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I am submitting herewith a dissertation written by Jessica Nina Lester entitled "The Discursive Construction of Autism: Contingent Meanings of Autism and Therapeutic Talk." I have examined the final electronic copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy with a major in Educational Psychology and Research.

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The Discursive Construction of Autism: Contingent Meanings of Autism and Therapeutic Talk

A Dissertation Presented for the

Doctor of Philosophy Degree

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Jessica Nina Lester

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Dedication

To one of my greatest teachers and dearest friends,

Rachel Panashe,

without whom I would never have come to this work, to these understandings.

You have taught me so much about communicating, loving, and being.

I hope one day you will read this text, make your own connections and/or disconnections,

and show me all that I have yet to make sense of.

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"…we never write on a blank page, but always on one that has already been written on" (de Certeau, 1984, p. 43).

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Abstract

This dissertation was a discourse analysis study, drawing upon discursive psychology, poststructural understandings of discourse, conversation analysis, and a social relational model of disability. The purpose of this study was to explore how autism was performed as an interactional event among children with autism labels, the therapists who work with them, and their parents, in the context of a pediatric therapy setting. I interrogated how the participants' everyday discursive practices were shaped and, at times, constrained by the social and political institutions that often work to define autism and the related, official plans of treatment. A total of 12 families agreed to participate, resulting in the participation of 12 children with autism labels, three to 11 years of age, six fathers, and 11 mothers. The participants included three speech therapists, two occupational therapists, one physical therapist, one teacher/social group facilitator, and one medical secretary/sibling support group facilitator. Data sources included conversational data from the therapy sessions of the participating children and their therapists, 14 parent interviews, eight therapist interviews, documents used within the therapy sessions, demographic surveys/information from the participating therapists and parents, and two interviews with a state advocate and clinical directors focused on qualifying for services. Findings from the interview data highlighted the varied meanings and performances of autism, while pointing to the related political and social conditions that make the naming and treating of autism (im)possible. Findings drawn from the therapy session data pointed to how the participants' discursive practices worked to reframe "behaviors of concern," and to transgress normative communication patterns. The following conclusions were drawn from the findings:

(a) autism, as a construct, remains open to multiple meanings, while being inextricably linked to institutionalized practices; (b) in therapy talk, therapists and children with autism labels often co-construct alternative accounts of problematic behaviors; and (c) therapy talk can function to reframe non-normative communication and behavioral patterns, expanding what is constructed as "acceptable." The findings point to the complexities of defining and performing autism labels, and highlight the ways in which therapy talk can function to reframe behaviors and communication patterns presumed to be pathological.

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Prologue

Eleven children named autistic
not “feebleminded,”
not “schizophrenic.”
For this, said Kanner (1943/1985),
was a “unique ‘syndrome,’ not heretofore reported”
(p. 41).

They
had stereotyped movements
lacked “initiative...requiring prompts”
showed a “limitation of spontaneous activity”
“paid no attention to persons”
had “no affective tie to people”
(Kanner, pp. 13-24).

Diagnosis:
“inborn autistic disturbances of affective contact”
Classification:
Autistic Disorder
Principal Issue:
“inability to relate themselves in the ordinary way”
(Kanner, p. 50).

Asperger (1944/1991) confirmed
These children had a
“genuine defect in their understanding of the other person”
and
“no real love for anybody” (p. 81, p. 40).

Twentieth century disorder produced.
Autism:
defined
described
assumed
reified.

Years pass,
professional explanations proliferate.
Yet outsiders (aka experts) still name

“the aloof, the passive, the odd” child
Autistic (Frith, 1989, p. 62).
Concerns pervade
Rightfully so
for 1 in 110 children diagnosed each year.

Medicalize
Pathologize
Essentialize
Spectacularize
Public imagination captivated.

Chapter I

The Construction of Autism

With the Center for Disease Control (2009) recently reporting that approximately one in 110 children in the United States are diagnosed with some form of autism each year, the public's imagination remains captivated and concerned. Considered to be the most widely researched child psychiatric disorder (Wolff, 2004), autism is a product of varied and at times conflicting disciplinary knowledges, with multiple institutional discourses and histories contributing to its production (Nadesan, 2005). Most predominately, autism has often been positioned within a discourse of disease and deficit, with metaphors of "medical intervention" and "cure" frequently evoked within both medically-oriented research communities and popular media outlets (Broderick & Ne'eman, 2008, p. 469). Further, as medical and scientific literatures have represented autism as a biological fact to be understood primarily through the lens of positivistic methodologies (Glynne-Owen, 2010; Rocque, 2010a) and the "assumptions of the natural sciences," the social conditions and everyday practices that make possible the naming, representing, treating, and performing of autism have been often overlooked (Nadesan, 2005, p. 2).

As such, over the last 60 years, the metaphors and meanings that have framed the construct of autism have been situated within deficit and medical models of autism, relying primarily upon a binary divide between the cultural notion of "normal" and "abnormal" (Ashby, 2010; Broderick & Ne'eman, 2008; Davis, 1995). Central to these representations of autism is

an image of the individuals with autism labels as isolated and disengaged due to marked social, communication, and behavior impairments (see Appendix A for DSM-IV autistic disorder diagnostic criteria). Additionally, public stories told about autism often conflict with and contradict one another, with some versions describing the individual with autism as "imprisoned within, waiting to be reclaimed" (Maurice, 1993, p. 32), while other versions constructing autism as "*not* just a 'shell' within which a 'normal' child is waiting to get out" (Happe, 1994, p. 6). The culture of autism that not so long ago was the province of a small group of individuals is now everywhere, with talk shows (e.g., Winfrey, 2007, "The Faces of Autism" on *The Oprah Show***)**, television series (e.g., Trilling and Massin, 2010, *ABC* television series "Parenthood"), and popular magazines (e.g., Rosen, 2010, *Ladies' Home Journal*) working to shape the public's imagination and ways of talking about the construct of autism. It seems that the dominant autism story "is fractured by *dissoi logoi*, a scrambled collection of competing, contesting 'truth claims'" (Avery, 1999, p. 119), particularly when the public stories of autism meet the private, everyday practices of individuals with autism labels and their families, friends, therapists, and teachers.

While acknowledging that the available regimes of talking about and representing autism likely shape how children with autism labels and their families make sense of and perform autism, I also align closely with the literature pointing to the ways in which individuals manage, take up, resist, and/or contest dis/ability[1] labels (Mehan, Hertwick, & Meihls, 1986; Rapley, Kiernan, & Antaki, 1998) in their ordinary, everyday life (de Certeau, 1984). Although some scholars, as well as dis/ability rights activists (Charlton, 1998; Shapiro, 1994), have placed

[1]Throughout this text, I separate "dis" from "ability" (dis/ability) to emphasize the presumption of ability and competence that I take up when working with and for individuals with dis/ability labels.

increasing emphasis upon the socially constructed, culturally contingent, and contested nature of disabilities (Corker & French, 1999; Oliver, 1990, 1992), such as autism, little work has specifically attended to the situated and discursive contexts within which children with autism labels and their families perform and make relevant their own understandings and representations of autism.

Statement of the Problem

Since the construction and popularization of autism as a diagnostic category in the 1940s (Asperger, 1944/1991; Kanner, 1943/1985), the extensive research on autism has focused on identifying, describing, and treating children who exhibit what Kanner originally called "fascinating peculiarities" (p. 217). With the prevailing models of research in autism situated within deficit and medical models of representation (Glynne-Owen, 2010), the majority of research within the field of autism[2] has focused on identifying the (presumed) core deficits, etiology, and effective treatments for what has come to be named a spectrum of autistic disorders (Biklen et al., 2005; Nadesan, 2008; Osteen, 2008). For example, much of the research on the talk[3] of children with autism labels has focused on identifying and describing their *peculiar* and *deficient* linguistic characteristics (e.g., Hobson, Lee, & Hobson, 2010; Janzen, 2003; Krantz & McClannahan, 1993), as well as the various methods by which to improve or correct such presumed deficiencies (e.g., Charlop-Christy & Kelso, 2003; Koegel, Shirotova, & Koegel,

[2]Within the "field of autism," I include those specialists, researchers, clinicians, parents, and teachers who have contributed to the growing body of literature surrounding autism. I do not presume that individuals with an autism label do not also contribute to the field. However, within the dominant discourses of the field, the autobiographical work of individuals who identify as autistic remains emergent and is often dismissed (Biklen et al., 2005).
[3]"Talk" includes both verbal and nonverbal modes of communication.

2009). Further, studies on autism have typically been experimental or quasi-experimental in design, with little research focused on exploring the lived experiences and daily practices of individuals constructed as autistic (Alexander, Cowdry, Hall, & Snow, 1996; Glynne-Owen, 2010)

With a predominant focus on etic and highly medicalized representations of autism, little research has aimed to understand autism from an emic perspective. As Biklen et al. (2005) noted, qualitative inquiry within a field as highly medicalized as autism is inherently challenging, as "most of the language of the field assumes a shared, normative perspective" (p. 14). Nevertheless, there is a small, yet growing corpus of qualitative studies focused on the life stories of individuals with autism labels (e.g., Ashby, 2010; Ashby & Causton-Theoharis, 2009), everyday practices of "high-functioning children with autism and Asperger syndrome" (Ochs, Kremer-Sadlik, Sirota, & Solmon, 2004, p. 147), and identity construction of individuals with autism labels (Bagatell, 2007). Although some conversation analysis studies exist, examining the organization of the talk of individuals with autism labels (Stribling, Rae, & Dickerson, 2007; Wootton, 1999), little research has applied discursive approaches to understanding dis/ability as situated and locally produced (O'Reilly, 2005c; Rapley et al., 1998). Further, to my knowledge, no study has specifically focused on how children with autism labels and their parents and therapists discursively manage and produce this construct. Thus, there is a need to explore and interrogate the situated, discursive practices of such individuals, attending to the ways in which the construct of autism is produced and the discourses of dis/ability and treatment/intervention are deployed and navigated.

My study sought to investigate the discursive practices of children with autism labels, as well as those of their parents[4] and therapists.[5] Through this in-depth examination, I considered how the participants managed, contested, resisted, and made relevant the varied and layered meanings of autism through talk-in-interaction. Moving away from an etic perspective, I took up discourse theory and analysis, situating this work within a discursive psychology framework (Edwards & Potter, 1993), that was informed by poststructural understandings of discourse (Derrida, 1981; Foucault, 1971; Howarth, 2000), certain aspects of conversation analysis (Sacks, 1992), and a social relational model of disability (Thomas, 2004).

Purpose of the Study

Within this study, I had multiple aims. While the overarching purpose of this research was to explore how autism is performed as an interactional event among children with autism labels, the therapists who work with them, and their parents, I also worked to interrogate how this "talk" was shaped, and perhaps, at times, constrained by the social and political institutions that often work to define autism and the related, official "plans of treatment." So, as I sought to explore the everyday talk of children with autism labels, as well as those of their parents and therapists, I positioned their talk within and, at times, against the broader institutional contexts that the participants made relevant in their social practices. Further, as I attended to how the participants managed the meanings of autism through talk-in-interaction, I interrogated the ways in which "problematic" moments with and/or "concerning behaviors" of the participating

[4]Throughout this text, I refer to parents and legal guardians interchangeably.
[5]Throughout this text, "therapist" refers to all types of professionals that might work with children with diagnostic labels of autism within institutionalized settings (e.g., play therapists, occupational therapists, speech therapists, educational therapists, etc.).

children with autism labels were made relevant, reframed, and worked through in the context of waiting room conversations, occupational, speech-pathology, and physical therapy sessions, and hallway conversations among therapists, children with autism labels, and their parents and/or caretakers.

I was particularly interested in exploring a therapeutic setting where autism was explicitly a topic of focus, taking note of the ways in which this contingent category was made relevant in naturally[6] occurring interactions. The talk of a therapist and a child with an autism label, as well as the talk between the parent of the child and the therapist, provided insight into how autism was performed and worked up as the therapist, child, and parent encountered the nosological clustering of symptoms and institutionalized practices of remediation. I oriented to the discourse of intervention/therapy sessions for children with autism labels as forms of talk-in-interaction[7] that embodied social practices specific to the given institution. In that the relevance of autism, as an attribute, depended upon the particular setting in which the talk occurred (Goffman, 1964), I selected a setting with a heightened focus on the social attribute of interest (i.e., autism) (Cazden, 1970). Thus, positioning the everyday practices as institutional allowed me to consider how particular institutionalized discourses and technical practices were enacted and lived through patterns of meaning and action. While doing so, I recognized that issues around *treating* autism were not monolithically put into practice, but instead constitute the innumerable practices "by which…users reappropriate the space organized by techniques of sociocultural production" (de

[6]"Naturally occurring" discourse is that which is not produced solely for the purposes of a research study or instigated by a researcher (Edwards, 1997; Potter, 1997; Wood & Kroger, 2000).
[7]"Talk-in-interaction" references talk and other interactional events (e.g., gestures, non-vocal aspects of talk, bodily movements, etc.). More particularly, the phrase is connected to the conversational analysis perspective that studies interactions as organized and embodied layers of social action.

Certeau, 1984, p. xiv). So, I aimed to complicate understandings surrounding autism, pointing to the tensions across institutionalized spaces, discourses, and practices.

Research Questions

My in-depth examination was accomplished through a research approach that drew from discursive theory and analysis, one emphasizing and attending to the local, everyday discursive practices (Potter, 2005) of the study's participants. While staying close to the everyday language practices (de Certeau, 1984) of the participants, I also worked to position my interpretations at the intersection of the local practices and the broader social and political frameworks made relevant within the data set. Thus, in order to explore how autism is performed as an interactional event, I worked to methodologically and theoretically position this study within a discursive psychology approach (Edwards & Potter, 1993; Potter, 1996; Potter, 2004; Potter, Edwards, & Wetherell, 1993) that was informed by poststructural understandings of discourse (Derrida, 1981; Foucault, 1971; Howarth, 2000) and some of the work of conversation analysts (Sacks, 1992). As I engaged in recursive reflexivity (Hertz, 1997; Pillow, 2003; Skeggs, 2002), collected and analyzed the data, and shared the various iterations of this work with the research participants, the following two primary research questions were developed through an iterative process and served to frame this research project:

1. What are the various meanings of autism and how are these meanings performed within and through the discursive practices of therapists and parents of children with autism labels in their everyday interactions?

2. How do children with autism labels and their therapists and parents discursively manage and account for the behaviors and communication approaches made relevant in therapy?

Although a discursive framework served as this study's overarching theoretical and methodological framework, the social relational model of disability (Finkelstein, 2000; Reindal, 2008; Thomas, 1999, 2001, 2004) also informed this work, as I made sense of the data and framed the epistemic and ontologic assumptions that grounded how I oriented to the notion of dis/ability. (See Chapter IV for a complete description of this study's theoretical/conceptual frameworks).

Definition of Terms

As the process of doing this research study evolved, so too did how I named all that I attempted to make sense of. Within this section, I define the key terms and concepts that were used throughout this project. I aimed to align each definition with the purposes and presuppositions of the study, acknowledging that each definition has shifted through the data analysis process and as I have shared my interpretations with the research participants. This alphabetical listing serves to make the reader aware of some of the claims and commitments that framed this inquiry.

1. *Autism/Autistic Disorder:* For the purposes of this study, I define autism as a social construct with multiple and shifting meanings. In defining autism as a social construct, I attempt to move away from highly medicalized definitions of autism as being a biological truth comprised of a triad of deficits, including: (1) impaired social interaction, (2) lack of

or limited imagination, and (3) delayed and/or limited communication (Frith, 1989). Instead, I suggest that the emergence, labeling, and treatment of this "disorder" are embedded within institutionalized histories, cultural practices, and discursive practices (Nadesan, 2005), and meaning of any kind is never simply given or guaranteed. With such a definition, it is important to note that in this work I did not attend to or deny claims regarding the biogenetic aspects of autism, but instead focused on autism as made relevant in discourse. Finally, while acknowledging that person-first language was originally intended to be emancipatory in nature, naming individuals with dis/ability labels as people first (e.g., person with autism), I agree with Broderick and Ne'eman (2008) that such language may actually serve to reify autism as a "thing" of tangible reality. Thus, recognizing that "autism is a concept *developed and applied, not discovered*" (Biklen et al., 2005, p. 12), I cautiously used the phrases "person with an autism label," and "children with autism labels" when referring to individuals diagnosed with autism or presumed to be autistic.

2. *Cognitivist/Cognitivism:* Considered a mainstream approach within social psychology, cognitivism assumes that people's descriptions and accounts reflect their mental frameworks of the social world (Horton-Salway, 2001). As such, within a cognitivist perspective, discourse is viewed as a methodological resource for research, with participants' discourse serving to represent mental states and other cognitive entities (e.g., shared knowledge, scripts, categories, memory, emotion, etc.). In contrast to cognitivist notions, the discourse framework which I drew upon took a post-cognitivist position (Kitzinger, 2006), attending to psychological constructs within discourse if, and only if,

they were made relevant by the situated and discursive practices made visible through the talk and/or texts of the participants. It is important to note that even within this post-cognitivist position, I did not necessarily deny the existence of mental states; however, I did not attempt to discover them outside of showing how they were worked up into existence through language (Potter & Edwards, 2003).

3. *Dis/ability*: With views of dis/ability ranging from the conventional notions of tragedy to the more progressive idea of independence and interdependence (Danforth & Gabel, 2008; Reindel, 1999), the concept of dis/ability is both a multidimensional (Altman, 2001) and an "extraordinarily unstable category" (Davis, 1995, p. xv). For the purposes of this study, I maintain that people construct varied meanings about dis/abilities through talk, frequently drawing upon multiple cultural meanings and bodies of specialized knowledge. Further, I define dis/ability as situated and discursively constructed. With this study also drawing upon a social-relational model of dis/ability (Finkelstein, 2000; Reindal, 2008; Thomas 1999, 2001, 2004), I further defined dis/ability, along with all social phenomena, as non-neutral and potentially political, "understood to be woven through, and out of, cultural ideas and discursive practices" (Thomas, 2002, p. 49). Yet throughout this text, as I move within and across theoretical frames and empirical phenomena (Wodak, 1999), I attempt to highlight the presumed politic and power of dis/ability as it was made relevant by and with the participants. It is also important to note that I differentiate between impairment effects and the construct of dis/ability, with impairment effects referring to restrictions of activity (Thomas, 1999) (see Chapter IV for further discussion of concepts related to this study's theoretical framework).

4. *Discourse*: As this study employs a discursive approach that relies upon discursive psychology and the related poststructural understandings of discourse, it is important to define discourse within and across discursive traditions (see Chapter IV for a discussion of the notion of discourse in relation to this research study). First, I view discourse as action-oriented, which led me to focus primarily on what the discourse was *doing* within a given interaction. I presume that whenever we interact, verbally or nonverbally, we are engaged in some form of social action or activity (Drew & Toerien, 2011). Second, I view discourse as constructed and constructive. Subsequently, within this project, I considered the actual words and rhetorical devices employed within the participants' interactions, as well as how the discourse constructed a particular version of the world (Potter, 2004). Third, I considered discourse to be situated; thus, I understood psychological concepts as being bound up and embedded within interactions. With discourse understood to include varied forms of interaction (e.g., gesturing, apologizing, grinning, etc.), I presumed that discourse encompasses both verbal and nonverbal ways of sharing with another and/or oneself (Gilbert & Mulkay, 1984). Finally, while I often analytically maintained a more restricted notion of discourse, I also drew upon other discursive traditions when discussing the notion of discourse(s) (Potter & Hepburn, 2008), desiring to maintain a more inclusive and analytically useful definition of discourse (Howarth, 2010). At times, (e.g., Section I: The Historical Construction(s) of Autism in Chapter III), I oriented to discourse more broadly, attending to the institutionalized histories, discourses, and practices (Foucault, 1972) implicated in the construction and continual re-construction of autism. The term discourse(s), then, also

refers to broader discourses that make visible the institutionalized histories and practices that organize and socially bound what is said about a topic (Foucault, 1972). For example, the discourses of medicine, education, and childhood psychiatry are all implicated in how autism was/is made real and socially organized. Thus, as Foucault noted, discourses within the broader social process act to legitimate certain versions of the world, privileging and maintaining a given truth about the world/subject.

5. *Impairment Effects*: With impairment effects defined as restrictions of activity resulting from living with an impairment, I make a distinction between dis/ability and impairment effects. Thomas' (2004) seminal article points to the necessity of differentiating between impairment effects and dis/ability, viewing dis/ability as relevant only when restrictions of activity are socially imposed upon an individual with impairment(s). For example, an individual with an autism label may have a limited ability to verbally express himself. This limitation is an effect of the individual's impairment and does not indicate dis/ability, but may become "the marker for other restrictions of activity which do constitute dis/ability" (Thomas, 1999, p. 43). If the individual's "limited" verbal expression results in not being allowed to participate in social events with peers or to communicate through alternative means (e.g., communication device or facilitated typing), a dis/ability emerges. Thus, like Osteen (2008), I do not deny the bodily realities of impairment. Yet, like Tremain (2005), I acknowledge that if impairment is a prerequisite for disability, the distinction between disability and impairment is somewhat of a "chimera" (p. 10). So, throughout this study, I attended to how such "realities" were made relevant, dealt with, and negotiated within social practices.

6. *Institutions:* While difficult to define, institutions are commonly associated with certain technical practices and physical spaces/buildings (e.g., hospitals, clinics, schools, and courts of law). Though some theorists (e.g., Agar, 1985) have defined institutions as spaces that inevitably produce binary and asymmetrical roles (i.e., the institutional authoritative expert and the non-expert client), I do not orient to institutions as spaces in which the individual rights of the "less powerful" are inevitably and automatically "crushed" by the coercive and one-sided imposition of the powerful. Instead, similar to discursive psychologists Benwell and Stokoe (2006), I presumed that institutional spaces are bound up with power, yet argue that this institutional power is co-constructed and achieved through negotiation, persuasion, and, at times, consensus (Foucault, 1972; Tannen, 1987). As made relevant in the data, the participants' discursive practices were shaped and, at times, constrained by the social institutions, clinical setting, insurance demands, larger bodies of research or "proven" approaches related to autism, etc. Nevertheless, in this study, I oriented to institutional power and institutions themselves as "comprised of paradoxical, fluid and contradictory processes and practice" (Grant & Iedema, 2005, p. 49). Such a definition allowed me to analyze how the participants themselves make relevant institutionalized practices and moments of power.
7. *Institutional Talk/Institutional Interaction:* Interactional events that are considered institutional are those in which the "participants' institutional or professional identities are somehow made relevant to the work activities in which they are engaged," as well as the goals and purposes that may be specific to a particular setting (Drew & Heritage, 1992, p. 4). Institutional interactions often have characteristics that set them apart from

other everyday interactions, making them distinct and explicitly linked to the space in which they are produced (Drew & Toerien, 2011). I considered this study's talk, particularly the talk specific to the therapy sessions, to be institutional and part of the broader regime of "addressing issues" related to autism. Although the physical setting in which an interaction occurs does not determine the institutionality of talk, this study's site was particularly ideal for exploring institutional interactions between therapists and children with autism labels.

Delimitations

The following delimitations created the boundaries for this study, serving to limit its overall scope. First, while I do not argue for the dismissal of treatment/intervention or discredit the arguments occurring within the field of autism regarding effective interventions, it was not relevant to this study to consider whether the actual interventions and/or individual therapists were effective in treating the research participants with autism labels. Second, although I acknowledge the ongoing concerns regarding a "late or inaccurate diagnoses" of autism (Tomanik, Pearson, Loveland, Lane & Shaw, 2007, p. 921), for the purposes of this study, I was only interested in autism as made relevant in the everyday discourses and social practices of the participants. Third, I chose to interview the parents of the participating children rather than collect or analyze the diagnostic reports for each participating child. This allowed me to attend to what the parents, those who live and interact with the children with autism labels on a daily basis, made relevant about their child's autism label rather than simply the author of the diagnostic report. Viewing each interview as a conversational encounter (Potter, 2003), I

attended to what the parents made relevant, while recognizing that my questions were "just as much a topic of analysis as the interviewee's answers" (Potter & Wetherell, 1987, p. 165). Fourth, even though I collected 175 hours of conversational data from individual and group therapy sessions, for this project, I focused solely on the 70 hours of individual therapy session data, with the remaining group therapy session data being analyzed in a different, yet related study. Finally, I selected to collect data within only one context/site. In doing so, I recognized that within this study's methodological approach the sample size was dictated by the research questions, with "the success of a study…not in the least bit dependent on sample size" (Potter & Wetherell, 1987, p. 161).

Limitations

There is one primary aspect of this work that perhaps limits, by choice, the claims I make regarding my findings: a lack of generalizability. I do recognize that some discursive studies may position their claims as "generalizable actions performed by a rhetorical strategy" (Goodman, 2008, p. 268). Yet, I take up the concept of generalizability as that which is *produced* by the researcher rather than *discovered* through the research (Edwards, 1997; Potter, 1996). In other words, I assume that all scientists, whether engaged in qualitative or quantitative work, "traffic in versions, descriptions, theories…" of the world that are grounded in their epistemic and ontologic views (Edwards, 1997, p. 45). As such, in crafting my findings as generalizable or not, I considered my positionality (Aretxaga, 1997; Noblit, Flores, & Murillo, 2004; Tillman, 2002), as well as the discourse tradition in which I situated this study. I worked, then, to position my claims at the intersection of the everyday language practices of the

participants, my own cultural, political, and social situatedness, and the broader socio-political context. As I did so, I entertained, yet found no definitive response to, the "paradoxical notion of the universal as simultaneously impossible and necessary" (Butler, Laclau, & Zizek, 2000, p. 10).

Significance of the Study

Prior to delving into what I believe are three of the main ways in which my study contributes to the emergent body of literature that discursively examines dis/ability and institutional talk, I believe it is important to explicate how I make sense of the concept of "significance." Viewing the "significance" of this study as being discursively accomplished, as I actively participate in the making and remaking of this study's major claims (Kvale, 1995), I move away from the idea that I alone can definitively name that which is *most* fruitful within my work, knowing that I offer only one of many possible explanations (Potter & Wetherell, 1987). Thus, I view my findings as "instructive statements" that point the reader to key features within the discursive accounts and institutionalized practices that I believe would otherwise go unnoticed (Shotter, 1993, p. 34). In doing so, I invite the reader, and invited my research participants (Howarth, 2010) (see Chapter V for further details), to evaluate the significance of this work (Wood & Kroger, 2000), recognizing that at times "...the conversation between writer, reader and characters, should be allowed to wane before additional voices interject themselves into the dialogue" (Barone, 1995, p. 72). Situated within my acknowledgement that my way of making sense of the data will always be "partial and positional" (Noblit, Flores, & Murillo, 2004, p. 22), I present three ways in which I believe my study contributes to understanding how

autism, and dis/ability more generally, is performed and made relevant through situated discourse.

First, through analyzing therapeutic/intervention sessions in a discursive fashion, I believe I provide an alternative understanding of the "treating" and "doing" of autism. With most language within the field of autism presuming a medicalized and normative perspective (Biklen et al., 2005), this study shifted the gaze away from pathologizing the individual labeled with autism to considering the situated, discursive practices of those individuals who daily encounter the diagnostic label of autism. Tracy (1995) suggested that a fruitful study is one that is "implicative for the scholarly community," providing new and productive ways by which to "reframe old issues, create links between previously unrelated issues, and raise new questions that are interesting and merit attention" (p. 210). Thus, I propose that this work provides new ways to frame autism, opening up a space to consider how socially constructed notions of "dis/abled" and "normal" contribute to the production of individuals with diagnostic labels of autism.

Second, while recognizing the importance of the literature focused on how culturally and historically contingent discourses construct the notion of dis/ability, such literature has been critiqued for theorizing in a manner that is far removed from the situated practices of individuals who daily encounter or live with a "dis/ability" (Oliver, 1992; O'Reilly, 2005c; Rapley et al., 1998). Thus, this study's attention to the discursive practices of children with autism labels, as well as their parents and therapists, offers a differing perspective into how people manage, contest, and make relevant the meanings of autism, non-normative forms of communication, and the doing of therapy. With such a focus, I make explicit the varied ways in which autism and

therapy is performed through talk (both verbally and nonverbally), displaying how the performance of autism is accounted for and made relevant.

Finally, this study makes important methodological contributions, as conversational and discursive research focused on dis/ability is quite limited (Mehan et al., 1986; O'Reilly, 2004; Rapley et al., 1998). It is my hope that this work offers theoretical and analytical insights specific to discursive researchers investigating the constructs of autism and dis/ability.

Organization of the Text

In Chapter I, I presented the introduction to this study, outlining the purpose of the study, the research questions, the relevant definitions and terms, the delimitations and limitations, and the significance of the study. In Chapter II, I unpack the epistemic and ontologic presuppositions that I brought to this work, making transparent my positionality. In Chapter III, I include a literature review focused on the construction of autism in relation to those institutional histories, research traditions, and cultural representations that have shaped and continue to re-shape the present day discourses surrounding the "doing" and "performing" of autism. I draw upon literature from several traditions, including disability studies, anthropological understandings of dis/ability and the body, conversation analysis, discursive psychology, and to some extent poststructuralism. Chapter IV includes a description of this study's discourse analysis approach, and an explication of discursive psychology (Edwards, 1997; Edwards & Potter, 1993; Potter, 1996), poststructural understandings (Derrida, 1981; Foucault, 1971; Howarth, 2000), and aspects of conversation analysis (Sacks, 1992). Further, I briefly highlight the ways in which the social relational model of disability (Finkelstein, 2000; Reindal, 2008; Thomas 1999, 2001,

2004) informed how I oriented to the notion of dis/ability, highlighting some of the related literature.

Within Chapter V, I focus on outlining this study's methodological framework, delineating the underlying epistemic and ontologic assumptions, methods of data collection, and data analysis. I specifically describe the research approach I employed to examine the discourse data. In addition, I discuss how I gained access to the research site and selected the participants, along with the methods for warranting my claims and maintaining standards of quality. In Chapter VI, I present a thick description of the research site and the participants. Chapter VII focuses upon the findings primarily related to the parent and therapist interviews, and the first research question. Chapter VIII presents the analyses/findings focused on the second research question, drawing upon data from the therapy sessions and hallway/waiting room conversations. In Chapter IX, I discuss the implications of this work, make recommendations for future research, and put forth my overarching conclusions. Finally, constructed as the Epilogue to this text, I offer a response to the Prologue. Crafted primarily with the words of my participants, the Epilogue offers a counter-response to the Prologue, which was crafted with the words of some of the most influential autism researchers from the past (Asperger, 1944/1991; Kanner, 1943/1985) and present (Frith, 1989). I now turn to share my positionality, highlighting my role in the research process.

Chapter II: Positionality Statement

Throughout this text, I acknowledge my "role in making and remaking social science as we know it today" (Morgan, 1983, p. 376), and aim to make explicit the presuppositions I bring to this project. As a researcher, I position myself as a subject who is always negotiating, constructing, and reconstructing my multiple, intersecting social locations (Fine, 1994). I challenge objective and realists' notions of discursive research, and, in such challenging, locate the positionality of the researcher and the practice of reflexivity (Watt, 2007) as critical to the research process (Aretxaga, 1997; Pillow, 2003; Skeggs, 2002; Tillman, 2002; Walkerdine, Lucey, & Melody, 2002). I also assume, like postcritical ethnographers Noblit et al. (2004), that I "exist within a critical discourse that in part makes" me "responsible for the world" I am producing when I describe, interpret, and critique social phenomena of interest (p. 24). Thus, throughout this project, I turned back on myself, acknowledging the personal and political dimensions of my positionality and the intersectionality of my own identities (Crenshaw, 1991).

With my presuppositions influencing the ways in which I chose to represent the participants, data set, and findings, in this chapter, I attend to my positionality and acknowledge that my representations have consequences (Hall, 1997). My own histories, privileges, and political and moral commitments acted to shape this work; thus, I feel it is important to share, prior to presenting the literature, methods, or findings, what brought me to this project and why I desired to examine the construct of autism. Below, I share some of the ways in which I have come to this work and my epistemic and ontologic assumptions of relevance.

Chapter Overview

I begin this chapter by making explicit the professional commitments and personal beliefs that motivated me to pursue this work. Then, I share the epistemic and ontologic assumptions that I brought to this research, intending to make clear my role within the research process. Finally, I share how I engaged in recursive reflexivity, as well as how I worked to interrogate and be transparent about my positionality throughout this text.

Personal Commitments and Musings

With undergraduate degrees in cell biology and education, a graduate degree in special education, and a graduate certificate in autism spectrum disorders, I am certified and professionally prepared to work with children and adults with dis/ability labels. More specifically, with my professional knowledge focused on eliciting alternative modes of communication with children who are named "non-verbal" or "verbally challenged," my most recent professional work has been with children with dis/ability labels associated with "communicative challenges," particularly autism. By professional standards, I maintain the credentials and training required to identify and teach children with dis/ability labels. I have the power to label, name, and "fix" children with "abnormalities." In my daily, therapeutic work with children and adolescents with autism labels, I often struggle with and against my own desires to fix and render docile (Foucault, 1995) those who are named "abnormal."

When it comes to autism, these "abnormalities" are often linked to specific, visible behaviors. For instance, some people with autism labels might move their bodies in ways that are unfamiliar to me or others, touch an object repeatedly, or turn away when called upon.

Donnellan, Hill, and Leary (2010) suggested that professionals are frequently trained to see such behaviors as "autistic" and worthy of being "targeted...for reduction" (p. 1). Power, then, is often located in a class of skilled professionals, with these "credentialed experts" retaining "a sense of their validity by relying on tradition, deference to authority, and inherited privilege" (Brantilinger, 1997, p. 438). Becker (1963) noted that:

> ...social groups create deviance by making the rules whose infraction constitutes deviance, and by applying those rules to particular people and labeling them as outsiders. From this point of view, deviance is not a quality of the act a person commits, but rather a consequence of the application by others of rules and sanctions to an "offender." The deviant is one to whom that label has been applied; deviant behavior is behavior that people so label. (p. 9)

I am, at times, troubled by my own power and normatively-laced "ideological inheritance" (Kincheloe & Steinberg, 1993, p. 302), and have come to question the labeling of another person's way of being as "abnormal" or "deviant."

As a believer in the existence of multiple ways of making meaning (i.e., my way of understanding the world is not more real than that of another), I am unsettled by the suggestion that another's way of being is strange. For me, then, social norms and expectations are social constructs, with consequence. They are not universal laws that hold for all time, and are indeed open to critique and challenge. Yet, my belief that dis/ability is a social creation does not result in my denial of the existence of *real* biogenetic factors or impairments of some kind. However, I presume that ideas related to autism, or dis/ability in general, emerge from various sources and reflect power relations "between the defined and those who do the defining, and shift over time

and in relation to social and cultural context" (Biklen et al., 2005, p. 47). Further, I agree with Nadesan (2005) that people with autism labels often become:

> ...sites for the operations of complexes of institutional practices and bodies of knowledge...whose socially marked forms of otherness do not preclude their ability to love and desire, to make some sense of their world, and to seek to act upon it in ways that promote their sense of well-being. (p. 179)

With a niece and a very close friend diagnosed with autism labels, I am intimately familiar with the ways in which material institutions, professional identities, and cultural values work to frame and constrain the meanings of autism. Thus, as I engaged in this research, I assumed that autism, like any other phenomenon, is not knowable as objective truth, but is always open to interpretation. I question, then, those totalizing ideological horizons that work to deny the contingency and contestability of constructs such as autism (Howarth, 2000). For to me, autism is a list of behaviors that is only known as it is made relevant through discourse. The construct of autism and what counts as "intervention" does not rest at any level of static meaning, but performs instead a play, of signifiers, with shifting signification (Barthes, 1973).

In this study, I took up a disability studies perspective (Barnes, Oliver, & Barton, 2002), orienting to the disabling effects of impairments as located in culture rather than solely being a natural consequence of impairments. While I do not deny that impairments exist, I do suggest that dis/abilities are always lived and performed in and through the discursive positioning of self and others, social and environmental arrangements, and technologies available within a given context (Lewiecki-Wilson, 2003; Osteen, 2008). I do not argue for a dismissal of "treatment," but instead suggest that in lieu of simply accepting autism as that which is equivalent to a list of

symptoms, we, as community members, should strive to ask how such a "condition" came to be regarded as a condition and work to understand and learn how to acknowledge and accommodate for differences. Donnellan, Hill, and Leary (2010) noted that in the professionalization of the "interactions with people with autism, we have trained professionals, parents and others to interpret what happens in terms of simple, binary views of behavior (i.e., good/bad or positive/negative)" (p. 2). With an over focus on targeting and reducing these presumably inappropriate behaviors, "the solutions (which) lie in social and political transformation, architectural and technological redesign" have been largely ignored (Potok, 2001, p. 162). Like Donnellan et al. (2010), I suggest that meaningful, respectful, and useful supports/interventions "require a deep and local knowledge of the individual" with an autism label (p. 15). Further, intervention must extend beyond fixing and rendering docile (Foucault, 1995), aiming instead to accommodate or adjust interactions, tasks, and environments in order to support others in working around and with impairments (Donnellan, Leary, & Rebledo, 2006).

Over the last eight years, I have engaged in frequent, almost daily conversations with adults and children with dis/ability labels who have continually questioned my taken-for-granted assumptions and reminded me that "when you understand people, when you have committed to them, and when you have learned from them, you advocate for them…where advocating means trying to promote their world view as reasonable" (Noblit, 1999, p. 8). These interactions and unfolding friendships have taught me that the legitimation of the dominant culture's view of what successful functioning looks like is partly "marked by acquiescence and consent" (Charlton, 1998, p. 34); thus, it falls upon me, as a community member, to challenge and question how typical and atypical behaviors come to be taken-for-granted truths. Further, I argue

that the goal of intervention should not be to "fix" the individual with an autism label, but rather to collaboratively work to find comfortable and effective ways to increase participation with each other (Donnellan et al., 2010). As Sinclair (1992), who identifies as autistic, suggested:

> If you would help me, don't try to change me to fit your world. Don't try to confine me to some tiny part of the world that you can change to fit me. Grant me the dignity of meeting me on my own terms...recognize...that my ways of being are not merely damaged versions of yours. Question your assumptions. Define your terms. Work with me to build more bridges between us. (p. 302)

It is from this committed and, at times, troubled place that I engaged in this study. From a place of commitment to individuals with autism labels, I recognize anew that I have never been named autistic, learning dis/abled, handicapped, etc. Instead, I daily take up many social categories laced with privilege. Thus, as a researcher, practitioner, friend, and aunt to individuals with dis/ability labels, particularly autism labels, I am learning daily to continually reflect on how I manage, contest, and make relevant the identities, minds, and selves of others.

Certainly, my positionality does not stand still and is indeed subject to critique, as I continue to ask: What role does my discourse play in making the representation of autism visible or invisible for those within my community of practice? How do my words as a researcher participate in reifying potentially oppressive notions related to individuals with socially constructed labels, such as autism? Situated within my hope that this research serves to question taken-for-granted representations that function to spectacularize, essentialize, and pathologize autism, the above questions informed each step of this work.

Epistemic and Ontologic Assumptions

Throughout this study, I took up a social constructionist position (Berger & Luckmann, 1967; Woolgar, 1988) that drew upon the anti-foundational and poststructural roots of discursive psychology (Potter & Hepburn, 2008). At the center of this position, I remain intrigued by the ways in which discourse acts to constitute the social world (Phillips & Hardy, 2002). Viewing discourse as being non-neutral and co-produced in situated interactions (Wetherell, 2001), I take up discourse as a social practice by which reality is constructed (Potter, 1996; Potter & Wetherell, 1987). Alongside my claim regarding the non-neutral, political nature of language, within this study, I attended to issues of power and dis/ability as they were made relevant in the discursive practices of the participants. With the site of this study centered on the participants' descriptions, claims, and assertions, the focus of knowledge production stayed close to the discourse itself.

Instead of assuming that a world actually exists and waits to be discovered, I prefer exploring "how the socially produced ideas and objects that populate the world were created in the first place" (Phillips & Hardy, 2002, p. 6). As Pauly (1991) noted, humans do not "discover reality...they use symbols to construct the world in which they live. In this view, reality is an accomplishment rather than an entity out there, waiting to be uncovered" (p. 2). To me, then, reality is something that is constructed by a given community, with language acting as the mediator for the construction of that reality. With such, I believe that my view of reality or truth is only one of many views or truths. I do not suggest that my understanding of what is real is more true than another person's version of what is real; rather what is real or true only arises in locally-constructed and occasioned discourses (Edwards, 1997).

Maintaining Reflexivity

With both the researcher and the researched viewed as active producers of knowledge, throughout this study, I engaged in recursive reflexivity and maintained a stance that resulted in "exploring and illustrating rhetorical constructions through analyzing one's own analysis" and evolving interpretations (Potter & Wetherell, 1984, p. 184). I worked, then, to decenter "my unreflexive self," in hopes of creating, as Richardson (1997) stated, "a position for experiencing the self as a sociological knower/constructor" (p. 153). This reflexive stance was not one that resulted in "a comfortable, transcendent end-point," but instead left me with "the uncomfortable realities of doing engaged qualitative research" (Pillow, 2003, p. 193). As I navigated through these uncomfortable realities, I oriented to writing as a means of inquiry (Ellis, 2004; Goodall, 2000), allowing for outside readers to consider the ways in which I worked through my own beliefs and taken-for-granted assumptions. This recursive reflexivity worked to layer my understandings of the data and the theories which informed my data collection and analysis process.

Throughout this study, I maintained a research journal, chronicling my struggles with, and at times against, my own assumptions regarding the meanings and performances of autism. Through this journaling, I intended to critically reflect upon my research decisions and routinely make note of my analytic and theoretical ideas. Situated out of and within this reflexive space, I aimed to remain aware of my own tendencies to project my beliefs, assumptions, and theoretical perspectives upon the data. I stored this journal on a password protected blog site (http://reflexiveresearcher.blogspot.com/), inviting committee members and a colleague engaged in similar methodological work to view and respond to my posts. From July 2009 to September

2010, I made 107 posts, with the majority of the posts being made during the data collection process (May 2010 to August 2010). I engaged in a series of interchanges with individuals who offered insights and posed questions related to my posts. As I began more intensive analysis of the data (September 2010 to February 2011), I transitioned my journaling to a memo format within the Atlas.ti™ software package (see the "Data Analysis" section in Chapter V), allowing me to link my journaling more explicitly to the data set and analysis process.

As I spent time engaging in reflexively writing about my hunches, questions, concerns, and initial interpretations surrounding this work, there were indeed moments in which I felt alienated and distanced from my initial presupposed theoretical ideas. In these moments of theoretical distance, I acquired new and at times surprising insights. My understandings about the construct of autism, notions of therapeutic intervention, and discourse theory itself have now been complicated. For example, I came to this work believing, perhaps naively so, that dis/ability labels threaten one's identity. My understandings were simplistic, and even a bit monolithic. Now, these understandings are complicated, layered, and certainly still unfolding.

For me, these shifts in understanding were always informed by my positionality and made explicit as I engaged in reflexive research. Thus, throughout this text, I share relevant entries from my research journal, in hopes of making clear to the reader that I am/was always present in this work, while also making visible the ways in which I interrogated my positionality as I interacted with the participants, made sense of the data, and employed specific theories and methodologies of choice.

Chapter Summary

In this chapter, I first make explicit my positionality, highlighting those professional and personal commitments most relevant to this work. Second, I described the epistemological and ontological assumptions that I carried to this study. Finally, I presented one of the ways in which I engaged in recursive reflexivity, as well as how I hoped to make visible my positionality throughout this text. In the next chapter, I present a history of the construct of autism and describe and critique the literature related to this study.

Chapter III: Review of the Literature

The purpose of this research was to examine how autism is performed, made relevant, and contested within interactional events between children with autism labels, the therapists who work with them, and their parents. Orienting to dis/ability as constructed through talk-in-interaction, I considered how the concept of autism/disability was constructed and made sense of by individuals who experienced it on a daily basis. While viewing autism as embedded within everyday practices, I also acknowledge that as a "twentieth-century disorder" (Nadesan, 2005, p. 29), autism is always already situated within a broader social history of specific disciplinary knowledges and institutional histories that contribute to the making and re-making of the construct of autism (Rocque, 2007). As such, within this literature review, I attend both to research specific to this project's goals, and to the key historical texts displaying the varied meanings of autism.

It is important to acknowledge that my own history and political commitments, as discussed in Chapter II, act to shade the lens through which I interpret and represent the institutionalized discourses, histories, and practices that sustain particular "truths" (Foucault, 1972, 1980) regarding autism. Throughout this text, I worked to maintain reflexivity about my own knowledge production (Hertz, 1997), recognizing that my representation has consequences (Hall, 1997). For, as Edwards (1997) noted, "discourse is primarily what we produce, we academics, researchers, and writers of books on cultural (and other) psychologies. We traffic in versions, descriptions, theories…" (p. 45). I acknowledge, then, that I present only one of many possible interpretations and explanations regarding the history of autism and related empirical

studies, and choose not to view my own interpretation of the varied theoretical and empirical studies as a neutral and realist explanation.

Chapter Overview

This chapter is divided into two primary sections. Section I provides an overview of the historical construction of autism, presenting the seminal writings of Kanner (1943/1985) and Asperger (1944/1991), as well as others. Through the consideration of these landmark writings, I point to the institutional histories that have contributed to the ways in which autism has been predominately defined and researched. Section II reviews the empirical studies situated within qualitative methodologies. Within this section, I review literature around the firsthand accounts of individuals with autism labels and their parents, overview the relatively small number of ethnographic studies focused on the construct of autism, and review related literature that attends to the conversational and discursive practices of individuals identified with autism. Prior to delving into the historical construction of autism, I first describe the search methods I used for reviewing the relevant literatures.

Search Methods

From 2007 to 2010, I engaged in a series of literature searches that allowed me to (1) explore the theoretical and seminal writings that highlight the varied cultural, historical, and biogenetic arguments made in relation to autism, as well as the associated institutionalized practices; (2) identify the relatively few qualitatively-oriented research studies that focused on autism; (3) locate articles, texts, and empirical studies explicating my theoretical frameworks; (4)

contact those frequently cited scholars whose work theoretically, methodologically, and/or substantively related to this project; and (5) systematically delimit my search process. Recognizing that autism is one of the most prolifically researched childhood phenomena (Wolff, 2004), and that it is viewed by some as a cultural obsession (Broderick & Ne'eman, 2008; Osteen, 2008), I was not surprised that preliminary searches resulted in well over 6,000 citations on "autism." Thus, I realized early on in the search process that delimiting the search was essential.

In determining which articles were pertinent to this review, I utilized four approaches. First, I searched six education and social science databases (PsychInfo, ERIC, Academic Search Premier, Education Full Text, Dissertation Abstract, and Web of Science), using key words such as "autism and discourse," "parents and children with autism," "history of autism," "autism and conversational analysis," and "autism and (speech, occupational, physical) therapists." A variety of other key words were paired with these aforementioned key words, including "discourse analysis," "discursive psychology," "identity," "experience," "disability studies," "disability theories," "social model of disability," and "social relational model of disability." Further, in that this study draws upon research from multiple disciplinary contexts, including sociology, I searched social science databases with the same key words (Social Sciences Abstracts and Sociological Abstracts/Sociofile CSA). Since literature on autism spans only 60 years, I selected not to limit my search by years, hoping to locate all of the seminal writings. I also checked the number of times Web of Science cited articles relevant to my study, hoping to locate the most prominent researchers and salient articles. The field of autism is dominated by medicalized

approaches to interpreting autism; therefore, I infrequently identified researchers who were engaged in relevant discourse-oriented research.

The second method I utilized was searching the reference lists from the articles and texts I located during my initial searches. I then developed a list of the key handbooks and texts outlining the evolution of autism as a dis/ability label. Many of the texts outlining the evolution of dis/ability theories referenced a computerized, publicly available archive developed at the University of Leeds, termed The Disability Studies Archive UK, Centre for Disability Studies (http://www.leads.ac.uk/disability-studies/archiveuk/index.html). I thoroughly searched this database, which included difficult to find articles and historical documents no longer in print. I also created a list of key handbooks and texts specific to one of this study's theoretical and methodological frameworks, discursive psychology (Edwards, 1997; Edwards & Potter, 1993; Potter, 1996). Many of the discourse-related texts referenced a publicly available site describing the work of the most frequently cited researchers in the Department of Social Sciences at Loughborough University, UK, termed Discourse and Rhetoric Group (DARG) (www.lboro.ac.uk/departments/ss/centres/darg/dargindex.htm). I thoroughly searched this database, locating seminal articles.

Third, as I searched the literature, I contacted many of the most frequently cited authors via email. Specifically, from June 2008 to August 2008, I conversed with sociologists Thomas, Reindal, and Shakespeare regarding their perspectives on the most relevant studies and theoretical papers focused on understanding dis/ability from a social, cultural, and historical perspective. From May 2009 to November 2009, I conversed with Hepburn, Potter, Edwards, and Antaki, all discursive psychologists from Loughborough University in the United Kingdom.

These researchers responded by sharing additional theoretical papers focused on discursive psychology, or discourse research in general. Through them, I was directed to Michelle O'Reilly at the University of Leicester, who greatly assisted me in identifying related research occurring within European contexts (October 2009).

Finally, for the purposes of this study, I only incorporated texts, articles, and dissertations that specifically related to this project. In total, I located two related dissertations, eight seminal texts, over 20 more broadly related texts, and well over 100 articles. I selected to include/review only those that: (1) assisted me in presenting the historically and culturally contingent nature of autism; (2) attended to the application of discourse research within the field of autism; (3) provided historical insights into the evolution of autism and dis/ability theories in general; and (4) qualitatively considered the experiences of parents of children with autism labels, as well as the children/adults with autism labels. In doing so, I desired to move beyond the many bodies of literature situated within medical and/or deficit models of autism. Nevertheless, when exploring the historical construction of autism as a diagnostic category, I drew upon many of the more medically-oriented seminal writings and research studies that have shaped and continue to re-shape autism.

Section I: The Historical Construction(s) of Autism

In this first section, I begin by presenting the reader with a brief history of autism as a diagnostic category, highlighting the historical and political conditions through which the construct of autism was made possible. I first discuss the rise of the concept of "normal," highlighting how the advent of concepts such "normality" and "pathology" created new ways for

professionals to identify, label, treat, and even seclude individuals viewed as different. I next describe the seminal writings that have historically framed the cultural meanings of autism. As I do so, I point to the ways in which the emergence of *autism as pathology* has been embedded within particular institutional histories and discourses. I then move to the present-day conceptualizations of autism, pointing to the varied definitions and metaphors that have come to represent a person with an autism label. I conclude this section by describing how the histories and assumptions that act to (re)shape the meaning of autism have influenced how autism is studied today.

To frame the upcoming section, the words of Hayakawa (1957) provide insight into how I make sense of the construct of autism or any other dis/ability label:

> The question, "What is it really?" "What is its right name?" is a nonsense question...one that is not capable of being answered...the individual object or event we are naming, of course, has no name and belongs to no class until we put it in one...what we call things and where we draw the line between one class of things and another depend upon the interest we have and the purposes of the classification. (pp. 115-116)

Thus, as I present the landmark events/writings prior to and after the emergence of autism as a diagnostic category, I attend to the commitments of the key figures within the history of autism. Furthermore, as I recount the history of autism, I acknowledge that I am not capable of isolating all of the intersecting contexts that have contributed to the production of autism (White, 1978). Thus, I offer the paragraphs below as one of many possible interpretations of the history of autism, choosing not to view my own interpretation as neutral, realist, or complete.

Before the category of autism. Embedded within a matrix of institutional and professional discourses, autism was constructed in the 1940s as a diagnostic category. With several overlapping institutional histories, discourses, and persons implicated in the creation of autism as a diagnostic category, I avoid representing the history of autism as a chronological list of events. Instead, I attempt to highlight the complex and varied discourses that have enabled its production (Nadesan, 2008). I begin this historical re-telling by briefly describing how the advent of the concepts of "dis/ability," "normality," and "pathology" engendered new ways for professional bodies and society at large to identify and label those viewed as different (see Braddock & Parish, 2001, for a complete history of dis/ability). With individuals labeled with autism only named "autistic" due to their presumed deviation from "the ordinary way" (Kanner, 1943/1985, p. 50), it is important to consider when the concept of an "ordinary" or "normal" way of being initially appeared within the social landscape.

Within many of the oldest historical documents, there are descriptions of people with physical impairments and/or behaviors that today would be identified as a dis/ability (Braddock & Parish, 2001). Bodily differences have been noted throughout many societies, yet the meanings of such differences have varied across time, space, and place. For instance, in ancient Greece, children born with "deformities" were viewed as being a sign that the gods were displeased; most of the "deformed" children became victims of infanticide (Woodill & Velche, 1995). It was not until the advent of industrialization that the notion of dis/ability appeared. In fact, the word "normal," as signifying that which does not deviate from a norm, rule or principle, did not enter the English language until 1840. Prior to this time, the root word "norm" referred to a carpenter's square, with "normal" meaning "perpendicular" (Davis, 1995). As Davis noted:

> ...the social process of disabling arrived with industrialization and with the set of practices and discourse that are linked to late eighteenth- and nineteenth-century notions of nationality, race, gender, criminality, sexual orientation, and so on...the very term that permeates our contemporary life—the normal—is a configuration that arises in a particular historical moment. It is part of a notion of progress, of industrialization, and of ideological consolidation of the power of the bourgeoisie. (p. 24, p. 49)

Thus, the contemporary understanding of "normal" is embedded within eighteenth and nineteenth century discourses and practices. More particularly, during the 1830s there was a growing interest in statistics, with the notion of a standard, bell-shaped curve coming to represent the idea of a majoritarian "norm." With a "norm" symbolizing the "average man," Davis (1995) suggested that a "middle way of life" became justified and reproduced through the discourses emerging from the public fascination with statistics (p. 26). Through such justifications, the bourgeoisie were positioned as the "mean," with the majority of the population presumed to fall within this normative range (i.e., the central arch of the curve).

