioning in this elusive, multi-modal syndrome is emerging from the area of strengths research. It is becoming clear that some of the best-known deficits of autism, when better understood from a neuropsychological and sensory processing perspective, can be viewed as some of the greatest assets. Therefore, the study of deficits actually includes within it the study of strengths (though from a new and different perspective).

This project takes the stance that, as highly trained professionals, educators are the most appropriate and best equipped providers when it comes to designing their classroom culture, creating effective learning experiences for their students, and making decisions about specific interventions for autistic students. In providing effective educational experiences for autistic students, what educators need from the field of psychology is not a lesson in how to do their jobs, but rather an accessible and empirically supported understanding of the neurology of autism and its implications for autistic perception and cognition (teachers do not need more fish, they need to know how to fish for themselves). The next section of this review therefore summarizes the most influential historical theories and most exciting emergent hypotheses in light of autism strengths findings with the purpose of providing detailed and relevant neuropsychological information for educators on the current best understandings of autism in the psychological research with the ultimate aim of translating that information into practical educational applications into applied pedagogical practice.

Disease Model Research and the Search for the "Core Deficit"

Since the original delineation of the autism syndrome in the 1940s by Leo Kanner, many models have been advanced to explain the heterogeneous, enigmatic patterns of atypical performance that characterize autism. Most of these theories have sought to determine a single "core deficit" which can explain these disparate impairments and atypicalities. The vast majority of the research on autistic functioning, emerging as it does from a deficit-model paradigm, has focused on impaired rather than enhanced abilities, however, a few threads of recent work have begun to reverse this trend (e.g., Biklen & Burke, 2006; Mottron, Peretz, & Menard, 2000; Winter-Messiers, 2007).

In the last three decades, the various influential hypotheses modeling the underlying neural substrates of autism have coalesced into three main theories which currently dominate autism research: the theory that autism is caused by a deficit in Theory of Mind (ToM), that is, a deficit in the ability to impute mental states to oneself and others (Baron-Cohen, Leslie, & Frith, 1985), the executive function (EF) hypothesis, which contends that autistic symptoms are a function of deficits in ability to plan and monitor complex actions (Ozonoff, Pennington, & Rogers, 1991), and the weak central coherence hypothesis, which conceptualizes autistic dysfunction as a tendency to focus on local details at the expense of global wholes (Happe & Frith, 2006).

Each of these theories has been extensively researched, generating enough confirmatory results to influence continuing research investigations on all three hypotheses. However, in each case, contradictory evidence has emerged to the extent that none has been fully endorsed by the autism research community as *the* "core deficit" so assiduously sought. Because these theories would not have the influence they do without substantial support, this review will presume they are well-described already, and leave the summarizing of confirmatory findings on autism deficits to others (e.g., see Schmitz & Rezaie, 2008, for a comprehensive review). As has already been indicated, the current review will instead examine examples of disconfirming evidence that has emerged in contradiction of these deficit-based conceptualizations.

Historical Review: Challenging the Three Influential Theories of the Etiology of Autism

"Theory of Mind" deficit hypothesis. The Theory of Mind (ToM) model was the earliest of these three hypotheses to be put forward (Baron-Cohen, Leslie, & Frith, 1985). Deficits in the ability to form a "Theory of Mind" (ToM) are often measured by a "false belief" task to determine if the subject is able to understand that others may have false beliefs because they lack information on the true state of affairs as known by the subject (Stefanatos & Joe, 2008). The "Sally Ann" unexpected transfer test is a well-known version of this task (Ann puts an item in a box. Sally moves the item from the box to a basket while Ann is out of the room.

Typically developing children tend to realize that when Ann returns, she will look in the box where she left the item, while children with the hypothesized ‘poor theory of mind’ are more likely to believe that Ann will look in the basket where the test subject knows the item actually to be.)

Such a measure would be an excellent diagnostic tool if the responses of autistic individuals were consistent, however, even the original proponent of this model acknowledged in a review, a decade after her original publication, that failure rates for autistic children on ToM tests vary as widely as 40% to 85% (Happe, 1995). Findings such as these have led researchers increasingly to conclude that the Theory of Mind hypothesis may, in fact, describe heterogeneous skills sets which are not unitary constructs, and which may follow widely varying developmental trajectories (Robinson et al. 2009).

Nor does Theory of Mind appear to be consistent across domains of ability. A recent study on inner dialog in autistic children conducted by the original proponents of ToM (and others) provides evidence that suggests at least some preserved ToM abilities in autistic children. Participants were 25 children diagnosed with ASD (of whom three were female), and 20 moderately learning disabled children, (of whom five were female). Subjects were matched for chronological age, verbal mental age, performance IQ and full scale IQ. Drawing on Vygotsky’s notion that inner speech, as an internalization of external dialog mediates higher metal functions (Vygotsky, 1962, as cited in Williams et al., 2007), the researchers suggested that if the transition to dialogic modes requires adequate experience of interpersonal relations, autistic children would be expected to make use of inner speech for problem solving in a more limited way. The research design took advantage of the “phonological similarity effect.” This is an effect where phonemically similar items are better retained in short term memory than visually similar items and is taken to be an artifact that is a robust indicator of inner speech (Hitch, Woodin, & Baker, 1989). The investigators presented the participants with three serial recall tasks and found that, rather than demonstrating deficits, autistic children showed no significant difference in performance as compared to learning disabled children in the use of inner speech to assist in recall, as long as children were matched for verbal mental age (as measured by verbal IQ on the WISC III). These researchers concluded that use of inner speech as a problem-solving strategy appeared to be intact in autism.

Another way that has been used analyze ToM is to evaluate subjects' ability to assess the mental states of others based on their ability to process emotional information observed from facial data. A study by Krysko & Rutherford (2009) examined the ability of autistic adults to detect threatening faces in a crowd as an indication of facial processing efficiency. The study took advantage of the "anger superiority effect" (Ashwin, Wheelwright, & Baron-Cohen, 2006) in which angry faces are detected more quickly than faces displaying other emotions, (presumably due to the evolutionary advantage of keen ability to perceive threat). Participants were 38 males with "high-functioning autism" (HFA) ranging in age from 20 to 54 with a mean age of 29.3, and 19 males with a history of typical development (TD) between 20 and 46, with a mean age of 28.6. Subjects were matched on full scale IQ (FSIQ) as measured by the WAIS III. The study found that autistic men showed ability on threat detection tasks equal to that of TD men, demonstrating both similar reaction times and similar accuracy. The only impairment found was that the autistic subjects' accuracy declined when presented with large crowd sizes. The researchers noted that the experimental design was not sufficient to determine if autistic subjects were using a typical or an atypical processing strategy, but suggested that an atypical processing strategy might explain the decay at larger numbers. It is also possible (though not addressed by the researchers in their discussion) that such impairment could be a result of an unrelated capacity issue such as limits to working memory or the sensory/emotional overload of processing so many faces.

The ToM hypothesis predicts that autistic children will not only fail to impute mental states to others (cognitive knowledge), but will show impairment in processing and understanding others' emotions (affective awareness). A study on ability of autistic subjects to recognize emotions in others examined the ability of autistic children to recognize and report both "non-social" and "social" emotions in others (Williams & Happe, 2010). This study compared 21 "high functioning" students diagnosed with autism (IQ above 70) to 21 children with general learning disability (the ages of the subjects were not given). The test group included subjects with a diagnosis of autism (n = 18), Asperger's Disorder (AD; n = 2), and PDD-NOS (n = 1). All autistic subjects attended specialist autism schools, while all LD students attended schools for children with developmental and special education needs. The study was designed to replicate seven recent studies finding that "high functioning" autistic individuals (IQ above 70) have preserved ability to recognize "non-social" expressions in photographs of faces ("social" expressions were defined to be those dependent on social context and meaning such as embarrassment, pride, and guilt, as opposed to "basic" emotions like fear, happiness, and sadness). The researchers noted in their review that several other studies have suggested that even with preserved ability to recognize non-social emotions in others, autistic children process "social" emotion atypically and may not connect it to their own experience. This study sought to distinguish the ability to *recognize* interpersonal or "social" expressions from the ability to *process* and *understand* the observed emotion (as evaluated through provision of a relevant and coherent narrative), as well as to delineate level of impairment in each domain. Contrary to expectations, the researchers found *no* difference in level of impairment between the two groups. Although the researchers did find a significant correlation between ability to describe emotion in self and the ability to recognize emotion in others in both groups, their hypothesis that autistic children would show impaired ability to process and derive meaning from social emotion was decisively not supported by the data. In other words, ability to recognize and understand emotion in others was preserved in the autistic subjects.

These four studies have provided evidence that the ability to impute and reflect on the mental states of others (which the ToM hypothesis would predict to be impaired in autistics) is, on the contrary, at least partially preserved, does not reliably distinguish autistic from non-autistic subjects, and furthermore may vary greatly between subjects independent of ASD status. Additionally, ToM abilities such as accurate performance on unexpected transfer tasks have been found to be more plastic and amenable to training in autistic individuals than originally thought (Krysko & Rutherford, 2009; Pellicano, 2010). Though some researchers clearly believe that the Theory of Mind construct remains a useful frame for inquiry, enough variability in ToM abilities in people with autism has been demonstrated by studies such as these to cast doubt on the unitary nature of the construct.

"Executive functioning deficit" hypothesis. Another candidate for the proposed "core deficit" in autism is the hypothesis that autism symptomology can be explained by a deficit in executive functioning (EF). EF includes a variety of higher order cognitive skills used in problem solving and attainment of goals including planning, working memory, mental flexibility, response initiation, response inhibition, impulse control, and self-monitoring (Robinson et al. 2009). Planning and execution can be measured by tasks such as the Tower of Hanoi (TOH, a subtest of the D-KEFS; Delis, Kaplan, & Kramer, 2001) while instruments such as the

Wisconsin Card Sorting Test (WCST; Grant & Berg, 1981) give an indication of cognitive flexibility (ability to shift cognitive set). As with ToM, deficits in EF in autistic subjects have been extensively replicated (see Hill, 2004, for a review), however, recent research is beginning to suggest that EF, like ToM, is likely a multi-dimensional ability construct with areas of intact performance and a pattern of impairments more closely correlated with IQ—especially verbal IQ—than with autism status.

One study providing a closer examination of EF skills emerged from an attempt to reconcile the divergent literature findings on impaired verses intact inhibition in autistic children (Adams & Jarrold, 2011). Participants were 15 children with ASD (12 male), 15 children with moderate learning disabilities (7 male), and 15 typically developing children (4 male) all matched for non-verbal mental ability. All participants were between 6 and 12 (with the TD group skewed younger to facilitate mental age matching).

The researchers theorized that the divergent findings on EF performance might be due to conflation of two types of inhibition—prepotent response inhibition[23] on the one hand and resistance to distractor inhibition on the other. Accordingly, the researchers measured their participants on two tasks—one a "stop-signal" task to measure inhibition of prepotent response (ability to disengage from a behavioral pattern at will, once established), and one a "flanker task" to measure resistance to distractors (ability to continue an intended behavioral pattern despite attentional disruptions). The researchers found that autistic children did not differ from controls in prepotent response inhibition when matched for semantic knowledge, however, the subjects

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[23] Prepotent response inhibition is the ability to inhibit an established response. For example, in a test that mostly flashes large X's on a computer screen, a test subject might be asked to hit the space bar every time an X appears on the screen, but not for any other letter. Refraining from pushing the space bar in those infrequent non-X cases involves the ability to inhibit a "prepotent" or *habituated* response.

did differ significantly on the flanker task, and unlike the TD children, showed no benefit from increase in target size or target distance from distractors. The investigators concluded that inhibition can be fractionated into different systems, but that prepotent response inhibition specifically appears to be intact in autistic children. The researchers also observed that autistic children were in fact *better* than TD children at discriminating target from distractors when perceptual load was high. The researchers argued that this finding suggests that impairment on the flanker task may have been one of impairment in executive function ability to control focus rather than impairment of inhibition—if lack of inhibition *only* was responsible, it should have shown up as impairment on both tasks. In other words, the lower resistance to distractors was due to greater perceptual capacity or "a greater tendency to process interfering distractors rather than a deficit in the ability to inhibit interference that these distractors cause" (Adams & Jarrold, 2011, p. 1062).

In addition to response inhibition, the areas of planning, mental flexibility and generativity have also produced mixed findings, especially when research is concentrated on autistic children who test as having normal level IQ (Robinson et al., 2009). In a large study attempting to remedy the lack of well controlled research in these areas, the Robinson team (2009) used four commonly used EF measures to assess a large pool of participants (n = 54 HFA, n = 54 TD, 12 of each female, the rest male; matched for age, FSIQ, receptive vocabulary, and gender). To test planning ability, the researchers used the Tower of London (similar to the TOH);[24] for mental flexibility, the WCST;[25] for response inhibition, a computerized version of

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[24] These two tests involve three pegs and five disks of graduated size. The goal is to move the disks from an original arrangement to a target formation on a new peg arranged from smallest on top to largest on the bottom. There are two rules: you may move only one disk at a time and you may never place a larger disk on top of a smaller one. Ability is measured both by number of

the Stroop test[26] as well as the Junior Hayling Test[27] and for generativity, a verbal fluency task similar to subtests on the Delis-Kaplan Executive Function System (D-KEFS).[28]

The researchers found significant impairments in the autistic group on planning and inhibition, but preserved performance on mental flexibility and generativity. Their results teased out some interesting and surprising patterns on the last two measures in the autistic group: for example, they found preserved ability to switch cognitive set on the WSCT combined with poor ability to self-monitor using feedback. On the verbal fluency task, they found generativity rates equal to the performance of TD children, that unexpectedly included a larger number of perseverative responses (in other words, equal performance was maintained due to a larger number of responses overall even though a larger number were repeats than for the TD subjects). Both of these performance patterns suggest preserved output ability despite a tendency toward higher numbers of perseverative responses—in other words, the autistic group's performance suggested the possibility of *superior* ability (relative to TD children) tempered by a tendency toward perseverative responses. The researchers suggested that this performance pattern may be

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moves and by duration of time to solution, with longer planning time before starting taken to be indicative of better developed executive functioning.

[25] The WCST is a test involving sorting cards with colored symbols by attribute (color, number, shape). No directions are given other than "I will tell you if you guess is correct or not." The rule governing the determining attribute changes every ten cards. Performance is evaluated both on flexibility of rule testing attempts (e.g., perseveration on an incorrect solution shows poor cognitive flexibility) and ability to rapidly perceive an underlying rule change and "switch set" (this is taken to indicate ability to be responsive to changing conditions).

[26] The Stroop test is a test of response inhibition. Each test relies on the tendency of the human brain to favor certain types of responses—for example, the dominance of the left hemisphere (which includes verbal processing) over the right (which includes visual). That initial response pull must be resisted to be successful on the test. On the Stroop test, subjects must, for example, indicate the ink color in which a name of a color is written, rather than the color word itself. Performance is gaged by both speed and accuracy.

[27] A sentence completion task measuring cognitive flexibility in the form of speed of generating creative responses.

[28] A listing task measuring cognitive flexibility in the form of divergent thinking; for example: in the span of one minute, name as many examples of a category as possible, (e.g., "animal").

explained by impairment in the ability to self-monitor performance (e.g., poor ability to remember or filter out responses that had already been given) rather than atypicallity in the underlying EF ability in question (mental flexibility and generativity, respectively). Overall, the team concluded that their heterogeneous findings on the four EF measures further support the notion that executive function is a multidimensional construct with distinct cognitive components following independent developmental trajectories. The suggestion of perseverative responses as a unique and poorly understood facet of autistic cognition, which complicated but did not ultimately impair performance, emerged as a fascinating but not well understood outcome of this research.

“Weak central coherence” hypothesis. The third theoretical contender for the “core deficit” in autism is the weak central coherence hypothesis (WCC), characterized by an observed and atypical tendency in autistic individuals to focus on local detail rather than the gestalt of the whole (Frith, 2003; Happe & Frith, 2006). The central coherence deficit model “predicts a local bias that results from an imbalance in the integration of information at different levels” (Mottron et al., 2000). This tendency was proposed by Mottron, Belleville, & Menard (1999) as a hierarchization deficit (HD) or impairment in the ability to integrate elements into higher levels of organization, leading to compensatory emphasis on elementary perceptual functions.

Interestingly, the features attributed to WCC (that is, a tendency toward enhanced local processing) have been consistently conceptualized in the literature as impairment, even though such “symptoms” have been documented in autistic subjects through evidence of *superior* performances on visuo-spatial tasks such as finding hidden patterns, being able to mentally segment and manipulate pattern components, or the ability to reconstruct patterns from incomplete information. This enhanced pattern recognition performance has been taken to be a function of superior ability to pre-segment designs into constituent parts (Pellicano, 2010). Findings of superior performance have paradoxically been interpreted as deficits in this model because initial findings suggested that high performance on such "low level" processing may come at the expense of global integration and contextualized meaning (Mottron et al., 2000).

In order for the WCC hypothesis to fit the criteria for a core deficit explanatory account of autism, evidence of atypical processing must be evident across domains (Pennington & Ozonoff, 1996). While several studies have identified an emphasis in local processing in visuo-spatial modalities, (further explicated below), Mottron et al. (2000) conducted a study to determine if local processing effects in autistic subjects would be evident in the domain of music processing. Participants were 13 non-savant children and adolescents with "high functioning" autism (HFASD) and 12 TD participants matched for age, non-verbal IQ (on the WAIS or WISC), and laterality (handedness). To ensure ability to perform the task and to avoid complication by intelligence factors, all participants were 10 years or older, and of normal intelligence (FSIQ greater than 80). The participants were given a complex task of identifying variations in musical features despite transformations across pitch (e.g., transposition). While the WCC hypothesis would predict poor global and enhanced local functioning, the investigators in fact found that both group's performances showed a global processing advantage—changes in pitch did not obscure their perception of melody contour similarity. This finding was interpreted to indicate that autistic participants had intact processing of global music features.

In addition to intact global processing, ASD subjects outperformed TD subjects in the detection of modified melodies—in other words, they showed the local advantage predicted by the WCC model, but *without* the predicted global deficit. In addition, the authors noted that their findings did no more to substantiate the HD hypothesis (poor integration between levels of processing along with local-to-global interference) than previous research, meaning that the HD hypothesis remained unsupported at the behavioral level (Mottron et al., 2000).

If enhanced local processing is not necessarily related to impaired global functioning, then findings of such enhanced processing do not effectively substantiate the WCC hypothesis. It has been suggested elsewhere by the authors above (Mottron & Burrack, in press, as cited in Mottron et al., 2000) that exceptional perceptual abilities, evidenced by an emphasis on local processing, may instead be a compensatory strategy as conceptualized by Kappur's (1966, as cited in Mottron et al., 2000) Paradoxical Functional Facilitation (PFF) model (a model that explains such phenomena as enhanced auditory perception findings in visually impaired subjects—the idea that when one sense is lost the others sharpen to compensate). However, the fact that findings of exceptional perceptual performances in autistic subjects are not always correlated with impaired global processing undermines the likelihood that enhanced perceptual abilities are, in actual fact, a compensatory neurological strategy; rather perceptual abilities and global integration abilities appear to be unrelated domains. More importantly, if exceptional perceptual abilities are consistently part of autistic presentation, and if they occur across modalities, such a finding would imply that they result from a similar underlying neural mechanism rather than representing a skill-based (e.g., learned) compensation for a deficit in global processing (Bonnel et al., 2003). Simply put, superior local processing (in the form of such abilities as pattern recognition etc.) appears to be part of how autistic brains are wired, rather than some sort of acquired compensatory functioning prize for having poor processing at the global level.

Though the phenomenon of high performance on perceptual tasks requiring local processing may not be satisfactorily explained as yet, it is certainly well documented across a number of studies. Just a few examples are summarized in the following list:

- An auditory perception study (referenced above) also provided additional support for the finding of enhanced performance on elementary processing tasks with an inquiry into pitch sensitivity (Bonnel et al. 2003). Participants included 12 adolescents with HFASD (11 male) and 12 TD male adolescents matched for chronological age, laterality, and global IQ. The TD group showed the normal pattern of higher performance on a discrimination task than on a categorization task, while the clinical group performed the same on both tasks, outperforming the TD group in both cases.
- A study of visual acuity tested 15 HFASD subjects against 15 controls and found that not only did the clinical group outperform the controls, but demonstrated a mean visual acuity 2.79 times better than average. To put this in perspective, the authors note that birds of prey have a visual acuity which, on average, is only two times better than humans. (E. Ashwin et al. 2008).
- A study of spatial abilities using a human sized labyrinth[29] matched 16 HFASD adolescent males of average IQ with 16 controls matched for age, gender, education, performance IQ, and laterality (Caron, Mottron, Rainville, & Chouinard, 2004). On three route-learning tasks, the two groups performed with no significant differences; however, on map drawing, the clinical group significantly outperformed the TD group on accuracy, and on the execution of a learned route, the clinical group demonstrated similar accuracy with significantly greater speed.
- A study investigating ability to discriminate between highly similar stimuli conducted on 8 adults with HFASD and 10 controls, found that, while typical controls outperformed

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[29] How fun would that study be!

the clinical group on pre-exposed (already learned) stimuli, the clinical group did better when the stimuli were novel (Plaisted et al., 1998). Additionally, though the clinical group showed less *improvement* in their performance between the learning phase and the test phase, the researchers speculated that this was because the clinical group learned the task so quickly that they were already at a high level of accuracy during the learning phase before they even *began* the test phase.

While these studies indicate the possibility of a fascinating range of perceptual strengths in the autistic subjects studied, perhaps the most well documented area of enhanced perceptual functioning among autistics is in the area of pattern recognition. Shah and Frith (1983) first called attention to the exceptional abilities of autistic children in pattern recognition tasks when they published a study on the consistent outperformance of controls by autistic subjects on the embedded figures task (EFF). They later (1993) replicated their findings using the WISC block design subtest.[30] The researchers noted that embedded figures and block design tests, while having somewhat different demand characteristics, are basically similar in underlying skill capacity: "in both tasks, the tendency to see the whole has to be resisted in favor of seeing the constituent elements" (Shah & Frith, 1993, p. 1362).

These results have been replicated many times since, including by Jolliffe and Baron-Cohen (1997) who concluded that autistic subjects are not only more accurate on the EFF, they are significantly faster. In their introduction, written in the last year of the twentieth century,

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[30] High performance on the WISC block design subtest (sometimes only apparent when testing the limits, if processing speed is slow—a common feature of autism) is so common for autistics of normal intelligence and above, that it is one of the flags I look for to cue me to pursue more in-depth assessment when considering if an assessment client might be autistic. That said, not all autistic children perform well on the block design subtest—that it to say, as has been emphasized many times in this dissertation, autism is a very heterogeneous syndrome and there are no easy litmus tests.

these researchers pave the way for a new type of thinking about the symptoms of autism—one of the first incidences in the literature of this new conceptualization to emerge: “[The autistic subjects’] superior performance (in relation to their mental age) on the EFT therefore suggests we should not in all respects conceptualize autism as a disability, but in some respects consider it as *a different type of information-processing system*” (p. 527, *emphasis added*).

Four New Theories: Emergent Conceptualizations of Autistic Functioning

The paradigm shift presaged by the above Jolliffe and Baron-Cohen (1997) statement, has begun to change the way many researchers think about autism and in the last decade and a half. Since the beginning of the new century, several new models of autistic functioning have emerged that attempt to provide more neutral and spectrum-based models of autistic difference. The next section briefly reviews four of these newer ways of conceptualizing autistic functioning.

The “systemizing-empathizing” model. Responding to critiques of the Theory of Mind model, and seeking a description for autism that was more balanced and less pathologizing, Baron-Cohen (2002, 2003) put forward a new model characterizing autistic functioning as falling along two dimensions—empathizing and systemizing—with the former describing the capacity to understand how *people* work, and the second describing the capacity to understand how inanimate *things* work. The model places all people diagnosed with autism (and indeed all people) somewhere along a spectrum on both dimensions (Baron-Cohen speculated that autistics are generally high in systemizing and low in empathizing).

In putting forth this theory, Baron-Cohen (2003) combined the above referenced literature on Theory of Mind deficits with the evidence of perceptual enhancements discussed above, to create a new model which purported to account for the full range of autistic symptoms on a continuum which, at the upper ends, “blends seamlessly with normality” (p. 189). The empathizing-systematizing theory was based on the as yet not well-tested neuroscientific hypothesis that autistic disorders are linked to hormonal effects on the developing brain—specifically that high fetal testosterone is the biological mechanism underlying autism (Baron-Cohen, 2003). Relying on research that purported to demonstrate the distribution of female brain types as skewed toward empathy and male brains toward systemizing, Baron-Cohen (2003) argued that people with autism, as a group, were even more likely to skew toward systemizing, and that such functioning was a manifestation of what he dubbed “extreme male brain.” Baron-Cohen (2002) supplied further evidence for his two-dimensional model of autistic functioning by citing the established heritability of the syndrome and referencing family studies that showed higher concentrations of engineers and people in other lower empathy/higher systematizing professions.

Though seductive in its neat categorizations and tidy conclusions, the far-reaching extrapolations and heavily gendered assumptions in the empathizing-systemizing model raise immediate red flags. “From a feminist perspective, [this] essentialist version of autism is a disturbing reconstruction of gender and disability stereotypes in the guise of new scientific knowledge” warned Bumiller (2008, p. 973).

Bumiller (2008) pointed out that Baron-Cohen’s (2002) reductionist view was dangerous for three reasons, first, because it normalized autism (by placing us all “on the spectrum”), thereby minimizing the needs of those with significant challenges; second, because it conflated autism with maleness, suggesting that treating autism is different only in degree from the problems associated with socializing boys—a stance that “potentially reassures those who believe that mainstream education can easily respond to these children’s needs” (Bumiller, 2008,

p. 973); and third, because reducing autism to an essentialist, binary construct concerned primarily with cognition style vastly oversimplified the complexity of the condition and ignored completely the atypical sensory, physical, and perceptual aspects. Bumiller does not address the fact that equating autism with maleness amplifies the very significant issue that autistic girls are already very likely to be missed by common diagnostic practices and instruments (Szalavitz, 2016).

The impulse toward simplification is one that has been seen over and over in attempts to model, categorize, and develop standardized and empirically testable diagnoses and treatments for autism, and indeed for types of disability across the spectrum of human experience. As Bumiller (2008) has pointed out, cloaked in the rhetoric of an ethic of care, these standardized management approaches have done little to address the unique challenges of individuals, serving instead the needs of the capitalist state to categorize and control so as to reduce the disruptive influence of difference and the high costs of investing in real care: “These theories are emblematic of the kind of practices and policies that either minimize the consequences of accepting the disabled into the mainstream or justify their exclusion” (Bumiller, 2008, p. 975). Though Baron-Cohen remains extremely influential as one of the giants of autism research, his recent (2002) attempt to make a career-defining theoretical contribution to the body of autism conceptualization stands out as oddly counter-scientific, strikingly sexist, and largely unhelpful in a field that is struggling for better grounding in rigorous methodology and thoughtful research.

The “sensory-motor perspective.” In a 2010 publication, Donnellan et al. explicitly introduced their research goals with a critique of deficit-based conceptualizations and a call for an alternate perspective on autism etiology. They began their analysis with a close analysis of the function of the labels that have been applied to the unfamiliar manner in which many autistic people move their bodies (rocking, flapping, freezing until cued to move, etc.). This analysis follows how such labels inform interventions in a topsy-turvy example of how a social construct (notions of normalcy) can “create” scientific sounding theory (variations conceptualized as “deviations,” therefore characterized as deficit), which in turn drive interventions (which then target deviations for extinction through behavioral modification). Such a backward approach is common when theory is not built up from data but instead backed into from already drawn and culturally-driven assumptions. The behaviors of autism, in the very strangeness of their presentation they argued, have indeed become a screen on which the internal conflicts of the scientific observer are easily projected: if behaviors are labeled volitional, they may be interpreted as oppositional, if labeled meaningless, they may be ignored or taken as indicative of reduced cognitive capacity, if labeled avoidant (of interaction), they may be taken as indication of preference for relating (or not relating). Taken all together, Donnellan et al. (2010) stated, behaviors labeled autistic are typically targeted for reduction, and in many cases, it is simply the cultural construct interpreting the behavior that determines the socially desirable outcome and at the same time, provides the metric by which success is measured.

Explicitly setting out to challenge the primacy of research on the triad of impairments underlying these implicit constructs of deficit, Donnellan et al. (2010) identified an alternate area of challenge—sensory and movement differences—as the area of most significant and as yet, under-recognized challenge for autistic people. Critically, their investigation took as its starting point the experience of self-advocates themselves who identify “disturbances of sensation and movement [as] a constant concern, frequently constraining ability to communicate, related to others, and participate in life” (Donnellan et al., 2010, para. 7). While perceptual differences related to autism are widely included in the conceptualization of autism (e.g., see criterion B-4 in the DSM-5, APA, 2013), the moteric and somatic differences are less well known, less recognized as evidence of autism, and scantily researched.[31] Only recently have researchers begun to recognize and study patterns of impairment in people with autism in basic motor skills such as gait, posture, balance, speed and coordination (Green et al. 2009; Leary & Hill, 1996). This focus on basic motor disturbances brings an important critique of previously accepted assumptions about the condition.

For example, both self-advocates and research investigations now suggest that many "autistic behaviors" long taken as volitional and perhaps even enjoyable choices (e.g., self-stimming behaviors) may not be under full conscious control after all; moreover, atypical ways of moving may, in fact, be more neurological than psychological (e.g., due to physiologic autonomic impulse rather than driven by psychologic self-soothing, as has been assumed).[32] This

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[31] Ironically, this may be partly due to deficit model thinking itself, in which only impairments and not enhanced differences are followed. For example, the possibility that autistic people might have perceptual impairments has often been dismissed due to documented superior performance on motor tasks such as Block Design on the Wechsler Intelligence Scale for Children (WISC; Wechsler et al., 2003). Given that autism often includes a lack of ability to generalize such highly specific skills, these assumptions appear unjustified. Also, a classification system which places sensory abilities into a binary classification system of either deficit or enhancement has no way to classify a sensory ability which is *both* deficit and enhanced ability (e.g., high sensory acuity) depending on context.

[32] Even autistic people themselves may not be fully accurate reporters of the degree of volitionality of behaviors that are semi-volitional or partially under conscious control. Such behaviors can often be partially controlled for limited amounts of time through the use of high degree of attentional control, however, this is not the same thing as full volitional control, especially if little attention can be spared for anything else (such as paying attention in school or to social situations). Additionally, if a social norm has repeatedly reinforced the idea that one should be able to be in control of a behavior, one may come to believe that idea, even if the behavior is, in fact, mostly outside of conscious control. This is a message I see subtly conveyed in school settings by IEPs that imposed expectations on students regarding control of semi-volitional behaviors such as attenuated eye-contact, flapping, or other semi-volitional movements. The result is that autistic students, who are often highly perceptive and aware, internalize the adult-imposed idea that they are actively defiant and failing at what is subtly implied to be an easy task. Internalizing such a self-image is a dangerous recipe (in some cases) for *actually* becoming a defiant failure, when all routes to success are unavailable.

recognition has implications for all sorts of assumptions about autistic development. For example, if motor abilities are delayed and/or not under conscious control, does it make sense to talk about a lack of reciprocity in infant responses as a *social* phenomenon? (Thelen, 1997, personal communication, as cited in Donnellan et al., 2010).

Framing observed phenomena as neurologic symptoms rather than as autistic behaviors has profound implications for the meaning assigned to actions in assessment of interpersonal interaction abilities and therapeutic treatment approaches. In a review of the literature, for example, Leary and Hill (1996) tabulated 42 “movement disturbances” associated with established movement disorders and correlated them with analogous “symptoms” or “behaviors” of autism. To name just one example out of the 42, a movement called a “tic” in someone with Tourette’s syndrome “is most often assumed to be a ‘behavior’ (and therefore a conscious choice) in a person with autism” (Donnellan et al., 2010, para. 30). The researchers proposed that making the shift to viewing autistic behavioral phenomena as neurologic symptoms would help avoid the tendency to view symptoms from within a framework of culturally normative assumptions: “It is useful to suspend social interpretations of the symptoms so as not to mistakenly ascribe intent and volition to individuals whose behavior may be contrary to what really is intended and able to be communicated” (Donnellan et al., 2010, para. 31). At the same time as these authors encouraged the assignment of less meaning to some actions, they urged that other behaviors often considered meaningless (such as echolalia and delayed echolalia) be investigated for communicative meaning.

Such a stance, they argued, has the potential to profoundly change treatment approaches—for example, contrary to the core mechanism of the Applied Behavioral Analysis

(ABA)[33] approach, if observed behaviors could be seen as neurologic rather than volitional, an entirely different response would be called for: “reprimands and contingent praise would not be used to change a recognized neurological symptom” (Donnellan et al., 2010, para. 36). Donnellan et al. (2010) suggested instead an alternate framework for working with people with autism—one that is based on relationship, collaboration, personalization, and comfort.[34] Donnellan et al.’s work lays the groundwork for viewing the motoric and perceptual differences in autistic functioning as neurologic and innate—traits to support, seek to understand, and/or work around, rather than volitional behaviors to target for change. This understanding provides an important alternative framework for consideration of academic interventions in school settings and in composition of 504 and IEP accommodations and goals.

The “enhanced perceptual functioning” hypothesis. The Enhanced Perceptual Functioning (EPF) hypothesis, puts forward a third strengths-based model for autistic functioning (Mottron et al., 2012). Mottron and his team argued that the peaks of ability and superior perception that are often associated with the autistic phenotype are not unusual exceptions, but in fact reveal a core difference in the cognitive processing of autistic people which may extend even to the level of neural functioning—possibly as basic as, “an intrinsic modification of the learning properties at the cortical tissue level in autism” (Bonel et al., 2003, p. 231). As an illustration of this idea, Mottron et al. (2012) made the case that autistic savants are not atypical examples of the autistic phenotype but merely at the high end of a pattern of exceptional perceptual abilities and performance peaks on pattern recognition tasks manifesting

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[33] A popular treatment for “severe autism” which targets behavioral change in children up to 40 hours a week (see Chapter I for a more in-depth discussion).

[34] I would add such social model of disability approaches such as accommodation and adjustments to the environment to that list.

in a majority of autistic people, relative to their general intelligence.

In their review, Mottron et al. (2012) coined the term “veridical mapping” to describe the ability to perceive multi-level isomorphic relations—that is, to create a cognitive map of “reciprocal relation among either concrete or abstract materials which preserves their structure, despite structure-irrelevant differences” (p. 214). It is this cognitive architecture, Mottron and his team argued, which enables savants to develop their unbelievable abilities and more generally predisposes autistics to excel in the manipulation of systems displaying traits of large-scale isomorphism (similarities across levels of complexity) such as letters, notes, numbers, and units of 3-D construction. Needless to say, such neural correlates as higher connectivity between perceptual processing regions and other regions of the brain provide exciting possibilities for future research. However, a review of those efforts is beyond the scope of this paper.

The “Intense World” theory. An especially exciting new area of theory on autistic neural substrates has emerged in the last decade from the Brain Mind Institute in Switzerland. There, neuroscientists working on mapping the smallest units of processing in the brain (minicolumns) have documented direct biological evidence for the first unifying theory of the etiology and neurobiology of autism. Henry Markram, a neuroscientist working on the largest brain mapping project in the world, became interested in understanding autism in new ways as he tried to come to terms with difficulties of his autistic son whose struggles did not fit the classic deficit-based, “mind-blind” conceptualizations described in the Theory of Mind model of autism (Szalavitz, 2013). Together with neuroscientist Kamila Markram, Henry Markram has spent a decade developing a new, biologically-based model of autistic functioning that turns traditional conceptualizations on their heads (K. Markram & Markram, 2010; Markram, Rinaldi, LaMendola, Sandi, & Markram, 2008; and K. Markram, Rinaldi, & Markram, 2007).

The Markrams and their team based their paradigm-shifting theory on the observation that valproic acid (VPA, a mood-stabilizing drug sometimes used as a treatment for epilepsy and bipolar disorder), when administered to pregnant women, causes an incidence of autism in their children 11–100 times greater than in the general population. Using an animal model, the team mimicked the hypothesized neural tube insult in humans through a dose of valproic acid (VPA) to pregnant rats on embryonic day 12.5. Through this procedure, the Markrams created many of the same neural differences frequently observed in human autistics. These include (in both autistic humans and VPA-exposed rats) reduction of the trigeminal and hypoglossal motor nuclei, (that is, loss of motor neurons in the face related to sensation, biting, and chewing), loss of neurons in the abducens nucleus and in the oculomotor nucleus (related to motor components of vision), almost total loss of the superior olive, an auditory relay nucleus (involved in auditory processing—the first site of convergence of information from left and right ears), loss of cerebellar neurons (especially Purkinje cells—responsible for inhibitory control of lower cortical functions), and abnormalities in the serotonergic system (an imperfectly understood brain system with implications for the regulation of attention and anxiety). Behaviorally, the VPA-exposed rats also exhibited cardinal traits of human autism including decreased social interactions, increased repetitive behaviors, enhanced anxiety, locomotor hyperactivity, lower sensitivity to pain, hyper-sensitivity to non-painful stimuli, impaired pre-pulse[35] inhibition, and enhanced eye-blink conditioning (Markram et al., 2007, K. Markram & Markram, 2010).

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[35] Pre-pulse inhibition describes the ability of a typically functioning nervous system to repress an unnecessary startle response when warned that a stimulus is coming. For example, when warned by a moderate noise that a blast of white noise is coming, a person with a typically functioning nervous system quickly adjusts to a lower level of arousal in response to the loud blast, thus saving the unnecessary expenditure of energy by down-regulating their fear response. This represents an adaptive capacity. Having impaired pre-pulse inhibition means that no matter how much the nervous system is primed by the cuing signal, the startling stimulus results in a

Research on VPA-exposed rats allowed the Markram's team to link together disparate findings on human autism with fMRI imaging, the most significant of which relate to the neocortex (which is central to higher-order cognitive functions including perception, attention, and memory), as well as the amygdala (involved in everything from reading social cues, to the establishment of fear responses, anxiety, and regulation of autonomic and hormonal responses—for example, hyperactivation of the amygdala has been implicated in the dysregulation of PTSD). Most significantly, the Markrams hypothesized that in both rat and human versions of autism, the "autism" condition resulted not in a *deficit* in responses to social cues or processing of emotional information, but a hyper-activation of cortical processing and a hyper-reactive amygdala response to social cues (K. Markram & Markram, 2010). In other words, "autistic" rats and autistic people appear to be processing so much socially relevant information (including enhanced fear and anxiety processing) that the overflow of information leads to withdrawal and decreased social interaction as a protective mechanism. This process of stress activation with related shut down/withdrawal response then contributes to the under-activated amygdala findings identified in early imaging studies that had lent support to the idea that autism is a condition of social under-sensitivity (e.g., Baron-Cohen et al., 1999). In other words, the Markrams found an initial *over*-activation response of the amygdala which *preceded* the shut-down response—a response they argue was missed by earlier studies documenting only the subsequent withdrawal/hypo-activation phase.

Many researchers have studied the activation of various brain regions in autism. What is unique about the Markrams' work with rats is that their findings now demonstrate that this hyper-reactivity goes all the way down to the smallest known unit of micro-processing in the

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high level of arousal and the nervous system is unable to adapt or down-regulate to a lower level of arousal, but instead responds with the same intense startle/fear reaction every time.

brain—local neural microcircuits or minicolumns. A neocortical minicolumn consists of a core line of vertically ascending pyramidal and inhibitory neurons along with their connections and input/output axons, usually containing about 120 neurons, consistent in size across species (Markram et al., 2007). Research on both rat and human subjects has found that autistic (or in rats, autistic-analog) brain development results in abnormally accelerated neuronal growth in early development (with particularly abnormal overgrowth in basic sensory areas of the frontal cortex as well as in the limbic system, amygdala, and hippocampus) followed by arrested growth after puberty, resulting in an ultimate total brain size only 1–2% larger than typical brains (Markram et al., 2007). The end result of this atypical growth pattern at the neuronal level is an increased number of abnormally narrow, tightly packed minicolumns with greatly increased dendritic interconnectivity as compared to that of neurotypical brain development (typically double the number of both inhibitory and excitatory direct connections as found in control subjects; Markram et al., 2007).

An interesting corollary of the Markrams' findings is the way the findings corroborate some of the above discussed theories which were derived from indirect observation of human behavior rather than direct brain research. The weak central coherence theory of autism for example, suggested a functional bias towards localized detail based on indirect observation of the behavior of human autistic subjects (e.g., Mottron et al., 1999). This lead researchers to hypothesize that short-connections neural connections might be over-developed at the expense of more global ones. The Markrams' (2010) direct observation of neuronal activity in the brains of VPA-exposed rats indeed revealed an increase of around 50% in local connectivity of neurons at the minicolumn level. As a network, because excitatory connections slightly outnumbered inhibitory connections (especially in the amygdala) these neuronal connections resulted in hyper-excitability of neuronal networks. At the affective and behavioral level (whole system level), neuronal hyper-excitability manifested as a run-away activation and impaired habituation to sensory stimuli (K. Markram & Markram, 2010). In other words, the Markrams theorized, increased connectivity at the neuronal level, especially of excitatory connections, appears to result in an information processing style in which, compared to typical people, autistics take in a larger amount of information about sensory (and sensory-based emotional stimuli), and process that stimuli in a way that is enhanced with regard to detail and intensity, which results in failure to accommodate to mildly startling stimuli (low habituation) as well as reduced ability to self-soothe (excitatory feedback sustaining high arousal), leading to sensory-emotional overwhelm therefore triggering a self-protective withdrawal (K. Markram & Markram, 2010).

In addition to enhanced neuronal connectivity, VPA-exposed rats demonstrated elevated plasticity in neuronal connectivity. Specifically, long-term potentiation (LTP), the neuronal mechanism widely understood to underlie memory formation was doubled in VPA-exposed rats in response to a conditioning protocol. Postsynaptic LTP, already saturated at the mini-column level, was particularly enhanced beyond the mini-columnular range resulting in “a remarkably increased capacity for rewiring microcircuits as a result to stimulation and learning experiences” (K. Markram & Markram, 2010). Such a hyper-plastic response at the neuronal level has implications not only for learning and memory, but for the rapid establishment of amplified, generalized, and extinction-resistant fear memories. Simply put, neural hyper-plasticity might be good for certain kinds of learning, but it also appears to mean that for autistics, some phobias or rigid reactivity may be all too readily established after only the briefest of exposures to even mildly traumatic stimuli.

Though anxieties and phobias are known features of autism widely described in observational descriptions, according to K. Markram and Markram (2010), only two studies have investigated fear processing in autism (Bernier et al. 2005, as cited in K. Markram & Markram, 2005, and Gaigg & Bowler, 2007, as cited in K. Markram & Markram, 2010). Meanwhile, VPA-exposed rats clearly demonstrated enhanced fear conditioning and resistance to extinction at three months (Markram et al., 2008). The Markrams (2010) suggested that poor ability to extinguish acquired fears has significant impacts on social behaviors including phobias (flight response), activation-induced inflexibility (freeze response), anxiety attacks that include aggression (fight response), as well as reduction of finesse and perceptual awareness in social situations. Additionally, they theorized that elevated fear response may even *accelerate* the development of autistic traits such as a strong preference for a limited repertoire of safe stimuli, and a limiting of the perceptual field through perseverational hyper-attention to safe stimuli.

Based on these findings of neuronal hyper-connectivity and hyper-plasticity, the Markrams have put forward a new unifying theory of autism they describe as the “Intense World Theory.” According to this theory, the enhanced connectivity and responsivity of the autistic brain results in excessive neuronal processing and storage at the microcircuit level, which is then proposed to produce hyper-perception, hyper-attention, and hyper-memory that are the core traits of autism. In addition to these core autistic traits, an additional dimension—hyper-emotionality (arising from hyper-functionality of the amygdala and limbic system)—has been proposed as a “thermostat” which influences the degree of impact of these enhanced domains of functioning on affective experience. Rather than equating autism with a neurologic deficit or etiology, the “Intense World” label poetically captures the internal experience of sensory intensity and heightened processing as a phenomenon created by the hyperfunctioning of neural networks in structures associated with basic sensory processing and emotional regulation throughout the brain.

These abilities, though enhanced at the micro-circuit level, have been hypothesized to cause larger systemic difficulties, because once activated, the minicolumns become abnormally autonomous and difficult to coordinate with other microcircuits through top-down cognitive mechanisms.

> Hyper-reactivity and hyper-plasticity are therefore proposed to cause exaggerated perception to fragments of a sensory world that are normally holistically correlated and multimodal, and furthermore to cause hyper-focusing on fragments of the sensory world with exaggerated and persistent attention. (Markram et al., 2007)

If autism is understood to be a type of enhanced processing and elevated emotional response, many autistic behaviors such as repetitive patterns of behavior and differences in social interaction take on a very different meaning:

> The lack of social interaction in autism may therefore not be because of deficits in the ability to process social and emotional cues as previously thought, but because a subset of cues are overly intense, compulsively attended to, excessively processed and remembered with frightening clarity and intensity. (K. Markram & Markram, 2010, p. 10).

If this is true, interpretations of autistic behavior must be rethought:

> Autistic people may, therefore, neither at all be mind-blind nor lack empathy for others, but be hyper-aware of selected fragments of the mind, which may be so intense that they avoid eye contact, withdraw from social interactions and stop communicating. (Markram et al., 2007, p. 87)

The Markrams' research turns on its head the long-accepted maxim that autistics lack empathy. The Intense World conceptualization proposes that the withdrawal responses anecdotally observed in autistic people are caused at a neurobiological level by runaway anxiety and fear responses, even as early in life as the eye-gaze avoidance observed in infants. Eye gaze has been strongly correlated with amygdala activation (Dalron et al., 2005), however, if amygdala processing is enhanced so that activation is associated with a fear response (K. Markram & Markram, 2010), eye gaze, even for a neonate, could quickly become aversive, leading to a self-reinforcing cycle of avoidance, missed opportunities for learning in the social domain, and increasing discomfort, stress, and withdrawal from social interaction. Additionally, as mentioned in the previous chapter, the construct of empathy is actually two discrete skill sets—the ability to *perceive* the internal states of others and the ability to *express* an appropriate response (even typically developing neonates begin to learn appropriate expression of eye gaze responses from the first days of life). The Markrams have suggested that observed social difficulties in autism lie not in a deficit in *perception* of the internal states of others (except inasmuch as that that perception appears to be *overly* saturated and therefore overwhelming and aversive), but rather in underdeveloped social skills in interaction and communication resulting from a lifetime of social avoidance due to the aversive nature of certain types of social stimuli. The distinction has critical implications for how autistics are regarded and treated.

Despite being researchers first and foremost, the Markrams (2010) themselves were keenly aware of the political implications of their findings and the potential impact of reframing the autism discussion:

> The first, and perhaps most important, step toward a unifying theory of autism is to turn from the traditional view of impaired intellectual capabilities and the popularized stigma

> of mental retardation because this view excludes a large body of scientific, anecdotal data, and alternative interpretations of enhanced brain functions. (p. 19)

The shift proposed by the Markrams (2010) also has critical implications for treatment interventions, as many current treatment approaches are designed to *increase* the receptive emotional capabilities of autistic patients. The Intense World Theory approach argues that the problem of autistic brain development is not that certain cognitive capacities are *under*developed (such as a capacity for Theory of Mind) but that disproportionate early growth of simpler functions in neocortical processing areas may cause an excessive flow of information from sensory areas to higher integration areas such as the prefrontal lobe, which in turn prematurely accelerates the growth of these more complex processing areas. This proposed mechanism of autistic functioning matches evidence of neuronal overgrowth of these higher order brain areas in autistic subjects (Carper, Moses, Tigue, & Courchesne, 2002; Courchesne et al., 2001). This possible mechanism of development, in which highly specific perceptual processing at the microcircuit level outruns the development of higher order integration abilities, may account for the exceptional autistic capabilities for specific tasks often seen in combination with impairment of holistic processing.

If autism is the result of hyper- rather than hypo-functionality at the neuronal level, the question must be asked whether common treatments for autism might be counterproductive. For example, the anecdotal accounts mentioned in the prologue relating poor outcomes for use of ADHD type stimulant medications in autistic children make sense—further activating an already hyper-aroused nervous system would indeed invite only greater reactivity. But in their discussion of possible future research, the Markrams (2010) take the hyper-reactivity principle a step farther still, opening up revolutionary territory in asking what would happen if very early intervention were aimed at *reducing* the activity of the hyper-functional sensory perceptual responses and *muting* the hyper-reactive emotional system until normal developmental growth allowed other higher brain regions the chance to catch up with the overgrowth in basic sensory and frontline emotional processing areas. In other words, they ask, what if hyper-sensitive autistic infants could be identified early and shielded from the overwhelming and intrusive world of stimuli around them?

The Markrams posit that an "intense world" reaction (a self-reinforcing cascade of sensory filtering and withdrawal) might even occur as a kind of tipping point set off at a critical period of neurodevelopment—one which could possibly be avoided through targeted treatment (K. Markram & Markram, 2010). What if, they propose, instead of enriched sensory environments and directive behavioral reinforcement to reduce repetitive behaviors, autistic children were surrounded by highly predictable, low stimulus environments until their higher cortical functioning was mature enough to better organize disjointed perceptual processing?[36] What if early pharmacological interventions were targeted at blocking memory formation, reducing stress response, and enhancing memory extinction until critical brain development processes were complete around the age of six? What if behavioral treatments for autistic children focused on stress-reduction and fear extinction-based rehabilitation, rather than increasing interaction and sensory load? The design of educational curriculum and the goals of therapeutic interventions informed by such an approach might indeed look very different.

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[36] As a researcher who is also the mother of an autistic child, I sometimes wonder if my son was instinctively creating such an experience for himself by sleeping through most of his first year (see personal account in appendix E). For much of that year, he slept literally up to 20 hours a day and strongly preferred safe and highly repetitive activities such as swinging in a mechanical swing or gazing at his slowly turning hands during his awake hours. Is it possible he was intuitively protecting himself from overstimulation until his brain was mature enough to engage in rudimentary filtering?

Implications and repercussions of the Intense World theory. Although preliminary results of such interventions with VPA-exposed rats are promising (Szalazvitz, 2013), the outcomes of radical treatment approaches such as these may take many years even to come to a point of testing on human autistics if they are ever tested (additionally, such treatments are predicated on improvements in diagnostic capture of autistic infants).

The Markrams' work has evoked high levels of interest both within academic circles and beyond. That said, any ethical discussion of the Markrams' proposals must mention that many autistic activists are skeptical of reductionist scientific approaches that have often infantilized autistic subjects and simplified their challenges—how close can rat models really come to modeling human experience, they wonder (Joel Smith, personal communication). However, the tectonic shift in thinking due to a neurobiological understanding of autism as enhanced, rather than deficit functioning, remains a significant swing, and this change in thinking is beginning to influence in significant ways, both the academic and activist conversations about autism. One way of gauging an article's impact is the number of sources that have cited it. Google Scholar indicates that the articles by the Markrams and their research team (collectively) been cited nearly 2000 times in the last decade, and more than three dozen published studies have extended the VPA rat research, including five presented at the 2013 Society for Neuroscience meeting.

These citation statistics make it clear that the shift from a deficit model to a model of enhanced functioning is changing the playing field. Maia Szalavitz, a neuroscience reporter investigating the Markrams' work interviewed several leaders in autism research for a human interest article entitled, "Intense worlds: The boy whose brain could unlock autism." Laurent Mottron, originator of the enhanced perceptual functioning model and one of the few researchers studying autism from a sensory perspective, stated in his interview that he no longer views autism from a deficit perspective. Referring to the Markrams' findings, he notes, "Our points of view are in different areas [of research,] but we arrive at ideas that are really consistent" (as cited in Szalavitz, 2013, Kindle Locations 251-253). Even the proponents of the most influential competing theory—the Theory of Mind deficit model—are taking notice. Baron-Cohen is receptive to the theory: "I am open to the idea that the social deficits in autism-like problems with the cognitive aspects of empathy, which is also known as 'theory of mind'–may be upstream from a more basic sensory abnormality." Frith, on the other hand, one of the earliest and most respected pioneers in the field, is not convinced: "It just doesn't do it for me, I don't want to say it's rubbish, but I think they try to explain too much" (as cited in Szalavitz, 2013, Kindle Locations 263-264).

As the general press coverage above demonstrates, the theory has clearly struck a chord in the larger public discourse. Articles on Intense World Theory have appeared in *Time* magazine and *Psychology Today*, and the above referenced article by Maia Szalavitz (2013), explaining the Intense World theory for a non-scientific audience, made the top three "most recommended" articles on the on-line magazine *Matter: Deep Intelligent Journalism About the Future* just days after its Dec 13, 2013 publication (due, in no small part, to enthusiastic distribution through the online autistic community).

Perhaps most significantly, the implications of the Markrams' theory have been met with excitement and the affirmation of recognition in the autistic activism community. Ari Ne'eman, founder and president of the Autistic Self-Advocacy Network, states with cautious optimism, "There are elements of the intense world theory that better match up with autistic experience than most of the previously discussed theories. The fact that there's more emphasis on sensory issues is very true to life" (as quoted in Szalavitz, 2013, Kindle Locations 265-267). In an interview of the Markrams on the web-based community for autistics called *WrongPlane*t, the interviewer refers to the widespread acceptance of the theory almost as an almost as an aside on the way to another question—as if everyone in the conversation already took the assumptions of Intense World Theory for granted:

> Many members of the autistic community have embraced Intense World Theory, claiming it to be an accurate reflection of their own experiences, and a radical departure from the outdated and socially stigmatizing disease models of the past. Why has it taken so many years for the scientific community to draw a conclusion which autistics themselves find to be quite obvious? (Holman, 2009, para 12)

These are stakeholders who are keenly aware that the deficit model of autism does not seem to be offering effective solutions. Steve Silberman, author of the 2015 book, *NeuroTribes: Thinking Smarter About People Who Think Differently,* agrees in his 2013 interview with Szalavitz:

> We had 70 years of autism research [based] on the notion that autistic people have brain deficits. Instead, the intense world postulates that autistic people feel too much and sense too much. That's valuable, because I think the deficit model did tremendous injury to autistic people and their families, and also misled science. (as quoted in Szalavitz, 2013, Kindle Locations 270–272)

On the Perceptual Horizon: Where We Go From Here…

Autism research, which, in the time of Kanner's first profiles showed initial interest in perceptual and sensory experience, has for many decades been more concerned with social impairment and its proximal neural causes. Only with the recent upsurge in interest in the perceptual abilities of autistic people has research attention returned to perceptual experience and the cognitive correlates which underlie perceptual processing as a route toward possible paradigm shift in the understanding of autistic functioning. Research on unique sensory-motor functioning (Donnellan et al., 2010), enhanced perceptual abilities (Mottron et al., 2012), and the neurobiology of the Intense World Theory (K. Markram & Markram, 2010) have set the stage for a new, more optimistic conceptualization of autism to emerge. This research, in concert with the political and social developments outlined in the introduction, suggest significant changes on the horizon in educational, social, and legal approaches to the support and treatment of autism.

Chapter III: Methods

At its heart, this is a project concerned with the experience of autistic students in mainstream classrooms and the way current understandings of autism impact their educational experience. Within this overarching concern, the teacher training project seeks to influence the system of received understandings and practices that surround autism through a process of collaboration and education developed in cooperation with local stakeholders. This study takes as its target for transformation not the recipients of education ideology—students—but, at the most local level, its creators—that is, classroom educators teaching autistic students in inclusion classrooms.

In large part, this choice to focus on educators is informed by the philosophy that, in any struggle for greater recognition of rights and social justice, there are two kinds of actors—at the center of the struggle, the members of the concerned group, and close beside them, their allies and supporters. While allies can be important to the success of a struggle, when allies attempt to speak *for* members of the marginalized group, those allies may instead perpetuate the dynamics of the oppressive dominant culture by eclipsing the voices of the very group they seek to help. Respectful social justice practice suggests that the best use of ally efforts is to focus on the education of other members of the *dominant* culture (peers of the allies) rather than seeking to influence or represent members of the marginalized group themselves. Therefore, as a researcher, my position as former teacher and current academic advocate makes me best aligned to address the needs of educators. In simplest terms, from a social justice perspective, as a neurotypical ally, the most respectful focus of my efforts is on raising the awareness of my neurotypical peers rather than on teaching autistics directly.

This project emphasizes two important principles—first, it attempts to address a real-world issue in a concrete way (a need for teacher education regarding autistic inclusion students), and second, it attempts to do so in a way that collaborates with local stake holders as co-contributors. The principles of action research closely match both these criterion, and therefore, action research was selected as the appropriate research methodology for this study.

Definitions of Action Research

Action research is a very broad category of qualitative research approaches that share certain attributes. According to Reason and Bradbury (2006) editors of the *Handbook of Action Research*, these include the following five action research hallmarks (p. xxii):

1) concerned with practical, real-world problems
2) involving participants as collaborators
3) drawing on many ways of knowing
4) embracing a value-oriented perspective with relation to bringing about change in the larger world
5) viewing the process of research as a living, emergent cycle

Craig (2009) identified eight key characteristics. For her, action research was marked by context ("natural setting" as opposed to experimental), researcher embeddedness (researcher-as-instrument), triangulation (multiple forms of data), descriptively rich findings, stress on process over product, ongoing inductive analysis, meaning making as goal of analysis, and finally, a cyclical design where findings inform future practice (p. 7).

Action Research as a Dissertation Methodology

In their book, *The Action Research Dissertation,* Herr and Anderson (2005) expanded further on the central tenets of action research when applied in a dissertation format. They began by acknowledging that, in some ways, the goals of a dissertation directly contradict the philosophy of action research, however, they stated that they believe that some principles of action research may still be applied in modified versions. First, because the individualized structure of dissertation work contains task demands inconsistent with fully collaborative research, they emphasized the importance of finding ways to meaningfully include collaborative input, even when the research is organized and implemented by a solo dissertation author: "participation, or at least ongoing feedback should be sought from other stakeholders in the setting or community in order to ensure a democratic outcome and provide an alternative source of explanations" (Herr & Anderson, 2005, p. 4).

Essentialist notions[37] of experimental science embedded in the expectations of doctoral institutions may also come into conflict with the social constructionist worldview[38] central to action research, which understands all research as value-laden and taking place in a society "characterized by conflicting values and an unequal distribution of resources and power" (Herr & Anderson, 2005, p. 4). As academics are often outsiders operating in cultural arenas that "do not share consensus on basic aims" (such as, for example, the most effective ways to approach the education of autistic students), "reflexivity is crucial because action researchers must interrogate received notions of improvement or solutions in terms of who ultimately benefits from the actions undertaken" (Herr & Anderson, 2005, p. 4) Put another way, the action research

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[37] Essentialism, in this case, refers to the philosophical stance that all things are defined by an objective and universally shared meaning objectively located within that thing. The term "essential" refers to the idea that there is an irreducible "essence" or truth located in each thing that is the same for all observers because it is located in an inherent way within the object and is not affected by the stance of the observer or context of the observation.

[38] Social constructivist worldviews believe that meaning is relative, culturally referenced, and rooted in social context. Social constructivism refers to the philosophical stance that holds that meaning does not exist in any objective way, but instead is constantly and emergently created through processes of shared meaning construction based on commonly held cultural referents and beliefs.

principle of reflexivity asks researchers to be alert to common beliefs and stereotypes about the topic under investigation, and to vigilantly reframe and critique those “received understandings” so as to consider them from new perspectives. An example of such a reframing is the discussion in Chapter I of this dissertation, of the way that the social model of disability critiques deficit-based medical model thinking as a worldview that frames autism as a set of problems located within individuals rather than as a mismatch between individual needs and context based expectations. (See Chapter I for further examples of the action research principle of reflexivity in critiquing current “received understandings” of effective education of autistic students.)

Finally, dissertation authors must grapple with the conflict between the *rigor* demanded by scholarly research and the *relevance* demanded by the change-oriented focus of an action research paradigm: “Unlike traditional social science research that frowns on intervening in any way in the research setting, action research demands some form of intervention” (Herr & Anderson, 2005, p. 5). Put more succinctly, the “double burden” of action research includes both *research* (the generation of new knowledge about the practice in question) and *action* (intervention with the aim of producing improvement or change).

Perhaps the most unique feature of action research is the collaborative, emergent, and cyclical nature of the process. It is also the feature with the longest history, going back to the group-dynamics movement of the early 1940s and the work of Kurt Lewin, who was the first to develop a theoretical framework for real world collaborative problem solving that made Action Research “respectable” in the social sciences (Herr & Anderson, 2005, p. 11). In the seventies, revolutionary thinkers like Paolo Friere (author of *Pedagogy of the Oppressed*) developed Lewin’s framework from its early applications in factory production and site-based management, into a form of radical social critique and social action, characterized by the signature cycle of *plan-act-observe-reflect* (Herr & Anderson, 2005, p. 9). This iterative cycle allows the researcher to increase knowledge of the practice under study by collecting locally relevant data, analyzing the data according to values grounded in the community, implementing interventions derived from analyzed data, and observing real world consequences of those interventions in preparation for the next cycle of action and reflection.

While action research is enjoying a resurgence in recent years (Reason & Riley, 2008), a great deal of that application has been in the field of education and social work, in projects which emphasize the action component more than the research component (Craig, 2009). Accordingly, relatively few action research studies can be found in the published literature, let alone the psychological literature. Herr and Anderson (2005) attribute this to researchers who are "more interested in generating knowledge that can be fed back into the setting under study than generating knowledge that can be shared beyond the setting" (p. 6). However, while action research dissertations must maintain a focus on local knowledge and immediate needs, they can also rise to the standard of academic research by making knowledge claims that are generalizable or transferable.

Action Research Verses Dissertation Format: Negotiating a Compromise

As mentioned in the discussion above, this project seeks to compromise between the individual research demands of a dissertation format and the more collaborative research structure core to action research principles. One way in which this project represents a compromise between action research and traditional dissertation requirements is that some steps in the research process have been adapted either in favor of collaboration (action research priority) or academic knowledge production (dissertation research priority). For purposes of illustration, a few examples of compromise between these two task demands in this project are detailed below.

In the first case, the typical dissertation process was adjusted in order to be responsive to participant-identified relevance (action research priority). This happened when initial contact with the group of stakeholders, intended solely to determine if the group would like to participate in the project (and when), ended up including a component of unplanned collaboration initiated by the stakeholders. In an email discussion created by the school administrator that included seven teachers, the educators consulted with each other by email and shared with me, the researcher, their desire for more emphasis on the training component. This request was also discussed during telephone calls between myself and the school administrator in charge of organizing the training experience. This preliminary planning discussion resulted in a doubling of the originally planned time allotted for informational presentation (two hours instead of one). This change allowed more emphasis on presentation of psychological research on the neurology of autism as well as sensory aspects of autistic processing and cognition. Although these interactions occurred as part of a negotiation that happened before the educators decided officially to participate (and therefore outside of official dissertation research protocol), it clearly represents the kind of stakeholder input emphasized by action research, and as such, is included in this methodology write up as part of the iterative process of creating relevant and applied solutions to participant-identified challenges.

In the second case, the research process was adapted in the direction of formal academic demands (dissertation research priority) in that the structure and format of data gathering, which included surveys and a focus group, was developed independently, by the researcher in coordination with the dissertation committee, with no direct input from the stakeholders. A fully collaborative action research format would have sought formal stakeholder input in deciding how the effectiveness of the intervention was to be measured. This compromise in the development of outcome measurement instruments was due to the fact that under dissertation conditions, Internal Review Board (IRB) approval cannot be granted for a project that is not yet formulated; therefore I, as the researcher, at the point before the project was designed, did not have formal IRB permission to ask the stakeholders directly for information about their needs and preferences. These two grey areas, in regards to the early stages of action research project development, are excellent examples of the tensions between the values of applied, responsive action research, and the requirements of an academic dissertation. In both cases, the requirements put into place grew out of value systems developed to promote the interests of the stakeholders (in the case of action research, the value system emphasizes embeddedness and responsiveness, in the case of institutionally sponsored research, the value system emphasizes protecting the rights of the participants through institutional review), however, it is interesting to note how the resulting tension is emblematic of the differences in worldview of each of the competing systems.

Because the training presentation that formed a significant part of the intervention measured by this dissertation was developed as part of the literature review phase of the project rather than as part of the action research phase, it was developed before formal contact with stakeholders, and therefore represents another compromise in the direction of traditional academic structure rather than community involvement. (That is to say, the design of the intervention followed a more traditional format in which the researcher develops and then tests an intervention rather than an action research format in which a researcher might work with stakeholders in a collaborative and iterative process to design a desired intervention).

In lieu of direct stakeholder input, the design of the training was informed by my “embeddedness” as stakeholder myself in the general landscape of autistic education. This embeddedness includes my experiences as a past middle school teacher, my current experience as a parent of an autistic teen inclusion student in a large city school district, my practice as a mental health worker serving young autistic clients, and my experience as an academic advocate working for a small private neuropsychological assessment clinic. This fourth role brought me into contact with a wide variety of teachers and families over a period of two years. Frequent meetings with school IEP teams as well as individual teachers focusing exclusively on practical problem solving for individual students in general education settings provided powerful opportunities for me to gather a great variety and depth of information about teacher needs in a variety of school districts. The beta version of the teacher training was developed based on this real-world experience of educator challenges, which I encountered as a mental health provider and advocate. In these ways, the first iteration of the action research process (design of the training materials and data gathering instruments) attempted to reflect, in spirit, a collaborative and responsive approach, though it cannot be said to fully represent the values of action research because the input did not come from the specific group of educators involved in the project, and was not formally organized as part of the action research endeavor.

While these adaptations of the initial steps of the action research process represents a compromise of action research values, the process resulted in some clear benefits as well. Specifically, the ability to offer a fully developed training at the initial participant contact point provided three important advantages for the study—first, as an unfunded researcher-originated study, providing a fully developed training during our one approved point of contact allowed me to offer participants something of immediate and applicable value in exchange for their participation (as stated above, a true action research project would have originated from the needs of the stakeholders rather than the researcher, so the issue of remuneration would have been quite different). Second, the participants were very specific about the limited amount of time they could give to the project—providing an already developed package of training and data gathering instruments allowed the process to fit into the time they had available, and therefore met a different expressed need of the stakeholders—respect for their limited time. Third, a main purpose of this study was gathering educator input on what types of training and informational resources would be most helpful to them. Offering a training that included different styles and formats for presentation of information provided concrete examples as a kind of “jumpstart” to initiate discussion of potential training resources and formats; the participants’ ability in the subsequent focus group to reference recent and specific examples of information and formats offered as part of the training allowed for more generative discussion and suggestions on the part of participants.

The third aspect of compromise in this study between the needs of an individual researcher-driven dissertation and the principles of action research has to do with the iterative quality of action research. As a time-limited study, this project represents only one complete iteration of the *plan-act-observe-reflect* cycle of action research. This project conforms to a single cycle of action research as follows: an intervention and data gathering package was designed and approved (plan), it was implemented with a group of educators (act), data was gathered and analyzed in the form of findings (observe) and these findings were integrated and expanded upon in the discussion chapter (reflect). Out of this reflection emerged ideas for content for a future resource website and generalized findings that will inform future iterations of the training materials (plan). It should be noted that, while user feedback can be important to the ongoing quality management of a resource website, gathering such feedback can accomplished through informal means such as user feedback comments, and need not be considered an official part of the research process (e.g., the collection of ongoing user feedback is deemed to fall into the category of public communication that need not be submitted for review by Internal Review Board).

Action Research Epistemology

Generalizability. Methods for creating generalizable knowledge include creating practices that can be utilized by other communities, theory that can help explain similar problems in other settings, or products and instruments that are applicable beyond the immediate practices under study (Herr & Anderson, 2005, p.6). Examples of action research studies that created a product or theory used beyond the local practice under study include Ballenger and Cazden (1998) who contributed to the theory base in early childhood literacy and Mock (1999) who developed and validated the "Personal Vision Scale" to explore transformational leadership strategies.

Another method for evaluating whether the findings (action plan) are generalizable, is to observe the degree to which the implemented actions continue to be used by the local community after the research phase is over. When change occurs as a result of external demands or top-down agenda, it is less likely to be authentically embraced by local stake holders, therefore, a good criterion of generalizability in action research is the degree to which change is motivated by internal conviction. Local ownership of the change process is based on the premise that "a practitioner's internal conviction is influenced by a mixture of personal understanding and personal feeling or faith (volunteerism)" (Herr & Anderson, 2005, p. 62).

Delineation of knowledge interest. A critical aspect of any research method is its understanding of the influence of the worldview of the researcher, and how that worldview does or does not influence the selection and interpretation of data. While phenomenology is perhaps best known for the practice of examining and "bracketing off" researcher bias (Cresswell, 2007) several schools of qualitative research (including even some action researchers—e.g., Craig, 2009) demarcate a preliminary stage of self-examination with the goal of removing researcher bias from the analytic process ("epoche"). Philosopher Jurgens Habermas (1972) is the most referenced author refuting the claim that bracketing is even possible; Habermas argued that knowledge production is always colored with the perspective of the knower, and communication always shaped by the operations of power governing all social interaction. In response to attempts to separate researcher bias from the subject under investigation, "Habermas insisted that such a separation was an illusion that is ultimately shattered through the process of self-reflection" (Herr & Anderson, 2005, p. 27). Obscuring researcher bias serves not only to mystify the production of knowledge, but also to confuse or conflate the goals of the investigation, and muddy the selection of research methodology. For that reason, rather than attempting to obscure or "bracket off" researcher bias, I have chosen instead to clearly delineate my biases with regard to the topic of autistic inclusion. I have done this by highlighting my embeddedness in the autistic education landscape as a former teacher, a mother of an autistic teen, an activist in the autism community identified with the Neurodiversity Movement, and a mental health worker and educational advocate involved in negotiations with school districts regarding inclusion students. In the spirit of Habermas' self-reflection, I have also written a personal account of my experience raising my autistic son, which can be found in Appendix E.

In addition to clarifying research interest by identifying the location of the myself-as-researcher vis-à-vis the research endeavor, another method of de-obscuring the relative power interests of the participants and researcher is to clearly identify the knowledge interest of the project. Habermas identifies three possible and distinct knowledge "interests" or research goals—technical, practical, and emancipatory—each associated with a school of research methodology (Herr & Anderson, 2005, p. 27). Consistent with the transparency inherent to the action research worldview, it is therefore incumbent upon the researcher to clarify the specific knowledge interest outcome toward which the project is oriented.

In this case, as a project focused on investigating applied solutions for the education of autistic inclusion students, the *knowledge interest* of this investigation can therefore be said to be decidedly *practical*, rooted as it is in the experiences of myself as a researcher (both as a teacher and as a mental health practitioner/educational advocate) and in the teaching experiences of the stakeholders. Practical interest is associated with narrative and interpretational approaches to analysis that seek to uncover participant understanding of the practice under study for the purposes of practical application: "Interpretive understanding seeks to generate knowledge that informs and guides practical judgments" (Herr & Anderson, 2005, p. 27). The interpretive sciences include phenomenological and hermeneutic methods such as textual, conversation, and discourse analysis (Herr & Anderson, 2005). This dissertation will use a simple interpretive approach for the analysis of qualitative data, drawing on an essentialist framework to gather content-level information about educator beliefs and practices (see the section on qualitative data analysis below for greater explication of qualitative data analysis procedures).