Furthermore, the construct of "normal" was only made possible by comparing the object of one's study to something else. The very construction of a dis/ability presumed "that the person with disabilities is in some sense damaged while the observer is undamaged" (Davis, 1995, p. 14). It is within this comparative framework that the "pathological" or "deviant" body materializes. Canguilhem (1989) suggested that "normal" is always compared to that which is constructed as "pathological," with the two constructs being mutually constituted. He stated that "every conception of pathology must be based on prior knowledge of the corresponding normal state" (p. 51), for "this normal or physiological state is no longer simply a disposition which can

be revealed and explained as fact, but a manifestation of an attachment to some value" (p. 57). Therefore, through a priori standards that were situated within culturally and historically contingent values and practices, that which counted as "normal," "dis/abled," or "pathological" was constituted.

More specifically, for Europe and North America, rapid industrialization, coupled with the medicalization of society, resulted in standards of normative development and behavior often situated within the discourses and practices of the discipline of psychiatry, with psychiatry itself an advent of the nineteenth century (Shorter, 1997). As Foucault (1995), a student of Canguilhem, noted:

> The power of the Norm appears through the disciplines...Let us say rather that, since the eighteenth century, it has joined other powers—the Law, the Word (*Parole*) and the Text, Tradition—imposing new delimitations upon them...normalization becomes one of the great instruments of power at the end of the classical age. For the marks that once indicated status, privilege and affiliation were increasingly replaced—or at least supplemented—by a whole range of degrees of normality indicating in a homogeneous social body but also playing a part in classification, hierarchization and the distribution of rank. (p. 184)

With the nineteenth century psychiatric standards and nosological frameworks greatly influencing the construction of autism, I now turn to explore some of the key psychiatric beliefs and "discoveries" that contributed to the emergence of autism in the twentieth century. I also point to the ways in which psychological and educational discourses and practices served to build the interpretive frameworks needed in order to name certain behaviors autistic.

(Re)considering the seminal texts. The two most prominent figures in the history of autism are Leo Kanner (1894-1981) and Hans Asperger (1906-1980). Despite the fact that Kanner's seminal article, "Autistic Disturbance of Affective Contact," was published only one year prior to Asperger's 1944 doctoral thesis in which he described children with what he named an "autistic psychopathy," the two psychiatrists were unfamiliar with each other's work. With Kanner's work based at Johns Hopkins in Baltimore and Asperger's work housed in University Children's Hospital in Vienna, the two men never met. Although both men are credited for their contributions to child psychiatry, Kanner's work, written in English, has received far more attention (e.g., at present, Kanner has been cited 4,047 times). In fact, Asperger's work, written in German, has not been widely translated, thus receiving far less attention (e.g., at present, Asperger has been cited 909 times) (Wing, 1981). It has been suggested that "Kanner was the father of autism as a diagnostic category," while "Asperger was the father of the concept of the autism spectrum" (Grinker, 2007, p. 59).

Viewing the emergence of autism as embedded within particular institutional histories and discourses, I do not view Kanner's and Asperger's descriptions of "infantile autism" as neutral and ahistorical accounts. Instead, I view the early constructions of autism as situated within and out of certain disciplinary practices and discourses. Thus, as I present relevant excerpts from the seminal texts, I attempt to link their understandings to the broader discourses of their day (particularly for Kanner). Further, as I represent and analyze seminal writings around autism, it is my intention to highlight how these particular writings were produced and consumed, emphasizing their social and political impact.

Kanner. Although Kanner is credited for coining the term "autism" as a diagnostic category, it was Eugene Bleuler (1857-1939) who first used the term in 1908 and again in 1911 to describe what he viewed as one of the primary psychological symptoms of schizophrenia. Bleuler used the term autistic to explain his "psychotic" patients' proclivity to withdraw into a world of fantasy (Alexander & Selesnick, 1966). He believed that the "schizophrenic autistic" experienced a separation from reality, resulting in affective disassociations and a disintegration of personality. With much writing and debating about schizophrenic autism occurring within psychiatry circles during the 1920s and 1930s, it is not surprising that both Kanner and Asperger elected to use the term "autism" to describe the children they viewed as affectively withdrawn.

In addition to the influences of the psychiatric discourses specific to schizophrenic autism, the institutionalized segregation of people deemed "mentally ill" (Foucault, 1965), as well as the increase in the social surveillance of children with the advent of compulsory education, engendered the necessary social conditions for the creation of autism (Nadesan, 2008). Although a full review of the many distinct yet overlapping disciplinary histories is beyond the scope of this chapter, it is important to recognize that a multitude of institutionalized practices, originating in the nineteenth century in particular, contributed to the production of autism. For example, Kanner's and Asperger's very studies of children were embedded within the vast history of the emergence of childhood as a qualitatively unique social stage with "abnormal" and "normal" forms of development (see Aries, 1962, *Centuries of Childhood* for the complete history). Although I confine much of this discussion to the nineteenth and twentieth centuries, I acknowledge that the historical timeline is quite extensive. For example, in the 1600s, Locke suggested that children were likely qualitatively different than their adult

counterparts. Further, the formalization of public and private education for children in Europe and North America in the nineteenth century "demanded the creation, codification, and distribution of standards of normality" (Nadesan, 2008, p. 61).

Situated within the public and professional discourses surrounding the "deviant" child and normative views of development (Piaget, 1924/1928), Kanner (1943/1985) published his seminal article describing the 11 children he examined at Johns Hopkins, displaying what he believed was a "unique 'syndrome,' not heretofore reported" (p. 41). Although he drew upon Bleuler's description of schizophrenic autism, Kanner believed that the children he saw were not "feebleminded" or "schizophrenic," but instead had what he termed infantile autism. He suggested that the children's fundamental issues were their:

> ...*inability to relate* themselves in the ordinary way to people and situations from the beginning of life. Their parents referred to them as having always been "self-sufficient;" "like in a shell"; "happiest when left alone"...This is not, as in schizophrenic children or adults, a departure from an initially present relationship; it is not a "withdrawal" from formerly existing participation. There is from the start an *extreme autistic aloneness* that, whenever possible, disregards, ignores, shuts out anything that comes to the child from the outside. (p. 41)

Further, describing the children as exhibiting "delayed echolalia" (p. 43), "excellent rote memory" (p. 42), and an "anxiously obsessive desire for the maintenance of sameness" (p. 44),

Kanner, like most in his discipline, constructed autism as a deficit, while also maintaining that some children with autism were quite intelligent.[8]

It is also important to note that of the 11 children in Kanner's study, three were female, all were white, five were described as having enlarged heads, and three were identified as being nonverbal. Although Kanner did not suggest a causal relationship between the parents' dispositions and the child's autism, his value-laden description of the children's parents were quite telling (Waltz, 2005). Kanner (1943/1985) concluded:

> In the whole group, there are very few really warmhearted fathers and mothers. For the most part, the parents, grandparents, and collaterals are persons strongly preoccupied with abstractions of a scientific, literary, or artistic nature, and limited in genuine interest in people. Even some of the happiest marriages are rather cold and formal affairs. Three of the marriages were dismal failures. The question arises whether or to what extent this fact has contributed to the condition of the children. (p. 50)

So, it was with Kanner's descriptions of the 11 children and their parents that an official discourse surrounding autism started to evolve. Kanner's version of truth regarding autism implicitly and explicitly linked autism to certain social and economic norms and parenting styles (see Simpson and Quinn, 2006, *PBS* documentary "Refrigerator Mothers" for an exploration of the effects). Further, the claims of autism as innate to the individual captured the public and professional imagination, driving much of the research that ensued. Yet even with the term

[8]Since Kanner (1943/1985) used the word "intelligence" in his original writing, I incorporate it when describing his beliefs about the 11 children he examined. However, in using it, I acknowledge its varied and socially-constructed nature. Further, over the last 60 years, autism has become increasingly associated with incompetence and intellectual dis/ability (Biklen et al., 2005). Thus, with a desire to avoid the reification of the notion of "intelligence" as real, I use the word with caution.

"infantile autism"[9] entering the psychiatric nomenclature by 1944, for many years to come, much to Kanner's dismay, the new disorder's official name remained "schizophrenia childhood type" (Grinker, 2007).

Asperger. Even though Hans Asperger's (1944/1991) research with the four children he identified as having an "autistic psychopathy" is recognized as seminal, his study is considered far less systematic than Kanner's (Wolff, 2004). Nevertheless, the way in which Asperger described the four children he examined makes visible his contribution to the construction of autism. He reported that the children had a tendency to use peripheral vision, maintained an obsessive need to keep objects in a particular order, and exhibited inattention. For Asperger, these four children possessed a "genuine defect in their understanding of the other person," and displayed "no real love for anybody" (1944/1991, p. 81, p. 40). Thus, similar to Kanner, he attended to the perceived social differences of the children. Yet, in comparison to Kanner's 11 cases, Asperger's patients were all described as being highly verbal and intelligent, while also having a tendency to talk extensively about a unique subject of interest. Lorna Wing, a British autism researcher, introduced Asperger's work to the English-speaking world in 1981, changing the term "autistic psychopathy" to "Asperger's Syndrome." It was not until Wing's 1981 publication that Asperger's work became better known and researched within the medical community, being recognized by some as related yet distinct from what Kanner had described as infantile autism. Popularly called "The Little Professor Syndrome" (Osborne, 2000), Asperger's Syndrome emerged as a less severe form of autism. Ultimately, it was Asperger's work that was

[9]"Infantile autism" was also referred to as "Kanner's Syndrome."

used to justify the construction of a "spectrum" of related but unique syndromes ranging in severity.

Building on the work of Kanner and Asperger. Alongside the work of Kanner and Asperger, a multitude of medical researchers and clinicians contributed to the construction of autism. Each contribution was not without material consequences. This was particularly true for the work of popular psychologist, Bruno Bettelheim. Building upon the work of Kanner, Bettelheim (1903-1990) gained international fame for his view regarding the cause of autism. Coining the phrase "refrigerator mother," Bettelheim suggested in his book, *The Empty Fortress* (1967), that autism was caused by an emotionally distant, cold, and ambivalent parent. He claimed that "...the precipitating factor in infantile autism is the parent's wish that his child should not exist" (p. 125). As a holocaust survivor himself, Bettelheim also suggested that the world of the autistic child was analogous to a Nazi concentration camp. With the popularity of the book, the notion that "refrigerator mothers" cause autism became widely accepted in popular culture and to some extent within academic circles.

Bernard Rimland, a psychologist, medical researcher, and father of a son with a label of autism, was the first to mount a critique of Bettelheim's work, while also offering an alternative explanation for the cause of autism. In his seminal text, *Infantile Autism* (1964), Rimland claimed that autism was not caused by external forces, but instead was biological in origin. He supported this claim by pointing to the many autistic children born to parents who were not "cold" (Bettelheim, 1967) or "limited in genuine interest in people" (Kanner, 1943/1985, p. 50). Among other points, he noted that many of the siblings of children with autism labels do not have autism. While Rimland's counterclaims served to weaken the common practice of parent-

blaming during the 1960s and 1970s, Osteen (2008) suggested that "covert parent-blaming endures throughout contemporary autism literature (as well as in autistic people's actual families)" (p. 11). In her seminal work, Happe (1994) offered what autism "is" and what it "is not," providing a clear presentation of many of the assumptions that have shaped the field since the questioning of Bettelheim's work:

> Autism is *not* caused by "refrigerator parenting." Autism is a biologically based disorder. Autism is *not* confined to childhood. Autism is a developmental disorder which lasts throughout life. Autism is *not* always characterized by special, or "savant," skills. Autism is found at all IQ levels, but is commonly accompanied by general learning difficulties (mental handicap). Autism is *not* just a "shell" within which a "normal" child is waiting to get out. Autism is a severe disorder of communication, socialization and imagination. (p. 6)

Ignoring the social and cultural processes involved in identifying and labeling an individual with autism, the above definition captures the pervasive ontological views of autism as a stable reality. Despite such realist descriptions of autism, there remains a lack of consensus among experts regarding what autism really is. A prime example of this is noted in the unstable and often contested psychiatric criteria used to diagnose autism.

Contemporary trends and understandings. Despite the prolific clinical work around autism since Kanner's 1943 publication, it was not until 1980 that the American Psychiatric Association incorporated the criteria for the diagnosis of autism within the *Diagnostic Statistical Manual of Mental Disorders* (DSM) (American Psychiatric Association, 1980). Since that time, autism has remained within the diagnostic manual (under Pervasive Developmental Disorders),

with expansive changes to the criteria being made over the last 15 years. The most recent edition of the manual includes three categories for what is commonly called autism spectrum disorders. The categories include the following: Autistic Disorder (entered manual in 1994), Pervasive Developmental Disorder-Not Otherwise Specified (PDD-nos; entered manual in 1987), and Asperger's Disorder (entered manual in 1994). Half of the 16 criteria must be met for an individual to be professionally considered "autistic" (see Appendix A), with a diagnosis of Asperger's Disorder requiring that only two-thirds of that half be met (Gernsbacher, Dawson, & Goldsmith, 2005). A diagnosis of PDD-nos is applied when behaviors are interpreted as being "subthreshold symptoms" (Gernsbacher et al., 2005).

The assumption that there is a "lesser variant of autism, together with the recognition of autism in children with normal intelligence" (Fombonne, 2003, p. 504), most likely contributed to the proliferation of autistic disorders. Despite what seems like an extensive classificatory system, many researchers within what is now referred to as a "field of autism," suggest that the scientific taxonomies for autism remain in flux (Rosenberg, Daniels, Law, Law, & Kaufmann, 2009, p. 1099). There exists great controversy and inconsistency regarding diagnosis. For instance, Mayes and Calhoun (2004) reported a lack of evidence for the DSM's most current rendition of Asperger's Syndrome as being distinct from Autistic Disorder. Further, Sanders (2009) suggested that Asperger's Disorder and the Autistic Disorder are not qualitatively distinct, but are instead "different quantitative manifestations of the same disorder" (p. 1560).

Although it is beyond the scope of this research project to review the large body of literature displaying the lack of consensus among clinical researchers of autism (e.g., Gillberg &

Ehlers, 1998; Hooper & Bundy, 1998; Szatmari, 2000), I argue that this "lack of consensus" points to the socially constructed nature of scientific knowledge. As Gergen (1985) noted:

> The degree to which a given form of understanding prevails or is sustained across time is not fundamentally dependent on the empirical validity of the perspective in question, but on the vicissitudes of social process (e.g., communication, negotiation, conflict, rhetoric)...'what counts as what' is inherently ambiguous, continually evolving, and free to vary with the predilections of those who use them. (p. 268)

Thus, with the "reality" of "what counts" as autism extending its boundaries to include more and more children over the last 60 years, the prevalence of autism cases has not surprisingly escalated.

With the Center for Disease Control (2009) reporting that one in 110 children born in the United States will be diagnosed with some form of autism, major media outlets have reported on what is constructed as "a mysterious upsurge" of epidemic proportions ("A Mysterious Upsurge in Autism," 2002). Yet many leading figures within the field of autism suggest that there is no such epidemic, attributing the increases in diagnosis to the broadening of diagnostic criteria and greater public awareness (Frith, 1989; Gernsbacher at al., 2005). Regardless of the ongoing debates, the construct of autism remains the most prolifically researched of all child psychiatric disorders (Wolff, 2004). With the vast majority of the field's research focused on identifying the etiology, neurological differences, genetic markers, and "appropriate" treatment approaches, autism is often assumed to be an ahistorical and "real" entity. Further, the dominant models of research in autism are quasi-experimental and situated within medically-oriented frameworks, often serving to reify the notion of autism as solely biological.

Biklin (2005), a scholar in the field of disability studies who studies inclusive practices and the life narratives of adults with autism labels and other dis/ability labels, pointed to the contradictory understanding of autism, suggesting that perspectives on autism range from an "autism-inside-the-person" viewpoint to more fluid, culturally situated notions of autism (p. 35). From his perspective, the dominating contemporary perspective is that of "autism-inside-the-person," with the majority of "experts" in autism viewing autism as neurologically-based and internal to the individual. For instance, constructing autism as being primarily internal to the child, Trevarthan, Aitken, Papoudi, and Robarts (1998) stated that the "primary cause of autism is related to the 'instructions' for brain development that control the way a child's mind grows and learns from experience" (p. 4). These researchers further suggested that most individuals with diagnostic labels of autism have "marked deficits in attention and intelligence" (p. 2), with "the core of their motivation for relating to other persons" being "'absent' or inaccessible" (p. 3). Biklen et al. (2005) noted that the commonly made assertion that particular neurological differences produce certain "autistic" behaviors remains elusive, yet is rarely acknowledged by researchers as such. The majority of autism-focused research represents autism as being "natural" and "physiological," i.e., a biologically-based, neurological disorder in origin, yet "proof" is not required in making such claims (Biklen et al., 2005, p. 36).

It seems that from positions of "scientific" power and authority, many researchers whose work focuses on the "medical facts" of autism make quite specific ontological claims about autism, describing it as "pathological" in contrast to "normal." Historically, descriptions of an autistic "pathology" have included the construction of autism as a biological disorder of the brain (e.g., Kanner, 1943/1985), a personality disorder (e.g., Asperger, 1944/1991), and an ego

attachment disorder (e.g., Bettelheim, 1967). Although contemporary researchers construct autism as a continuum of communicative and cognitive impairments, there remains an explicit attempt to theorize autism as a "definitive" entity whose origins can be discovered "in the [person with autism's] faulty genetics, neurological impairments (e.g., of the amygdala), or impaired biochemistry" (Nadesan, 2005, p. 20). Situated out of and within these accounts of autism, a ubiquitous metaphor of autism as disease has emerged (Broderick & Ne'eman, 2008). Nadesan (2005) suggested that the present-day researchers' implicit and explicit representations of autism as disease, "implies a lack of reflexivity about how autism is constructed through our representational practices in research, in therapy, and in popular accounts" (p. 20). Yet, as Nadesan noted, the ontological model of autism as disease likely persists because it draws upon a commonsensical, taken-for-granted knowledge about disease and medicine. Rocque (2010b) suggested that people with autism labels are frequently constructed as "deficient" due to the fact that they have been "assessed according to a model of embodiment that assumes one developmental trajectory, one 'normality' that is too narrow to include them" (p. 12). Broderick and Ne'eman[10] (2008) further suggested that the current metaphor of autism as disease works to maintain the binary divide between "normal" and "abnormal," reinforcing the notion of autism as being "abnormal" or deviating from the "norm."

With the dominant representations of autism imbued with material consequences for individuals with autism labels, their families, researchers, therapists, and physicians, it is striking that most of the research does not acknowledge autism as "a particular and fluctuating construction of reality, varying with one's goals, audience, frame of reference, and point of

[10]Ne'eman, a disability studies scholar and dis/ability activist, self-identified as an "Asperger's autistic" (Broderick & Ne'eman, 2008, p. 475).

view" (Duchan, 1998, p. 108). These predominately etic and highly medicalized representations of autism rarely consider the "actual" experiences and daily practices of those individuals labeled with autism. Historically, people with dis/ability labels have never been positioned or even allowed to "control the referent 'disability'" and the "terminology that has been used to linguistically represent the various human differences referred to as 'disabilities'" (Mutua & Smith, 2006, p. 122). Much of the research focused on autism has assumed that the researchers themselves know exactly what it means to be autistic, thereby entitling them to speak for the labeled person (Biklen et al., 2005; Glynne-Owen, 2010). In fact, across the vast body of literature, a given researcher's assertions, such as, "autistic children show minimal emotional attachment" (Lovaas, 1987, p. 1), are rarely generated through interacting with or considering the everyday practices of people with autism labels. Instead, such assertions are typically based on experimental research that presupposes deficits and bases its conclusions on a list of assumed abnormal behaviors (Glynne-Owen, 2010). With my own research study situated within a qualitative approach working from an emic perspective, it is particularly relevant to review the small, yet growing corpus of qualitative studies focused on the everyday practices and social worlds of individuals with diagnostic labels of autism and their family members.

Summary. In this first section, I presented the reader with an abbreviated overview of the history of autism as a diagnostic category. First, I described the origins and social consequences of the addition of the notion of "norm" to the English language. Through this, I highlighted how "normal" was positioned in contrast to "pathological." Second, I discussed the varied and interwoven institutional histories and disciplinary discourses that contributed to the twentieth-century creation of autism as a category. More specifically, I showed how the

nineteenth-century descriptions of childhood schizophrenia and the increasing focus upon observing and managing the development of the child, influenced the "discovery" of and early writings about autism. Third, I described and analyzed the seminal writings that offered initial descriptions of autism as a diagnostic disorder. Finally, I briefly highlighted the contemporary notions surrounding the diagnosis of autism, pointing to the present-day concerns and primary metaphors surrounding autism. I also pointed to the dominating focus of the majority of research around autism, emphasizing its general lack of attention to the perspectives and practices of those individuals labeled with autism. In the following section, I explore the most relevant qualitatively grounded studies related to the construction of autism.

Section II: Review and Analysis of Selected Empirical Studies

In this second section, I review some of the qualitatively-grounded empirical studies that examine the perceptions, social worlds, and/or discursive practices of those individuals labeled with autism, as well as those who live and work with them. I draw upon literature from multiple disciplines, including education, sociology, anthropology, discursive psychology, and disability studies in education. First, I discuss the vast number of parent memoirs, as well as the growing number of autobiographical accounts of individuals with autism labels. Second, I review the empirical studies focused on the experiences of parents of children with autism. Third, I present the research focused on the experiences and practices of individuals with diagnostic labels of autism. Although also grounded in qualitative inquiry, I then review the studies that draw upon discursive research traditions separately; thus, I conclude this section by presenting the small body of autism-related research situated within discursive research traditions. In doing so, I

point to the ways in which my study contributes to the broader scholarly conversation, noting where my study is similar to and different from the existing research.

As noted in Section I of this chapter, the discourses surrounding autism are dominated by deficit-oriented beliefs and practices, with positivistic paradigms framing most of the research conducted (Glynne-Owen, 2010). Further, with the meanings of autism embedded within medicalized language, emic explorations become challenging. As Biklen et al. (2005) noted:

> It is inherently challenging to do qualitative inquiry in a field as highly medicalized as autism, for most of the language of the field assumes a shared, normative perspective of an observable reality. It is common in scientific accounts of autism to treat autism more or less as a relatively stable concept…even talking about autism becomes difficult. (pp. 11-12)

Thus, as I emphasize in the paragraphs below, even within the qualitative work surrounding autism, many researchers implicitly and explicitly reify the notion of autism as an "observable" and "stable" reality. As I present the literature, I point to the tacit assumptions that guide each study, allowing me to compare those to my own research project. I begin by considering the popularized accounts of autism written by families and individuals with autism.

Parent memoirs and autobiographical accounts. Over 50 published memoirs written by parents of children with autism exist, spanning back to the 1960s. Osteen (2008) suggested that in general, dis/ability memoirs present dis/ability as an individual concern, minimizing the influence of culture and society. He further noted that the majority of parent memoirs surrounding autism display "the praiseworthy need to show respect for their loved ones and celebrate their achievements," yet often act to reify dominant stereotypes about autism (p. 17).

The existent parent memoirs can be divided into two categories: "pathographies, or illness narratives," and accounts focused on describing a specific therapeutic approach (Waltz, 2005, p. 428), with few focused on the lifeworld of the individual with autism. Fischer (2008) noted that many of the parent memoirs and autobiographies focused on specific intervention approaches follow the pattern of a "conversion narrative," whereby "a record of the quest for a transformed or redeemed self" is presented (p. 51).

Osteen (2008) noted certain patterns across the parent memoirs. For instance, most of the parent narratives describe their own struggles in labeling their child "autistic," wondering whether such a label would be "liberating or imprisoning" (p. 19). Additionally, most of the narratives present a tension between viewing autism as "a gift" and feeling that autism is a real and "unconquerable, debilitating force" (p. 19). Although not without critique, many of the memoirs dared to talk back (hooks, 1989) to the dominant psychiatric discourses of their day, often using their child's experience to generalize about medicine, education, etc. For example, Park (1967) wrote one of the earliest and most heralded memoirs, *The Siege*, describing her family's struggle to understand and treat their daughter with autism. Park's strong critique of Bettelheim's concept of "refrigerator mother" is "credited as a watershed event in the history of autism," acting to push back on the dominant view of her day (Waltz, 2005, p. 429). Although most of the research on the "effects" of a dis/ability diagnosis presumes a paradigm of loss, some parent memoirs (e.g., Park) respond with activism and a rejection of stigma. While some memoirs seem to embrace medical models and seek a cure (Waltz, 2005), most display multiple and, at times, contradictory positions towards ability and dis/ability, moving from orienting to a

child with an autism label as disordered or abnormal to normalizing and making ordinary those behaviors that might otherwise be pathologized (Avdi, Griffin, & Brough, 2000).

Alongside these parent memoirs, there are a growing number of autobiographical accounts written by individuals identified as autistic. Most notably, Grandin's (Grandin, 1996; Grandin & Scariano, 1986) and Williams' (1989; 1994) autobiographical accounts provide a vivid description of their life experiences, without a parent or researcher narrating or providing second-hand information. Temple Grandin, instead of presenting herself as fundamentally out of touch with others and the world around her, wrote about her life as one filled with friends and motivating interests, all of which led her to engage with the world around her. Nevertheless, similar to what other individuals with autism labels have written (Williams, 1989), Grandin described how challenging it was for her to maintain connectedness with others, leading her to acquire strategies (e.g., a squeeze machine that assisted her in calming her sensory system by providing deep pressure) that helped her to socialize and engage with others. When describing her childhood, Grandin (1993) further pointed to her desire to be with others, but also her need to deal with the challenge of doing so, stating, "when I was a child I craved the feeling of being hugged but then I withdrew because I was overwhelmed by the tidal wave of sensation" (p. 108). In Barron's (Barron & Barron, 1992) autobiographical account, he offered explanations for the behaviors that others pathologized or linked to an inherent deficit. For instance, he described his preference for solely talking about the states within the United States as linked to his desire for structure within conversations, and his desire to feel in control. While he acknowledged that his conversations with others were often "fragmented and disjointed," he stated that, at the time, what mattered most was engaging in conversations that resulted in him being recognized by

others, and allowed him to feel "powerful" and steer "the talk where" he "wanted it to go" (p. 107). Similar to other adults with autism labels (e.g., Rentenbach, 2009), Barron viewed autism as part of who he was, but cautioned that autism was only one of his many identities.

Biklen et al. (2005) suggested that many autobiographical accounts present the person labeled with autism as "growing, changing, and achieving new subjectivities through engagement with the world" (p. 51). However, he also emphasized that the majority of these autobiographical accounts are written by individuals who self-identify or are named by outsiders as high functioning, with "high functioning" often being code for using a verbal form of communication and being highly accomplished, in line with social norms. Biklen is one of the few scholars who has collected and helped to publish the self-narratives of minimally verbal and nonverbal autistics; to date, six such narratives have been published with his assistance (see Biklen et al., 2005). Through his work, individuals with autism labels who utilize augmentative or alternative forms of communication (Beukelman & Mirenda, 1998) were provided a forum by which to share their life narratives. Although there are other accounts written via alternative modes of communication (e.g., Rentenbach, 2009), many such accounts are only now being published.

Jones, Zahl, and Huws (2001) thematically analyzed the personal blogs or internet-based accounts of five individuals who self-identified as autistic. Their findings indicated that, in contrast to the scientific literature suggesting that people with autism have deficient or non-existent emotions, the authors of these personal narratives wrote often about their emotional experiences, describing feelings of alienation from and frustrations with the world around them. Davidson (2010) applied a critical discourse analysis framework to 45 existing autobiographies

of individuals who self-identified as autistic. She concluded that the individuals with autism had heightened senses, thereby struggling to process environmental stimuli. She argued that this sensory difference resulted in their unjust exclusion from community spaces, in that individuals without autism labels often failed to make the needed environmental accommodations. Overall, many of the personal accounts of living with a label of autism counter the popular stereotypes and medically-based assumptions that surround autism, often presenting alternative discourses about autism.

Parental experiences. Beyond the memoirs and autobiographical accounts, there is a small yet growing body of empirical work examining the experiences of the parents of children with autism, which includes both survey research (Brogan & Knussen, 2003; Mansell & Morris, 2004; Wolf, Noh, Fisman, & Speechly, 1989) and qualitatively grounded work. In the following paragraphs, I present an overview of six qualitatively-based studies, all of which are focused on some aspect of the parent's experience with a child with autism. I review these empirical studies related to the parents' experiences around two major themes: (1) seeking and acquiring a diagnosis of autism and (2) parent roles and performances following a child's diagnosis of autism.

Seeking a diagnosis. Literature on the experiences of parents seeking and acquiring a label of autism for their child is quite limited, with most research around diagnosis focused on refining psychiatric taxonomies (e.g., Hooper & Bundy, 1998; Szatmari, 2000). There are a growing number of studies focused on such experiences, with most drawing upon medically-based perspectives; however, they provide insight into the ways in which parents may make sense of the process of their child being labeled autistic.

Midence's and O'Neill's (1999) grounded theory study focused on the diagnostic experiences of four families in North Wales with children, aged nine to 12, diagnosed with autism. A total of seven parents participated in semi-structured interviews focused on their experiences prior to, during, and after the diagnosis of their child. From their data, the researchers developed six categories to represent their participants' experiences, which appeared to align chronologically with the events surrounding the diagnosis. The first category, "behavioral development," represented the parents' initial concerns with what the participants described as their child's "different" and "bad" behavior (p. 277). The second category, "confusion," reflected the participants' challenge in understanding their child's behavior (p. 278). For all of the participants, an "incorrect diagnosis," the third category, preceded the eventual diagnosis of "autism," the fourth category (p. 279). After the diagnosis of autism, the parents reported that they were "getting the support they needed," with support being identified as the fifth category (p. 281). The sixth category, "acceptance/adaptation," represented the participants' acceptance of their child's diagnosis. The researchers concluded that the diagnosis provided the parents with a way to justify and make sense of their child's behaviors, stating that the participants came to view autism as a "part of their child's personality" (p. 283).

Nissenbaum, Tollesfson, and Reese (2002) conducted a similar study; however, they also included professionals engaged in diagnosing children. Situated within a naturalistic inquiry approach, the researchers interviewed 11 nonmedical professionals involved in diagnosing children with autism, and 17 white, middle to upper class parents of children diagnosed with autism. The unstructured interviews asked questions regarding the definitions of autism, diagnostic process, and the initial process of receiving and giving a diagnosis. Overall, the

researchers reported that the participating parents and professionals held differing views on the life outcomes of children diagnosed with autism, with parents maintaining a far more optimistic outlook. The professionals felt that parents were unrealistic, requiring them to engage in "educating the families" about the nature of autism (p. 34). For both the parents and the professionals, the official language of the DSM-IV was utilized to describe and make sense of autism. As in the study described above, the participating parents reported that the autism diagnosis helped them to make sense of their child's behavior, as well as qualify for and acquire "appropriate" services for their child.

Conducting a hermeneutic phenomenological study, Woodgate, Ateah, and Secco (2008) explored the experiences of Canadian parents with a child with autism. Researchers asked parents to describe their life before, after, and during the diagnosis of their child. Twenty-one parents from 16 families were recruited through a parent support group, with the participants' children being three to nine years of age. Over a period of 16 months, a total of 19 joint and individual interviews were conducted. Following a transparently reported and notably thorough analysis, the researchers developed an essence and three themes to represent the parents' collective experience. The reported essence was phrased "living in a world of our own," with parents describing their life as isolated and at times hopeless (p. 1078). From this sense of isolation, the parents were reported to engage in "vigilant parenting" (theme 1), while also "sustaining the self and family" (theme 2) and "working toward a healthy balance" (theme 3) (pp. 1079-1080). The researchers pointed to the participants' overall sense of isolation as stemming from society's lack of understanding, while also comparing the participants' experiences to those of parents of chronically ill children.

Summary and analysis. Within each of the studies previously mentioned, the researchers drew upon psychiatric nosologies to describe autism and make sense of the parents' experiences with diagnosis. In doing so, the inherent challenges of doing qualitative work around a highly medicalized construct emerged (Biklen et al., 2005), as presumably interpretive research was confined to a priori frameworks of "autism as deficit." For example, each article began with medicalized definitions of autism and descriptions of autism as a "threat to the well-being of families" (Woodgate et al., 2008), immediately evoking an "abnormal-normal" binary and a metaphor of "autism as disease." One study (Woodgate et al., 2008) constructed the accounts of their participants similarly to what Waltz (2008) named "pathographies," or illness narratives (p. 428). As Broderick and Ne'eman (2008) noted, the majority of literature that offers "support for medically framing autism with a disease model comes from within the non-autistic community" (p. 459). In other words, those individuals not labeled with autism tend to orient to and reinforce notions of autism as a deficit, disease, and threat. Through this, the person labeled autistic is frequently left as an "off-stage character," yet "referred to constantly, invoked with great passion and pomp, but not fit to offer any lines of actual dialogue" (Broderick & Ne'eman, 2008, p. 471).

With researchers explicitly and/or implicitly stating that autism is a "part of" a child (Midence & O'Neill, 1999, p. 283), while failing to theorize and question that notion, the "disabled body" is made into a discrete object rather than a "set of social relations" (Davis, 1995, p. 11). A medical diagnosis often attributes agency to symptoms that are eventually projected to being within a person (Harper, 1998); thus, the diagnosis functions "to externalize the problem and project it within the person" (Avdi, Grifin, & Brough, 2000, p. 249). Finally, it appears that when exploring the diagnostic process with parents, both the participants and researchers

deployed the dominant, medically-based ways of speaking about autism. While recognizing that one's way of speaking "does not necessarily induct the speaker into the assumptions and beliefs of that language" (Davies, 2003, p. 281), it does seem that the above studies did not offer a new reading on the experience of autism.

Performances and roles. Beyond seeking a diagnosis for their child, parents of children with autism labels are reported to play a significant role in the services their children receive from professional bodies (Feinberg & Vacca, 2000). Further, as Nadesan (2005) noted, the performative aspects of autism are quite apparent in the daily experiences of parents of children with autism. She stated that:

> ...autism has a performative component, as known by every parent who struggled to meet the criteria for government and educational services for their children. For the social services agent, I [as a parent of a child diagnosed with autism] must stress (and even exaggerate) Kamal's [her son] maladaptive behaviors. For his teachers, I stress Kamal's high intellect in order to avoid having him labeled as "mentally retarded." For his peers, Kamal performs "normality" in the context of the school playground by stifling his odd interests and masking social awkwardness in order to "fit in" with the other children. (p. 2)

An exploration of such performativity is noted in studies that consider the roles that parents assume when advocating for services and facilitating the growth of their child following a diagnosis of autism. I reviewed one study that explicitly explored the roles of mothers as activists/advocates (Ryan & Cole, 2009), one that examined parents' self-reported roles in negotiating relations with educational professionals (Stoner & Angell, 2006), and one that

considered the role of "other" within the narratives of parents of children with autism labels (Gray, 2001).

Ryan and Cole (2009) interviewed 36 mothers of children with autism labels regarding their interactions with health professionals and involvement in parent-based autism support groups. The participants were from the United Kingdom and their children ranged in age from three to 53. Using an a priori framework of activism and parent advocacy, and orienting to autism as a socially embedded construct, the researchers analyzed the interview data and developed interlinking themes to represent the diverse experiences of the mothers. The researchers' overarching finding was that in some form or another, mothers of children with autism labels engaged in collective activism and/or advocating for the rights of their children, while also indicating that they mothered their children with autism labels differently than their non-autistic children. Some mothers primarily worked to get their child's educational needs met, while others spoke of "fighting" for their child's rights in political forums (p. 48). While less than half of the participants were involved in support groups for parents of children with autism, a few of the mothers took up more activist roles, raising public awareness within public forums and meeting with lawmakers. In addition, the researchers indicated that many of the participants oriented to their child's dis/ability within a social model framework, with dis/ability viewed as being constructed by social and cultural processes versus being fully internal to the child.

Stoner's and Angell's (2006) qualitative case study also examined how parents of children with autism labels experience their interactions with professionals, specifically K-12 professionals. Four white, middle class American families participated in this study, with only heterosexual married couples invited to participate. A total of eight parents were interviewed

three times, with all of the families having sons from six to eight years of age. Unlike Ryan's and Cole's (2009) research, this study did not assume that autism was a socially embedded construct, but instead drew upon the broader discourses of special education policies and practices. The researchers employed "role theory" to make sense of their data, defining roles as patterns of "behaviors and attitudes constituting a strategy for coping" (p. 184). Focusing on the reported behaviors of the participants, the researchers assigned certain roles to the participants' behaviors (i.e., negotiator, monitor, supporter, and/or advocate) as they interacted with K-12 professionals. The researchers concluded that the role taken up by the parents depended upon the degree to which they trusted the professional and their child's context-specific needs.

When Gray (2001) analyzed the narratives of parents of children with autism, he noted that some parents experienced the role of the "other," in that the "experience of illness is one that runs counter to deeply embedded cultural values of normality" (p. 1257). According to Gray, the parents' experiences with the role of "other" brought "significant emotional distress," with each parent reconstructing their life narratives after experiencing the "formidable challenges" of autism (p. 1247). This narrative inquiry study focused on the life narratives of three Australian parents of children "severely affected" by autism, aligning closely with the assumptions of research around illness narratives conducted by Becker (1999). Gray concluded that each parent narrative drew upon unique "culturally sanctioned master narratives" of science, politics, and faith. Each participant's reconstruction of their experience situated them within certain contexts, be it church settings or political positions (e.g., lobbying).

Summary and analysis. The three studies above maintain distinct assumptions regarding autism; yet, they each provide descriptions of how parents may make sense of a child being

diagnosed with autism. Although Ryan and Cole (2009) failed to provide a clear description of their methodological framework, this study provided an example of how the *becoming* of a mother of a child with a dis/ability label entails a unique performance of "activist." Further, this is one of the few studies on the experiences of parents that explicitly worked from a position of dis/ability as being political and socially constructed. Considering that Stoner and Angell (2006) assumed a deficit-orientation to autism, it is not surprising that they made few connections to the social processes of autism. Despite the research studies described above making no explicit links to the performativity of autism, considering autism as a social process may prove fruitful. For example, how might an understanding of parental roles expand by also attending to the social and political factors that likely influence which roles are situationally relevant to a given parent? To some extent, Gray (2001) attended to the positions that parents of children take up in relation to the discourses of autism upon which they draw. However, Gray's belief that a narrative of autism was similar to an illness narrative evoked a metaphor of autism as disease. Like many of the other qualitative studies reviewed thus far, Gray's own descriptions of autism were confined to medicalized language and deficit models of dis/ability. Broderick and Ne'eman (2008) stated that "representation is established by who can claim control over the narratives used to define a person, place, experience or term, and the parent narrative has had far more time to disseminate than the self-advocate one" (p. 471). While the above studies provide some intriguing insights into the experiences' of parents and professionals around the diagnostic category of autism, each study also displays the challenges of doing qualitative work around a highly medicalized construct. Who then claims control to "produce and sustain" truths (Foucault, 1980, p. 133)?

Experiences of individuals with labels of autism. As I turn now to review the very small number of studies that focus on the life worlds and practices of individuals labeled with autism, I review research that, at least to some degree, is grounded in the assumption that:

> Any person dealing with a person diagnosed as mentally retarded (or intellectually impaired, or learning disabled) should specifically consider the possibility that the observed disability could be accounted for not by an all-encompassing general difference but by a more parsimonious assembly of particular symptoms—that 'mental retardation' may be, both in any given case and in its wider conceptualization, inadequate as an explanatory concept, undefinable as a scientific entity, and unhelpful as a clinical diagnosis. (Borthwick & Crossley, 1999, para. 39)

In other words, autism, mental retardation, and many other dis/ability labels are not necessarily representative of an inherent, "all-encompassing" deficiency, but are always already socially embedded. Further, many of the studies below eschewed the research community's tendency to focus on the experiences of parents of children with autism labels and professionals, instead seeking to consider the lived experiences of those labeled with autism. In total, I located only six empirical studies that maintained an interpretive perspective, focusing also upon the life worlds of individuals labeled with autism.

Bagatell (2007) carried out an ethnographic study that focused on the process of identity construction of a 21-year old male with Asperger's Syndrome. With the dominant views surrounding autism casting doubt on the subjective experiences of those labeled autistic, few researchers have explored the making and re-making of the identities of individuals labeled with autism. Thus, Bagatell's study is particularly significant, for it speaks back to the prevailing

"assumption that social worlds hold little importance" for individuals with labels of autism (p. 413). Over a nine month period, she collected in-depth interviews and made participant observations in order to construct a narrative of her participant's complex and shifting identities. With the participant not acquiring a label of Asperger's until he was 15 years of age, Bagatell reported that, following the diagnosis, the participant constructed a new life narrative to reframe his experiences and behaviors. In doing so, the participant conceptualized his behavior as "normal" versus "deviant," yet still struggled to "fit in" (p. 419). Bagatell suggested that the process of "fitting in" became more about the constraints of the social world than about the participant's behaviors. As the participant navigated through his social world, his "Asperger" ("Aspie") identity became one identity among many, yet it was filled with tension. For example, as a member of a group for people with autism, the participant found a space where he was viewed as "normal." However, the researcher reported that the participant felt tension, even within a space that he identified as safe and welcoming. This tension was described as emerging, as the participant struggled to work through and make sense of "the authoritative voices reminding him on a daily basis of the importance of fitting in and of his marginalized position" and the "voices of the Aspie community that reminded him that he could live a meaningful life as a person with autism" (p. 422). The researcher concluded that people with autism labels are often presented with conflicting discourses about who they are and what they can become, resulting in challenges as the individuals work to construct and reconstruct their identities. She suggested that other researchers shift their focus from the presumed deficits of autism to the complex and creative social participation of those individuals labeled autistic.

Rosetti, Ashby, Arndt, Chadwick and Kasahara (2008) conducted an interpretivist study in which they explored the actions and/or performances of individuals labeled with autism during communication "training" sessions. More particularly, they considered notions of competency and agency "amid behaviors and actions traditionally linked with incompetence" (p. 364). All eight of the participants in this study were labeled with autism and typed to communicate, with three being teenagers and five being adults. Over a nine month period, the researchers interviewed and observed the participants working with various professionals who were assisting them in learning how to communicate via typing. Through a phenomenological analysis, the researchers suggested that the participants "troubled traditional notions of independence" by re-conceptualizing independence as including supports from other people and objects (p. 368). Further, the participants performed agency through their nonverbal actions that could be easily misinterpreted by non-autistic professionals as moments of incompetence or purposeless behavior. Challenging the view that dependence in some tasks or communicative "oddities," such as humming in a rhythmic pattern or laughing loudly in response to a question or command, is a sign of incompetence, this study offers a new reading on the behaviors of individuals with autism labels. Laughing loudly or humming, for example, was interpreted by the researchers "as meaningful and necessary for communication" (p. 370). This particular perspective was quite unique in that it explored the experiences of individuals traditionally considered "low functioning" due to their differing form of communication (i.e., typing).

In a theoretically similar study, Ashby and Causton-Theoharis (2009) used seven published autobiographical accounts of adults and adolescents with autism as a source of qualitative data. They specifically selected those texts that (1) had more than eight passages

focused on "competence, intelligence or smartness," (2) focused on childhood and adolescent years, and (3) represented a wide communication range, including alternative communication systems (e.g., typing) (p. 504). Using a narrative inquiry approach, the researchers explored the ways in which the texts addressed issues of competence, noting how the participants made sense of the constructs of intelligence and mental retardation in relationship to broader institutional practices, such as intelligence testing. Explicitly eschewing psychiatric definitions of autism as "abnormal functioning" (p. 501), the authors turned to the individuals labeled autistic as the "experts" (p. 502). Across the texts, the researchers noted that there was a problematic performance of knowing versus doing. Further, what was often assessed was not understanding but performing, or the ability to do something in a particular way, with the correct way being specific to a given test and assessor. For example, many of the participants described experiences where they failed to comply with a professional assessor who then named them incompetent. For them, it was not that they did not understand; they simply did not perform as they were asked. One of the analyzed texts, written by Barron and Barron (1992), described being asked by an examiner to draw a house with a square and triangular roof. However, the individual with an autism label did not understand that the assessor wanted the two shapes to be positioned together and became frustrated when he was told that he was incorrect. When he realized what the examiner wanted, something of which he knew how to do, he had already become frustrated by the examiner's presumption that he was incompetent and decided to give up trying further.

Thus, within each of the texts, those labeled autistic and incompetent found ways to reframe their challenges as an issue of performance not lack of ability; they were capable, but

unable to perform for a particular examiner. Additionally, many of the "experts" (i.e., authors of the analyzed texts) described an awareness of how their speech was not conventional, as they did not always use words to convey their ideas. Consequently, this inability "to convey" ideas "through speech" resulted in constructions of incompetence (p. 506). Further, having a label of autism was not always viewed as useful, for at times it drew attention away from understanding the individual as a complex and competent person, with intersecting and multiple identities. With incompetence and mental retardation often linked to autism, the "expert" authors spoke of the challenges of being seen as anything but incompetent, as once "seen through a lens of retardation, the person behind the label" was "obscured" (p. 508). The authors of this study offered an alternative reading of the notion of competence, allowing those labeled autistic to do the reframing. Furthermore, they pointed to the ways in which communication and competence function as intersecting concepts, often resulting in the exclusion of those individuals who communicate in nonverbal or simply non-normative ways. They suggested that educators and researchers alike should expand their definitions of intelligence and normative performance, with an intent to "no longer disqualify people from this thing we call the human race" (p. 514).

Summary and analysis. The three studies above offer new perspectives and readings of the subjectivities of those labeled autistic. Although Bagatell (2007) does not fully disclose her data analysis process, her study provides insight into the social ways in which those named autistic make sense of their daily life. Of particular import are the two studies drawn from the field of disability studies in education (Ashby & Causton-Theorharis, 2009; Rossetti et al., 2008). With disability studies scholars typically engaged in post-positivistic inquiry, much of their work seeks to understand the emic accounts and practices of individuals with dis/ability

labels. Thus, within the studies of Ashby and Causton-Theorhari (2009) and Rossetti et al. (2008), autism is jointly constructed by the researchers and participants, at least to some extent. With each of the above studies orienting to dis/ability as a social construct embedded within shifting cultural and political processes, a new way of speaking about autism emerges and "the possibilities of being one or another person may open up and shut down as we speak one language or another, or move from one discursive landscape to another" (Davies, 2003, p. 281). Thus, with a shift away from the discursive landscape of medical models of autism, a picture of competence is made possible as new ways of framing and talking about autism are made available.

Research within the discourse traditions. With "qualitative impairments in communication" being one of the criteria used when diagnosing autism (American Psychiatric Association, 2000, p. 59), it is not surprising that a large body of research exists documenting what are presumed to be "universal" linguistic deficits of individuals with autism labels (Hale & Tager-Flusberg, 2005, p. 519). Much of the literature on the conversational patterns of people with autism comes from clinical linguistic studies and has focused on identifying and describing the "unique" characteristics and deficiencies of language use (e.g., Seung, 2007), as well as the various methods by which to improve or correct such difficulties (e.g., Sarokoff, Taylor, & Poulson, 2001). This particular body of literature maintains that autism is "real" and "observable," with the language of people with autism positioned as pathological and in need of remedying.

Discourse research traditions move beyond notions of linguistic structure or language as being representative of a given reality (e.g., autism); yet discourse research is not a unitary

entity, but rather includes several approaches and philosophical frameworks. Most discourse traditions maintain that discourse does not exist in a vacuum or somehow possesses some abstract meaning. Rather, discourse is understood as "shared and social, emanating out of interactions between social groups and the complex societal structures in which the discourse is embedded" (Phillips & Hardy, 2002, p. 4). In the next paragraphs, I describe several key studies that cross discourse traditions and that focus on the construct of autism.

Linguistic anthropology and conversation analysis. Elinor Ochs, a linguistic anthropologist, directed an ethnographic study at the University of California, Los Angeles of the everyday lives of children, aged eight to 12, with labels of Asperger's Disorder and high-functioning autism (Ochs & Solmon, 2004). Although the study broadly attended to the social worlds of the sixteen participating families, the research team gave particular attention to the children's conversational interactions with family members during dinnertime, with peers and teachers during the school day, and in transit to and from school. The corpus of data included 320 hours of video and 60 hours of audio-recorded naturalistic data, and was analyzed using conversation analysis techniques. A full issue of *Discourse Studies* (2004) was devoted to the work of Ochs and her research team in which she hoped to introduce "discourse analysts to ways in which autism organizes discourse" (Ochs & Solmon, 2004, p. 139). Like psychiatric definitions, Ochs and Solmon defined autism as "a neurological disorder that hinders social, cognitive, and emotional functioning of affected persons" (p. 139). Yet, she also described autism as a "condition" that is both neurological and social, examining autism, to some extent, from a socio-cultural perspective (Ochs, Kremer-Sadlik, Sirota, & Solmon, 2004, p. 147). Overall, Ochs suggested that children with Asperger's or high-functioning autism have distinct

discourse qualities, being "subtly but systematically different from unaffected discourse" (p. 139). For example, Kremer-Sadlik (2004) reported that the participating children with autism labels answered 75% of all question-answer sequences appropriately, especially as their family members modeled acceptable interactions and corrected the child's speech to match normative expectations. In contrast to cognitive psychological literature, the majority of the participating children were described as accurately detecting another speaker's communicative intentions, resulting in the production of relevant answers to questions posed. Furthermore, Sterponi (2004) reported that the participating children displayed an understanding of social rules, initiating conversations with peers in which they called upon others to negotiate moral positions. In the 2004 journal issue, Ochs concluded that her research team's intentional shift away from researching autism in "laboratory settings" made possible new insights about autism "against the backdrop of everyday social behavior" (p. 143).

Stribling, Rae, and Dickerson (2006) conducted a conversation analysis on the talk of an adolescent girl with autism. Like Ochs, the researchers defined autism within a medical framework, highlighting "empirical evidence" that suggested linguistic deficits (p. 428). They analyzed six hours of video recordings of the participant within the context of her special education classroom. The researchers provided a detailed interactional analysis showing the interactions of the participant with autism and the school staff. It was noted that the participant displayed two forms of verbal repetitions: (1) an immediate repeating of the prior speaker's utterance or (2) a delayed repeating of her own prior talk. The authors suggested that the participant's repetitions constituted an adaptation to interaction that allowed her to display pragmatic competence despite her limited lexicon.

Summary and analysis. Each of the conversation analysis studies described above grounded their findings in richly displayed data, proffering interpretations that were tightly coupled with their data set. Nevertheless, both Ochs and Solmon (2004) and Stribling, Rae, and Dickerson (2006) explicitly, and at times implicitly, assumed that autism organizes discourse versus discourse organizing the construct of autism. While pointing to how the speech patterns of people with autism unfold in everyday interactions, the researchers' claims of "competent" versus "incompetent" speakers were very much steeped in universal understandings of language, with variable speech patterns associated with pathologies far more than social differences. Furthermore, the above researchers oriented to competent communication as linked to verbal speech, with alternative forms of communication minimized or simply ignored. As such, to some extent, the research acted to pathologize the discourse of individuals with autism labels, as well as reify autism as a real and undeniable condition. Although Ochs et al. (2004) suggested that autism occurs within a socio-cultural context, such a perspective was limited to acknowledging that people with autism are "participating members of social groups and communities" (p. 147). Thus, the construct of "social" was contained within a belief in autism as an observable reality that likely results in a certain type of discursive production. From this perspective, then, the conversational practices of people with autism are presumed to reflect inherent deficits, versus language itself making such deficit a social reality.

Foucauldian-oriented discourse research and discursive psychology. The next two studies problematize notions of autism as solely biogenetic, pointing to how people's talk and the broader ideological representations may shape the meanings of autism. Each study primarily drew upon Foucauldian (1972) notions of discourse and analysis, attending to people's

deployment of the broader discourses of medicine, dis/ability, and human development. Further, each of these studies primarily focused on the parents of children with autism.

Drawing upon symbolic interactionism and a Foucauldian-oriented analytical framework, sociologist Rocque (2007) conducted a two-year ethnographic study of autism. Within this dissertation study, Rocque carried out participant observations in two special education classrooms in the Southwestern region of the United States, while also conducting 40 semi-structured interviews with parents of children with autism labels and school staff. All of his participants were white, suburban, mostly middle class, and primarily women. He was particularly interested in exploring the embodiment of autism by attending to the ways in which the parents and school staff "call forth, manage, mediate, cajole, strengthen, and shape the subjectivity of persons with autism" (p. 1). While also examining historical writings around autism, Rocque suggested that autism interventions often serve to "reform" children with autism labels into self-regulated and docile beings. Alongside the attempts to make the autistic identity docile, he noted many attempts by the mothers of children with autism labels and autistic activities to "(re)articulate the dominant discourse of autism, thus carving out a space for alternative autistic identities" (pp. iii-iv). Mothers of children with autism often reframed their child's behaviors as explainable and not necessarily indicative of an inherent pathology on the part of their child. In a recent publication of his dissertation findings, Rocque (2010a) further analyzed this notion of mothers of children with autism labels who act as mediators of selfhood, suggesting that they worked to actively interpret for others their child's "odd" behaviors as reasonable and rationale for those individuals who "typically are not equipped to understand what mothers believe are the self-expressions of their children" (p. 487). Autism, then, was

constructed as always produced in relationship to others' interpretations and presumptions about normative and non-normative behaviors and communication patterns.