Researcher positionality. As a research method concerned with deconstructing the traditional distinctions between researcher and subject, action research emphasizes clear delineation of relationship between researcher and collaborators, and careful exploration of the relative operations of power and authority of all involved parties. Action research is an umbrella term that includes many flavors of participatory research. The spectrum ranges from collective-action, community-originated research on one end (insider researcher working *with* local co-collaborators) to the co-optation of communities on the other, using token collaboration in which local members are consulted but granted no real power or influence (outsider performing research *on* local community). Participatory Action Research (PAR), perhaps the best known of the action research variations, falls somewhere in between these two extremes, appearing in various forms of reciprocal collaboration including both insider-outsider teams, and outsiders at a somewhat greater remove working with insiders (Herr & Anderson, 2005).

The project of creating teacher training resources undertaken by this dissertation is an approach that falls farther toward the researcher-as-outsider end of the spectrum, constituting a style of engagement which Herr and Anderson (2005) categorize as being "for/with" local collaborators, and falling into a category described as "consultation: local opinions asked, outsiders analyze and decide on course of action" (p. 40). In this form of action research, the outsider researcher seeks to balance the power differential inherent in the researcher-researched relationship by offering or collaborating with participants on something of value to the local community:

> Researcher conceives of an intervention, such as participation in a support group, but works to cultivate joint leadership and design with the participant…the researcher is not organic to the group under study, but is offering service or an intervention to them, perhaps for mutual benefit. (Herr & Anderson, 2005, p. 82)

In the case of this dissertation project, the offering of a service or intervention of value to the local community included the educational value of the training on the neuropsychology of autism and the peer consultation opportunity of a focus group of local stakeholders. Stakeholders received benefits in the form of training as well as the discussion with professional peers, while I as researcher benefited in terms of data gathered to satisfy dissertation research goals (e.g., the intervention provided mutual benefit).

Research goals and validity criterion. Psychological research that operates from within an essentialist epistemology is evaluated according to standards of rigor that are well defined and familiar in the tradition of psychological research, however, these categories of meaning do not apply as well to qualitative research in general, and to action research in particular. Several authors have formulated alternative standards of quality by which the validity of action research may more appropriately be assessed. For this project, the alternative framework of rigor by Herr and Anderson (2005) has been adopted.

Herr and Anderson's (2005) framework links validity criterion to the five research goals identified by many action research traditions, most of which have already been touched on above: "(a) the generation of new knowledge, (b) the achievement of action oriented outcomes, (c) the education of both researcher and participant, (d) results that are relevant to the local setting, and (e) a sound and appropriate research methodology" (p. 54). In interaction with these goals, five criterion for valid inquiry create a standard against which to measure action research validity: outcome validity (the extent to which actions are implemented); process validity (the extent to which inquiry is framed in a manner that permits ongoing learning in the system under study); democratic validity (the extent to which research is done in collaboration with co-investigators and the effectiveness of outcomes for the primary stakeholders); catalytic validity (the degree to which there is change in the system under study and in the participants themselves including the researcher); and dialogic validity (the degree to which received solutions and research findings are interrogated through critical and reflective dialog for alternate explanations and goodness-of-fit) (p. 55–57).

Research Focus for the Project

Following the study development guidelines outlined by Craig (2009), a research umbrella statement was developed which drove the inquiry phase of this study. For this project, the umbrella statement was:

> *What do general education teachers need to know to more effectively teach autistic inclusion students?*

Under this umbrella question, the following themes or lines of inquiry were identified by myself as researcher as possible areas for investigation:

Table 1

Themes of Inquiry

Knowledge:	What information and resources may help?
Understanding:	What conceptualizations, theoretical stances, or lenses may help?
Strategies:	What interventions, accommodations, techniques, structures, and practices may help?
Systemic Structures:	What legal information, intervention documentation (e.g., IEP, 504), district structures, school resources, classroom culture, and family interaction may help?
Tools:	What curricular models, curricular design principles, accommodation practices, assessment techniques, rubrics, etc. may help?

These identified themes were used to inform the research statement below and to design the educator focus group schedule of questions (which appears in Appendix B).

Research statement. As a framework to guide inquiry, action research requires a clear, simple statement identifying the aim of the research. For this project, the research statement is:

> *The purpose of this study is to explore the experiences and training/support needs of general education teachers in their work with autistic inclusion students.*

In the pursuit of this goal, I met with a group of general education teachers for a session that included a training presentation, a measure that collected data on the impact of the training, a survey of user preferences regarding the proposed website resource, and finally a smaller focus group discussion aimed at fostering dialog about educator experiences, challenges, and concerns in teaching autistic inclusion students (see "Procedures" below for a more detailed account of this process). Focus group discussion was guided by the identified themes of inquiry detailed above, and summarized in the following question:

> *What knowledge, understandings, strategies, systemic structures and tools are/would be helpful to educators in teaching such students?*

The information gathered through this process was obtained with the goal of improving future training offerings and informing content and planning for the proposed website resource.

Definition of Terms

Medical model vs. "Social Model of Disability." These terms arise from the disability rights movement, with the social model of disability being proposed as an alternative to the dominant medically framed way of viewing disability. The term "social model of disability" was coined by disability rights activist Mike Oliver in a paper presented in 1990. The term represents the idea that the experience of disability within the context of culture is a socially constructed understanding of difference that marginalizes particular ways of being while uncritically constructing others as normative. In practical terms, for an educational setting, a medical model views disability as a set of traits and behaviors existing within an individual. The remedies that flow from this assumption focus on changing the individual by changing behaviors and modifying traits through treatments such as therapy and medication. A social model of disability assumes that differences in functioning arise from a mismatch between the individual and their context. Problem solving within a social model places emphasis on adjusting the environment to create more universal access as well as supporting the individual to interact optimally with the given environment. The social model of disability does not seek to minimize or negate the experience of disability, but rather to shift the focus of problem solving efforts to adapting environments for individuals rather than changing individuals to meet the demands of environments. The teacher training portion of this project takes elucidation of the social model of disability as one of its central points. Evaluating the impact of this training in terms of its effectiveness in communicating an understanding of the social model of disability is one of the four topics addressed in the quantitative pre- and post-measure. The pre- and post-measure can be viewed in Appendix D.

Behavioral and emotional domains. The web search (Appendix A) found that the large majority of interventions and supports available to educators concerning autistic inclusion students focused on the behavioral aspects of their functioning. For the purposes of the Likert-type measure, this category has been labeled “behavioral *and* emotional” to foreground the idea that behaviors are a manifestation of inner experiences, and that the nature of that inner experience, even if poorly understood, is important to consider. “Behavioral” refers to that which can be externally observed and (somewhat) objectively recorded (given that all recording of information involves a process of selective attention and interpretation). The label “emotional” is used instead of “affective” (the term more commonly used by psychologists) to better communicate the intent of the label to educators.

Cognitive and perceptual domains. This category is included in the Likert-type measure to reinforce the difference between the majority of existing autism interventions (behavioral), and the area targeted by this project: teaching approaches and resources for educating autistic students in ways that support and take advantage of their neurological differences. “Cognitive” refers here to ways of thinking and processing (which can be distinctively different in autistics), while “Perceptual” refers to the manner of uptake and integration of information (which can also be distinctively different in autistics).

Methodology

Action research is primarily defined as an approach concerned with daylighting the operations of power in a process that valorizes local collaboration in the service of implementing and evaluating an action plan. That is to say, action research is more worldview than methodological technique. Within its broad ideological framework, a great variety of data analysis techniques may be employed while remaining consistent with the epistemology of action research. Analysis techniques include both quantitative and qualitative methods, with data analysis techniques ranging from simple descriptions of themes in the data to the most nuanced of hermeneutic dialogic analysis.

Design. This study uses a mixed methods design. There were two quantitative measures: The first quantitative measure was an eight-question instrument using Likert-type response scale questions administered as a pre- and post- repeated measure for a total of two measurements (consistent with the retrospective pre- and post- design format, both measurements were administered *after* the training intervention, however, participants were asked to rate their knowledge at two different points in time; see Appendix C for instrument). This measure was used to determine if participants felt there had been a change in their level of knowledge and understanding as a result of their participation in the project, as well as to determine if they believed there were differences between their understanding of the behavioral versus the cognitive and developmental aspects of autism. The second quantitative measure was a simple user-interest survey regarding different types of information the participants, as potential users, might like to see on the website (see the "Quantitative data analysis" section below for more detail).

The qualitative portion of the study consisted of a one-hour focus group discussion. Participation in the focus group was by self-selection and consisted of a subgroup of those teachers (n = 9) who participated in the teacher-training component. The focus group took place after a half hour break for a school-provided lunch.

The focus group discussion took place over the course of one hour, was led by me the researcher, as discussion facilitator, and was tracked by a research assistant to provide backup audio recording and capture the order of the speakers. As facilitator, I guided the discussion through the use of the following schedule of prompting questions and follow up prompts. The prompts (see Table 2) were displayed on an overhead video projection screen slide throughout the discussion for easy reference by all participants at any time during the discussion.

Table 2

Prompts

Intro: each participant please briefly share why this topic is of interest to you.
What areas of vulnerability do you see in autistic inclusion students—especially in their ways of learning—that educators may want to consider when designing curriculum?
What strengths do you see in autistic inclusion students that educators can use when designing curriculum?
Are there any specific areas where you wish you had more tools, strategies, or more support for teaching autistic inclusion students? What would those look like? What kinds of support would be easiest for you to make use of? What kinds of support would be most motivating to use?
Are there structural obstacles in your teaching environment that make it difficult to provide the kind of education for autistic students you wish to provide?
What else do you want to know more about when it comes to teaching autistic inclusion students?

After the focus group, I transcribed the verbal content of the discussion from the audio recording with names of students removed, and participant names represented by two letter codes (changed to participant numbers for further anonymity in this dissertation). Some non-word utterances or group responses (such as laughter or choruses of agreement) were represented, however, no attempt was made to represent subtle non-verbal content or other interactions.

After the focus group discussion was transcribed, it was coded using an essentialist framework[39] to track content-level information about educator interests and practices. Data from the conversation were grouped into categories with the aim of providing a summary of practical, experienced-grounded information that might be useful to the participants and others like them. During the subsequent analysis phase (see Discussion in Chapter V), some categories were combined into Core Themes resulting in a smaller number of overall qualitative findings for the

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[39] That is, a framework accepting “essential” or readily-apparent meanings at face value.

study. (See Figure 1 below for a graphical representation of the process created specifically for this dissertation by the author of the process of grouping data into categories and then into core themes.)

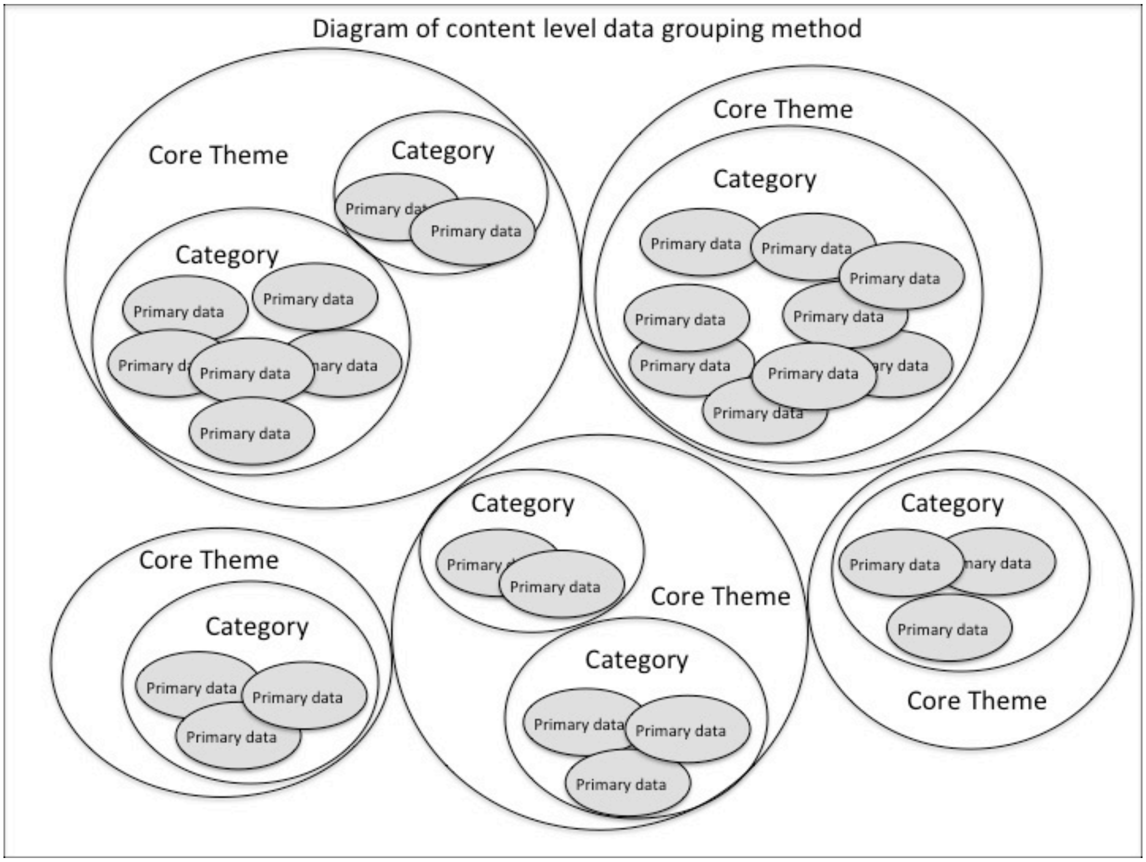

Figure 1. Data Grouping Method. Data grouping method created by the author for this study showing how data is grouped first into categories and then into supervening core themes.

Scope. Action research projects are, by design, inductive and reflexive, representing an on-going iterative process implemented in cycles of *plan-act-observe-reflect.* Dissertations, by design are more unidirectional and bounded. Because of the task demands of a doctoral dissertation, this project represents an artificially bounded snapshot of the iterative cycle of action research that may best be conceptualized as a pilot study or initiation phase of an action research process. Specifically, this project could be said to encompass one full cycle of action research fed back into initial planning for a second cycle: a review of the literature combined with practical work experience in the field was used to create (*plan*) a training presentation and focus group intervention (*act*). Data collected (*observe*) from the focus group and other sources was analyzed (*reflect*) and fed back into the proposal for the website design (*plan*).

Population. The overall aim of this study was to improve the educational experience of autistic inclusion students in general education settings. Given that autistic students occupy a position of low power in the educational landscape, intervention at the level of student engagement would be a powerfully transformative project indeed, and very much in keeping with the emancipatory aims of action research, however, for reasons already explained, student engagement is not the focus selected for this project, but rather ally-to-ally education. Another tenet of action research valorizes research project selection grounded in researcher positionality—that is to say, it is a value of action research to emphasize *insider* positionality through targeting research toward one's own community to the greatest extent possible.

In terms of positionality, my insider status as a previous member of the target demographic (educators) combined with my current work doing pediatric neuropsychological evaluation which brings me into regular contact with educators negotiating the challenges of teaching autistic inclusion students, goes some way towards balancing my outsider status as non-teacher and an academic researcher engaged in the creation of knowledge partially for my own benefit. Another consideration in population selection is that, given the potential for shifting operations of power in a local setting (classrooms), intervention at the level of influencing educators is proposed by this project as a similarly powerful avenue for facilitating meaningful change. Accordingly, the target population selected for this study was general education teachers.

The group of teachers selected for this project represented the entire teaching staff of a small parochial school in a small city/large town in the Pacific Northwest. The presentation was offered as part of the school faculty's pre-service training in August. All participants were teachers at the school where the training was presented, and all knew each other well as colleagues. Among the participants, classroom grade levels ranged from pre-K to middle school, and the group included both general classroom teachers and teachers with areas of specialization such as a reading specialist, a music specialist, and a diversified learning specialist. Further demographic data was not gathered, however, all participants presented as White and all but three as female. In experience, they ranged from recently graduated early career educators to highly experienced classroom teachers.

The training presentation was administered to the full group, while a smaller group of participants opted into a subsequent focus group (all focus group members were female). This mixed methods design, utilizing different group sizes for the two data gathering sections of the project, maximized the gathering of quantitative data from the larger group ($n = 25$) while keeping the focus group to an optimal small size ($n = 9$) for the facilitation of meaningful dialog (Herr & Anderson, 2005).

Procedure. The process began through a search for a possible group of educators to participate in the project. Because the format of the project was designed to follow action research principles, priority was placed on finding a group that actively desired to participate in the proposed project based on ways the project could provide benefit to their group. In addition, it became clear that while certain requirements must be met to conform to the expectations of the dissertation format, keeping with the action research spirit of the project meant offering resources to stakeholders in a way that prioritized the group's needs and wishes to the greatest extent possible.

Principals of two regional schools were contacted through networking connections during the 2013–2014 academic year. One was the principle of a large comprehensive middle school in an urban suburb of Seattle, the other the principal of a small Catholic pre–K through eighth grade school in a small Pacific Northwest city outside of Seattle. Both principals expressed interest in the offered program of a free teacher training followed by a survey and focus group, and all Institutional Review Board (IRB) arrangements and school district permissions were submitted and approved for both schools. Ultimately, one principle (of the middle school) moved on from her position, and her successor did not respond to multiple attempts at contact so that school had to be dropped from the study.

As mentioned, a second school had already expressed interested and been approved through IRB for inclusion in the study. While the administrator expressed moderate personal interest in the project, in order to better understand the needs of the project stakeholders (the educators in his school), he initiated an email-based conversation with members of his staff to assess the level interest in participating in the project. The seven staff members that responded to the initial query expressed strong enthusiasm for the topic and interest in participating, especially in the training aspect of the project, however, logistical concerns about participating were expressed. (The staff had already invested a great deal of outside-of-classroom time in an accreditation renewal process that year and felt they could not commit to further in-person meetings). A discussion of how to conduct the focus group aspect of the project in a minimally demanding way resulted in a request to conduct the focus group as an online discussion.

In response to this request, an attempt was made by myself as researcher to organize the project according to the format the staff preferred. Due to the fact that information shared in written form online involves unique issues regarding IRB permission and the safeguarding of privacy (it is extremely easy for anyone involved in the project to make and distribute copies of online material in ways that might fall outside of the full consent or knowledge of other participants) it was necessary to complete a second pass through a full IRB process for the proposed revision to the focus group format. Because of factors beyond my control, this review ended up taking longer than expected, the academic year ended, and with the beginning of the new school year, a new administrator had been hired, rendering the initial negotiations over procedure no longer valid. The new administrator did not respond to initial attempts at contact.

Serendipitously, after a break of a number of months, contact with the school was re-established with the new administrator through a mutual acquaintance. Unaware of earlier attempts at contact, the administrator at this point responded enthusiastically, with the renewed support of the original seven teachers interested in the project. The administrator suggested that because the aspect of staff interest that was highest was in the training component of the project, and because the staff were no longer "burnt out" by participation in the accreditation renewal process (now a year in the past), his preferred approach was to again wait until a new academic year, and to include the training as part of the week of pre-service training provided annually to all educator staff at the school. Accordingly, the training took place at the beginning of the academic year of 2015–2016. Due to stakeholder feedback, in accordance with the principles of action research as was discussed above, the original one-hour training was deepened and expanded to two hours, and the focus group discussion format was returned to the original plan of in-person verbal discussion.

On the day of the training, the educators who agreed to participate in the training intervention and focus group were informed of the elements of the project (the level of their requested participation) as well as the risks and benefits of participating. Risks were deemed low (in accordance with IRB review) and were projected to include possible discomfort at learning information that contradicted previously held beliefs, as well as discomfort in negotiating disagreements with peers. Benefits included learning about the neurology of autism, autistic cognition and perception, and suggested teaching strategies to support autistic neurology and learning, as well as the opportunity to discuss strategies with peers. Those participating signed an informed consent form (see Appendix D). Participating educators were invited to attend a three-hour workshop that included a two-hour informational training presentation and the administration of the retrospective pre- and post-measure (see Appendix C), as well as the user interest survey (see Results in Chapter IV). Those who opted to remain for the third hour participated in a one-hour focus group discussion (transcribed excerpts can be found in Results in Chapter IV).

The two-hour informational presentation covered topics drawn from my review of literature and web resources as well as my personal experiences as a parent, and professional experience interacting with providers in the educational field over two years of employment at a neuropsychological assessment clinic. In order to include a sample of first person autistic perspective, the training also included materials created by and directly quoted from my teenage son, an autistic student mainstreamed in a general education middle school setting, from a presentation he and I made to the Association for Autistic Community Conference (Caspe & Caspe-Detzer, 2014). Overall, the training presentation topics included: (1) an overview of common misconceptions about autism, (2) a basic explanation of the neurology of autism and implications for learning, (3) illustrations of common school experiences from an autistic perspective, (4) the social model of disability verses medical model thinking and implications for curriculum design, and, (5) autistic functioning in the classroom.

The one-hour focus group following the training was moderated by me, in the role of facilitator, using a focus group schedule (see Appendix B) to channel discussion according to the group facilitation guidelines outlined by Wilkinson (2008). A primary and a back-up audio recording were created to provide a fail-safe for data capture. An assistant helped with the distribution of surveys, the operation of recording devices, and with noting the sequence of speakers (for clarification purposes during transcription and quote attribution). During transcription, focus group conversation was transcribed at the level of conversational content (as opposed to orthographic detail) to match the level of data analysis (content analysis rather than ethnographic analysis).

Data Collection.

Quantitative. Quantitative data was gathered in two formats—a set of Likert-type items and a user interest survey. The Likert-type items measured self-reported knowledge and structural support at two points—before and after the training. This is often called a "pre- and post-measure" or is sometimes described (more accurately) as a "post- then pre-retrospective design" (Klatt & Taylor-Powell, 2005). Post- then pre- retrospective designs have several advantages. Besides taking less time and therefore being less intrusive, they tend to avoid the response shift bias that results from overestimation (or underestimation) of knowledge in the pre-test condition. That is to say, when participants respond to a questionnaire before an intervention, they may overestimate their abilities given the lack of specific context, or on the other hand, they may not "know enough to know what they know." When the participants answer the same question again after the intervention, they are doing so at that point based on their new knowledge, so that they are completing the pre- and post- measures based on two different frames of reference. This can create a problem in capturing self-reported change (Rockwell & Kohn, 1989), which can mask program effectiveness (Howard, 1980). Specifically, many interventions are effective precisely because they teach participants what they don't know (and begin to fill in the gaps with new knowledge), leading to the paradox that after intervention, the participants realize (and report) that they know less than they thought they did, resulting in flat or decreased ratings of competence and knowledge at post-test. The best time to ask about knowledge shift can be right after it has happened, when the new learning and previous gaps in knowledge are still within immediate awareness. Post- then pre- designs have been shown to have improved validity over pre- and post- designs in that results more closely match interview data (Howard, Millham, Slaten, & O'Donnell, 1981).

Qualitative. The qualitative portion of the mixed methods design utilized in this dissertation collected information through a focus group format: "Focus groups are a good choice of method when the purpose of the research is to elicit people's own understandings, opinions, or views" (Wilkinson, 2008, p. 189). Focus group research falls into two general categories—essentialist questions (which seek to identify opinions and information based on content-level data analysis) and social constructionist research (which seeks to understand collaborative meaning making through discursive or conversation type methods of analysis; Wilkinson, 2008). An essentialist framework assumes that people have relatively stable beliefs and opinions that the research seeks to draw out. A constructionist framework seeks to uncover how beliefs and ideas about the world are socially constructed and negotiated in the moment-to-moment transactions of social interaction.

Although the overall stance of this dissertation is grounded in a constructivist worldview, the purpose of data collection in this phase of the project was *not* primarily aimed at exploring the process of meaning construction among educators. Rather, this phase of inquiry relied for the most part on an essentialist framework to gather content-level information about educator beliefs and practices for the practical goal of designing useful trainings and resource materials. (Thomson, 2004, is an example of a focus group study utilizing an essentialist framework that used content level analysis to describe young participants' views of the age of legal heterosexual consent.) That said, even an essentialist framework acknowledges that beliefs and opinions can shift as a result of learning and integration of new material.

Focus group data collection is facilitated by clear research goals and questions. In the focus group procedure outlined by Wilkinson (2008), focus group discussion is "focused" through the use of a schedule or series of questions. Equally important to the process, the researcher, acting as a facilitator, actively works to keep discussion flowing by posing questions and encouraging participants to interact with each other (rather than with the researcher). Wilkinson encourages the use of "people management" skills on the part of the facilitator to draw out quieter participants and reign in talkative ones (p. 190).

Quantitative data analysis. The quantitative portion of this mixed methods project consisted of an eight question Likert-type instrument (see Appendix C) with a range of five possible answers on a continuum from strongly agree to strongly disagree. A range of five options is the most common sized range for Likert-type items because it gives enough choices for shading of detail without so many choices that participant answers tend to cluster to the middle. As mentioned above, educator attitudes were effectively measured at two points, (even though the instrument was administered only once at a point directly after the training intervention), with sections referencing self-reported levels of knowledge both before and after the training.

The Likert-type items on the quantitative instrument were designed to tap three underlying constructs: (1) educator evaluation of their own competence in various domains; (2) educator awareness of the difference between behavioral interventions and cognitive interventions; and (3) educator opinions of structural supports available in their school environment. Because the Likert-type items on the instrument attempted to measure different underlying constructs, the set of eight items cannot be said to be a “Likert scale,” but rather, a collection of Likert-type items. This heterogeneity of underlying or latent factors has the advantage of gathering information on a wider set of topics, but the disadvantage of making inferential statistical analysis of summative data inappropriate, as the responses cannot be meaningfully aggregated.

As the data could not be aggregated into a single scale, results from each Likert-type item were evaluated individually. At a theoretical level, the question of appropriate statistical analysis for Likert-type measures is a thorny one about which there is much disagreement in the field of statistics. The most important debate is whether Likert-type data is ordinal-categorical (e.g., Cohen, Manion, & Morrison, 2000) or whether it can be treated as interval-level data (e.g., Blaikie, 2003), which would allow various comparisons of means for significant differences. The debate turns on whether the distances between points can be assumed to be uniform[40] or whether these data could better be said to represent categories rather than amounts. Likert scale data is often treated as interval (continuous) data (Blaikie, 2003) in which case, the data can be viewed

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[40] For example, is the distance from “neither agree nor disagree” to “agree” the same as the distance from “agree” to “strongly agree”? If this is the case, averaging all responses to a single item could provide a meaningful measure of central tendency, however, the answer to this question is far from a foregone conclusion.

as dependent sample data (same sample group measured at more than one point) and the various points of measurement can be statistically compared using inferential statistics such as means and standard deviations.

Choice of statistical test depends on the design of the intervention and schedule of observations. In this case, the intervention (training and/or focus group) is the Independent Variable (IV) and it is categorical. The Dependent Variable (DV) is the outcome measured by the Likert-type instrument. As explained above, there is some debate as to whether the DV—the data generated by Likert responses—is ordinal (categorical) or interval (continuous). If the data is viewed as ordinal, Marion (2004) recommended the Friedman analysis of variance by ranks as appropriate for instances involving three or more observations of one group with one ordinal DV; this test is designed for sample sizes between 5 and 20. However, Baguley (2012) charged that the Freidman test (invented by free market economist Milton Freidman), was an “imposter” test because it was not the nonparametric equivalent of a repeated measures ANOVA (as generally claimed), but rather an extension of the sign test, a much weaker measure that ignored the sizes of differences between participant groups. Baguley instead recommended using a rank transformation version of the ANOVA (a procedure best done with SPSS software).

If, on the other hand, the data is treated as interval (without a rank transformation being applied first), a one-way repeated measures (within subjects) ANOVA (also called ANOVA with replication; Salkind, 2007) could be used. The selection of this statistical test rests upon an assumption of normality. Treating the data as parametric may be a somewhat vulnerable assumption because Likert data often violate assumptions of normality and homogeneity of variance (Nanna & Sawilowsky, 1998). It must be taken into account when considering the use of ANOVA analysis that responses to Likert-type items are often polarized by strong opinions or negative experiences, and can be skewed by various influences such as central tendency bias (avoiding the extremes), acquiescence bias (agreeing with presented statements) and social desirability bias (attempting to conform to socially rewarded beliefs), all of which would tend to skew distributions in various ways. Therefore, before analysis can be applied, the data must be assessed for adherence to normal distribution, especially given the small sample size in this data set.

In the case of the findings from this project, a Shapiro-Wilk test for normality revealed that the data did not, in fact, conform to assumptions of normal distribution. Based on this finding, a non-parametric tool—the Wilcoxon signed-rank test—was deemed an appropriate statistical procedure, although, as noted above, as a sign test, it is a weaker method of analysis (meaning that it is more likely to miss differences that actually exist).

Qualitative data analysis. Focus group inquiry represents a format rather than a method of data analysis. Within this model, data analysis may take many forms. This study used a basic qualitative approach of identifying meaningful segments of information through codes that were then grouped in to categories. This level of analysis is consistent with what Craig (2009) described as a "descriptive reality approach"—a practical data analysis method designed to take into account the real-world exigencies of action research. In addition to straightforward analysis of content-level themes, the approach is characterized by other hallmarks of action research—an analysis of the data which presents a vivid, *descriptive picture* of the practice under study, and a reporting of integrated findings in a way that is *useful* to participants for providing insight and improving practice (Craig, 2009, p.166).

Analytic process. Miles and Huberman (1994) recommended beginning the process of data analysis by writing reflective summaries of research experiences to begin to identify similarities and patterns in the data. These summaries were written in the form of "field notes" or a summary of immediate observation recorded just after the focus group discussion. After this initial identification of emergent themes, the next step involved the creation of codes to demarcate meaningful segments of data in the transcript of the focus group discussion, (sometimes called open coding; Creswell, 2007). Code labels may arise from the literature review (theoretical codes), from the content of the data (descriptive codes) or from the actual words used by participants (*in vivo* codes). This intuitive, emergent approach to coding has been described by Crabtree and Miller (1992) as an "immersion strategy"—one in which categories are "not prefigured and which rely heavily on the researchers intuitive and interpretive capacities" (Marshall & Rossman, 2011, p. 208). Because the goals of this study are so heavily content driven, codes derived from the data most frequently represented the descriptive codes category.

At the next stage of analysis, patterns of meaning noted by participants were clustered into categories that were "internally consistent but distinct from one another" (Marshall & Rossman, 2011, p. 215). These can be illustrated, when appropriate, by representative quotations from the data (Wilkinson, 2008). Categories were further analyzed by organizing them according to relationships among categories (Craig, 2009). Depending on the nature of the emergent categories, the researcher may opt to overlay a supervening level of analytic organization by grouping categories into typologies to represent relationships between categories (for example, by using a continuum or matrix, Marshall & Rossman, 2011). For the purposes of this analysis, the information from this one-hour discussion was fairly straightforward and required organization mostly at the level of categories. The organization of categories into typologies or

“Core Themes” was done to a minor extent. The rationale for this supervening level of organization, where used, can be found in the Discussion chapter (Chapter V).

The final step in each iteration of the process of action research is some sort of summation of the data analysis in a useful form that can be fed back into the system under study. In a traditional research project, these would be presented as the findings, however, “some have asked whether action research studies have finding since reports of action research often tend to focus more on process” (Herr & Anderson, 2005, p. 86). Because the aim of action research is not only generation of knowledge but also social change, findings are often presented by alternate means—either fed directly back into the process under study by way of recommendations and modifications, or disseminated beyond the immediate site through some medium such as a documentary video—video production is an increasingly common component of action research dissertations (e.g., Asten, 1994). In this sense, future iterations of the training created as part of this project and the eventual creation of the website that will be informed by research findings both represent a dissemination of findings very much in the spirit of these examples. For the purposes of dissertation requirements, however, a summary of findings and their application to the process of teacher resource design can be found in the traditional results and discussion sections (see Chapters IV and V).

Chapter IV: Results

The ultimate goal of this dissertation project was to create training and curricular resources for educators that included material succinct enough to be highly usable, while being rich and innovative enough to offer a unique and valuable perspective in the rapidly growing field of autism education resources. The immediate goal for this study was to gather information from working teachers as to what types of resources and training materials they would find valuable, effective, and unavailable elsewhere. The below data were gathered in the form of a mixed methods user survey and focus group following a two-hour teacher training.

Recruitment

As mentioned in the methods section, two groups of educators were initially identified as potential participants in the project, however, due to changes in school administration, one school was dropped from the study. The training and focus group presentation occurred at the remaining school in August of 2015 as part of pre-service educator training. All teachers employed by the school were required to attend the training and were joined by their vice-principal (the administrator in charge of organizing the training) resulting in a study group size (n) of 26. Completion of the survey, as outlined in the Informed Consent document (see Appendix D), was clearly indicated to be optional, however all participants chose to complete it. Participation in the one-hour focus group following the training was optional, and nine teachers chose to participate.

Statistics and Data Analysis

User data was gathered in three forms (two quantitative and one qualitative): (1) a retrospective pre-and post-test survey regarding the effectiveness of the teacher training utilizing eight Likert-type items; (2) a user survey regarding user preferences for types of potential resources for the proposed website; and (3) a one-hour focus group discussion.

Quantitative Findings

The retrospective pre- and post-test measures, (as discussed in greater detail in the Methods section in Chapter III), were administered together immediately following the two-hour teacher training. The Likert-item measure focused on the content delivered in the training (content which may eventually be imported into the website in simplified format) and the user-preference survey asked about preferences for website content.

Findings from the review of relevant literature for this project had suggested that available training and resource materials seem to heavily emphasize the behavioral aspects of autism (often referred to as the “social-emotional” domain in special education terminology) rather than differences in autistic cognition, including processing and perceptual (sensory) differences. It seemed possible, given this difference in emphasis, that educators would feel more prepared to support autistic behaviors than to design curriculum appropriate for uniquely autistic cognition.[41] One goal of this project was to test the hypothesis that in the pre-training condition, teachers would feel more prepared to address autistic behavioral functioning than to address cognitive differences in autistic students. Therefore, the first four Likert-type items in the Likert scale measure asked the same question twice, once for the social-emotional domain and then again for the cognitive-behavioral domain. Items five and six were designed explicitly to measure the impact of a specific component of the training—information designed to educate

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[41] That said, autistic behaviors can be very dramatic, and it is possible that such behaviors take up an inordinate amount of teacher attention. If teacher concern with preparedness to address behavior is high while teacher knowledge regarding autistic cognition differences is low, it would be expected that little difference between domains would show up on the paired Likert-type items or even that behaviors would be identified as an area that teachers feel less prepared to address.

teachers on the social model of disability verses traditional medical model understandings. The last pair of question sought to capture teacher attitudes toward the structure and support they receive in their school community.

The eight Likert-type items that made up the measure were analyzed individually or pair-wise. They were not summed to create a Likert scale because they were formulated to tap discrete and unrelated underlying constructs. Because items were analyzed independently (or in some case, in pairs), results are presented below item by item or in applicable cases, pairwise.

As discussed in the methods section (see Chapter III), the obtained Likert-type item data are usually considered ordinal, and therefore, appropriate methods of statistical analysis are open to debate. A power analysis suggested that the sample size was of sufficient size to produce robust results (a sample size of 26 yields a power of .8 which is deemed good). de Winter & Dodou (2010) suggest that for sample sizes greater than ten, where the data falls basically in a normal distribution, a parametric analysis (a t-test) can be applied without significant risk of false positive results. Based on visual inspection of the data, distribution appeared to be basically normal (in terms of kertosis, and in most cases, skew), so the first attempt at analysis involved applying a paired t-test (two measurements of the same group, one-tailed because direction of change matters). Findings of non-significance despite large differences in means between measurements suggested high possibility that the risk of type II errors (that is, risk of missing significant findings when they actually exist).

At this point, a Shapiro-Wilk test analysis for normal distribution was applied to each set of data (Al-Therapy Statistics, 2015). It was determined that all distributions violated assumptions of normal distribution to some extent. This finding, together with the ordinal nature of the data, suggested that a non-parametric analysis (such as the Wilcoxon signed-rank test) would be a more appropriate statistical test, though less robust. Similar assumptions as above were applied to the analysis (continuing the use of a one-tailed threshold because direction of change matters, and employing the use of a 95% confidence interval). The following results and effect sizes were calculated using an online statistical calculator provided by Al-Therapy, an organization in Oxford, England that provides free online statistical analysis tools for psychologists.

Missing data. In three cases, a respondent did not indicate a value in the pre-test condition. No respondent did this on more than one item (out of the eight), and the missing data were distributed randomly, never occurring on the same item for more than one respondent. In each of these cases, the incomplete data pair was omitted from the analysis of those items (the statistical result was calculated based on a $n = 25$ for those three items). The omission is so indicated in each case below.

Pre- and post-test Likert-type item results.

Item (1) I understand the common behavioral and emotional aspects of Autism Spectrum Disorder (ASD). The first item sought to capture participants' self-report of their level of knowledge regarding autism in terms of behavioral and emotional functioning. One participant did not indicate a level of knowledge before the training, so this incomplete data pair was eliminated from the analysis, resulting in an $n = 25$ and 24 degrees of freedom for this item. Change in response to intervention was found to be significant at $p < .05$ with an effect size of $r = .62$. Conventions regarding effect sizes on the Wilcoxon signed rank test recognize this to be a large effect size (Pallant, 2007, p. 225). (See Figure 2 below.)

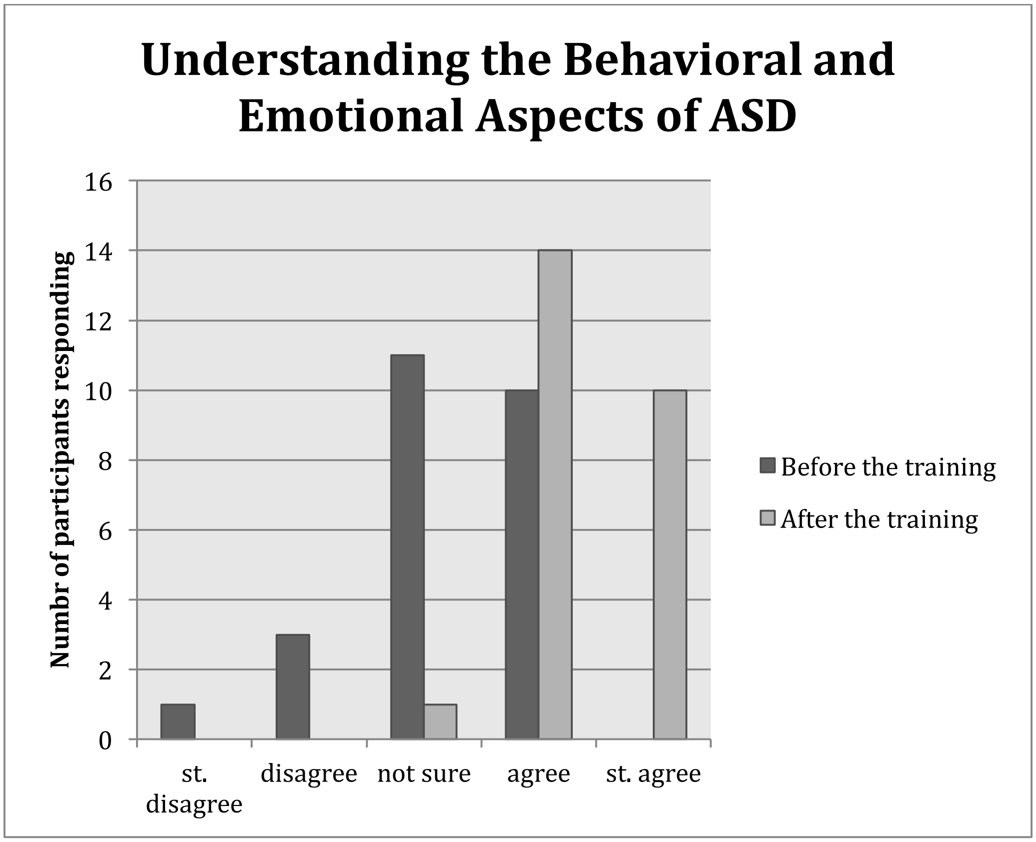

Figure 2

Item (2) I understand the common cognitive and perceptual aspects of ASD. The second item assessed general knowledge concerning autistic cognitive and perceptual functioning. All participants indicated both pre- and post-test level of knowledge, resulting in an n = 26 and 25 degrees of freedom for this item. All other statistical operations were applied as above. The change in response to intervention was found to be significant at $p < .05$ with a large effect size of $r = .57$. (See Figure 3 below.)

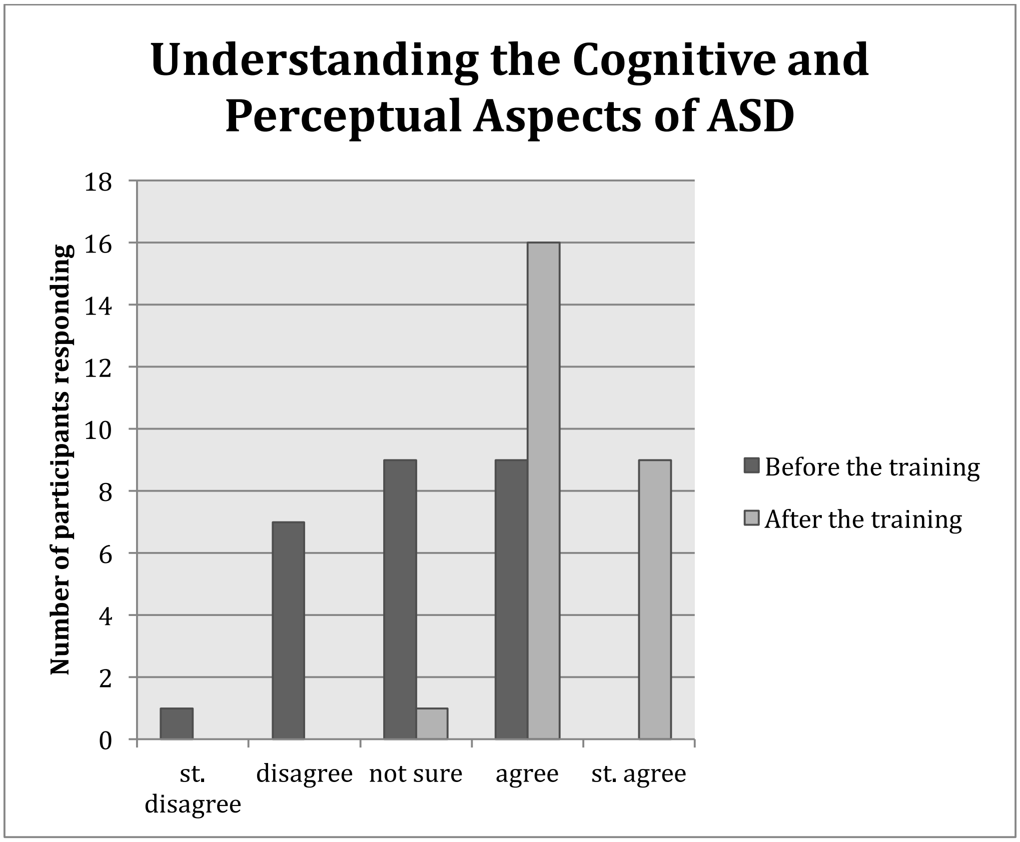

Figure 3

Comparison of understanding of behavioral verses cognitive domains. As stated in the methods section, one reason to divide the questions into domains of emotional/behavioral vs. cognitive/perceptual is that current available training materials and resources seem to emphasize the emotional/behavioral aspects of autism far more than the cognitive and perceptual differences. This study hypothesized that teachers may endorse a lower level of understanding of the cognitive differences characteristic of autism, especially in the pre-test condition. To test this hypothesis, an analysis was performed comparing the pre-test responses on each of the first two items.

Visual comparison of pre-test responses suggests that before exposure to the training, there was a slight difference between the two domains in the level of understanding that teachers endorsed. That is, teachers endorsed a slightly higher level of understanding of behavioral and emotional aspects of autism verses the cognitive and perceptual aspects, however, the difference was found to be non-significant at p = .05. (See Figure 4 below.)

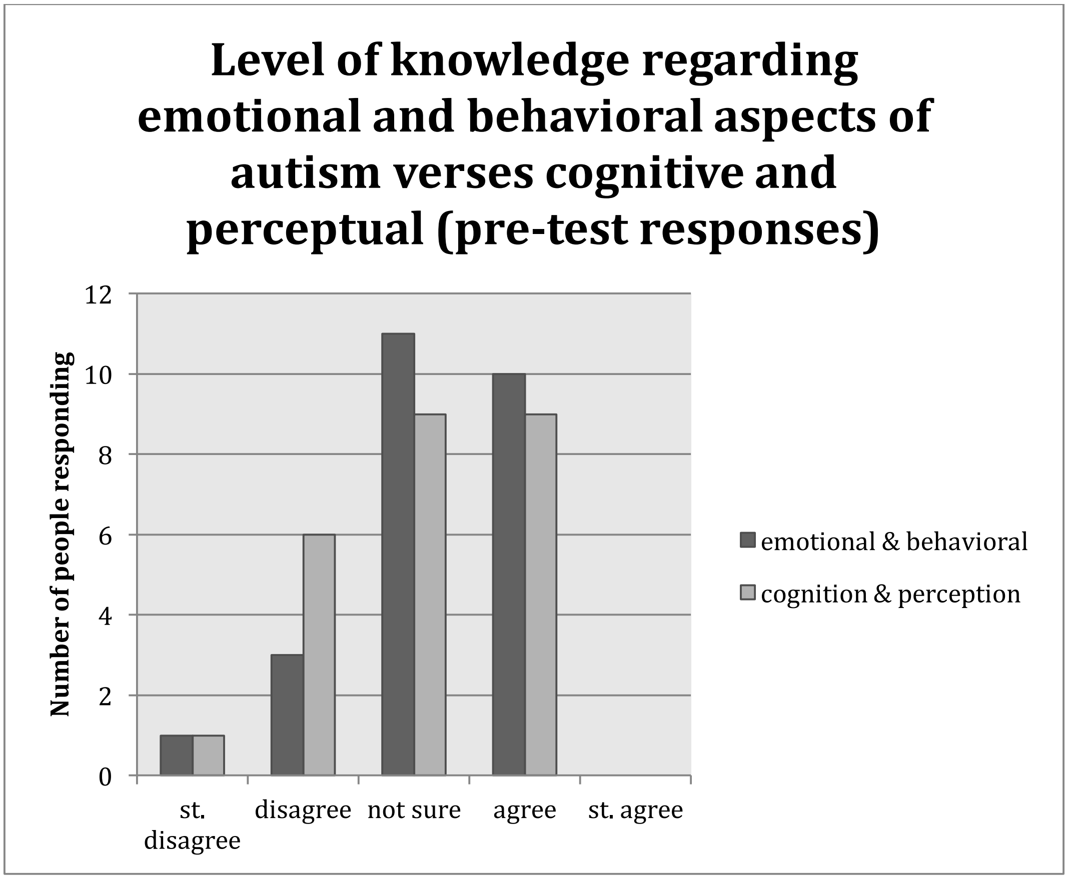

Figure 4

Item (3) I feel prepared to address behaviors of ASD inclusion students in my general education classes. The third item asked teachers about their self-reported level of preparedness to address the behaviors of autistic inclusion students. One participant did not indicate a pretest level of preparedness, resulting in n = 25 and 24 degrees of freedom. The change in response to intervention was found to be significant at p < .05 with a large effect size of r = .57. (See Figure 5 below.)

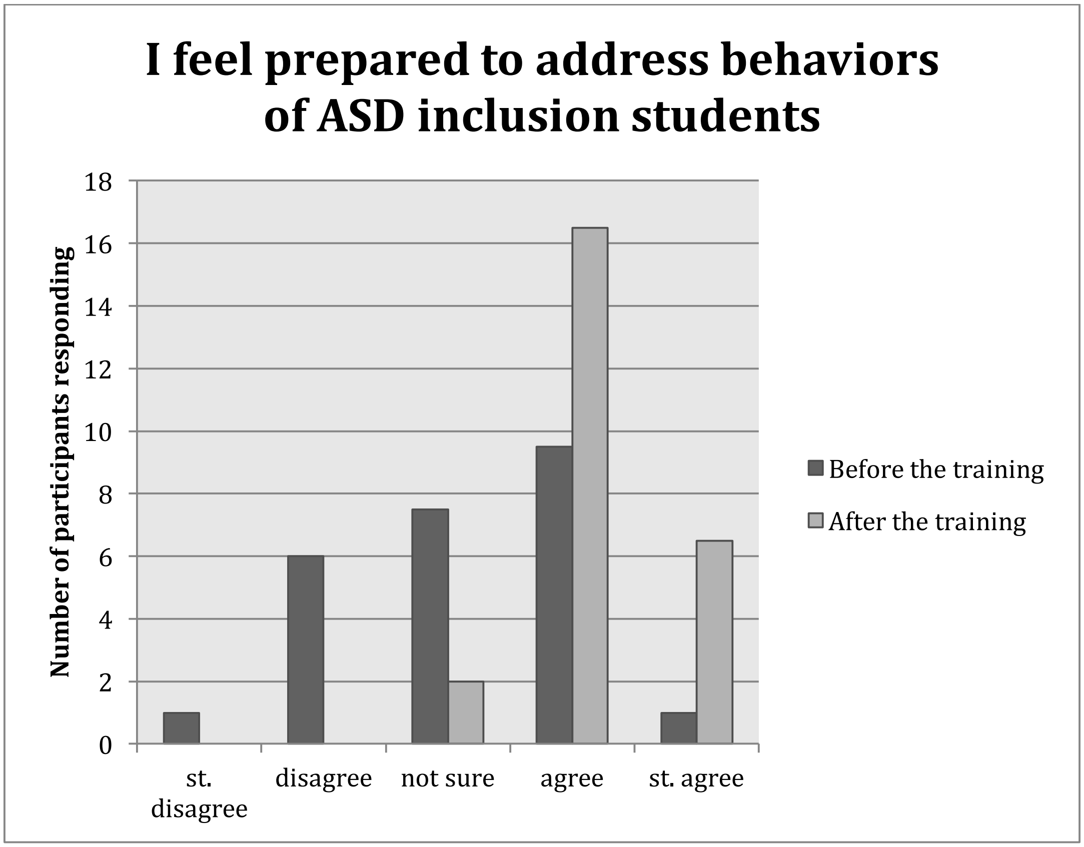

Figure 5

Item (4) I feel prepared to teach academics effectively to ASD inclusion students in my general education classes. The fourth item asked teachers about their self-reported level of preparedness to teach academics to autistic inclusion students. All participants indicated both pre- and post-test levels of preparedness resulting in n = 26 and 25 degrees of freedom. The change in response to intervention was found to be significant at $p < .05$ with a large effect size of $r = .58$. (See Figure 6 below.)

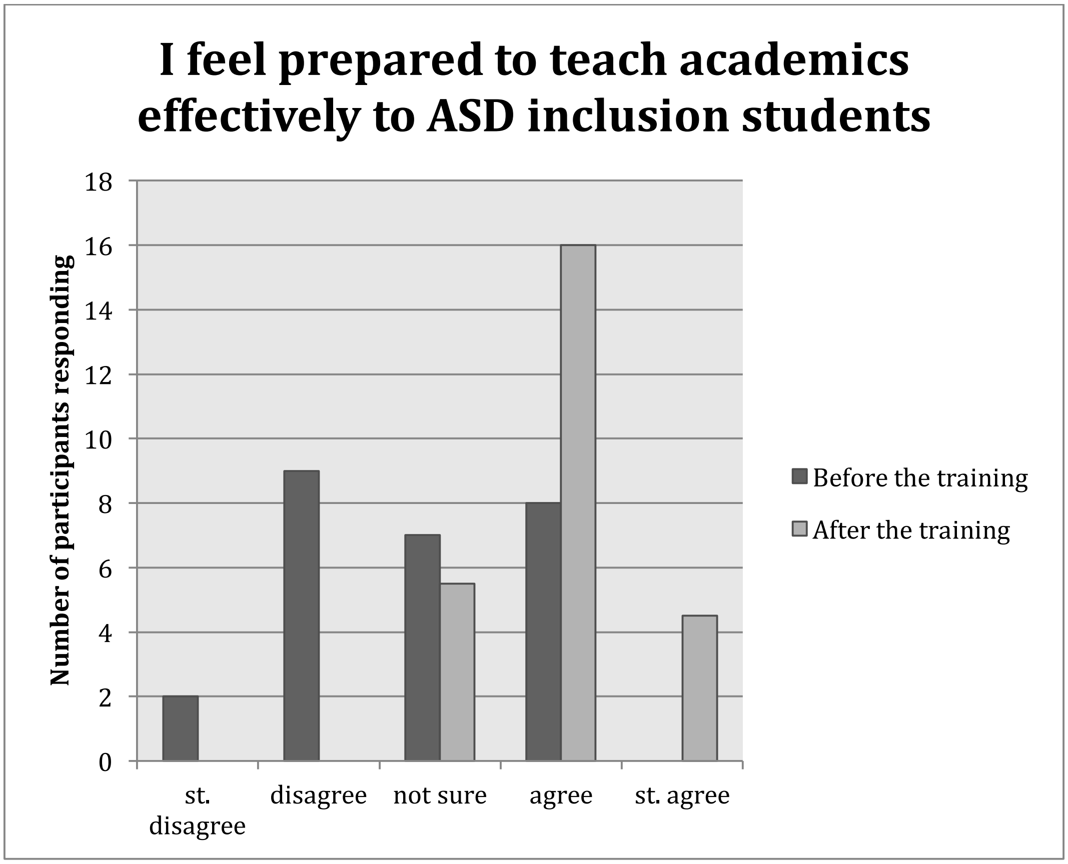

Figure 6

Comparison of level of preparedness before exposure to training. Again, to test the hypothesis that teachers may feel more prepared to address the behavioral needs of autistic students than to design curriculum that takes into account the unique processing of autistic students in terms of cognition and perception, a comparison of pre-test results was performed. Again, slight differences in levels of endorsement for preparedness before training were evident on visual inspection, but were found, on statistical analysis, to be non-significant at p = .05. (See Figure 7 below.)

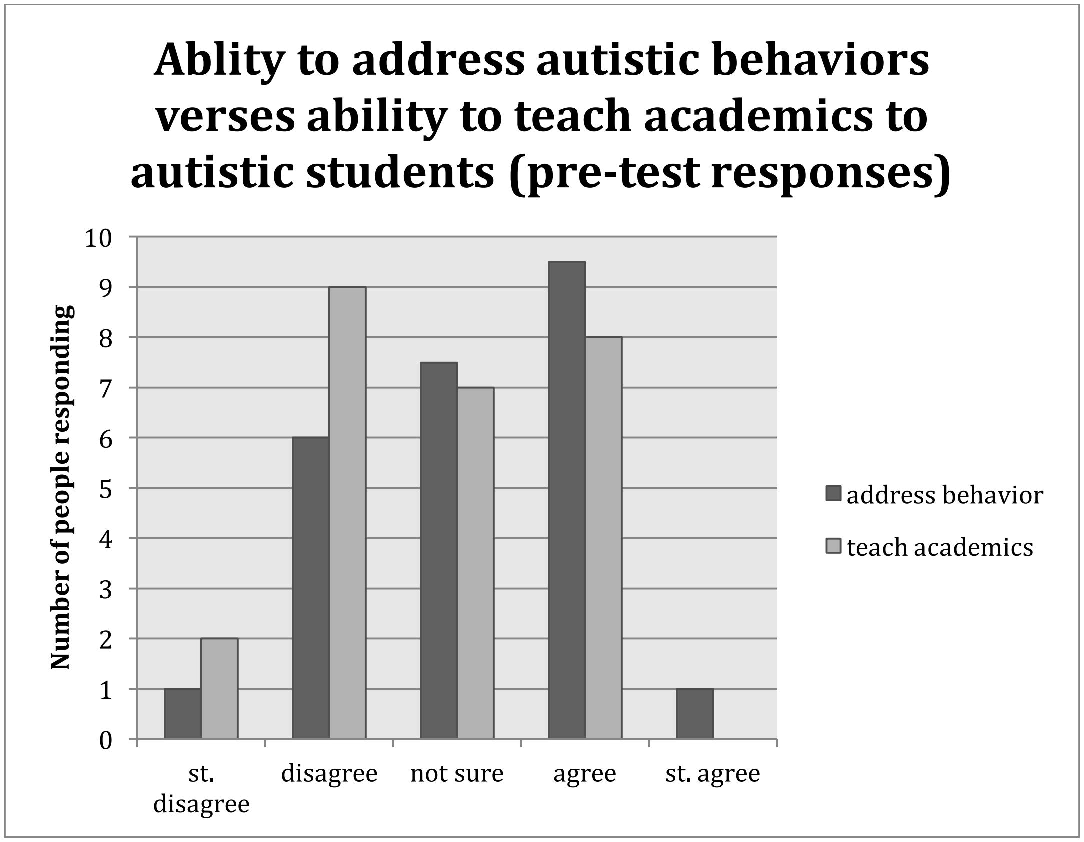

Figure 7

Item (5) I understand medical model thinking verses the social model of disability. The fifth item asked teachers specifically about understanding the difference between the "medical model" and the "social model of disability." This information is representative of a paradigm shift that was one of the main areas of emphasis for the training. Of all the questions, items five and six most specifically measure the effects of the training intervention itself. One participant did not indicate a pre-test levels of understanding resulting in n = 25 and 24 degrees of freedom. The change in response to intervention was found to be significant at $p < .05$ with a large effect size of $r = .60$. (See Figure 8 below.)

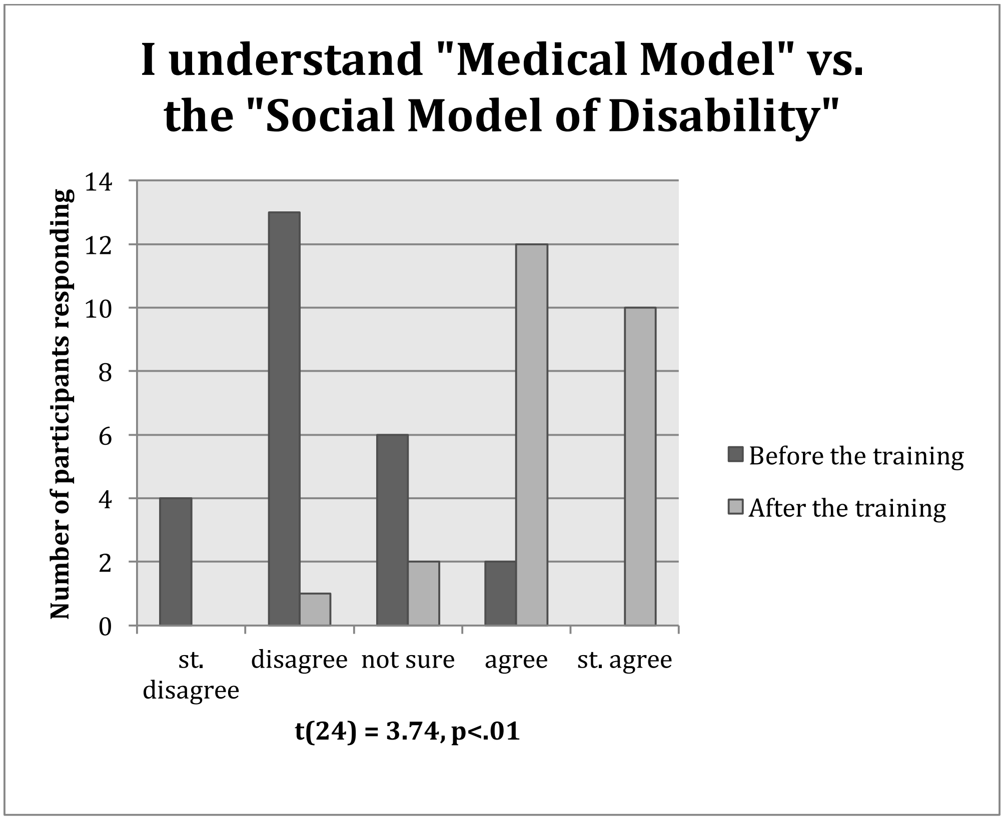

Figure 8

Item (6) I understand the implications of the social model of disability in addressing the needs of ASD students in general education classrooms. The sixth item focused on self-reported educator understanding of how to implement a social model of disability approach in their applied teaching. Again, this paradigm shift in conceptualization of student challenges and in teaching practice constituted one of the main thrusts of the training, so this item was designed to measure through self-report the impact of the intervention. All participants indicated both pre- and post-test level of knowledge, resulting in an n = 26 and 25 degrees of freedom for this item. All other statistical operations were applied as above. The change in response to intervention was found to be significant at $p < .05$ with a large effect size of r = .59. (See Figure 9 below.)

Note: unlike the pairwise comparisons performed on the first two pairs of items, no pretest comparisons were performed concerning the fifth and sixth items. This is because the fifth and sixth Likert-type items were designed to measure different aspects of effectiveness of the training intervention, and because each item taps a different construct, a comparison of pre-test findings would make no sense.

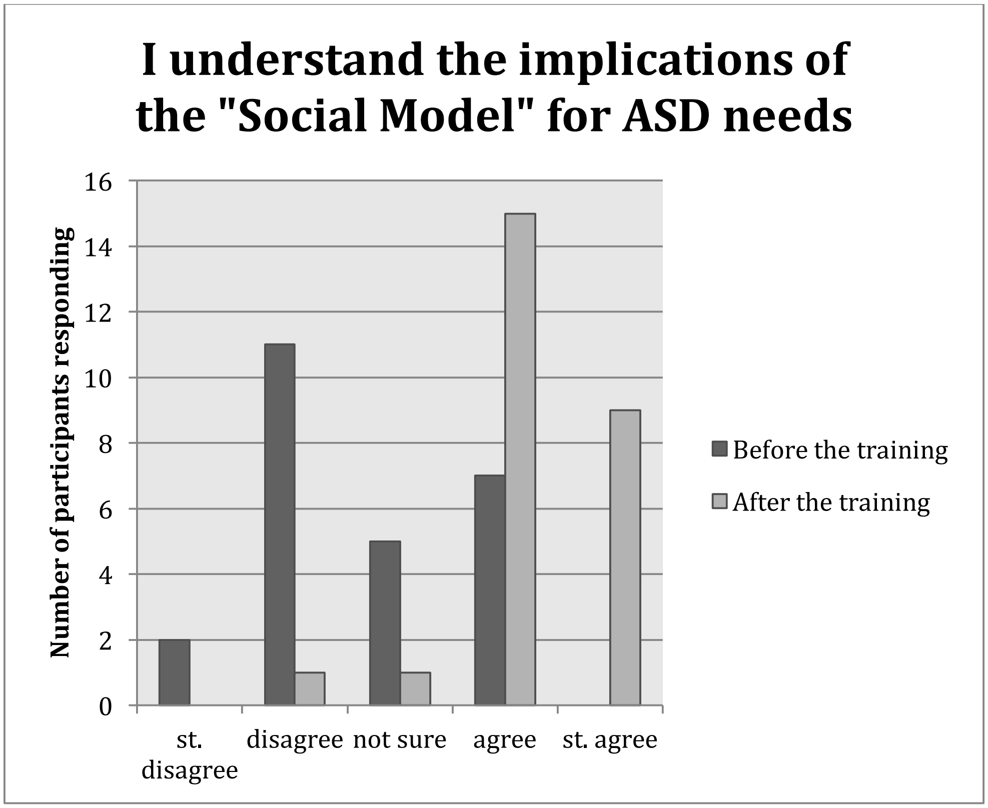

Figure 9

Item (7) I feel the structural supports in place in my school environment provide adequate and appropriate support for ASD students in terms of their behavioral and emotional functioning. The seventh and eighth items focused on school structure. As the training did nothing to change school structure, any changes in ratings must therefore be taken to reflect shifts in attitude toward existing school structures that may have occurred as a result of the training. On item seven, all participants indicated both pre- and post-test level of knowledge, resulting in an n = 26 and 25 degrees of freedom for this item. All other statistical operations were applied as above. The change in response to intervention was found to be significant at $p < .05$ with a medium effect size of $r = .42$. (See Figure 10 below).

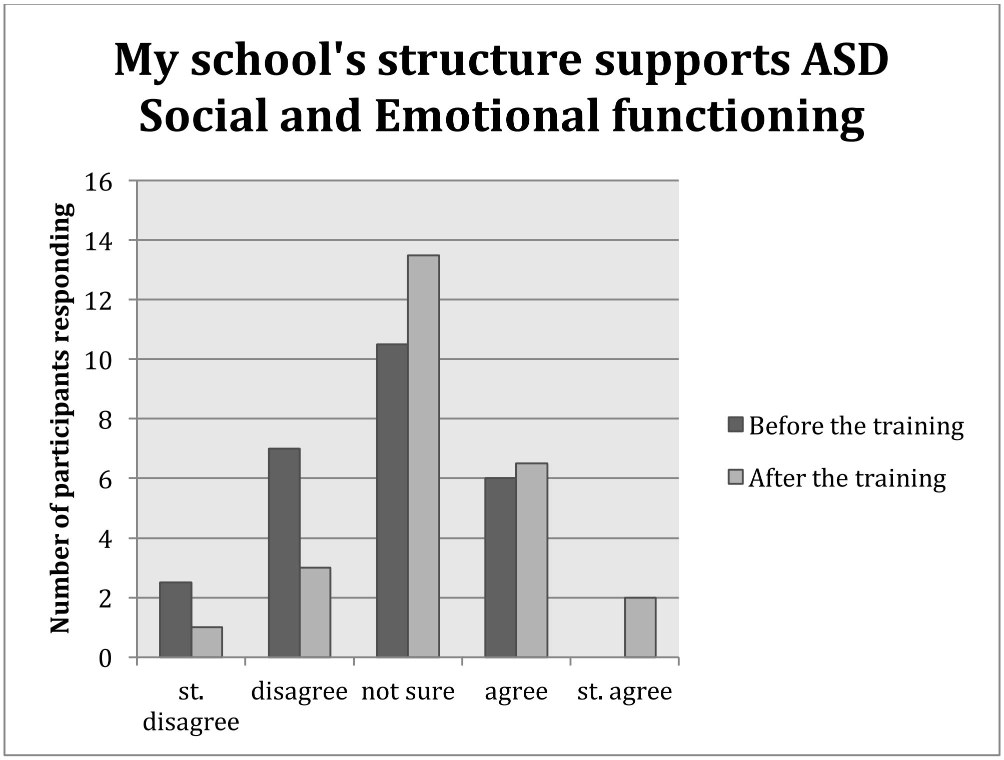

Figure 10

Item (8) I feel the structural supports in place in my school environment provide adequate and appropriate support for ASD students in terms of their cognitive and perceptual functioning (ways of learning). The eighth and final item again addressed school structure, but from the perspective of supports for autistic cognitive and perceptual functioning. Again, any change should be taken to reflect change in attitude toward existing structures rather than changes in structure. All participants indicated both pre- and post-test level of knowledge, resulting in an n = 26 and 25 degrees of freedom for this item. All other statistical operations were applied as above. The change in response to intervention was found to be significant at $p < .05$ with a medium effect size of $r = .41$. (See figure 11 below.) As above, because the last two Likert-type items tap structural variables and not levels of self-rated teacher performance, a comparison of pre-test responses was deemed irrelevant.

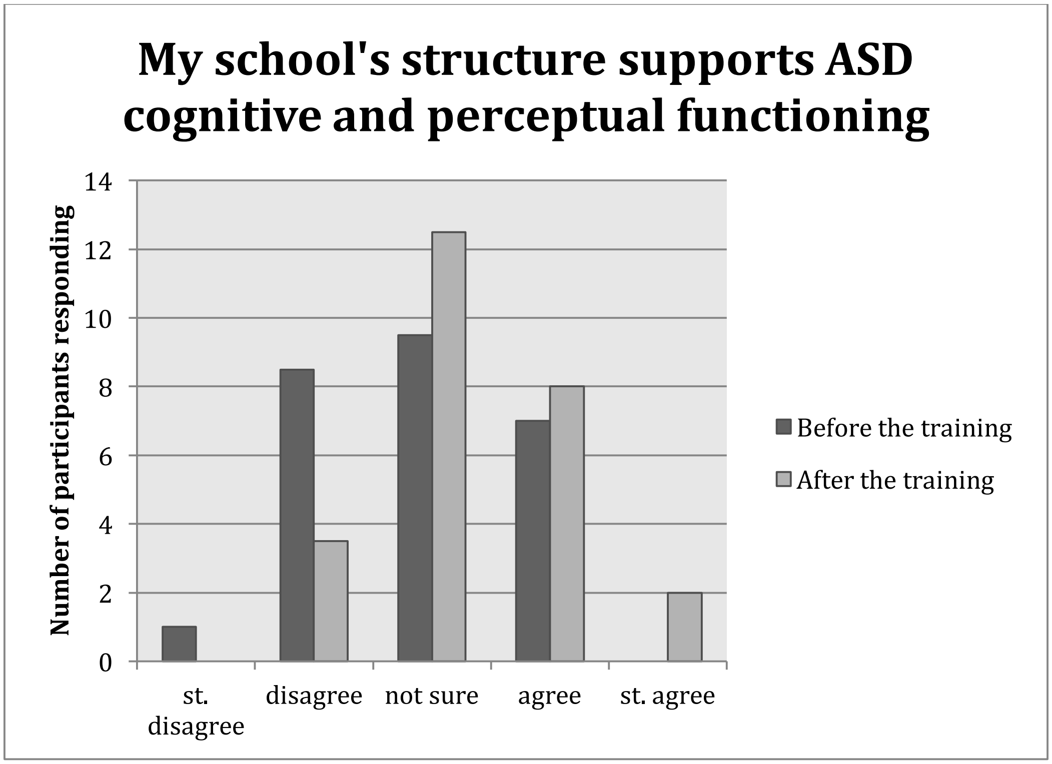

Figure 11

Finally, although the Likert-type items cannot be combined into a Likert scale, it is perhaps useful to consider and compare the data and the various effect sizes of the interventions as a factor in planning for future possible applications of the materials developed for this training. Table 3 below presents a summary of the Likert-type item results and effect sizes (where applicable) for easy comparison:

Table 3

Summary of Likert-type Item Findings

Likert-type Item	Significant at p < .05?	Effect Size	Effect size descriptor
I understand the behavioral and emotional aspects of ASD (n = 25)	yes	r = .62	large
I understand the cognitive and perceptual aspects of ASD (n = 26)	yes	r = .57	large
Comparison of pre-test knowledge of bx/emo vs. cog/percept.	no		
I feel prepared to address the behaviors of ASD inclusion students (n = 25)	yes	r = .57	large
I feel prepared to teach academics to ASD inclusion students in general ed. (n = 26)	yes	r = .58	large
Comparison of pre-test levels of preparedness to address behaviors vs. teach academics	no		
I understand medical model thinking vs. the social model of disability (n = 25)	yes	r = .60	large
I understand the implications of the social model in addressing the needs of ASD students in general ed. (n = 26)	yes	r = .59	large
I feel my school structures provide adequate support for ASD students (bx & emo) (n = 26)	yes	r = .42	medium
I feel my school structures provide adequate support for ASD students (cog & per) (n = 26)	yes	r = .41	medium

User survey. The second kind of quantitative data gathered was feedback from potential website users collected through a survey where participants were simply asked to indicate their level of interest in several potential types of content for a possible resource website (see Appendix C: Quantitative Measures, for the full text of the User Survey). As this data constitutes a single measurement of ordinal data, no statistical analysis has been applied.

The participants were asked to rate the following categories on a scale of one to five with one being “not interested” and five being “very interested.” Each of the histogram bars in the visual presentation of the data represents an average of the ratings given by the 26 participants. All 26 gave complete responses to all items. Because user interest was, in general, quite high in all categories, differences between categories were small and compressed near the top of the scale. Figure 12 below summarizes the findings from the User Interest survey for quick reference.