Avdi, Griffin, and Brough (2000) conducted a discourse analysis study of eleven semi-structured interviews of parents with a child with autism, drawing upon a Foucauldian perspective. They also followed a particular version of Billig's (1996) approach, eventually developing thematic understandings of the broad discourses used when parents talked about their child's "problem" (i.e., autism). Overall, the parents primarily drew upon the discourses of normal development, medicine, and dis/ability. As parents shifted their constructions of their child from being normal to disabled, they drew upon the discourse of normal development, often comparing their child with "abstract notions of universal developmental stages" (p. 246). They also deployed a medical discourse when talking about autism as a "reified, clearly delineated condition," with some parents displaying ambivalence towards the notion of a "real" diagnosis. The researchers suggested that when the parents constructed their child as an "other," they tended to draw upon discourses of dis/ability. Interestingly, once a child was diagnosed as autistic, many parents no longer constructed their child as "normal," as the two categories (autistic versus normal) were viewed as mutually exclusive. The researchers concluded that the parents held ambivalent and at times conflicting meanings of autism, with deficit-models of dis/ability dominating the ways in which the parents oriented to their child following his/her diagnosis.

In contrast to the primarily macro-level analysis of the two studies described above, studies that draw upon a more micro-level analytical framework, particularly a discursive psychology approach, often attend to micro-level aspects of the participants' talk. With

discursive psychology studies employing some aspects of conversation analysis (Sacks, 1992) to interpret the participant's interactional sequence, such work claims to maintain a close focus on the local and situated talk of the participants. Although there is a vast body of literature drawing upon a discursive psychology framework, a very small corpus of discursive psychology research examines dis/ability (e.g., O'Reilly, 2004; Rapley, Kiernan, & Antaki, 1998), with only one study examining the construct of autism.

Fasulo and Fiore (2007)[11] examined autism from an interactionist and ethnomethodologically-oriented analytical perspective, while also situating aspects of their work in the traditions of discursive psychology. They recorded and analyzed conversations that occurred during 10 therapeutic sessions, with the participants including a therapist and two boys, aged ten and thirteen, with "high functioning autism" (p. 226). One of the stated goals of the study was "to show that therapeutic intervention could be strengthened if it was founded on a better awareness of the nature of talk-in-interaction" (p. 225). Drawing upon the work of Ochs et al. (2004) and others who view autism as a condition resulting in unique discursive patterns, Fasulo and Fiore (2007) explicitly drew upon conversation analysis, pointing to the functions of discursive patterns in autism while implicitly drawing upon medicalized discourses to define autism. They oriented to the unique talk of autistics as doing something functional within interactions, potentially resulting in the therapist having an unrealistic model of conversational sequences. Findings suggested that the educational objectives of the therapeutic program conflicted with the way in which the therapist discursively carried out the therapy session. For example, one goal was to improve the children's "correctness of speech," yet the researchers

[11]Fasulo and Fiore (2007) conducted their study in Italian. They did not discuss the translation process and its relation to their data analysis process.

indicated that many of the therapist's "corrective" conversational turns stifled another goal of improving social interaction (p. 240), as the children often stopped speaking upon being "corrected" by the therapist. Additionally, the therapist engaged in continual questioning of the children, assuming that this approach would elicit appropriate language. However, the researcher showed how such questioning shifted the "dialogue" to an "interrogation" session (p. 240). The researchers concluded that therapists should learn to make sense of the unique conversational patterns of children with autism labels, resisting their tendency to privilege expected patterns of speech.

Summary and analysis. To some extent, the work of Avdi et al. (2000) and Rocque (2007, 2010a) challenge the pervading view of autism as an observable reality that is ahistorical and located outside of culture. Positioned within research traditions that take up dis/ability as a discursive entity, Avdi et al. and Rocque offer insights into how broader discourses facilitate and limit the ways in which parents of children with autism labels talk about and make sense of autism. Desiring to not make the individual labeled an "off-stage character," continually invoked but not present to share their own perspectives on their everyday experiences (Broderick & Ne'eman, 2008, p. 471), I believe it would be useful and important to conduct similar studies with individuals labeled with autism positioned as the primary speakers. Further, as Advi et al. (2000) noted, a common critique of macro-level analytical work is that it may be "over-interpreted to produce meanings that were not originally contained in the talk or text" (p. 252). Nevertheless, with both of the above studies providing interpretative analysis grounded in representative excerpts from their data sets, such potential critiques were accounted for.

While the work of Fasulo and Fiore (2007) still relies upon medicalized descriptions of autism, their work holds particular promise for researchers interested in exploring institutionalized talk in relation to autism (i.e., therapy talk). Although Fasulo and Fiore attended to the discursive practices of children with autism, they primarily focused upon explicit ways by which to enhance therapeutic interventions. Thus, there remains a need to explore how children with a label of autism manage, contest, and produce this dis/ability construct, particularly situated within and against broader discourses and socio-political contexts. Furthermore, and more importantly, the implicit assumption that autism organizes discourse pervades the conversation analysis and discursive psychology research traditions, with Fasulo's and Fiore's study being no exception. With autism constructed as "pathological," discourses become viewed as "affected" or "unaffected" by autism, thereby evoking a binary of abnormal-normal.

Positioning my current research project within this small body of more poststructurally-oriented (Rocque, 2007, 2010a) work, as well as the post-cognitive views central to the discursive psychology tradition (Potter & Edwards, 2003), I moved away from medicalized notions of autism and binaries that act to construct "normality" and "deviance." Further, I attempted to move beyond a consideration of discourse as being either at the micro- or macro-level, and instead both theoretically and analytically worked to navigate within and across what are often distinctly named micro- and macro-level discourses (Blommaert, 2005). While I relied most heavily upon an analytic framework which attends closely to the discursive features made relevant within the local and situated talk of the participants (Edwards & Potter, 1993), I worked to position each claim in relation to the broader discourses and socio-political context (see Chapter V for a further discussion of the findings). As such, this research project was positioned

within a discourse analysis approach that drew heavily upon discursive psychology (Edwards & Potter, 1993), particular aspects of poststructural understandings of discourse (Derrida, 1981; Foucault, 1971; Howarth, 2000), and a social relational model of disability (Thomas, 2004), all of which I describe in the next chapter.

Summary. In this second section, I presented the reader with the small body of literature that examines the perceptions, social worlds, and/or discursive practices of individuals with autism labels and the people who live and work with them. First, I described the parent memoirs and autobiographical accounts of individuals with autism labels. Second, I discussed the literature focused on the experiences of parents of children with autism labels. Third, I reviewed the few studies that attend to the lived experiences of individuals with autism labels. Finally, I presented an overview of studies within discourse research traditions that examine autism.

Chapter Summary

In this chapter, I first (re)constructed the history of autism, describing many of the seminal writings and events that contributed to the development of autism as a diagnostic category. Second, I reviewed the empirical studies that examined the experiences, life worlds, and discursive and conversational practices of individuals with autism, as well as those living and working with individuals with autism. In the next chapter, I discuss the theoretical frameworks that informed this work.

Chapter IV: Theoretical Frameworks

With this study's theoretical frameworks serving to situate the study within a broader scholarly conversation, as well as provide theoretical and analytical focus (Fowler, 2006), I now turn to explicate the theoretical and analytical frameworks that informed how I designed the study, collected and analyzed the data, and generated the findings and related implications. I aim to make explicit the various theories and schools of thought that influenced how I engaged in the research process. At the same time, I hope to make explicit how, in the process of doing this research, my theoretical[12] understandings were challenged and altered (Lather, 1986). Finally, I situate that which informed this study within a belief that "discourse theorists must remain methodological bricoleurs and refrain from developing an all-purpose technique for discourse analysis…totalizing master methodology would serve only to repress new and alternative forms of analysis" (Torfing, 1999, p. 292). I invite the reader to challenge the ways in which I pursued this project and offer new possibilities for engaging in discourse work.

Chapter Overview

I begin this chapter by sharing how, throughout the dissertation process, I attempted to work within and across discourse traditions, while privileging a discursive psychology (DP) approach. I share my theoretical and methodological journeys, all of which taught me much about how I might, and even should, take up the research process. I broadly describe the discursive approach I took up and the ways in which I now understand discourse, the research

[12] It is important to note that theory in and of itself is a construction. As Noblit (1999) noted, "theory...is historicism. Theory is not truth" (p. 11).

process, and dis/abilities. Next, I transition to an explication of the theoretical frameworks that informed this research, outlining critical aspects of DP (Edwards, 1997; Edwards & Potter, 1993; Potter, 1996), poststructural understandings (Derrida, 1981; Foucault, 1971; Howarth, 2000), and the social relational model of disability (Finkelstein, 2000; Reindal, 2008; Thomas, 1999, 2001, 2004). While I aim to make explicit the ways in which I navigated across felt epistemic and ontologic tensions, I acknowledge that "new paradigms are often ghosted by their history in ways that are difficult to recognize, acknowledge, and transform" (Worthen, 2004, pp. 19-20). Thus, as I present the various theoretical understandings, I accept that no "pure" methodological framework exists, and remain committed to transparency around the methodological and theoretical choices that shaped this work.

Navigating within and across Discourse Traditions

When I began this research study, I hoped that my unfolding understanding of discourse theory would continue to inform and shape the ways in which I navigated within and across discourse traditions and made sense of my own epistemic and ontologic claims. Initially, I designed this research as drawing solely upon DP, as both a theory and method. Yet, I did not take up DP as an a priori framework to be forced upon the data, but instead as one that informed and shaped how I creatively analyzed the data, wrote my findings, and generated explanations/implications. My ongoing theoretical and methodological musings are illustrated by the following research journal entry:

June 18, 2010 10:46 am

I sit in this research site everyday—mostly observing, sometimes talking to people—as I sit, I'm beginning to orient to the discourse as situated not just within a certain institutional, localized space, but also within a multitude of institutionally informed practices and histories (e.g., speech-pathology, parenting, pediatric medicine, child development, impairment, sickness, etc). How can I not attend to the ways in which both macro- and micro-level discursive practices are taken up and deployed? How might I move within and across discourse traditions?

While throughout this project I maintained a primary focus on and commitment to a DP framework, I broadened my theoretical scope, exploring and taking up poststructual claims that emphasized that the connections "between the signifier (the sound-image) and the signified (concept) is internal to language and can never be fully determined, but are organized around the 'play' of different signifiers" (Howarth & Stavrakakis, 2000, p. 20). I assumed that meanings are never guaranteed, but instead are negotiated, as "...things can acquire different meanings and functions in different historical contexts and situations" (Glynos & Howarth, 2008, p. 167).

Ultimately, I chose to consider multiple theories and schools of thought and to engage with the felt epistemic tensions and contradictions. Like Cherrington and Breheny (2005) suggested, I took up a discursive approach as "a theoretical position (locatable as poststructuralist, social constructionist, orientated to process and concerned with material conditions) as well as a declaration of methodology" (p. 91). In taking up a discourse approach, I viewed the site of knowledge construction as being situated within everyday interactional events, yet also worked to position these interactional events in the broader social and political

context. I took seriously Wetherell's (1998) critique of poststructuralists who in taking a global view of discourse may fail "...to explain how their perspective might apply to what is happening right now, on the ground in this very conversation" (p. 395). I also considered her critique of conversational analysts who she suggested "rarely raise their eyes from the next turn in the conversation" (p. 402). So, as I adopted a DP framework, which draws upon both poststructural and conversation analysis perspectives, I worked to engage in a detailed analysis of how participants build the local particulars of the events in which they are engaged both in and through conversations (Schegloff, 1992). In other words, I took note of the ways in which the participants' very interactions worked to co-construct certain versions of abstract concepts, such as autism and dis/ability. I presumed that their situated talk was always *doing* something, informed but not determined by broader structures and institutions. Finally, as I engaged with discourse theory, I also closely attended to dis/ability theory, acknowledging that despite extant scholarship exploring race, gender, sexuality, and class, etc., little discursive research, and critical research in general, has interrogated dis/ability (Goodley & Roets, 2008). For me, the significance of attending to dis/ability theory was situated in "its radical challenge to the medical or individual model of disability" (Barnes & Mercer, 1997, pp. 1-2).

So, with multiple theories serving to inform this work, in the paragraphs below, I focus on the overarching frame of discursive psychology, highlighting its major influences and pointing to the way in which I now orient to a more expansive notion of discourse. Then, I describe the social-relational model of disability (Thomas, 2004) and briefly explicate the ways it informed my study.

An Overview of Discursive Psychology

The DP framework is viewed not simply as a set of methods, but as a methodological approach with explicit and consequential assumptions (Edwards, 1997; Hepburn, 2003; Potter, 2003). Emphasizing local practices and knowledges (Scott, 1998), I aligned my use of DP with qualitative inquiry approaches that attend to insiders' perspectives and everyday practices (de Certeau, 1984). With discourse analysis forming the basis of a distinctive form of DP, this framework is both theory and method; further, it is "a perspective on the nature of language and its relationship to the central issues of the social sciences," entailing "not only practices of data collection and analysis, but also a set of metatheoretical and theoretical assumptions" (Wood & Kroger, 2000, p. x).

Throughout this research, I took up the idea that language, in all its forms, is constitutive rather than representative or reflective of a social or cognitive reality. The history of the notion of language as functioning to *do* something or as constitutive, not simply representing some hidden meaning or cognitive process, can be traced back to the earlier works of linguistic philosophers such as Wittgenstein (1958) and Winch (1967), as well as the later works of Berger and Luckmann (1967). Prior to Wittgenstein and other linguistic philosophers, the arguments of the seventeenth century philosophers Descartes (1637/2006, 1641/2008) and Locke (1689/2006) most notably influenced the modern day idea of the human mind and language (Rorty, 1979). Prior to Descartes, the Greeks believed that knowledge could simply be acquired directly, with the human eye being the metaphorical image representing the notion that individuals directly perceived their surrounding world. Following Descartes' philosophical contributions, the metaphorical image of an eye was replaced by that of a mirror, with perception still viewed as

essential to acquiring knowledge (Potter & te Molder, 2005). However, knowledge was still understood as being indirectly represented within the mind. With Descartes' well known mind/body dualism permeating many of the assumptions regarding the mind, the stage was set to treat "perception as the mind's mirror on the world" (Potter & te Molder, 2005, p. 7). Nearly fifty years after Descartes, the ideas of Locke (1689/2006) further shaped the ways in which cognition has come to be understood. Locke, more closely attuned to the nature of knowledge and reasoning, hypothesized that knowledge is directly derived from experience. He stated that "the internal operation of our minds perceived and reflected on by ourselves, is that which supplies our understandings with all the materials of thinking" (Locke, 1689/2006, Bk I, Ch. I, pt. 2).

In relation to the role of language, Harris (1988) suggested that Locke conceptualized language as the conduit for internal thoughts and representations. He understood words as simple signs and symbols representative of human thoughts. Locke (1689/2006) stated:

> Man, though he have great variety of thoughts, and such from which others as well as himself might receive profit and delight; yet they are all within his own breast, invisible and hidden from others, nor can of themselves be made to appear. The comfort and advantage of society not being to be had without communication of thoughts, it was necessary that man should find out some external sensible signs, whereof those invisible ideas, which his thoughts are made up of, might be made known to others. (Bk. III, Ch. I, pt. 1)

While the notion that ideas are hidden and potentially discoverable behind one's words is one espoused by many cognitivists today, it is historically linked to the writings of Locke; it is this

notion that ideas are hidden and discoverable that post-cognitive theorists do not presume (Edwards, 2006; Kitzinger, 2006).

Descartes and Locke were not the only philosophers who contributed to the understanding of the human mind and language. However, many of their assumptions remained unchallenged until the work of linguistic philosophers such as Wiggenstein (1958). In fact, some suggest that Wiggenstein provided the most thorough critique of the Cartesian models of thinking and behaving (Potter, 2000). His writing challenged the dualist approach to truth and certainty, rejecting the assumption that thinking, knowing, and seeing are simply by-products of internal mental representations. Wiggenstein instead postulated that mental concepts are grounded in communicative actions carried out by members within a particular discursive community. In many ways respecifying how the mind and language were conceptualized, Wiggenstein's postulation was a radical move away from the purely mentalistic notions of human thought. Further, as Derrida (1981) noted, the structuralist idea that meanings are always constructed in and through a system of signs, results in each meaning being constructed in relation to something else; in other words, every word, idea or concept brings with it all other words, ideas, or concepts that are different from it. However, Derrida, like other poststructuralist went beyond such structuralist ideas, and suggested that in order to reify a particular meaning, positioning it as a superior representation of reality, all of the words, ideas, or concepts that shape its meaning are subordinate (Hepburn, 1999). In the context of this study, then, dis/ability does not even make sense without the concept of ability, with its very meaning differing from and being evaluated against, while still incorporating, its opposite, in situated and contextually specific ways.

So, as many social scientists negotiated a crisis of representation and legitimization within their own work and research traditions (Clifford & Marcus, 1986; Geertz, 1988; Marcus & Fischer, 1986), language is no longer understood to directly correspond to a given segment of reality. This is known as the discursive/linguistic turn in social science. Even though discourse research can be traced back to the 1920s, it was during the 1980s that the discourse research traditions flourished. Within each of these discourse traditions, the shared and fundamental assumption is that, first and foremost, language is viewed as constitutive of social life, constructing objects and minds, as well as the grander social world. Each tradition maintains that discourse does not exist in a vacuum or somehow possesses some abstract meaning. Rather, discourse is understood as being shared and embedded within "complex societal structures" (Phillips & Hardy, 2002, p. 4).

As a broad framework, DP attends to how *"*'psychology' and 'reality' are produced, dealt with and made relevant by participants in and through interaction" (Hepburn & Wiggins, 2005a, p. 595). Within other research traditions, such concepts have historically been studied through laboratory experiments, tests, surveys, and interviews, resulting in technical accounts of psychological states. For example, following participation in an educational activity, students might be asked to rate the extent to which they felt motivated to participate in a given activity. Their rating may then be presumed to directly correspond to their motivational level, with a psychological construct such as motivation presumed to be an internal, stable state that is quantifiable. In contrast, DP orients to constructs, such as learning or motivation, as "objects in and for interaction," whereas psychology is "understood as part of the discourse, as a feature of practices in a range of settings" (Potter, 2005, p. 789). In lieu of giving accounts of research

participants' psychological or emotional states and cognitive processes or assuming an underlying explanation for why people say or think as they do, DP chooses to view mental states, motives, and thoughts to be features which are situated in and made visible through discursive practices.

DP asserts three fundamental principles related to the way in which discourse is defined (Potter, 2004). First, discourse is understood as being action-oriented, leading the analyst to primarily focus on what discourse is doing within interaction. Second, discourse is viewed as constructed. Therefore, the analyst considers the actual words and rhetorical devices employed within interactions, as well as how the discourse works to construct and stabilize certain versions of the world. Finally, discourse is considered situated, being bound up and embedded within a given interaction. The situatedness of discourse occurs in three ways. First, discourse is situated within a conversational sequence. For example, within a given interaction, a participant's talk typically follows and orients to the talk that was voiced prior. Second, discourse is institutionally situated, as it is often generated within institutions, and gives sense and structure to such institutions (Potter & Hepburn, 2008). Finally, discourse is rhetorically situated, as constructions are often built in ways that counter alternative arguments. Such constructions are built to provide norm-oriented accounts for one's actions and beliefs (Edwards, 1997).

While I analytically and theoretically was informed by DP's more restricted notion of discourse, over time, and through further study, I extended my understanding of discourse to include, as Laclau and Mouffe (1985) suggested, all objects and actions situated within the system in which meaning is produced, and by historically specific systems of rules and a system of differences (Foucault, 1971). While DP's definition of discourse certainly overlaps with

Laclau's and Mouffe's definition, DP approaches to discursive research tend to focus on micro-level conversational features to a greater extent than does the research linked to Laclau and Mouffe. Nevertheless, Laclau and Mouffe, who do not deny the usefulness of considering the conversational and linguistic features of talk, consider most closely the broader social and political practices and structures that shape and perhaps even constrain discursive practices. For Laclau and Mouffe (1985), who draw upon post-Marxist and poststructural positions (Laclau & Mouffe, 1987), discourses are always partially fixed and contingent, characterized by a surplus of meaning that is never exhausted. While such notions of discourse supported my own epistemic and ontologic orientations (see "Positionality Statement" in Chapter II), this particular perspective on discourse was far more useful at a theoretical level than at an analytical level.

As an example of the DP methodological approach, I offer an illustration drawn from Edwards' (1999) work around interactions within a counseling session for couples with marital challenges. Within this extract, the female participant (Connie) discussed the events which occurred prior to her husband leaving her. Note that the transcript includes conventions developed by Jefferson (2004) (see Appendix G); I maintain the exact formatting of the original publication.

Extract 1 (DE-JF:C2:S1:4)

1 *Connie*: At that poi:nt, (0.6) Jimmy ha- (.) my-
2 Jimmy is extremely jealous. Ex- extremely
3 jealous per:son. Has a:lways ↓been, from
4 the da:y we met. Y'know? An' at that point
5 in time, there was an episo:de, with (.) a

6 bloke, (.) in a pub, y'know? And me: having

7 a few drinks and messin' (0.8) That was it

8 (0.4) Right? And this (0.4) got all out of

9 hand to Jimmy according to Jimmy I was

10 a:lways doin' it and .hhh y'know a:lways

11 aggravating him. He was a jealous person

12 I: aggravated the situation. .h And he

13 walked out that ti:me. To me it was (.)

14 totally ridiculous the way he (0.8) goes o:n

15 (0.4) through this problem that he ha:s.

(pp. 273-274)

Within Extract 1, one of the many constructs Edwards highlighted and analyzed was "jealousy." Edwards, offering one interpretation of the "talk," suggested that perhaps Connie constructed "jealousy" as being a lasting quality of Jimmy's personality, as something that existed long before she "aggravated the situation." Edwards further considered the social implications of Connie's description of Jimmy as "extremely jealous" in relation to the institutional context (i.e., counselling session). He argued that within this particular context, emotionally-laden terminology, such as "jealous," may have acted to turn the focus toward internal events (e.g., Jimmy's jealous disposition), and move the attention away from the event (e.g., Connie's behaviour at the pub) toward which the emotion (e.g., "jealousy") is directed.

It is from this perspective that DP approaches all attributions and expressions of experience, internal states, and activity. Instead of jealousy being viewed as existing or not

existing as an internal cognitive reality or emotional state, DP focuses on the ways in which emotions, minds, and selves are made relevant in talk. Talk, then, is viewed as produced for interactional and social purposes, instead of being viewed as simply reflective of internal happenings. Therefore, the discourse analyst chooses to focus on that which is available to her (the participants' talk), in lieu of attending to that which is assumed unavailable (the internal experience) or accessible only through interviews or researcher intervention. It is important to note that the researcher's positionality always frames the very act of interpreting what is available in the talk, thus, making it important for the analyst to make explicit her presuppositions and engage in recursive reflexivity.

Not surprisingly, the way in which discursive psychologists have come to make sense of and study discourse has been deeply influenced by other discourse traditions, as well as the seminal work of key discourse researchers. In the next section, I highlight two research traditions that have deeply influenced DP and point to DP's epistemic and ontologic assumptions.

Historical influences. Although much of the DP tradition can be traced back to work emerging out of the Discourse and Rhetoric Group (DARG) at Loughborough University in the United Kingdom during the late 1980s and 1990s (for a complete history, see http://www.lboro.ac.uk/departments/ss/centres/darg/dargindex.htm), the earlier discourse traditions of conversation analysis and ethnomethodology deeply influenced the assumptions espoused by DP. Prior to expounding on DP's overarching assumption of discursive constructionism, I provide a necessarily brief description of both ethnomethodology and conversational analysis.

An ethnomethodological approach emphasizes the ways by which people make sense of and order their social worlds. In 1963, sociologist Harvey Sacks published one of the earliest ethnomethodological writings within which he suggested that the ways in which people self-characterize are central to the social world. This social world was conceptualized as being constituted by and organized with "versions and representations" of the social world itself (Potter, 1996, p. 42). Sacks argued that the site of study should be the way people describe their social world. Shortly thereafter, Garfinkel (1967) contributed to the development of ethnomethodology, focusing his work on the methods people use for making their description of the social world reasonable and justifiable. He stated that ethnomethodological studies aim to "analyze everyday activities as members' methods for making those same activities visibly-rational-and-reportable-for-all-practical-purposes, i.e., 'accountable,' as organizations of commonplace everyday activities" (p. vii). Since its early development, then, there have been a wide range of ethnomethodological studies focused on the everyday activities, with many focused on workplace activities. For instance, some studies have considered the very doing of research in laboratories (Lynch, 1985), while others have considered the local social orders involved in doing piano improvisations (Sudnow, 1978). Heap's (1990) ethnomethodological study explored how interruptions or repairs made by reading teachers during oral reading lessons with elementary aged children had a locally sensible function, as the teachers oriented to their task as monitoring each reader's performance and compliance with the social order.

Although there are many concepts within ethnomethodology that continue to influence work within DP, I focus on two in particular: indexicality and reflexivity. Indexical expressions are those expressions that are local, time bound, and situational. Such expressions are "those

whose sense depends on the local circumstances in which they are uttered," like 'you' or 'yesterday'" (ten Have, 2004, p. 21). The lasting influence of this particular ethnomethodological concept is seen in how DP orients to discourse as situated, focusing on a sequence of talk as occasioned or part of a given social setting. Reflexivity, in an ethnomethodological sense, refers to the idea that people's descriptions of the world are not just about something, but that they are also doing something (Garfinkel, 1967). In other words, the descriptions are involved in "being both about and a part of" the world, pointing to the constitutive nature of language (Potter, 1996, p. 47).

With strong ties to ethnomethodology, conversational analysis (CA) has aligned closely with the concepts of indexicality and reflexivity, applying such concepts specifically to conversations. More exactly, CA can be defined as the study of natural talk-in-interaction, with its origins traced back to the well-known lectures of Sacks (1992) and the work with his colleagues, Jefferson and Schegloff (Sacks, Schegloff, & Jefferson, 1974). Most famously, Sacks rejected Locke's assumption of language as simply being made of signs used to transport thoughts from mind-to-mind. Within CA, it is assumed that what people say is not accidental, or simply a way to transmit thoughts from the brain out into the world, but that the words used are selected intentionally in relation to the contextual role they play within a given interaction. With its disciplinary home in sociology, CA successfully eschewed the study of cognition and built a large repertoire of empirical work, showing how an interaction can be explained by a set of variable, yet somewhat predictable and orderly conversational principles (for a summary see Potter & Wetherell, 1987). For instance, in many contexts, there is a shared understanding that a speaker's greeting, such as "Hello, how are you?" will be followed by the *appropriate* kind of

response by the recipient, such as "I'm fine" or "Hi, good"; rather than "Well, my car just broke down and my brother's in the hospital; so really I'm not well." While there are a range of possible responses, there are indeed formulaic conversational openers, for instance, or certain expectations regarding how talk should proceed, albeit always specific to a given context.

Potter and te Molder (2005) described four assumptions that are shared by CA, ethnomethodology, and DP. They included a belief that (1) discourse is the medium of action; (2) discourse is locally and situationally organized; (3) the way the participant orients to the interactional sequence is basic to understanding the interaction; and (4) the analytic approach of choice is the study of natural interactions. Moving beyond that which is shared, constructionism is what sets DP apart from both CA and ethnomethodology, serving also to ground DP's epistemological and ontological claims.

Epistemological and ontological assumptions. The epistemic position of both the researcher and what is researched is a distinctive feature of the DP approach (Potter & Hepburn, 2008). With the site of study centered on participants' descriptions, claims, and assertions, the focus of knowledge production never moves beyond the discourse itself, apart from when the interpretation of the research moves from the analyst's world onto the page in the act of representation. Additionally, the written texts and journal articles of the discursive psychologist are not viewed as neutral, realist versions of the world (Potter, 1996). Instead, the discursive analyst is actively engaged in constructing a particular version of the world. Within a DP perspective, knowledge is considered situational and socially organized as it varies across different moments within conversational interactions (Garfinkel, 1967). Potter and Hepburn (2008) stated that "understanding is not something floating in a phenomenological space but

something structurally located," with social organization being an ongoing accomplishment negotiated by individuals engaged in an interactional event (p. 286). Ontologically orienting to the social world from a constructionist perspective, DP views talk and texts as constituting social realities.

Viewed as "radically constructionist," DP draws upon anti-foundational and poststructuralist perspectives (Potter & Hepburn, 2008, p. 275). Although quite similar to social constructionism (Gergen, 1994; Harré & Gillet, 1994; Shotter, 1993), DP's brand of constructionism, discursive constructionism, has its roots within sociology of science (Woolgar, 1988) and non-foundational philosophy. Subsequently, discursive constructionism shares a rejection of static foundations of truth. While social constructionism makes no claim of non-foundational principles, Potter (1996) described DP's perspective on constructionism as somewhat different in at least two ways. First, DP views discourse itself as constructed (e.g., how words are put together within an interaction). Second, DP attends to the ways in which the world is constructed within discourse. In other words, "descriptions are constructed (how are accounts built?) and constructive (how do accounts build the world?)" (Hepburn, 2003, p. 176). In addition, DP orients to constructionist notions by focusing on the particularities of participants' discourse, viewing them as situated categorizations and understandings.

It is important to highlight that in DP's conception of constructionism, phenomena are considered in terms of the role they play in descriptions, categories, and orientations constructed by the social participants. For example, Wiggins (2002) studied the "mmms" that people made while eating, showing how "mmms" worked to produce spontaneous expressions of pleasure. Within this research, Wiggins also showed how "mmms" were socially organized and

coordinated between the different speakers/eaters, acting as food compliments. Research focused on utterances, such as "mmms" or nonverbal discourse, moves beyond simply recording expressions and/or nonverbal behaviors and instead focuses on how gesture, for instance, contributes to the ongoing interaction of the participants. DP does not conceptualize gesture, gaze, and other expressions as "information leakage" that only "a skilled analyst can detect behind the backs of the participants" (p. 290). In contrast, for a discursive psychologist, phenomena such as "mmms" or gaze are conceptualized as being central parts of the world that is constructed through the ongoing interaction.

With a focus upon the way participants make sense of the verbal and nonverbal components of a given interaction, discursive psychologists avoid the privileging of an a priori framework and/or discipline specific theories (Stokoe, 2008a). For example, the discourse analysts would not attempt to analyze the conversational data of children with autism labels and their therapists while drawing upon an a priori framework, such as those linked to theory of mind deficits in individuals with autism labels (Baron-Cohen, Leslie, & Frith, 1985). Instead, the discourse analyst would focus upon the embedded, discursive practices of the social actors, not starting "with a predefined model of the human actor," but with what participants make relevant in their discourse (Potter, 2003, p. 791). Thus, as I describe below the ways in which a theory of choice, the social relational model of disability, informed how I oriented to dis/ability, I briefly point to what the social relational model of disability was used to do within this study. With little research drawing upon data from either children with autism labels or the social relational model of disability, this study's explicit attention to a social relational view of dis/ability situates

this project within current scholarly conversations within the field of disability studies in education.

Recasting Dis/ability

Historically, dis/abilities have been constructed as biological truths, with the medicalization of bodies resulting in "problems" being viewed as discrete diseases that only legitimated agents (e.g., psychiatrists, health professionals, etc.) are capable of discovering, naming, and treating. The social model of disability opposes a medical orientation to dis/ability and defines dis/ability in relation to the social and built environment, "arguing that disabling environments produce dis/ability in bodies and require interventions at the level of social justice" (Siebers, 2008, p. 25). Within this study, I oriented to dis/ability, and autism more particularly, as inseparable from the cultural models that define it, recognizing that: "The ideology of ability makes able-bodiedness compulsory, enforcing it as the baseline of almost every perception of human intention, action, and condition, and tolerating exceptions only with difficulty" (Siebers, 2008, p. 103). By assuming that a dis/ability category is an interactional resource, I epistemologically oriented to the "able-bodiedness" or "dis/abled-bodiedness" as being produced by and existing in discourse (Coupland & Gwyn, 2003). Like McSwite (2001), I critique the reification of the body as located outside of discourse, and suggest instead that the body is located in discourse. In other words, the "world of words" which "creates the worlds of things" (Lacan, 1977, p. 65) includes the body.

Social Relational Model of Disability

Within the social relational model of disability, Thomas (2004) conceptualized dis/ability as relevant only when socially imposed restrictions of activity are experienced by people labeled dis/abled. In other words, dis/ability is created when restrictions are social in origin and made relevant by the social actors. Arising from the philosophical criticisms and definitional limitations of the social model of disability, Thomas (1999, 2001, 2004) and others (Finkelstein, 2000; Reindal, 2008) suggested that there is a need to reconsider "social relational" components when conceptualizing dis/abilities. The traditional social model of disability focused on the social aspects of dis/ability, pointing to dis/ability as an ahistorical and non-universal social creation (Corker & Shakespeare, 2002).

Although important in emphasizing and theorizing the ways in which varied social, cultural, and historical contexts create and name dis/ability, the social model of disability is often critiqued for failing to consider the personal and social consequences of impairment effects (Reindal, 2008). Subsequently, an "over-socialized understanding of impairments" has emerged, making it difficult to discuss and theorize the experience of impairments as potentially separate from the socially created notions of dis/ability (S. Reindal, personal communication, June 2008). The social relational framework addresses this over-socialized perspective, separating dis/ability from impairment effects. Within this framework, dis/ability is viewed as a social construct, as well as a "form of oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional wellbeing" (Thomas, 1999, p. 60). However, with dis/ability only coming into play when there is a restriction placed on one's activities, Thomas (2004) suggested "that it is entirely possible to

acknowledge that impairments and chronic illness [may] directly cause *some* restrictions of activity—but such non-socially imposed restrictions of activity do not constitute 'disability'" (p. 581). She defined the three major elements of the social relational model as follows: (1) Barriers to being—refers to behaviors, thoughts, and/or comments having a negative effect on the individual's sense of self, impacting what they feel they are and can become; (2) Barriers to doing—refers to physical, economic, and material barriers which restrict or prevent people from doing certain activities; and (3) Impairment effects—restrictions of activity resulting from living with an impairment.

From this perspective, *impairment effects* and *dis/ability* are viewed as being interactively experienced by individuals, with both components merging together. For example, an individual with an autism label may express him/herself nonverbally, with the sole use of nonverbal communication being defined by some as an *impairment effect*. The individual's nonverbal mode of communication, however, does not indicate dis/ability from a social relational perspective, but may become "the marker for other restrictions of activity which do constitute disability" (Thomas, 1999, p. 43). For example, if the individual's non-verbal mode of communication results in him/her not being allowed to participate in social events with peers or in being viewed as abnormal, a dis/ability then emerges. When people in positions of power determine that this individual cannot perform certain activities or participate in a particular setting due to his/her impairments, the individual then experiences a dis/ability as his rights are denied.

Within my data collection and analysis process, I was particularly interested in exploring the ways in which participants worked to reframe discursively the "behaviors" of the children

with autism labels as acceptable or unacceptable, noting the ways in which dis/ability was made relevant. Further, I was particularly interested in the ways in which impairment effects were worked up discursively and put on display in ways that created possibilities and constrained and/or regulated who and what one could be and do (Pace, 2009). In this project, I positioned the body as a site of discourse (Morgan, 2005), with the body being denaturalized and reconstituted "as an effect of discourse...a socially constituted body: multiply reconstructed in the various manners of speaking that resource our body talk" (Potter & Wetherell, 1987, p. 361).

Throughout this research project, I also oriented to dis/ability critically, and took up Wodak's (1999) notion of critical, in which "critical":

> ...does not mean detecting only the negative sides of social interaction and processes and painting a black and white picture of societies. Quite the contrary: Critical means distinguishing complexity and denying easy, dichotomous explanations. It means making contradictions transparent. Moreover, critical implies that a researcher is self-reflective while doing research about social problems. (p. 186)

Further, I recognize that social life is constructed in contexts of power (Noblit et al., 2004), e.g. one individual is labeled while the other does the labeling. As such, I acknowledge the non-neutral and political nature of language and view dis/ability as being (1) a social construct; (2) political; and (3) made relevant through discourse. Yet, despite my claims regarding the non-neutral, political nature of language, within this study, I take up DP's relativistic position, attending to issues of power and/or dis/ability only as they are made relevant by the participants. I am interested in exploring if and how the participants of this study take up impairment effects, barriers to being, and barriers to doing. It is important to note that the social relational model of

disability informed the way in which I made sense of the notion of dis/ability. With this study situated within the participants' descriptions and assertions, the focus of knowledge production emphasized the participants' discourse itself.

Chapter Summary

In Chapter IV, I presented the reader with a summary of the theoretical ideas which informed this research, maintaining a focus on DP and the social relational models' distinctive features. First, I provided an overview of the ways in which I worked to understand discourse research across traditions. Then, I highlighted the most salient aspects of DP and the ways in which discourse is defined and oriented to. Second, I presented a brief overview of the ways ethnomethodology and conversational analysis influenced the theoretical and analytical assumptions held by DP. Third, I described the epistemological and ontological positions maintained by discursive analysts, focusing upon the notion of discursive constructionism. Finally, I briefly discussed the social relational model of disability, emphasizing how its inherent assumptions regarding dis/ability informed this work. In the next chapter, I describe the methods used in this study.

Chapter V: Methods

The purpose of this study is to examine how autism is performed as an interactional event between children with labels of autism, the therapist(s) who work with them, and their parents. For children with diagnostic labels, and their families who frequently interact with a variety of professional bodies and participate in a variety of "intervention" programs, a therapeutic/clinical setting provided a useful forum for examining how the construct of autism is made relevant and managed in the talk of people within a natural setting (O'Reilly, 2004). I employed a discursive psychology (DP) approach, in order to attend to how discourse both constructs the social world and is a part of the social world (Edwards, 1997; Potter, 1996). Prior to delineating the assumptions, theories, and methods that framed this study, I provide an outline of the chapter.

Chapter Overview

In this chapter, I first remind the reader of the research questions. Second, I present an overview of the epistemological and ontological views of this study's research approach. Third, I briefly describe the site of data collection and the participants. Fourth, I delineate the data collection procedures and subsequent data analysis process, attempting to transparently outline and illustrate how I applied a discursive framework to the data.

I include examples from previous studies of several conversation analysts (e.g., Drew, 2004; Sacks, 1992) and discourse analysts (e.g., Horton-Salway, 2001) to clarify the ways in which I analyzed and interpreted this study's data set. More particularly, I draw upon O'Reilly's (2004) dissertation research which focused upon family therapy sessions with

"children who have diagnosable problems" (M. O'Reilly, personal communication, October 2009), as well as her related research studies (2005a, 2005b, 2005c, 2006, 2007, 2008a, 2008b). Similar to my study, O'Reilly's extensive research focused upon institutional talk (i.e., therapy sessions with therapists, "concerned" parents, and children), while also orienting to the idea of dis/ability from a social constructionist perspective. Although O'Reilly's research does not attend to how autism is performed as an interactional event, the ways in which she took up a DP perspective aligns, to some extent, with this research project, offering numerous examples of how to make sense of conversational data situated within institutional settings. Like O'Reilly, I framed this methodological process as emergent. Hence, what I describe below was not a static process, but one that evolved over the course of this study.

Research Questions

From the pre-phase components of this study to the writing and reporting of the findings, a continual re-evaluation of the research questions, methodological approach, and findings occurred. Recognizing that research questions are subject to change as the research process unfolds (Rapley, 2007), my initial research questions, (1) What meanings of "autism" are performed in the talk of parents, therapists, and the child with an autism label? and (2) How does "autism" work within talk to account for "problematic" or "autistic" behavior(s)?, changed as I collected and analyzed the data, and began to share my initial interpretations with the participants. The final research questions were:

1. What are the various meanings of autism and how are these meanings performed within and through the discursive practices of therapists and parents of children with autism labels in their everyday interactions?
2. How do children with autism labels and their therapists and parents discursively manage and account for the behaviors and communication approaches made relevant in therapy?

As I examined how autism is performed as an interactional event, I methodologically positioned this qualitative work within a DP framework, drawing upon aspects of the discursive action model (Edwards, 1997; Edwards & Potter, 1993; Potter, 1996), related poststructural notions of discourse (Derrida, 1981; Foucault, 1971; Howarth, 2000), and conversation analysis (Sacks, 1992). The following sections briefly explicate the rationale for this methodological choice and the research approach that I employed.

Rationale

This study took up certain aspects of the discursive action model (Edwards & Potter, 1993), a DP approach to examining conversational data. Like other qualitative approaches, the discursive action model allows for an inquirer to attend to the meaning(s) within social life (Winch, 1958). However, it moves beyond attempting to understand how people within a given context attach meaning to their world, not viewing discourse data as a way to access what occurs within an individual's mind. Instead, this methodological approach offers a theoretical and analytical lens by which to consider the social actions initiated and achieved by what people do in and with their talk.

I chose this methodological approach for three reasons. First, my interest in the discursive construction of autism closely aligns with this approach. With the discursive action model "designed to link different features of participants' discourse together in a systematic manner, paying particular attention to workings of these features in participants' social practices" (Potter, Edwards, & Wetherell, 1993, p. 388), this discursive approach supported the overall aims of this project. Second, in that I presuppose that the meaning of autism is situationally constructed through talk, I desired to select a methodological approach that would allow me to examine how the participants accomplish, manage, and contest the meaning of autism. Since the discursive action model focuses on exploring what people do with their talk, as well as how certain versions of the world are constructed and maintained, this methodological approach fits with how I orient to the notion of constructing meaning. Therefore, I aligned this project's research questions and data analysis process with the assumptions of this particular discursive approach.

Finally, as a researcher, there are certain epistemic and ontologic assumptions that act to shape and frame how I study and interpret the world. I sought to maintain continuity between my own epistemic and ontologic beliefs, and those inherent to my methodology of choice. Thus, when determining whether to employ a DP approach, I first critically considered whether its theoretical and philosophical assumptions aligned with my own. Recognizing that my presuppositions regarding knowledge construction and the nature of reality align with the philosophical underpinnings of DP, I carried out this project with a sense of continuity.

Research Approach

As noted in Chapter IV, DP is both a theory and an analytic method, with empirical work from conversation analysis (Sacks, 1992) and ethnomethodology (Garfinkel, 1967) influencing its fundamental theoretical and analytical assumptions. In this section, I provide a description of the DP approach, presenting only that which was most relevant to the analytical approach of this study. I begin with a general overview of the discursive action model, a DP framework that I drew upon in making sense of the data. Then, I provide a brief description of how conversation analysts, in particular, define and attend to category work and turn-taking organization (Sacks, 1992). With both conversation analysis and DP being well-established modes of inquiry (for fuller descriptions of conversation analysis and DP see Hutchby & Wooffit, 2008, *Conversation Analysis*, and Edwards & Potter, 1992, *Discursive Psychology*), I will necessarily present an abbreviated description.

The Discursive Action Model

The assumptions of the discursive action model, a DP framework developed by Edwards and Potter (1993), are consistent with those of DP described in Chapter IV. Although the various components of the discursive action model overlap, the related ideas have been organized into nine subparts and three broad themes: (1) action, (2) fact and interest, and (3) accountability. Table 1 itself is simply a means by which to organize the various ideas often considered when analyzing discourse; the included ideas are not intended to function as an a priori framework, as DP approaches are considered emergent and variable. While maintaining a commitment to the

emergent nature of DP work, I offer Table 1 and the subsequent discussion as an illustration of the various components of the discursive action model.

Table 1

The Discursive Action Model Framework (Potter et al., 1993, p. 389).

Action

1. The research focus is on action rather than *cognition* or *behavior*.
2. As action is predominantly, and most clearly, performed through discourse, traditional psychological concepts (memory, attribution, categorization, etc.) are reconceptualized in discursive terms.
3. Actions done in discourse are overwhelmingly situated in broader *activity sequences* of various kinds.

Fact and Interest

4. In the case of many actions, there is a *dilemma of stake or interest*, which is often managed by doing attribution via factual reports and descriptions.
5. Reports and descriptions are therefore constituted/displayed as *factual* by a variety of discursive devices.
6. Factual versions are *rhetorically organized* to undermine alternatives.

Accountability

7. Factual versions attend to agency and accountability *in the reported events*.
8. Factual versions attend to agency and accountability in the current speaker's actions, including those done *in the reporting*.
9. Concerns 7 and 8 are often related, such that *7 is deployed for 8, and 8 is deployed for 7*.

The first focus of the model is that of action (points 1, 2, and 3). Within this focus, the discourse analyst attends to what people actually *do* with their talk (point 1). So, in lieu of giving accounts of research participants' psychological states and cognitive processes, or seeking an underlying explanation for why people say something or think as they do (point 2), this approach assumes that mental states, motives, and thoughts are all features which are situated in and made visible through discursive practices. As a result, phenomena previously understood from a cognitivist perspective are reconceptualized within the discursive framework.

To illustrate how this model works to reconceptualize a concept such as remembering (point 2 and 3), consider the following excerpt from a study focused on conversations within a rape trial (Drew, 1990, as cited in Edwards et al., 1993). The counsel for the defense (C) is questioning the prosecution's witness (W), who is the victim of the alleged rape:

C: [referring to a club where the defendant and the victim met]: It's where girls and fellas meet, isn't it?

W: People go there.

In an analysis of the above excerpt, Edwards et al. (1993) suggested that both the counsel and the witness produced particular versions of the activities that occur at a club. The discourse analysts pointed to how the counsel's description of a club as a place "where girls and fellas meet" implied that the club's clientele had particular expectations of one another (a frequent description used by the defense within rape trials). In turn, the witness's response, "people go there," perhaps acted to neutralize the implications related to the implied expectations of the club's clientele. As reported across the literature on the talk of rape trials (Edwards et al., 1993), "memory" can be discursively reworked as being that which is constructed by inferences that

often make "available the responsibility" of the involved parties (Potter et al., 1993, p. 391). Thus, in this particular extract/analysis, remembering is reworked as a discursive construction of reality that performs a particular social action. In a similar way, in this research study, I aimed to rework autism as a discursive construction of reality that is not representative of a biological truth, but instead made real in everyday conversations.

The second focus of the discursive action model is related to how people construct accounts in order to make them seem factual (points 4, 5, and 6). For example, when describing a position, people, including social scientists, often rhetorically organize their description in a way that makes the account seem believable. In doing so, the speaker, orienting to the possibility that their description may be dismissed or discredited, often discursively works to undermine alternative explanations (Billig, 1996; Potter, 1996). Constructions, then, are often built in ways that counter alternative explanations. For example, in Woofit's (1992) work on people's accounts of paranormal events, he noted that when people describe such unbelievable events, the accounts are rhetorically constructed to resist the skepticism of non-believers. Such constructions are built to provide "norm-oriented accounts and justification for" actions and beliefs (Edwards, 1997, p. 9). Thus, discursive psychologists often explore how the discourse itself is built and performed within a given situated interaction. Furthermore, discursive devices such as vivid descriptions, narratives, and corroboration are often deployed when constructing these factual accounts (Edwards & Potter, 1993). This analytical approach, then, does not treat a participant's account as a way of discovering their internal experiences, but instead views the account as actively constructing a version of the world. In relation to my study, I attended to the ways in which the participants, particularly the participating parents and therapists, made

relevant and (re)framed the behaviors/actions of the participating children with autism labels as reasonable and/or easily explainable.

The final focus within the discursive action model is that of accountability, or the ways in which people routinely attend to issues of agency and responsibility in their talk (points 7, 8, and 9). As noted above in the example from the rape trial, accountability is often constructed through a speaker's inferences about the responsibility of a given party. Edwards and Potter (1993) pointed to the ways in which blaming and exoneration are accomplished in courtroom talk:

> Courtroom testimony is a special kind of talk, but it is developed from, and draws upon, the resources of mundane talk. It is a routine feature of conversation, and a special feature of courtroom dialogue, that establishing 'what happened' is done with regard to issues of personal responsibility, such that the psychological categories of memory and attribution have to be seen as intimately connected, even as mutually constitutive. Reporting of events carry their attributional implications with them, and are constructed precisely to do that. (p. 53)

Consequently, the question for the discourse analyst is not, "how do people understand their responsibility?" but "how is a version of an event constructed to imply responsibility?"

To illustrate how the discursive action model conceptualizes accountability and blame, I offer a brief excerpt analyzed by Potter et al. (1993). This particular excerpt was drawn from an interview with British Prime Minister Margaret Thatcher in which she was asked whether she was to blame for the resignation of her chancellor.

Thatcher: I tried very hard to dissuade the Chancellor from going (2) but he had

> made up his mind and in the end I had to accept his resignation and appoint someone else.

When analyzing the above excerpt, Potter et al. suggested that it is possible to make sense of Thatcher's talk as nothing more than a "neutral telling of the facts" (p. 395). However, for the discourse analyst, when attending to the discourse of a speaker, it is important to explore when/how the individual claims credit for or distances themselves from a reported event; it is through this that the doing of accountability is made visible. So, for Potter et al. (1993), Thatcher's response was designed, not to neutrally tell, but to display her lack of blame. In relation to my research, I considered the doing of accountability in the talk of the therapists and parents as they each participated in constructing certain versions of the individual child with an autism label. Further, I attended to how the therapists discursively recast the "concerning behaviors" of children with autism labels as being external to their way of being, and positioned the children as capable of "working through" the behaviors that had been worked up as challenging or in need of being adapted (e.g., "angry outbursts").

To summarize, for this discursive approach, it is critical to consider the action, construction, and rhetorical organization of the participants' discourse. For as talk performs particular actions (e.g., justifying, blaming, etc.), certain versions of reality are constructed and positioned in relation to alternative explanations and accounts (Horton-Salway, 2001). It is also important to note, however, that within this framework, the researcher is often positioned as the final authoritative voice, with very few discourse analysts inviting participants to evaluate and speak back to the researchers' interpretations. With a personal commitment to engaging in social science as "an activity done in public for the public," which acts "to clarify, sometimes to

intervene, sometimes to generate new perspectives" (Flyvberg, 2001, p. 166), in this project, unlike most discourse studies, I shared my interpretations with the participants as a means of opening up communication and complicating and deepening understanding (Anders & Diem, 2008; Tracy, 2010; see "Warranting Claims and Standards of Quality" below for a complete description).

Conversation Analysis

As Edwards (2006) indicated, within a DP approach, discourse is not understood as being synonymous with internal reality, feelings, knowledge, or external reality but as that which produces certain versions of events, minds, selves, and identities. This approach focuses not only on the way an account is constructed, but also upon the details of the interaction. With discourse viewed as situated within a conversational sequence, a discourse analyst attends not only to the words being said, but also to conversational features used, such as pauses, overlapping speech, or the way in which conversational turns are designed. The analyst attempts to make sense of the function of the relevant conversational features, noting what a particular feature acts to *do* in a given interaction. Yet, it is important to note that a DP approach to interactional organization and sequence structure is not as fine-grained as that of a conversation analysis approach (Hepburn & Wiggins, 2007), with some versions of DP promoting analysis that considers the relationship between micro- and macro- level discourses (Wetherell, 1998).

Like DP, a conversation analysis approach contends that when people talk, it is not simply descriptive. Rather, the conversation itself is the site of social action (Drew, 2004). For instance, when someone says, "would somebody like some more ice tea," the talk is not simply

about the topic of "tea," but, as Schegloff (2007) noted, the talk might also be about "doing an offer" (pp. 1-3). One speaker, through talk, is offering something to another. Thus, the very social activity can be understood through a focus on interaction (Drew & Toerien, 2011). Sacks (1992) notably warned researchers not to rely upon their intuition to surmise the cognitive states of their research participants. He stated:

> When people start to analyze social phenomena, if it looks like things occur with the sort of immediacy we find in some of these exchanges, then, if you have to make an elaborate analysis of it—that is to say, show that they did something as involved as some of the things I have proposed—then you figure that they couldn't have thought that fast. I want to suggest that you have to forget that completely. Don't worry about how fast they're thinking. First of all, don't worry about whether they're 'thinking.' Just try to come to terms with how it is that the thing comes off. Because you'll find that they can do these things. Just take any other area of natural science and see, for example, how fast molecules do things. And they don't have very good brains. So just let the materials fall as they may. Look to see how it is that persons go about producing what they do produce. (p. 11)

For the most part, conversation analysis has followed Sack's suggestion, focusing its work on the organization of actual talk rather than constructs that might underlie talk. With its disciplinary home in sociology, conversation analysis has built a large repertoire of empirical work, showing some of the situated ways in which conversational features function within talk to produce social activities (Sidnell, 2009).

Within this study, I drew upon only those conversation analytic principles that were relevant to my data set and interpretations (Liddicoat, 2007; Sacks, Schegloff, & Jefferson, 1997). In that a discursive approach attends primarily to that which was made relevant by the participants, the language features I determined to focus upon were not identified prior to the data collection process (see Hutchby & Wooffit, 2008, *Conversation Analysis* for further discussion on conversational features). As I paid particular attention to those conversational features made relevant in the talk of my participants, I actively sought to make connections between my interpretations of what was happening in the talk with what was already reported in the vast body of conversation analysis literature. For instance, in Chapter VIII, I present an excerpt from this study's data set and my related interpretation in which I point to the function of silences, a conversational feature, in the therapy session talk. Indeed, the conversational features I decided to focus on were informed by my positionality, research focus, and the participants' suggestions themselves (see Chapter VIII for a further discussion on the participants' interest in the function of silences in therapy talk). Nevertheless, in order to provide the reader with a broader understanding of the ways in which a conversation analysis approach informed my analysis process, I highlight just two conversational features that I explored, at some point, during my analysis process: category work and turn-taking organization (Sacks, 1992).