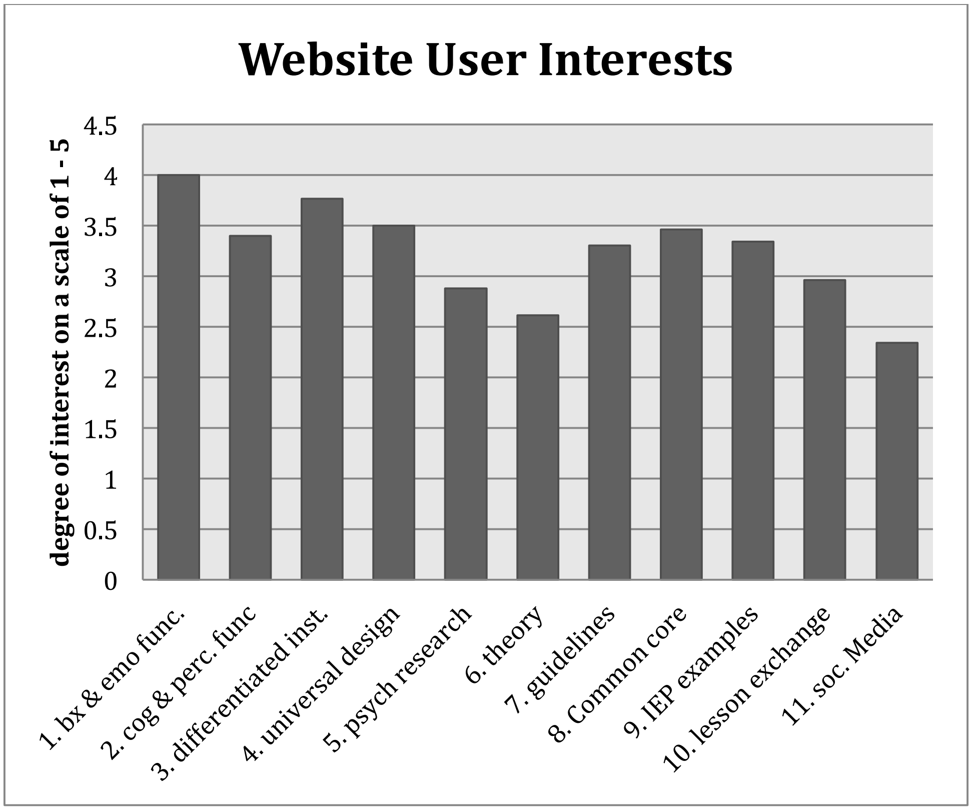

Figure 12

Qualitative Findings

The first step in coding the data was to designate general theme labels. Coding labels that served as touchstones for themes emerged from the focus on small segments of data. These segments of data were then clustered into themed groupings, which were then summarized into a theme statement. The final step—the below summation of the data—is intended to provide a useful form of information, both in capturing the themes of the discussion for the participants themselves, and to inform the construction of future revisions to the training module and materials for the proposed website. Note: Under each theme label, the following data summations include summaries of content (labeled "Category") supported by illustrative quotes from participants (labeled "primary data"). Following the theme summaries, at the end of the qualitative data findings section, there is a list of recommendations intended to serve as seed content for future website construction.

Findings by category.

Category one: Meaning. The first theme includes reasons participants gave on why the subject of teaching autistic inclusion students is important and/or interesting to them. This was the first question, and as such, generated little discussion or back-and-forth, but rather served as an introduction, with everyone speaking in turn and speaking at least once. Participants identified several reasons that led them to choose to be a part of the focus group, including personal experiences with an autistic family member or former students; empathy for, or a passion for working with autistic students due to their educational focus (e.g., "diversified learning"); as well as wanting to be a better (more effective or more compassionate) teacher.

Meaning (primary data). One participant summed up most of the range of interests mentioned by members of the group:

> I have a friend whose son is autistic, and just to learn more about it . . . and also I've taught autistic students . . . but just any information I think would be beneficial, different strategies . . . I think it's just—the more information you have, you know, the better you can help . . . students. (Participant 1)

Category two: Interests. One of the major thrusts of the project was to find out what subject areas teachers are interested in knowing more about, what tools they need, and what approaches they find most helpful. When asked what they were most interested in gaining from future trainings or a resource website, teachers gave answers with a strong emphasis on practical strategies and techniques. Some expressed a desire for learning about inclusion and changing school culture, some focused on supporting students, such as learning methods for teaching self-regulation skills or designing individualized curriculum, and some focused on the larger school community, for example, by expressing interest in improving communication with families. Many interests were voiced by multiple participants: three out of the nine participants mentioned a desire for practical ideas and strategies, three focused on learning how to promote inclusion in classroom culture, and two mentioned self-regulation skills.

Interests (primary data). Common to most of the comments relating to their needs as teachers was a strong sense of empathy for students. One teacher commented that she wanted:

> Different strategies, different things to work on with kids who have, kind of like you said—anxiety, and you know, like the break downs and the meltdowns. I'm a reading specialist, and sometimes I can work with kids who just overload—everything we're working with is just really hard. (Participant 2)

Many seemed motivated not simply by the needs of students but by a sense that serving the needs of all students is a commitment that arises out of their sense of integrity as a teacher. A music specialist indicated:

> Sometimes, if I'm not aware of what needs they have, and how to best approach them, it's not a, you know, it can be a very overwhelming experience too. So, to educate myself to be really a more compassionate teacher. (Participant 3)

As mentioned above, several teachers cited the importance of including families in the process:

> We have children on the spectrum, and some things work and some things don't, and I want to make sure that they could be included in our school—I mean as far as we can, and that we're not losing those children, that we're dealing with having words for their families as well as them. (Participant 4)

Category three: Challenges.

Subcategory: student challenges. When asked what challenges autistic students face, the participants began by discussing what their *own* challenges were in teaching autistic students at first, and only later shifted to focus on the challenges facing autistic students themselves. In terms of discussing the challenges faced by autistic students, participants noted common autistic overwhelm behaviors like meltdowns, crying, aggression, and withdrawal. They noted that some classes, like specialist classes, may be especially overwhelming, and certain academic demands may be especially triggering, especially if there is shame triggered by a meta-message that this task "should be easy." They discussed the effects of social stigma in both the larger school community and among families. They described a sense that the usual methods of problem solving such as reasoning don't work with a highly-activated child, and the concern they have for students experiencing the urge to self-harm. Finally, there was an interesting brief discussion of the challenges in responding to uneven developmental trajectories in ASD students.

A few cognitive challenges were discussed such as different styles of processing (e.g., being able to listen without looking), the impact of anxiety on ability to focus, and a need for longer time for processing emotional issues. (Interestingly, many of the issues brought up regarding autistic student challenges were major points of emphasis in the training that immediately preceded the focus group discussion, and in several cases, when these challenges were mentioned, participants clearly identified their comments as new information they had just learned in the training. This suggests that, with the exception of "meltdowns," the training about some of the specific challenges facing autistic students provided, at least in some part, new information for participants.)

Student challenges (primary data). Teachers discussed both widely known and less obvious challenges experienced by autistic students. A disruption to functioning that is especially obvious in the primary grades is emotional dysregulation:

> I had a lot of experiences, well, last year, with students who would just emotionally shut down . . . so a lot of the tears . . . and just like outbursts of screaming, I . . . you know . . . I don't know what's wrong . . . just like, you know, verbal . . . obviously, this child is upset. (Participant 5)

Older students may face less difficulty in this area, but their increasing social awareness results in other challenges:

> I think one frustrating thing is the social stigma because in [another teacher]'s example she had a parent on board and willing to explain it to the classroom, but I think that

> sometimes when you move past the primary grades, it's this wanting to be like everyone else, so we're not discussing, you know, what makes this person different. (Participant 1)

As mentioned above, one teacher brought up the nuanced idea that unspoken, implicit assumptions can result in disruptions to regulation:

> To, you know, be able to take him to that next step to feel that I'm supportive of him, you know, rather than just this, you know, expectation that "you're supposed to be able to do this," which is, I think, a big thing that could be overwhelming to him. (Participant 3)

Subcategory: teacher challenges. Many of the above comments that happened to address autistic student challenges came from sections of the discussion other than the specific question about what challenges autistic students face. As noted previously, the teachers responded to the autistic student challenge question by discussing their own challenging experiences teaching autistic students. During this discussion, teachers acknowledged a range of common teacher challenges including feeling helpless and frustrated, feeling caught between meeting needs of autistic students vs. the needs of other students, trying to serve undiagnosed or unidentified kids with special needs, integrating new students into autism-positive class culture, and calming them*selves* after dealing with explosive behaviors in students. A large portion of the discussion focused on the ethics of sharing protected medical information about students. This concern reflected a desire to balance respect for privacy with open dialog aimed at creating a difference-embracing class culture. Teachers also discussed the challenges of building trust with families who do not necessarily know whether they can trust the school as an ally, and may have reactive shame associated with having a child who is "different." Finally, teachers discussed their own challenges in getting the training and information they want when their planning time is so constricted and broken up.

Teacher challenges (primary data). The most salient experience brought up by teachers were personal feelings of helplessness and frustration arising from lack of knowledge and lack of tools as to how to handle the needs of autistic students. Again, teachers displayed high levels of empathy, even in acknowledging their own difficulties. One commented by describing a difficult experience as: "Where I feel like the child is in pain and really suffering, and I feel like I'm helpless, because I'm not quite sure what to do with them at the time, and there's you know, twenty-five other students" (Participant 6). Another seemed to suggest that her rational understanding of autistic functioning was not always available to her in the moment, but that, with distance, she could use it to better understand and have compassion for autistic ways of learning. "It's easy to get frustrated, like you said, when someone isn't working, or isn't like, a self-starter, but like, they're not, like, taking it in, and understanding… like, 'Oh, you were talking to *me*,' [general laughter]." (Participant 7)

Category four: Autistic strengths. When asked about the strengths of autistic students, participants were quickly able to identify many areas of aptitude. Participants began by identifying some widely-recognized, almost stereotypic areas of autistic strength (e.g., a tendency toward quick acquisition of algorithmic understanding, hyperlexia, memory for detail, and affinity for construction with toys such as Legos). They then began to relate their observations of some strengths not often associated with autistic functioning, including the ability to form especially deep and loyal friendship bonds, the ability to pay attention in unconventional ways,[42] the ability to make unorthodox connections between ideas, and to express these understandings in unusual ways that may resonate for other students (or may communicate the idea to other students better than the teacher can), and a tendency to be more

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[42] That is, to be able to pay better attention while looking away, fidgeting, listening to white noise or music, or actively moving their body either in place or around the room.

practiced at self-awareness and communicating around their needs, given that they have to work so much harder at that self-awareness than other students do. This final observation suggested to the teacher that expressed it that the autistic children she described were practicing a skill that would become a character strength for them as adults.

Autistic strengths (primary data). The discussion of strengths was particularly surprising because the teachers spent very little time discussing stereotypical autistic strengths such as math ability and pattern recognition, and most of the time describing traits they had observed first hand that, in the not so distant past, would have been directly contrary to the common stereotypes of autistic functioning. First, they expressed openness to the idea of strengths in learning that diverge from widespread classroom expectations:

> That really struck me, with a student that I taught last year that, you know, as a teacher you want everybody to be doing the same thing and you come to the realization that that's not necessary for everybody and it's ok. And I mean he could be…he's paying attention, I mean, he's not, you know, looking at the board…but he's getting it. And so that's just…I really saw that with a student that I taught last year. (Participant 1)

In another example of diverging from stereotypes about autism, a participant described an ability to form loyal and deep friendships:

> When you have a good classroom culture of acceptance, that, ah, those students who are autistic, they ah, they form friendships like . . . and bonds that are so close and so tight, ah, with other students, ah, that can be so beneficial for both them as well as the other students in the classroom. (Participant 8)

Perhaps the most unusual observation concerned the above-mentioned heightened ability to be self-reflective, and to find language to express needs. The participant noted that not all autistic students she has observed demonstrate this strength, but she identified family culture as a key factor in fostering this ability:

> I feel like a lot of our kids on the spectrum have to work harder all the time. And so they are a lot more aware of what works and what doesn't work, with the support from home….I feel like the kids who do have support from home just have a better understanding of what works for them, and can communicate it when they're not feeling anxious and overwhelmed. And that's something I feel like…that not all of our students are that good at self-reflecting on what works for them. 'Cause they never had to stop and think of things. Maybe it just comes automatic for them—they never had to work through a struggle. And so I think that's a really good strength . . . for the adults then . . . you know—they turn into these adults then. (Participant 2)

Category five: Resources. On this topic, participants identified unsurprising concerns about the lack of training and limited access to information that they experience (as teachers at a parochial school, they commented that their school's ability to provide training is particularly resource-poor). This manifested as uncertainty about appropriate language to use when talking about the experience of autistic students, lack of knowledge about resources in the community, or ability to refer to service providers outside of school. Particular frustration was expressed regarding experiences referring to general medical practitioners or mental health practitioners for identification of learning challenges, and lack of information about next steps to recommend to families. On the other hand, participants expressed positive feelings about accessing families as resources. Finally, participants expressed concerns about lack of guidance regarding limits of sharing protected medical information in a context of creating pro-autistic classroom culture.

Resources (primary data). Families were identified as an important source of support:

> Having a partnership with the family and outside resources. Ah . . . being able to have some kind of communication um, so that you have a follow through . . . having the buy-in from the outside resources—the parents, and even the staff here at school. (Participant 4)

On the other hand, teachers expressed uncertainty about supporting families in accessing medical and psychological resources:

> A lot of times, where you're trying to get help you say, you know, "maybe you should talk to your doctor" and then they'll come back and say, "the doctor says they're within normal range," and then you're like, "Well now I don't know what to tell you. It's not, you know, working out here very well and how can we help this. . . ." But we don't have anybody to lean on either. (Participant 6)

Participants identified barriers to trust between families and teachers as an obstacle to building relationships.

> Yeah, that shame factor from the parents? Is huge! [others: "yeah, yeah"] . . . And I think, it can get, you know, when you can get by it then you're working as a team. And sometimes, in the midst of trying to get the, you know, the diagnosis, or the label, you know, you're bumping up against that thing of . . . of shame, you know, and "are you in my court?" you know. And I have a son who is on the spectrum, and so that, that is really hard to know, to deal with that—will they ever understand? Are they in . . . are they a support? Are we working as a team? And you know, I would love to see that really be felt by the parents and by the community [other participants: "yeah"]—that this is a safe place to be for all kids. (Participant 3)

Despite these barriers, teachers felt they had an important role to play in educating not only students, but families.

> When *I* took special ed. classes, that was the model—was behavior mod—So it's a very different understanding—you know, how to promote that culture of education and acceptance and inclusion you know . . . that can have amazing impact…sometimes it's freeing that parent to say—it's ok to have this child be the way the way that they are. [others: "yeah…"]…and you are well loved and well accepted . . . that's hugely powerful. And parents yearn for that…and fear the school setting because they may not feel that that will happen. (Participant 3)

The participants spent a long time discussing the ethics around protected medical information in particular.

> I had a student who was having…you know a disturbance in the classroom, and a new kid had just, you know, come in and was like "Woah, what's the matter with him?" You know, and the other kids, you know, don't have a good answer for that either—"Well, you know, he's special"—but they're not . . . you know, they don't really know how to explain, and I'm not there to put private information out either, so it's really hard as an educator. (Participant 1)

One teacher realized while she was speaking that she would like to more actively find out what parents want and do not want shared:

> My son has a friend who is autistic, and I don't know if the mother wants . . . and I guess I should ask her because, you know, we're asking the kids to give this kid a little extra leeway—well why? Why doesn't he have to behave the way that we do. So I guess, even in my own personal life, I have to ask the mother how she feels. [laughter] Do you want them to, you know, know that? Can we talk about it openly . . . or . . . ? (Participant 1)

Another speaker also underlined the ethical challenges of addressing meltdowns:

> Knowing how to talk . . . having tools or strategies of how to talk to other students about a student's melt down or their break down . . . because that's something I struggle with—I want to have a classroom culture, and you know, sometimes I'll include the student in the discussion, or I'll have the student be pulled out for something for a few minutes . . . but then how to go about talking to the other students about it when I myself might not have the whole picture, or I don't know the language that I should be using, exactly, to describe what's going on with the student and how they can be helpful to that . . . their peers. (Participant 8)

Category six: School culture and structure. Participants used this question as a jumping off point to talk about how proud they were of what they viewed as their school's strong culture of inclusion. They identified this culture as being a function of being a small school, as well as being a school founded in a Catholic value system that promoted the values of honoring each person and decentering teachers' experience, by prompting them to openly question their own methods when faced with challenge. Participants identified several factors related to school structure in which they felt supported their school culture of inclusiveness, including strong communication and camaraderie among faculty, friendships among school families, and cohesiveness between classrooms as students moved from grade to grade. They also used the time to discuss some ways they could improve consistency of strategies across classrooms such as incorporating a standardized "safe place" and sensory breaks/items into every classroom in ways that destigmatized their use by being open to be accessed by all students.

School culture and structure (primary data). The teachers' pride in their school showed up as respect for students and for each other.

> [The students] are so inclusive. I mean, I'll have known those children from preschool all the way on up and [other teacher] and I'll watch the eighth graders and just how amazing they are . . . and what a wonderful job that our staff has done to have those children really embrace those other children and to help with the differences. (Participant 4)

Another teacher spoke about her experience with the relationship between her class and a specific autistic student:

> They're very accepting of his differences and, ah, he was just a complete, you know, member of the classroom, and there was no difference between him and everyone else that, you know . . . it was [others: yeah] it was really wonderful to watch. (Participant 1)

One participant attributed this positive culture to effective support and training for teachers:

> In schools that I've been at where it doesn't happen, you know, some of it is that knowledge, that education, and to be able to have skills to be able to do it so you're not feeling powerless or overwhelmed in that situation [others: "mmm"] that you have the resources to be able to support the teacher, and then, you know, with that then comes that ability to see that person, verses just that, you know, that *they're* causing the problem. (Participant 3)

One participant cited the school's Catholic value system as a unique aspect of the school that supported an open-minded approach to challenges:

> Because we're supposedly, you know, based in Catholic/Christian teaching, that kind of is a piece that I know I will go to if I—am I behaving in a way, in a way that's respectful, you know, that's honoring that person. And that helps me to rethink something, or to say, you know, I need to try again or find another strategy or something . . . (Participant 3)

Several participants focused on the aspects of their school's culture that promoted a particularly supportive environment.

As a general value, sense of community and mutual support was mentioned by several participants. "The cohesiveness . . . you know—that we all speak to each other . . . " (Participant 4). This sense of community was mentioned by another participant: "You know, it's camaraderie, it really is—I mean like you care about them so much but at the same time, like, you're really hard on yourself [yeah], like, like you were saying [yeah] . . . 'I've been there too'" (Participant 7). Community was cited as a key support for teacher emotional regulation:

> And I think that's the other thing in this community, you know, the teachers . . . like I can go to anyone and, even a meltdown—you know they can be over in a second, and I'm still, you know, like, "Oh my gosh!," You know, I'm still sweating and upset [laughter] and like, "Did I do that right, did I say that right?" And it's nice to go to someone and be like, you know, like, this happened, and just to have that validation back as a teacher, and that there's no judgment, and everyone is like, you know, caring, wants the best—I feel like we have that support to go to each other for help. (Participant 2)

Category seven: Practical application. Participants responded enthusiastically to the practical application topics both by sharing strategies they had found useful, by bringing up challenges for which they lacked effective strategies, and by brainstorming ideas for what they thought might help them. The practical, applied emphasis of the teachers' discussion (encouraged by focus group questions aimed at evoking practice-based challenges and needs) meant that these three topics dominated the focus group discussion throughout much of the second half of the hour, resulting in as many coded entries for applied practices as for all the other sections put together. To make the analysis of this large category manageable, practical application themes have been divided into three sections: “techniques,” which includes general guiding ideas or practices; “strategies,” which includes specific activities or interventions; and “tools,” which includes guides and references that provide information or summarize concepts for teachers (e.g., professional development resources, quick references, decision trees, etc.). In all three categories, teacher discussion moved freely between practices or resources they already employed and practices or resources they would like to learn more about. Both are summarized below.

Subcategory: Techniques. This category includes broad ideas that set the tone or created a classroom culture supportive of successful teaching of inclusion students. Teachers cited examples of practices that worked for them, such as adapted instruction designed in the philosophy of Universal Design for Learning (UDL) to better meet the needs of all learners. Such UDL curriculum was discussed as including multiple sensory modalities in instruction, providing re-presentation of information in an alternative format, or breaking tasks up into a greater number of steps to focus on processing only one piece at a time. Other strategies endorsed by the teachers focused on the idea that learning can only take place when a child is well regulated and calm. Ways to promote regulation offered by the participants included starting with validating the student’s feelings when challenges arise, recognizing limitations such as auditory processing deficits, being creative in designing alternative approaches, and providing extra scaffolding and time to transition before expecting readiness for new learning. Another example of emphasizing self-regulation skills was the use of sensory interventions such as sensory materials and low interaction demand in a safe spot, or large muscle "heavy work"[43] to promote emotional regulation.

A large number of comments focused on working at the class culture level to create an atmosphere of inclusion and acceptance. Examples of ways to promote inclusion included showcasing unique abilities (autistic strengths), teaching respect for different ways of processing (with the idea that *all* students have unique learning styles), minimizing shame (through promoting acceptance of variations in learning approach) and normalizing sensory interventions (through universal application—examples of inclusion techniques using sensory interventions included having everyone routinely do "chair push-ups," and encouraging every student to access a classroom "think spot" for the opportunity to withdraw from sensory overstimulation).

Teachers also commented on culture at a school-wide level, expressing a desire for more consistency between classrooms on how students' reactive behaviors were addressed, and greater outreach to parents to support the message that the school wished to destigmatize autistic behaviors and promote full inclusion of autistic students. Two participants commented that parent outreach could take the form of an invitation to meet or a suggestion of the idea of speaking to the class about their child's ways of experiencing the world—an approach already employed by one parent last year.

Techniques (primary data). Techniques ranged from specially designed instruction for specific students to more general adaptations for the entire class. For example, many teachers liked the idea of a withdrawal area or "think spot," and several minutes were devoted to how

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[43] "Heavy work" is a term commonly used by occupational therapists to describe gross motor activities that involve strenuous activity and engage coordinated, often bilateral large muscle movements. It can involve pushing, carrying, or dragging heavy things as well as wearing weighted clothing. Heavy work is useful in promoting sensory integration and fuller presence in physical bodily awareness.

they could make this practice more a part of their school culture as a whole. One teacher was asked how she implemented this technique:

> It's called the "think spot" and so if they need time to go and think about what was happening . . . I've also seen it called like, cool—your cool off spot, or whatever, and they just go and they have a corner where they can just sit and just relax and they're not, they're not expected to be a part of the discussion but they're expected to be working through whatever they're dealing with at that moment. (Participant 8)

When the topic of Universal Design came up, it became apparent that some teachers were more familiar with the idea than others, and the group spent some time educating each other on the concept, asking and answering questions. The learning diversity specialist offered that, "This idea of using multiple modes, and multiple sensory ways of engaging. The Universal Design idea is that: cast a wide net—it's better for everybody" (Participant 9). Other teachers, more recently graduated from teaching programs shared what they had learned. Universal Design is:

> Using good teaching strategies for everybody . . . like, that's how I've always thought of it anyway. Like just using multi-sensory, a lot of the time. And you probably do it . . . but you don't know what its . . . like, new term is, you know? I learned it as UDL just 'cause I just got my master's degree. (Participant 5)

One participant shared the idea that UDL is not just for those with learning differences:

> When you are specially designing your instruction for [autistic students], it's just so beneficial for everybody else, because you change if from just a visual sort of lesson or an auditory, or . . . but you like incorporate other things . . . Or you lay off other things—like we're just going to process this right now. (Participant 7)

Another reiterated this idea, pointing out how using a sensory activity for the whole class destigmatizes the activity:

> It's good to have the same kind of strategies for everybody—we're all going to do some chair push-ups now. I think you set up a class culture—it's not just something this one child has to do—we're all doing it [others: "uh-uh, yeah"]. It kind of takes away the shame of the fact that you have to do something different…to be here in a system the same as everyone else. (Participant 2)

Finally, in discussing general techniques for improving instruction for autistic students, participants spoke of adjusting their general emotional support for students. "Just validating the child's feelings is huge, and we worked—[the diversified learning specialist] helped a lot with a few students—all their plans had to do with that" (Participant 5). Participants also referred to a process of reevaluating their approach when hitting an instruction roadblock.

> Obviously, this child is upset and they don't want to write, or read, or do math or whatever, and so, as I looked at my teaching style and strategies, and the curriculum, um, just like…and [the diversified learning specialist] helped me a lot too, but just like, how could I make things, as I was presenting them, that would be, like, helpful for that student. (Participant 5)

Subcategory: Strategies. On many occasions, teachers spoke about specific strategies that they already use or that they learned in the training and would like to use more. These included communication strategies such as beginning statements or questions with a student's name, instruction strategies such as using a rhyming approach, instead of a sound-it-out approach to adapt phonics lessons, and emotion regulation scaffolding such as pairing a validation of the student's feeling with a restatement of teacher expectation, or using a familiar, repetitive phrase during times of activation. Processing accommodations included offering assignments in written form as well as verbal, using visual schedules or photos rather than written guides, and using “heavy work” to support sensory integration and down-regulation.

In addition to strategies for teaching autistic students, the participants discussed class-wide strategies to promote normalization of diversity (including neuro-diversity), such as making all differences more visible (e.g., gender, interests, learning styles), teaching directly about brain function and variability in learning styles, teaching students to value everyone’s unique giftedness, and generally teaching respect for differences. They also discussed strategies for bridging between school and home such as coordinating with families to learn what works at home or to standardize language use between school and home, and reaching out to next year’s and last year’s teacher as students progressed through grades at the school. Finally, the participants discussed the importance of teacher training and self-reflection, including empathy for the experience of struggling students, and the ability to see a struggling student as a person and not a problem.

Strategies (primary data). Direct instruction strategies included both cognitive and sensory approaches. One teacher described teaching reading to a student with poor auditory processing:

> So like, how would I modify the, you know direct instruction of sound, for a kid who can’t sound out a word, and it became a lot of like, he needed a memory clue, like he needed a visual. And so, and then we did rhyming and things like that. So that we could tie in a learning piece of something new, but like, he would start out with benefit of, “You know this,” like, “you know where we need to go, and this is what it sounds like.”

> And so I think that that helped with the meltdown of like, you know, he wasn't starting to cry as soon as I said, "Ok, what sound is in such-and-such word." (Participant 5)

Another teacher spoke about how a sensory strategy made a big difference in self-regulation for an autistic student:

> For that…student, scuffing the floor was a huge help for this student—his breakdown would often be like aggression, like hitting himself or hitting the table or kicking, and just the beginning, and then he would calm down almost immediately. But it was just that—you need to be safe, in a safe place, and if scuffing out—we have these new floors now that they get scuff marks easily…and the action of kicking and scuffing the floor—it's still the action, he got that aggression out, but in a helpful way. And he always felt really helpful—"Thank you so much, this hallway looks so nice, Mr. [Custodian] is really going to appreciate this!" [general laughter] . . . And that was a nice productive thing to do rather than just remove yourself from the room—here's your task. (Participant 2)

Subcategory: Tools. This category was initiated by a question asking what tools participants would like to support them in working with autistic inclusion students. Often, the participants referenced examples of tools they had found helpful in other areas as they brainstormed what they thought would help them in the future.

At first, the discussion focused on the idea of a website specifically. Teachers mentioned their desire for a centralized, trusted resource that would allow them to find many strategies, guides, and tools all in one place without having to search for or vet them. Such a website might also be helpful, they indicated, if it included a directory of service providers by area. The teachers had a lot to say about format (they wanted formats that would be easily accessible to them during their very limited time for research), speaking emphatically about the need for simplicity such as graphic communication of information in the form of flow charts or info graphics to help them quickly scan for and retain important information. They requested guides in the form of "if you see this, it may mean this, and you might try this" or "red flag" guides of behaviors to be especially aware of. One participant cited the "What are You Teaching Autistic Children" handout that had been included in the training packet as an example of a simple, helpful graphic design that still conveyed a lot of useful information. Overall, the group agreed that website tools would be most helpful if they included clear recommendations for teacher intervention (e.g., clear action to take), but the participants also seemed particularly drawn to charts exploring possible motives or meanings for student behaviors, such as list of possible reasons for aggression that was included in the training handout.

Several teachers referenced other trainings they had found helpful. One teacher expressed a desire for videos modeling teacher behaviors similar to a "Love and Logic" series she recalled benefiting from in learning specific ways to validate emotions. Another mentioned a training on Executive Functioning she had attended, but expressed a desire for similar material created with primary grade students in mind. (Jokingly, the participants asked if such materials could be ready in two weeks, by way of acknowledging the large scope of such a project as creating video trainings).

Several teachers cited what they found most helpful from the training preceding the focus group. These included specific strategies like pairing emotion validation for the student with restatement of teacher expectation, and beginning questions and comments with a student's name. Others cited broader concepts from the training like the social model of disability, understanding the need for extra time for processing, the idea that Alternative and Adapted Communication (AAC) is often very helpful for communication about topics beyond the curriculum (where one might not think to apply it), and the very large influence of anxiety on autistic functioning.

The bulk of the discussion, however, focused on brainstorming specific tools that would be helpful that the teachers did not currently have—a kind of wish list of information and supports. These included such guides as guidelines to variable developmental trajectories that might be expected to be seen in autistic students, and a "tool kit" of problem solving skills to teach to students with high reactivity. Teachers also asked for guidance on how to handle several typical autistic behaviors such sensitivity to touch and proximity of other students, requests such as "don't look at me," and melt downs. They asked for several kinds of guides on how to conduct conversations about autism, from specific requests like how to talk to students about meltdowns, to more general requests about how to lead a discussion with a whole class about autism (in discussions that both include or do not include autistic students), to techniques for opening dialog with families about autism and the destigmatizing autistic behaviors. One participant requested a printable resource to give to parents debunking autism myths.

Tools (primary data). While highly engaged in the final question of the focus group discussion relating to tools that teachers might find useful, one participant wanted to emphasize what a complex challenge it can be to effectively support the many aspects of functioning presented by autistic students:

> I feel like we get a handle on behavior and then something else totally different that deals nothing with behavior, could be with academics, could be with, I don't know, communication…it just falls apart. But you know—how do we, how do we like get, like, the whole child, like get, like the best therapy for helping them. (Participant 7)

In response to the question "What tools would you find useful?" participants readily volunteered specific ideas including simple guides, clear checklists, and bite-sized pieces of professional development instruction:

> This is what the adult can do, this is how it helps. Like 'cause we've all seen… like if you go along the list of when a child… [others: yes, yes] these are the break-downs—like "when a child isn't looking you in the eye, this might mean this". . . you know, just the things we see every day…I feel like, in this format, really helps. (Participant 2)

Another participant suggested:

> Or like videos that model [teacher interventions]. Like I watched something on emotion coaching [that] really helped me figure out like how to structure choices, and like what, what… like good examples. And this flow chart, like, really reminded me of emotion coaching and like that validating piece of, "I see that you are frustrated, like, tell me your emotion, if you can verbalize it, and like, let's learn, like, some strategies for, you know, like problem solving skills." (Participant 5)

A third participant wanted a guide to interpretation of behaviors in students:

> Back to your original question about tools…maybe like a tool to say like, "if you're seeing this, you know, maybe this is happening," or I don't know …but like, as the symptoms change or as their, their autism takes on like, different stimuli and stuff, like how can we see that and…help them. (Participant 7)

Category eight: General concepts. Several teachers opting to stay for the focus group demonstrated a fairly high level of knowledge about autism, and shared many opinions about appropriate methods for teaching autistic inclusion students. These included the idea that autistic functioning is a continuum, that autistic behaviors vary greatly day to day and from student to student, and that sensory sensitivities are a big part of autism. As noted above, the participants discussed the principles of Universal Design for Learning (UDL) including multiple modality presentation, awareness of all kinds of learning needs, and the idea that UDL curriculum planning creates a better learning experience for all students, not just students with learning differences.

Several concepts appeared to crystalize during the discussion itself as a result of integrating new ideas. One of these was the realization that understanding anxiety as the root of challenging behavior results in greater teacher patience and empathy, and that conceptualizing positive meanings for behaviors in general allows teachers to stay calm (as opposed to assuming a student is willfully not listening, for example). Another participant realized, as she was describing an experience of hers, that she would like to be more direct in asking the parents of autistic students how much information they would like shared at school. Another topic focused on the idea that teachers may increase their ability to respond well when they examine their own approach as a possible area for change, rather than trying to change the child. A specific example given was recognizing they ways a teacher may be contributing to escalation in her students through her own actions. Another discussion topic focused on the idea that giving meaningful self-regulation tasks communicates respect to students in a way that a simple request for self-removal does not. Finally, two participants remarked that teachers in general tend to be hard on themselves. This comment was followed by several comments focusing on how proud the participants were regarding what they had accomplished in terms of school culture and inclusion.

General concepts (primary data). The final stage of the focus group discussion appeared to be a time of integration and crystallization of new concepts. A frequent theme articulated was that teachers felt they had gained a new understanding of autistic processing differences and the role that anxiety and activation play in autistic behaviors and capacity to learn. Teachers brought together their personal experiences, their experiences teaching autistic students in the past, and their new learning from the training:

> As a parent, my own shift over the summer has just been like, there's nothing wrong with the *kid*, [laughter] there's something wrong with me [laughter], like, he is throwing this fit because I am like, continuing to escalate him. And so like, how do I do that with my students. If I'm doing it with my own *child* [laughter] I'm probably doing it pretty frequently with my poor little students. (Participant 5)

Another participant cited material from the beginning of the training:

> I think something that helped me today was the myths. I mean, not that I ever bought into those personally, but I would hear, you know, just different things, and so even if that's something that we can send home to our parents, like, you know, like this is what we learned and then have, like you verbally gave them to us, but just like bullet points or something of why they're not true, and what to do, like when we see or hear those myths being perpetuated. (Participant 5)

Another discussed how information in the training helped her to understand the need for greater processing time:

> I think that what was really helpful was the processing piece. Because I think it's something that is like something we may know that is like, this child may need a little more time to process, so that's something that can go for everyone in the classroom, that they need time to, you know, deal with their emotions, but that in an autistic student, that time could be increased was *so* valuable to know because, you know—you want to get

> things resolved, you know, before they go home, and that they may not be the case, I think, was really, you know, [others: yeah] just so valuable to learn today. (Participant 1)

Finally, two participants cited the importance of thinking about student behavior in terms of expressions of anxiety: “And the anxiety piece. [Others: “Yes. Yeah, yeah.”] You know…that a lot of their difficulties stem from that anxiety” (Participant 3). Conceptualizing student behavior as arising from anxiety was cited as having an influence on teacher behavior as well:

> Just to think that that…to have that thought—ok this child is feeling super anxious, this is—you know we all, I feel like it gets you to that calming, you know—be more patient, I mean, you’re automatically more patient when you realize there’s more pain, you know, involved in it, then just like, you know, a tantrum, because they’re being stubborn, you know, like—there’s a big difference. (Participant 2)

Chapter V: Discussion

This study was designed to test the premise that general education teachers desire and would benefit from training and resources for teaching autistic inclusion students. The results of the user survey on areas of website interest show moderately high to high levels of interest in all suggested categories. The results of the pre- and post-measure show that the participants reported themselves as experiencing definite benefit from the training offered as a part of this project. Finally, the results of qualitative analysis corroborate a high level of interest in teaching strategies as well as clear learning and integration of new ideas from the offered training.

Discussion of Quantitative Findings

Pre- and post-test Likert-type items. The eight Likert-type items were designed to measure the effects of the training intervention by asking teachers to self-rate their level of knowledge and institutional support for teaching autistic students in general education settings. In the case of the first four Likert-type items, each area was subdivided into two categories: emotional and behavioral functioning in the first case, and cognitive and perceptual in the second. This distinction was made based on the hypothesis that currently available teacher training and resources on autism appear to focus almost exclusively on the behavioral and emotional aspects of autistic functioning, and offer very little on the differences in cognition or perception that are coming to be understood as core features of the condition.

While this study found minor differences in teacher knowledge before exposure to training in these two areas, the differences were not significant. That is to say, the participants in this study endorsed approximately the same level of understanding and preparedness to address each of the two domains in the pre-training condition. This finding of no significant difference could be due to several factors. One possibility is that since educator training tends to focus very heavily on student cognition putting somewhat less emphasis on behavior management, the difference in preparation and professional development may have compensated for any differences in the specific case of autistic students. Another possibility is that because the distinction between behavioral and cognitive domains of autistic functioning may be an unfamiliar distinction in the field of education, teachers may not be accurate reporters of their own levels of awareness—in other words, the neglect of the unique features of autistic cognition in educational literature may be pervasive enough that teachers have not given much thought to that aspect of functioning as a separate category, and may therefore not have a clear sense of their level of understanding. A third possibility is that despite the relative paucity of resources addressing autistic cognition in the literature and review of web resources, teachers feel they have enough information to have a level of understanding and preparedness of autistic cognition on par with their understanding of autistic behavioral functioning.

While comparisons between pre-test conditions across domains of functioning found no significant difference, comparisons between the pre-test self-reports of level of understanding and preparedness verses post-test understanding and preparedness were significant in every case, showing large effect sizes in the direction of reported benefit from training on all items. The first two items addressed basic understanding of autism. On a statement regarding understanding of the behavioral and emotional aspects of ASD, only ten participants indicated that they agreed that they felt they understood to some degree, while after training, 24 out of 25 endorsed either agree or strongly agree. On the question regarding level of understanding of cognitive and perceptual aspects of ASD, nine participants endorsed “agree” on the pre-test rating, while 25 out of 26 endorsed either “agree” or “strongly agree” after training. These results suggest that participants felt strongly that they benefited from the training. Participants also reported their levels of understanding of the two domains as being very similar prior to training, and reported their levels of understanding as having been increased to a similar degree by the training.

- **Hypothesis:** Training would increase teacher understanding of behavioral and emotional aspects of autistic functioning: **supported.**
- **Hypothesis:** Training would increase teacher understanding of cognitive and perceptual aspects of autistic functioning: **supported.**

The next two items addressed level of preparedness to address autistic behavioral/emotional needs and academic needs. When asked to indicate level of agreement with a statement about preparedness to address autistic behaviors, ten participants endorsed "agree" or "strongly agree" before training. That number went up to 23 out of 25 endorsing "agree" or "strongly agree" after training. When asked about preparedness to effectively teach academics, eight participants endorsed "agree" in the pre-test condition while 20 out of 26 endorsed "agree" or "strongly agree" in the post-test condition.

In the case of items three and four, the number of participants who indicated agreement was somewhat lower than on items one and two, especially on the question regarding teaching academics (as would have been predicted by the hypothesis that fewer training materials available in this area might show up as lower self-ratings of teacher preparedness). Because these latent constructs are quite different, it is possible that they were affected differentially by the lecture/focus group intervention, thereby influencing direction of change in opposite directions (for example, the intervention included information designed to support curriculum design for autistic inclusion students, which may have made educators' evaluation of their own competence increase; at the same time, the presentation included information designed to sensitize educators to the common misconceptions about autistic functioning which paradoxically may have made their evaluation of their own levels of knowledge and competence go down.)

It is notable that while participants' reported level of preparedness to teach academics increased, it did not increase as much after the training intervention as in the other areas. While this topic was addressed in the training, the portion concerning academic interventions in the teacher training was shorter than some of the other sections. The Likert-type instrument results suggest that a focus on academic approaches and curriculum design is a definite area of need for educators and would be an area for improvement or expansion in future trainings.

- **Hypothesis:** Training would increase teacher preparedness to address behaviors of autistic students: **supported.**
- **Hypothesis:** Training would increase teacher preparedness to teach academics to autistic students: **weakly supported.**

As mentioned previously in the results section, the difference between preparedness to support behaviors in the pre-training condition was compared to readiness to teach academics in the pre-training condition. No statistically significant difference between the two pre-training conditions was found.

- **Hypothesis:** Teachers are less prepared in the area of understanding autistic cognitive functioning than in the area of understanding emotional and behavioral aspects of autism (before training): **not supported.**
- **Hypothesis:** Teachers feel more prepared to address autistic behaviors than to teach academics to autistic students (before training): **not supported.**

The fifth and sixth items were designed to measure level of understanding of the social model of disability, one of the most emphasized topics in the training. The fifth item asked if participants understood the difference between the medical model and the social model of disability. Before the training, two participants endorsed “agree,” while after the training, 22 out of 25 endorsed “agree” or “strongly agree” yielding one of the largest effect sizes in the study. These results indicate that the training was extremely effective in its goal of educating participants on the difference between medical model thinking and the social model of disability. The sixth question asked participants to go a little further and assess whether they could *apply* the social model of disability to the needs of autistic inclusion students. Before the training, seven participants indicated that they agreed they could do so. After the training, 24 out of 26 endorsed “agree” or “strongly agree.” (It is an interesting artifact that more participants reported that they could *apply* a concept than reported that they agreed they *understood* it—reasons for this discrepancy can only be speculated upon—perhaps it has to do with the extremely applied nature of the work of teaching.) Overall, the training appears to be highly effective at communicating how the social model of disability can be applied to meeting the needs of autistic inclusion students. This encouraging finding suggests that the training was successful in one of its primary goals, and that this section should be retained in future trainings to support the goal of supporting a conceptual paradigm shift in participants.

- **Hypothesis:** Training would increase teacher understanding of the social model of disability: **strongly supported.**
- **Hypothesis:** Training would increase teacher ability to apply the social model of disability to supporting the needs of autistic inclusion students: **supported.**

The contrast between the moderately positive results on the practical area of teaching academics and the strongly positive response to the theoretical construct of the social model of disability is notable, though it is not possible to determine if this difference was due to relative emphasis or effectiveness in the training or to some other factor (e.g., that communicating a single paradigm shift in a short amount of time is simply easier than communicating details about a large number of practical and applied skills). The decision to focus the training mostly on communicating a high level conceptual idea rather than on specific, applied teaching techniques was a deliberate one based on the principle that a conceptual framework can inform curriculum design, while specific examples of curriculum design do not necessarily add up to a paradigm shift in educator approaches to autistic inclusion students. Additionally, examples of specific curriculum are functionally infinite and could never be covered comprehensively, while providing a theoretical understanding that drives shifts in approach can flexibly inform future curriculum planning. That said, the weaker shift in response to the item regarding preparedness to teach academics does suggest that guidance in curriculum design is an area of need which future training design would do well to support with more thoroughness.

The last two Likert-type items provided statements relating to participants' perceptions of the level of support for serving autistic inclusion students provided by their school's structure. Because a training cannot change the structure of a school, it was surprising that responses to these items increased at all, which implies that the higher level of knowledge provided by the training may instead have affected participants' attitude toward their school's structure. The change, however, was small compared to other items and involved a much smaller number of positive responses both before and after training. Before training, six participants endorsed "agree" in response to feeling supported in the two domains (behavioral/emotional and cognitive/perceptual). After the training, eight respondents endorsed "agree" or "strongly" agree. Nevertheless, this response was found to be significant according to a Wilcoxon signed-rank test (although not when analyzed with a paired t-test). The statement regarding school support for cognitive and perceptual functioning of autistic inclusion students, seven endorsed “agree” before training, while ten endorsed “agree” or “strongly agree” after.

Again, this result is significant, but with a weaker effect size than most of the other items. The small increases in positive endorsements for a factor that could not logically have been influenced by the training suggest a possible weakness in the study design: placing two items related to rating the environment after six items related to indicating positive changes in themselves may have influenced the participants towards a positivity bias—in other words, there may have been some slight unconscious resistance to indicating no change after a pattern of indicating improvement on six preceding items. While the training could not have brought about material change in school structure, there are possibly other plausible explanations for this change in ratings for school structure, which is that some aspect of the training could have caused a shift in teacher understanding of or attitudes toward existing school structures. (An example of this is a discussion that took place during the focus group wherein teachers discussed the fact that several of them were already using the school chapel as a “think spot” or away space for students who needed somewhere quiet to withdraw—this discussion is an example of a shift in understanding or utilization of an existing resource. It is not possible to determine whether such shifts in understanding were at play in the results on Likert-type items seven and eight which is an inherent weakness in quantitative measures.)

- **Hypothesis:** Training would have no effect on teacher attitudes toward school supports for social/emotional functioning of autistic students: **not supported**
- **Hypothesis:** Training would have no effect on teacher attitudes toward school supports for cognitive/perceptual functioning of autistic students: **not supported**

The most notable aspect of the final pair of items is that the number of participants who felt supported by their school was markedly lower than the number of positive endorsements related to relying on their own resources of knowledge and preparedness. This frustration over feelings of lack of support was corroborated in the focus group (discussed in detail in the qualitative results discussion below).

Clinical significance of pre- and posttest findings. Overall, the results of the Likert-type item survey strongly support the effectiveness of the teacher training presentation, especially in educating participants on the concept of the social model of disability. The smaller number of positive endorsements and slightly weaker effect size in the area preparedness to teach academics indicate this as an area of need that could be targeted for improvement in future trainings. The ratings of school structural support suggest that these teachers, despite their increased positive feelings about their own abilities after the training, felt that they could be more strongly supported by their school structure, even though the quantitative measurement of their attitude as a group toward their school structure became slightly more positive after the training. (As noted, this increase may simply have been an artifact of positivity bias based on the order of the items on the measure and should be interpreted with caution.)

These findings suggest that the participants found the training a useful intervention and rated their level of benefit as high in all categories relating to their understanding and preparedness to teach autistic inclusion students. It is assumed that these self-reported shifts in pedagogical understanding will have impacts on teacher behavior, and by extension, on the experience of autistic students in the classroom. However, given the limited scope of this project, there is no way to know conclusively if this is the case.

User Survey Results. As a straight forward interest survey, no statistical analysis was applied to the user survey findings (other than averaging all participant responses on each item into a single aggregated rating), however, the raw numerical results are still useful in informing priorities in website design. The most obvious result was that participants liked every option offered—no choice was collectively rated lower than “moderately interested.” This suggests that participants were in general eager for resources and information on teaching autistic inclusion students.

Despite this race to the top, there was still enough variability in the results to offer some utility in making design priority decisions. The highest area of interest was in resources to support the behavioral and emotional functioning of autistic inclusion students. Requests for resources on cognitive and perceptual function were rated more than a point lower than desire for resources on behavioral and emotional needs. This suggests that the preponderance of attention in available educational literature and resources evident in the literature and web review may exist in response to existing user need. That is to say, attending to behavior and emotion regulation is the squeaky wheel of autism needs—without sufficient emotional regulation on the part of students, after all, teaching is quite challenging—emotional meltdowns are difficult for both teachers and students, and impossible to ignore for the classroom community as a whole. As support for behavioral regulation is an area that is already amply covered by existing web resources, this finding suggests that more could be done to make such resources more accessible or user-friendly. A useful web resource might be an annotated listing of available resources to make them more readily available to educators with limited time for research or ability to evaluate available resources for professionalism.

While autistic regulation challenges are one of the more obvious manifestations of autistic functioning in the classroom, the greater emphasis on desire for resources to support autistic behavior may reflect a limited understanding of the drivers for emotional dysregulation. It is possible that autistic student frustration could be lowered and regulation supported through indirect strategies by means of such methods as planning for design of academic tasks specifically to lower anxiety (e.g., limited choice, less reliance on auditory information, more attention to breaking tasks into smaller steps); at the same time, attention to creating academic experiences designed specifically for unique aspects of autistic cognition could lower anxiety through increased engagement (e.g., tasks requiring analysis of details rather than selection of details, tasks requiring student to find examples of a defined pattern rather than generate a pattern definition from given examples—e.g., bottom-up cognitive tasks building up from detail rather than to-down from principle). That said, the investigation of such a hypothesis is beyond the scope of this project. Ultimately, the difference between participant requests for resources in the two domains was small—the participants clearly wanted supports for both domains.

The second highest area of interest was in information on differentiated instruction for autistic students. Since differentiated instruction is the applied practice of teaching to differences in cognitive functioning, this result suggests that while understanding the theoretical basis of autistic functioning in the cognitive realm may not be quite as interesting to teachers, *applied* techniques for teaching to the unique cognitive needs of autistic students was high on their list. Interest in Universal Design for Learning (UDL) and application of Common Core principles tied for third, adding further support to the idea that teachers are interested in understanding cognitive functioning in practical and applied terms relating to constructs (such as UDL and common core expectations) that are hot button issues in the educational field at present.

The area of lowest interest was in a social media platform. This may reflect the very limited time teachers have for professional development or it may have been influenced by the high level of face-to-face community experienced by teachers in this particular school, both of which were strong themes in the focus group discussion (discussed further below). As noted in the literature review, such discussion groups exist already, and, in combination with the lower interest expressed by participants in this study, would suggest that creating a social media platform for discussion should be a low priority for this project. This is useful information as, prior to this survey, the creation of such a group was high on the tentative priority list.

The area of second lowest interest on the user survey was in the theoretical principles driving curriculum design, followed by the idea of psychological research summarized for an educator audience. One of the clearest messages of the combined results of quantitative and qualitative data in this project was that the participants appreciated theoretical understanding (such as the strong emphasis on understanding the social model of disability in the training) but only when such understanding was grounded in distinctly practical and applied strategies for improving their professional teaching skills and ability to deliver educational benefits to their students. When queried in the form of a user-survey, theoretical understanding of psychological information for its own sake was not endorsed as especially interesting by this group of participants—a distinction that can be difficult to remember for psychologists such as myself, who are highly immersed in the world of theory. On the other hand, the positive comments in response to the training that participants offered after the session (and therefore were not captured on audio recording) strongly emphasized appreciation for the theoretical and neurobiological aspects of the training. Many participants said they were excited by learning such information because it was not information they could easily get anywhere else, and because it helped them makes sense of autistic functioning in entirely new ways. This is an irony of quantitative measurement—what people endorse on a brief numerical measure does not always align with what they say in more nuanced conversational feedback—and it confirms again that a mixed methods design was an effective approach for gathering a robust picture of teacher needs at this site.

Limitations of the quantitative inquiry. As noted above, the increase in positive endorsements for school structural support suggest the possibility that some positivity bias (sometimes called "optimism bias") may have been operating in the response pattern of the respondents, causing them to answer more strongly in the positive even on items where actual change was unlikely to have occurred. While more apparent on the items regarding school structure, this response pattern bias, along with social desirability bias (the desire to please the presenter by reporting a positive experience), may have subtly influenced other response patterns as well. In addition, while a retrospective pre- and post-survey design has certain strengths as detailed in the methods section, answering patterns are more vulnerable to what has sometimes been called hindsight bias (overestimating one's previous level of knowledge because it is hard to remember the state of not knowing once one has learned something new). On the other hand, findings appear to be sufficiently robust to indicate meaningful change despite the influence of various factors on response patterns. However, results should be interpreted with caution because, like all self-rated measures, this study captures only the participants' perceptions of their level of understanding and preparedness, rather than providing an objective measure of knowledge.

Other limitations of the study include the fact that the sample was a convenience sample that was very similar in ethnic, class, and even religious demographics. As demographic information was not gathered on study participants, only very general statements can be made concerning the homogeneity of the sample group, however, the most obvious limitation in this regard is that the teachers were all employees at a small private, parochial school. Lack of demographic data limits the generalizability of these results, and future research would benefit greatly from recruiting a more diverse population of educators in a public school setting.

Finally, the ultimate goal of this study was to improve the quality of education delivered to autistic inclusion students. However, this study measures only teacher self-perception relating to theoretical understandings of pedagogical approach, it does not measure changes in applied teaching practice resulting from the training, or more saliently (though even more difficult to capture) improvements in educational *outcomes* for autistic students. An action research project with greater scope might consider similar measures and focus group research with other stakeholders in the community such as families of autistic students and older autistic students themselves to gain a broader picture on the effects of this type of teacher training on the direct experience of autistic students and their families.

Discussion of Qualitative Findings: Focus Group Data

Research statement. The purpose of this study is to explore the experiences and training/support needs of general education teachers in their work with autistic inclusion students.

Focus group findings by theme. Qualitative data from the focus group discussion was transcribed and coded at a content level into eight categories: (1) meaning; (2) interests; (3) challenges (both student and teacher); (4) autistic strengths; (5) community resources; (6) school culture and structure; (7) practical application (techniques, strategies, and tools); and (8) general concepts. Some of these eight categories contained only a small amount of discussion and ideas (for example, the categories “meaning” and “interests” framed the beginning of the discussion, but as fairly categories that tended toward fairly abstract and general statements, did not contribute very much to the overall understanding of the topic). Other categories served to focus discussion of concrete and specific experiences (such as the “challenges” category—which focused on detailed experiences that teachers had encountered teaching autistic students). By far the most compelling topic for the participants was the discussion of “practical application”—this discussion included recounting specific practices and incidents they have experienced in the past, explaining approaches they already used, identifying areas where they lacked appropriate strategies, and brainstorming resources that might be useful to them in the future.

As mentioned above, the first two categories (meaning and interests) appeared to be a kind of “warm up” period as participants worked up to engaging in the discussion more deeply and more collaboratively. During this period of the discussion, the nine participants introduced themselves to the facilitator (they were already well known to each other) and gave their reasons for interest in the topic. These reasons for interest in the topic reflected personal interests, desire for professional development, and/or desire to improve school culture. All participants indicated high investment in the discussion. Other than being demonstrative of engagement, however, these comments did not contribute significantly to the five core themes identified below and have been either left out, or where appropriate, moved to a more appropriate “Core Theme” below.

The last of the eight category groupings in the Results chapter (Chapter IV) is labeled “General Concepts.” In the summary of results, seemed salient to group these statements together at the end because they occurred chronologically together in a period of integration of new information and crystallization of emergent understanding at the very end of the focus group discussion—this could be thought of as a category grouping based on chronological process. For the purposes of the Discussion chapter, rather than coding by content (as was done for the Results Chapter) the analysis has been re-grouped by thematic content. Therefore, these summative comments from the final eighth coding group ("General Concepts") have been regrouped with their appropriate content theme—that is their most closely related "Core Theme" (See Figure 1 on page 131, for a visual representation of this grouping process).

Because the first two categories did not contribute much content-wise to the discussion, and because the data in the last category has been regrouped, the below analysis is therefore grouped into five core content themes ("Core Themes") that represent the most salient themes to emerge from the discussion. The five Core themes are: (1) Challenges, (2) Autistic Strengths, (3) Community Resources, (4) School Structure and Culture, and (5) Practical Application. In addition to analysis of surface-level content, the following discussion will consider some more subtle and overarching patterns of meaning that coalesced over the course of the discussion.

Core theme: Challenges. The first surprise of the discussion emerged in response to the question about challenges. Although the "challenges" question was clearly worded to capture the idea that it addressed challenges faced by autistic *students* in a general education setting, teachers very quickly moved away from student challenges and began to speak of the challenges they *themselves* had faced while attempting to teach autistic students. Possibly this shift in focus occurred because the struggles of autistic students may be primarily experienced by teachers through their own attempts to intervene and support those student challenges. The group focus on teacher struggles may also have been due to some reticence on the part of teachers to focus on negative aspects of autistic experience. (Additionally, as focus groups are a format geared to evoke reflections on *personal* experiences, it should be said that it is not at all surprising that participants considered their own experience first.) While valuable information emerged from that discussion, the shift remains notable.

Another possible reason this shift occurred is that teachers may have had some initial subtle difficulty in identifying directly with autistic experience. It was certainly the case that they expressed feelings of confusion and helplessness when attempting to elucidate some of the behaviors of autistic students. Such feelings often emerge when attempting to understand seemingly inexplicable behavior, which would suggest that, despite the high levels of concern evident in teacher comments, some aspects of their students' behavior remained opaque to them.

The challenges experienced by teachers that were discussed during this portion of the focus group centered mostly on dealing with the emotional lability and dysregulation of autistic students. In some ways, these behaviors are both the most widely known and yet the most inexplicable of behaviors associated with autistic experience. Many stereotypes exist about "meltdown" behavior, and addressing these behaviors is the focus of some of the most intensive (and some argue, the most damaging) of autistic therapies. In this way, the discussion began by adopting a dominant cultural narrative about autism—a narrative which casts autistics as "other" and autistic behavior as foreign and frightening—and which, in the context of the focus group discussion, resulted in a dynamic where teachers and autistic students were portrayed as being on opposing sides of a struggle for control.

Although the participants' comments during this portion of the discussion were caring and ethically motivated, they clearly emerged from a framework of teacher-as-manager rather than teacher-as-partner-in-learning. This portion of the discussion provided a clear example of medical-model thinking—a stance that locates the problem as located in the student, while attempting (albeit in ways that clearly arose from a stance of wanting to be respectful and responsible), to solve “the problem” of disruptive and intrusive dysregulation. It was during this period of the discussion, for example, that teachers focused on the question of protected medical information and how much to disclose about autistic students. These questions, while very important, distinctly place teachers in the position of arbiter and manager of explicitly medical information, and students in the position of dependent and acted-upon subject.

Although the participants did not spend very long discussing the challenges of autistic students from the point of view of autistic students themselves during the discussion of the question on that topic, a high level of awareness of student challenges emerged more clearly later, in response to other questions (once the discussion moved into the more applied discussion of strategies). As the conversation turned to more concrete and specific classroom interventions, participants began to bring in personal experiences with autistics in their own lives, and to speculate on the internal experience of their autistic students in ways that indicated the kind of concrete more connected empathy and understanding that transformed opaque behaviors into behaviors that made sense. For example, one teacher described her attempt to be supportive of a student only to realize that her expectation of “you’re supposed to be able to do this” may have felt overwhelming to him—the teacher speculated that a possible reason for this overwhelm was that her attitude of “this should be easy” may have minimized the student’s experience of finding the work in fact to be very challenging and therefore triggering for his anxiety. In that moment of realization, the teacher highlighted the understanding that struggling with work that “should be easy” is even more discouraging than struggling at something hard, and she speculated that the student might have felt ashamed. The teacher’s ability to empathize with the student’s experience by recognizing the role of shame—an empathy which seemed to emerge in the process of recounting the specific details of the experience, demonstrated a shift from looking at the student's behaviors as possibly disengaged or obstructionist, to understanding them as an intense yet normal and obvious response to feeling one's experience minimized.

In so doing, the participant shifted from medical model thinking to a social model of disability by recognizing that the frustrated reaction was not a "symptom" existing within the student as a constant and discrete trait (e.g., over-arousal—an autistic trait), but rather a situational response triggered by her unexamined assumptions and projected judgments about task difficulty level, which was conveying to the student an unintended socially-based message of shame (e.g., an understandable and socially contextual anxiety response—a very normal response given the context).

Making such a shift is a powerful tool for teachers because it makes the difference between feeling helpless to deal with difficult an inexplicable autistic behavior (a symptom), and being empowered to evaluate the environment and analyze one's own actions for contributing factors (a social dynamic or environmental factor) which are within one's own power to change. Many comments from participants captured such initial feelings of frustration. Many more captured that ah-ha moment as the participants recounted moments of shift in which they came to see autistic behavior as a normal and understandable response (given autistic differences in processing) to the context.

One participant described the process of learning through a parenting workshop to identify her own contributions to the arousal of her own child, and then extrapolating from that experience for application in her teaching work:

> As a parent, my own shift over the summer has just been like, there's nothing wrong with the *kid* [general laughter] there's something wrong with me [laughter], like, he is throwing this fit because I am like, continuing to escalate him. And so like, how do I do

> that with my students? If I’m doing it with my own child [laughter] I’m probably doing it pretty frequently with my poor little students. (Participant 9)

This comment reflects a reframing of student arousal as a response to the context, rather than a manifestation of an internal trait.

Another teacher (Participant 7) spoke a little ruefully at how easy it was to get frustrated “when someone isn’t working”—a characterization which subtly reflects a teacher-versus-student stance (struggle for control)—however, she quickly pivoted to a place of identifying with autistic experience, referencing material from the training (specifically the mental resources or “bandwidth” needed to transition to a new task, as well as differences in autistic auditory processing—reframe from oppositionalism-as-struggle-for-control to processing-speed-as-obstacle-learning, a challenge which calls for a very different remedy and makes empathy much easier). The participant demonstrated her understanding of student experience by speaking in the voice of a student processing information after a delay, “Oh, you were talking to *me*!” The laughter that followed her description suggested widespread identification with her experience among the other participants. Another teacher referenced the power of informed empathy directly, saying, “You’re automatically more patient when you realize there’s more pain, you know, involved in it, than just like, you know, a tantrum because they’re being stubborn . . . there’s a big difference” (Participant 3).

The difference that Participant 3 referenced is a very important difference in attribution because it completely changes how teachers respond: student behavior as a logical response to identifiable situational factors as opposed to student behavior as a basically inexplicable symptom that is located within the student. Educator comments such as these appeared to reflect an emerging sense of efficacy on the part of the participants—although it is never a happy thing for a teacher to encounter a student in pain, understanding that suffering as resulting from identifiable causes in the environment (social model of disability) places far more power in the hands of both the teacher and the student to make changes that can ameliorate the difficulty than when student reactions are cast as internal and immutable traits. These participant comments demonstrate concrete and immediate changes in outcome of adopting a social model of disability stance when conceptualizing the needs of autistic students.

As described above, initial participant response to the question of autistic challenges resulted in a conversational detour into personal teaching challenges characterized by an unexamined alliance with dominant culture patterns of medical model thinking, while discussion that took place later in the hour (in response to other questions) reflected a far higher level of empathy with autistic experience (as though seeing it from the inside rather than the outside), as well as situational rather than inherent attribution of autistic behaviors. Both discussion took place *after* exposure to a training outlining the impact of medical model thinking and emphasizing the power of reframing behavior through the social model of disability. This shift in the discussion begs the question: What else changed between the initial discussion of autistic challenges—which positioned autistics as other and as a source of challenge to teachers—and the later discussion—which positioned the experience of teachers and autistic students more in parallel, as people facing challenges together, and began to explore situational contributors to behavior with far more empathy? The answer may possibly lie in the discussion summarized in the next section.

Core theme: Autistic strengths. In addition to the passage of time over the hour of discussion (which may have allowed for greater processing and integration of information from the training) one thing that occurred between the two discussions outlined above was the focus group question about autistic strengths. This discussion was perhaps the biggest surprise of the hour. It was only with hesitation that I even included this question in the focus group schedule because such discussions can sometimes lead to shallow and patronizing praise of stereotyped traits that sensationalize disability (sometimes called "inspiration porn"[44]—a phenomenon that activists in the disability community outspokenly oppose). In such a short timeframe as a one-hour focus group discussion, there was a very real risk that discussion would stay on this objectifying, superficial level. However, perhaps because the question was worded to direct the teachers toward "what you have observed" rather than "what do you believe," that is not what transpired.

When asked to describe autistic strengths, teachers had a surprising range of observations. After initially identifying some concrete differences in cognitive processing that are often present in autism—such as pattern recognition, hyperlexia, or quick learning of algorithms (many of these comments briefly referenced specific and evidenced based information recently learned in the training)—the participants began to describe traits they themselves had observed firsthand in their own students.

For example, focus group participants described observing particularly deep and loyal friendship bonds in their autistic students. This is an autistic trait well-acknowledged within autistic culture, but one runs contrary to common stereotypes such as the idea that autistics do not feel emotion or empathy. The participants also described strengths in paying attention and

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[44] "Inspiration porn" is a term coined by the late Australian disability rights activist Stella Young (2014). She purposely used this provocative construction to alert people to the ways in which images and narratives of the disabled are consumed for inspirational purposes by abled people using the experiences of the disabled to "feel good" about themselves through being inspired solely on the basis of the person's disability. Stories where an abled teenager is lauded for inviting a disabled (and often unnamed peer) to prom, or where a team indulgently allows a disabled team member to shoot one basket are common examples.

tracking (even if students might not appear to be paying attention to casual observers). Another autistic strength that participants appreciated was ability to make unorthodox connections and insights, and ability to express ideas in perhaps unorthodox ways that nevertheless resonated with other students, perhaps better than teacher-generated ideas. Again, these descriptions of divergent thinking and ability to connect with peers run counter to common assumptions (and even DSM diagnostic definitions), which describe autism primarily in terms of *lack* of social and communication skills. That said, this particular description observation profoundly echoes observations made by Hans Asperger more than eighty years ago:

> Autistic children have the ability to see things and events around them from a new point of view, which often shows surprising maturity. This ability, which remains throughout life, can in favorable cases lead to exceptional achievements which others may never attain. Abstraction ability, for instance, is a prerequisite for scientific endeavor. Indeed, we find numerous autistic individuals among distinguished scientists. (1943, as cited in Silberman, 2015, p. 103)

Such strengths in divergent thinking are well acknowledged within the autistic community, though they representing a particularly poorly studied area of autistic functioning in the research literature.

The most remarkable description during this portion of the focus group discussion came from a teacher who said that she experiences her autistic students as having higher levels of self-awareness, as well as more intentionality in advocating for their needs. She contrasted this to her neurotypical students, saying: “Not all of our students are that good at self-reflecting on what works for them. ’Cause they never had to stop and think of things. Maybe it just comes automatic for them” (Participant 3). Autistic students she observed, on the other hand, “who do have support from home, just have a better understanding of what works for them, and can communicate it when they're not feeling anxious and overwhelmed" (Participant 3). Given that a large emphasis of most social skills curriculum (such as widely used instructional materials by Michelle Garcia Winner, 2007; and Paula Kluth, 2009, 2010) focus on developing these particular social skills, it is possible that autistic students may be receiving more instruction than the general population in these areas when they receive targeted support.[45]

Overall, the picture of autistic functioning that emerged from the teacher discussion departed clearly from the dominant cultural narratives and official medical (DSM) descriptions of autistic behavior. This appears to have been the result of asking teachers to draw on their direct experience of autistic students rather than on general or received notions of autistic functioning. Perhaps the more important finding, however, is that it seems likely (or at least possible) that the alternative narrative constructed by the participants may have been a contributing factor in shifting the subsequent discussion of autistic students to one that was far more allied, empathetic, and situationally attributional. This possible finding, if true, has obvious implication for the importance of research into and broader awareness of autistic strengths.

Core theme: Community resources. One reason the school in this study welcomed the opportunity to participate in this project was that, as faculty at a parochial school and as a

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[45] As the parent of an autistic teen, my own experience raising an autistic teen matches closely with this observation. I also work on such activities with clients both in *in vivo* school settings and one-on-one therapeutic settings. That said, I personally have not observed that skills learned from social skills activities such as the popular Winner worksheets lead to understandings that generalize very well (generalization is a particularly difficult skill for many autistics). What is far more powerful is when teachers and families support the development of skills of self-reflection and self-advocacy by supporting those skills to help students deal with critical, real world problems during applied "teachable moments." An example of this is the "cell phone incident"—a personal experience which my son wrote up to explain difficulties in auditory processing and anxiety-related activations as part of a presentation for his Association for Autistic Community Conference presentation (Caspe & Caspe-Detzer, 2014), which was also included in the teacher training module for this dissertation.

community, the participants rarely had the opportunity to benefit from training offerings given by trainers from outside their school. The sense of resource scarcity continued into discussions of school structure and policy, including community referrals (e.g., lack of information on how to refer a student for a psychological evaluation, lack of knowledge of resources in the community, etc.). On the positive side of the equation, the participants felt that the tight-knit nature of school families and the broader school community were an important source of support, however, they acknowledged that relationships with families were not always collaborative. Again, participants expressed a high level of experience-based empathy for parents of special needs students, being in a position of not knowing who was really "on their side." One participant mentioned that she herself was the parent of an autistic son, and described the feelings of parents toward the school as sometimes skeptical: "are they a support? Are we working as a team?" (Participant 6).

An area of particular concern was that participants felt they did not have the resources to learn how to have respectful conversations about difference that included acknowledgement of an autistic student's differences in a way that respected privacy of protected medical information. The participants clearly expressed the desire to create classroom cultures that were accepting of a wide range of abilities and ways of being, but they did not want to violate students' privacy by talking about specific students' abilities or diagnoses. Another thread of comments reflected a desire to normalize a wide range of differences without singling out specific students.

Managing student privacy is an important concern. It was partly addressed within the teachers' own discussion—one teacher realized as she was speaking that she would like to ask directly for permission and greater guidance from the family about what information to share—however, providing guidance for appropriate strategies for classroom discussion of difference remains a highly salient area to address in future trainings. Participants themselves suggested a possible resource that would be helpful to educators, in the form of a "talking points guide" that suggested themes and clarified the boundaries of appropriate classroom discussions of neurodiversity.

Core theme: School culture and structure. While the participants expressed some frustrations about lack of resources, they expressed very positive opinions about their school's culture. Their focus on culture (as opposed to structure) may explain the seeming divergence of opinion from the Likert-type items asking about school structure—that is, when the teachers were asked if they felt supported by their school structure in meeting the needs of autistic students, most respondents endorsed "disagree" on the Likert-type item. When the smaller group discussed how they felt about school structure, most participants expressed very positive feelings. This may have been because the Likert-type items asked only about structure (which implies functions such as administrative support, policies, and common practices) whereas the focus group question, while it included a mention of structure, was interpreted by the participants to be mostly about community and culture.

The discussion of school culture focused strongly on staff cohesiveness and camaraderie. In effect, participants seemed to be suggesting that an inclusive and supportive culture at the staff level translated into an inclusive culture at the classroom level in a kind of positive parallel process. One teacher described the non-judgmental support she felt from other staff in dealing with her own anxious arousal after negotiating a meltdown with an autistic student: "I'm still, you know, like, Oh my gosh!, You know, I'm still sweating and upset [general laughter] and like did I do that right, did I say that right?" (Participant 3). In other words, just as students can have moments of activation and be supported by their teachers, teachers can also have their moments of activation and be supported by other staff in validating ways that make a big difference in improving functioning and decreasing shame. Again, this account illustrates a view of autistic arousal as a response to the environment that is not so very different from responses experienced by teachers. This conceptualization represents a highly empathetic and contextualized view, and represents a worldview in line with a social model of disability. A participant articulated this empathy by saying, “we’ve all had days that we’ve all felt like shit, we all know how horrible that day is…and just to have that thought—ok this child is feeling super anxious. I feel like it gets you to that calming” (Participant 3).

The participants in the study acknowledged some aspects of their particular school’s culture that are fairly unique, such as being a small school, a school where families have many children enrolled (because they tend to be large Catholic families), a school where students typically stay from pre-K through the end of middle school, and a Catholic school. These are factors that are not widely found in public schools, however, the presence of a school culture of warm mutual support can exist in many institutions. The take-away message of the data summarized in this core theme is that school culture is an important and possibly undervalued factor contributing to the classroom experience of autistic students. It seems possible from this example, that school attitudes toward not only student, but teacher anxious arousal, may have a profound impact such that interactions between staff members may have repercussions for teacher-student interactions down the line.

Core theme: Practical application. As mentioned above, it was during the practical application discussion that participants’ real awareness of autistic student struggles emerged. Like most dedicated educators, their primary concern is in the day-to-day applied experience of classroom teaching, and it was on this topic that their true expertise emerged. The participants used this time to educate one another, share inspiration, ask questions, and brainstorm ideas for resources that might be helpful. The discussion included both general principles (such as the idea that UDL curriculum serves all students better) to specific practices (such as creating a box of sensory soothing items in a "think spot" area of the room or school that is open to everyone). Like the practical problem solvers their profession trains them to be, when brainstorming areas in which more tools might be helpful, they didn't just identify areas of need, they suggested fully blown solutions for the kind of guides and resources that would be helpful (down to the specific content and formatting details I should undertake as designer).