Category work. In regards to category work, as I analyzed the data, I attended to the descriptive categories or identities that were deployed, managed, and oriented to in the participants' talk (Antaki & Widdicombe, 1998). As I made sense of the various meanings of autism and how they were performed in the participants' everyday language use, I considered whether and how presumed categories of dis/ability and autism were made relevant by the

participants. In both DP and conversation analysis work, membership categorization (Hester & Eglin, 1997; Sacks, 1992) is considered in relation to how speakers sequentially assemble a category and related activities in order to accomplish a particular social action. For instance, occasionally I noted that the participating parents oriented to the therapists as maintaining a special position of "autism expert," thereby entitling the therapists to hold a precise and technical definition of autism. Sacks pointed to an example of membership categorization within children's stories in which the children's author wrote: "The baby cried. The mommy picked it up." Sacks suggested that the readers of this book identify the "mommy" as being the "mommy" because of the membership category of "family." The category "family" acted to categorize the "mommy" and "baby" as being linked to particular actions (category-bound activities) and/or characteristics (Stokoe, 2010). Therefore, certain conventional expectations constitute a "mommy's" or "baby's" normative behavior, being made relevant and/or accounted for in talk. In relation to my study, I took note of how dis/ability categories (e.g., autism) and category-implicative descriptions were used in conjunction with talk about and with the child with an autism label, therapist, or parent. Yet, as Stokoe (2010) noted, I did "not assume from the outset which...categories and activities participants may combine" (p. 62). I did, however, remain particularly attuned to moments in which dis/ability categories were made relevant, resisted, reframed, and/or linked to particular actions and/or institutional practices.

Turn-taking. Turn-taking organization, a fundamental conversational feature, refers to the ways in which speakers take turns during a conversational sequence, with each turn constructed to *do* something in the interaction. When analyzing conversational turns, it is important to consider how the turns are designed in relationship to where in a conversational

sequence they occur, what action is being done by each turn, and who the turn is addressed to (Drew & Toerien, 2011). Initially, I did not intend to give any particular attention to this conversational feature; however, when I first shared my initial interpretations of the data with the participating therapists (see Chapter VIII for full description), many of the participating therapists asked if I had "considered wait time" and the "non-typical ways that conversations occur" in the context of therapy sessions with the children with autism labels. As Megan,[13] one of the participating therapists, stated (October 8, 2010 from 1:00 to 2:00 pm):

> So, have you looked at turn-taking like with wait time stuff? Like the pauses? Because I think a lot of the children we work with have patterns that are dispreferred; so what often happens is people fill the space after 'How are you?' with a million questions. Like it totally makes people uncomfortable when people don't answer a question. Then, what happens when the kid answers the question like a minute later? I mean we make that normal in this space, but a lot of people who come to our place really struggle with that. I was just wondering if you analyzed what that was *doing*, as you say.

The participating therapists were particularly interested in turn-taking organization, as they viewed the silence/wait time between each turn as often being longer than usual (i.e., dispreferred wait time), resulting in many children with autism labels being misunderstood as incompetent when in fact they were just taking more time to respond. Thus, after my first meeting with the participants, I returned to the data and more closely attended to turn-taking organization, considering what it was doing across the data.

[13] Throughout the text, pseudonyms are used.

Comparing conversation analysis and discursive psychology. Although conversation analysis and DP hold many of the same assumptions regarding the locally organized and action-oriented nature of talk (Potter & te Molder, 2005), the epistemic claims of this study's DP approach are quite distinct. Potter and te Molder (2005) described four assumptions that are shared by conversation analysis, ethnomethodology, and DP. They included a belief that (1) "talk is the medium of action;" (2) "talk is locally and situationally organized;" (3) the way the participant orients is "basic to understanding talk-in-interaction"; and (4) generally the analytic approach of choice is the study of natural interactions (p. 3). Moving beyond that which is shared, constructionism and an anti-foundational orientation sets DP apart from both conversation analysis and ethnomethodology, serving also to ground DP's epistemological and ontological claims. Situated within a social constructionist perspective, the discursive action model views the researcher as actively constructing a particular version of the world. As Edwards (1997) noted, "...discourse is primarily what we produce, we academics, researchers, and writers of books on cultural (and other) psychologies" (p. 45). As such, as I analyzed the data, I worked to reflexively attend to my role in the creation and production of this study's findings.

Method

In the following paragraphs, I describe gaining access to the site and inviting the therapists, parents, and children to participate, provide relevant information about the participants, and explicate the data collection and analysis process.

Gaining access to The Green Room. In that the aim of this study was to examine the naturalistic talk of children with autism labels, as well as that of their therapists and parents, when selecting a research site, I gave particular attention to the types of settings in which such data might be available. Further, with a broader interest in talk that occurs within institutionalized settings, I considered settings that might provide talk-in-interaction between the participants of interest within an institutionalized context (e.g., therapeutic setting). Thus, for the purposes of this study, I invited the participation of a private pediatric therapeutic clinic (pseudonym: The Green Room[14]) that provided a variety of educational and health-related therapies and supports to children with developmental dis/ability labels and their families. Located in a mid-sized city in the Midwest region of the United States, The Green Room offered group and individual therapeutic sessions in occupational therapy, physical therapy, and speech-pathology therapy to well over 80 families and their children with dis/ability labels living in a bi-state area. The Green Room also provided group therapy sessions for children with dis/ability labels, often focused upon the development of daily living and social skills within the context of group and structured and unstructured play settings.

In the summer of 2009, I began conversations with the directors of The Green Room, Megan and Drew. I shared my research interests; they shared their concerns and hopes for the community, particularly in relation to children with dis/ability labels. When I spoke about the possibility of conducting my dissertation research at their site, one of the directors, Megan, responded as follows: "Please let us know if we can be of help. We hope you will consider doing your research in the area." During the months that followed, Megan, Drew, and I

[14] Throughout the text, self-selected pseudonyms were used (See "Decisions around Re-presenting Participants" in Chapter VI).

occasionally communicated via email, writing to each other about professional development opportunities, potential funding sources for further program development, community concerns related to dis/ability awareness, and non-profit funding opportunities for the families with whom they worked.

Approximately eight months prior to beginning this research study, we met again face-to-face; at this time I more explicitly described this research project and the theories informing it and outlined the nature of the data I was most interested in exploring. At one point during this conversation, Drew said, "We will be your dissertation site. You can easily go from group settings, to one-on-one therapy settings, to therapists-therapists conversations, to parent-therapist conversations. This is all happening in our place." Then, Megan said, "I want you to bring your findings back to us because I think so much of our work is unconscious; like we are just doing stuff and aren't really considering what it is doing." Over the course of two weeks, we engaged in several email exchanges in which I shared a copy of my dissertation proposal and a more concise outline of the related research goals, and they shared about the children and therapists who they felt would be willing to participate in the study.

Participants. Following Institutional Review Board approval (see Appendix B), I traveled to the research site and worked closely with the directors to identify and contact parents whose child (1) had a diagnostic label of autism, and (2) participated in at least one of The Green Room's therapeutic activities, ranging from group social activities to speech therapy to occupational and physical therapy. The directors also identified the therapists who worked with the participating children/families. Through purposeful sampling, I recruited the participation of three speech therapists (two of whom were also the directors of the site), two occupational

therapists, one physical therapist, one teacher/social group facilitator, and one medical secretary/sibling support group facilitator. Table 2 provides the pseudonyms, professional titles, and the number of years the therapists/staff member has worked at The Green Room.

Then, with the assistance of Megan and Drew, I invited the participation of 14 families with children with autism labels who worked with the participating therapists. Each parent was individually approached by their primary therapists and was introduced to me and to the research project. After speaking to me in The Green Room's waiting room area for approximately ten minutes, all but two of the families immediately agreed to participate. One family did not transport their child to the site, as the child qualified for state funded transportation; thus, the child's primary therapist called this particular family to share about my research study and sent the consent form and demographic survey home with the child and his transport caregiver. This particular family did not choose to participate in the study. The other non-participating family did not give consent until after the data collection process had already ended; thus, they were not included in the study.

Of those families invited, a total of 12 families agreed to participate, resulting in the participation of 12 children with autism labels, aged three to 11 years, six fathers, and 11 mothers. Table 3 provides the pseudonym of each participating child, as well as the demographic information (i.e., age, gender, and race) and diagnostic label(s) provided by the participating parents. Table 4 provides the pseudonym of each participating parent, along with the name of their child and whether they participated in a face-to-face interview.

Table 2

Participating Therapists' Demographic Information.

Pseudonym	Professional Title	Total Years at the Site
Bria	Occupational Therapist[a]	4
Drew	Speech Pathologist/Clinical Director	4
Jennifer	Speech Pathologist	2
Megan	Speech Pathologist/Clinical Director	4
Michelle	Teacher/Autism Specialist	4
Patricia	Physical Therapist	1
Samantha	Medical Secretary	½
Seth	Occupational Therapist	½

[a] Throughout the text, I did not always distinguish between whether the participant was a physical therapist, medical secretary, teacher, etc. Instead, I attempted to make such distinctions relevant as they were made relevant by the participants.

Table 3

Relevant Information for Participating Children.

Child's Pseudonym	Age	Gender	Race	Diagnostic Label
Billy	6	Male	Caucasian	Asperger's
Chance	3	Male	Caucasian	Autism[a]
George	4	Male	Caucasian	PDD-nos[b]
Noodle	7	Female	Caucasian	Chromosomal Deletion/Autism
Picasso	9	Male	Caucasian	Autism
Saturn	7	Male	Native American	Autism
The Emperor	7	Male	Caucasian	Autism
Thomas	5	Male	Caucasian	Autism
Tommy	7	Male	Caucasian	PDD-nos/ADHD[c]
T-Rex	7	Male	Caucasian	Autism/ADHD
Diesel Weasel	11	Male	Caucasian	PDD-nos/Bipolar/OCD[d]/ ADHD/Tourette's
Will	8	Male	Caucasian	Mental Retardation/Autism[e]

[a] Chance's mother wrote "autism" with the explanation that it was not yet a "formal" diagnosis as his pediatrician "wrote autism on his referral."
[b] Pervasive Developmental Disorder, not otherwise specified.
[c] Attention Deficit/Hyperactivity Disorder
[d] Obsessive Compulsive Disorder.
[e] At present, the state in which this study occurred does not yet to apply the term Intellectually Disabled in lieu of Mental Retardation. Will's mother indicated that his school diagnosed him as Mentally Retarded and a doctor told her "I think he has autism."

Table 4

Participating Parents Relevant Information.

Parents' Pseudonyms	Parents' Child	Parent Participated in Interview
Maria	Billy	Yes
John	Billy	Yes
Sara	Chance	Yes
Joel	Diesel Wiesel	Yes
Diane	Diesel Wiesel	Yes[a]
Natalie	George	Yes
Melissa	Noodle	Yes
Alisha	Picasso	Yes
Jupiter	Saturn	Yes
Susan	Saturn	Yes
Amelia	The Emperor	Yes
Steven	The Emperor	No
Andrea	Thomas	Yes
Susan	Tommy	Yes
Anna	T-Rex	Yes
Samuel	T-Rex	No
Lily	Will	Yes

[a] Joel and Diane requested to be interviewed together.

Pseudonym selection. Being sensitive to the power inherent in naming others, I invited all of the parents, therapists, and children to select their own pseudonyms (see Chapter VI for details). The directors of the clinic selected a pseudonym for the site, while the majority of the participating parents and therapists simply wrote a name on the demographic survey or requested that I select one for them. I, the therapists, or parents asked many of the children, "What name would you like Jessica to use when she writes the story about what she has learned from you?" For many of the children, the process of selecting a pseudonym took several weeks, and for some it took months, as many of the children indicated they wanted "to think 'bout it." Most of the children came to their decision as they discussed their ideas with their therapists, while some children came to their decision with their parents. For other children, primarily those children who were still actively working to establish a means to communicate with others, the therapists and parents together selected a pseudonym that represented for them something about the child and/or their work with him or her.

Data Sources and Collection Procedures

According to Potter and Wetherell (1987), for the discourse analyst, the sample size is dictated by the research question, with "the success of a study…not in the least bit dependent on sample size" (p. 161). While it is relatively common within other qualitative traditions to collect multiple forms of data, a DP approach preferably focuses upon naturalistic conversations, while still remaining open to the collection of additional types of data. Discursive psychologists define natural interactions as those interactions that are not necessarily fashioned by the researcher or primarily produced for the purposes of a given research study (e.g., phone conversations, talking

with a friend at a party, etc.) (Edwards, 1997; Potter, 1999). In other words, such interactions would occur whether the researcher was present or not. Further, naturalistic conversations may also be institutionally structured, such as counseling sessions, an elementary school classroom lesson, or therapy sessions (O'Reilly, 2004). With my study focused on how children with autism labels and their therapists and parents interacted within a therapeutic setting, I focused on both the mundane aspects of the conversations (Sacks, 1992), as well as how the institutional talk deviated from ordinary, day-to-day talk. Further, I sought to understand the context in which the talk was situated.

Overview of data sources. From May 31, 2010 to August 13, 2010, I collected the following sources of data: (1) 175 hours of conversational data within the context of the group and individual therapy sessions of the participating children and their therapists, as well as the waiting room conversations between the therapists and parents that immediately preceded and followed these sessions; (2) 14 parents interviews, which ranged from 22 minutes to 84 minutes and averaged 41 minutes; (3) eight interviews with each of the participating therapists/The Green Room staff members, which ranged from 10 minutes to 42 minutes and averaged 22 minutes; (4) 654 pages of handwritten field notes focused on the individual therapy sessions that I observed, as well as the observations I made of the day-to-day practices of the participants at The Green Room; (5) documents used within the therapy sessions, as well as those documents/artifacts that were a part of the everyday practices of The Green Room (e.g., image of the insurance codes used by the therapists to acquire insurance coverage for the participating children); (6) Demographic surveys/information from both the participating parents and therapists (see Appendix C and Appendix E); (7) a 20 minute unstructured interview with the clinical directors

regarding insurance claims; (8) a 79 minute unstructured interview with the state advocate focused on qualifying for services and acquiring an autism diagnosis; (9) email correspondence between the participants and myself focused on qualifying for insurance coverage and state-based services, as well as their written responses to my interpretations; and (10) audiorecordings of and 20 pages of observational/field notes from the face-to-face meetings in which I shared my interpretations of the data with the participants and invited their evaluative responses. During the course of the data collection, I remained on site, spending approximately 332 hours at The Green Room.

Therapy session data. Of the 175 hours of therapy session data I collected, 105 hours were within group therapy sessions. In addition to their individual, one-on-one therapy sessions, 10 of the participating children attended group therapy sessions. These group therapy sessions typically lasted three hours, with two groups being offered each day and facilitated by Michelle, a participating teacher/autism specialist. These groups were open to all children regardless of their diagnostic label(s). Thus, of the data collected, 15 children without autism labels also participated in these group therapy sessions. The parents of these 15 children consented for their children's interaction to be recorded, with these 15 children also being informed individually about the purposes of my research. These parents were not interviewed in that they did not have children with an autism label.

For the purposes of this dissertation research, I determined to focus solely on the 70 hours of individual therapy sessions and related waiting room and hallway conversations, with the group therapy session data to be analyzed in a future study. I oriented to the group therapy data as potentially offering insights as to the ways in which children with autism labels and children

with other dis/ability labels interacted with each other as they engaged in fairly unstructured play. Early on in the data analysis process, I decided to analyze the group therapy session data in the context of a related, yet separate study, as my dissertation research focused on the meanings of autism and the ways in which therapists, parents, and children accounted for and reframed non-normative behaviors and communication patterns in therapy talk.

For the purposes of this study, each therapist audio recorded their individual therapy sessions with each of the participating children with whom they worked (see Table 5), as well as their interactions with parents in the waiting room before and after each individual therapy session. I provided the therapists with a list of all the participating children and parents, reminding them to turn off their recorders when they spoke with individuals who were not participating in the study; no non-participating individuals were recorded. Many of the individual sessions were already being video recorded by the therapists, as they consistently shared DVD recordings of their work with the children's parents and extended family members and/or caregivers. Thus, the therapists also video recorded all of the individual therapy sessions on their MAC laptops and then transferred the videos to a shared jump drive.

Table 5

Therapists Working with Each Child.

Participating Child	Primary Therapists Working with Child
Billy	Bria, Jennifer, Seth, and Michelle
Chance	Drew, Megan, and Michelle
George	Bria and Michelle
Noodle	Bria and Megan
Picasso	Megan and Seth
Saturn	Drew, Megan, and Michelle
The Emperor	Bria, Jennifer, Megan, Michelle, and Seth
Thomas	Drew, Jennifer, Michelle, and Seth
Tommy	Bria, Drew, Jennifer, and Michelle
T-Rex	Bria, Drew, and Michelle
Diesel Weasel	Bria and Michelle
Will	Jennifer, Michelle, Patricia, and Seth

By analyzing the existing video recordings in addition to audio recordings that were researcher-initiated, I hoped to attend carefully to the non-verbal aspects of communication that have been noted as being salient within interactions. For example, in their conversational analysis of the interactions between professional staff and individuals with dis/ability labels, Finlay, Antaki, and Walton (2007) pointed to the importance of gestures unaccompanied by sound in such interactions. Thus, recognizing that many of the children within this study used forms of communication that did not include verbalizing as their primary communicative method, the video-based data was useful as I became more familiar with the participants. However, in that children were included within the recordings, the Institutional Review Board required that I view the video recordings at the research site. As such, I was only allowed to store the audio recordings on my password protected computer. Consequently, due to the size of my data set, I was not able to review and transcribe the full 70 hours of video recorded individual therapy sessions prior to leaving the research site. Hence, for the purposes of the dissertation research, I relied primarily upon the audio recordings of the conversational data, as well as my observational/field notes of each therapy session.

Observational/field notes. In addition to the digitized audio recordings and transcriptions of all the audio recorded data, I maintained observational notes pertinent to each of the therapy sessions I observed, as well as any spontaneous face-to-face interactions with the participants. These notes contained what Merriam (1998) referred to as observer commentary, defined as that which includes "the researcher's feelings, reactions, hunches, initial interpretations, and working hypotheses" (p. 106). As I entered the research site and brokered relationships with the key site gatekeepers and participants, I determined to position myself

primarily as an observer, while at the same time engaging relationally with the participants as my research unfolded.

As I made and recorded my observations of the therapy sessions, I attempted to attend to both the verbal and non-verbal communication. Knowing that I would likely be unable to work through and transcribe all of the video data, I gave particular attention to taking note of the ways in which nonverbal communication was salient within the interactions of the participants. Thus, my observational/field notes often included the participants' turn-by-turn nonverbal communication sequence in connection to the verbal interaction. In that I had continual access to the audio recordings of each individual therapy session, waiting room, and hallway conversation, I attempted to focus my observational/field notes on the nonverbal aspects of the conversations. For example, I wrote the following during an observation of a therapy session with Jennifer and Will: "(1) Jennifer puts Will's right hand on her cheek and says, 'Hi'; (2) long silence (maybe 6-7 seconds), during which time Jennifer looks at Will, while Will looks at the wall; (2) Will makes eye contact with Jennifer; (3) the moment Will makes eye contact Jennifer smiles and raises her eyebrows; and (4) Will taps Jennifer's right leg with his left hand." I presumed that the nonverbal aspects of the communication were always doing something in situated and occasioned ways. Further, in that many of the participating children did not always (if ever) use verbal speech to communicate, it was particularly important to take note of the ways in which the children, therapists, and parents used their bodies and other communication devices to communicate; none of which were captured on the audio recordings.

Quite often, as I would observe a therapy session, I would begin by initially mapping out the therapy room, noting what types of equipment and/or documents were present and where the

child, therapists, and I were positioned in relationship to each other. I would then record (in part), turn-by-turn, the interactions, giving most of my attention to the nonverbal communication between the therapists and children, as well as the parents. In addition to this, in my observational/field notes, as I would transition from one therapy session to another, I often wrote my unfolding hunches and unfolding questions. Throughout, I remained aware of the way in which my very presence and the audio recording equipment in the therapy sessions might be oriented to as a discomforting, gazing eye (Geils & Knoetze, 2008; Tabor, 2001). I worked with the children and therapists as they became accustomed to the equipment and my constant presence within the therapy space. I asked them often where they preferred for me to sit and observe and/or whether they preferred for me to not be present for a particular aspect of a given session.

Interview data. Although the recordings of the individual therapy sessions served as a key data source, I also conducted interviews (see Appendix D and Appendix F) with the participating parents and therapists. Throughout the interviews, I viewed myself as an active participant within each conversation, where I, along with the parents or therapists, co-created "through the intersection of two subjectivities, the interviewee and the interviewer" (Richardson, 1997, p. 165). I viewed all of my data, interviews and naturalistic interactions, as discursive events (Potter & Wetherell, 1987), and assumed that by "...asking participants about particular topics" I would learn "...about the culturally circulating discourses that are invoked in producing answers" (Benwell & Stokoe, 2005, p. 124). Also, it is important to note that I participated in the interview conversations; thus, I included and analyzed my talk as well. However, much of

my talk was what Edwards and Stokoe (2004) referred to as normative interviewer talk, as I aimed to elicit participants' constructions rather than making relevant my own.

Prior to initiating data collection, I met with all of the therapists, parents, and children at the research site, inviting the consenting parents to participate in an interview at their convenience. In total, 14 of the 17 participating parents participated in an interview at The Green Room (12 interviews conducted on-site) or a more convenient location of their choosing (2 interviews conducted off-site) (see Table 4). Diane and Joel, the parents of Diesel Wiesel, one of the participating children, requested to participate in the interview together. The remaining 12 parent interviews were only attended by one of the participating parents/caregivers.

During the interviews with the participating parent(s), I invited the parent to complete a demographic survey (see Appendix B) and respond to a few questions related to their child. These questions took the form of a semi-structured interview (see Appendix D), during which I asked the parent(s) questions about their child. During these encounters, I attempted to avoid imposing a definition of autism, instead beginning the parent conversations/interviews by asking: "What things might you want someone who has just met your child to know about him/her?" In doing so, I hoped to explore what the parents chose to make relevant about their child. For example, I only used the word autism if the parents used the word during their interview. During my initial meeting with each individual therapist, I invited them to complete a demographic survey (see Appendix E) and participate in a semi-structured interview (see Appendix F). The eight participating therapists/staff members participated in an interview at The Green Room.

I aligned each interview question with this study's research questions (see Table 6), as well as its underlying epistemic and ontologic assumptions. Furthermore, the questions posed on the demographic survey (e.g., Does your child have a diagnostic label? If yes, what is/are the diagnostic label(s)?) allowed me to gather information to be used to develop a rich, thick description of the participants and the research site (Hatch, 2002). The demographic information sheet for the participating parents/children includes the following information: participants' name/pseudonym, gender, race, age, diagnostic labels, and contact information. The demographic information sheet for the participating therapists included the following information: name/pseudonym, professional title, age, gender, race, years working at The Green Room, years/months working with each participating child, and contact information. In constructing the tables, which share some of the collected demographic information (Table 2 and Table 3), I attempted to highlight the information that was made most relevant in the data, while also providing information that worked to deepen contextual understandings.

In that all of the participating parents made relevant concerns regarding their child's diagnosis, insurance coverage, and advocacy issues during their interviews and waiting room conversations with the therapists, I decided to collect additional contextual information. After having collected data for over one month, I requested to interview Megan and Drew, the directors of The Green Room, again. During the course of this brief, unstructured interview, I specifically asked them to describe how children with autism labels acquire insurance coverage at their clinic. In that I hoped to better understand the tension-filled process of deciding to seek or not to seek a diagnosis of autism for one's child, several of the participating parents, as well as Megan and Drew, directed me to meet with one of the primary family advocates in the area. So,

near the end of July 2010, Ruth, a family advocate, agreed to participate in an unstructured interview focused solely on insurance and state-based diagnosis requirements, and the qualifying for and receiving of inclusive services.

Table 6

Research Questions in Relation to Interview Questions/Data Sources.

Research question	Interview questions
(1) What are the various meanings of autism and how are these meanings performed within and through the discursive practices of therapists and parents of children with autism labels in their everyday interactions?	Parent Protocol—Questions 1, 2, 3 Therapist Protocol—Questions 1, 3
(2) How do children with autism labels and their therapists and parents discursively manage and account for the behaviors and communication approaches made relevant in therapy?	Parent Protocol—Questions 2, 3 Therapist Protocol—Questions 2, 4

Data Analysis

Within this study's analytic approach, I focused upon what the talk-in-interaction was doing, accounting for both the patterns within the corpus of data and the deviations from such patterns (Potter & Hepburn, 2005). As explicated in the above description of the discursive action model (see Table 1), DP, and conversation analysis related illustrations, as I analyzed the data, I attended to specific discursive features of the discourse, and spent far more time analyzing the data than collecting it (Taylor, 2001). More specifically, this study's analytical framework primarily employed the theory and analytic method of DP (Edwards, 1997; Edwards & Potter, 1993; Horton-Salway, 2001; Potter, 1996), while minimally drawing upon conversation analytic techniques (Sacks, 1992). When drawing upon conversation analytic techniques, I considered many conversational features considered fundamental to interaction, such as conversational turns, membership categories (category work), and turn-taking design, as well as other features that were made relevant in the participants' talk (see Research Approach above for more complete descriptions and illustrations of conversation analysis). Yet, my analysis always moved beyond the micro-level of the conversation, as I positioned my interpretations in relation to discursive psychology and disability studies literature. Furthermore, I explicitly attempted to consider the broader discourses and institutional practices in which the participants' talk was situated.

Similar to other qualitative approaches, I took an interpretive and emergent approach to analyzing the data. To analyze the data generated in this study, I attended to discursive resources and features made relevant by the participants across the data set (Drew & Toerien, 2011; Rapley, 2007, Wood & Kroger, 2001). More specifically, I carried out six broad phases of data

analysis, with several sub-phases/steps included within each phase: (1) intensive listening (Wood & Kroger, 2000); (2) transcription (Potter & Wetherell, 1987); (3) repeated reading and listening (Potter & Wetherell); (4) selection, identification, organization, and further analysis of patterns across the discourse segments (i.e., episodes or segments of talk) related to the various discursive features and/or broader discourses and institutionalized practices; (5) generation of explanations/interpretations; (6) reflexive and transparent sharing of findings. In the following paragraphs, I outline the step-by-step analysis process.

Within the DP framework, the first layer of intensive analysis begins with the listening and re-listening of the audio recordings. Thus, for the purposes of this study, I began the intensive analysis with listening and re-listening to the audio recordings of the entire data set, listening at least two times to each audio recording. These initial, repeated reviews of the data allowed me to familiarize myself further with the conversations and identify initial sections that I found surprising or simply intriguing. Throughout this first step, I recorded notes and reflections in relation to those sections that I found most striking (Rapley, 2007).

According to Potter and Wetherell (1987), within DP, transcription is understood as "a constructive and conventional activity," and is positioned as a critical component of the analysis process (p. 166). I oriented to the process of transcription as an interpretive and "selective process" that reflected my theoretical "goals and definitions" (Ochs, 1979, p. 44). The initial transcription process, the second step of the analysis, inevitably occurred concurrently with the first analysis step and the data collection process. I personally transcribed the 70 hours of therapy sessions, 14 parent interviews, eight therapist interviews, and two interviews focused on insurance and diagnosis issues. I began with an initial verbatim transcription of each recording.

Then, I reviewed the transcripts and recordings again, while making further additions and corrections to the verbatim transcripts. I then imported the audio files and verbatim transcripts into Transana, a computer application for discourse analysis (Fassnacht & Woods, 2005). I used Transana to create an audio waveform file that served to visually represent the amplitude of sound over the duration of a given audio file (see Figure 1). The waveform was particularly useful for identifying pauses between speaker turns. I bracketed each turn in the conversations with time codes, which allowed me to later come back and select certain excerpts to be played and re-played.

Third, I read and listened to all of the transcripts in their entirety, searching for and identifying patterns and conversational features (e.g., turn-taking organization), as the following broad, discourse analytic questions sensitized the process: (1) What is the discourse doing?; (2) How is the discourse constructed to do this?; and (3) What resources are present and being used to perform this activity? (Potter, 2004; Wood & Kroger, 2000). As I engaged with the data, I also considered the three broad themes of the discursive action model. These initial readings allowed me to become more familiar with the overall interchanges, as well as begin the initial labeling of the transcribed data set, "preparing the way for a much more intensive study of material culled through the selective coding process" (Potter & Wetherell, 1987, p. 167). During these readings, I attempted to "avoid 'reading into' the data a set of ready-made analytic categories," allowing instead for that which I found "interesting" to be sensitized by my research interests, as well what the participants made relevant (Edwards, 1997, p. 89).

Concurrent to the aforementioned analytical step, I imported all of my typed observational/field notes, research journal reflections, transcripts, and documents used by the

participants in the course of the therapy sessions (e.g., powerpoint constructed by a participating child and his therapist during a recorded therapy sessions) into Atlas.ti™ (Muhr, 2004), a qualitative data software package that I utilized to systematize the analysis process. As I read and re-read the data, I began to name or label segments of the discourse, taking note of patterns of the talk from the actual words of the participants and from concepts drawn from discourse theory, conversation analysis, and the social relational model of disability (Coffey, & Atkinson, 1996).

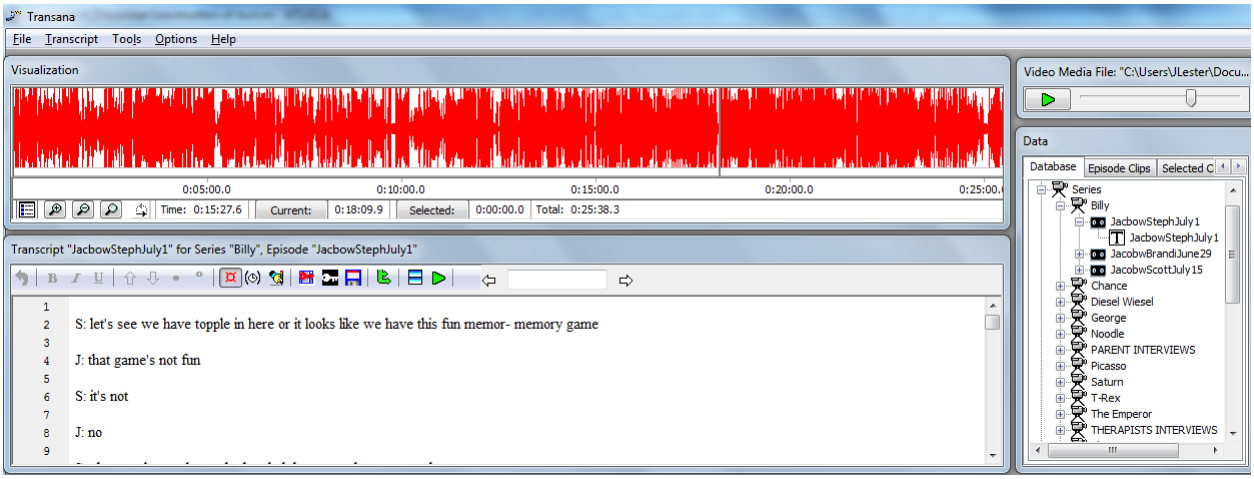

Figure 1. Screenshot of Transana Software Package, Showing Waveform, Transcript, and Audio File.

Recognizing that my own positionality influences the way in which I engage in any analysis process, I decided to begin by analyzing my research journal, as that was the data in which I reflected upon my presuppositions and recorded my initial hunches. Taking advantage

of the features available within Atlas.ti™, I systematically annotated the data, constructing detailed theoretical and analytical memos as I worked across my research journal, observational notes, and therapy-session related documents.

Next, I used my research questions to select specific portions of the transcripts for a more close and iterative analysis. I carefully considered how the language was being used to perform autism as an interactional event. Analyzing the interviews and therapy session data in relation to my evolving research questions, I noted (1) the ways in which the parents/therapists described the children; (2) how they worked up a notion of autism and/or explicitly talked about and around the meaning(s) of the autism; and (3) the ways in which "doing therapy" was accomplished discursively. Initially, I created lists/descriptions of common language features within selected excerpts, organizing and identifying patterns across the discourse segments (i.e., episodes of talk) related to specific conversational features of focus (e.g., turn-taking organization). I labeled selected excerpts with this developing list/description of common features, as well as the analytical framework being developed as I continued to annotate my research journal, observational/field notes, and therapy-related documents.

In preparation for a more fine-grained analysis, the selected excerpts were isolated and organized into "audio/transcript collections" within Transana. I then applied a modified version of the transcription system developed by conversation analyst Gail Jefferson (2004) to the audio/transcript collections. Such allow for a more detailed transcription, as conversational details (e.g., pauses, prosody, gaps, intonation, etc.) may be represented in an alternate form to sound (see Appendix G). Recognizing that it is impossible to include all of the relevant details within a transcript, I added only those symbols that were relevant to the claims I made and that I

believed would "provide readers with data and evidence" to determine whether "alternative interpretations" might be plausible (Hammersley, 2010, p. 566). Furthermore, when I met with the participants, I explicitly asked them: "What was it like to read the excerpts with the transcription symbols included?" While one of the therapists preferred to read the excerpts without symbols, stating, "I think it takes away from the, for me, it took away a little bit from the interest of the topic," she also later stated, "I would just have to learn the transcription better and then I could kind of conjure meaning from it" (Drew, December 17, 2010) (Appendix I). The parent and other therapists who provided feedback and evaluated my findings indicated that the symbols helped them "feel" and "hear" the talk, allowing them to better follow my interpretations.

Following the addition of the transcription symbols to the selected excerpts, I created a report of the excerpts (see Figure 2) and imported them into Atlas.ti™ for further analysis (see Figure 3). I then carried out several more rounds of analysis, working across the interview and conversational data. As I did so, I further refined and identified patterns and variability across the data. I also created extensive memos of selected excerpts, later incorporating the analysis of a given excerpt directly into the findings chapters.

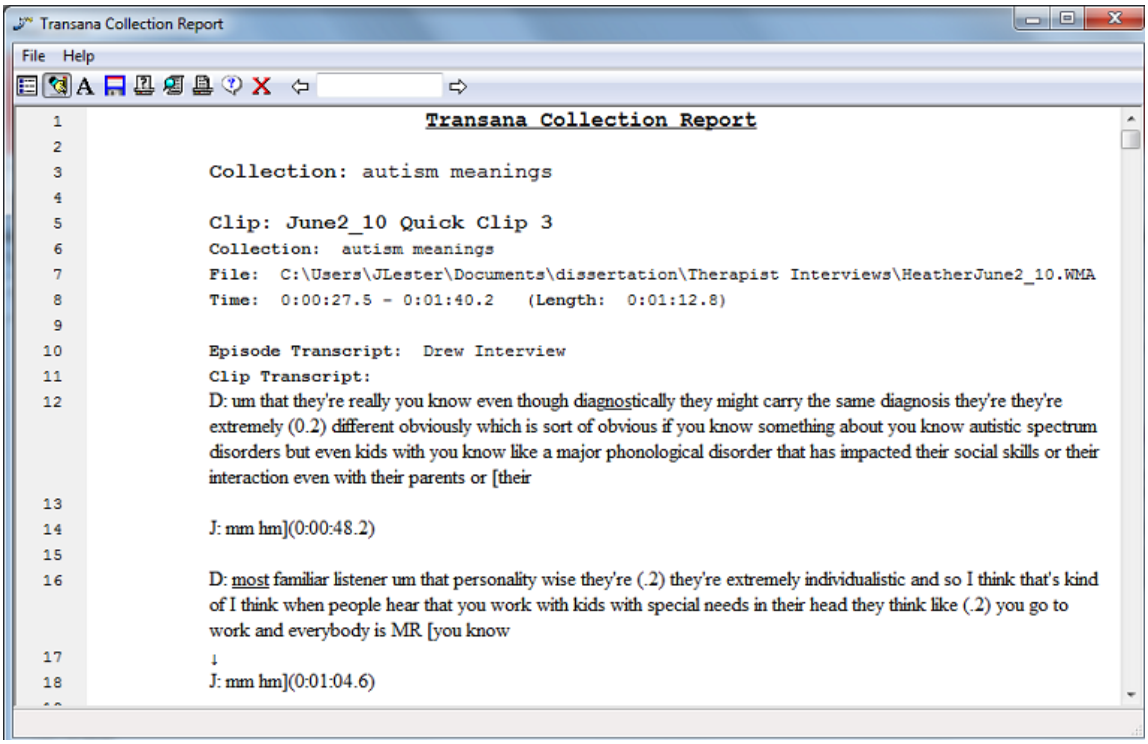

Figure 2. Screenshot of Report of Selected Excerpts.

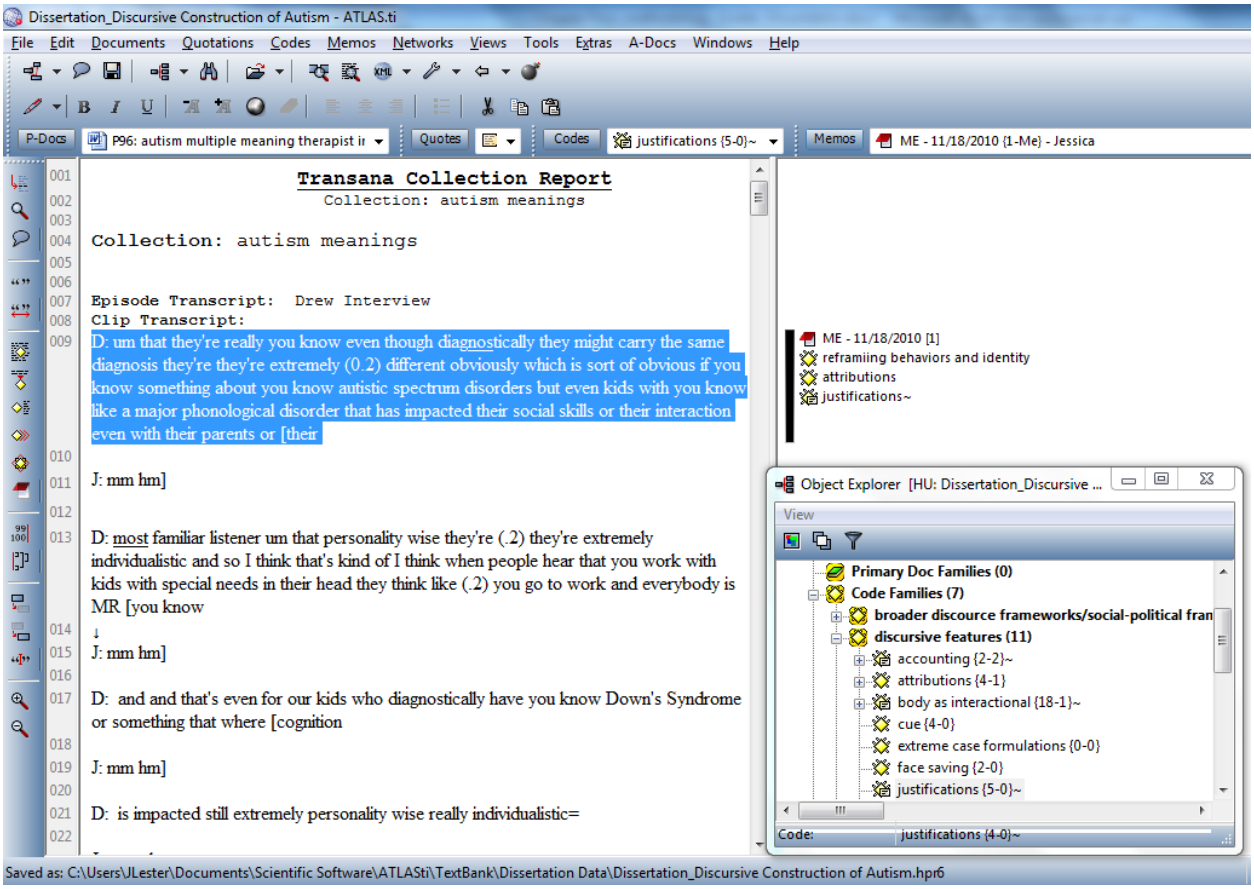

Figure 3. Screenshot of Imported Extracts in Atlas.ti™.

Next, after identifying patterns and variability across the data, as well as attending to the sequential relationships within the interactions, I formed tentative explanations about the functions of various discursive features used within the data set and began to write up the findings. As I did so, I paid particular attention to the epistemic and ontologic claims of the DP approach, noting where and how language features were made relevant in the participants' talk. I compared the tentative explanations across the corpus of data, as well as in relation to the broader bodies of literature, until I reached a "final" iteration of the findings. As I generated these tentative explanations, I continually remembered that, as Wood and Kroger (2000) noted, "interpretations themselves are always contextualized and provisional. There is always the possibility of a new interpretation" (p. 165).

Finally, I worked to reflexively report my claims and explore the applicability of the findings. I did this by sharing my unfolding interpretations and theoretical and analytical understandings with some of the participants, acquiring their feedback over the course of several months (see the next section).

Warranting Claims and Standards of Quality

While systematically outlining the nature of the data analysis is an important aspect of the research process, it is also critical to take measures to verify the authenticity and trustworthiness of my findings. Continually aware of my positionality and partiality, I approached the interpretation of my data as an emergent process, grounding my findings in the corpus of data and intentionally seeking ways to warrant my claims. Further, to warrant my claims, I carried

out specific activities, aligning with the theoretical perspectives of DP and particular poststructural orientations to analysis (Howarth, 2000).

First, I acknowledge the need for reflexivity within the research process, recognizing "that texts do not simply and transparently report an independent order of reality. Rather, the texts themselves are implicated in the work of reality-construction" (Atkinson, 1990, p. 6). In acknowledging such, I assume that my interpretation is situated and stands as one of many possible explanations (Howarth, 2000; Taylor, 2001). Through memos, journaling, and recording and electronically saving each analytical and theoretical decision, I now leave an audit trail that permits an outside researcher to review and become familiar with my decision-making process (Creswell & Miller, 2000). Further, I preserved my sanitized data set in such a way that it can be made available to certify that the "data exist...and that the interpretations have been made in ways consistent with the available data" (Guba, 1981, p. 88).

Second, with the participants' talk being understood as having shifting and multiple meanings, I intentionally sought out alternative cases and explanations (Potter, 2004; Wood & Kroger, 2000). In seeking out negative instances/deviant cases or variability, I attended to inconsistencies and diversity within the natural talk of the participants (Potter & Wetherell, 1987).

Third, I supported each of my explanations with detailed evidence and explications, showing how the participants oriented toward and worked up a given claim. By thoroughly and transparently presenting how each claim is supported by excerpts from the corpus of data, I provide space for the reader to evaluate my claims (Potter, 1996). In that discourse analysts place great emphasis upon reader evaluation (Potter), I leave room for "others to speak, for

tension and differences to be acknowledged" (Richardson, 1997, p. 168). Additionally, throughout the findings chapters, I incorporate my positionality, at times quoting directly from my research journal, intending to produce trustworthiness and relational ethics with the reader (Guba, 1981; Lather, 1986). Within each of the individual analysis chapters, I lay out the various discursive devices that I noted within the data set, unpacking what the feature did and how it was sequentially and rhetorically handled (Antaki, Billig, Edwards, & Potter et al., 2003). One of the key ways in which the discourse analyst produces trustworthiness with the reader is by demonstrating their primary arguments by illustrating the steps involved in the analysis of a given excerpt of the data. In lieu of simply telling the reader about the given argument/interpretation and then pointing to an excerpt that illustrates the researcher's point, the discourse analyst shows how she analyzed a given excerpt and came to particular interpretations (Wood & Kroger, 2000).

So, in the findings chapters, I present excerpts and then provide thorough analysis and interpretations of each, making visible the ways in which I oriented to and made sense of the data. While the analytic process consisted of generating a corpus of examples for each pattern, I only presented a small number of these excerpts in the findings chapters as representational of the larger body of data. Further, as I reported my claims, I took into account and hoped to avoid what several well-known discursive psychologists have identified as common shortcomings in much discourse analytic work (Antaki et al., 2003). These analytical shortcomings include such things as under-analyzing by simply summarizing the data set or presenting a multitude of quotations with little analysis offered. Aware of potential shortcomings and my desire to

soundly warrant my claims, I engaged in several analytic techniques in order to validate my research findings.

While I value deeply the role of reader evaluation, I also take seriously the idea that researchers should share their interpretations with those stakeholders involved with and interested in a given study (Flyvberg, 2001). So, I positioned the evaluation of this work within a broader community of scholars who I asked, and continue to ask, to "…judge the interpretations proffered, and the adequacy or inadequacy of discourse theory…to engender plausible accounts of the social phenomena" (Howarth, 2000, p. 130). In addition, over the course of nine months, I invited colleagues and scholars, whose research I believed was relevant to the conversation in which I hoped to engage, to review my work and offer critiques and suggestions to refine the ways in which I produced and shared my understandings.

Further, although as of August 14, 2010, I was no longer at The Green Room on a daily basis, as I began to engage in more intensive data analysis, I occasionally communicated with the participants via email and phone to share my initial interpretations. In October 2010, I returned to The Green Room and shared with seven of the eight participating therapists/staff members an abbreviated version of the theories which informed the work, several of my initial interpretations, and how I was organizing the dissertation text (Appendix H). For the duration of one hour, all of the participating therapists engaged in an open dialogue with me about the data and my initial interpretations. It was during this discussion that I was directed to more closely consider turn-taking organization (see Chapter VIII: Accounting for Problems and Redefining Communication). During this conversation, I explicitly talked about how I did not view our time together as a way to determine whether "I got it right," as a *real* version of the world does not

exist independent of our constructions of it (Wood & Kroger, 2000). So, there was no need to ask whether my analysis and interpretations were "true," thereby corresponding to an independent world. Instead, I viewed my interaction with the participants as an opportunity "...for *collaboration* and reflexive *elaboration*" (Tracy, 2010, p. 844). We spent our time together discussing my interpretations, alternative interpretations, and considering together the practical implications of this work.

The participating therapists requested to receive copies of my dissertation chapters immediately and suggested that we meet again soon for a longer period of time. Thus, in December of 2010, I met again with four of the participating therapists (Megan, Drew, Bria, and Jennifer), across two separate meetings (December 17th and December 23rd), and discussed my evolving interpretations, implications, and conclusions (Appendix I). I met with Megan and Drew for approximately one hour via Skype and with Bria and Jennifer face-to-face at The Green Room for approximately one hour. I also met face-to-face with Maria, a participating parent, at a local coffee shop on December 25, 2010. Maria and I met for two hours, during which time I shared both "handouts" (Appendix H and Appendix I) with her. I requested her feedback and evaluation on my interpretations. All of these meetings with the participants were audio recorded and later transcribed, allowing me to include their verbatim responses and return to their evaluative responses as I refined my findings chapters. I discuss the participants' responses to my interpretations at the end of each findings chapter (see Chapter VII and Chapter VIII). I am scheduled to meet with the remaining participating parents in May of 2011.

In order to publicly disclose my systematic analysis process, I followed the suggestions of Anfara, Brown, and Mangione (2002) and provided a mapping of the analysis process, as

shown in Appendix J. In that I did not carry out a thematic analysis resulting in theory development, I adapted the suggested code mapping table to align more closely with this project's discursive approach. The initial iterations included "manageable chunks" or discourse segments of interest (p. 32), each linked to the overarching discourse analytic questions and theories which informed this work. Through multiple iterations of analysis, common patterns and variability across the data were noted, organized and further analyzed, each linked to conversational and discursive features of interest, as well as to the broader discourses and institutionalized practices and structures. When possible and theoretically meaningful, these noted discourse segments (i.e., excerpts of interview or therapy talk data) were then organized in relation to one another.

As I moved across the data set, I carried out multiple levels of analysis, refining often the ways in which I deconstructed and reconstructed the data set as I worked to the level of tentative explanations and interpretations. Yet, the recursive analysis process I pursued did not result in a set number of "coding levels," but continued to evolve as I engaged in new ways with the data and, in the spirit of the DP tradition (Edwards, 1997) and other qualitative methodologies (Ellis, 2004; Goodall, 2000), oriented to the very process of writing my research findings as inquiry in and of itself. Thus, necessarily so, what I display in Appendix J does not include all of the levels of analysis I completed, but instead shows only three iterations/levels of analysis. The first level displays the tentative labels I used during my first read of the data. The next level, which I developed after re-reading and re-listening to the data set multiple times, displays a more refined set of labels, highlighting how I was beginning to more narrowly focus on certain aspects of the participants' everyday interactions. More particularly, the discursive features I determined to

focus upon were more clearly delineated in the second level of analysis displayed in Appendix J. The final level displays the recurring discursive events or broader patterns that I eventually determined to focus upon, with some of the conversational features, broader discourses and practices, and various theoretical concepts informing this work being included as well. In this study, I did not aim to attend to a single conversational feature. Instead, I pointed to multiple and overlapping conversational features and broader discursive practices. Thus, in Appendix J, I simply provide the expansive list of the labels that I used as I moved from a more micro-level analysis to broader interpretations.

Finally, I considered Potter's and Wetherell's (1987) suggestion that the validation of findings is linked to the fruitfulness of one's work, referring to "the scope of analytic schemes to make sense of new kinds of discourse and to generate novel explanations" (p. 171). Tracy (1995) suggested that a fruitful discourse study is one that offers "productive ways to reframe old issues," creates "links between previously related issues," and raises "new questions" (p. 210). Thus, as I shared and continue to share my findings, I locate my work in relation to previously published work, pointing to the ways in which my claims provide a basis for new and fruitful understandings, as well as for further research.

Ethical Considerations

Throughout this project, I sought to address the ethical obligations relevant to this research study. With a commitment to protecting the participants, I adhered to all of the guidelines of the Institutional Review Board at The University of Tennessee, Knoxville. I recognized that:

> There is no direct or necessary relationship between ethics committee approval of a research project and what actually happens when the research is undertaken. The committee does not have direct control over what the researcher actually does. Ultimately, responsibility falls back to the researchers' themselves – they are the ones on whom the conduct of ethical research depends. (Guillemim & Gillam, 2004, p. 269)

Indeed, I began data collection only after acquiring the informed consent of the therapeutic site, therapists, and parents, and the assent of the children. Yet, there were additional steps I took to engage in ethical research practices.

First, I acknowledge that there was a power differential between me and the research participants, as it is "an exaggeration to suggest that the researcher and participants meet as equals" (Taylor, 2001, p. 20). I also recognize that:

> The qualitative researcher's perspective is perhaps a paradoxical one: it is to be acutely tuned-in to the...meaning systems of others—to indwell—and at the same time to be aware of how one's own biases and preconceptions may be influencing what one is trying to understand. (Maykut & Morehouse, 1994, p. 123)

So, as the individual who determined the parameters of the project and how the final claims were made public, I held and continue to hold a position of privilege and power. Furthermore, in that I was viewed as a researcher with a level of knowledge in relation to autism, I was occasionally positioned as an expert of some kind, and compelled to be transparent about my positionality with the participants. Throughout, I recognized that I must take steps to protect the participants, while I worked to maintain positive and fruitful relations with all involved. There were two explicit ways in which I worked to share or at least acknowledge my own power. First,

recognizing the power inherent in naming another, I invited all of the participants to select their own pseudonyms (see Chapter VI for further details). Second, I worked/struggled to position myself as an inquirer more so than an expert in a given field, particularly as related to autism. I carefully presented myself to participants as a qualitative inquirer with an interest in autism and a commitment to inclusive practices, not as an autism expert or as one with an ability or desire to "fix" a child's or another's way of being.

Second, consistent with my own assumption around the competence of individuals with dis/ability labels, I agree with Biklen et al.'s (2005) suggestion that a presumption of competence works to eschew the deficit-based presumptions in which dis/ability labels are embedded. Therefore, I not only gained the consent of the parents, but sought the assent of the children with labels of autism. Although the parents of the participating children were required to first sign a consent form indicating their willingness to allow their child to participate in this study, I also read/explained an assent form to each child, when appropriate, after acquiring some sense of rapport. This assent form was verbally shared at the level of the child's comprehension, as I worked with each therapist and parent to identify such. For two of the participating children, Diesel Weasel and George, I spent considerable time explaining my research and reasons for recording and observing their time with their therapists. Diesel Weasel, in particular, asked me many questions about the goals of this project and wanted to know where he fit in my overall research agenda. Throughout this research study, I presumed that the participating children were capable of understanding my intentions and interests.

Finally, while I am trained as a special educator and hold a graduate certificate in autism spectrum disorders, throughout this study, I desired to position myself as a researcher and

committed community member, not as an autism specialist/expert. At the same time, I recognized that "the separation of scientific and personal biography is in fact never possible" (Seale, 1999, p. 25). Thus, as I carried out data collection and analysis, and shared my findings both within this text and with participants, I aimed to interrogate my own power across structure, discourse, and practice, while engaging in recursive reflexivity (Pillow, 2003; Skeggs, 2002). As I reflexively considered my presuppositions, I worked to protect the participants, myself, and the integrity of this research. Yet while doing so, I did not assume nor seek a reflexive space devoid of complexities; instead, I recognized that this reflexive space of inquiry was not one that sought "a comfortable, transcendent end-point," but was "messy" and leaves "us in the uncomfortable realities of doing engaged qualitative research" (p. 193).

Chapter Summary

Within this chapter, I first described my rationale for using a DP approach. Second, I discussed my research plan, describing the discursive action model and particular aspects of conversation analysis. Third, I described how I gained access to the site, and offered a brief description of the participants, data collection procedures, and the data analysis process. Also, through my description of the ways in which I warranted my claims, I presented how I sought and maintained standards of quality. Finally, I discussed the ethical considerations related to this project, explicating how I acquired access to the data sources and fostered relationships with the participants. I now turn to present a description of the research site and participating children.