As has already been discussed, the tone of the focus group conversation had shifted by this point in the discussion from a problem-based narrative (medical model) to a situational attribution framework (social model of disability). Consistent with this stance, the types of solutions put forth by the participants tended to focus on a classroom culture or school culture level of intervention. Student-level interventions emphasized preventative interventions such as providing extra scaffolding, breaking down tasks into smaller steps, reducing the intensity or variety of sensory stimuli, providing sensory integration activities, and adapting expectations to accommodate slower processing or deficits in auditory processing. This is not to say that all comments were consistent with a social model of disability approach—some still clearly reflected more traditional discipline frameworks (which often attribute high levels of volition to students[46]). However, likely because of the ideational set provided by the preceding training, most participant recommendations clearly emphasized environment over individual-level intervention.

That said, it is important not to gloss over the hint of tension present in the understated suggestion of contradictory philosophies about student behavior and discipline expressed during

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[46] Such worldviews are often embedded in educational rhetoric in the practice of authoritarian consequences or subtle use of shame to influence children to stop making "bad choices."

the focus group. If this study were a program evaluation project rather than a pilot of a teacher training, the undercurrent of subtly conflicting worldviews present in this school community would be identified as a possible source of tension and miscommunication in this school's culture. If the model of thought used in this dissertation is applied, this tension could be described as the tension between the two conflicting philosophies described in the introductory chapter—on the one hand, a kind of "medical model" disciplinary approach to behavior (e.g., a stance reflecting the idea that the problem exists within the child who has full volitional control over his or her actions and must be given consequences that will influence him or her to make desired choices), and on the other, a "social model of disability" approach to behavior (e.g., the belief that the child is not yet able to govern all actions at all times, however, changing the environment may provide him or her with fewer triggers or better scaffolding for managing his or her own behavior). Since this project is not a program evaluation study, it shall simply be noted once again, that these two philosophies both exist, not only in this school's culture, but across common educational practice, and the subtle tension between them in the wider society is a source of much conflict as to how to support autistic students (not to mention neurotypical students) in general education.

While this study is not a program evaluation, it *does* represent an attempt to gather user input on resources to facilitate the education of autistic students. Therefore, because the participants generated so many detailed ideas on specific resources they would find helpful, it is saliently to include a comprehensive listing of participant suggestions:

Table 4

Teacher Requested Resources

Quick-guide Information for Teachers: • Resources provided in graphic or info-graphic format as much as possible (e.g., flow charts, if-then lists) • Behavior interpretation guide ("if you see this, you might suspect…") • "Red flag" guide for early identification of anxious arousal • Meta-message guide (how unintended messages of common adult communications may be perceived by and triggering to autistic students) • Clear recommendations for teacher responses to student behaviors • Scripts for emotion coaching • Steps for teaching problem solving skills
Trainings • Video training for teacher verbal techniques such as techniques for managing arousal • Suggestions for alternative methods of communication that can be used by teachers for students with processing differences • Guide to typical autistic variations in developmental trajectory • Information on executive functioning tailored to early elementary students
Resources in the Community: • A website hub as a clearinghouse of vetted resources • Directory of local healthcare and therapy service providers
Explanations of Behavior Guides: • "All behavior is communication" guide—possible motives or meanings for behaviors (similar to the "Reasons for Aggression" guide that was handed out as part of the training materials) • Summary of helpful information from training such as understanding the need for extra processing time, understanding the influence of chronic anxiety
Sensory Processing Issues: • Recommendations on practical ways to handle sensory sensitivities in the classroom (e.g., touch, smells, florescent lights, background sounds, close proximity to many other people) • understanding the influence of sensory and physical sensitivities. • Recommendations on handling reduced eye contact or aversion to being watched, or having work being looked at (e.g., "exposure anxiety")
Recommendations for autism ambassadorship to neurotypical students & families: • Recommendations on talking with neurotypical students about autistic traits such as meltdowns

- Recommendations on talking with neurotypical students about autism in general
- Techniques for opening dialogs with families (especially when students have no diagnosis)
- Techniques for destigmatizing autistic behaviors
- Resource to give to parents debunking autism myths

With the exception of video production, these suggestions all represent discrete resources that would be possible to generate without special technology or extensive research. All fit the strongly emphasized request that resources be succinct and easily digestible in the brief bits of time teachers have to allot to professional development during most work days. All together, these suggestions represent an exciting and rich set of requests that would be the foundation of a useful and interesting website.

Interpretation and practical significance of qualitative themes. The focus group data above has been discussed both in terms of content themes and some overarching themes of meaning and cultural significance. Several major meaning themes to emerge from the focus group discussion can be summarized as follows:

1. Reliance on dominant culture narratives about autism tends to produce a medical model approach to solving the “problem” of autistic behavior that is more likely to focus on stereotypical vulnerabilities.
2. Working from a framework of applied practice and direct observation appeared to activate participants’ experience-based empathy, resulting in an alternative strengths-based conceptualization of autistic students—in other words greater activation of empathy flows from first hand observation of strengths.
3. An important difference between medical model thinking and the social model of disability lies in attribution: locating the problem in the child tends to lead to the

assumption that behavior is volitional and implies a solution of attempting to change the child (or the child's behavior), locating the problem in the interaction between the child and the environment tends to lead to the assumption that behavior is a response to stimulus (not necessarily fully volitional) and implies a solution of altering the environment (including teacher behavior).

4. When educators adopt the framework of the social model of disability, more of the factors affecting the functioning of autistic students lie within their control. This appears to increase feelings of efficacy for educators in supporting autistic inclusion students.
5. Tensions in the school culture remain due to of the interaction of the different worldviews outlined in point three. These tensions reflect conceptual disagreement in the field of education as a whole.
6. Tensions between school and families can arise when dominant culture notions of shame relating to autism and/or disability color interactions. This stigma has implications for level of information about autism that families feel they want shared which in turn, has implications for classroom culture.
7. A culture of acceptance of neurodiversity appears to function better when it is actively engaged in both at the staff level and at the classroom level (a possible manifestation of positive parallel process).
8. Educators in this study were a rich resource of applied practice ideas and could readily say where many of the gaps in their resources occur.
9. Educators in this study provided a wealth of ideas for resource format and content for future trainings and/or website.

Commentary on qualitative findings. When taken together, the results of the quantitative measure findings align with the values and interests expressed in the focus group discussion. In the communication around the planning for the training, seven teachers and the vice-principal expressed strong interest in participating in the study. Twenty-six educators participated in the two-hour training, and as a result of the training, on the Likert-type items pre- and post- measure, they endorsed significant improvements in their level of knowledge and preparedness regarding autistic inclusion students, as well as significant increases in their understanding of the social model of disability framework. In the focus group, nine participant-educators confirmed and expanded on the benefits gained from the training, and expressed a clear desire for further training and resources that would increase their knowledge about autism and expand their repertoire of tools for effectively serving autistic inclusion students. Within a structure consistent with an action research framework, they were able to be very specific in their requests for resources and guides—both in format and content—setting the stage for clear next steps in the action research cycle: website design.

Limitations of qualitative findings. As has been noted several times already, the particular group of participants in this study knew each other very well and proved to need very little management in terms of including everyone actively in the conversation. It was therefore found that a relatively hands-off facilitation style worked best for the group.

That said, the role of the researcher was slightly complicated in this project by the fact that I, as researcher, assumed two very different roles in the two different sections of participant contact—during the training portion, I presented very much from the position of expert, while during the focus group section, I made a clear delineation about shifting into the role of facilitator, focused on eliciting the knowledge and opinions of the participants. At two points during contact with focus group participants—once during the middle of the focus group discussion and once after it was concluded—I was asked a question that clearly drew on my role as expert rather than my role as facilitator. In both cases, I made a clear verbal delineation (e.g., "I'm taking off my facilitator hat") both before answering the question and after the discussion of the query concluded, and then directed the group back to the focus group schedule questions. These digressions are worth mentioning because the overlap of "expert" role onto "facilitator" role undoubtedly colored the discussion in subtle ways, despite attempts at maintaining a clear sense of boundary between the two roles. This bleed-over effect would likely have been the case even if participants had not asked "expert"-tapping questions during the focus group, however, the fact that they did is valuable in that it daylights a phenomenon which might have gone undetected otherwise.

The bleed-over dual-role effect was an unanticipated consequence of structuring the participant contact to include both a training and a focus group discussion. On the other hand, the two-part structure of the contact provided a clear benefit in that information disseminated in the training clearly fed into the focus group conversation, and provided a large amount of concrete information to act as a springboard for detailed discussion.

As has been stated above, the worldview adopted by this project is that true bracketing of researcher bias is an illusion. Rather, the Habermas (1972) school of qualitative analysis would argue that the integrity of the project is greater when subtle influences, such as researcher role bleed-over are openly acknowledged, not only to the ultimate consumers of the research, but to the participants themselves in real time, as was done by clearly labeling the moments of role transition on the part of the researcher.

Future Directions

During this project, I found myself at the intersection of several very significant roles in my life—most saliently the roles of former teacher, autism scholar-practitioner, and autism parent. Being in that position meant engaging in this project with a very clear sense of perspective (e.g., bias) but also with a very clear sense of investment and commitment. Emerging on the other side, a few key concepts have coalesced which will guide my future work as I continue to parent, design trainings, and do clinical work with families, teachers, and school systems.

Three powerful concepts emerged from this experience for me as a researcher and developer of trainings. The first is that teachers are professionals hungry for information. The educators in this project not only expressed a high level of interest in complex neuropsychological information, they proved to be a rich source of detailed and data-based observations, able to make empathetic analyses and draw unconventional conclusions from their direct observations. This project confirmed my belief that treating teachers as intelligent, creative, actively involved professionals results not only in high levels of reported benefits from training (as shown by the Likert-type instrument study results) but in high levels of community engagement and peer connection (as shown by the focus group study results).

The second major concept to emerge from this research and training project is that shifting to a social model of disability empowers teachers to effect change because the target for change mechanism is at the level of environment (which is under greater teacher control) rather than the level of the individual. A specific outcome from this study is that the key to making a shift to a deep understanding of a social model of disability enables increased empathy for the experience of autistic student anxiety on the part of educators. What this study specifically and surprisingly revealed, however, is that a back-door route to that empathy is through data-based concrete observations of autistic student *strengths* as opposed to struggles. It is possible that this phenomenon came about because identifying with student strengths is a more positive entry experience of empathy than identifying with a sense of anxiety of which you, yourself (as teacher) may be the source. That said, the teachers in this study, like most professional educators, were highly engaged and committed professionals who were very willing to engage in empathy and confront their contributions to a system that creates anxiety in students.

Finally, this project reminds me as a psychologist, that if I want to create training materials that are relevant to teachers, while some theoretical information may be useful, I need to always ground my materials in frameworks that are extremely practical, highly applied, and immediately useful to working educators. At every step of my interactions with the stakeholders in this project, their requests focused on how to make the materials I would be offering more relevant to their everyday needs. Their requests emphasized materials that were brief, visually clear, face-to-face (rather than on-line or social media based), grounded in examples (rather than theoretical), tied to grade level and developmental level (rather than general principles), and grounded in their local community.

This study benefited greatly from the participation of this group of dedicated educators as well as from the contributions of my own son and the opportunity to observe the many clients and students I have worked with over the years. To all of them I owe a debt of gratitude for make possible this project, and ultimately the emergence of these final core observations. These three principles—respect for teacher professionalism, training that emphasizes empathy (for autistic strengths as well as the autistic experience of anxiety), and a primary focus on applied teaching practice—will serve to form the guiding principles of future training design based on the training piloted by this study.

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Appendix A

Review of Web Resources

Review of Web Resources

Because this project includes the proposal that a web-based resource would be an efficient method for delivering content to teachers as a future project, a review of currently available resources on the web provides a logical context for development of such a resource. Such a resource, by definition, would exist in a context outside academic peer-reviewed scholarship. However, just as an academic inquiry would use a search of existing literature to demonstrate relevance and uniqueness, it stands to reason that a proposal for a web-based project should likewise survey and evaluate existing web resources to demonstrate a context and need for the proposed resource.

A "literature review" of the web, however, presents certain challenges related to characteristics of the web itself. These include the lack of any type of external assurance of quality of publications, the fluid (and often obscured) mixing of academic objectives with political advocacy, fundraising agendas, and commercial ventures, as well as the endlessly bifurcating and rapidly evolving nature of the web itself. Under these circumstances investigating a cohesive "conversation" or even defining a delimited field of inquiry is almost impossible. What follows then is offered more in the spirit of a general overview or sampling perusal of available resources rather than making any claim to be an exhaustive or scholarly review.

Given these project parameters, a web search for teacher resource content was conducted. The following search terms were entered into the Google search engine as beginning points of the web review: "autism resources," "autism resources for teachers," "autism education," "teaching students with autism," "teaching children with autism," "teaching children with Asperger's'," "treatment of autism," "on-line community (forum)… teachers… autism," "special education on-line community (forum) autism."[47] Many hits yielded by these search phrases yielded websites with lists of on-line resources or links to other related sites that were then further investigated.

The worldwide web is an ever-changing landscape, and resources on autism range from professional websites created by major organizations, to commercial ventures selling products, to simple or bare-bones pages created by individual professionals, parents, or autistics wishing to share their experience. The web is a curious combination of ephemeral and enduring—some significant sounding endeavors that turn up on a Google search lead only to empty or broken links, while humble text-only documents not updated in over a decade still stand witness to a parent's investment and dedication.

As it is impossible, for the reasons discussed above, to conduct a rigorously academic search of the web, it may be helpful to view the following findings not as a review but as a kind of sampling of a layered world of qualitative data. The virtual world of the autism community,[48] though enormous, turns out to be not quite so daunting when the search is focused specifically on finding curriculum resources, psychological research applied to curriculum design, or on tracking down on-line communities of teachers where active discussion of teaching autistic students is taking place. In such a search, to loosely borrow a term from Grounded Theory

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[47] A note on search terms and labels: As discussed elsewhere in this paper, labels for autism are fraught with meaning and political consequence. Although other sections of this dissertation make a point of using the labels "autistics" as advocated by the activist autistic community, by necessity, web search terms must reflect language in common usage if they are to capture the desired information. For the sake of clarity, the web search discussion below refers to the content of websites in the language used by the website or the search term used to find it.

[48] Note: the phrase "autism community" is here used to refer to the community of all people and entities concerned with autism, including parents, professionals, medical and educational organizations, and autistics, while "autistic community" is used to collectively denote autistic people themselves (both officially diagnosed and self-identified). This usage has been popularized and promoted through channels such as autistic blogs and Facebook pages, as well as activist groups (personal communication, Zoe Cannon.)

(Glasser & Holton, 2004), there begins to be a sense of “saturation” when, by iteratively following embedded links, the search either loops back on already visited sites, or diverges into unrelated territory. That is to say, though no specific trail can ever truly be exhausted, there begins to be a general sense of the lay of the land. That said, the web review below is only a snapshot of the general offerings of autism resources at the close of 2013.

Documenting such a web search also presents challenges as, with the exception of the first category below (books and pamphlets published in an online format), most of the resources do not meet the threshold for peer review generally considered necessary to be included in an academic bibliography. For that reason, resources are listed with their links in bulleted lists at the end of the appendix, however, they do not appear in the bibliography of this dissertation.

The web search for this project focused on two general areas that sometimes overlap. The first was websites that offer materials and resources for teachers (including everything from legal and IEP guidance, to continuing education credits, to lists of tips and strategies, to products and books, to downloadable lesson plans and teaching materials). The second was active online community forums that provide a place for educators to discuss their experiences teaching autistic students and share resources and strategies. The results of the search are discussed below. All links were active as of December 18, 2013. Findings have been sorted into categories for purposes of organization and comparison.

Pamphlet or book length resources. The resources in this section are longer, evidence-based publications put out by large foundations or academic institutions, available free online for viewing or download. They are professional quality, extensively researched resources, made available free of cost through government programs or private grant money.

The most comprehensive resource is Educating *Children with Autism*, a 307 page, fully scanned book describing the state of autism research in 2001, along with legal considerations and instructional application. As a full-length book written close to the psychological research on which it draws, it operates from a deficit stance. As a lengthy, formal text, it is unlikely to find an audience beyond academics and possibly special education teachers, however, it is clearly a useful document for that intended audience.

The *Autism Spectrum Disorders Primer* is a much briefer and more accessible pamphlet, explaining the classic deficit-based categories of the DSM diagnosis, and the basics of ABA and environmental support strategies, and written in typical IEP language. At six pages, however, it is so brief that it barely touches on the difference between various kinds of autistic challenge across the spectrum, and it has almost nothing to say about classroom strategies beyond basic behavior management.

The two pamphlets produced by Autism Speaks, *Educating Students with Autism* and *Supporting Learning in the Student With Autism,* are written in a very teacher- and parent-friendly format, and contain much useful information pertaining to behavioral management strategies and interventions. They clearly address autism from an exclusively behavioral, social, and sensory perspective, with no attention to academic subjects or differences in learning beyond differences in communication style that might impact academic performance.

One of the best resources in this category is a guide not about autism specifically at all, however, it addresses many autistic behaviors from an etiological perspective. *Making Sense of Sensory Behavior* lays out in clear, lay-person's language a research-based, theoretical framework for behavioral manifestations of sensory behavior, describes typical and atypical examples, and recommends practical and relevant interventions in an organized manner. On the other hand, although this information might be somewhat useful for a general education teacher, most of the interventions would require a one-on-one aide for classroom implementation.

The most targeted resource in this section is the 141-page *Teaching Students with Autism, A Resource Guide for Schools.* It goes far beyond the DSM diagnostic categories to include principles of autistic learning and cognition, communication pragmatics, and unusual patterns of attention and response to sensory stimuli. Each section is organized beginning with a theoretical overview and followed by implications for instruction. The instructional strategies sections include the specifics of task analysis, discrete trial methods, functional behavioral analysis, environmental structuring, positive reinforcement options, and planning for transitions. The last third of the book provides case studies including IEPs with many examples of full inclusion programs. Like most special education materials, however, this book too is written almost exclusively from a deficit stance, and focuses its intervention recommendations almost entirely on behavioral and social domains, with only four pages devoted to instructional strategies for academic content. It is also Canadian and undoubtedly reflects national differences in special education law. Nevertheless, even if some of the details of legal applications of IEP language differ, the instructional strategies remain eminently practical and valuable to U.S. teachers, especially those working in special education.

Finally, the most relevant guides for American teachers are put out by the Organization for Autism Research (OAR) and include *An Educators Guide to Autism* and *An Educators Guide to Asperger's Syndrome*. The OAR is a well-funded non-profit institution that raises funds, conducts scholarly research, and disseminates grants. These two longer pamphlet-length resource guides are provided, along with several other evidence-based guides, for free download (and include such topics as guides for employers and military families, and how-to information for families on navigating special education, transitioning to adulthood, and consuming scholarly research). The guides for educators include research-based, applied guidelines in structuring the classroom, educating peers, managing behaviors, and communicating with parents. The guide for educators on autism, at 60 pages, gives general overview information and descriptions of how some typical autistic behaviors may manifest in a school environment. At nearly 100 pages, the guide on Asperger's is significantly more specific and helpful for general education teachers than the guide regarding autism, with interventions divided by grade level, and more comprehensive delineation of likely behaviors and possible interventions. A long appendix at the end gives suggested academic accommodations, however, these accommodations, while excellent and detailed, are basically structural accommodations to support behavior that do not explore ramifications for academic content and differences in cognition and learning.

Publishers' websites. This unusual category contains only one example of a publisher's website organized by topic area that includes a section on teaching students with autism. As far as this search was able to determine, most publishers do not go beyond descriptions of specific products. This one website, however, includes general information as well as lengthy excerpts from books offered by this particular publisher.

Resources pages (lists of links). The examples in this section are pages of resources with lists of links to other websites and teaching resources, though in and of themselves they do not provide information on autism, as resource lists located on the websites of well-established and well-funded organizations, they do, however, give a sense of the available resources on the web overall. For example, the fact that similar lists of links appear in different places lends credence to the authority of the listed resources. The first site listed in the table of links at the end of Appendix A under this category is a very "homemade" site created by a parent documenting his odyssey of learning about his autistic son who was 20 in 2004, (the date of his most recent update), however, this parent-generated site, though older and unpolished, is a site which is referenced in several other places on the web, so it is included here. The middle two lists were created by established non-profit institutions of education, and are representative of similar lists elsewhere. The last list is a list of nine resource articles on behavioral topics located on the very popular lesson plan exchange site “Share my Lesson” (note: although the list can be viewed by anyone, the linked resources are available only to members, however, membership is free and available to anyone who chooses to share their information with the ad-funded website).

Professional and non-profit organizations offering Continuing Education (CE) credits and/or workshops. These sites represent offerings by both private and public educational institutions that offer continuing education (CE) credits on the topic of teaching students with autism—some online, some by video conference, and some in person—with widely varying fees and admission requirements. The Northwest Educational Service District, for example, offers a full annual schedule of modestly priced CEs on a variety of autism topics ($30/day) offered at locations around the Pacific Northwest in person and by video conference, and open to anyone. Paula Kluth, author of several popular books on inclusion teaching and differentiated instruction, offers a schedule of workshops on her website that are closely aligned with the goals of this dissertation project. The best and most comprehensive online course selection is offered by the National Association of Special Education Teachers, which also includes some free material on its site. Most of their materials, however, including registration for CEs, is behind a membership paywall and can only be accessed by users who demonstrate that they are special education teachers, trainees, or professors, and who pay annual dues of $55.

Private educational institutions offering continuing education units. These are programs with tightly controlled application and ideology which focus on offering educational services for autistic students, but which also offer training or continuing education units (CEUs) to teachers for a fee. They tend to have passionate and dedicated practitioners, and to be very expensive, with a subtle tone of "proselytizing" in their web presence (the Lovaas Institute's certification in ABA is included in this section, for example). While they all offer continuing education trainings for teachers, only TEACCH claims to be appropriate for instituting in general education settings. Nevertheless, most of the interventions involved in the outlined methods are too time intensive for practical use by general education teachers.

Online articles on teaching mainstreamed autistic students. These are links to stand-alone online articles (as opposed to postings of academic or general press articles). These are typically located in the "resources" sections of general autism resource websites or teaching websites. Many of these appear to be collections of "tips" and strategies, with not much offered in the way of theoretical rationale. Others (such as the articles on *Education World*), offer a more empirically-based approach, though many treat on topics other than teaching autistic students in general education classrooms.

YouTube videos. There is some great material available on YouTube relating teachers' experiences and advice, but as these resources are in a format outside the scope of this dissertation project, a small sampling is included in the list of links at the end of Appendix A only to gesture to the fact that these types of resources exist.

Commercial websites. These are commercial websites that feature products to support autistic students that also include free information and/or resources for teachers. This is probably the most confusing category covered in this review of web resources. These sites are notable for their slick customer interface and attempts to blur lines between research-based information and profit-motivated sales pitch. Most of these websites offer free materials in addition to products for sale, but while some include testimonials and articles by "experts" supporting their approach, none include evidence of a theoretical explanation or rationale for their approach beyond anything but the most basic explanation such as un-explicated references to ABA therapy. Some, like *Positively Autism*, are a confusing mix of homey personal advice with embedded links to commercial products that appear at first glance to be non-commercial resources like the rest of the site. Others, like *National Autism Resources* and *Different Roads* clearly present themselves as commercial enterprises and target autistic students as the intended end user of their products, however, their curriculum materials appear to be a rather random selection of simple workbooks and resource books not even designed for special education students. Other sites like *Do2learn* offer a large amount of academically appropriate free materials and useful information on everything from IEPs to job finding tips for adults with autism, however, again, the line between free materials and commercial products is blurred, with many extension materials available only behind a paywall.

Non-profit shareware websites. The Zac Browser is a website offering resources designed to provide structural supports for autistic students (visual planners, etc.). The site also appears to include interesting crowd-funded products publicized through a *very* slick on-line presence. These products appear to have the potential to be useful tools for general education teachers, especially as technology becomes more ubiquitous. Given that these products represent a delivery structure for resources, more than academic content or pedagogy, they are somewhat tangential to this project, but interesting nonetheless, and worth further investigation.

General information websites with autism sections. The sites in this section are aimed at providing broad overview information either for general education educators or for families with autistic children. Within their broader focus, these sites include small amounts of information on teaching children with autism in general education classrooms. The main information formats included in these sites tend to be brief guides generally focused on behavioral management strategies in the form of tip sheets or informational bullet points. They are useful as far as they go, but tend to be organized in a scattershot manner with no headings and no unifying theoretical framework. With the exception of Grandin's piece (2002), which includes several autistic aptitudes, these guides tend to operate from an implicit deficit stance with an almost exclusively behavioral focus.

Websites for teaching children with sensory needs. This category includes a single website with a variety of resources targeted at students with sensory needs (as opposed to autistic students specifically). It includes teaching strategies, tips, and materials for students with special learning needs or sensory needs. This is actually one of the most useful and extensive sites in this review in that it includes many "ERIC digest" article briefs (summaries of peer-reviewed articles created under a Department of Education grant), case studies, a glossary, and four downloadable lesson plans. The entire "e-Ready" Special Education website was created under a New England Conservatory (NEC) grant by "The Source for Learning, Inc." a not-for-profit company offering web-based teaching resources.

Applied Behavioral Analysis (ABA) resources. The one website in this category, specifically offering resources to teachers using ABA intervention techniques, is a very attractively-designed website with several tutorials and a variety of downloadable educational content. It is aimed at the most basic level of functional skills for autistic learners such as those that are served in self-contained special education classrooms. Beyond letters, numbers, the human body, and shapes, it contains little academic content.

Online communities and discussion forums. Online communities, forums, and discussion groups are, by nature, more difficult to summarize than content websites. The annotations below cannot come close to summarizing the large range of content and only describe the general "feel" of the website.

General education communities. The first section in this category includes online community/discussion forums for general education teachers that include autism threads. Classroom 2.0 is one of the largest online communities of teachers. It describes its mission as emphasizing pedagogically sound integration of technology into the classroom. The forums section, with thousands of threads, is searchable by key word. Searches of autism, Aspergers', and special needs bring up many hits, indicating that these are active topics of conversation on the site, however, degree of attention to cognitive or perceptual difference was not possible to determine.

Lesson plan sharing. Another category of web-based community is online forums for teachers designed for professional collaboration and the sharing of lesson plans. These websites are a hybrid of content hub and community forum exchange. The resources on these sites are generally organized by grade level and subject. Some include categories for special education but none contain a category for inclusion lessons or Universal Design curriculum. (The resources labeled "special education" tend to be designed for self-contained rather than inclusion settings.) These websites demonstrate that online exchange of lesson plans is a lively online community phenomenon, although, as far as this web search was able to determine, there are no forums with threads specific to academic inclusion of students with autism or even IEPs in general. Also included in this section is Paula Kluth's blog because she frequently shares lesson plan suggestions on her on-line platform.

Autistic community forums. These sites represent a sampling of online communities and discussion forums for autistics that include threads about school experience and strategies for navigating education. These websites were included in this review because autistic students are the most important stakeholders in this endeavor. There are many instances of autistic discussion board topics concerning educational experiences, some poignantly reflective, some deeply moving, some passionately political, and many that would be significant and useful to help general education teachers understand the autistic experience of school. Not surprisingly, this search did not locate any examples of discussions of specific pedagogy or curriculum approaches among these discussions, however, the firsthand experiences of autistic students offer a rich and detailed insider view that can offer important insights for curriculum design and classroom culture. These links, and others like them, represent a valuable resource, as long as educators follow posted requests to respect the community and not regard participants as research subjects.

Web-review: findings. The websites reviewed above represent a sampling of available resources in a descriptive summary format that is more representative than definitive. The findings from this search suggest that general information on autism is widely available from advocacy organizations, federally-funded institutions, and educational organizations (both public and private) offering training and CE's, shareware websites, commercial product websites, autistic community forums and even YouTube videos. While these are all rich sources of information, very few directly address the needs of general education teachers as identified by this dissertation project because none meet all three of the following criteria: 1) a focus on *pedagogical* approaches to teaching inclusion students (or stated differently, the sensory and cognitive processing differences typically experienced by autistic students that affect learning), 2) a grounding in an evidence-based perspective, and 3) an offering of resources in a free, easily-accessible format.

This search also found broad availability of general tips and strategy lists for special education teachers of autistic students or even general education teachers with autistic inclusion students. These sources are often quite interesting, but of limited utility for supporting autistic learning given the lack of organization or empirical foundation, as well as the widespread focus on behavioral intervention rather than cognition and processing. Several of the on-line articles and resource sites (the resources provided by *Education World* and *Teachers First* are the best examples) also relate to topics relevant to teachers of inclusion students, however, few were academically rigorous, many address all students with special needs rather than focusing on autistic students, (specifically autistic inclusion students), and most were focused on behavioral interventions rather than support for cognition and processing.

Several teacher lesson plan sharing websites were explored. These sites indicate that sharing of specific academic content is a lively medium of professional collaboration in online communities. Many of the sites were organized by subject area and grade level and several included areas for self-contained special education, however, none were organized in such a way that content aimed at special education *inclusion* curriculum was readily searchable. Similarly, online teacher forums indicate that discussion of inclusion of autistic students has many active and interesting threads. The multiple and lively discussion threads already in existence suggest that the proposed Facebook discussion linked to the proposed teacher resource hub may be duplicating current online activities.[49]

Finally, and perhaps most salient to a scholarly endeavor, search findings indicate robust availability of empirically based and formally published pamphlet and book-length guides on the web available for free download. As valuable sources of empirically validated information, these resources could provide effective support for teachers and could easily be made more accessible by being included and reviewed on a resource website as proposed by this dissertation. While these guides are authoritative and useful in helping teachers to gain an understanding of autistic differences and learn general strategies for structuring a general education classroom in a way that is conducive to successful inclusion of autistic students, they have four areas of relative weakness that this dissertation project proposes to supplement.

First, they emphasis intervention at the behavioral level—an important intervention indeed, but one which does not take into account differences in autistic cognition, processing, and engagement with academic material (e.g., specific strategies for supporting autistic learning). Given the wealth of behavioral intervention guidelines already available, this dissertation project proposes to focus instead on implications of autism research for academic application and curricular design.

Second, these guides emphasis intervention at the individual level with little attention to structural variables in the environment. In other words, these guides implicitly operate from medical model assumptions that place the source of difficulty within individual autistic children. This leaves teachers with few options for effecting change at a systemic level.

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[49] The discussion of quantitative results in Chapter 3 further supports this possibility, with the finding that a Facebook page for community discussion was the least popular option for respondents among the possible resources suggested on the survey.

Third, these guides, in many cases, may be prohibitively long for easy access by general education teachers who must balance the needs of many students in addition to mainstreamed autistic students. This dissertation project proposes the presentation of information in brief chunks, digestible in the short amounts of time available to teachers during busy planning times.

Fourth, these guides are static and reflect research that is, at the most recent, ten years old (with the exception of the 2012 *Autism Speaks* pamphlets that include only behavioral and no academic guidelines). This project proposes not only to provide academic interventions based on current research findings, but to do so in an evolving and responsive format that allows teachers to seek professional collaboration and build community connection around the challenges and benefits of autism inclusion.

Table 5: List of Web Resource URLs

Pamphlet or Book Length Resources

- Autism Speaks: *Educating Students with Autism* http://www.autismspeaks.org/sites/default/files/sctk_educating_students_with_autism.pdf
- Autism Speaks: *Supporting Learning in the Student With Autism*
- http://www.autismspeaks.org/sites/default/files/sctk_supporting_learning.pdf
- British Columbia Ministry of Education, Special Programs Guide. *Teaching Students with Autism, A Resource Guide for Schools.* (2000). http://www.bced.gov.bc.ca/specialed/docs/autism.pdf
- Falkirk Council Social Work Services: *Making Sense of Sensory Behavior, A Practical Approach at Home for Parents and Careers* http://www.falkirk.gov.uk/services/social_work/children_and_family_services/support_for_children_affected_by_disabil/making_sense_of_sensory_behaviour.pdf
- National Association of School Psychologists: *Autism Spectrum Disorder, A Primer for Parents and Educators* http://www.nasponline.org/resources/handouts/Autism204_blue.pdf
- Organization for Autism Research: Life Journey through Autism Series. http://www.researchautism.org/educators/index.asp
- The National Academies Press: *Educating Children with Autism* http://www.nap.edu/openbook.php?record_id=10017&page=R1

Publishers' Websites

- O'Reilly Patient Centered Guides—Autism (includes book excerpts from *Pervasive Developmental Disorders: Finding a Diagnosis and Getting Help* [Waltz, 1999] permission granted for reproduction). http://oreilly.com/medical/autism/news/classrooms.html

Resources Pages (Lists of Links)

- Autism Resources. http://www.autism-resources.com/
- National Education Association: Autism Resources for Teachers http://www.nea.org/home/15151.htm
- Northwest Education Service District 189: Autism Links. https://www.nwesd.org/aop/links
- Share My Lesson: Autism Resources page
- http://www.sharemylesson.com/teaching-resource/Autism-Resources-50000219/

Professional and Non-profit Organizations Offering CE's and/or Workshops

- Future Horizons Autism Center for Continuing Education. http://www.autismceu.com
- Northwest Educational Service District 189: Autism Outreach Project. https://www.nwesd.org/autism
- National Association of Special Education Teachers: Autism Spectrum Disorder Series http://www.naset.org/2561.0.html
- Paula Kluth: Toward Inclusive Classrooms and Communities http://www.paulakluth.com/work-with-me/
- Universal Class: Online Course—Autism Spectrum Disorders for Teachers, CEU Certificate. http://www.universalclass.com/i/course/autism-for-teachers.htm
- University of Wisconsin STOUT: Online Professional Development Courses for Teachers—Autism course: http://www.uwstout.edu/soe/profdev/courses.cfm#autism

Private Educational Institutions Offering CEU's

- Lindamood-Bell Learning Processes (privately held company). http://www.lindamoodbell.com/learning-centers/asd/
- Lovaas Institute (privately held company). http://www.lovaas.com/index.php
- University of North Carolina TEACCH Autism Program. http://teacch.com

Online Articles on Teaching Mainstreamed Students With Autism

- Different Roads (commercial site). *Reinforcement Development Strategies for Teaching Students with ASD.* (Dr. M. Taubman, no date). http://www.difflearn.com/product/reinforcement-development-strategies-for-teaching-students-with-ASD/expert-articles
- Education World: Special Education Resources. (Several articles) http://www.educationworld.com/special_ed/
- National Autism Center: Boston Parents Paper. *Puzzling Through—New Ways to Teach Children with Autism* http://www.nationalautismcenter.org/pdf/boston_parents_paper_puzzling_through.pdf
- Online Asperger's Information and Support @ MAAP: *Tips for Teaching High Functioning People with Autism* http://www.aspergersyndrome.org/Articles/Tips-for-Teaching-High-Functioning-People-with-Aut.aspx
- TeachThought. *Autism Awareness Month: 6 Strategies for Teaching Students with Autism.* (Heick, 2013). http://www.teachthought.com/teaching/autism-awareness-month-6-strategies-for-teaching-students-with-autism/

YouTube Videos

- ABA Classroom Case Study 2008.

http://www.youtube.com/watch?v=w9N0_7D_Re8

- Autism Teaching Tools: Understanding High Functioning Kids. http://www.youtube.com/watch?v=9aW9xk-1Vsc
- Children With Autism: One Teacher's Experience. http://www.youtube.com/watch?v=8HW7TRJU7PM
- CNN report: Teaching Autistic Children. http://www.youtube.com/watch?v=G9oYALCTAKE&list=PL591E56FFEC327B4E
- Creative Teaching: Teaching Children With Autism. http://www.youtube.com/watch?v=oaySIKKeteA
- Differences Between Asperger's and High-Functioning Autism. http://www.youtube.com/watch?v=LOlHvazQvGM
- Essentials for Educators: High Functioning Autism and Asperger Syndrome. http://www.youtube.com/watch?v=_S35NDMuoJ4
- Mild Autism and Effects on School. http://www.youtube.com/watch?v=8PV4aU3W5cM
- Teaching Students with Autism http://www.youtube.com/watch?v=APY2akeZPLk
- Understanding Autism: A Guide for Secondary School Teachers. Produced by Research Autism (a 2 hour documentary in four parts) http://www.youtube.com/watch?v=4yAAOI6JUsM
- Using Visuals to Teach Children With Autism. http://www.youtube.com/watch?v=RO6dc7QSQb4

Commercial Websites

- Autism Sparks: Teaching Your Child With Autism http://autismsparks.com
- Adapted Mind (Commercial website offering a large variety of lesson plans for students with learning differences across the curriculum organized by grade level—appears to be targeted at parents rather than teachers. Does not mention autism or contain any discussion of pedagogical stance.) http://www.adaptedmind.com/index.html
- Different Roads to Learning: Tools for Kids on the Spectrum Since 1995. (Books, toys, manipulatives, and apps including general education curriculum materials) http://www.difflearn.com
- Do2learn, a suite of products for teaching social skills and behavioral regulation, especially for visual learners http://www.do2learn.com
- National Autism Resources (Toys and learning products designed for children with autism, includes a section for "classroom resources" that includes of toys and curriculum books). http://www.nationalautismresources.com

- Positively Autism (website created by an ABA specialist offering trainings, tutorials, and some free materials. Includes embedded links to commercial products not labeled as such). http://www.positivelyautism.com/whatwedo/

Non-profit Shareware Websites

- Zac Browser (a web browser for children with autism) http://zacbrowser.com
- Zacpicto (a virtual assistant visual schedule manager for children and adults with autism) http://zacbrowser.com

General Information Websites with Autism Sections

- Child-Autism Parent-Café. *Strategies to Promote Successful Inclusion Experiences.* http://www.child-autism-parent-cafe.com/autism-students-in-inclusive-classrooms.html
- Indiana University Bloomington: Indiana Institute on Disability and Community. *Teaching Tips for Children and Adults with Autism* (Grandin, 2002). http://www.iidc.indiana.edu/?pageId=601
- Teaching Community—Where Teachers Meet and Learn. *22 Tips for Teaching Students With Autism Spectrum Disorders* (Hensley). http://teaching.monster.com/benefits/articles/8761-22-tips-for-teaching-students-with-autism-spectrum-disorders

Websites for Teaching Children with Sensory Needs

- TeachersFirst: Special Education Information for Teachers (e-ready) http://legacy.teachersfirst.com/sped/prof/index.html

ABA Resources

- Tools to Help You Teach http://www.educateautism.com

Online Communities and Discussion Forums: General Education Communities

- Classroom 2.0 Forum. Search: “autism” http://www.classroom20.com/forum/topic/search?q=autism

Online Communities and Discussion Forums: Lesson Plan Sharing

- Connected Educators: Online Communities of Practice in Practice http://connectededucators.org/online-communities-in-practice/
- Online Teacher Communities http://www.uft.org/linking-learning/online-teacher-communities
- Paula Kluth, Towards Inclusive Classrooms and Communities. http://www.paulakluth.com
- Share My Lesson http://www.sharemylesson.com/middle-school-teaching-resources/
- Teachers First—Thinking Teachers Teaching Thinkers, general autism resources http://www.teachersfirst.com/spectopics/autism-asperger.cfm
- Teachers First—Thinking Teachers Teaching Thinkers, special needs lessons plans http://legacy.teachersfirst.com/sped/prof/index.html

- Teachers Teaching Teachers http://www.teachersteachingteachers.org
- We Are Teachers http://www.weareteachers.com/homepage

Online Communities and Discussion Forums: Autistic Community Forums

- Autism Now: You Empowered http://autismnow.org/in-the-classroom/
- Wrongplanet: School and College Life discussion board http://www.wrongplanet.net/forum14.html&sid=466b96be44fee016194c17ee281a0a0b

Appendix B

Focus Group Schedule

Focus Group Schedule

The following questions (informed by the inquiry guidelines above) will be used as a "schedule" to organize focus group conversation with the goal of positioning educators as local experts and eliciting their experience and knowledge. The questions will be provided on paper to every participant along with blank paper and pencils.