Chapter VI: Constructions of the Research Site and the Participating Children

While few studies that draw primarily upon discursive psychology extensively share the contextual complexities of a given data set, I argue for the importance of presenting my findings in relation to their situated meanings (Geertz, 1973) and acknowledge that meanings cannot be divorced from the context(s) in which they are produced (Tracy, 2010). As such, in this brief chapter, I offer a more thorough description of the research site and the participating children. As I present this description, I recognize that what I share is partial (Noblit et al., 2004), and that much about each child, therapist, and parent remains untold (Krog, 1998). Further, I work to emphasize those attributes that were made relevant by the participants across the data.

Chapter Overview

I begin by briefly discussing why I chose to make sense of context the way I did. Then, I introduce the reader to my decision-making process around selecting and representing the participants. Next, I provide a more detailed description of the research site, summarizing briefly how the therapists and parents oriented to the site and its many activities and institutional goals. After this, I move to describe briefly the participating children and, when available, the participants' explanations as to why they selected a certain pseudonym. This thick description assists in providing a contextual reference for the detailed analysis that follows it in the next two chapters.

Considering Context

In that few DP studies have attended to context to the degree to which I do in this study, I believe it is important to clarify the way in which I oriented to context and my rationale for including a thick description of the site and some of the participants. First, it is vital to note that across discursive approaches to research, it is presumed that discourse does not exist in a vacuum or somehow possess some abstract meaning. Rather, discourse is understood as "shared and social, emanating out of interactions between social groups and the complex societal structures in which the discourse is embedded" (Phillips & Hardy, 2002, p. 4). Yet, the extent to which the context or "complex societal structures" are considered in analysis varies across, and even within, a given research tradition. Second, and more generally, within qualitative approaches to research, context is not monolithically defined, as it is never self-evident and rarely agreed upon. Goodwin and Duranti (1992) noted that context "means quite different things within alternative research paradigms, and indeed within particular traditions context seems to be identified more by situated practice, by *use* of the concept to work with particular analytic problems, then by formal definition" (p. 2). They continue by stating that a technical and precise definition of context is impossible, yet suggest that it important to consider and perhaps even value the multiple and differing perspectives on context. Thus, with context positioned as a difficult to define and contested construct, how did I make sense of it in this study?

Even now, after having completed the first iteration of this research, I still find the very idea of context difficult to demarcate and even to write about. Nevertheless, throughout this study, I aimed to make sense of why I felt compelled to attend to context far more than the 'usual' DP study. Early on in the data collection process, I began considering the role of context

in this work, as well as research in general. I read and considered carefully the extant literature (e.g., de Kok, 2008) focused on context in research, specifically as related to a discourse analysis. I struggled to determine whether I should or should not construct and share a thick, rich description of the research site and participating children. I was hesitant to give up what I felt such a contextual understanding might offer to my analysis of the participants' discursive practices and to those individuals who might one day read this research study. My initial reflections around this issue are illustrated with the following research journal entry:

> June 6, 2010 1:15 pm
>
> I'm beginning to wonder why most discursive psychologists and pretty much all conversation analysts think context is not necessarily relevant. Can we consider talk outside of the context in which it was produced? Isn't meaning constructed in situated and *contextually* bound ways? This is what I believe. For instance, my observations at the site are really important to me right now as I take note of the manuals, children's files, and intake forms being grabbed in the midst of their "talk." Sure, the participants make them relevant, yet being here, I (will always) argue, allows me to understand things in a different and even a more layered way. For instance, there is a form that reminds the therapists to "remain silent" after giving a command to a child, waiting for however long the child needs them to wait. This form is never "talked" about (verbally), but frequently handed to parents, and functions to structure what is institutionally expected when interacting with the children.

Later in this same journal entry I spoke about the very doing of research and how, as the research instrument myself, I make sense of the context in embodied ways. I stated:

> I also believe that research is an embodied practice—one in which, as the research instrument and interpreter, it is important to state that I was present, that I was in the context, part of the context of interest, day in and day out.

For me, this notion of doing research as an embodied endeavor was a vital aspect of making sense of the phenomenon of interest (Duranti & Goodwin, 1992). Volosinov (1929/1973) spoke to this notion of being present as a researcher as well, stating:

> At the outset of an investigation, it is not so much the intellectual faculty for making formulas and definitions that leads the way, but rather it is the eyes and hands attempting to get the feel of the actual presence of the subject matter. (p. 45)

So, from the outset, I believed that context, regardless of how I defined it, meant something to me as an interpreter. Further, the longer I was at the research site, the more I was able to make sense of the participants' everyday interactions in nuanced, situated, and complicated ways.

Furthermore, as a qualitative researcher, I often pursue a particular research study because of an interest in a given context (Paulus, personal communication, December 2010). Albeit difficult to define, I view a 'context of interest' as that which frames a potentially intriguing or problematic construct, everyday experience, way of talking, and/or institutionalized practice. When I first learned about The Green Room (through a friend) about five years ago, I was intrigued by the many families and children that contrasted, in a positive way, The Green Room with other institutional spaces, such as hospitals and schools. Over time, I began to wonder whether The Green Room, as an institutional space, might offer rich opportunities to explore new ways of framing dis/ability labels and therapy in general. So, when I began this study, I desired to construct a rich and layered understanding, and with time came to view the

context itself as what I "...needed to know about in order to properly understand the event, action or discourse" (van Dijk, 1997, p. 11). I oriented, then, to my own meaning-making process, as well as that of the participants,' as a "highly local" process that was "dependent upon the situation and the particular moves and countermoves of its people" (Tracy, 1998, p. 7). Similar to van Dijk's suggestion, in this research there was "... no a priori limit to the scope and level of what counts as relevant context" (p. 14). Instead, I went about defining context in relationship to what the participants made relevant about the context, my own positionality, and the focus of this research. My task, then, was to answer the following question: What should I establish as the scope and level of what counts as relevant context?

To answer the above question, I first turned to the literature focused on the position of context in discursive research. As I moved from the literature focused on conversation analysis to that which focused on critical discourse analysis and discursive psychology, I noted little consensus about the role of context in analysis. Moerman (1977, 1988), for instance, proposed that contextual resources or context in general is external to talk, with the analytic task of the conversation analyst being to consider context as only that which is intrinsic to and made relevant in interaction. Like conversation analyst Schegloff (1991), many conversation analysts suggested that context should be considered only insofar as the researcher can point to the ways in which the participants' talk makes a given contextual factor relevant. At the same time, Schegloff suggested that "contextual information can be drawn upon when an adequate account for some specifiable features of the interaction cannot be fashioned from the details of the talk and other conduct of the participants....but rather that this must be otherwise invoked by the analysts" (pp. 65-66). In contrast to a notion of relevant context as *only* that which is intrinsic to

talk, those conversation analysts who study institutional settings use context in slightly broader ways, attending to speakers' institutional roles (e.g., therapist) or technical information about the aims of a setting (Drew & Heritage, 1992). While this research study was informed by certain aspects of conversation analysis, in relationship to context, I drew upon a more flexible and open approach to context, drawing heavily upon some discursive psychologists' suggestion that discourse is produced in relation to broader structures and institutions (Wetherell, 1998). I also took into account critical discourse analysts' suggestion that:

> Discourse is not produced without context and cannot be understood without taking context into consideration...Discourses are always connected to other discourses which were produced earlier, as well as those which are produced synchronically and subsequently. (Fairclough & Wodak, 1997, p. 277)

Like Fairclough and Wodak, I view discourse as being produced in context, while, at the same time, the discourse produces the context itself. Furthermore, like the majority of discursive psychologists, I too embrace the idea that contextual attributes, such as race, gender, and dis/ability, indeed depend upon the particular setting in which talk occurs (Goffman, 1964). While many conversation analysts seek to make universal, context-free claims about interaction (ten Have, 1999), I take up a DP stance that works from an anti-foundational perspective, positioning the analyst's claims as constructed, situated, and open to re-interpretation (Potter, & Hepburn, 2008).

So, with no intent to make universal claims, but instead attend to the particularities of The Green Room, I faced difficult decisions regarding what aspects of the context and which contextual factors (i.e., race, age, etc.) to report. Determining what was and was not contextually

relevant was not a straight forward process, yet was grounded in my desire to consider context from the perspective of the participants' themselves. Bateson's (1972) words illustrated well the importance of analyzing context in connection to a participant's perspective:

> Suppose I am a blind man, and I use a stick. I go tap, tap, tap. Where do I start? Is my mental system bounded at the handle of the stick? Is it bounded by my skin? Does it start halfway up the stick? Does it start at the tip of the stick? But these are nonsense questions...The way to delineate the system is to draw the limiting line in such a way that you do not cut any of these pathways in ways which leave things inexplicable. If what you are trying to explain is a given piece of behavior, such as the locomotion of the blind man, then, for this purpose, you will need the street, the stick, the man; the street, the stick and so on, round and round. But when the blind man sits down to eat his lunch, his stick and its messages will no longer be relevant—if it is his eating that you want to understand. (p. 459)

Following Bateson, then, in this study, I hoped to consider what participants treated as relevant about the context, and assumed that the context itself was shaped by the activities being performed at a given moment. So, I aimed, to connect the analysis of context to the activities and everyday interactions that the participants used when building social realities, recognizing that the participants were always situated within multiple contexts. More specifically, I did not presume that simply because I asked the participants to share their age, gender, race, professional titles, and dis/ability label(s) (see Appendix C and Appendix E) that it was relevant to my analysis.

In the end, I chose not to include all of the demographic information that the participants provided (see Table 2, 3, and 4). Instead, I carefully considered the scholarly discussions being had in the broader body of literature focused on autism and disability studies, as well as that which was made relevant in the everyday practices of the participants. I recognized that a dis/ability label does not exist in a vacuum, "but intersects with other markers of identity including, but not limited to gender, race, ethnicity, nationality, sexual orientation, and age" (Conner & Bejoian, 2007, p. 9). With the focus of this study on such dis/ability "markers," I reported and considered the participating children's dis/ability labels, as made relevant by their parents and therapists (see Table 3 in Chapter V). Further, with the majority of research within disability studies focused on adult, European-American males (Conner & Bejoian, 2007), I hoped to include children with autism labels (aged three to 11), not adults, and subsequently chose to report their age. With the male to female ratio of individuals with autism labels ranging from 6:1 to 17:4 (CDC, 2007), I anticipated having far more male than female participants. Indeed, this was the case, with 11 of the 12 participating children being identified by their parents as males. In that there is an ongoing debate regarding the reasons why young boys are diagnosed with autism at a far higher rate than young girls (Park, 2009), I chose to include the children's genders in Table 3 (see Chapter V). Additionally, on two occasions, a spontaneous, waiting room conversation between parents occurred, in which the participating parents hypothesized about why more males than females might be diagnosed with autism labels.

Beyond age and gender, I pondered often about those racial identities made relevant by the participating parents; all the while recognizing that this study was carried out in a predominately White state. Particularly in relation to racial identities, Bell (2006), a disability

studies scholar, suggested that the field of disability studies has insufficiently considered the intersectionality of identities of individuals with dis/ability labels, resulting in a predominately White version of dis/ability. Aware of Bell's suggestion, I chose to report what the participating parents reported as their child's race. All but one participating child identified as White,[15] with one child being identified as Native American. I did not report the gender, race, or age of the therapist; I did not find this demographic information to be analytically relevant, nor did the children and/or parents orient to these factors as relevant. I did, however, report the number of years each therapist had worked at The Green Room, as this was made relevant by the parents, as they often talked about which therapists had worked with their child the longest or the shortest amount of time. I also decided to list the professional title(s) that each therapist reported on their demographic survey, delineating which therapists were physical therapists, occupational therapists, speech-pathologists, teachers, autism specialists, or medical secretaries. In that I oriented to the talk as institutional, I presumed that the "participants' institutional or professional identities" would perhaps be "somehow made relevant to the work activities in which they are engaged" (Drew & Heritage, 1992, p. 4). In regards to the participating parents, on the demographic forms they completed, I only asked them their name, attempting to keep the focus of the study on the children themselves. Thus, in Table 4 (see Chapter V), I reported only the relationship between a participating parent and his/her child.

Overall, my intent in offering a thick description and interrogating broader, contextual information in Chapters VII and VIII, is to provide the reader with a means by which to better

[15] All of the participating parents who identified their child as White wrote "Caucasian" on their demographic form. Saturn's mother and father both told me in their individual interviews that they were a "Native American family," with Saturn's mother also writing "Native American" on the demographic form she completed.

understand how the participants went about their everyday interactions and how I made sense of the data. Further, I suggest that what I chose to report and how I constructed each description of the site and participants highlights my own commitments as a researcher. Certainly, in reading my description and account of how I came to view something as relevant or irrelevant, a reader can become familiar with my stance as a researcher and orientation to the participants and the research site.

Decisions around Representing Participants

When deciding how to introduce the reader to the participating site and the therapists, children, and parents with whom I interacted, I returned to my observational/field notes and research journal to identify the ways in which I had already begun to construct the participants through my own language use. I wondered whose descriptions/constructions I should draw upon; solely my own representations or the participants' as well? Do I describe in equal detail all seven therapists, 12 children, and 17 parents? Further, I recognized that names often work to construct certain versions of one's identity and way of being; they matter to the individual named. I wondered then whether I should choose names that captured my own constructions of the children. Should I randomly select a name and simply move the research process along? Should I ask the participants to select their own names/pseudonyms? To answer these questions, I decided to turn to the data, which included my research journal, observational/field notes, interviews, and therapy session interactions.

I noted that throughout my data collection process, I made explicit how I struggled with my own language use. When I first began collecting data, I presumed that my awareness of the

problematic nature of the medical models of dis/ability made me exempt or at less less likely to use language that worked to pathologize the participating children. Yet, I quickly learned that I often drew upon the dominant ways of constructing children with autism labels, as I too am always already a part of the discourses, practices, and structures which I interrogate (Habermas, 1988). The following paragraph, taken from my research journal, illustrates my struggle well:

> July 11, 2010 2:29 pm
>
> I have begun to realize how careful I have to be in order to steer clear of language that works to pathologize behaviors. It is so steeped into my way of speaking; I do attach certain language to observed behaviors. I've been trained to see the flittering hand in front of the face as stimming behavior—but in my observational/field notes, I must push myself to just describe what "it" (whatever "it" is) did in the relational space of interaction, not simply say, "She stimmed by doing this...". Some days it is particularly difficult and I've begun to see why Biklen et al. (2005) said that it is so very challenging to do qualitative inquiry with topics deeply steeped in medicalized language. How do I even talk about this stuff? How?

While I struggled with my own language, I was struck repeatedly by how the majority of the participating therapists and parents reframed the children's "behaviors" as normative, or at least as something capable of being understood. For instance, what I named a "stimming behavior" in my observational/field notes, many of the participants named "one of the ways he expresses himself." Across the data, the children were described with fluid and shifting identities. It was the parents' and therapists' descriptions of the children, in particular, that often stood in contrast to my own, pushing me to reframe the ways in which I wrote and spoke about

each child participant. So, when answering the question about whose descriptions/constructions I should draw upon, my own or my participants,' I decided to draw heavily upon the participants' representations, using in-vivo descriptions taken directly from the parents' and therapists' interviews. In response to the question about whether to describe in equal detail all seven therapists, 12 children, and 17 parents, I reconsidered the purpose of this research. With an intentional focus on the child/individual with an autism label, I decided to focus primarily on describing the children, as this was the focus of most of my interview questions and my observational/field notes as well.

Below, I describe the child participants in greater detail and offer a brief description of the participating site. In that the identities of the therapists, parents, and state advocate were not made as relevant in the context of this study, I do not provide descriptions of these participants beyond that which was presented in Chapter V. Within the below description, I present the rationale offered by many of the participating children and/or therapists and parents for a given child's pseudonyms, highlighting how these accounts worked to build a certain version of the participating child and, in some cases, the construct of autism. I begin with a brief description of the site itself, named by Megan, Drew, and Bria, "The Green Room."

The Green Room

As I engaged in the research process, my understanding of and relationship with The Green Room and the participants evolved (Boellstorff, 2003). Over time, I began to view the site as a space where the participating parents and children came in hopes of finding new ways to communicate with their child and to improve their child's ability to function independently (e.g.,

cross the street safely, get dressed independently, etc.) and socially engage with their peers. I also came to view the site as a space that fostered relationships between parents, therapists, and children, for many, during the course of their spontaneous waiting room interactions, and for some, over the course of several years. The Green Room's directors, Drew and Megan, explicitly spoke of their hope that the parents and children who came to their space oriented to it as "welcoming" and "not like institutionally feeling." When I asked the directors to select a pseudonym for the site, they hesitated, asking if it was possible to keep their "real name," as they viewed their site name as "one big metaphor that represents what we think about our work." While this was not possible for reasons related to maintaining the anonymity of the participants, I did encourage the directors to take their time in selecting a pseudonym and to share freely what they desired for outside readers to know about their site. Approximately two months after I had completed the data collection, Drew, Megan, and Bria wrote me an email requesting that I use the pseudonym "The Green Room" when referring to their clinic. Bria and Megan wrote specifically why they desired this pseudonym, with Bria stating, "I would say that green rooms are where celebrities sit to await their big interview with Oprah or Leno—like the place you go before you communicate to the world." Megan added (September, 28, 2010 at 12:00 pm):

> A green room IS a place where the 'fames' gather before 'going on'...there is a lot of pre-communication preparation that goes on before their communication becomes 'public.' I also think that being in the green room is a 'calming' experience before you get in front of a bunch of people in 'public.' It is kind of like therapy...therapy prepares you for the real life communication that goes on in the 'community/real world.'

Thus, it seemed that for the therapists, much like the participating parents, The Green Room was constructed as a "calming" space with opportunities to expand communication.

While the amount of time each participating child spent per week at The Green Room ranged from 60 minutes to 300 minutes, with the specific amount of time often being tied to a given child's insurance coverage, most of the therapists maintained an eight to nine hour workday. In general, each individual therapy session lasted 30 minutes and often included a two to five minute conversation with the child's caregiver in the waiting room prior to and/or following the therapy session(s). While the therapists typically had only one to two minutes between each child's therapy session, they often used that time to return to their shared, central office area, retrieve their next client's/child's file, and share a brief story about their previous session(s) with another therapist. Quotes drawn from individual therapy sessions were also often posted on a central white board in the main office, chronicling "funny" and "adorable" conversations with the children with whom the therapists worked. For example, one quote that remained on the board throughout my time at The Green Room was: "I wish I was a Wiccan—they make medicine out of nature." Another quote, posted during the last month of the data collection process, was: "I'm going to be a doctor, an artist, a teacher, and an animal healer…and I'm going to do it well…so I will be rich, right?"

Each morning before the children arrived and each afternoon as they were leaving for the day, the therapists often shared stories about the participating children who came to the clinic; further, this was one of the primary ways that the therapists spontaneously interacted with me when I was working or simply observing within the main office area. In many ways, my relationship with each therapist was localized around specific stories about individual children.

This particular aspect of my unfolding relationship with the participants is illustrated by the following research journal entry:

> July 11, 2010 5:32 pm
>
> Every day it seems that the therapists and I are becoming closer and closer as we affirm over and over again, through smiles, pats on the back, and countless stories, that the participating children are the most beautiful, delightful, funny beings around. As time goes by, occasionally I'll get a text, an email, a pat on the shoulder, or a "I have a story to tell you about George," that reminds me that this place, these therapists, seem to work to find joy in *understanding* the children and *interpreting* their behaviors, just like many of the participating parents said they wished many more people in society would take the time to do.

It was through storytelling that I came to better understand how the therapists oriented to the participating children as they accounted for what happened in a given therapy session.

Finally, it is important to note that all of the participating families chose to come to The Green Room, with many describing their decision to come to The Green Room as driven by their desire to bring their child to a place that "didn't feel so clinical." During his interview, one father, Joel, described dropping his child off at The Green Room as being comparable to "dropping our kid off at, you know, with friends or family." He went on to say:

> ...when you call The Green Room or you email one of the therapists, you get a response and it's, it's not "Hello Mr. X thank you for replying," you know, it's "hey Joel what's going on." You know, it just has that feel to it all the way around and we're, I mean, I'm

a lot more comfortable bringing Diesel Weasel here than I ever, ever was at the hospital, I guess.

While all of the children who participated in this study had at one time received therapies at other private clinics and/or hospitals, at the time of this study, The Green Room was identified by the participating parents as being their child's primary site of therapeutic support.

The Participating Children

As I turn to offer a further description of each child, I focus on what the participants made relevant about the child's pseudonym. It is important to note that when the participating child did not express with words, writing, sign, or any other form of communication a pseudonym preference, I then asked their parents. When the parent expressed no preference, I then asked the participating therapists to select a pseudonym, if possible, in collaboration with the child. I refer the reader to Table 3 in Chapter V for a review of demographic information of interest, including gender, age, race, and diagnostic label(s).

Meet Billy. Jennifer, one of Billy's therapists, developed a pseudonym based on the lead male actor in the movie *Twister* whose name was Bill. In that Billy was fascinated with tornados and enjoyed collecting and sharing tornado-related facts, Jennifer wanted his name to relate to one of his primary interests.

Meet Chance. Chance's primary therapist, Drew, selected his pseudonym, stating that the name Chance was fitting "because if I had the chance to get in one kid's head for ten minutes, he's who I would pick." Drew situated much of her desire to "get in" Chance's "head" around

what she described as the main "conundrum" of autism, stating: "Chance is a kid whose expressive skills are better than his receptive skills; that's kind of a conundrum to me."

Meet Diesel Weasel. Diesel Weasel spent several months selecting a pseudonym. Initially, a variety of Pokémon characters were selected, but in the end, he wrote me an email (October, 4, 2010 at 5:35 pm) requesting the pseudonym "Diesel Weasel...because that was a joke on *Ice Age: Dawn of the Dinosaurs*." He added, "I guess it just came to mind (I saw the movie over the weekend), and... it just sounds kind of fun!"

Meet George. During one of his occupational therapy sessions, George told Bria that he would like me to refer to him as "George." When Bria asked what the name George meant to him, George indicated that this was a name that his grandmother sometimes called him.

Meet Noodle. Noodle's pseudonym was selected by Megan, who provided a rationale for why she selected this particular pseudonym. She wrote in an email (September 24, 2010 at 10:01 AM) the following:

> Noodle, that will be her pseudonym—that is what her mom calls her sometimes...among a few inappropriate, but endearing terms—ha! I like Noodle for her because she sometimes flops down on the floor like a noodle when she doesn't want to do something; but also I love noodles—they are my favorite food, and she is my favorite patient.

Meet Picasso. Picasso did not use a lot of words to communicate. Instead, according to his mother, "he loves to draw." Megan, one of the therapists he worked with, selected the pseudonym Picasso in that she orients to him as "artistically inclined."

Meet Saturn. Saturn's father, who referred to himself as Jupiter, selected his son's pseudonym. During his interview, Jupiter indicated that Saturn was the most fitting pseudonym

for his son in that "Saturn is our favorite planet because it's colorful and has rings and that makes it unique." He further stated that his son is very interested in the solar system; thus, when he talks to his son about being flexible when the unexpected occurs, he often uses the planet "Saturn" as the key example. He stated, "Saturn is flexible 'cuz it spins and has rings... and so we'll engage in conversation where he will refer to me as Jupiter and I refer to him as Saturn."

Meet The Emperor. The Emperor was frequently described as an avid Disney fan and was heard singing Disney tunes as he participated in therapeutic activities or waited in the waiting room area. Thus, his therapists determined that it was fitting to name him "The Emperor" in that "he likes the Disney trailer of *The Emperor's New Clothes* and that he really wants to be in charge these days."

Meet Thomas. According to his mother, everywhere Thomas goes, he carries a box of trains. One of his therapists, Jennifer, felt it was fitting to develop a pseudonym that highlighted his passion for "Thomas the Tank Engine." Thus, Jennifer selected the name Thomas.

Meet Tommy. Tommy, described by his mother as a "big talker," engaged in two weeks of negotiation about his pseudonym with his therapist Megan. Eventually, he decided that "Tommy" was fitting, as he liked cats and that was his cat's name. When describing the process of Tommy selecting a pseudonym, Megan wrote (September 24, 2010 at 10:01 am), "I am currently in negotiations with "Tommy" (who really wants his name to just be his name)...will let you know by Friday (since it actually takes him that long to negotiate and compromise)." One week following this email, Megan wrote again, stating (October 1, 2010 at 10:01 am):

> Final name is "Tommy." It is his cat's name, but also came from my idea of picking a name from a list on the internet. Runners up included: "Toostrong7" and Bruster

Rooster. He also told me that he should be in the Guinness Book of World Records for his "negotiation skills."

Meet T-Rex. When asked about a pseudonym, T-Rex and his therapist quickly decided that a dinosaur or mammal name would be the "obvious choice," as he "knows everything about animals." As his primary therapist Drew noted during her interview, "When working on question formulation or whatever, we'll use animal cards 'cuz that's his thing."

Meet Will. In his therapy sessions at The Green Room, Will spent a great deal of time working to articulate his name, as well as the names of the most important people in his life (e.g., family members). His therapist, Jennifer, selected the pseudonym Will, as it was similar to the name of one of his closest allies.

Chapter Summary

In this chapter, I offered a more thorough description of the research site, presenting those characteristics that were made most relevant by the participants, while also presenting the way in which I oriented to context. In doing so, I discussed my decision-making process around how and what to focus on when describing The Green Room and the participating children, in particular. I also provided a brief description, provided by the therapists, parents, and/or participating children, regarding the selection of the participating children's pseudonyms. In the next chapter, I present the main findings of this study, beginning with the first research question. Prior to doing so, I provide a brief overview of what I focus on in Chapter VII and Chapter VIII.

Overview of Findings Chapters

As I collected and analyzed the data and began sharing my interpretations with the participants, I faced difficult decisions about where to start and what to include/exclude in my discussion of the findings. Ultimately, in the first iteration of this work, the questions I brought to the data and chose to explore and share with others point to my own commitments, as well as those made relevant by the participants. This research was indeed "the storying into being of an account," where I both wrote and was written into all that I chose to share (Walkerdine, Lucey, & Melody, 2002, p. 181).

In the two findings chapters that follow, I invite the reader to engage with and question the findings, as I seek to produce knowledge that is layered (Bochner, 2009) and imbued with multiple and competing perspectives (Noblit & Engels, 1999). Each chapter re-constructs, in partial ways, a particular aspect of this project. Chapter VII, with a focus on the interview data of the therapists, parents, and state advocate, describes the varied meanings and performances of autism while pointing to the related political and social conditions that make the naming, performing, and treating of autism possible. Chapter VIII, drawing upon data from the therapy sessions, presents the noted patterns across the participants' discursive practices, highlighting the ways in which the therapists' and children's interactions worked to reframe "behaviors of concern" and to transgress[16] normative communication patterns.

[16] I use the word "transgress" to highlight the ways in which the participants, particularly the therapists and parents, worked beyond and often against the mainstream perspectives (Foucault, 1977) on what counted as "good" communication.

Chapter VII: The Meanings and Performances of Autism

I now present the findings related to my first research question: What are the various meanings of autism and how are these meanings performed within and through the discursive practices of therapists and parents of children with autism labels in their everyday interactions? Throughout this chapter, I focus on the participants' discursive practices, highlighting how they constructed and managed the meaning(s) of autism. Further, as I consider how particular institutionalized discourses and technical practices were enacted and lived through patterns of meaning and action, I work to complicate understandings surrounding autism, emphasizing tensions across institutionalized spaces, discourses, and practices. I draw upon my analysis of the eight therapist interviews, 14 parent interviews, observational/field notes, my research journal entries, and email exchanges between me and the therapists. Within this analysis, I also incorporate the two unstructured interviews, one focused on the insurance coverage process at The Green Room and the other on state-based diagnosis requirements related to qualifying for and receiving medical and other therapeutic services.

Chapter Overview

In this chapter, I first present the ways in which the various meanings of autism are produced and situated within a broader context, pointing specifically to the state- and insurance-specific requirements which shape the meanings and performances of autism. Then, I move to more explicitly consider how the participating parents and therapists produced and discursively managed the construct of autism, illustrating how the meanings of autism were constructed in

fluid and at times contradictory ways. After this, I more explicitly illustrate the ways in which the participating parents and therapists discursively performed the meanings of autism in situationally-specific ways, while working to account for and reframe behaviors often constructed as problematic or non-normative by the majority of society. I conclude this chapter by sharing the participants' responses to these findings.

Analyses/Findings

I organize and share my findings around two prominent and overlapping patterns (or actions of the participants' talk) generated through the analysis process: (1) the ways in which the parents and therapists constructed and made relevant the contingent and fluid meanings of autism, and (2) the ways in which parents and therapists reframed and accounted for the child's non-normative behavior, making relevant the performative aspects of autism.

Attending to the particularity of the talk. In both of the findings chapters, I offer a detailed analysis of each noted pattern, presenting illustrative excerpts along with my interpretations. The analytic process consisted of generating a corpus of examples for each pattern that served to illustrate the varied meanings and performances of autism, yet I present below only a small number of these excerpts.

As I discussed in Chapter V, throughout my analysis of the data, I broadly defined the very notion of a pattern or a recurring discursive event. While the word "recurring" or even "pattern" might evoke the sense of a unified idea or an overarching theme with minimal variability, I do not orient to it as such. In this study, I sought to identity common ways in which the doing of therapy was managed in and through the discursive practices of the participants.

Yet, even while identifying commonalities, as a discourse analyst, I also sought and presumed that each pattern was variable; each interactive moment was locally situated and not without contradiction (whether I noted it or not).

Indeed, my descriptions and interpretations of the interview and therapy talk are of a particular place, as I attempt to present the meanings of autism and The Green Room itself in complicated and situated ways. More particularly, I struggled not to present The Green Room in a monolithic way, attempting to write in a way that did not presume "homogeneity, coherence, and timelessness" across the data set (Abu-Lughod, 1991, p. 154). So, I acknowledge that each interview and therapy session were particular events, never pursued in entirely uniform ways, despite the overarching commonalities.

In presenting the findings, then, I do not offer broad themes or patterns that function at the level of generalities. Thus, I qualify my use of the word pattern. I do not aim to move to the level of generalities or suggest that the patterns I share offer a complete picture of the meaning of autism, the doing of therapy, or are translatable to all therapeutic settings with children with autism labels. Instead, I work with and attempt to make sense of the data in local and always partial ways, and desire not to construct the participants as invariable and without contradiction.

Selecting excerpts. In selecting the excerpts for this chapter, I faced difficult decisions, such as where to begin and end a given excerpt and whether I should include all of the transcription conventions used during my analysis process. Ultimately, I aimed to present enough evidence to allow the reader to put forward alternative interpretations (Hammersley, 2010), while also selecting excerpts that show the variability within my data set. As such, I invite the reader to engage critically with the excerpts and with my interpretations of them and to

re-interpret and offer alternative understandings. I turn now to explicate the broader context in which I situate the discussion of the varied meanings and performances of autism.

The Broader Social and Political Context: The Economy of Autism

I situate my analysis and interpretation of the varied meanings and performances of autism within the broader political and economic context made relevant by the participants, focusing in particular on the expenses associated with "treating" autism and the process of qualifying for primary insurance and Medicaid coverage. When I first designed this study, I had no intention of exploring the broader discourses and institutionalized practices associated with a family/child with an autism label and/or other dis/ability label(s) qualifying for primary insurance or Medicaid coverage. However, throughout the data collection and analysis process, I was struck by the degree to which the meanings of autism were often inextricably linked to the economically-related aspects of seeking and receiving therapeutic services. Early on in the data collection process, I pondered often about the ways in which the "doing of therapy" was informed and shaped by insurance companies, noting the following in my observational/field notes:

> June 2, 2010 8:30 pm
>
> Even in these first few days of data collection, I have been particularly struck with the ways in which the therapists move from 30 minute sessions to filing documents to making insurance notes—their movement appears to be situated between the therapy sessions with each child and the insurance note-taking/report-making. There are even discussions between the more experienced and the more novice therapists about how to

> perform differently for a parent, an insurance provider, and a doctor. The more experienced therapists often say to the new therapists, "You need to write this way when you are writing for an insurance company."

As I interviewed the therapists and parents and made observations at The Green Room, I began to orient to the meanings of autism as being bound up in those institutionalized practices that were explicitly tied to a given family's insurance policies and/or the state-based healthcare mandates related to autism.

The participating therapists, who seemed to be working at the intersections of the demands of insurance companies/Medicaid requirements and the expressed needs of a child/family, sought to acquire coverage for all of the therapies they provided to the participating children; yet, in that the state in which The Green Room was located did not have a specific health insurance mandate for autism (American Speech-Language-Hearing Association, 2010), a diagnostic label of autism did not guarantee that an insurance company would offer coverage for individual therapy sessions. In fact, a child needed to be diagnosed with a discipline-specific label (e.g., expressive language delay) in order to receive services from professionals such as speech pathologists, occupational therapists, and physical therapists. Even in the main office area of The Green Room, the therapists were visually reminded (see Figure 4) of specific diagnostic labels and codes (see Table 7), based on The International Classification of Diseases-9 (ICD-9) (American Medical Association, 2010), that needed to be used when requesting insurance coverage.

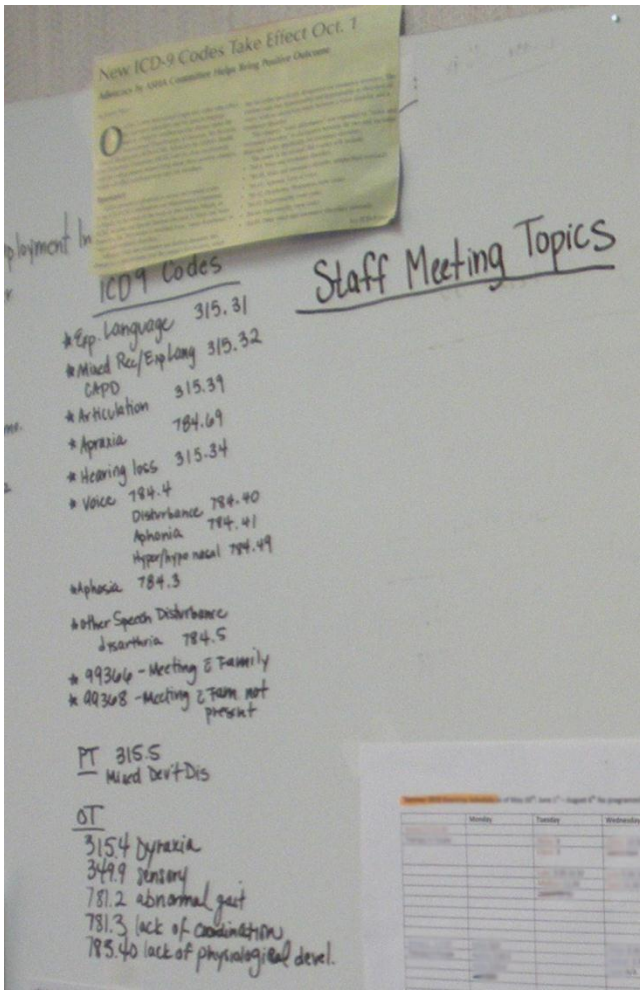

Figure 4. Picture of Whiteboard with ICD-9 (American Medical Association, 2010) Medical Codes (Taken on June 2, 2010 at The Green Room).

Table 7

The ICD-9 (AMA, 2010) Codes Posted in The Green Room's Central Office.

Diagnostic label	ICD-9 Code
Speech-Language Pathology	
Expressive Language	315.31
Mixed Rec/Expressive Language	315.32
Articulation	315.39
Apraxia	784.69
Hearing loss	315.34
Voice	784.4
Disturbance	784.40
Aphonia	784.41
Hyper/hypo-nasal	784.49
Aphasia	784.3
Other Speech Disturbance	
Dysarthria	784.5
Meeting with Family	99366
Meeting with Family; Not Present	99368
Physical Therapy	
Mixed developmental disability	315.5
Occupational Therapy	
Dyraxia	315.4
Sensory	349.9
Abnormal Gait	781.2
Lack of Coordination	781.3
Lack of Physiological Development	783.40

While all of the participating children held primary insurance policies, only six of the participating children qualified for Medicaid, a healthcare program within the United States typically for individuals "...with low incomes and limited resources" (Social Security Administration, 2010, p. 16). Based on my interview with the state advocate and the official government documents (Social Security Administration, 2010), if a child is less than 18 years of age and meets the Social Security definition of dis/abled, which is not explicitly linked to autism labels, and the child's resources fall within the eligibility limits, s/he can qualify for Supplemental Security Income (SSI). In most states, if a child receives SSI payments, they also qualify for Medicaid. In the state in which this study occurred, to qualify as "disabled" under Medicaid standards, the child needed to be diagnosed by an official state approved clinician, most often a psychologist, who then determined whether the child was "mentally retarded"[17] and/or exhibited "significant" functional limitations.

According to the participating therapists and state advocate, qualifying for Medicaid under the dis/ability category was specific to the child's identified area of need (i.e., cognitive impairment) and not necessarily based on the family's income. Thus, the recommendations of the state-approved assessor were taken into consideration by a state appointed board that then determined whether the child qualified for a medical (developmental disability/mental retardation) waiver. If the child qualified, s/he would no longer receive a bill from The Green Room, or any other therapeutic center, and would then have access to a variety of services, including community help, respite care, and transportation.

[17] While I am well aware of the controversy and critique surrounding the term "mental retardation," the state in which this study occurred used this term in lieu of intellectual disability (ID); thus, in this text, I maintained the dominant language of the state.

While the official government documents that described Medicaid qualification constructed the process as a fairly step-by-step, easy to understand procedure (Social Security Administration, 2010), the participants oriented to qualifying for Medicaid as "confusing" and "frustrating." Megan, in an email exchange in which I asked for clarification about the process of qualifying for Medicaid, wrote:

> December 4, 2010 2:00 pm
>
> I think that this process is really confusing for patients/parents/families. Because although it is "Medicaid," the people you speak with are totally separate. I couldn't even tell you who I would refer parents to for questions. We've met with a human services agency about the differences, and some of their caseworkers don't even understand it. Frustrating and confusing.

When I interviewed Ruth, the state family advocate, I asked explicitly about the process of qualifying for Medicaid. She constructed the process as "very judgmental" and "like the luck of the draw," positioning whether a child qualified or not as unpredictable and often "frustrating for the families."

At The Green Room, out of the 70 waiting room conversations analyzed, I witnessed five conversations in which a therapist encouraged a parent to consider seeking Medicaid coverage, articulating that such coverage would provide them with additional resources and opportunities to access therapies and activities in various community spaces. When I inquired further, asking Drew and Megan "who benefits when a family gets Medicaid coverage," Megan replied via email:

December 2, 2010 8:05 pm

> We both win when the child can have continuous therapy all year. Most insurance plans have a limit on how many visits you get per year. As few as 20...but as much as 90. A child like Noodle, for example, who comes three times a week, runs out of visits in October or November. So her Medicaid waiver allows us to actually bill Medicaid for her November and December therapy (which she would not otherwise receive....and consistent therapy is so very important to her). Medicaid in our state reimburses something like $38 per session (which would be impossible to run a business on solely...unless you were a sole proprietor who had no employees). But I guess you could look at it as being a difference of them coming or not. If they are applying for the waiver, it often means that they cannot afford the out-of-pocket expenses...therefore they would not get services due to finances. With the waiver, kids will get the help they need with the financial stressor removed.

Her reply pointed to the "economy" which surrounds "treating" children with autism labels, highlighting the benefit of acquiring a waiver. So, although for many families, Medicaid coverage provided services that allowed for qualifying children to participate more fully in the community in which they lived (e.g., funding for an aide to assist a child while s/he attends a local gathering), the state officials and policy makers, those individuals who worked to define what counted as "marked and severe functional limitations" (Social Security Administration, 2010, p. 6), ultimately determined if and how a child could qualify for Medicaid services.

Of the six families who qualified for Medicaid, one parent in particular spoke explicitly about the process of qualifying for Medicaid. In Excerpt One (see Appendix G for transcription

symbols), drawn from the interview data, Lily oriented to her son being labeled "mentally retarded" as being related solely to their family's need to acquire Medicaid coverage, moving then to undermine the validity of how the diagnosis of "mental retardation" was determined.

Excerpt One

1 *Jessica*: Did they diagnose him↑

2 *Lilly*: They did (1) I needed him diagnosed for him to be on Medicaid (1)

3 *Jessica*: okay=

4 *Lilly*: =and the f- um (2) the psychologist who did it (1) wasn't very patient with him=

5 *Jessica*: =Mm hm (1)

6 *Lily*: and you know he just kinda (2) fifteen minutes and you know he had figured out

7 he was mentally retarded

8 *Jessica*: Mm that's what the psychologist said↑

9 *Lily*: yeah=

10 *Jessica*: =After fifteen minutes↑

11 *Lily*: Mm hm=

12 *Jessica*: =Mm=

13 *Lily*: because he couldn't get answers and stuff from him you know (2) and (2) so

14 (1) I did not like that (2) assessment at all (.)=

15 *Jessica*: =I would imagine not (.)

16 *Lily*: because he is <u>not</u>=

17 *Jessica*: =Mm hm=

18 *Lily*: =I mean he <u>can</u> learn you know=

19 *Jessica*: =Mm hm

In the above excerpt, Lily began by linking her son's diagnosis of mental retardation to the institutional practice that makes Medicaid coverage possible. She made explicit that she simply "needed him diagnosed for him to be on Medicaid," accounting for why she pursued further testing and a diagnosis of mental retardation (line 2). Yet, after offering a justification for seeking a diagnosis, she moved to undermine the validity of her son's diagnosis of mental retardation, questioning the very way in which the psychologist determined that her child was "retarded" (lines 4-7). She reframed her son's failure on the official assessment (line 13) as not being due to some intrinsic inability, but to the psychologist's impatience and the little time he spent with her son. After I affirmed Lily's dislike of the assessment (lines 14-15), stating "I imagine not," she moved to clarify why she "did not like that assessment." Her next move provided an account of both what her son is and what he can do, with Lily stating, "because he is not... I mean he can learn you know." With added emphasis on what her son is "not," as well as what he "can" do, Lily constructed a version of her son as something other than mentally retarded (lines 16-18). She worked up the construct "mental retardation" as being indicative of not capable of learning, an attribute from which she distanced her son.

Like the participants in Rocque's (2010) study, Lily negotiated and maintained in talk a positive identity for her son, accounting for and reframing his performance/behavior as being due to something outside of him—namely the psychologist's inappropriate, yet necessary, assessment practices. In doing this, she distanced her son's identity from the construct of mental retardation and positioned his very diagnosis of mental retardation as being inextricably linked to the process of acquiring Medicaid, not any real, inherent inability to learn. His multiple and

fluid identities, then, as Foucault (1972) would argue, were discursively constructed and reconstructed, shifting continuously in relation to the broader social and political contexts.

When I later asked Lily, "when you say autism, what does that mean to you?" she returned to the construct of mental retardation, stating, "and what it means when I think of autism, I don't think of mental retardation." Like many of the participating parents whose children qualified for Medicaid, Lily positioned mental retardation in contrast to autism, with the validity of a diagnosis of mental retardation being perhaps resisted by positioning the diagnosis as necessary only because of the state-based Medicaid requirements. This resistance to and distancing from the label of mental retardation, in particular, points to the common cultural presumption that a "label of 'mental retardation' implies a permanent and severe developmental limitation" (Greenspan & Mann, 2003, p. 639), and carries with it some level of stigma (Major & O'Brien, 2005). Perhaps then by distancing her child from a label that has historically suggested a "permanent...limitation," Lily, like all of the participating parents, worked to construct her child as competent, and as she later stated, as someone who "can learn (.) you know."

In many ways, the complex process of acquiring an official dis/ability label(s), primary insurance coverage, and a Medicaid waiver was imbued with economic and material barriers (Howell, 2004; Johnson et al., 2003; Riebschleger, Sosulski, & Day, 2010); for some of the participating children, this process acted to restrict and at times prevent them from participating in certain activities, at least until their families could find a way to qualify (i.e., until the child performed as "significantly impaired" according to the officials of the day). Informed by the social-relational model of disability (Thomas, 1999, 2001, 2004), I interpreted these institutionalized constraints as examples of barriers to doing, with dis/ability coming into play as

restrictions were placed on the participating children and families. While the therapists, parents, advocates, and even the children themselves, worked across several institutional structures, the power to name, perform, and treat autism was "...never localized here or there...never appropriated as commodity or a piece of wealth," but "...exercised through a net-like organization" (Foucault, 1980, p. 98).

So, it was within a context in which those institutionalized practices that make naming and treating autism (im)possible that the participants produced contingent and at times contradictory meanings of autism. I move now to explore the ways in which these meanings were worked up discursively and functioned to position autism as an unstable construct with multiple, yet always consequential, meanings.

Pattern One: Contingent Meanings of Autism

Though I did not always succeed, throughout the interviews with the parents and therapists, I attempted to avoid imposing an a priori definition of autism, working to create space for the parents and therapists to share how they oriented to the participating child. I began the parent interviews by asking, "What things might you want someone who has just met your child to know about him/her?" and the therapist interviews with "What things might you want someone to know about the children you work with?" In doing so, I hoped to first consider what the parents and therapists chose to make relevant about the participating children. Although I only invited those children to participate in the study that the therapists and parents identified as having an autism label, I presumed that a diagnostic label of autism did not necessarily indicate that the child's parents or therapists oriented to autism as a biological and stable construct. In

other words, I did not presuppose that I was the only speaker who oriented to diagnostic labels as social and historical constructions (Bynum & Nutton, 1981). I recognized that "identity ascription of any kind, and by academics as much as by anyone else, is always occasioned by some interactional or institutional circumstance" (Rapley, Kiernan, & Antaki, 1998, p. 825). As such, I decided to use the word "autism" only after a participating parent or therapist made it relevant, which all of the participants did at some point during the course of their interview. When they did make it relevant, I always asked, "When you say autism, what does that mean to you?" By questioning in this manner, I was engaging in what Edwards and Stokoe (2004) referred to as normative interviewer talk, aiming to elicit participants' constructions rather than immediately making relevant my own with equal footing.

I next share the most common ways in which parents and therapists talked about the meanings of autism. The excerpts and analyses/interpretations I share highlight how the participants oriented to autism as a fluid, contradictory, and negotiable construct, rather than as a unitary entity. Most of the participating therapists and parents did not use the category of autism in a way that assumed there was a common and shared definition. Instead, when they talked about autism, they negotiated its meaning as contingent and situated, often within the context of everyday events and/or institutionalized practices. The majority of the participants oriented to the meanings of autism as (1) always produced in relationship to institutionalized practices and requirements (e.g., insurance demands as illustrated in the previous section); (2) untenable and apt to receive multiple meanings; and (3) representative of a different or non-normative way of thinking. In relationship to the notion of autism as a unique or different way of thinking, many of the participating parents (11 out of 17) and a minority of the therapists (2 out of 8) went one

step further and oriented to autism as a potential "gift" or "advantage." A minority (7 out of 17) of participating parents oriented to autism as something to overcome or defeat, with none of the therapists orienting to autism as such. Finally, for all of the participants, at some point in the interview process, the *actual* meaning or *truth* of autism was minimized, as the impairment effects of the child were positioned as being most relevant.

I begin with Excerpt Two, illustrating the contingent and unstable nature of autism. In response to my interview question ("When you say autism, what does that mean to you?"), few participants offered a straightforward definition of autism. Instead, like Melissa, the majority of the participants oriented to autism as difficult or even impossible to define, making evident how "extraordinarily unstable" the category of autism is (Osteen, 2008, p. 10). Excerpt Two illustrates well this dilemma.

Excerpt Two

1 *Melissa*: Well you know everybody's is so (.) <u>different</u> (1) you know like (8) the
2 whole concept of autism (5) I don't know how I would explain that↑ (1) cuz
3 everybody's my experience with autism is so different (.) than my girlfriend who
4 has=
5 *Jessica*: =Hm=
6 *Melissa*: =a son who's verbal↑ (.)
7 Jessica: Mm hm=
8 *Melissa*: =you know our (3) our (1) goals for our children may somewhat be the
9 same↑ (.)
10 *Jessica*: Mm hm (.)

11 *Melissa*: but our <u>experiences</u> are so different he's not (2) he doesn't have the the

12 yeast stuff that Noodle does he doesn't have the (1) the um (5) food allergies that

13 Noodle does=

14 *Jessica*: =mm hm=

15 *Melissa*: =you know so m- my experience is so much different than hers you know

16 auti- (2) it's a lifestyle really for us=

17 *Jessica*: =hm=

18 *Melissa*: =you know it's (2) it's (2) just >part of our daily normal< life=

19 *Jessica*: =mm hm=

20 *Melissa*: =that=

21 *Jessica*: =mm hm=

22 *Melissa*: =I don't know how↑ I would explain I really honestly don't=

23 *Jessica*: =mm hm (2)

24 *Melissa*: tuh you know is (2) I would just say well it's (1) <blah blah blah cognitive

25 blah blah blah de- disorder but> for me is I don't know how I would explain it=

26 *Jessica*: =mm hm=

27 *Melissa*: =personally I <u>don't</u> honestly know how I would explain it

Melissa's initial statement emphasized that autism, as a "concept," is variable and individual, stating that "everybody's is so (.) <u>different</u>." Melissa, as a parent of a child with an autism label, perhaps could have taken up the category entitlement to speak about and define autism in a definitive and expert-like manner (Potter, 1996). Yet, Melissa's orientation to and attempt to manage the dilemma of defining autism is made evident as she continued speaking. As she

defined the "whole concept of autism," long pauses were noted (lines 1-2), with pauses often signaling some type of interactional trouble (Speer, 2001). Perhaps, in this case, the interactional trouble is the very process of coming up with a definition of autism. I was particularly struck by Melissa's next statement: "I don't know how I would explain that↑ (1) cuz everybody's my experience with autism is so different." I oriented to this as significant in that Melissa, not offering a monolithic textbook definition of autism, instead situated the definition of autism in the experiences of parents with a child with an autism label. Autism, then, was defined in relation to the unique, everyday experiences of those who *lived* with or around autism. Following her claim of not knowing how to explain autism, she further accounted for why making sense of and explaining autism was impossible, contrasting her experience with that of her girlfriend (lines 3-6). She made relevant that her girlfriend's son is "verbal" (line 6), implying then that her daughter, Noodle, is nonverbal. This distinction is particularly relevant in that the broader discourse surrounding autism is rife with distinctions between verbal and nonverbal individuals with autism labels. Osteen (2008) noted that even within the autism advocacy community, distinctions are frequently made between verbal and nonverbal individuals, with verbal abilities being associated with high-functioning autism and nonverbal abilities being associated with low-functioning autism. Thus, I found it particularly intriguing that Melissa moved to suggest that her goals for her daughter are at least somewhat similar to her girlfriend's goals for her son (line 8). She could have said, for example, that because her daughter was nonverbal, her goals were remarkably different from her girlfriend's. Yet, such a move may have risked positioning her daughter as less competent, even lower functioning.

Nevertheless, Melissa did make relevant what was different about her experience, pointing to Noodle's allergies or bodily realities/impairment effects (lines 11-12).

Yet, while her goals for her daughter were somewhat similar to those of her girlfriend, Melissa returned to all that made her experience with autism unique, stating: "my experience is so much different than hers you know auti- (2) it's a lifestyle really for us." Rather than simply being an afterthought or minimally relevant in her day-to-day living, Melissa located the meaning of autism as being bound up in all that her life entails. Indeed, she reaffirmed this idea by stating that "it's (2) just >part of our daily normal< life." She positioned, then, the doing and performing of autism in everyday events. Sacks (1984) noted that within talk, speakers often go about "doing being ordinary" (p. 416), positioning their everyday experiences as nothing out of the ordinary or indicative of an aberration of some kind. In this case, Melissa oriented to her lifestyle as being nothing extraordinary, while still linking it to autism. I interpreted this move as constructing autism as something *not* to be spectacularized, as she positioned it as nothing more or less than what she lived day in and day out.

Melissa concluded by returning to the dilemma and perhaps the impossibility of precisely defining autism, stating that "I don't know how↑ I would explain I really honestly don't." When she finally came to offer what she would say to someone else about autism, her lexical choices are particularly interesting. She used the phrasing "blah blah blah" prior to both the term "cognitive" and "disorder" (line 25). Perhaps, the inclusion of "blah blah blah" functioned to position the precise, medical definitions of autism as ambiguous and hard to explain, pointing to the impossibility of *really* making sense of autism apart from its performance in everyday events/life. "Blah blah blah" may also have functioned to minimize or resist the medicalized or

technical jargon associated with autism. She emphasized that she "honestly" does not know how to explain autism, claiming responsibility for her inability to answer (Edwards & Fasulo, 2006). Further, by reemphasizing that she does not know how to explain autism (line 27), Melissa made visible, once again, the challenge of defining autism. Thus, Melissa's talk never precisely defined autism, at least not in academic or medicalized language, yet it always located its *real* meaning in everyday, individual experiences.

As I analyzed both the therapist and parent interviews, I did not assume that the therapists held expert knowledge while the parents maintained lay knowledge. Quite often, researchers presume that there are "recognizable stocks of knowledge that are made manifest and visible" through specialized and technical vocabularies (Housley & Fitzgerald, 2002, p. 74), with certain social categories owning these knowledges while others do not. Yet, discourse research has shown that the relationship between expert and commonsense explanations is ambiguous (Gilbert & Mulkay, 1984; Horton-Salway, 2004), and that expertise is locally produced in the process of building up an account. Thus, I attended closely to how the therapists negotiated the complexities of the social category of autism and assumed that they possessed no special ownership on the *real* meanings of autism.

Even with this orientation, I was still somewhat surprised that none of the participating therapists offered a technical or medical definition of autism. Instead, like the participating parents, the therapists never constructed autism as something that could be known, but produced a meaning of autism that was contingent and difficult, if not impossible, to define. In Excerpt Three, Bria, an occupational therapist, took up my question about the meaning of autism and accounted for why she no longer knows what it means when someone says autism. As someone

who indeed is familiar with the official definitions of autism and was continually positioned as an "autism expert" by the participating parents, Bria's response was particularly intriguing, as she too took up the idea that autism is not definable.

Excerpt Three

1 *Bria*: Um I think <I've (.1) grown to almost>have such a broad definition of autism
2 that I >don't even have one anymore< um and I'm not even sure I know=
3 *Jessica*: =mm hm=
4 *Bria*: =<u>specifically</u> what I would call autism anymore because to me it's <u>such</u> a
5 spectrum like if someone says oh well this child has autism like I don't think that
6 that necessarily >means↑ <u>any</u>thing to me < anymore↓ because I it because it could
7 mean so many things=
8 *Jessica*: =mm=
9 *Bria*: =it could mean that they just have some sort of social problems or have a little
10 bit of um the Asperger type traits or it could be someone who is totally nonverbal or
11 <u>absolutely</u> anywhere in between=
12 *Jessica*: =Mm hm=
13 *Bria*: =So (3) I don't know I think it's at this point so defined that it's undefined

In Excerpt Three, Bria, responding to the same question as Melissa, distanced herself from *really* knowing how to define autism, leaving the definition itself open and ambiguous. Bria began by stating that she has "grown" to have a "broad definition of autism." So broad, in fact, that she no longer knows how to define autism. Her use of the word "grown" implied that in the past perhaps she had a clearer definition of autism (lines 1-2), yet as time has passed she has grown to

orient to autism as an indefinable entity. Much like Melissa, Bria claimed not to know what to "specifically" call autism and then moved to account for her inability to answer my question ("When you say autism, what does that mean to you?"). While Melissa located the meaning of autism in her individual, day-to-day experiences, Bria did not. She positioned autism as a "spectrum" with multiple meanings (lines 5-7).

At present, autism is constructed in the medical literature and popular media outlets as a spectrum, with this particular term being one of the primary ways of talking about autism. Bria's choice of the word "spectrum" emphasized her focus on the idea that what comes to be named autistic includes a wide range of possibilities (lines 4-5). Such a focus perhaps also functioned to justify her claim that it is no longer possible for her to name precisely what autism means, with the "spectrum" itself implying a vast range of possibilities. She then named what autism "could mean," naming "social problems," "Asperger type traits," and "someone who is totally nonverbal" as possibilities (lines 9-10). This naming worked to construct a boundary of sorts around what "could" count as autism, with her choice of the word "could" leaving open the possibility that other meanings are possible. She further complicated the meaning of autism by stating that its meaning could be located "absolutely anywhere in between," as even in defining autism, it remains "undefined" (lines 11-13). I suggest that Bria's talk pointed to the idea put forth by many disability studies scholars (Altman, 2001; Biklen et al., 2005, Osteen, 2008) who suggest that autism, as a dis/ability category, is a floating signifier (Foucault, 1972; Laclau & Mouffe, 1985), itself void of meaning and thus open to receiving multiple and at times conflicting meanings. To say that autism is a discursive category recognizes that all attempts to locate differences between who is autistic and who is not autistic is untenable. Certainly, both

Melissa's and Bria's talk, as well as the majority of the other participants, pointed to just that—autism, as a floating signifier, does not rest at any level of static meaning, but performs instead a play, of signifiers, with shifting signification (Barthes, 1973).

As the parents and therapists constructed these ambiguous and untenable meanings of autism, they also frequently spoke of autism as "thinking outside the box (.) coming up with new ways to solve problems" (Jupiter). One of the participants (Samantha) spoke of the "unique" ways in which children with autism made sense of the world, while another (Megan) described the children with autism labels as possessing "a lot of little fantastically secret things." Two of the participating parents, Nicole and Amelia, even named autism as potentially being a "gift."

Excerpt Four and my interpretation that follows illustrate how autism was worked up as an advantageous gift. Just prior to the start of this excerpt, Nicole had described her son George as "being a happy boy" whose "behavior's a little bit different." She linked his "behaviors" to "his autism," defining further his frequent "meltdowns" as being the result of his "disability." Yet, after I asked "so what does autism mean to you↑" Nicole quickly moved to distance George's abilities from the notion of dis/ability, reworking how she made sense of his identity and the very construct of autism, as shown in Excerpt Four.

Excerpt Four

1 *Nicole*: So (.) you know I hate tuh I hate tuh even (.) sometimes call it a disability
2 sometimes I feel that it is but sometimes I think (2) you know it's gunna be (.) to his
3 advantage 'cuz maybe he sees things differently (.) than we do=
4 *Jessica*: =Mm hm=

Nicole: =and he he will able to figure things some out you know finger figure things out that we can't so it may be a a gift↑ (.)

Jessica: Mm hm=

Nicole: =some time so yeah=

Jessica: =Can you say a little bit more about that↑ (.)

Nicole: Um well if he were um (1) you know he could maybe he can uh process (.) visualize something and (.) um see it differently than I can and maybe um (1) uh you know make it work to his advantage down the road in a job↑ (.)

Jessica: Mm hm (.)

Nicole: So yeah hopefully he can see um maybe even some good in things that we (.) that we can't [or we

Jessica: mm hm]

Nicole: don't or you know (1) so (.) I hope I hope (1) you know he can use what he's got you know to his advantage=

Jessica: =Mm mm=

Nicole: =later in life and find one certain area that he <u>loves</u> and and uh you know he loves fans and vents and air conditioners and furnaces maybe he'll invent something for them and you know somebody's got to be interested right↑ and um (.) you know maybe it'll be a huge moneymaker for him someday

Nicole began by stating that she "hates" to call autism a dis/ability, implying that to be named disabled is undesirable (line 1). Edwards (1999) noted that it is particularly relevant to consider how emotions are used in discourse to link specific ideas together. Everyday understandings and

uses of emotions do not simply reflect mental states (Edwards, 1999), but instead point to the "...cultural values and the prerogatives of power that some members of this society currently hold" (Lutz, 1990, p. 204). So, it is particularly telling to consider how in the above excerpt, the word "hate" is deployed in relation to dis/ability. Historically, being named dis/abled has been linked to social exclusion, stigma, and deficits (Braddock, & Parish, 2001) and has rarely, if ever, functioned as a desired social category. Thus, to "hate" to associate autism with the notion of dis/ability perhaps evokes the broader discourses and institutionalized practices that construct being a member of a dis/ability category as aversive.

Yet, while Nicole oriented to autism as being a dis/ability, she softened her claim with the word "sometimes" (Edwards, 2000), leaving open the possibility that autism does not solely function as a dis/ability. She moved to complicate and rework the meaning of autism, stating that autism is "gunna be (.) to his advantage" (lines 2-3). So, she constructed autism as fluid and flexible, functioning as both dis/ability and advantage. The "gift" of autism was worked up in connection to (lines 3-5) George's *real* differences—"he sees things differently (.) than we do" and "he will able to figure things some...that we can't" (lines 3-5). Nicole's use of the pronoun "we" constructed a contrast between a person with autism and a person without autism. Not only does George have a gift, he is positioned as different from us, the presumed majority. When I asked Nicole to clarify further (lines 10-11), she moved to name George's advantage more precisely, naming his ability to "process" and "visualize" as exceptionalities. These were particularly interesting lexical choices in that popular and medical discourses surrounding autism often point to visualizing capacities as exceptionalities for many individuals with autism labels (e.g., Grandin & Scariano, 1986). I was particularly struck by how Nicole eventually moved to

link George's advantage to "one certain area that he loves" (lines 20-23). Earlier in the interview, Nicole had described George's "obsessions" with fans, vents, furnaces, and air conditioners as being part of his dis/ability and as inherent traits oriented to as oddities by those who do not know George well. Yet, now, these "obsessions" are no longer pathologized, but reframed as a potential advantage.

Siebers (2008) suggested that "it is easy to mythologize dis/ability as an advantage" in that "disabled bodies" are oriented to as "unusual" and bend "the rules of representation to such extremes that they must mean something extraordinary" (pp. 63-64). Some have suggested that a sentimentalized notion of dis/ability works to minimize the realities of being oriented to as different and living with *real* impairment effects. Davis (1995) noted that in "narrativizing an impairment, one tends to sentimentalize it and link it to the bourgeois sensibility of individualism" (p. 4). While the move to romanticize dis/ability categories can be seen throughout popular media and indeed has been criticized within disability studies literature (Osteen, 2008), it is important to consider the alternative. Consider how Nicole might have otherwise constructed her son. What if, for example, Nicole had only worked up a definition of autism that included a deficit orientation? What if she had solely constructed autism as nothing more than a disabling impairment? She could have drawn upon the dominant discourses surrounding autism that orient to an "autistic brain" as "broken" and in need of being "fixed" (Osteen, 2008, p. 12), with no advantage to be found. Perhaps, then, the construction of autism as a deficit stands in contrast to the construction of autism as a gift. I argue that whether one "reads" Nicole's orientation as a romanticized notion of autism or not, her discourse worked to complicate understandings of autism. Autism was not simply oriented to as a dis/ability, for it

somehow also functioned as a gift. The positioning of George's identity then was negotiated and fluid, including, in the same moment, both a dis/ability, which Nicole "hates" to call it, and a gift.

While some (11 out of 17) of the participating parents spoke about autism as being a potential "gift," linking the very notion of autism to a special way of thinking, a minority (7 out of 17) of the parents oriented to autism as something to be overcome or even to "beat." In an attempt to include examples that point to the variability within my data set, the next excerpt illustrates this notion of overcoming, curing, or even defeating autism. Just prior to the start of Excerpt Six, Alisha had listed all of the skills and abilities that her son Picasso has recently acquired, all of which medical doctors told her he would never achieve.

Excerpt Five

1 *Jessica*: What do you mean beat it↑ can you say a little bit more about that↑ you've
2 said that twice (.)
3 *Alisha*: Um (4) I <u>really</u> believe that I can get Picasso to a point and my other son to
4 points that we can possibly drop that diagnosis=
5 *Jessica*: =Mm hm=
6 *Alisha*: =I want I want autism gone I want autism out of our lives=
7 *Jessica*: =mm hm=
8 *Alisha*: =I want it to be in the past (.)
9 *Jessica*: mm hm (.)
10 *Alisha*: So even if Picasso has an Asperger's diagnosis someday I'm okay with that
11 as long as we're able to just (.) make that step forward

The excerpt began with me requesting clarification around Alisha's use of the term "beat." Alisha took up my question by emphasizing her belief that the diagnostic label itself will one day be dropped (lines 3-4). With two sons with autism labels, only one of whom participated in this study, Alisha referenced both of her children when elaborating on her use of the phrase "beat it." Alisha positioned this notion of beating autism as being synonymous with dropping or ridding of the diagnosis itself. Autism, then, was constructed as representing something undesirable, something that she wanted "gone" and in the "past" (line 6 and line 8). Alisha's next move positioned an Asperger's label as a more desirable label, naming it a "step forward" (lines 10-11). Alisha's construction of Asperger's as a "step forward" evoked the concept of autism as a spectrum of variable disorders, moving from undesirable to more desirable, from low-functioning to high-functioning. Osteen (2008) noted that there is a rift in the "autism culture" that divides the "so-called 'high-functioning' and the 'low-functioning' people" with autism labels (p. 6). In fact, much of the popular writing around autism has constructed individuals with autism labels as either savants or worthy of public attention only after they have overcome their autism (Osteen). With autism constructed as a spectrum, certain autism labels, particularly Asperger's, are constructed as better or more desirable than the other autism labels, even being oriented to as a "step forward."

Indeed, the popularized claim that autism is something to beat, overcome, or defeat (McCarthy, 2007) is not without contestation. For instance, some autism experts construct autism as a "developmental disorder which lasts throughout life" (Happe, 1994, p. 6) and can never be defeated. Disability scholars and advocates have also participated in this conversation, critiquing the very notion of overcoming a dis/ability and linking the mere suggestion to deep

seeded cultural prejudices against individuals with dis/ability labels (Ferguson & Asch, 1989). Indeed, Alisha's construction of autism was not without complication; recasting a child as recovered or even potentially recovered, according to some, only serves to omit irreducible human differences, with bio-remedies placed as the force that will potentially recapture what a child might *lose* to autism (Rocque, 2010b). Yet, if she had taken up the common construction of autism as a threat to the very humanity of her child, would she still have been able to position her son as competent and capable of learning how to do all that the doctors said he would never learn to do (e.g., being potty trained, communicating his needs, etc.)? While few participants oriented to autism as something to be overcome, Alisha's talk, like the majority of the participants, also continued to point to the common pattern of constructing autism as fluid and shifting. Indeed, the dominant autism story remained "fractured by *dissoi logoi*, a scrambled collection of competing, contesting 'truth claims'" (Avery, 1999, p. 119).

While the meanings of autism remained elusive for the majority of the parents and therapists, at some point in each participant's interview, the participant emphasized the realities of the participating child's impairment effects. As they did so, the participants often minimized the value and importance of even considering or talking about a particular child's *actual* or *real* dis/ability label. Instead, the participants concluded, like John, a participating parent, that "at the end of the day we're still going through the same process." Drawn from the interview data, Excerpt Six illustrates how John moved to emphasize the realities of his son's needs.

Excerpt Six

1 *John*: So um (1) 'cuz I don't know PDD-nos what does that mean well it means he
2 has autism but what does that you know oh he's high functioning autistic okay so

now does that mean that you know there's an upgrade from PDD-nos on to Asperger's and that Asperger's is maybe (.) maybe a little bit better understood or maybe more socially accepted [you know

Jessica: mm]

John: that I you know I don't know (1) but you know at the end of the day we're still (1) going through the same process=

Jessica: =Mm hm=

John: =the same classes the same The Green Room the same you know help at the public school system the coaching the constant (.) you know um I guess (.) fostering and mentoring at home =

Jessica: Mm hm=

John: =to help him with his uh disability=

This "process," as described by the participants, included acquiring and providing assistance and support to the participating children as they learned to function in institutional and community spaces that privileged communication styles and ways of behaving that were often remarkably different than their own. The child's limitation, like Thomas (1999) suggested, was oriented to as an effect of the individual's impairment and did not indicate dis/ability, but became "the marker for other [potential] restrictions of activity" (p. 43). So, as the participants spoke of the realities of needing to identify ways to teach a child, for instance, how to safely cross the street or communicate with an alternative communication device, they frequently minimized the importance of defining the meaning of autism. Instead, they emphasized that regardless of the

child's "official" label, the child would potentially benefit from outside therapies, most of which were out of reach without an insurance-approved dis/ability label.

The participants' emphasis on a child's impairment effects is a particularly intriguing finding; in recent years, disability studies scholars have expressed concern regarding an "over-socialized understanding of impairments," which makes it difficult to discuss and theorize about impairments as being potentially separate from the socially created notions of dis/ability (S. Reindal, personal communication, June 2008). Some disability scholars have minimally attended to impairment, perhaps for good reason, as French (1993) aptly noted:

> It is no doubt the case that activists who have worked tirelessly within the disability movement for many years have found it necessary to present disability in a straightforward, uncomplicated manner in order to convince a very skeptical world that disability can be reduced or eliminated by changing society, rather than by attempting to change disabled people themselves. (French, 1993, p. 24)

Nevertheless, it is possible, as Thomas argued (2004), to consider the ways in which impairments may "directly cause some restrictions of activity, while maintaining "that such non-socially imposed restrictions of activity do not constitute 'disability'" (p. 581). Not only is it possible to attend to impairment effects, but some would suggest it is also imperative. As Shakespeare and Watson (2002) stated: "We are not just disabled people, we are also people with impairments, and to pretend otherwise is to ignore a major part of our biographies" (p. 11).

So, in this study, I aimed to consider autism as a dis/ability category in complicated ways, hoping not to over-socialize my understandings of impairments, while simultaneously viewing autism as always being discursively constructed and reconstructed. As I did so, I sought to

attend to how the participants made impairments relevant, noting how "needing help" was often coupled with a child's *real* impairment effects. The following paragraph, taken from my research journal, illustrates my commitment to considering the bodily realities/impairments of the participating children, as made relevant in the data:

> July 18, 2010 7:02 pm
>
> There is something that I'm calling "ethic of the participants" or something like that; I do not want to omit or avoid discussing the challenges of impairment. Here's what I mean. I am often tempted to say, "All labeling is wrong." Yet, I now believe this is far too simplistic. I've now listened to too many parents describe the disabling effects of their child's impairments. I can't talk about my data without making explicit the *real* moments of challenge the children, parents, and therapists make relevant in their everyday practices. The participants, therapists, and children shared/worked up these "real" moments in which a child experienced disabling impairments and "help" was needed. One participating father said that he didn't care what "they" called it, just give his kid some help. I argue that sometimes scholars who take up "radically constructionist" positions risk minimizing the everyday *real* moments of challenges of children and families. What does it do to say even *bodily realities* are socially constructed? What does that do for the child who is being excluded from the educational system or struggling to learn how to brush his teeth, say hello to his friend, or safely cross the street? I think we need to complicate our understandings.

With autism, located at the intersection of biology and society (Osteen, 2008), I turn now to share my analysis/interpretation of an excerpt that illustrates how many of participating

parents, and some of the therapists, discursively minimized the label of autism and other dis/ability labels, while at the same time making relevant the *real* needs of the child. The minimization of the child's "official" label was coupled with an emphasis upon the needs of the child, which I came to interpret as the impairment effects (Thomas, 2004). Consider the following excerpt taken from the interview of Joel and Diane, the parents of Diesel Wiesel. The excerpt begins with Diane describing the process of acquiring a diagnosis for Diesel Wiesel.

Excerpt Seven

Diane: we had to go through he had to go through everything and check everything until (.)

Joel: it took us a while but I think this was around five and a half↑ (.)

Diane: yeh that was when he was on about when he started on medication (1)

Joel: and that's when we first said alright we're going to try one you know and=

Jessica: =mm hm=

Joel: =see (.) and it just evolved over the years you could see alright this is obviously more than ADHD=

Jessica: =mm hm=

Joel: =it's well then you get the PDD-nos↑ because they don't know what else to call it and (2) I don't care what they call it (laughs) anymore you know I wrote diag- his diagnosis down (points to demographic form) but I don't=

Jessica: =mm hm=

Joel: it it's it doesn't matter (.) call it what you want (2) you know he needs help↑ he needs accommodations

The excerpt began with Diane recounting the required ("we had to") technical process that led to Diesel Wiesel's diagnosis, serving to link the meaning of Diesel Wiesel's diagnostic labels to the very institutionalized practices that made their naming possible (lines 1-2). Similar to many of the other participants, Joel described the diagnostic process itself as one that "evolved over the years" (line 7), never standing still or without questions. His use of the word "evolved" evoked a sense of fluidity with the very diagnostic process itself. The initial diagnosis of ADHD was not constructed as invariable, with Joel positioning the *real* issue being "obviously" something "more than ADHD" (line 8). Perhaps, his use of the word "obviously" functioned to position a differing diagnostic label as reasonable and logical. When Joel introduced his son's most recent dis/ability category of PDD-nos, he did not orient to the diagnostic label as being obvious and representative of some internal biological state. Instead, he minimized the label's veracity with the statement, "because they don't know what else to call it" (lines 10-11). Joel continued by emphasizing that he doesn't care what "they call it," with "they" likely referring to the psychologist and psychiatrist who diagnosed their son, both of whom he and Diane spoke of earlier in the interview. Further, not knowing what to call "it" pointed to the *realities* that something was adrift with Diesel Wiesel. Yet, the very individuals that most would presume to hold expert knowledge, i.e., the psychologists or diagnosing experts, were positioned as not knowing what to call "it."

Prior to pointing to the demographic form (see Appendix B) that Joel and Diane had completed in order for their son to participate in this study (line 11), Joel laughed. When I engaged in the analysis, I was surprised by the location of the laughter and decided to consider its function further. First, I presumed that our interview talk, focused on a child with multiple

consequential diagnostic labels, was sensitive and potentially troubling for the speakers. Thus, as I attempted to make sense of what Joel's laughter might be doing discursively, I drew upon Jefferson's (1984) conversation analysis work around the way in which laughter is often used in talk that focuses on potentially troubling topics. Jefferson reported that in "talk laced with trouble," speakers often deal with the trouble or discomfort by deploying laughter (p. 351). She noted that laughter typically functioned to suggest that "although there is this trouble," the speaker is "managing" and dealing with the "trouble lightly" (p. 351), while simultaneously making relevant just how troubling the topic is. So, I interpreted Joel's laughter as functioning to add levity to a troubling and serious topic—his son's multiple diagnostic labels.

Joel concluded by pointing to the demographic form in which he had responded to the following two questions: "Does your child have a diagnostic label? Yes or No (circle one)" and "If yes, what is/are the diagnostic label(s)?" On this form, Joel had circled "yes" and written the following diagnostic labels: "PDD-nos, Bipolar, OCD, ADHD, and Tourette's." As he pointed to the form, both Diane and I looked down at the form, as Joel continued with, "it it's it doesn't matter (.) call it what you <u>want</u>." The phrase "it doesn't matter" worked to undermine the legitimacy of the diagnostic labels and suggested that something else far more important was at stake. As was true of all of the participating parents, the *reality* of needing help for their child often trumped the veracity of a given label. While some parents took up labels with more adamancy than Joel, all of the participating parents emphasized the *realities* of not always knowing how to support their child. So, as was made relevant in Joel's talk, the diagnostic label was only a means to an end—the key that opened the door for "<u>help</u>" and "accommodations" (line 14). In many ways, the participants' talk worked to undermine the "truth" of untenable

diagnostic labels, complicating the meanings of autism and pointing to the ways in which impairment effects or reduced functioning of any kind might become a socially created dis/ability (Reindel, 1999).

Pattern Two: Performative Acts of Autism

Early on in the data collection process, I began to consider the ways in which the shifting meanings of autism were linked to performances of 'normality,' 'abnormality,' and even 'exceptionality.' In Nadesan's (2005) historical account of the making and remaking of autism, she spoke of the performative aspect of autism, stating:

> ...autism has a performative component, as known by every parent who struggled to meet the criteria for government and educational services for their children. For the social services agent, I [as a parent of a child diagnosed with autism] must stress (and even exaggerate) Kamal's [her son] maladaptive behaviors. For his teachers, I stress Kamal's high intellect in order to avoid having him labeled as "mentally retarded." For his peers, Kamal performs "normality" in the context of the school playground by stifling his odd interests and masking social awkwardness in order to "fit in" with the other children. (p. 2)

Nadesan's words capture the social, political, and economic constraints that shape the performative aspects of autism, pointing to how parents of children with autism labels make *real* varied versions of autism for particular audiences. As I began to take note of the performative component of autism in the interview data, my interpretation of the parents' and therapists' accounts became more and more complicated. No longer did I orient to the parents' and

therapists' accounts as solely performing 'normality,' 'abnormality,' 'disability,' or 'ability.' Instead, autism was performed in shifting and even at times conflicting ways. My initial understandings of this particular aspect of the data are illustrated in the following research journal entry:

> June 2, 2010 8:30 pm
>
> In a parent interview today, I was struck by how "autism" was not separated from the spaces in which the child and parent traversed. "Autistic" was not how the mom first described her son. Autism was made relevant for a reason. It only came up in the context of certain spaces and events. When discussing the neighborhood in which they recently moved, the mother said that the neighbors noticed right away that something was "different" about her son Saturn. She continued, "...all we had to do was say, 'Okay look Saturn has autism and this is the way it is and he's not ignoring you. He just doesn't know how to address you or to identify with you just yet. But if you give him some time he will.'" About school, she said, "They had never worked with an autistic child. So, I had to tell them what that meant and how to teach him and that he is a very smart boy." So, as she and her son navigated these spaces, autism was performed in varied ways, for different audiences.

One of the ways in which all of the participating parents and therapists performed autism discursively was to reframe the children's (non-normative) behaviors for diverse audiences. While many researchers cast framing and reframing events as a cognitive entity or task (Shmueli, Elliott, Kaufman, 2006), I orient to this concept discursively and suggest that speakers frame and reframe events as they work to make sense of them in coherent and believable ways. Thus,

much like Edwards and Potter (1993) speak of building accounts in ways that are believable to others, I orient to the idea of reframing as the way in which the participants re-accounted for an event or behavior, offering an alternative explanation or account that functioned to frame anew an event and/or behavior assumed to be (potentially) problematic. So, while the majority of the parents recounted a time in which their child's actions were (mis)interpreted as "odd" (e.g., flapping hands when excited) or "inappropriate" (e.g., screaming instead of using words to communicate) by others/outsiders, they all worked to reframe their child's actions as understandable and at times even "normal" to insiders. The participating therapists, while they too worked to reframe the children's behaviors as always explainable and not without reason, typically moved away from describing the children as "normal," rarely "eliding difference in order to validate neurotypical experiences" (Osteen, 2008, p. 9). When the therapists reframed the (non-normative) behaviors and ways of communicating, they offered technical reasons (e.g., sensory integration challenges) for a particular behavior and/or named the exclusionary, social practices that might have led to a problematic behavior (e.g., no access to a communication device in public space). These (mis)interpretations of the child, not the child him/herself, were critiqued and reframed by the parents and therapists, with the "misunderstood behaviors" being reframed as reasonable and always explainable.

In order to illustrate the primary ways in which the therapists and parents oriented to the performative components of autism, I present three excerpts. The first excerpt focuses on what many of the therapists referred to as "looking autistic." The second excerpt highlights the elaborate work of performing normality. The final excerpt presents an account in which the deployment of a dis/ability category is made in relation to others' potential (mis)interpretations.

When talking about the meanings and performances of autism, the therapists, in particular, made relevant the subjective nature of being diagnosed with an autism label. In Excerpt Eight, Megan pointed to the "look" of autism and questioned the veracity of the expert's decisions to diagnose Chance, one of the participating children, with an autism label.

Excerpt Eight

1 *Megan*: Chance that little boy↑ his pediatrician diagnosed him↓ (.1) and I'm sure↑ to
2 the pediatrician he <u>looks</u> very autistic 'cuz he has some of those sensory things
3 going on↓ and some of those behavior things and you know (.) language that hasn't
4 developed (.) so I think (.1) even, I don't know, even psychologists sometimes they
5 they will see a child for one evaluation visit and have to make a diagnosis based on
6 that one visit (.) um (.) and I don't think they always know=
7 *Jessica*: =Mm hm=
8 *Megan*: =Like if they look autistic and they meet the criteria (.) then they're gunna
9 get a diagnosis basically

In the above excerpt, Megan began by referencing Chance whose "pediatrician diagnosed him" (line 1). Her move to name who ("pediatrician") diagnosed Chance is particularly relevant in that across the interview data, both the participating therapists and parents spoke often about the need to educate general pediatricians about the needs, or impairment effects, of children with autism labels. While an autism diagnosis is typically made by a range of health care providers (Allen, Robins, & Decker, 2008), specialists in developmental dis/abilities, such as developmental neurologists or child psychologists, are oriented to in the broader and publically available discourse as the most skilled autism diagnosticians (CDC, 2010). Thus, Megan's move

to make the "pediatrician" relevant is telling, and points to both the local and broader discourse about who is and is not qualified to name someone autistic.

Megan next stated, "I'm sure↑ to the pediatrician he <u>looks</u> very autistic" (lines 2-3), implying that there are specific, visible characteristics, physical markers, or performances that increase the chances of being named autistic. In many ways, Megan's emphasis on the "look" of autism points to the performative aspects of the body, highlighting the way in which a body might be oriented to and "read" by experts as autistic or non-autistic, normal or abnormal, etc. She then named what it is that "looks" autistic to the pediatrician, including "sensory things," "some of those behavior things," and "language that hasn't developed" (lines 3-4). As Garland Thomson (1997) noted, within discourse, particular identities are produced and located "within a hierarchy of bodily traits that determines the distribution of privilege, status, and power" (Garland Thomson, 1997, p. 6). So, it is not surprising that Megan's list ("sensory thing," "behavior things," and "language that hasn't developed") matched, to some extent, the common ways of talking about, producing, and locating autism, with particular "bodily traits" being noted, including (1) social, (2) communicative, and (3) behavioral deficits (see Appendix A for DSM-IV autistic disorder diagnostic criteria). Further, three-part lists often work to discursively create a sense of completeness and representativeness (Bowker & Tuffin, 2007; Edwards & Potter, 1992). Thus, perhaps Megan's three-part list functioned to construct autism as something that is prescriptively determined, yet just as ambiguous and open to interpretation as the official DSM-IV criteria.

Although displaying initial tentativeness about offering any concrete judgment of her own, stating "I don't know" (Edwards & Potter, 2005; Potter, 1997), Megan introduced the idea

that “even psychologists...don’t...always know” (lines 5-6). While psychologists are typically positioned as the key diagnosticians of autism (Allen et al., 2008), Megan oriented to “even” their diagnostic abilities as being questionable. Similar to Lily in Excerpt One, Megan undermined the validity of the diagnostic process, suggesting that the psychologist likely cannot *really* “always know” because “...they will see the child for one evaluation visit.” All of the participants who offered critiques of the diagnostic process for dis/ability labels pointed to the minimal time the diagnostician spent with a given child. Perhaps such critiques imply that as an “expert” spends more time with a child, s/he may discover how to more accurately interpret or read the “look” or “characteristics” of autism, eventually being better able to determine whether the child is *really* autistic or not.

Megan concluded with an if/then conditional statement: “Like if they look autistic and they meet the criteria (.) then they're gunna get a diagnosis essentially.” Conditional statements often function to distance speakers from being directly accountable for their statements, as such statements are often constructed and taken up as being factual (Potter, 1996). In this case, her final if/then statement pointed again to what happens when a child “looks autistic.” Megan oriented to this “look” or performance of autism in the presence of a diagnostician as inevitably resulting in a diagnosis of autism.

In other words, if Chance or any other child “looks autistic” enough to a diagnostician, he will be *discovered* as such. As many disability scholars have noted, “the nondisabled gaze is the product of a specific way of seeing which actually constructs the world it claims to have discovered” (Hughes, 1999, p. 155). Thus, as was made visible in Megan’s talk, autism remains “...a list of symptoms or behaviors or representations that can be studied and discussed, but it is

not knowable as a truth. It must always be interpreted" (Biklen et al., 2005, p. 3). So, it seems that Megan's account leaves open the possibility that autism is always already open to interpretation and contestation by those "experts" most often deemed responsible for determining whether a child *really* is autistic, as well as those individuals who live or work closely with the child with an autism label. The construct of autism, never located as inherent to the child, is only made real when it is negotiated between the key social actors (i.e., diagnosticians) and the child's very performance of the "autistic look."

The next excerpt, drawn from the interview data, illustrates the ways in which some parents went about performing normality. In this excerpt, Alisha constructed her son as "a very typical little boy," locating who he is in relation to a normative backdrop, which is itself a discursive construction (Locke & Edwards, 2003). To some extent, Excerpt Ten points to the variability or those discursive patterns that were not common within my data set, as few parents went about performing "normal" as elaborately as Alisha did. The excerpt begins just after I asked Alisha, "if others were to meet your son what would be some things that you'd want them to know about him↑."

Excerpt Ten

1 *Alisha*: um (2) he is very affectionate he has feelings just like everyone else he has
2 likes and dislikes just like any other child um (.) there's a lot of things about him
3 that are very typical (.)
4 *Jessica*: Mm hm=
5 *Alisha*: =um (.) even how he expresses even though it sometimes doesn't always
6 seem like it↑ in many ways is a very typical little boy=

7 *Jessica*: =Mm hm can you talk a little bit about that↑ (.)

8 *Alisha*: Um you know he enjoys he loves playing outside he loves the trampoline

9 he'd probably live in it if we let him um he loves chocolate chip cookies and

10 pancakes and he loves to watch cartoons he likes to he loves to draw (.) um and he

11 you know he works really hard in school↑ and he actually gets very good grades in

12 school um he's an excellent speller he's a very good reader he reads above his grade

13 level even though we can't have a conversation=

14 *Jessica*: =Mm hm=

15 *Alisha*: =he (.) he reads wonderfully loves Alvin and the Chipmunks↓ you know

16 very typical things that (1)

17 *Jessica*: Mm hm=

18 *Alisha*: =normal kids (.) like↑ and very age appropriate

In response to my first interview question ("What things might you want someone who has just met your child to know about him?"), Alisha, like the majority of parents and therapists, began by making relevant all that Picasso *possessed* and *could do*. She began by describing Picasso, her son, as "affectionate" and having "feelings" (line 1); the majority of parents, and all of the therapists, made similar statements about the children they spoke about. Making emotional qualities relevant was particularly significant in that one of the prevailing assumptions about autism is that people with autism labels inherently lack the ability to relate to others, possessing "no affective tie to people" (Kanner, 1943/1985, p. 24). Thus, with Picasso constructed as affectionate and having feelings, Alisha perhaps resisted or at least distanced herself and her son's identity from the dominating discourses of autism that would likely cast Picasso as

possessing a "genuine defect" in the "understanding of the other person" (Kanner, p. 81). Instead, she constructed her son as "normal," bolstering this claim of normality by describing all that made Picasso a "very typical little boy" (lines 6-15). Further, she worked to normalize and reframe that which could be named an impairment effect—Picasso's communication difference. While Picasso was described by his mother and therapists as minimally verbal, here, Alisha reframed his communication as "in many ways...very typical."

Her use of the phrase "even though it sometimes doesn't always seem like it↑" implied that perhaps there were communicative differences that other people might name as atypical. Sacks (1984) suggested that "doing being ordinary" is a common feature in talk, a recurring pattern in everyday social life. To present one's self or the identity of another as an ordinary social participant implies normalcy; thus, Alisha's descriptions of Picasso as enjoying being outside or liking to eat chocolate chip cookies functioned to discursively define all of the specific actions that identified her son as typical and normal (lines 9-11) (Locke & Edwards, 2003). Further, Alisha's examples of what makes Picasso typical pointed to the cultural assumption that there is a natural set of practices, actions, and behaviors common to all *normal* children.

With dis/ability categories often positioned as being synonymous with incompetence, particularly when an individual is considered minimally verbal (Biklen et al., 2005), perhaps Alisha's description of Picasso as an "above" par student functioned to counter the presumption of incompetence (lines 11-12). While Alisha constructed Picasso as competent, she did not avoid naming what he could *not* do, stating "even though we can't have a conversation." Yet, she continued by linking what Picasso could not do to what he could do: "he (.) he reads wonderfully." Perhaps by emphasizing what Picasso can do (i.e., "reads wonderfully"), Alisha

minimized what some would name Picasso's primary impairment effect (i.e., "can't have a conversation").

Some disability studies scholars have critiqued the ways in which "most popular representations of autism...impose neurotypical formulae or conventions" on people with autism labels, ignoring social differences through the validation of the "neurotypical experiences" (Osteen, 2008, p. 9). Indeed, I acknowledge this tendency and the overarching pattern in the broader discourse to impose and privilege certain social conventions. Certainly, one might "read" Alisha's account as imposing neurotypicality on Picasso, perhaps to the demise of his differences. Yet, I propose that the very task of negotiating normality, abnormality, autistic, or non-autistic identities is filled with contradiction and is a rather fragile endeavor, perhaps far more complicated than the binary constructions of typical versus non-typical or normal versus abnormal, notions which are often critiqued by disability studies scholars (Thomas, 1999, 2004). I argue that Alisha, like all of the participating parents and therapists, engaged in the fragile and contradictory task of performing difference, normality, and even autistic or non-autistic identities in fluid and shifting ways. Much like Butler (1990, 2004) argued about the performance of femininity, I suggest that all aspects of autism are constantly being negotiated, taken up, and reproduced as performative acts that function to reinforce certain discourses and ideologies surrounding autism and dis/ability in the culture at large. These performances often act to position the very notion of an autistic or non-autistic child as being a natural truth, something that is *really* achievable; yet, to achieve typicality or normality is impossible, as it too is a discursive construction, always shifting across time and place.

I further propose that solely suggesting that performative acts of normality elide differences (Osteen, 2008) ignores the challenge of living in a society that is politically, socially, and economically structured to privilege those who speak and act in normative ways. So, while Alisha's discourse perhaps functioned to construct Picasso as a "typical" child in many ways, she, like the other participating parents, produced such constructions within a social and political context that privileges highly verbal people who behave in normative ways (e.g., people should not their flap their hands to communicate excitement, but instead should use words or widen their eyes with surprise, expressing themselves in more "acceptable" or normative ways). If Alisha had described Picasso as minimally verbal, perhaps the competency and even humanity of her child would be jeopardized or at least questioned by outsiders. As Lewiecki-Wilson (2003) noted, "we [the majoritarian culture] often demand some verbal response from another as proof of their humanness" (p. 157). Nelson's (2004) official statement to the United Nations pointed to the ways in which individuals with autism labels are misunderstood and excluded, stating that "we, [people with autism labels], experience discrimination in various forms, often because of our different use of language and communication..." (p. 1). Thus, it is important to interpret the discursive practices of the participating parents and therapists in relationship to the exclusionary practices and policies that they and their children encountered daily.

Across the parent interviews, I noted that each parent shared a story or account of a time or place in which they felt compelled to make their child's diagnostic label relevant. I noted that many of these retellings were linked to notions of dis/ability and normative and non-normative ways of behaving and speaking. For the parents, making autism relevant to outsiders was almost always linked to the ways in which the participating children were oriented to by outsiders as

troubled or even "unruly" and "misbehaving" (John). At times, autism and other dis/ability labels were used to reframe discursively the child's way of being, accounting for *why* the children screamed or moved their bodies instead of using words, for example. Autism, then, functioned to explain the participating child's non-normative ways of speaking and behaving, perhaps even making the non-normative more reasonable and justifiable.

In the next excerpt, Nicole offers one such account, illustrating how specific events or encounters in public places were linked to the performance of autism as a dis/ability, with the dis/ability category itself functioning to explain her child's non-normative behavior.

Excerpt Eleven

1 *Nicole*: When I when I when a stranger sees George I sometimes feel like I have to
2 offer up if he isn't (.) uh if his behavior's a little bit different that he's autistic and
3 sometimes I want=
4 *Jessica*: =hm=
5 *Nicole*: =people um to know that um we had an incident yesterday at um at a
6 business where he um had a meltdown in the bathroom because the bathroom door
7 wasn't locking and it was very upsetting to him and then some employees came in
8 and tried to get in and see if he was okay and it was you know you could hear him↑
9 throughout the whole building so sometimes you know (.) I I want people to know↑=
10 *Jessica*: =mm hm=
11 *Nicole*: that he has a a disability

Nicole, responding to my first interview question, ("What things might you want someone who has just met your child to know about him?"), emphasized that outsiders or "strangers" orient to

her son George in ways that compel her to "offer up an explanation" (lines 1-2). Nicole's use of the word "see" pointed to this idea of an autistic "look" or body, implying that there is something about her son's actions or way of being in the world that automatically positioned him as different or non-normative to outsiders. She then shared an example of an event that resulted in George's differences being noted by outsiders. George's meltdown at a business was apparently not ignored but heard by everyone (lines 7-8). While Nicole stated that the bathroom door locks were simply "upsetting" to her son, she implied that it was quite troubling to the store employees (line 7). In fact, later in the interview, Nicole returned to this "incident" and further explained that the business employees came to the bathroom to determine whether they needed to call for further assistance or security.

This event, a "meltdown" and the response of the business employees, was used to rationalize why Nicole might make relevant and even name her son's dis/ability (line 2 and line 11). Further, as broad categories that are both open to interpretation, the terms "autism" and "disability" functioned to reframe the "meltdown" as explainable, perhaps even justifiable. If a child is constructed as autistic and has a meltdown, perhaps the meltdown is oriented to as more justifiable, as autism is then positioned as a disabling entity that caused the meltdown. However, if a child is constructed as non-autistic and has a meltdown, the child may simply be positioned as "unruly" and "misbehaving," as John spoke about in his interview. Sacks (1992) reported that a common rhetorical pattern in discourse is to resist being accountable for an action or situation by defining that action as commonplace, normal, or expected (Edwards, 1997). It is possible then that Nicole's deployment of the terms "autism" and "disability" functioned to distance

herself and her son from being the sole individuals responsible for the meltdown, with autism or a dis/ability positioned as being responsible for the meltdown instead.

A body named "a little bit different," "autistic" or "disabled," much like other bodies, is always already an object of discourse caught up in multiple systems of meanings and representation (Bordo, 1992; Foucault, 1977; Turner, 1984). Normative behaviors in a business space do not typically (if ever) include meltdowns or looking "a little bit different." So, in the above excerpt, Nicole's construction of George's behavior as "a little bit different" also illustrated the ways in which his body might be constructed and oriented to by others as troubled. Rather than orienting to how the bodies or actions of the participating children were *perceived* by others, I oriented to how the children's bodies or actions/behaviors themselves were sites of discourse, with their bodies/behaviors often being constructed as autistic, disabled, abled, normal, abnormal, etc. Foucault (1972) suggested that discourses constitute and even regulate the body in certain ways, "exercising upon it a subtle coercion...obtaining holds upon it at the level of mechanism itself—movements, gestures, attitudes, rapidity: an infinitesimal power over the active body" (p. 137).

The body, as a site of discourse and performance, can also resist and re-invent identities. As Carlson (1996) noted, "performance can work within society precisely to undermine tradition, to provide a site for the exploration of fresh and alternative structures and patterns of behaviors" (p. 15). Yet, few parents worked to perform autism in ways that positioned their children's non-normative behaviors as "alternative structures and patterns," possibly functioning to redefine and rework all that is named typical or normal development. Nevertheless, the parents did speak of the ways in which the participating therapists assisted them in making sense of their children's

behaviors/actions and communication styles, helping them and their children to redefine all that counted as successful functioning. The therapists, who often explicitly taught the children how their very bodies were oriented to by outsiders, seemed to go about the work of co-constructing and reframing with the children, in particular, all that might be oriented to by others as problematic. This discursive work of reframing most often occurred in the one-on-one therapy sessions of the participating children and therapists. Possibilities for new identities and ways of making sense of what might be named non-normative were produced in the everyday practices of the children and the therapists. While the construct of autism remained untenable, indefinable by the majority of the participants, the negotiation of the fluid and shifting identities of the children occurred in the everyday work of doing therapy. Prior to sharing the findings related to the very doing of therapy, I share the participants' responses to the above interpretations, many of which further layered my own understandings of the meanings and performances of autism.

Participants' Responses to the Findings

From October 2010 to December 2010, eight of the participants (seven of the eight participating therapists and one of the 17 participating parents) shared their responses to the above findings. Seven of the participating therapists shared their responses to these findings over several weeks and even months, sending me an email, calling me, or sharing with me face-to-face their unfolding reactions to my analyses/interpretations. Although I was only able to meet with one participating parent, she too responded to my interpretations, further expanding my understanding of the construct of autism. Many of these participants read all or some of the findings included in this chapter and then shared their response with me. Few of the participants

responded to and evaluated every single aspect of my interpretations; however, the majority of the participants tended to focus on one particular facet of the findings.

Below, in an attempt to highlight the variability of the participants' responses, I share several quotes from the participants, each pointing to various aspects of the above findings. I begin with an email response from Megan (December 12, 2010 at 10:02 pm) in which she explicitly responded to the ways in which the meanings of autism are inextricably linked to the process of qualifying for insurance and Medicaid coverage. She stated:

> It is really something else to read through about all the processes. We live them everyday, but it makes me sad to think of how these children can be reduced to a label for economic purposes. What is meaningful to families and therapists is not always meaningful for insurance companies. So, we find ourselves being as clever as possible with regard to "how" we write our goals, so that we can maximize contact time with our kids (and provide the most meaningful therapy and strategies that we know how).

Megan's response reiterated the way in which the broader institutionalized and technical practices functioned to constrain and limit the everyday work of the therapists and at times constrain the amount of support children with autism labels acquire. Her response also pointed to the notion of working against these potentially constraining institutionalized practices, with "clever" insurance goals functioning to increase the therapists' contact time with the children. Further, like all of the participants who responded to and evaluated my interpretations, Megan positioned herself as *living* the discursive practices and institutionalized practices that I wrote about, stating: "We live them everyday." Maria, the participating parent who offered a response

to my work, said something similar to Megan, stating: "I live this. This is my life. So I get what you are writing about" (December 26, 2010). Maria also shared that Medicaid was beyond her family's reach as her son was denied coverage two times because he was not considered "mentally retarded by the experts." Even as the participants offered responses to my findings, the meanings of autism, as produced in the context of insurance and Medicaid requirements, were made relevant again and again.

While the therapists, in response to the findings presented above, reiterated the ways in which the meanings of autism were untenable, positioning again its very meaning as always shifting and unfolding, the participating parent stated the she was "surprised that the therapists spoke about autism as they did. I'd expect therapists, not really the parents, to have a more concrete definition." Maria pointed to Excerpt Three as she spoke, the excerpt in which Bria constructed autism as indefinable. Maria continued by stating, "I like how open-minded the therapists are, but I'm just surprised that they didn't state a more concrete definition of autism since they are therapists." Maria's response highlighted the presumed distinction between lay and expert knowledges, with particular social categories (e.g., therapists) positioned as holding some knowledge that others do not hold (Housley & Fitzgerald, 2002). Yet, as discourse studies continue to highlight, the distinction between expert and lay knowledge remains ambiguous and always locally produced and negotiated (Horton-Salway, 2004). Maria continued by emphasizing the reasons why making autism relevant to others is often useful. She shared the following:

> Every year, I tell the people at my son's school that he has autism. He asks me to. He feels so relieved that others at the school know that his difference can be explained by

something. He just smiles when I ask, "what do you want me to tell them?" He tells me to tell them that he has autism. He wants them to know that there is a reason that he struggles sometimes.

Maria responded further by offering a definition of autism, one which was different from her interview data, pointing to the continual construction and reconstruction of autism. Maria stated that "autism is a sensory thing that then looks like a child behaving badly but they are really just having a sensory issue that probably makes it hard for them to communicate." I was struck by how even in the response to my findings, another example of how a child's behavior might be reframed as explainable was produced. While I did not orient to Maria's definition as indicating that my interpretations were "right" (Tracy, 2010), I do view her talk as further illustrating how the participants worked to discursively reframe the behaviors of their children.

Similarly, Bria and Jennifer, responded to my findings by reiterating how the behaviors of the participating children are frequently misinterpreted by outsiders. Bria stated: "I feel like we therapists try to look more at what the children can do and what they're doing and interpret it, but you just hope everybody would do that." Jennifer, in response to Bria's statement, added: "You know there's always a why. It's not like the children are just being naughty. People just think they're being naughty, you know, without always adding the why to it." These responses again made relevant the ways in which the participants' talk created alternative frames for understanding a child's behavior and perhaps even their identity. No longer was the child simply "naughty," but s/he was, more than anything else, misunderstood.

Another participant, Samantha, responding by email (November 29, 2010 at 5:51 pm), shared of a dream she had that reminded her of my research. She stated:

> In my dream, I went to the doctor for a regular check-up only to be told that I was being diagnosed with autism. I laughed and said "WHAT?!?" as my doctor told me again that I had autism — I just sat there in utter disbelief and began to argue that that was impossible as I was "normal" – I have a job, a husband, a child – and I function "normally"— I just kept repeating that I was "normal"...I hope someday the diagnosis of autism doesn't automatically come with the stigma of being not "normal."

Samantha's response pointed to the ways in which the meanings of autism are often performed as something that is abnormal and even pathological. Like many of the other participants, Samantha included what she hoped might be different in the future, that "the diagnosis of autism doesn't automatically come with the stigma of being not 'normal.'" Samantha's response functioned to emphasize the possibilities of changing, perhaps even in positive ways, what autism might represent in the future.

While there are still many more participants I have yet to share these findings with, the participants' responses thus far have served to expand and further challenge my interpretations. As I continue to share my findings with the participants and others, indeed new meanings and performances of autism will likely be generated.

Chapter Summary

In this chapter, I shared the findings related to my first research question: What are the various meanings of autism and how are these meanings performed within and through the discursive practices of therapists and parents of children with autism labels in their everyday interactions? I first described the ways in which the meanings of autism are linked to the

institutionalized practices associated with qualifying for insurance and Medicaid coverage. I then presented the variable meanings of autism, illustrating the ways in which the discursive construction of autism occurred in "a space of multiple dissensions" (Foucault, 1972, p. 155). I next pointed to how the parents and therapists made the performative aspects of autism relevant in their talk. Finally, I shared the participants' responses to the findings within this chapter. In the next chapter, I present the findings related to my second research question.

Chapter VIII: Accounting for Problems and Redefining Communication

While the interview data provided me with an opportunity to consider closely the meanings and performances of autism, I also desired to attend to the ways in which the everyday practices of doing therapy were constructed and managed by the participating children, parents, and therapists. Further, I took seriously Sacks' (1992) suggestion that:

> ...if we are to understand and analyze participants' own concepts and accounts, then we have to find and analyze them not in response to our research questions, but in the places they ordinarily and functionally occur – 'in the activities in which they're employed.' (p. 27)

With this intention, I aimed to collect and analyze data that moved beyond responses to my interview questions, recording naturally occurring data such as therapy sessions and hallway and waiting room conversations that occurred between parents, therapists, and children. In doing so, I more closely attended to the everyday, ordinary activities of the participants.

Indeed, in the very process of doing therapy, meanings and performances of autism were made relevant; yet, as I made observations at The Green Room and engaged in ongoing dialogue with the participants, I determined to focus my analysis of the therapy and waiting room conversations around my second research question. With a desire to more broadly consider the discursive practices of the participants as they engaged in therapy, I eventually settled upon the following research question: How do children with autism labels and their therapists and parents discursively manage and account for the behaviors and communication approaches made relevant in therapy? In constructing a response to this research question, the focus of this

chapter, I drew upon my analysis of the therapy sessions, waiting room and hallway conversations, documents related to the therapy sessions, one related parent interview, my research journal, and observational/field notes.

Chapter Overview

In this chapter, I first present a brief description of the ways in which the therapists oriented to the purposes or goals of therapy. I then provide an overview of the typical sequence of a therapy session. I next share, almost in its entirety, one therapy session that illustrates many of the patterns that I noted across the therapy session talk[18]; through this session, I focus on how the participants accounted for and reframed "problematic" behaviors in the very process of doing therapy. After this, I illustrate how the participants' everyday talk worked to transgress (Foucault, 1977) normative communication patterns. I then conclude by sharing the participants' responses to the findings included within this chapter.

Analyses/Findings

I organize and share my findings around two overlapping patterns generated through the analysis process of the therapy talk: (1) the ways in which the therapists and children accounted for "problematic" behaviors/actions as explainable, solvable, and likely due to outsiders' (e.g., caregivers, peers, etc.) misinterpretations; and (2) the ways in which the participants negotiated the very communication process, redefining what were acceptable communication patterns.

[18] The phrase "therapy session talk" or "therapy talk" includes waiting room conversations, hallway interactions, and other data sources (e.g., documents used in the therapy session) related to the therapy sessions.

Attending to the institutionality of the talk. I oriented to the very doing of therapy as specific to the institutional site of focus (i.e., The Green Room). As such, I viewed the talk as institutional,[19] while acknowledging that the institutionality of talk was not determined by the setting alone. Instead, its institutionality was related to how the participants oriented to their institutional or professional identities as being relevant to the work activities in which they were engaged (Drew & Heritage, 1992). Further, the institutionality of the talk was made visible by the particular and specific ways that the everyday interactions within The Green Room were constructed as distinct from what many conversation analysts refer to as mundane conversations or those conversations not necessarily linked to some type of overarching institutional goal (Drew & Toerien, 2011), such as providing therapeutic assistance to a child with an autism label. For instance, at The Green Room, there were certain things that were pursued in and through the interactions between the participants, as the therapists offered guidance and specific interventions to the children.

Therapeutic conversations, then, differ from mundane conversations (O'Reilly, 2006), as the members within the therapeutic relationship often take up certain identities (e.g., therapist) and deploy specific rights (e.g., a therapist offer advice and assistance to a child). The therapists, for example, taught children how to tie their shoes or use a communication device, while the children practiced tying their shoes or typing on a communication device. Additionally, institutional talk is often informed and shaped by reference to the goals or explicit purposes of a

[19] I distinctively use and apply the notion of "institutionality of talk" or "institutional talk," drawn from conversational analysis literature (Drew & Heritage, 1992) and my discussion, particularly in Chapter VII, of the broader institutionalized discourses and practices caught up in multiple systems of meanings and representation (Bordo, 1992; Foucault, 1971; Turner, 1984).

given setting (Atkinson, 1982). Prior to presenting the findings/analyses related to the broad patterns noted above, I describe the institutional goals of The Green Room, drawing upon my observational/field notes to provide an overview of the sequential activities involved in a typical therapy session. In the therapy talk excerpts and interpretations I offer below, I attempt to point to the ways in which the institutional goals of The Green Room were made visible in the talk of the therapists and children. So, as I present my analyses/interpretation of excerpts below, I invite the reader to evaluate and offer alternative interpretations, reading all that I share in light of the institutional goals of The Green Room, as well as my own positionality.