Intro: each participant please briefly share why this topic is of interest to you.

Focus Group Questions:

- What areas of vulnerability do you see in autistic inclusion students—especially in their ways of learning—that educators may want to consider when designing curriculum?
- What strengths do you see in autistic inclusion students that educators can use when designing curriculum?
- Are there any specific areas where you wish you had more tools, strategies, or more support for teaching autistic inclusion students?
    - What would those look like?
    - What kinds of support would be easiest for you to make use of?
    - What kinds of support would be most motivating to use?

If time:

- Are there structural obstacles in your teaching environment that make it difficult to provide the kind of education for autistic students you wish to provide?
- What else do you want to know more about when it comes to teaching autistic inclusion students?

Appendix C

Quantitative Measures

Please create a unique and memorable identifying code______________

Thank you for taking this survey. Please indicate your level of agreement with the statements below. In the left-hand column, answer how you feel now, then in the right hand column, think back to how you felt before this course.

Now (After the class):						Before the class:				
Strongly Disagree	Disagree	Not sure	Agree	Strongly agree		Strongly Disagree	Disagree	Not sure	Agree	Strongly agree
					I understand the common **behavioral and emotional** aspects of ASD*					
					I understand the common **cognitive and perceptual** aspects of ASD					
					I feel prepared to address **behaviors** of ASD inclusion students in my general education classes.					
					I feel prepared to **teach academics** effectively to ASD inclusion students in my general education classes.					
					I understand **medical model** thinking verses the **social model of disability.**					
					I understand the implications of the **social model of disability** in addressing the needs of ASD students in general education classrooms.					
					I feel the structural supports in place in my school environment provide adequate and appropriate support for ASD students in terms of their **behavioral and emotional** functioning.					
					I feel the structural supports in place in my school environment provide adequate and appropriate support for ASD students in terms of their **cognitive and perceptual** functioning (ways of learning).					

***ASD** = Autism Spectrum Disorder, including Asperger's Syndrome, High Functioning Autism, PDD-NOS, and all other variations of autism.

An important goal of this presentation is to gather educator feedback to inform the development of a web-based resource for educators. Please indicate your level of interest in the following types of information:

	Very interested	Fairly interested	Moderately interested	A little bit interested	Not interested
Type of information:					
Resources and information on addressing the **behavioral and emotional** functioning of ASD inclusion students					
Resources and information for understanding **cognitive and perceptual** functioning of ASD inclusion students					
Information on differentiated instruction for ASD inclusion students					
Information on universal design curriculum that includes ASD inclusion students					
Discussion of psychological research on autism written for an educator audience					
Level of information:					
Theoretical principles for ASD inclusion curriculum design					
General guidelines of ASD inclusion curriculum design					
Discussion and examples of adapting Common Core learning objectives for ASD inclusion students					
Suggestions/examples of learning (IEP) goals that take into account ASD differences in perception and cognition					
A platform to exchange ASD inclusion lesson plans with other educators					
A social media space to discuss experiences ASD inclusion teaching experiences with other educators					

Appendix D

Informed Consent Document

The Autism Exchange Pilot Study

Informed Consent

Project Focus: Students with autism often find school very challenging. The number of people diagnosed with Autism Spectrum Disorders (ASD) is increasing every decade, while at the same time, the trend toward greater inclusion of special needs students means that general education teachers are more and more likely have ASD students in their classrooms.

Project Purpose: I am asking you to take part in this research project in your role as an educator. I am interested in your experiences and questions about teaching ASD inclusion students. The findings of the research will be used to help develop a web-based resource to support educators teaching ASD inclusion students in general education classrooms.

Your Participation: If you decide to be a part of this project, you will participate in a presentation on autism that includes a five-minute survey about teaching ASD students and web resources for teachers. Some participants may choose to stay for an additional one-hour focus group discussion as well.

Follow up: Two or three months from now, you will be invited, if you wish, to review a beta version of a web-based resource for educators. The website will have been created based in part on your input through the survey and focus group. Your review comments on the website may be used to contribute to improving the website. Looking over the website and answering a few questions should take about half an hour (although you are welcome to take longer).

Risks: The risks associated with this project are low. They could include a sense of questioning one's competence teaching ASD inclusion students or frustration with available resources. For focus group participants, risks could include the discomfort of exploring differences in teaching philosophy and approach between colleagues.

Benefits: The possible benefits of this study include learning about recent psychological research on autism and the implications of that research for your teaching. Focus group participants may benefit from the opportunity for professional collaboration with other educators in your school community. Perhaps the most important benefit of this project is for students. If you take part, your input will be used to help develop a website resource designed to support teachers in delivering high quality education to ASD inclusion students.

Taking part is voluntary: Your participation is entirely voluntary and may be withdrawn at any time with no penalty to you.

Confidentiality: All of your responses will be kept confidential and you will not be asked for any personal information. Survey responses will be reported as group totals (in aggregate format). If you participate in the focus group, some of your comments may be used in the research write up, however, all identifying information will be removed. At any time, you may choose not to answer any questions or survey items.

Questions about the study: If you have any questions about this study, you may contact the researcher Ariel Caspe-Detzer at [redacted] or acaspe@antiochsea.edu. You may also contact her research supervisor, Jane Harmon-Jacobs Ph.D., at 206-268-4822 or jharmonjacobs@antioch.edu.

Questions about your rights: If you have any questions about your rights as a research participant, you may contact Dr. Mark Russell, Chair of the Antioch University Seattle Internal Review Board, 206-268-4810.

Consent Statement:

I have read and understood the information above. The researchers have answered all the questions I had to my satisfaction. They gave me a copy of this form. I consent to take part in the Autism Exchange Pilot Study.

Signature: _______________________________Date: ___________

Witness: _________________________________Date: ___________

Appendix E

Counting to Five: A Personal Journey

Counting to Five, A Personal Journey

Autism is a condition about which accurate information is both essential and elusive. Misconceptions and myths abound. I learned the importance of autism awareness early in my second son's life. Because the picture of autism emerging from personal accounts is in some ways very different from the conceptualization outlined by the research literature, and because parenting a child with autism gives a window into the experience like no other, I have chosen the unusual step of including in this academic dissertation a decidedly non-academic account: my own personal story.

* * * * *

Let me preface this story by saying that I am not a worrier. I am the kind of mom who trusts my boys to climb fifty-foot trees, has encouraged them ride public transit from the age of ten, and who moved *from* the suburbs back *to* the city when they were school age, for the diversity and opportunities. It takes a lot to get me concerned. Let me also include the background that I am the oldest of six siblings spread out over 17 years, and before I landed in my current doctoral concentration of pediatric neuropsychology, I had been a middle school teacher, a child care provider, a camp counselor, and a youth music leader. I've worked with a lot of kids.

Most baby stories (especially ones about autistic kids) start out with memories of what a beautiful, happy baby they were. My son Avi wasn't. He was strange-looking—splotchy red and scrawny, born three weeks early (just on the edge of premature), with not enough fat under his skin and too many wrinkles around his squinted-shut eyes. But I wasn't worried. The moment he started nursing, he was precious to me, and he gained baby fat quickly. It was actually my mother-in-law (who has had the grace never to say "I told you so," even though she turned out to be right in the end) who was the one to worry. At three months, my mother-in-law was the first to suggest my second son Avi might be autistic.

Avi was an excessively "good" baby who slept a lot and cried hardly at all. He liked to swing in his battery-powered swing and gaze at the ceiling fixture, while I was able to get all sorts of things done. Life with two kids was supposed to be harder, but things were going great!

Avi showed little interest in mouthing toys or playing interactive games like peek-a-boo. He also had low muscle tone, was very slow to reach motor milestones, and had exceptionally poor balance and coordination. When you picked him up, he didn't instinctively curl into you like a baby monkey, he flopped and gangled unexpectedly. At three months, there was still no sign of the anticipated "social smile," but the real clincher for my mother-in-law was his avoidance of eye contact.

In January of 2001, only a few research articles had made the popular press about poor eye contact as an early sign of autism. Fewer than a dozen studies referencing differences in eye contact as a predictor of autism show up in a pre-2001 search of the PsychINFO database. Somehow, the threshold of five-seconds of sustained eye contact was being referenced in child development resources at that time, and I remember trying over and over during the next several weeks to get Avi to hold my gaze for the count of five. By the time I reached the count of four, however, he always looked away.

At his five-month check-up, I asked my family doctor, "Is there any chance Avi has autism?" My doctor was an enthusiastic young man who worked at a small local practice along with our sons' godfather. He was a recent graduate of a top medical school, and an ardent activist for public health and immunizations. I lived in a small town at the time, and I remember once seeing Avi's doctor and his daughter bike up and take a seat in the grass to watch my middle school humanities class perform *The Tempest* in the gazebo at Elizabeth Park. This was a man who was neither a stranger, nor an overworked cog in a medical corporation; he had no reason to rush and every reason to care. He looked Avi over with genuine concern and earnestly told me he could see no cause for concern. I'm sure doctors hear nervous, overblown worries from anxious parents all the time, but what this doctor didn't know was that I am not a worrier, and that I would not have asked the question if there were not real reason for concern. But I took him at his word and did not worry.

What he didn't know (because few doctors, and even few psychologists knew it at the time), was that by five months, Avi already showed many signs of autism. Besides active avoidance of eye contact and lack of interpersonal interaction such as the social smile, Avi had low muscle tone (thought to be related to "poor vagal tone" or underdevelopment of the tenth cranial nerve) leading to significant delays in motor milestones such as rolling over or scooting, early signs of disaurthria (poor enervation of the trigeminal nerve leading to inhibited sensory feedback in the face and especially around the mouth area). This disaurthria is what lay beneath Avi's disinterest in mouthing objects and his rejection of solid foods until past age one. He also showed significant sensory sensitivities like avoidance of touch and hypersensitivity to noisy environments (from which Avi was protecting himself by withdrawing into hypersomnia, sleeping 16–20 hours a day, even as he closed in on 12 months). Avi's reaction to noise was particularly ironic when I learned at 11 months that he was also hearing impaired, a condition that has been linked to autism (through the mechanisms of underdeveloped cranial nerve) in at least one little-known study from 1977 (Walker, 1977).

By 10 months, however, with unreliable mastery of sitting, no sign of crawling or scooting, and increasing behaviors such as fixation on nearby objects like his own slowly twisting hands, it was obvious to everyone that Avi was not progressing as typically expected. By the time he was finally assessed by an occupational therapist at 11 months, his motor skills and responses to his environment were only at the level of a two- to three-month-old. He showed significant deficits in all domains and marked lack of development in the executive function skills of motor planning. In retrospect, I think that conceptualizing his delays as skill deficit did not describe Avi's challenges as accurately as seeing his failure to develop those skills as a kind of active avoidance and withdrawal, however, the result was similar—for whatever reason, Avi was not able to interact with and learn from the world around him, and as the need to withdraw intensified and the avoidance deepened, he was falling farther and farther behind the developmental trajectory of his peers. Although I did not have a diagnosis at that point, I now had clear assessment data (from that occupational therapist) that Avi was not developing normally, and my doctor felt terrible that he had missed the signs. As a result, he became my advocate in getting expedited access to occupational, neurologic, and genetic assessment services through Group Health in the closest big city—Seattle. His admission of regret is the only time a doctor has ever openly without qualification apologized to me.

When Avi was age 11 months, we started seeing an occupational therapist weekly, and she did two powerful things for Avi and for me. First, she pointed out that though, as an OT, she could not give an official diagnosis (beyond the non-DSM category, "Sensory Integration Dysfunction"), whatever Avi's eventual diagnosis, the recommended interventions for the range of neurodevelopmental disorders affecting sensory driven development were essentially the same—actively engage the child in the sensory experiences they are avoiding. Diagnostic uncertainty and even more powerfully, parental guilt about not seeking appropriate and timely treatment can be huge hurdles in beginning therapy. By assuring me that whatever the eventual diagnosis, sensory processing support would be a useful intervention, she side-stepped the parsing of labels and I dove right in.

Second, the Occupational Therapist prescribed a regime of specific sensory stimulation in several domains targeted at stimulating Avi's ability to receive and process sensory information. For the boy who could not tolerate holding anything, I was to place toys in his palm and hold his fingers closed around them while he squirmed. For the boy who wanted only to nurse, I was to gently but firmly hold spoonfuls of applesauce in his mouth and support his mouth to stay closed around the spoon while he drooled it down his chin looking surprised and mildly repulsed. For the boy who lay limp and turned away when I held him, I was to brush his arms and legs with a plastic surgery scrub brush and move his arms through the motions of patti-cake, singing close to his face while I did so.

The results were dramatic and immediate. My "easy" baby, who was missing the world though constant sleep, suddenly came face-to-face with a flood of new sensory information. Instead of effortlessly and constantly dropping off to sleep, he began to scream for two or three hours a night (not an unusual pattern for neonates, but rather shocking—and a lot louder—in a 1-year-old). The reaction was not immediate in response to stimulation encountered during the day, but rather cumulative, peaking at the end of the day, as ability to process the new load of sensory stimuli overwhelmed his immature processing abilities. (The comparison to neonates is purposeful—I believe that the "awakening" Avi experienced as he began to process the sensory information he had been avoiding was a lot like what newborns go through in their first months of life—and his response was similar—overwhelm and overstimulation as he struggled to integrate all that new information.)

For two weeks of the new sensory experience regime, Avi tolerated the interventions reasonably well as we did them, but he reacted with a pent-up and overwrought irritability (e.g., rage) for hours each night. I worried about his suddenly increased sensitivity, but there was not really any going back—even when I eased off on the interventions, his world had already cracked open; like a snake with brand new skin, he was really *feeling* for the first time, and it was overwhelming, uncomfortable, and foreign.

At the end of two weeks almost exactly, something suddenly shifted. It was as if Avi's brain snapped into gear, sensory pathways began to rewire, and he began to develop. He stopped screaming each night, stopped sleeping excessively, started eating real food, began really looking at the world around him, including people and faces. He started scooting forward to pick up objects and toys, and even began mouthing them like a normal baby. He was still behind—he didn't crawl until 16 months, but he walked less than two months later, and the next month began a wobbly run. At one year, his hearing impairment was finally detected by a standard screening that was one of a battery of neurologically related tests that was almost an after-thought (at the time, Washington was one of seven states that didn't do infant hearing screenings), and after getting hearing aids, he began to babble and talk.

I was fortunate to be able to take time off work during Avi's second year, and that time was a blur of learning (for me) to navigate social services for the under-3 set. We attended different therapy and social group offerings every day of the week. Even a broken leg at 11 months didn't slow him down. The broken leg too, was a result of Avi's constellation of autism traits: my brother was giving him a shoulder ride and didn't realize that Avi's excessively low muscle tone meant Avi couldn't adequately balance—when Avi began to fall, my brother managed to keep hold of only one leg, which cracked in my brother's grasp in a spiral fracture as

Avi twisted in his fall. (Better than a cracked head, but still traumatizing for all involved). It was lucky we went to the hospital to get the leg checked out "just in case"—thanks to the low sensitivity to pain common in autistics (K. Markram & Markram, 2010), Avi hadn't even cried when the paramedics checked him out.

By the age of 4, with the exception of lingering balance and coordination issues, Avi had caught up with all his developmental milestones in motor and language domains, and was beginning to show some of the quirky strengths of pattern recognition and exceptional perceptual memory of the autistic mind. At age 2, Avi taught himself to use a computer mouse to play "Maisy" games, and then, at age 4, with some help from his older brother, but without any adults even really noticing, Avi taught himself to read (hyperlexia—early reading without much instruction—is associated with autism). Skipping elementary readers, Avi dove right into the *Harry Potter* series right along with his four-years-older brother. At a holiday party just after he turned five, Avi surprised everyone by winning his first game of *Blokus* (a game fitting complex geometric shapes together) against experienced adults, while still learning the rules. Avi would go on to love board games and strategy games of all kinds, fixating eventually on Rubik's Cube type puzzles as an area of special interest (deep and passionate interest in a very specific subject is a common phenomena among autistics; Winter-Messiers, 2007). At 13, Avi learned *Autocad* so as to be able to plot and 3-D-print cube puzzles of his own design. In sixth grade he won science fair honorable mention for a project on using Minecraft to model electrical circuit design, and then in seventh, was selected as the winner of his school's science fair, for a psychological test researching autistic ability to pre-segment patterns and the pilot of a test he designed to measure pattern recognition. Over the summer before high school, Ave taught himself Java programing and geometry. Even writing, once his greatest area of challenge, has become an area of real strength—while he works harder, needs more support, and takes longer than typical kids his age to organize his rich recall, he has developed into a strong and descriptive writer who captures the emotional experience of his subjects and puts himself passionately into his work. In fact, his sixth-grade social justice project researching the way schools respond to students with autism turned into a fifteen page paper, which then became the seed that inspired this dissertation (in fact, some of my general press citations on teachers expressing concern over lack of training come from citations he found for his sixth grade paper).

Despite all his accomplishments, Avi is no savant genius. In second grade, while he could understand systems of algebraic equations, he consistently got the arithmetic wrong (autistic understanding is often fragmented and poorly integrated). At nine, he could recite the dialog and plots of entire movies but couldn't tell you the main idea or make any kind of guess as to what characters would do next, if I paused the movie and asked. From toddlerhood on, Avi was beginning to show the stereotypical and widely recognized traits of autism: cognitive inflexibility, extreme dysregulation around disruption of routines, rapid escalation of aggression leading to physical conflict with his brother and cousin (he had no other close friends and resisted parental efforts to foster peer connections), as well as emotional meltdowns over discordant sensory triggers—triggers which he could rarely describe, and of which others were barely aware.

As Avi progressed through elementary school, his impulsivity, suggestibility, and lack of executive control began to cause serious issues. Worse yet, his unusually large vocabulary and formal way of speaking caused unfamiliar adults to relate to him as *more* mature than his age, which tended to cause them to view his unregulated or avoidant behaviors as conscious and volitional. Avi seemed to have a particular talent for triggering the more authoritarian adults in his orbit. Folks like that, when faced with the kind of disposition that Hans Asperger once described as a “little professor” (as translated by Frith, 1991), appeared to take Avi’s unpredictable and mercurial lapses as intrusively personal. I’d check in after getting out of one of my graduate school classes to find messages from Avi’s school with barely controlled frustration and helplessness leaking through the starchy rhetoric about “poor choices” and “not listening.” Scare ‘em straight principals would lecture me about how Avi was a master manipulator who had me completely wrapped around his little finger, while making oblique and condescending suggestions of how to improve my obviously inconsistent parenting.

Time and again, I’d trot out autism 101, trying to educate administrators on the basic differences in neurologic functioning that, while they look an awful lot like resistance and manipulation, actually represent the far more primitive reactions of flooding, freezing, and fleeing. Of the three principals with whom I had this cyclical conversation throughout elementary school, the first refused to believe me at all, the second would nod and say, “oh how interesting,” but by the time of the next infraction, any new information would be completely swamped by her traditionalist beliefs. The third (and the youngest by far), in contrast to her colleagues, thanked me earnestly and worked with me after each incident to design a logical and related consequence designed to have real learning potential and reparative value for Avi and the classmates involved. Her program, which focused on creating opportunities for meaningful repair of peer relationships, and creating opportunities to reinforce desired successful behaviors based on Avi’s areas of strength, was by far the most effective.

In many ways, peers have been both more understanding of and more difficult for Avi to interact with than adults. In second grade, students in Avi’s class learned that Avi, who desperately wanted to belong, would do anything to feel accepted and cool, and yet his poor fluency in the language of social interaction meant he had no idea about what those things might actually be. Avi's vulnerability made him an all-too-tempting target for bullying (even by classmates who actually liked him well). The principal, a traditionalist just arrived from Georgia (the first of the three I mentioned above), jumped immediately to labeling Avi himself a "sexual predator," on very little evidence. Things might have gone very differently if Avi's teacher not been so aware of the dynamics of her class and so articulate in Avi's defense. It is not unusual, I learned later, for autistics and others who have significant impairments in the areas of impulse control and executive function (most often boys), to be slapped with such labels, with no awareness on the part of administrators of the dynamics of bullying and victimization operating make students who are actually victims of a power dynamic appear to be the aggressor. This is partly due to the fact that bullying incidents are so triggering to autistic students that they lose access to nuanced language and become unable to tell their side of the story in a way that sounds believable to administrators.

Adding to the difficulty of unraveling these difficult and emotionally flooding incidents was Avi's autistic tendency to verbally shut down and even cease laying down short-term memories as soon as the cascade of emotional arousal took over. When a smart, verbal kid can say nothing but "I don't know" (or Avi's favorite, "I don't want to tell you"—by which he means, I *can't* tell you, but I don't want to admit that I don't know because that's even more shameful) school authorities understandably feel they are not getting an honest response. It takes a lot of educating to convince them that Avi's inability to speak under such circumstances is not, in fact, oppositional or manipulative, but rather a reflection of his true experience—he really *doesn't* know quite what happened, and he certainly has no ability to explain *why* he engaged in the impulsive behaviors he may not even remember initiating. Requiring Avi to explain his behaviors, as adults so often do, only activates him more, making language processing and verbal response even more impossible.

Since then, as similar impulsivity reactions have emerged with puberty, and school officials more than once have tried to officially label Avi’s behavior on school records as “sexual harassment” even when he is the victim and not the initiator (this is especially touchy when the initiators are girls—I am a strong feminist and believe that all girls deserve to feel safe at school, but I also know that girls can engage in taunting behaviors resulting in very complicated power dynamics). I have learned to immediately call school officials out on their legal responsibility not to punish a child for a manifestation of a disability—even more so when any dynamic of peer bullying or emotional coercion is also at play (which, in every case for Avi, after enough calm investigation, has turned out to be the case). And here is where the official diagnosis of autism (which Avi finally received around the age of nine) became truly critical.

That diagnosis was not easy to get. As a doctoral student in clinical psychology, my knowledge and awareness of the characteristics of autism was building every year from the time I began the program when Avi was 5. As Avi progressed through elementary school, I became increasingly sure that Avi met criteria for a spectrum disorder, but when I went through the necessary channels with our health provider to get him diagnosed, the psychologist ignored my descriptions of his anxiety and reactivity (these traits are not emphasized in the DSM diagnosis, and many psychologists do not strongly associate them with an ASD profile). Instead the psychologist fixated on Avi’s poor regulation of attention on a computer measure, and insisted on a diagnosis of ADHD. Knowing that attention issues are often a part of ASD, and concerned about Avi’s basic safety and ability to continue to be mainstreamed, I reluctantly agreed to a medication trial of Adderall, a stimulant medication frequently used to treat attentional issues. At the time I did not know about the tendency of some autistics to be highly sensitive to stimulants.

The results of the Adderall were as dramatic (though in a negative direction) as our first sensory interventions nine years before—suddenly Avi was displaying violent tantrums for hours every night. This time, however, there were no developmental achievements to balance the downside. After a couple of weeks of afterschool meltdowns, the psychiatrist convinced me to try adding a booster dose to “even out” the afterschool rebound, but that only increased Avi’s activation and anxiety, adding to the mix depressed appetite and difficulty falling asleep (as well as difficulty waking in the morning). Avi’s irritability skyrocketed. When he got suspended for trying to grab a girl at recess and scrapping with a boy during a foursquare game, I concluded that the stimulant was only elevating aggression, and doing nothing to help regulate executive control, and I took him off.

Again, I learned anecdotally, and only after the fact, that stimulant medications are often disasters for kids with autism—their delicate brains seem to process the chemicals quite differently from the brains of typical kids or kids with true attention deficit disorder. A student in my doctoral program who was interning at an autism clinic at the time, told me that if providers at their clinic were working with an autistic kid who was thought might benefit from a stimulant, they usually recommended starting at a quarter of the normal dose. At that point, I just wasn’t interested in titrating up on another stimulant to try to find an appropriate level for Avi. For one thing, Avi was having no academic problems in school, so his attention regulation seemed pretty irrelevant to his ability to learn. I was far more worried that Avi’s anxiety, emotional volatility, and impulsivity would disrupt his ability to participate in the social and behavioral aspects of general education placement. I wanted him to be able to stay in his general education placement with his wonderful teacher he had had the good luck to be with for, at that point, three years.

I went back to the psychologist and confronted him with a more organized presentation of Avi's case, along with my frustration that he had ignored the symptoms I had identified as most problematic (anxiety and sensory reactivity). At that point, the psychologist admitted that he was on the fence in Avi's case, and agreed to change the diagnosis to PDD-NOS (Pervasive Developmental Disorder, Not Otherwise Specified), or, as it got recorded in Avi's IEP school records "Autism Spectrum" disorder. (At that point, the DSM had not yet changed to include all ASD diagnoses under one umbrella, but I knew the change was coming, and the school was flexible enough to use the phrase "autism spectrum" in anticipation of the coming shift. It was one case where I shamelessly used my in-process doctoral credential to influence the gatekeepers in charge of services in Avi's favor. I am keenly aware that not all parents have the privilege of my degree of education or access to such information let alone the ability to influence IEP team decisions to that degree.)

Three years later, in middle school, when Avi once again got into trouble for inappropriately impulsive social interactions with a girl, that diagnosis—including the particular phrase "autism spectrum"—turned out to be critical in getting him transferred to a public school program with a full-inclusion autism placement providing 1:2 aide support, where he had the structure and staff knowledge that he needed to appropriately support his behaviors at school. Whether he has the support he needs to reach his full cognitive potential or demonstrate academic achievement (at least as it is measured by standard grades) is a work in progress, but having him attend a middle school where teachers understood him and did not automatically pathologize odd behaviors was a significant support for his early adolescent development.

At the same time, while the autism team at that middle school was capable and professional, the limited ability of some of the school's general education staff to bring creative curricular engagement to the education of students like Avi brought home in a very personal way the impact of decades of autism research focused on behavioral deficits rather than exceptional cognitive abilities. The lack of structure to support the strengths (rather than just the remediation of challenges) of autistic students in such school settings highlights the fact that the battle is only half won.

Due to the disruptions that led to Avi's transfer between schools near the beginning of middle school, I once again investigated medication. This second time, however, I targeted the anxiety symptoms that are so often an under-diagnosed and under-studied part of autism. Since the events surrounding that school transfer, Avi has been on a low dose of Escatalopram, a selective serotonin reuptake inhibitor (SSRI), which appears to be helping him weather surges of anxiety during periods of intense emotional arousal. This medication is enough to help him keep hold of executive control and resist impulsivity. It is not perfect, but the medication seems at least now to be addressing the right issue—the anxiety and even fear reactions that come from having a highly sensitive nervous system that is poised to react in the extreme to every stimulus. Like any effort with a teenager, the medication and our family work on emotional regulation is a work in progress. For now, as Avi increases his ability to stay calm and connected in social interactions, and his academic independence and confidence increase, it is the best balance yet achieved.

The most important recent shift for Avi, however, hasn't been medication or even the increased helpfulness of appropriately targeted family and school support. It has been claiming for himself the label "autistic." Learning about, owning, and teaching others about the experience of being autistic has transformed him from passive observer to active self-advocate. Like many before him, understanding his own struggles has gone hand-in-hand with constructing a social meaning around the experience, and connecting with others through that social meaning. What began as a school project in sixth grade led him to make a presentation at a national conference for autistic community in 2014, as well as for a class of graduate students in neuropsychology and the presentation appears under Avi's name as lead author in the bibliography of this dissertation.

In my experience and observation, this emphasis on identity-claiming as part of autistic development is part of a growing trend in which practitioners in the field of autism treatment as well as autistics themselves are moving away from a focus on isolated functional and social skills, and towards rich and socially significant experiences of meaning making and interpersonal connection such as writing, poetry, theater, art making, documentaries, and interactive science demonstrations using engineering, math, and other symbolic means of communication (e.g., art therapy—Goucher, 2012; creative drama—Guli, Semrud-Clikeman, Lerner, & Britton, 2013; and sandplay—Lu, Petersen, Lacroix, & Rousseau, 2010, as well as my own personal experiences doing an internship stint at the Children's Institute for Learning Differences—a curriculum which included art, drama, music, and film making as regular parts of the curriculum for even the most impaired students).

Autistics themselves are leading the way toward adopting transformative and meaning-making modes of self-expression and communication. Mechanisms to titrate the flood of social stimulation so that interpersonal interaction becomes not only comfortable but rewarding and exciting—most significantly through interaction over the internet, but also including various methods of assisted communication—are making possible a whole new sense of community and culture among autistic people (for an excellent illustration of these methods, the documentary *Wretches and Jabberers* gives a powerful demonstration of the transformative power of alternative methods of communication, Biklen & Wurzburg, 2010). The intersection of the disability rights movement with the blossoming of autistic culture, as well as innovations in the conceptualization of autism (see chapter I) suggest that autism may actually be shaking off the sense of dread and disablement that have dogged it for so long.

In my research for this dissertation, as I was working on writing a summary of one of the most exciting new theories of autism, I passed on to Avi's father a popular press article that had recently surged across the autism communities of the internet explaining the theory's findings. "Wouldn't it be exciting," his dad said, after reading the article, "if, in a generation, these suggested treatments can mitigate the early developmental drawbacks of autism, and if people just come to look at having autism as a *gift*?"

An exciting possibility indeed.

In many ways, my understanding of autism over the course of Avi's life has mirrored the larger theoretical evolution in the academic and research communities. Back when I was a teacher (before Avi was born), my work with a variety of kids in the upper elementary and middle school grades of a creative independent school gave me a solid sense of the typical stages of cognitive development through which young people progress. Back then, I understood autism much as Leo Kanner described it in the 1940's: a condition of profound isolation—a brain turned in on itself incapable of empathy or emotional contact, indifferent to others, and completely unlike the emotive, creative, and highly engaged kids I coached through evidenced-based writing essays, creative history projects and Shakespeare productions in Elizabeth Park. Ah, what I didn't know then . . . To think that I would have an autistic son who loves and is great at *all* of those things.

Since that time, I've come to a very different understanding. My journey through autism with Avi, my stint at a therapeutic day school as a doctoral pre-intern working with moderately *and* severely autistic students, my internship work in pediatric neuropsychological assessment and work with families and teachers to design appropriate special education interventions, together with studying the emerging theories of autism detailed in the second chapter of this dissertation have all converged to convince me that autism is not a condition of isolation at all, but rather one of intense emotional experience and sometimes overwhelming interpersonal connections that can only be managed at times, through sensory muting and repetitive or controlled behaviors.

In my experience and Avi's, theories which conceptualize the autistic experience using a paradigm of oversensitivity rather than under-sensitivity do a far better job describing the intensity of affective awareness, the hair-trigger reactivity, and the self-protective avoidance and the withdrawal into the safety of highly predictable sameness that often results. Parenting Avi and working with other kids like him has convinced me that autistics may have trouble communicating or expressing typical empathy with others when emotional experience floods their processing, but they do not *feel* the emotions of themselves and others any less than typical kids. If anything, they feel them more.

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While Avi was my personal education in autism, I could not make the sense I have made of the experience without the work of major pioneers and thousands of researchers in the field. This dissertation reviews the history and culturally constructed meanings of this enigmatic and evolving syndrome from the first descriptions offered by Leo Kanner and Hans Asperger before World War II, to the most exciting recent developments in neurobiological brain modeling and emergent theory. The research portion of this dissertation relates the direct experiences of teachers in the classroom to these emergent ideas. We are currently at a point in autism research where the condition is beginning to be understood in entirely new ways, and revolutionary approaches to treatment and intervention are being suggested.

It is truly an exciting time to be in the autism field. Wherever we will be in our understanding of autism a generation from now, it will be a long way from where I was fifteen years ago, gazing into the eyes of my 3-month-old baby, counting over and over not quite to five.