The Green Room's therapeutic focus/goal. Across the literature on autism, the often stated goal of intervention has been to identify, target, reduce, and even eliminate the presumed deficits of people with autism labels (Glynne-Owen, 2010). Many of the most popular approaches to intervention have explicitly stated that the goal is to produce a *normal* or a close to *normal* child. Lovaas (1987), who is the developer of one of the most popular approaches to "treating" autism, stated: "...we hypothesized that construction of a special, intense, and comprehensive learning environment for very young autistic children would allow some of them to catch up with their normal peers by first grade" (p. 4). Barnes and Oliver (1993) noted:

> ...since psychological and physical impairments are presented as the cause of disability and handicap, it follows that they should be cured by psychological or medical intervention. People with impairments become objects to be treated, changed, improved and made 'normal.' (p. 4)

Certainly, the discourses surrounding autism interventions are rife with examples of *improving* people with autism labels, with few of the most popular approaches acknowledging the challenging task of doing therapy in a way that acknowledges and fosters social differences.

As I carried out this research study, I recognized the importance of attending to how the participating therapists oriented to their daily work, taking note of how they talked about the very purpose or goal of doing therapy. I did not want to presume that they too oriented to children with autism labels as "...objects to be treated, changed, improved and made 'normal'" (Barnes & Oliver, 1993, p. 4). So, as I spent time at The Green Room and carried out the data collection and analysis process, I began to make sense of the ways in which the therapists, in particular, oriented to their daily work. As I did so, I interpreted their work as not being about fixing a child or defeating autism, but instead about what they named "increasing functionality." One of my research journal entries pointed to my unfolding understanding of the very process of doing therapy:

> September 3, 2010 at 8:05 pm
>
> It is post-data collection, the beginning of intensive analysis; I no longer believe that all forms of intervention are designed to "police" someone presumed to be different. I believe such a notion is far too deterministic, simplistic. "Treatment" is layered, contradictory, and always filled with multiple and competing objectives; true of much in life.

Based on this unfolding understanding, I chose to inquire further as to the overarching goals of The Green Room, both by consulting the official literature and by asking Megan and

Drew to speak to the broadly stated objectives and purposes of therapy at The Green Room. In the following email, Megan responded with the following (December 21, 2010 at 10:28 am):

> Our goals are to teach children to meaningfully communicate with people through whatever means best suits them (e.g., verbal language, augmentative communication, pictures, schedules, etc.)—therefore maximizing their quality of life so they feel like a participant and/or contributor to society. That would be the long, long term goal. In the shorter term (while they are still kids) the goals are to teach the fundamentals of language and communication so that they can navigate social situations with as little stress as possible. Teach them strategies to read their bodies, understand their bodies, and regulate their systems so that they can participate in school, home, and community. We teach them to use communication in these situations so that they can make requests for what they need. We teach them to understand questions, answer them, and eventually ask them.

The official informational brochure that the therapists gave to families interested in participating in therapy at The Green Room included the following statement: "We believe that every child has the right to self-expression." This statement further emphasized the therapists' orientation to therapy as being about assisting a child as they learn to communicate in "whatever means best suits them," regardless of whether the communication modality was oriented to by outsiders as normative or non-normative. Another section of the brochure focused on occupational therapy services and included the following statement: "Our occupational therapists believe independence can be maximized with the right support." Another section, focused on the physical therapy, included the statement: "We believe that every child can increase awareness of

their body in space, thereby increasing success with movement activities." In both the occupational and physical therapy statements, The Green Room, as an institution, made explicit that they oriented to a child as being capable of being independent and experiencing increased success. When (and if) a therapist, for instance, did not pursue therapy in a way that presumably aligned with the goals of The Green Room, the clinical directors (Megan and Drew) responded by offering mentoring (i.e., developing therapy sessions together prior to the start of the day) and/or requesting to observe and offer feedback on individual therapy sessions.

As I analyzed the therapy session and waiting room conversations, I aimed to contextualize my interpretations in relation to these overarching institutional goals, recognizing that the talk itself was produced and managed in a context with particular, situated goals. Further, I took note of when and how such institutional objectives were made relevant in and through the participants' talk. For instance, I interpreted a therapist's orientation to a child falling to the floor, *not* as misbehavior but as a communicative act, as being related to the institutional goal of valuing "self-expression."

Throughout this study, I presumed that when the participants interacted with one another (with words, pictures, bodies, etc.), they were always doing some kind of activity or form of action in and through their talk (Drew & Toerien, 2011). Thus, as I examined the participants' discursive activities within the therapy sessions, I considered what their discourse was doing and how it was constructed to do a particular activity (Potter, 2004). As I observed, I recorded, over and over again, the very sequence of the therapy sessions, noting that there were distinct and recognizable activities that occurred in the waiting room, therapy rooms, and hallways of The Green Room.

Drawing upon my observational/field notes from June to August of 2010, the following sequentially outlines the activities and movements that occurred during a typical therapy session.

1. Participating child and parent/caretaker[20] entered The Green Room waiting room (see Appendix K for the Floorplan of The Green Room).
2. Samantha, the medical secretary who sat at the reception area in the waiting room, greeted the child, saying, "How are you today (child's name)?"
3. The parent said, "Hi Samantha." If the child did not respond to Samantha, the parent said to the child, "Say hello to Samantha." The child would say hello to Samantha or simply walk to a chair and sit down.
4. The parent and child sat in the waiting room together.
5. Typically, within approximately 20 seconds to two minutes of the child's arrival, their therapist walked out of the main office area into the waiting room and greeted the child.
6. Unless a parent presented a concern to the therapist in the waiting room, the therapist invited the child to come with them to one of the therapy rooms to "play" or "hang out."
7. The therapist and child walked, often hand-in-hand, to one of the therapy rooms.
8. The therapy session always began with the child and therapist negotiating about the game they would play during the therapy session. All of the therapists used games (e.g., board or card games) or other activities described by the child as "fun" (e.g., develop a powerpoint presentation). These games were linked to discussions and activities designed to teach language (e.g., pronoun use) and functional skills (e.g., tying shoes or

[20] Several of the participating children were brought to The Green Room by their respite care workers, grandparents, and/or parents' friends. These individuals, whenever being observed or recorded by me, signed a consent form, agreeing to allow me to observe and record their activities.

crossing the street) or to practice alternative responses to challenging or unexpected situations.

9. Drawing upon the analyses of the therapists' interviews and my observational/field notes, I concluded that each therapy session focused on a series of "functional skills" and/or addressed concerns that were made relevant by the parents in a private email or phone call to the therapist prior to the child arriving at The Green Room.
10. Upon the completion of the 30-minute therapy session, the therapist and child would either return to the waiting room or the child would transition to their next therapist (e.g., the speech pathologist would take the child to the occupational therapist's room).
11. If the therapist and child returned to the waiting room and the child's parent was present, the therapist would describe the session from start to finish and offer advice for practicing a skill and/or working through a concern at home. Typically the child was playing with the toys in the waiting room, which meant that this conversation most often occurred privately between the therapist and the parent.
12. The therapist would say goodbye to the parent and child, always waiting for the child to say goodbye in some way (e.g., brief gaze, slight raise in their hand, verbal goodbye, etc.).
13. If the child was transitioning to another therapist, the first therapist and/or child would briefly (typically no more than two minutes) tell the second therapist about the child's therapy session. The child's first therapist would say goodbye and wait, for however long it took, for the child to say goodbye, again, in whatever way they chose to do so.

In addition to the seemingly step-by-step flow of therapy, which I shared with seven of the eight participating therapists, I also carefully attended to the discursive resources (e.g., silences, lexical choices, etc.) that were present and used by the participants to perform particular activities. More particularly, I recognized that lexical choices are often one of the means by which speakers evoke and orient to the institutional context of their talk. Frequently, particular word choices are coupled with institutional goals. This was indeed the case at The Green Room, where an overarching curriculum or framework, *Superflex...A Superhero Social Thinking Curriculum* (Madrigal & Winner, 2008), informed what I came to orient to as their shared vocabulary for talking about problematic behaviors. This particular curriculum included a superhero character, Superflex, who was capable of defeating a group of "unthinkables," those characters representing social and behavioral problems. For instance, the therapists referred to Glassman (Appendix L), a common unthinkable, when talking about making a small problem into a big problem that resulted in a meltdown or an "earth shattering reaction." However, Superflex (Appendix M) was capable of defeating Glassman and preventing him from making small problems into big problems.

Excerpt One (see Appendix G for transcription symbols), drawn from a therapy session, illustrates how the therapists' word choices were intertwined within the very doing of therapy. The excerpt begins just after Billy, one of the participating children, had "calmed down" after having yelled that he wanted chewing gum and didn't want to do any of the suggested tasks. So, Billy and Bria, his occupational therapist, created a list of tasks, with chewing gum being included on the list, as well as swinging, buttoning a shirt, tying shoes, and handwriting. In this

particular excerpt, “Superflex” and “Glassman” are employed as part of the very doing of therapy.

Excerpt One

1 *Bria*: =First you pick and then I get to pick (2) kay=

2 *Billy*: =(Climbs on to the swing) (3)

3 *Bria*: (Pushes swing) thank you for being Superflex and using a nice voice (1) for a

4 second there I thought Glassman [was gunna come out

5 *Billy*: Whoa] (.)

6 *Bria*: You were almost being kind of rude but [then↑

7 *Billy*: ah] (.)

8 Bria: out comes Superflex↑

So, when a child was working with an occupational therapist to develop calming strategies in response to potentially “earth shattering reactions,” the calming strategy was often named a “Superflex strategy.” Also, if a child became upset (e.g., crying or refusing to participate) because of an unexpected event or undesirable request, the therapists would say, “Oh, I see Glassman. You can defeat him. I’ve seen Superflex do it before.”

Parents were also encouraged to use this language when dealing with challenging behaviors. I interpreted this language as positioning the “problem” as something that could be dealt with by the child him/herself and not as something inherent to the very makeup of the child. The statement, “I see Glassman. You can defeat him,” stands in striking contrast to, “You look angry.” The first statement, focused on Glassman, avoids indicting the child as inherently troubled, while also reminding the child that they are competent and capable of dealing with the

challenge at hand. In lieu of saying, "stop it" or "don't do that," the therapist positioned the responsibility for dealing with the challenging behavior on the child, while offering support and reminders about their favorite strategies. With Superflex coupled with individual strategies, specific to the child's preferences (e.g., deep breathing, drawing to calm down, walking away for a while, etc.), the child was offered alternative ways of responding and/or calming to the unexpected, strategies which they themselves had participated in constructing and practicing with their therapists.

Pattern One: Accounting and Re-accounting for "Problematic" Behaviors and Events

While the activities within each therapy session were in many ways shaped and at times constrained by insurance demands, as noted in Chapter VII, the therapists worked to be "as clever as possible" when writing their therapy goals and carrying out each therapy session (email from Megan on December 12, 2010 at 10:02 pm). In other words, they sought to creatively address the most relevant needs of the child, regardless of how it fit under the constraints mandated by insurance companies. One of the most notable aspects of the ways in which therapy was carried out at The Green Room was how the parents themselves informed the direction of a given therapy session. Parents made relevant their concerns and requested help around specific issues that were noted as concerning and/or problematic, particularly in other contexts (e.g., school, stores, home, etc.). Quite often, the therapy sessions addressed specific requests of the parents, typically shared with the therapists privately via email, phone, or face-to-face just prior to the start of a therapy session. Joel, one of the participating fathers, stated the following in his interview: "when you call here or you email one of the ladies and you you get a

response and it's it's not Hello Mister X thank you for replying for your or you know it's hey Joel what's going on."

I was struck by how the therapists did not seem to assume that what a parent reported as problematic, per the reports of the officials within other institutional spaces (e.g., teachers or psychologists), was inherently a result of the child's dis/ability or even *true*. A waiting room conversation between a therapist and a parent often focused on making sense of and reframing the official, outside reports and evaluations that might construct their child as incompetent. For example, during one of the recorded waiting room conversation, Susan, a participating parent, shared the following about her son's IQ scores with Megan, a participating therapist: "I'm wondering about his IQ scores (.) too because they [school psychologists] have him low average and I think he's higher than that." Megan responded by offering a different interpretation of the official IQ scores, stating: "I'm sure any new person a psychologist that would test him would just be like (.) 'cuz he can't sit still but if you like get used to that and just let it go↓ (.) and (.) still do what you're gunna do and just let him sit on the bouncey ball and have something in his mouth (1) if you get over that then he can do alot of stuff."

So, Susan's son's IQ score was not constructed as indicative of her son's inherent deficiency, rather the reports of outsiders (e.g., expert assessors) were put into question and reframed. Further, quite often, the therapists spoke, typically in the privacy of their office, about their concerns for the participating children, not because they displayed non-normative behaviors, but because others, outsiders, might "read" their movements, bodies, and ways of communicating as abnormal or even threatening. So, the therapists did not simply teach children

to use pronouns, make requests, tie their shoes, or cross the street safely; they taught them how to develop strategies to *deal* with how others might orient to them.

In the next four excerpts, I illustrate the way in which a concerning event or behavior, made relevant by a participating parent, was worked through in the very process of doing therapy. For example, prior to his son's usual therapy session, Joel, in an email written to Bria and Michelle, two of the participating therapists, reported that his son came close to hitting a teacher at summer school. The incident was reported as "serious" and "concerning" by school officials who already were considering alternative placements for his son, Diesel Weasel. Joel requested that the therapists speak to Diesel Weasel about the incident and help him develop other ways to interact at school. During his interview with me, Joel stated that he did not "worry about him [Diesel Weasel] as much as I worry about other people and the way they interpret him." Thus, this "worry" was made evident throughout the data collection process, with Joel, like many of the other participating parents, reporting often, to the therapists, about events in which his child was constructed as "troubled" or "problematic."

In the excerpts below, I present, only in part, segments from Diesel Weasel's 30-minute therapy session with Bria, an occupational therapist. The focus of this particular session was on the school incident that Joel had reported via the email. The four excerpts below illustrate the unfolding nature of the therapy talk, highlighting how an initial account of an event was not positioned as definitively true, but was rather left open for negotiation. Across the therapy talk data, the therapists and children often worked to co-construct an account that provided for the possibility that the concerning behavior or problematic event was not necessarily the result of an inherently troubled or dis/abled identity on the part of the child. Instead, within the context of

the therapy session, space was given for the child to offer an alternative account, even if it countered the *official* version proffered by outside authorities.

Diesel Weasel and Bria always incorporated, to some extent, the creation and review of a powerpoint into their therapy sessions. Diesel Weasel was particularly interested in computers; thus, he and Bria, at the beginning of each therapy session, always negotiated what newly acquired skills he might show Bria. She then worked to incorporate his developing skill set into the construction of a powerpoint entitled, "Working Out Social Skills," with a subtitle of "Getting people to see the real you—the real you is brilliant and fun" (see Appendix N for the slides that were referenced during this particular therapy session). Each therapy session, they either added to their developing powerpoint or simply discussed and applied what they had already co-constructed. The overarching goal of "working out social skills" was to allow people to see, as Bria stated, "who Diesel Weasel really is." Social skill development, then, was coupled with what Diesel Weasel had constructed (in previous therapy sessions) as the "real" him (Appendix N, Slide Four), which included the following:

1. Creative: "artful eye" and "magic touch"
2. Brilliant: high IQ, mind for figuring, & grade A science brain
3. Awesome: humorous, honest, & compassionate

As such, Diesel Weasel's "real" or true identity was positioned in contrast to the challenges that were often ascribed to him by outsiders (particularly his school teachers), casting him as "troubled" and perhaps not so awesome. This aspect of the therapy talk was particularly significant, as all of the therapists worked with the children to explicitly co-construct their "real" selves. These "real" selves, whether referenced as such or not, were constructed as competent

and capable of dealing with challenges (i.e., impairment effects and outsiders' misinterpretations) with supports and practice.

In all of the excerpts below, Bria and Diesel Weasel were positioned in front of a laptop computer and referenced verbally and/or nonverbally (gaze) the powerpoint slides related to their conversation. This particular therapy session began with Diesel Weasel requesting to show Bria something on the computer. After negotiating what he would show her, and for how long, they both agreed that Diesel Weasel could "pick his idea" first and then Bria would "pick" her idea. Excerpt Two begins just after Diesel Weasel finished showing Bria several icon tools.

Excerpt Two

Bria: Okay so (.) what do you think on a scale of one to ten↑ is (.) the whole grace situation for you at summer school right now↑ (.)

Diesel Weasel: Well like (.) with one being handling it good or handling it bad↑

Bria: Uh (.) let's make one handling it bad and ten (.) handling it excellently↓ (2)

Diesel Weasel: Well then it's probably a (.) somewhere between two and four↑=

Bria: Yeah that's that was kind of my impression in fact I'm not=

Diesel Weasel: =Somewhere between two and four and a half probably↓ (.)

Bria: I don't even know if I'm willing to go to four↑ I feel like one to three or two to three even (.) 'cuz I've I I heard about an instance >where um< you were really argumentative with one of the teachers and got into a situation where you almost hit someone which to me↑ if you're if you're almost to the point [where you're being physical

Diesel Weasel: I wasn't going to hit] her=

14 *Bria*: =Did she think you were↑ (.)

15 *Diesel Weasel*: She <u>thought</u> I was but I <u>wasn't</u> going to=

16 *Bria*: =Okay can you name=

17 *Diesel Weasel*: =That teacher takes <u>everything</u> badly↓=

18 *Bria*: =Really↑=

19 *Diesel Weasel*: =Yeah=

20 *Bria*: =She's kind of a sensitive person↑(.)

21 *Diesel Weasel*: =Well yeah too sensitive I <u>mean</u> every time I <u>mean</u> she just takes

22 everything negatively=

23 *Bria*: =Okay so let's do this=

24 *Diesel Weasel*: =so=

25 *Bria*: =Let's make (.)

26 *Diesel Weasel*: It's really not all my fault she just takes everything negatively↓=

27 *Bria*: =Kay I I can somewhat agree with you I can agree with you there I think

28 dealing with sensitive people is a <u>difficult</u> task for <u>anybody</u> (.) especially when

29 someone then is is in charge of you↑ and they're sensitive

Bria began by asking Diesel Weasel a question about "grace" in relation to school, introducing the school incident as the topic of focus. Note that she did not begin by telling Diesel Weasel that things were not going well at school; rather, she requested that he evaluate the situation (lines 1-2). Further, her use of the word "grace" perhaps pointed to their shared knowledge about particular phrases and lexical choices that they had previously co-constructed to represent certain things. As Bria spoke, both she and Diesel Weasel occasionally glanced down at the

computer screen in front of them, where the slide entitled "Grace" was visible (see Appendix N, slide two).

In a previous therapy session, Bria and Diesel Weasel had co-constructed the meanings and applications of the notion of grace, defining it as follows: (1) The degree to which someone can remain socially appropriate even when upset; (2) The ability to hold in one's initial reaction to things; and (3) To be able to put up with authority and get through the day. Yet, Diesel Weasel did not immediately answer Bria's question; instead, he requested for clarification about the meaning of her scale (line 3). I was particularly struck by Diesel Weasel's use of the word "handling" in response to her question. "Handling" implied that school was something that Diesel Weasel had to deal with or manage. Alternatively, he could have simply stated, "one being good and ten being bad;" yet, the use of the word "handling" possibly pointed to the effort Diesel Weasel exerted in attending school. Bria followed up his use of this word by adopting his language, equating "one" with "handling it bad and ten (.) handling it excellently." When a speaker repeats another speaker's lexical choice, it often functions to establish mutual understanding, being frequently used in negotiating or dealing with delicate matters/topics (Brown & Levinson, 1978). So, I interpreted Bria's use of the word "handling" as functioning to construct a sense of mutual understanding, as I realized that the topic itself was delicate and likely demanded care to be taken.

After a pause, Diesel Weasel constructed the school situation "somewhere between a two and four," making evident that he oriented to the situation as indeed problematic. Bria then agreed with his assessment, yet when she moved to state "in fact I'm not," Diesel Weasel interrupted her and reconstructed the situation as slightly better, adding half of a point to his

original assessment (line 7). Bria countered his claim, offered an alternative assessment of the school situation, and then moved to justify her claim by telling what she had "heard" (lines 8-9). Discursively, reported speech or telling someone what someone else has told you (e.g., "I heard that..."), while potentially functioning to increase the veracity of one's claim, also leaves open the possibility that there is an alternative version of the event in question. Some discursive research has also shown that reported speech often functions to invite an evaluation on the part of the recipient, indirectly requesting that the recipient evaluate the veracity of what was reported by others (Lamerichs & te Molder, 2009). I interpreted Bria's reported speech ("I heard") to be functioning to invite Diesel Weasel to evaluate the veracity of the report, noting across the therapy talk data that the therapists often presented a presumably "problematic" event as something they had "heard" about. While there was no evidence in my data set that the children explicitly questioned/wondered from whom the therapists had heard these things, the children, almost always, responded by affirming or offering a different account. In this way, I suggest that the therapists, in lieu of accusing the child, created space for the *official* version to be countered and reframed. The child, then, was positioned as knowledgeable and capable of evaluating the reported event.

Indeed, as illustrated in the above excerpt, Diesel Weasel responded to what Bria had "heard" by evaluating and countering the reported account, stating, "I wasn't going to hit her." When asked if the teacher "thought" he was going to hit her, Diesel Weasel emphasized that she "<u>thought</u>" he would, perhaps distinguishing between what the teacher believed was about to happen and *reality*, as he "<u>wasn't</u> going to" (line 15). Diesel Weasel moved then to offer an explanation as to why the teacher might have "thought" he was going to hit her, positioning her

as someone who simply "takes <u>everything</u> badly." Eventually, he distanced himself from being fully responsible for the school situation, linking the teacher's negative disposition to the event (line 26). While Bria could have certainly moved to counter his claim, she instead offered a qualified validation of his position (lines 27-29), stating that she "somewhat" agreed with him and then clarifying which aspect of his position she aligned with. Her use of a qualified agreement positioned Diesel Weasel as still being responsible for his actions, yet constructed his actions as potentially understandable.

Bria did not allow for the construction of the teacher as "sensitive" to be left unexamined. Instead, she discursively moved the conversation forward, going about the delicate work of identifying with Diesel Weasel why the teacher would have logically "thought" that he was going to hit her, as seen in Excerpt Three below. While there are many discursive features at work in the excerpt below, I focus primarily on how Bria went about the delicate task of dealing with a very personal and potentially face-threatening[21] problem. I also highlight the way in which the body, as an interactional resource, was used in accounting for the school situation.

Excerpt Three

1 *Bria*: But part of our job then↓ if we're gunna <u>deal</u> with authority and have a little
2 bit of grace about it↓ is to take the perspective of the teacher right↑ <u>so</u> let's take (.)
3 and let's make three short perspectives about her (draws three columns on a piece of
4 paper) we have a sensitive teacher we know she <u>thought</u> you were going to hit her↓
5 kay we're gunna get in in our mind we're gunna be the teacher now we're not gunna

[21] Face-saving or face work refers to maintaining or preserving, in talk, the positive self-image or face of one's self or another speaker (Goffman, 1967). When dealing with sensitive or delicate matters, the face or positive image of an individual may be potentially threatened. Thus, speakers often discursively work to save face and avoid threatening the positive image of self or others.

6 be Diesel Weasel and we're not gunna be Bria we're gunna be a very sensitive

7 teacher kay↑ (.) think of three reasons why she might have thought you were going

8 to hit her=

9 *Diesel Weasel*: =I was waving a fist↑ =

10 *Bria*: = Uh huh waving a fist write it down awesome=

11 *Diesel Weasel*: =(Writes "waving a fist" in one of teacher column)=

12 *Bria*: =Kay (2) what else we need three reasons why she might have been under

13 under the impression that you were going to hit (11)

14 *Diesel Weasel*: °Raising voice° (writes "raising voice")=

15 *Bria*: =Kay↑ (15)

16 *Diesel Weasel*: Um (5) man that's a lot of dandruff (brushes white specks of his

17 black sweater) I guess I was pretty upset when she started telling me to just she was

18 all like Diesel Weasel >be quiet be quiet be quiet be quiet< (.)

19 *Bria*: Okay so maybe (.) what she saw was like an emotional body↑ (.)

20 *Diesel Weasel*: Yeah=

21 *Bria*: =Okay I think that's valid (.)

22 *Diesel Weasel*: Emotional↑=

23 *Bria*: =Emotional yeah and maybe put emotional body 'cuz we can be emotional in

24 our head but not have an emotional body↓ but if you were showing an emotional

25 body I can see where she thought you were gunna hit right↑

With the third powerpoint slide displayed on their computer (Appendix N), Bria began by orienting Diesel Weasel to their already established notion of "authority" (line 1). With

authority having been defined in previous therapy sessions (by Diesel Weasel) as something to "deal" with and "sometimes difficult," I interpreted Bria's lexical choice as functioning, to some extent, to signal their shared knowledge and solidarity about the challenges of dealing with authorities. Further, Bria constructed the very task of dealing with authority with grace, as "our job," not "his job." Pronouns have been noted to index solidarity between speakers and to point to the differences, or lack thereof, of power between them (Ostermann, 2003). As I considered instances in other therapy sessions in which delicate matters were being pursued, I noted that the therapists often used first person plural pronouns, frequently stating "we need to" or "our job is to." In the excerpt above, with the potentially face-threatening topic of accounting for a school incident, I oriented to Bria's pronoun use as significant and as functioning to create some measure of equal footing, albeit institutionally limited (i.e., Bria was the therapist in charge, Diesel Weasel was the child who came for therapy).

After Bria moved to suggest that "dealing" with authority necessitated taking the perspective of the teacher (lines 2-3), she reformulated Diesel Weasel's previous construction, noted in Excerpt One, of a "sensitive" teacher *thinking* that he was going to hit her, while in *reality* he was not (lines 3-4). Other discursive research around therapeutic talk has reported that the "delicateness in the therapist's reformulations" is "more than conversational etiquette," as it functions to protect the client's face, while simultaneously fulfilling the institutional goal of helping (Kurri & Wahlstrom, 2007, p. 315). So, in lieu of Bria stating, "Why were you going to hit the teacher," she worked to align with Diesel Weasel, avoiding a direct accusation that might have threatened his sense of self and competence. Indeed, such delicate, face-saving moves are common in therapeutic talk, particularly when discussing personal problems (Goffman, 1967).

Even so, ever so carefully, eventually, the therapist encouraged Diesel Weasel to consider the reasons why the "sensitive teacher" might have "thought" he was going to hit her (lines 7-8). Diesel Weasel immediately identified his "waving fist" as one of the potential reasons that the teacher might have thought he was going to hit her, with his very body ("fist") being used to make sense of why the teacher oriented to him as threatening. In conversation, the body is often used as an interactional resource to hold others accountable for their actions or to offer an account for why things happened the way they did (Hepburn & Wiggins, 2005b, Wiggins, 2002). In this case, both Bria and Diesel Weasel oriented to and co-constructed the particular aspects of Diesel Weasel's bodily discourse ("waving fist" and "emotional body") that made his teacher's response justifiable.

Furthermore, Bria positioned an "emotional body" as being a "valid" reason for a teacher *thinking* he was going to hit her, with the body itself constructed as a *visible* ("she saw...an emotional body") discourse. Perhaps, then, Bria's focus on an "emotional body" functioned to make explicit to Diesel Weasel that outsiders might interpret his body in ways he does not intend. Additionally, one of the institutional goals of The Green Room was teaching the children "to read their bodies, understand their bodies, and regulate their systems so that they can participate in school, home, and community" (Megan, email on December 21, 2010 at 10:28 am). While Diesel Weasel, even in the above excerpt, maintained that he was not solely to blame, making evident that his teacher said "be quiet" multiple times and that he "was pretty upset," Bria, in the process of doing therapy, worked to further establish *why* the teacher might have had good reason to feel threatened, pointing to the role of his bodily discourse.

Following the above interchange, Bria then showed Diesel Weasel what his body might have looked like to the teacher, rubbing her hands up and down her legs and moving around the room quickly. She then reminded Diesel Weasel that his current teacher did not know his "preferences" nor understand his "sensory system very well." Hence, "it's not really" her "fault because" she did not "really know" you "very well." At the moment Bria began to distance the teacher from being fully responsible for the school situation, Diesel Weasel interrupted her. He turned to offer an account of what he believed "actually" happened, describing in great detail how he had attempted to help two boys build something and was told by the teacher to let the boys do it on their own. Bria requested that he "take the perspective" of the two boys and consider that they may not have wanted his help. Diesel Weasel responded by countering her suggestion, as seen next in Excerpt Four. As such, the initial account of an event was not positioned as definitively true, but was rather left open for negotiation.

Excerpt Four

1 *Diesel Weasel*: Well act- well actually it wasn't that they wanted to do it
2 themselves because actually it started out with only one kid over there but
3 then another ki- so then a second kid walked over and (.) the first kid lets
4 him join↑ (.)
5 *Bria*: Okay=
6 *Diesel Weasel*: =So and and and the kid and that second kid is really not
7 being much of a help↓ (.)
8 *Bria*: Okay=
9 *Diesel Weasel*: =Um um so then I come along and then I and then I get

yelled at for trying to help (.)

Bria: Okay↑ so I see your frustration then↓ it really wasn't about kind of intruding and being an interrupter for the group↑ °you were actually trying to join the group°=

Diesel Weasel: =Yeah (.)

Bria: Okay well that makes more sense were you able to tell that to your teacher [or do you feel like

Diesel Weasel: I tried to] but she but she wouldn't listen to me she just kept telling me off (1)

Bria: =Okay okay↑=

Diesel Weasel: =She wouldn't even let me talk (.)

Bria: Okay=

Diesel Weasel: =She wouldn't even let me tell her anything she sh- I mean every time I tried to every time I'd inhale to try to say something she just like she'd just keep on talking and be like (.) I mean it's just (1)

Bria: Frustrating=

Diesel Weasel: =Yeah frustrating and ridiculous and stupid=

Bria: =Okay↑ so before I was taking th- the um perspective of the teacher and we kind of talked about that and then we were taking the perspective of the kids for a little bit but now I see your perspective↓ how you were trying to join a group but you didn't feel super successful about that and then someone came along and told you not to even try and do it so at that point I

32 can see <u>why</u> you were <u>emotional</u> I can see <u>why</u> you were <u>upset</u> and <u>why</u> you

33 felt sad I <u>still</u> don't like these choices still don't agree with these choices I

34 feel like we have a lot of other things to do besides these things but I

35 understand why you felt bad I understand why that was kind of crappy deal↓

36 <u>so</u> we should probably practice joining a group↑ kay↑(.)

Diesel Weasel began by emphasizing what "<u>actually</u>" occurred. Grammatically, adverbial emphasizers such as actually, definitely, certainly, etc., have "a reinforcing effect on the truth value of the clause or part of the clause to which it applies" (Quirk, Greenbaum, Leech, & Svartvik, 1985, p. 583). So, immediately, Diesel Weasel positioned his claim as what he oriented to as the *real* school situation.

Throughout Excerpt Three, Diesel Weasel asserted a position that contradicted the idea that the teacher simply did not know him well, disaffiliating from Bria's explanation. Discursively, when counter-claims or positions are proffered, people often offer an account (Robinson, 2009). Indeed, Diesel Weasel offered an account, making a case for why the *real* issue was about being "yelled at" as he was attempting to join a group of potential playmates (lines 1-10). Bria responded by validating his account, stating, "I see your frustration," and later indicating that "before" she had one perspective on the school situation and now she had another due to this explanation (line 27). I interpreted her description of her changed perspective as pointing to one of The Green Room's common points of emphasis during therapy, one of which Diesel Weasel had discussed and practiced in previous therapy sessions: if someone misinterprets what you are saying or doing, attempt to explain what you feel *really* happened in a calm and logical way, as they might then better understand you. So, as Bria reformulated his

account, she stated what "actually" happened as being about "trying to join the group" (lines 12-13), making evident what she now better understood about the school situation.

After asking whether he had told his teacher of his frustration, Diesel Weasel indicated that talking to her was not an option (lines 17-24), perhaps providing evidence for *why* the school situation occurred in the first place. From his position, he was never provided with an opportunity to explain himself. It was no longer simply that Diesel Weasel was a "troubled" young boy with multiple dis/ability labels, many of which indeed evoked presumptions related to disordered and threatening behavior; rather, Diesel Weasel had been (1) misunderstood, even misinterpreted by his teacher, and (2) he was not listened to. The evidence he provided was positioned as justifying, at least to some extent, his "frustration" (lines 27-36), with Bria stating, "I can see why you were upset;" yet, Bria did not end here.

Even while validating Diesel Weasel's frustration, accountability for the school situation was not placed squarely on the shoulders of the "sensitive" teacher. Bria did not deny Diesel Weasel's part in the threatening act itself, stating, "I still don't like these choices," leaving open the possibility that there were a multitude of other options (e.g., Superflex strategies), other ways in which he could have communicated his frustration (lines 33-34). Yet, she also engaged in elaborate face-saving work, stating in a multitude of ways that his actions were understandable, emphasizing the she understood "why" he was "emotional," "upset," and "sad" (lines 27-36).

In this particular therapy session, responsibility for the school situation was never discursively placed solely on the shoulders of Diesel Weasel, but instead was dispersed, with no single person being solely accountable. I noted that across the data the therapy talk focused on dealing with problematic events, such as school-related trouble, other social actors and

institutions were always considered in the construction of the account. Further, across the therapy session data, there was an emphasis upon *teaching* the children perspective taking (Madrigal & Winner, 2008), which is presumably part of empathy, something which is typically presumed to be "deficient" or missing in individuals with autism labels (Frith, 1989). What was likely to be cast by outsiders (e.g., other caretakers) as linked to or directly caused by a child's impairment was recast and reframed by the participants of this study as having multiple, intersecting explanations. The child was constructed as being *partially* responsible, in need of learning additional strategies to communicate and express their needs, frustrations, and desires. However, others, including official authorities, teachers, caretakers, other medical professionals, community members, store owners, peers, etc., were also positioned as responsible, at least in part, for misinterpreting at times what a child was attempting to do or communicate, i.e., for jumping to conclusions. In this way, as the therapist and child worked to co-construct an account of seemingly problematic events, the child was never placed as the only individual in need of adapting. Others, particularly those who did not "know the child well," were constructed as part of the cause for problematic events or behaviors unfolding in other institutional spaces.

Doing therapy, then, was a fragile and complicated process, never simply about making the child accountable, or some other social actor accountable, but about saving face and identifying who or what else might be *part* of making sense of and accounting for an event constructed as problematic. Through the positioning of a child's account as valid and important for providing a layered understanding of an incident, I argue that the participants left open the possibility that the children's identities were far more layered than they were interpreted to be by others ("who did not know them well"). When the "real selves" of the children were given

opportunity to be heard, understood, and validated, perhaps, as Diesel Weasel wrote in his powerpoint, "others would have the benefit of knowing all my good qualities and would probably have a good time with me" (Appendix N, Slide Five).

This orientation toward the actions of the children as being explainable and understandable, with the problems themselves being due, at least in part, to outsiders' misinterpretations, was typically reemphasized in what the therapist shared with others after the therapy session had come to an end. Every therapy session concluded with the therapists either walking with the child to their next therapy session or walking with the child back to the waiting room to meet their parent. Typically, the therapist would briefly share with either the child's next therapist or the parent how the session unfolded. The therapist typically focused their talk on the child's behavior and/or the functional skill(s) that the parent had presented, at some point, as being problematic or worrisome. The therapists' accounts of their therapy session were constructed in distinctive ways, pointing to one of the shared institutional aspects of the therapy talk. Typically, the therapist offered a new account of the problematic event or concerning behavior and presented a logical explanation for the child's challenge.

As such, the "problematic" or "worrisome" events, behaviors, or communication patterns were positioned as explainable, even if the therapists, parents, or child had yet to construct an explanation. If, for example, a child was biting his shirt twenty-four hours a day, yet was not able to offer a verbal explanation as to why, the therapist would identify potential sensory based activities (e.g., sucking on a chewy toy or lollipop) that presented the child with whatever sensation they found appealing when biting their shirt. For instance, during a waiting room conversation between Bria, a therapist, and Nicole, a mother, Nicole described her son as having

a “rough start” to his day. Nicole indicated that George had been “aggressive” with another child with whom he was playing and that he was also “going to town” on “biting others” and “sucking his thumb.” Bria responded with, “you know the chewy might indirectly help with some of that because it’s a lot of proprioceptive input it’s a lot of um it’s just a lot of sensory calming.”

So, “biting” or “being aggressive,” then, was not oriented to as a “bad behavior,” but as explainable and potentially meaningful to the child, as well as something that could be addressed with particular strategies (e.g., chewy toy). Furthermore, when an incident occurred in spaces outside of The Green Room, such as that which was reported by Diesel Weasel, the therapists often shared the child’s account, acquired during the course of the therapy session, with the parent or other therapist, positioning the child’s claims as reasonable.

Excerpt Five illustrates the way in which many of the therapists re-accounted for the children’s “problematic” behaviors. The excerpt begins just after Diesel Weasel and Bria have walked to his next (group) therapy session. Diesel Weasel entered a therapy room in which other children were already present, as Bria privately shared an account of their therapy session with Michelle, another participating therapist.

Excerpt Five

1 *Bria*: He had a really good <u>day</u>↓ um the last thing we did (1) was we worked on
2 joining a group↑ (.) because he had a bi- that big thing that happened at school↑ with
3 the teacher was <u>actually</u> about him kind of trying to join a group of boys playing and
4 (.) not being super successful at it↑ and then feeling really really sad and frustrated

5 when then he was further asked to not be a part of it um ‘cuz they were doing a
6 building toy that he really liked↑ and he knew how to do it and they were kind of
7 having trouble so we just did like a quick role play at the end of how <u>he</u> went in and
8 then how he could be like hi I’m Diesel Weasel and I know how to play this game
9 and I know where that piece goes and like keeping his hands to himself (.) so that
10 they could offer it ‘cuz he was like hi I’m I I (Bria reaches her hands out towards
11 Michelle) you know I know how to do it so and °°he’s like a little emotional about
12 it°° like you know↑ °it was hard <u>so</u>° that’s where we are

In the above excerpt, Bria began by offering an evaluation of her therapy session with Diesel Weasel. Her lexical choices of “really” and “good” worked to construct a positive assessment of the session (line 1), a common pattern across the data. Over and over again, the therapist’s concluding summaries of a given therapy session began with a positive assessment. Even when a therapist began with “we kind of had a tough day,” they followed this more negative assessment with an account that framed the very meaning of “tough” as explainable and nothing out of the ordinary. The assessment of the session was always followed by a statement or series of statements that presented what was *done* in therapy.

In the excerpt above, Bria made relevant the “last” therapy activity, glossing over the elaborate amount of work that preceded “joining a group.” Even though the majority of the session was spent talking through Diesel Weasel’s incident at school, Bria focused on the final activity, perhaps making visible the institutional importance of identifying solutions to those issues that concern the children, their parents, and ultimately their participation (or not) in the broader community. Bria then offered a rationale for the final activity, constructing the school

incident as a "big thing." Her use of the word "big" possibly pointed to the seriousness of the incident. My observational/field notes also pointed to the seriousness of such an event, as the therapists spoke often (i.e., in hallway and private office conversations) about the importance of assisting Diesel Weasel to avoid school expulsion due to what others might orient to as threatening behavior.

As Bria produced a version of what happened at school, she assembled a range of evidence to support her claims. For instance, her emphasized use of the word "actually" functioned to reinforce her claim as valid. As noted above, adverbial emphasizers often function to reinforce the veracity of a claim (Quirk et al., 1985). In this case, her use of the word "actually" was linked to what Diesel Weasel was *really* trying to do, "join a group of boys and (.) not being super successful" (lines 3-4). So, Bria positioned Diesel Weasel's emotional state as an intelligible part of a sequence of events (Edwards, 1997). Who wouldn't be "really really sad and frustrated" if they experienced failure when attempting to join a play group? Further, one of Diesel Weasel's explicit therapy goals was to learn how to "maintain more friendships" (Appendix N, Slide Four); thus, not successfully joining a group was a sensible and obvious explanation within the context of The Green Room and Diesel Weasel's individual goals. Instead of suggesting that Diesel Weasel threatened a teacher, Bria implied that being "further asked to not be a part of" the group was, at least in part, an explanation as to why he became "frustrated."

I was particularly struck by the implications of Bria's re-telling, particularly in relationship to alternative accounts. Bria could have positioned Diesel Weasel's frustration as indicative of his dis/ability. Instead, while not evading that a challenge of some kind was

present, in this case his inability to join the group, Diesel Weasel was not positioned as being solely accountable for the event. His inability or failure to join a play group was situated within a particular context, a context which, as Diesel Weasel said in Excerpt Two, he oriented to as "ridiculous." What Bria constructed, then, as "hard" was not the threatening behaviors of Diesel Weasel, but what she oriented to as his unsuccessful attempt to join a group and then being "further asked" by an authoritative figure (i.e., teacher) "to not be a part of it." Who was at fault for the "big" school incident, then, was not a simplistic matter. Instead, Bria's account complicated the matter of accountability, for no longer was Diesel Weasel positioned as simply "threatening." Instead, he was constructed as having experienced social failures that then caused him to respond emotionally, yet understandably so. As such, "problematic" behaviors were never located solely in the individual with an autism label, but rather, to some extent, in society or outside institutions that were presumed to play a part in failing or succeeding to provide supports needed when working through challenges and/or interactions that may be far removed from the norm (Oliver, 1996).

As I moved across the data set, I noted that the therapists, in particular, discursively worked to locate the disabling effects of impairment in the surrounding culture rather than solely positioning something like an "emotional body" response as a natural consequence of an impairment (Thomas, 1999). Donnellan, Hill, and Leary (2010) noted that in the professionalization of the "interactions with people with autism, we have trained professionals, parents and others to interpret what happens in terms of simple, binary views of behavior (i.e., good/bad or positive/negative)" (p. 2). The therapeutic activities of The Green Room, however, rarely oriented to a child's behavior as either "good" or "bad," "positive" or "negative." Instead,

behaviors were presumed to be multifaceted, possessing multiple explanations, each with consequence. If, for instance, the child was simply presumed to be screaming or visibly emotional due solely to their dis/ability, the identity of the child as a competent human being would likely be threatened.

I suggest, then, that much of the therapy talk functioned to complicate understandings of non-normative behaviors, locating "problems" as not being exclusive to the child's personhood. The potential implication of such an orientation is illustrated by the following research journal entry, highlighting also what struck me as significant during the data collection process:

> July 21, 2010 5:19 am
>
> I'm finding over and over and over again in my mound of data that the participating therapists work up the notion that many of the causes of "problematic" behaviors lie outside of the child, at least in part. Perhaps then the concerning behavior can then more easily be addressed as it's not an out of reach deficit inherent to the child. The "outside cause" is often a teacher, a respite care worker, a glitch in the child's diet. Yet, here is the complicated piece—impairment effects are not denied. The therapist teaches "other choices" or ways of communicating that would have maybe resulted in something more positive transpiring. So, I wonder: What happens if one moves to position the "cause," e.g. the "emotional body" or "lack of bodily control," to be solely within the child's makeup, due to some disorder (undeniably socially constructed at that)? I think, maybe, if we position the "problematic" as *just* part of the child's behavior, and never consider other possibilities, it becomes easier to say: "There is nothing that can be done to assist

and support the child. I play no role in this. He is not self-expressing; he is misbehaving."

While the very co-constructing of accounts and explanations for the presumably "problematic" was inextricably linked to all that counted as "appropriate" communication, I turn now to more thoroughly examine how the participants negotiated the communication process, particularly when the child used something other than extensive amounts of verbal speech to communicate. Whereas the excerpts above illustrated a therapy session with a highly verbal child, the next section focuses on doing therapy with children who communicate in ways that do not necessarily involve a great deal of verbal interchange. In this way, I highlight the variability within the data set and the very process of doing therapy at The Green Room.

Pattern Two: Defining and Redefining Communication

While I ultimately settled on the research question noted above, coming to this decision was a difficult and lengthy process. As I analyzed the data, particularly the 70 hours of therapy and waiting room conversations, I realized early on that I needed to narrow my analysis, as there were many striking and telling discursive features across the data. When deciding how I might go about narrowing my analytical focus, I returned to my evolving research questions, and also began to ask the following questions: (1) Who has the power to decide what I choose to analyze most closely?; (2) Who has the power to determine the results I share first?; and (3) Who has the power to name the research questions that are worth asking (Kvale, 1995)? I recognized that I, as researcher, would ultimately determine the questions I brought to the data and chose to explore and share with others. Yet, I desired to make my decisions as transparent and open to

public critique as possible (Flyvberg, 2001). Thus, as I began to share my interpretations of the data with the participating parents and therapists (see Appendix H and Appendix I), I explicitly invited them to tell me what I was perhaps failing to make sense of, and to evaluate the interpretations I proffered (Howarth, 2000). So, while the research questions evolved throughout the study, they particularly evolved when I began to share my interpretations with the participants.

These ongoing interactions, while serving to open communication with the participants, also worked to complicate and layer my understandings (Anders & Diem, 2008). As illustrated above in the excerpts from Diesel Weasel's therapy session, one of the most personally striking findings of my analysis of the therapy talk data was the way in which the therapists and children co-constructed an account of a "problematic" event or behavior, reframing the presumed "problem" as explainable, solvable, and likely due, in part, to outsiders' (e.g., caregivers, peers, etc.) misinterpretations. I shared this interpretation/finding with the participants, talking through my analysis with illustrative excerpts. I now present below three excerpts that illustrate the ways in which the participants negotiated the very communication process and reframed what was constructed as normative and appropriate/acceptable communication. Prior to discussing the ways in which communication was defined and redefined in talk, I share how I came to this analytic focus.

After engaging in a discussion around alternative interpretations of the talk and the practical implications of the findings, the participating therapists suggested that I explore more closely "wait time" (i.e., silences and pauses between each turn) in the interactions between the

therapists and children. During one meeting with the participating therapists in which I shared my unfolding interpretations (October 8, 2010 from 1:00 to 2:00 pm), Megan stated:

> So have you looked at turn taking like with wait time stuff? Like the pauses? Because I think a lot of the children we work with have patterns that are dispreferred; so what often happens is people fill the space after "How are you?" with a million questions. Like it totally makes people uncomfortable when people don't answer a question.

So, I returned to the data of the therapy sessions and more closely attended to turn-taking organization, considering what the pauses and silences were doing across the data.

I was particularly intrigued by this additional analytic focus, as previous research has often suggested that pauses, nonresponses, or silence in general often signal a problem within the conversation itself (Pomerantz, 1984). Such research has pointed to a preferred pattern that speakers often take up: one speaker speaks at a time, with no or little gap between turns. An unexpectedly long pause may be oriented to as a reluctance to participate or may signal that a speaker has disengaged from the conversation itself (Sacks, Schegloff, & Jefferson, 1974). Jefferson (1989) noted that in Anglo and Dutch conversations, the length of comfortable silence, not without variation, clustered around a one second interval (0.9-1.2 seconds). When longer silences were not oriented to as problematic, they were typically associated with non-conversational activities, such as writing down a phone number (Goodwin, 1981).

While Jefferson's (1989) extensive work around conversational practices has provided much empirical evidence regarding how silences and gaps are often managed in talk, there is also a significant body of ethnographic and sociolinguistic work that has attended to the varied meanings of silences and conversational gaps across geographic spaces, family units, and

cultures. Tannen (1984, 1985), for instance, described the conversational style of New York Jewish culture as privileging simultaneous talk, with silences or lengthy pauses often signaling a lack of involvement in the interaction. On the other hand, Mushin and Gardner (2009) conducted a conversation analysis focused on silences in talk recorded in Australian Aboriginal communities. They reported that "comfortable silence" was much longer than Jefferson's (1989) one second interval "rule," with even 13 second silences not being correlated with interactional problems (p. 2049). Comfortable silence, then, varies across space and place.

Within the broader body of literature around autism, conversational pauses, silences, and/or non-responsiveness are often coupled with evidence of a pathology or communicative deficit; a defining and commonly agreed upon characteristic of autism is poor orientation to speech (Whitehouse & Bishop, 2008). In fact, the very assessments utilized to determine whether a child "has" a communication disorder privilege immediate responses to questions and requests, with pauses and/or silences of more than one to two seconds being viewed as problematic (Newcomer & Hammill, 1977). Without exhibiting an immediate response, the individual with an autism label may be quickly presumed to be intellectually disabled and incapable of participating with other social actors (Biklen et al., 2005). The autobiographical accounts of adults with autism labels have highlighted how people with autism labels are aware and troubled that others, most often those without autism labels, underestimate their competence and view them as inept due to a delayed or lack of verbal response (Retenbach, 2009; Sinclair, 1992). In fact, many such autobiographical accounts speak to the idea that people who use and expect verbal, immediate responses are demanding and wasting their "conversational energy on meaningless small talk" (Sinclair, 2010, pp. 10-11).

I was thus intrigued and somewhat surprised by the how the participants oriented to longer than expected pauses and how they oriented to silences as nothing unusual, in that these silences did not align with the aforementioned norms. Yet, I was also aware that the institutionality of talk is often "embodied first and foremost in its form—most notably in turn-taking systems which depart substantially from the way in which turn taking is managed in" other interactions (Drew & Heritage, 1992, p. 25). As such, I wondered if the ways in which the therapists oriented to silences pointed to the institutionality and particularity of the therapy talk. Across the therapy session data, I noted that silences, even up to 60 seconds, were not usually treated as problematic, particularly by the therapists. Instead, when a participating child did not respond to a parent's or therapist's request and/or question, the therapists simply waited, reworded/rephrased the question, or offered other modalities by which the child might respond (e.g., communication device or writing or signing). As I more closely considered silences and pauses, I also began to attend to how the therapists, parents, and children oriented to communication modalities that moved beyond using verbal speech. In that some of the participating children used some form of technology to communicate, or were learning to do so, I also considered the ways that the interactions between the participants, i.e., the very doing of therapy, functioned to redefine what counted as valid communication.

I begin with an excerpt drawn from a parent interview in which Amelia responded to my first interview question ("What things might you want someone who has just met your child to know about him?"). In her response, Amelia made relevant the need to "be patient" and wait for her son, The Emperor, to respond after posing a question.

Excerpt Six

Amelia: Um wow that's a good question um (4) eh (1) y- I guess i-i-it's to be patient [with him↑ I think

Jessica: hm

Amelia: a] lot of people ask him questions and then (1) it takes him it will take The Emperor a good thirty seconds sometimes to think of the answer but it's in↑ there=

Jessica: =Mm hm=

Amelia: =I mean he knows what you're saying to him and he knows the answer to what you're asking him↑=

Jessica: =Mm hm (1)

Amelia: sometimes it comes out and sometimes it doesn't so most of it is patience most of it is you know (1) don't expect >even though he looks< like he should react↑=

Jessica: =Mm hm=

Amelia: like everybody else's kid (1) he's not gunna react [like

Jessica: mm hm]

Amelia: everybody else's kid um (2) but he's (.) he's smart I mean he knows (1) he knows what's going on he knows (2) everything anybody else's child that age knows he [just can't

Jessica: Mm hm]

Amelia: just can't get it out so

In the above excerpt, Amelia initially acknowledged my question, paused, said "eh," and then paused again (line 1). She then said, "y- I guess i-i-it's," followed by "to be patient." I was struck by the way in which Amelia's initial pauses and repairs ("y- I guess i-i-it's") delayed the progressivity or forward action of the interaction. Behaviors and/or conversational features that stall the forward action of talk often signal some kind of trouble and/or that a delicate matter is being made relevant (Lerner, 1996).

As such, in my analysis of this excerpt, I closely attended to what followed Amelia's delay and oriented to the statement, "to be patient," as likely being of interactional import, making relevant what she *really* wanted others to know about her son. In lieu of offering a description of her son (which she did much later in the interview), Amelia began by emphasizing what others should do in response to The Emperor. She then moved to justify why being patient with The Emperor was indeed necessary, with 30-second silences constructed as a typical occurrence (line 5). By establishing that 30 seconds of silence is not unusual for The Emperor, Amelia pointed to the normative communication pattern of responding immediately after being asked a question or being given a command. Furthermore, by adding, "but it's in↑ there," Amelia perhaps attended to the societal presumption that long pauses or non-responsiveness is typically indicative of cognitive impairment. Thus, even though 30-second delays were common for her son, The Emperor was constructed as competent.

Like the parents of the other four participating children who communicated more nonverbally than verbally (Chance, Noodle, Picasso, and Will), Amelia, a participating parent, presumed that silence or a lack of response was not equivalent to not understanding what someone was saying (lines 7-8). Indeed, as Lewiecki-Wilson (2003) noted, historically, a verbal

response of some kind has often been connected to one's "humanness" (p. 157). Furthermore, conversation analysts have suggested that people often draw moral conclusions based on the absence of a response (Drew & Toerien, 2011). Thus, I suggest it is fair to presume that there is much at stake for Amelia. If, for example, she constructed a 30-second communication delay as pathological and indicative of a cognitive disorder, her son might have been positioned as a dis/abled body with little to no capacity to actively participant in the world around him. Yet, by constructing The Emperor as capable, even though he might take 30 seconds to respond to another speaker, Amelia left open the possibility that The Emperor is competent, "like everybody else's kid."

While Amelia certainly constructed her son as competent, she did not evade his communicative differences, stating, "sometimes it comes out and sometimes it doesn't." Yet, Amelia did not orient to this *reality*, or what Thomas (2004) might call The Emperor's primary impairment effect, as a static entity, for in the end "most of it is patience." Her move to reemphasize "patience" brought to the fore the idea that the *real* issue was not that her son was incapable, but that other speakers did not know how to interact with him or were simply impatient. She furthered this idea stating, "you know (1) don't expect >even though he looks< like he should react," also pointing to the idea of a look or body of normality. Perhaps, then, for Amelia, the construction of The Emperor as dis/abled occurred when his body was oriented to by others as *hearably* dis/abled; that is, when he failed to respond to another speaker, the speaker took note of this response and then "read" his performance as incompetent. While Amelia constructed The Emperor's impairment as *invisible*, as he looks like he should react, when spoken to, he failed to pass as an abled speaker (Davis, 2005). The Emperor, though, was

hearably anomalous to the degree that his communication patterns challenged the normative standards of communication, which Amelia highlighted well in her talk. Over and over again, with different phrases, Amelia made a case for her son's competence, moving from statements such as, "but it's in↑ there" to "he knows what you're saying to him" to "he's smart."

In offering a different "read" on The Emperor's silence, Amelia contrasted his reaction to that of other children, presumably children using normative communicative patterns (lines 14-17). While she acknowledged that The Emperor did not communicatively react like other children, she resisted the idea that he knew less than "anybody else's child that age." In comparing him to other children, Amelia indeed normalized his communication style and positioned him as being not that dissimilar from others (O'Reilly, 2004). Even still, Amelia made relevant the presumably recognizable issue: "he just can't get it out." Her use of the word "just" possibly functioned to minimize The Emperor's difficulty in getting "it out," reestablishing the *real* problematic issue as being how others orient to and interact with her son. Impairment effects, as Thomas (1999) noted, often lead to exclusion, to barriers to doing and being. Nevertheless, exclusionary communication practices could be conceivably avoided by orienting to non-normative communication patterns, such as 30-second delays, as nothing more than "just" signaling the need for "patience."

I was particularly interested in considering how silence, as a discursive resource, played out in the context of The Green Room. So, as I worked across the 70 hours of therapy data, I collected those instances in which silences or delayed responses were oriented to as relevant by the participants; this provided me with an opportunity to more closely consider how silences and/or non-responses were dealt with in interaction. Excerpt Seven illustrates the way in which

many of the parents and therapists often oriented to and worked through silence linked to initial greetings, often occurring in the waiting room of The Green Room. This particular interchange occurred about one minute after Amelia and The Emperor arrived at The Green Room. Both Amelia and The Emperor were sitting in the waiting room, waiting for The Emperor to have a speech-pathology session with Jennifer, one of his therapists.

The next excerpt begins just after Jennifer has walked out of the main office into the waiting room area.

Excerpt Seven

Jennifer: I think I'm ready↑ (Jennifer kneels down, positioning herself in front of The Emperor. She reaches her hand out to The Emperor.)=

The Emperor: =(Places his hand in Jennifer's hand)=

Jennifer: =(Gazes at The Emperor and moves his left hand to her right cheek, holding his hand throughout the interchange.) (3)

The Emperor: (Gazes directly at Jennifer, making eye contact with her)=

Jennifer: =Hi The Emperor (5)

Amelia: °Hello ° (Gazes directly at The Emperor) (1)

The Emperor: (Gazes at Amelia and then makes eye contact with Jennifer)=

Jennifer: =Hi The Emperor (4) hi (2) can you [tell me hi↑

Amelia: °the lights are on°] the lights are on but nobody's home=

The Emperor: =(Looks out the front door of The Green Room) duh duh duh=

Jennifer: =(Laughs) boo=

The Emperor: =(Looks at Jennifer)=

15 *Amelia*: =who is this↑ (points to Jennifer) (4) <u>The Emperor</u>=

16 *Jennifer*: =(Laughs)=

17 *Amelia*: =Say hello (2) who is <u>that</u> (points to Jennifer) (2) who is it↑=

18 *Jennifer*: =Am I George↑(1)

19 *Amelia*: Who is <u>this</u>↑ (2)

20 *The Emperor*: Halfie (1)

21 *Amelia*: who is [that

22 *Jennifer*: look] (Pats The Emperor's hand on her right cheek)

23 *The Emperor*: (Gazes directly at Jennifer, making eye contact with her)=

24 *Jennifer*: =Hi The Emperor↑ (3)

25 *The Emperor*: Hi Jennifer (.)

26 *Amelia*: [oof

27 *Jennifer*: (Laughs)]=

28 *Amelia*: =made me break a sweat there↑=

29 *Jennifer*: =(Laughs) we got there right↑

Jennifer began by announcing her presence and that she was ready to begin the therapy session (line 1). She then moved to kneel down in front of The Emperor, extended her hand toward his hand, as he extended his hand toward her (lines 1-4). She then held his hand near her cheek (line 5). Throughout this initial, primarily nonverbal interaction, Jennifer maintained her gaze on The Emperor. This initial, primarily nonverbal interaction was a common interactional sequence across the data, particularly in relationship to the initial greetings in the waiting room. This sequence pointed to the institutionality of the therapy talk, highlighting the ways in which

conversational sequences, such as an initial waiting room greeting, were performed in particular ways with a recognizable shape or sequence (Drew & Toerien, 2011). The therapists often greeted children, particularly those children who did not extensively communicate verbally, in the following, somewhat predictable sequence: (1) Therapist kneels down at the child's eye level, positioned just slightly below the child's line of sight; (2) Therapist extends her/his hand toward the child's hand; (3) Child places his/her hand in the therapist's hand; (4) Therapist moves the child's hand to touch his/her chin or cheek; (5) Therapist waits and pauses.

In the above excerpt, after a three second pause, The Emperor gazed at Jennifer (line 4), which she immediately responded to with, "Hi The Emperor." Note that the therapist did not fill the silence with requests or verbal commands, which is often what occurs in conversations filled with silences of this length (Pomerantz, 1984). Furthermore, Jennifer's response to The Emperor's gaze made relevant the action-oriented nature of his gaze. His gaze was attended to and responded to, making evident the interactional importance of gazing at another speaker. With lack of eye contact (Frith, 1989) often associated with a diagnosis of autism, and commonly taught to children by requesting that they look and then rewarding their look with some kind of item of interest (Lovaas, 1987), I was particularly interested in how the participating therapists might take up and make relevant eye contact. In the above excerpt, mutual gaze or eye contact was coupled with a greeting, pointing to the ways in which this nonverbal discursive resource (eye gaze/eye contact) was privileged and made relevant. Not surprisingly, then, Jennifer responded to The Emperor's gaze with a greeting two additional times in this excerpt (lines 9-10 and lines 23-24), with a multitude of additional instances of similar sequences noted across the data set.

As I analytically considered what eye gaze *did* in therapy talk, I made sense of this interactional resource in local and situated ways and presumed that its function was particular and not necessarily generalizable to other therapeutic contexts. Additionally, I kept in mind that while many cultures privilege mutual gaze between children and adults (Bullowa, 1979), there are indeed wide variations across contexts (Ochs & Schieffelin, 1984). Some caregivers encourage eye gaze patterns in interactions (Keller, Scholmerich & Eibl-Eiblesfeldt, 1988), with early socialization around eye gaze often being linked to cultural values (Keller, 2003). More specifically, at The Green Room, making eye contact privileged was something that the therapists considered in relationship to a given family's cultural preference. For instance, Michelle, a participating therapist, reported during her interview with me that she had recently worked with a child whose family "did not view eye contact as a polite" interactional resource; thus, she worked to communicate with the child in other nonverbal and verbal ways.

Nevertheless, in the excerpt above, Jennifer oriented to The Emperor's eye gaze with a greeting, pointing to the way in which eye gaze was institutionally coupled with official greetings. One speaker's greeting is typically responded to by the other speaker offering a greeting of some kind in return (Sacks, 1992). However, in this case, The Emperor did not return Jennifer's verbal greeting. Typically, when greeted, a preferred or expected response is for a speaker to reply with a return greeting, generally with promptness. When a dispreferred response occurs, such as a non-response to a greeting, the response is often oriented to as problematic and accounted for in subsequent conversational turns (Pomerantz, 1984). If, for instance, a greeting is not returned, the greeting may be repeated by the first speaker, implying that the first speaker assumed that the second speaker failed to hear or understand the greeting.

Another possibility is that the speaker who stated the first greeting might simply walk away and/or assume that the second speaker is incapable of responding or does not desire to respond. Yet, in the excerpt above, Jennifer waited, holding The Emperor's hand on her face and gazing at him (line 7). While Jennifer made no move to fill the silence, after five seconds, Amelia quietly voiced a "hello" (line 8), possibly making relevant her own discomfort with his non-responsiveness. After The Emperor gazed at Amelia, he immediately returned his gaze to Jennifer (line 9). Jennifer responded (again) to The Emperor's gaze with "Hello," further making relevant the situated, cultural norm linking eye contact to a greeting.

After another pause, Jennifer requested that The Emperor "tell" her "hi." Her request was interrupted by Amelia, who stated, "the lights are on...but nobody's home." This statement perhaps marked Amelia's discomfort and possibly her concern with her son's non-responsiveness. Following this statement, Amelia both directly and indirectly requested for The Emperor to respond. She began by simply asking "who is this," stating his name with added emphasis (line 15). Then, she directly requested that he "say hello" and repeatedly asked "who" his therapist was (line 15, line 17, and line 21). Her repeated questions and direct requests made relevant the import (at least for Amelia) of The Emperor (1) responding to a greeting with a greeting and (2) greeting his therapist by name. Additionally, with Jennifer's name never uttered by either Jennifer or Amelia, the presumption that The Emperor knew his therapist's name was made relevant.

Jennifer, on the other hand, laughed (line 13 and line 16) and said "boo." Laughter, as an action-oriented resource, has been shown to function as a way to add levity when reporting troubles or making complaints (e.g., Edwards, 2005), to deal with delicate matters (e.g.,

Haakana, 2001), to mitigate disagreement in meetings (e.g., Osvaldsson, 2004), or to manage dispreferred responses in television talk (Stokoe, 2008b). In the above excerpt, I interpreted laughter as functioning to both manage The Emperor's dispreferred response and deal with the delicate matter of what most would name The Emperor's primary impairment effect (Thomas, 2004), his minimal or delayed verbal response. Nonetheless, after seventeen turns (from the initial "hello" on line 7), The Emperor responded with "Hi Jennifer" (line 25). Following this, Amelia uttered "oof" and stated, "made me break a sweat." The use of the "oof" and the idiomatic expression, "made me break a sweat," made visible the troubling and delicate work of working with silences and dispreferred responses. Jennifer, on the other hand, laughed again and responded to Amelia with, "we got there." Jennifer's response perhaps worked to mitigate Amelia's hearable concern (e.g., "oof"), with Jennifer taking up her institutional role as a therapist, and ever so subtly challenging Amelia's concern about her son's non-normative way of greeting others.

All of the parents of those children described by the therapists and parents as taking longer than normatively expected to respond (The Emperor, Chance, Noodle, Picasso, and Will) emphasized the importance of waiting for a response or assisting the child to use an alternative means of communicating. Across the data set, the therapists, in particular, oriented to communication as extending far beyond the use of words, phrases, or sentences. With one of The Green Room's overt institutional goals being the "right to self-expression," what was included under this umbrella of "self-expression" went beyond normative communication expectations. Crying and screaming, for instance, were not oriented to as indicative of being

tired, cranky, or obstinate. Instead, such interactional resources were oriented to as communicatively relevant, often being linked to not having any other way to express oneself.

Excerpt Eight highlights this orientation, while also pointing to the ways in which communication devices were constructed as the proxy form of communication with words. In therapy, Noodle typically used a Dynavox, a communication device that allowed for Noodle to touch symbols, pictures, letters, and words on a screen, which then made audible what she selected. However, on this particular day, Noodle's Respite Care Worker[22] forgot to bring Noodle's communication device. After a private conversation among the therapists regarding how frustrating it is that people do not view a communication device as important enough to leave home with it, Megan, one the clinical directors, asked the respite care worker to return home and retrieve the device. They then decided to attempt to use sign language and pictures to communicate with Noodle during her occupational therapy session, with the hope that the device would arrive prior to her speech-pathology session.

In the following excerpt, Noodle, who had cried, screamed, and thrown materials across the room for most of the therapy session, ran toward the door just as her respite care worker brought her the communication device.

Excerpt Eight

1 *Noodle*: (Crying as she runs to the door as the respite care worker brings the
2 communication device into the therapy room)=

[22] The Respite Care Worker included in Excerpt Ten granted me permission to include her talk in my analysis. She was one of the individuals who, via Medicaid coverage, was hired to provide transportation to and from therapies and other supports to Noodle.

3 *Respite Care Worker*: =Hi I thought your nap would have helped↑ (.) (gives the
4 communication device to Bria)
5 *Bria*: Well I think she [is genuinely frustrated
6 Noodle: (Crying and moves to stand beside Bria)]
7 *Bria*: that she doesn't have her words↑ (sets up the communication device on the
8 table directly in front of where Noodle who is now standing) look now you can tell
9 me what you are <u>mad</u> about (3) come on let's talk about it (2) let's talk about it tell
10 me what's going on (4)
11 *Noodle*: (Navigates to communication page in communication device and clicks the
12 words/pictures) Please please I want I want please please all done (.)
13 *Bria*: All done I know↓ (stood up to leave the room with Noodle)

In the above excerpt, Noodle immediately made evident her preference for having a means by which to communicate with words, phrases, and pictures, as she physically moved to retrieve her device (lines 1-2). Her very bodily movement, as an interactional resource, made evident her desire to communicate with her device. Immediately after Noodle retrieved her device, the Respite Care Worker made evident how she oriented to Noodle's crying, stating, "I thought your nap would have helped." The Respite Care Worker constructed Noodle's crying as being caused by fatigue, eliding the possibility that the crying itself was a communicative act that held meaning for Noodle beyond her physiological needs (line 3). Bria, however, disaffirmed the Respite Care Worker's assessment and offered an alternative account. She positioned Noodle's visible (tears) and hearable (crying and screaming) discourse as indicative of her being "genuinely frustrated" that she did not have a way to communicate with words. Crying and

screaming, then, were reconstructed as expected and normal responses to not being able to communicate (due to no access) frustrations and "what you are mad about." Indeed, "anger," whether performed "bodily or linguistically, can be used/taken to signal that something is wrong or problematic" (Edwards, 1997, p. 170). Emotional states, made relevant in talk, are typically accounted for in terms of causal events (Edwards). In other words, Noodle was not simply mad; there was a cause.

Linguistic research has reported that in very young children who have very little speech (Ochs, & Schieffelin, & Platt, 1979) and in adults with aphasia (Goodwin, 1995), caretakers and peers often work to collaboratively establish what the young child or adult with aphasia is attempting to communicate. In this case, the Respite Care Worker offered one account (tired), with Bria offering an alternative account (no communication device). As Bria moved to set up the device, she encouraged Noodle to "talk" and "tell" her what was going on (lines 9-10). Note that a four second silence (line 10) was followed by Noodle navigating to a particular communication page on her device. Perhaps, then, silence did not always signal trouble or lack of understanding, but was simply part of how conversations unfolded when using her communication device. Noodle concluded by requesting to be finished, emphasizing her request through the repetition of the word "please" and the phrase "I want" (line 13). Bria affirmed her request verbally and physically (line 13), making evident the action-driven nature of Noodle's communication.

Across the data set, when the therapists interacted with the children who used sign language (individually invented or some official version), communication devices, pictures/symbols, writing, or drawing to communicate, they always invited the child to

communicate however they desired, thereby constructing communication as being something far more than verbal speech. Self-expression, then, one of The Green Room's overarching goals, was defined broadly, creating the possibility for therapy to be done in a way that privileges (at least partially) non-normative ways of being and communicating. In some ways, this privileging of non-normative ways of communicating points to the tensions between the goal of assisting children to become more functional and able to navigate the world outside of the therapy setting and the goal of and commitment to self-expression. For instance, if self-expression results in communicating in ways that outsiders orient to as "odd" or incomprehensible, the goal of assisting a child to become more functional is challenged, particularly in a society that privileges verbal communication that follows a very particular pattern. Perhaps, then, self-expression requires that society at large works to accommodate and support the self-expression and participation of children and adults who communicate in non-normative ways.

Transgressing the Normative: Reading across the Two Patterns

As I analyzed and made sense of the vast collection of therapy session excerpts similar to those presented above, I began to view the therapeutic talk itself as functioning to transgress normative ways of communicating and behaving. I oriented to transgression as that which involves pushing the limits or boundaries imposed by others that operate to establish what is deemed ordered or disordered, abled or dis/abled, or autistic or non-autistic; yet, as Foucault (1977) noted, while these boundaries themselves may never be fully transcended, challenging them is possible. According to Allan (1999), transgressive acts allow "individuals to peer over the edge of their limits, but also confirms the impossibility of removing them" (p. 48).

So, for me, the very positioning of the participating children as competent, regardless of their communication style and what might otherwise be named their impairment effects (Thomas, 2004), left open the possibility for the participants, particularly the children, to subvert norms and perform something other than an incompetent, dis/abled subject. For instance, Diesel Weasel was allowed to perform something other than threatening and troubled child, as what had been named threatening (his "waving fist") was reframed and reoriented to as explainable, albeit misinterpreted by outsiders. It follows then that the everyday work of the participating therapists was not simply about teaching or even training the child to respond to questions more quickly or behave more "appropriately." Instead, perhaps the discursive practices of the participants functioned to construct what Lewiecki-Wilson (2003) called "mediated rhetoricity" or a "language used for the benefit" of the person with a communicative difference (p. 161). According to Lewiecki-Wilson, this "mediated rhetoricity" requires "attention" to the individual's "embodied nonverbal performances and gestures," as their friends, family, and advocates work to "carefully and ethically co-construct narratives and arguments from" their perspective (p. 161). Perhaps, then, the excerpts and analyses/interpretations presented in this discussion highlight the ways in which the participants' discursive practices challenge the "perceived wisdom of those at society's center," providing "a context to understand and transform established belief systems" (Solorzano & Yosso, 2002, p. 156).

Indeed, as I collected and analyzed the data, it was my examination of the process of doing therapy, the daily interactions between the children and therapists, that moved me and challenged my own presuppositions about communication and appropriate versus inappropriate actions. This evolving understanding was captured in the following research journal entry:

July 21, 2010 10:31 pm

Today, this fieldwork has been a place of feeling deeply, feeling that I am responsible for all that I have stood witness to, at least in some small way. The participants have told me, taught me, shown me so much. One thing that keeps standing out for me is the *future*. "Who will be here for our child? Who will see what we see?" the parents ask me, often, usually through tears. What will the future hold for the child I observed today? Will those around him learn to be okay with the way in which he communicates? Can we learn to orient to silence as something other than problematic? Can we learn to engage in interactions that don't require or demand preferred, immediate responses? What would happen if we did? What would the future look like?

Now, I wonder and ask: what is my next step, not simply as a researcher, but as a friend, aunt, and teacher of individuals with autism labels, and as a community member committed to finding comfortable and effective ways to increase participation with each other across social and communicative differences (Donnellan et al., 2010)? This question was one that I asked the participants who agreed to read, evaluate, and respond to the findings presented above. I turn now to explore their responses to my question and to the findings presented above.

Participants' Responses to the Findings

As I stated in Chapter VII, from October 2010 to December 2010, I met with eight of the participants (seven therapists and one parent) to share the findings and invite their evaluations and responses to my interpretations. Below, I highlight the participants' responses to the findings I shared above. I again aim to point to the variability within the participants' responses.

I present several participant quotes that highlight how the participants made sense of the findings discussed in this chapter.

Overall, Maria, the parent participant, responded to this chapter's findings by reiterating the "value" and daily importance of her son interacting with the therapists at The Green Room. She continually said that nothing I wrote or said surprised her, but that "in the end, The Green Room is like a lifeline for me. They get it" (December 26, 2010). She described how she "loves" that she can call or email the therapists any time, "telling them that Billy [her son] had a tough day and we could really use their help," contrasting her experiences at The Green Room with her experiences at other clinical and educational institutions. She provided account after account of the therapists responding by adjusting their therapy session goals to respond to Billy's daily needs.

As Maria and I ended our meeting, she added, "All of us parents need someone to help us sometimes." I replied with, "Indeed." As we both stood to leave, she looked at me and said, "But I worry about the future. What will happen when the kids get older? What will happen when there is nowhere that they feel okay going to or that accepts them?" Maria's stated concern about the future was similar to how four other participating parents concluded their interviews, perhaps pointing to the social realities and challenges of being constructed as different and even abnormal by society (Thomas, 2004).

All of the therapists focused their responses on the potential implications of community members, parents, peers, and other professionals learning how to take up silences as communicative differences and not simply as "unsuccessful communication" (Drew); in their

responses, the first pattern noted in this chapter, Accounting and Re-accounting for "Problematic" Behaviors and Events, was discussed less frequently by the therapists. Megan (December 17, 2010) responded to the second pattern, Defining and Redefining Communication, specifically focusing on Excerpt Seven, stating the following:

> I think that is a meaningful thing to report because I think if you don't wait for him, you are not going to know what The Emperor's capable of, if you don't give him that amount of time. So, if he were to say, go see a new therapist somewhere else that he didn't, who wasn't that good and wouldn't wait for him, therapy would be way less effective.

Megan's response highlighted the value of reframing silences in talk as not indicative of cognitive impairment, but of communicative difference. She also defined "good" therapy as that which waits long enough to know that The Emperor is capable, maintaining a presumption of competence (Biklen et al., 2005). Drew further added:

> I liked that it [Excerpt Seven] was so obvious that it was taking so much effort and like come on back, come on back to get him to even respond to a greeting. I kind of liked that interpretation of it; it was like, "No seriously, we're still not there. He still hasn't even met a gaze and said hello yet."

Megan then suggested a potential implication of this chapter's findings, stating:

> I guess, when you think about it, so much about The Emperor is about people being uncomfortable with that pause or wait time or him not looking at them. It's not just about inclusion or just including The Emperor. I think the community sort of needs to include themselves in this. Or I think there just must be a better word for that, but they need to become active participants. I think, you know, like people in the community, I guess

> including teachers, but even beyond that, you know, instead of just looking and keep going that they would try to initiate some sort of conversation.

Megan's response pointed to the inadequacy of inclusion as simply being about including The Emperor in society, shifting the focus on how the surrounding environment and its social actors might change themselves. Instead of saying, "the community needs to include the child," she stated, "the community sort of needs to include themselves in this." Rather than suggesting that the child should be the first to change, to adapt, or to be fixed, Megan suggested that the community should be the one to adjust their interactions in response to the child.

When I met with Bria and Jennifer (December 23, 2010), they too emphasized the importance of reframing the very definition of communication. They both pointed to the societal presumption that verbal communication is equivalent to one's cognitive ability. In response to Excerpt Six and Excerpt Seven, Jennifer stated:

> The ability to communicate right away doesn't directly correlate with level of intelligence. If you don't talk, people automatically assume that your cognitive level is lower than expected, and that's for any kid who doesn't speak as we think they should or speak like we do, and that's always parents' first concern. You know, that's always something that they express, I think, when their kid doesn't talk, "I just don't want people to think that he doesn't know."

In response to Excerpt Eight, Bria pointed to how being nonverbal or using a communication device to communicate functions to mark a child as incompetent. She continued by sharing that Noodle had recently learned how to type on a keyboard with minimal physical support. After we discussed the extensive body of literature that reports that people who use something other than

words to communicate are presumed to be retarded, incompetent, and perhaps not even quite human (Lewiecki-Wilson, 2003), Bria proceeded to share that one of the school officials has questioned whether Noodle is "really typing, really communicating." She stated:

> One of the ladies at school, who isn't like a super invested women as a side note, said essentially that Megan was hitting the keys for her and that Megan just didn't realize that. Exactly what you said, right away people were like, "She is not typing. She's not the one who's doing it." And I just thought how unfortunate right away to discount it because even if it was kind of a fluke [i.e., Noodle typing words and accurately hitting the keys], she's learned so much already that even if we were hitting all the keys for her, I still think she would learn from that. So even if she believes that, I felt like she should have a different response than like totally negating everything and saying, "She doesn't need a keyboard. She doesn't need an iPad. She doesn't need any of that 'cuz she's not actually doing it. Like she can't do that." Like I lost sleep. That's how mad I was, and Megan was probably the same. That just, that's the one thing that kinda kills me, but that's one specific lady, but proves your point.

Indeed, across the meetings during which I shared the findings with the participating therapists, they each highlighted the importance of sharing with others the ways in which communication and seemingly "problematic behaviors" can be oriented to differently. More particularly, in response to this chapter's findings, the participants spoke of the practical implications of this research. They stressed the importance of sharing these findings with medical and educational professionals, parents, and other community members, and pointed to the ways in which we all

might move beyond deficit models of human functioning. When I asked Bria to say more about the practical implications of this research study, she stated:

> You know, I always think of Diesel Weasel. Like for kids who have major behaviors and major preferences and major outbursts, just to know that they don't necessarily hate you or the environment. They're just not filtering their emotions or their behaviors, their sensory information correctly. So, in the same way that you would wait for someone to talk, you'd wait for someone to totally calm down and then get through it and then come back and answer you, which is different than silence. But if there was education or an article or research out there about that that made it easier for people to disengage just for that time and then be able to automatically go and engage, I mean it'd be huge for Diesel Weasel.

Bria placed some level of responsibility on the surrounding community, suggesting that if people oriented to Diesel Weasel in a different way, new possibilities would be created that perhaps might reframe who and what he was and could become and do (Pace, 2009).

As I received ongoing feedback from the participants, I was reminded of Sinclair's (1992) description of his first encounter with a therapist who presumed he was competent; as an adult with an autism label, Sinclair self-identifies and is considered by many to be an advocate for those with autism labels. He said:

> They didn't think being autistic means being mentally retarded, being emotionally disturbed, or being deliberately obnoxious. They didn't think being spaced out means not paying attention. They didn't think an uneven performance means not trying...They had a vocabulary for talking about my life. (p. 294)

Even now, I wonder what, years later, Diesel Weasel and the other participating children will say of the therapists at The Green Room. Will they too say "they had a vocabulary for talking about my life"?

Chapter Summary

In this chapter, I shared the findings related to my second research question: How do children with autism labels and their therapists and parents discursively manage and account for the behaviors and communication approaches made relevant in therapy? I first described the overarching patterns across the therapy session data. Then, I presented a portion of a therapy session, illustrating the ways in which the children and therapists went about accounting for and reframing "concerning" behaviors. After this, I presented how the participants negotiated the communication process and made relevant what was considered normative and appropriate/acceptable communication. Finally, I shared the participants' responses to the findings. In the next chapter, I put forth conclusions and present a discussion of this research project, situating my findings in relation to the broader body of literature and pointing to several implications for practice and for research.

Chapter IX: Discussion, Implications, and Conclusion

The purpose of this dissertation research was to explore how autism is performed, made relevant, and contested within interactional events among children with autism labels, the therapists who work with them, and their parents. The research questions that guided this study were: (1) What are the various meanings of autism and how are these meanings performed within and through the discursive practices of therapists and parents of children with autism labels in their everyday interactions?, and (2) How do children with autism labels and their therapists and parents discursively manage and account for the behaviors and communication approaches made relevant in therapy?

I interrogated the fluid and contested meanings of autism, while also attending to the ways in which "problematic" moments with and/or the "concerning behaviors" of the participating children with autism labels were made relevant and reframed in the context of waiting room conversations, occupational, physical, and speech-pathology therapy sessions, and hallway conversations among therapists, children with autism labels, and their parents and/or caretakers. This study's research questions, my methodological choices, and the ongoing interactions with the participants certainly informed what I came to name as the overarching implications of this work. Throughout the two findings chapters, I implicitly and explicitly pointed to some of the implications of this work, as I also reported on the participants' own beliefs about the practical import of this study's findings. Now, in this chapter, I explicate in greater detail this study's implications, positioning those implications discussed in relation to broader bodies of literature, while also carefully attending to how and what the participants

named significant about the findings presented in Chapter VII and Chapter VIII. I begin with a brief summary of the organization of this research study.

Summary of the Study

In Chapter I, I began by introducing the reader to the statement of the problem, purpose of the study, research questions, relevant terms, delimitations and limitations, and the significance of the study. Then, in Chapter II, I made explicit my own positionality, pointing to the ways in which I both wrote and was written into all that I shared (Walkerdine, Lucey, & Melody, 2002). Next, in Chapter III, I presented the history of autism, viewing my historical retelling as only one of many possible interpretations. I also reviewed and analyzed relevant qualitative empirical studies, aiming to position this dissertation research within a larger scholarly conversation. In Chapter IV, I discussed the theoretical frameworks (Derrida, 1981; Edwards & Potter, 1993; Foucault, 1971; Howarth, 2000) which informed this work. I made explicit how, in the process of doing this research, my theoretical understandings were challenged and, in some ways, altered (Lather, 1986). Within Chapter V, I described this study's method, outlining how I designed the study, gained access to the research site, collected and analyzed the data, and sought to transparently share my findings. While few studies drawing upon discursive psychology present a thick description of the site and the participants, in Chapter VI, I offered a more extensive description of the participants, focusing on the participating children. Within Chapter VI, I also discussed the way in which I oriented to the notion of context, and the process of determining how and what to share about the participants and research site. I then shared my major findings in Chapter VII and Chapter VIII, with each

chapter focused on one of this study's research questions. Chapter VII focused on the meanings and performative aspects of autism, while Chapter VIII considered the ways in which the therapists' and children's interactions accounted for and reframed behaviors of "concern" and the very meaning of communication.

Chapter Overview

I begin this chapter by discussing the broader implications of this work. Then, I present several implications for practitioners working with children with dis/ability labels and their families. Next, I briefly point to how certain aspects of this study's findings might inform policy makers focused on dis/ability rights in relation to outside funding (e.g., Medicaid). I also share some of the more specific research implications, pointing to the ways in which this study's findings might inform how researchers go about examining dis/ability constructs and embodied differences. Finally, I offer suggestions for future research. In this final chapter, I also put forth my conclusions and point to the importance of continuing to interrogate and question the privileged and often taken-for-granted public discourses about autism.

Challenging the Dominant Discourses of Autism

I situate the findings of this study in the body of literature most often associated with disability studies, as I positioned dis/ability at the intersection of culture and biology and oriented to the disabling effects of impairments as located in culture (Barnes, Oliver, & Barton, 2002). Like other studies that view dis/ability labels as embedded within culture (Rocque, 2007), this study's findings pointed to how dis/ability is not a discrete object, but rather a "set of

social relations" (Davis, 1995, p. 11). Similar to Rocque (2010a) who reported that, for outsiders, mothers of children with autism labels reframed their children's behaviors as explainable and not indicative of deficiencies, the findings of this study also highlighted the ways in which parents, therapists, and the children themselves re-accounted for behaviors and communication styles that outsiders may have oriented to as "odd," "threatening," "troubled," or inevitably caused by autism itself. Similar to Nadesan's (2005) historical account of the making and the remaking of autism, the findings of this study make visible the social, political, and economic constraints that shape the performative aspects of autism as the participants made real varied versions of autism for particular audiences. Rosetti et al.'s (2008) study described how psychological examiners often failed to "read" the performances of individuals with autism in ways that allowed for alternative interpretations or explanations to be proffered as to why an individual was responding in the way that they were, with an inability to share ideas "through speech" resulting in constructions of incompetence (p. 506). Building upon Rosetti et al.'s work, my study's findings also point to the ways in which "behaviors and actions traditionally linked with incompetence" can and even should be reframed and reinterpreted (p. 364). For example, the idea that a child's "look" or way of moving their body or expressing themselves is "read" as plainly pathological, often results in misinterpretation by outsiders (e.g., the child is constructed as "threatening" or "incompetent"), something which was made relevant by the participants in this study over and over again.

Furthermore, much like the memoirs of parents with children with autism labels who felt tensions between constructions of autism as "a gift" and autism as a "real" and "unconquerable, debilitating force" (Osteen, 2008, p. 19), this study's findings also point to the ways in which

parents talked about autism in variable and, at times, contradictory ways. Similar to the autobiographical accounts of individuals with autism (e.g., Biklen et al., 2005; Retenbach, 2009) and those studies that examine such accounts (Jones, Zahl, & Huws, 2001), the therapists and parents of this study speak back to those psychiatric discourses that presume that if you "look" abnormal you must be abnormal. While very little discursive or qualitative research has focused on exploring autism as performed in everyday practices (Glynne-Owen, 2010), this study's findings offer a new means by which to "read" and orient to autism in research; rather than presuming that "autism organizes discourse" (Ochs & Solmon, 2004, p. 139), I presumed that discourse constructs the very notion of autism. Additionally, in that much discourse and conversation analysis research, as well as qualitative research in general, focused on autism has assumed "universal" linguistic deficits (Hale & Tager-Flusberg, 2005, p. 519), the findings of this study, standing in contrast to much research focused on autism, provide opportunity to consider how participants make sense of the communication and behavior of children with autism without presupposing that autism is *real* and carries with it particular traits (e.g., linguistic deficits).

Thus, I argue that the importance of this study's findings is found not in focusing on the correctness or incorrectness of a child's speech or behavior, but rather on how the participants co-constructed subjectivities that resisted full and final definition. Diesel Weasel, for instance, while struggling to communicate with a teacher, was at the same time oriented to as "competent," "threatening," and "misunderstood." As such, to set out any mutually agreed upon series of parameters about what counts as appropriate communication, behavior, or *real* autism

symptomology would be to close down, and thus normalize, what must otherwise remain a shifting nexus of biology and culture.

Indeed, as I carried out this research project, I assumed that meanings are never given or guaranteed, but instead are negotiated, as "...things can acquire different meanings and functions in different historical contexts and situations" (Glynos & Howarth, 2008, p. 167). The construct of autism, then, never rests at any level of arrested meaning (Barthes, 1973). Meanings are always open to challenge, critique, and even change. The talk about autism or any other construct is never trivial, as entire social realities are built in and through talk. As Foucault (1980) noted:

> Each society has its regime of truth, its 'general politics' of truth: that is, the types of discourse which it accepts and makes function as true...'Truth' is centered on the form of scientific discourse and the institutions which produce it...there is a battle 'for truth,' or at least 'around truth.' (p. 132)

So, it follows that if meaning is a matter of social convention and negotiation, at some level, the discourses that we come to take up and deploy as truth concern and involve all of us.

Perhaps, then, this research study contributes, at least in part, to this "battle for truth," pointing to the varied meanings and performances of autism and the potentiality of therapeutic talk that discursively reframes otherwise pathologized behaviors and ways of communicating. The current ways of orienting to and constructing notions of normal, abnormal, abled, or disabled "...reflect a series of choices made at different times between different possible worlds" (Skinner, 1998, p. 117). At each moment in history, we have opportunities to generate and offer new possibilities for discursively constructing and positioning one another (Weedon, 1987).

"Equipped with a broader sense of possibility, we can stand back from the intellectual commitments we have inherited and ask ourselves in a new spirit of enquiry what we should" (Skinner, p. 117) and can do in our everyday interactions, particularly with individuals "...whose physical, mental, cognitive and sensory abilities....fall outside of the scope of what is currently defined as socially acceptable" (Rauscher & McClintock, 1996, p. 198). I suggest, like Freire (1999), that through dialogue and a commitment to questioning taken-for-granted discourses, we can create moments of solidarity and perhaps even ruptures in the dominant discourses (Wetherell, & Potter, 1992) that work to pathologize, exclude, and stereotype those individuals with autism labels (Heir, 2002).

While the popular press and the medical and scientific literatures have represented autism as a biological fact to be understood primarily through the lens of positivistic methodologies (Glynne-Owen, 2010; Rocque, 2010a), the social and political conditions and everyday practices that make (im)possible the representing, treating, and performing of autism have been largely ignored (Nadesan, 2005). As such, the meaning of autism has been situated within deficit and medical models, relying primarily upon a binary divide between the cultural notion of "normal" and "abnormal" (Ashby, 2010; Broderick & Ne'eman, 2008; Davis, 1995). With the majority of the research in the field of autism either predating or simply disregarding the discursive turn, much of the literature on autism has worked from a realist position, resulting in a pathologized and fixed view of autism. Autism, then, has been presumed to be a natural entity, not a negotiated, contested, and fluid construction. Yet, while the dominant discourses construct autism as a biological truth to be named and treated, the everyday talk surrounding autism is, in

reality, "a scrambled collection of competing, contesting 'truth claims'" (Avery, 1999, p. 119), in that autism cannot be separated from the cultural models that define it.

Nadesan (2005) suggested that the significance of a study that examines the social construction of autism "extends beyond 'autism' as a distinct disorder to include the ideas and practices whereby we constitute everyday life and social institutions, including the processes that will ultimately produce the opportunities for personhood in the early twenty-first century" (Nadesan, 2005, p. 3). Thus, in many ways, this study's findings provide opportunity to reconsider and reimagine other identities for individuals labeled with autism, while pointing to the complicated and contingent nature of the construct of autism. Indeed, dominant and popularized discourses surrounding autism have often presented a monolithic version of people labeled autistic, frequently situating the meaning of autism within a medicalized and deficit-oriented framework. Broderick and Ne'eman (2008) have argued for the importance of counter-discourses and narratives that offer cultural critiques of medicalized notions of autism and alternative possibilities for making sense of embodied differences. I suggest that this study offers new possibilities for making sense of the contingent meanings of autism, being named autistic, performing ability and dis/ability, interpreting communicative and behavioral differences, and engaging in the very process of doing therapy.

I offer below some of this study's implications for practitioners (therapists, teachers, and others working with children with autism labels), those involved in making dis/ability policy decisions related to insurance and Medicaid coverage, and researchers. I position the implications in relation to Broderick's and Ne'eman's (2008) call for cultural critiques, and suggest that this study's findings challenge the "perceived wisdom of those at society's center,"

providing "a context to understand and transform established belief systems" about normality and abnormality (Solorzano & Yosso, 2002, p. 156).

Implications for Practitioners

I suggest three primary implications for practitioners, those diagnosticians, therapists, teachers, and caretakers who work with children with autism labels. I situate these implications in what I propose that this research provides for practitioners: new ways to discursively orient to and work with children with autism labels, opening up a space to consider how socially constructed notions of "dis/abled" and "normal" contribute to the construction of children with autism labels as competent, incompetent, abled, disabled, etc. First, I suggest that one of the key implications for practitioners rests on the very idea that autism is socially contingent. In lieu of presuming that this label is inherent to the individual, ahistorical, and exists apart from institutionalized and technical practices, orienting to autism as culturally and socially embedded leaves open the possibility for alternative meanings to be produced. Perhaps such alternative meanings will allow for the identities of those with autism labels to be constructed and reconstructed in ways that position them as competent, capable of participating in society, while likely requiring outsiders to make room for non-normative communication styles. Practitioners, then, by orienting to autism labels as having multiple and shifting meanings, might avoid constructing fixed and stable identifies for and with the children with whom they work, inviting the children themselves to offer accounts that function to shape and reshape their social realities.

Second, the varied performances of autism (Nadesan, 2005), and felt need of parents, in particular, to perform normality, abnormality, giftedness, etc., points to the importance of

professionals remembering that what they name *normal* or *abnormal*, *threatening* or *acceptable*, is always a matter of interpretation. Without denying the challenge of impairment effects (Thomas, 2004), the findings of this study highlight that what remains most challenging for those who live with and/or perform embodied differences is how the rest of society responds to and interprets that which is non-normative as fixed or pathological (particularly as this is demanded by the insurance requirements). I suggest that practitioners, like the therapists in this study, can and should create space for parents and children with autism labels to reframe non-normative communication or behavioral patterns.

With the consequences of being oriented to as threatening or exhibiting "odd" behaviors or communication patterns often resulting in exclusion from *full* participation in society, it is paramount that practitioners, as well as society at large, consider "reading" the discourses of the bodies of those labeled autistic from a different perspective. Throughout the data collection and analysis process, I wrote often of the significance of this particular finding. The following research journal entry captures well my musings about this:

> June 2, 2010 8:26 pm
> Not once did the child's flop on the sidewalk,
> in frustration,
> or sprawling body on the floor
> lead to being kicked out,
> constructed as inept or
> disabled.
> Instead, the child, said the therapist,

"Is a diamond,

perhaps at times in the rough,

but a diamond.

Don't judge him by his cover.

There's a lot under there."

Indeed, whether a child with an autism label or any other embodied difference, labeled or not, is included or excluded in society is often determined by how others (e.g., insurance companies), most often those at society's center, "read" the behaviors and communication of the individual positioned as different. Further, as displayed in the data, presumptions of competence were often made evident as the therapists oriented to non-normative behaviors as meaningful forms of communication. Thus, I suggest that practitioners consider the ways in which they might reorient to and reinterpret children whose communication and behavior fall far outside the norm, assuming always that non-normative behavior and communication is purposeful and worthy of being attended to.

Third, I suggest that there are specific discursive practices that facilitate talking about or working through fragile topics, such as personal problems or even the ways in which others might have misinterpreted one's behavior/body. For example, therapists in this study used particular discursive resources (e.g., pronoun use and lexical choices) to save face and position the children as capable of dealing with and making sense of their problems and challenges. Further, by expanding what counts as acceptable communication and reorienting to unexpected speech patterns (e.g., longer than usual silences) as meaningful, not simply problematic or indicative of a disorder, the therapists displayed possibilities for how other practitioners might

interact with and support children with autism labels and their families in ways that presume competence.

Implications for Policy Makers

For well over one hundred years, dis/ability policies have existed in Western societies, with the earliest policies typically equating dis/abilities with individual disadvantages (Baker, 2006). At present, the theoretical bases for most dis/ability policies fall somewhere in between a constructionist notion of dis/ability and an individual, deficit orientation to dis/ability, with a delicate balance being sought between "the extremes of individual or social responsibility for disability" (Baker, p. 177). Yet, in practice, current policies tend to retain essentialist notions of dis/ability, with responsibilities for providing social, economic, and political supports to individuals with impairment effects or embodied differences being only minimally positioned as a social responsibility. For instance, government policies, like Medicaid coverage, maintain essentialized and static notions of dis/ability categories, such as mental retardation and autism. Thus, as I noted in Chapter VII, acquiring supports for a child with an autism label is complicated and often filled with roadblocks.

Findings from this study further point to the material consequences of the government's and insurance companies' definitions of dis/ability, with tensions being noted between the expressed needs of families of children with autism labels and what "official" governing bodies ultimately provide. More particularly, in this study, the challenges and conflicts of acquiring Medicaid coverage were made relevant again and again by the participating parents, highlighting the ways in which the very meanings of autism were inextricably linked to governmental and

insurance-based definitions and assumptions surrounding dis/ability. This study's finding, then, point to the ways in which narrow, static, and even inexplicable definitions of dis/ability categories function to constrain and, at times, limit the degree to which children with autism labels are afforded opportunities to participate in meaningful therapies.

As such, I argue that in the ongoing development of dis/ability policy, the culturally contingent nature of dis/ability categories, such as autism, should be acknowledged and incorporated into policies of consequence (e.g., Medicaid). In lieu of positioning the "look" of autism or mental retardation as a definitively pathological and internal, static *truth*, as defined by the state appointed experts, perhaps the families and therapists working most closely with the child can be given more space to express their concerns and reasons for requesting additional supports. As shown in Chapter VII, many of the participants oriented to acquiring a diagnosis of mental retardation as what simply has to be done in order to acquire Medicaid coverage, with the very validity of such a construct questioned and undermined. Borthwick and Crossley (1999) aptly noted that "mental retardation may be, both in any given case and in its wider conceptualization, inadequate as an explanatory concept, undefinable as a scientific entity, and unhelpful as a clinical diagnosis" (para. 39). I argue, like Ashby and Causton-Theoharis (2009), that "mental retardation is not a useful construct to describe people with autism, or anyone for that matter" (p. 502). Drawing upon this study's findings, specifically those discussed in Chapter VII, I suggest that dis/ability policy makers carefully attend to the ways in which the material consequences of being labeled disabled *enough* to qualify for supports are made evident in the everyday language and practices of children with autism labels, their parents, advocates, therapists, and the "official" diagnosticians. Perhaps by expanding the "official" dis/ability label

definitions that determine the level of educational, community, and therapeutic support that children with autism labels acquire, dis/ability policy makers can more fully participate in inclusionary practices.

Implications for Researchers

First, I suggest that this study highlights the importance of examining social constructs, such as autism, in situated and local ways. At times, disability studies scholars have critiqued researchers for studying and talking about dis/abilities in ways that are far removed from the situated practices of individuals who daily encounter or live with dis/ability labels and/or failing to take into account the bodily and material realities of embodied differences (Oliver, 1996). Thus, this study's attention to the discursive practices of children with autism labels, as well as their parents and therapists, offers a means by which to consider a multitude of theoretical concepts that have been discussed, yet rarely considered in situated and everyday practices. For instance, Nadesan's (2005) historical account of autism discusses the varied performances of autism, yet this concept is not linked to the discursive practices of actual parents. While her impressive account offers rich understandings, indeed it is important to consider, in particular, how abstract concepts such as "performances of autism" are actually taken up and deployed in the practices of people who are simply going about their daily work. In pursuing research focused in the places people are "ordinarily and functionally" employing constructs of interest (Sacks, 1992, p. 27), rich and layered understandings might be generated.

Second, I believe this study illustrates the potential value of taking up a discourse approach that refrains "from developing an all-purpose technique for discourse analysis" but

rather draws upon a multitude of theoretical and methodological understandings (Torfing, 1999, p. 292). While this study was not without epistemic tensions, I suggest that its methodological rigor was found in moving within and across discourse traditions and drawing upon concepts and ideas that served to complicate and layer understandings. For instance, while few studies employing discourse analysis include context to the degree to which I did, I suggest that my inclusion of a rich, thick description of the research site and participants illustrates the value and potential found in situating discursive findings in relation to relevant contextual factors, broader discourses, and the situated, everyday practices of social actors. In lieu of stringently applying the rules of conversation analysis or solely focusing upon Foucault's broader notions of discourse, I suggest that this study points to the ways in which understandings are enriched by attending, when possible, to micro- and macro-level context and discursive practices. While not without contradiction and analytical and methodological lapses, by employing multiple frames to make sense of the data, I believe I engaged in a form of research that resulted not in "a comfortable, transcendent end-point," but instead left me with "the uncomfortable realities of doing engaged qualitative research" (Pillow, 2003, p. 193).

Recommendations for Further Research

First, even though there are some conversation analysis, discursive psychology, and other discourse-related studies that attend to nonverbal aspects of communication, focusing their analysis on video versus audiorecorded data and/or observational data (e.g., Goodwin, 2003), discursive research is often critiqued for its neglect of nonverbal behaviors (Benwell & Stokoe, 2006). Schegloff (2005) has suggested that researchers should shift from a focus on *talk-in-*

interaction to *talk-and-other modes of communication-in-interaction,* in an attempt to explore the embodied nature of interaction. I believe this is particularly important when working and researching with individuals who communicate in ways other than through verbal speech. Thus, it is my intent to return to the stored video recorded data and expand my analysis, attending more closely to how the body was deployed discursively by the participants (Urla & Terry, 1995). Despite the fact that several of the participating children in my study rarely, if ever, verbally expressed themselves, I was struck by the ways in which they pragmatically organized their interactions, using their bodies and the materials within the room to express their needs and/or initiate conversations. It is my intent to more closely attend to the ways in which children with autism labels use their bodies in situated and local ways to communicate with their therapists and children, engaging in discursive research that attends to *talk-and-other modes of communication-in-interaction.*

Second, as other researchers work to interrogate the construction and reconstruction of dis/ability constructs such as autism, I suggest that it is paramount to collect and analyze data in ways that are responsive to non-normative communication patterns and augmentative communication devices. Such research will require creativity, especially for those researchers, like me, who are verbal speakers limited by an inability to fluidly communicate through multiple modalities. Nevertheless, to date, very little research (Biklen et al., 2005) has pursued learning from and with participants who may not respond verbally to interview questions, for instance. So, I argue for research that does not require and demand verbal responses, but like the participating therapists in this study, works to redefine who can and should tell their "story."

Third, with very little discursive research focused on dis/ability (O'Reilly, 2004), there is indeed a need for further research that attends to the ways in which dis/ability categories are taken up, deployed, resisted, managed, and at times even contested. Further, even though there is extensive research that explores race, gender, sexuality, and class, etc., little discursive research, and critical research in general, has interrogated communication styles and behaviors that fall outside the norm (Goodley & Roets, 2008). I call, in particular, for research that employs qualitative methodologies and works against medicalized and deficit orientations to embodied differences and dis/ability categories (Biklen et al., 2005), recognizing that there are already a plethora of studies reporting on the deficiencies of children with autism labels (Glynne-Owen, 2010). Additionally, in that the majority of discursive research focused on autism presumes that autism structures discourse versus discourse structuring the meanings of autism (Ochs et al., 2004; Stribling, Rae, & Dickerson, 2006), the ways in which communicative differences might be understood in non-pathological terms has been understudied.

Fourth, to my knowledge, this study and the research of O'Reilly (2004) are the only discursive studies that examine therapy talk involving children. In fact, the discursive practices of children with dis/ability labels have been minimally considered, with most discursive research focused on dis/ability including only adults with dis/ability labels, most of whom use verbal speech to communicate (Rapley, Kiernan, & Antaki, 1998). So, there is much work yet to be done, particularly around the ways in which children perform varied meanings of dis/ability across contexts. For instance, the ways in which children talk with and about other children with dis/ability labels has been only minimally considered. I suggest that future research focus on

children's interactions across contexts, attending in particular to how children themselves navigate and co-construct meanings of autism and "acceptable" communication.

A Still Unfolding Project

I acknowledge that throughout this study, at times, my positionality kept me from seeing and making sense of all that I encountered. Reynolds (2008) suggested that one of the major pitfalls of social constructionist approaches to social science is that the researcher might appear to position herself outside of the very discursive practices she seeks to explore and interrogate, and, in the end, claim some superior insight. I make no such claim, rather I hope to continue to share these findings with the participants and others, inviting outside evaluations and critiques.

As such, over the next year, I intend to continue to engage and share my unfolding interpretations with the research participants. In May of 2011, I plan to meet with two different groups of participating parents, making available to them and inviting their evaluation of the ways in which I made sense of and wrote about the data. As I continue to meet with the participants, I hope that their unfolding stories and everyday interactions will inform how I share future iterations of this work. I plan to continue to ask the participants: "Where do you think I should take this research next?" and "What questions have I failed to consider?" I remain committed to sharing my interpretations with those stakeholders involved and interested in this study (Flyvberg, 2001). In collaboration with the participating therapists, I am also currently developing workshops focused on sharing the findings of this study with parents, grandparents, and other interested community members, particularly those findings related to the therapeutic talk, as presented in Chapter VIII.

Indeed, I have learned a great deal by sharing my interpretations with the participating therapists and parents, yet I remain troubled by how the participating children remain on the periphery of this dialogue. Historically, autism has been represented by those individuals, parents and therapists included, who have never themselves been named autistic (Osteen, 2008). I desire, then, to create space for the participating children to evaluate and comment on the ways in which I made sense of their everyday work. Although I have only just begun discussions with the parents and therapists about how I might meaningfully share my findings with the children, I remain aware of my own communicative limitations. I have yet to determine how I will share the findings with the children, many of whom use a form of communication different from my own. So, prior to sharing the findings with the children, I will likely begin by expanding the ways in which I communicate (e.g., learn how to better "read" the children's nonverbal communication and incorporate communication devices), while also working to gain the children's trust. While I interpret the lack of their evaluative responses as something that limits what I can and cannot say about this research, I take comfort in Frank's (2004) reminder that: "We act as best we can at a particular time, guided by certain stories that speak to that time" as "we engage" in an "unfinalized dialogue" (pp. 191-192). So, for me, one of the most important next turns in this "unfinalized dialogue" is to find ways to share my interpretations with and invite the evaluation of the participating children. I hope that as they engage with the findings, they will make their own connections and/or disconnections and will show me all that I have yet to make sense of.

Lessons Learned: Now a Part of My Story

With a commitment to transparency, as I shared in Chapter II and Chapter V, I believe it is important to return to my positionality, and situate the discussion and conclusions in relationship to the ways in which I made sense of the participants and the research site. First, I do not believe that therapy necessarily serves to render docile the presumably abnormal child. I suggest, instead, that therapy can, at times, function to assist children and adults as they work towards expressing and functioning in ways that are most comfortable and meaningful to them. Not without complication and contradiction, I argue that it is possible to do therapy in a way that pursues and values differences, while avoiding, to some extent, the continual legitimation of neurotypical and normative ways of communicating and being (Osteen, 2008).

How, then, did I orient to the very *doing* of therapy at The Green Room? Over the course of this study, I came to view the everyday practices of the participants, particularly the therapists, more often than not, as constructing and producing a version of successful communicating and functioning that moved beyond or at least challenged normative patterns of communicating/functioning. As I spent time analyzing the data, I wrote often in my research journal about how easy it was for me to sentimentalize all that occurred at The Green Room. I present below an entry from my research journal, highlighting some of my struggles during the process of analyzing the therapy talk:

> November 12, 2010 8:00 pm
>
> I find it so difficult not to romanticize what happens in the therapy sessions at The Green Room. The very fact that Diesel Weasel wants to come to The Green Room, yet resists leaving his house for any other activity, speaks volumes to me. Could it be that

> something remarkably different is produced in this space in comparison to those institutional spaces that Diesel Weasel describes as "painful" and, more often than not, refuses to enter? I believe so, but fear sentimentalizing what I have come to not only study, but also value deeply. Perhaps by exploring this particular space, new understandings, maybe even alternative discourses and ways of doing therapy can be generated. I must keep returning to the data, sitting with it, and taking note of the places where those discursive practices that have captured my attention are made visible.

I acknowledge that, at times, I struggled to present The Green Room in layered ways, often considering it myself a "safe space" for children with autism labels and their families, seemingly noting few "faults" or contradictory moments. Over time, I indeed came to view The Green Room as a remarkably different space compared to other institutions in which I had worked as a practitioner (e.g., school contexts) and/or had observed or collected data during various research projects.

Certainly, my respect for the everyday practices I observed at The Green Room influenced how I made sense of the data, interacted with the participants, and constructed this text. As such, while I aimed to maintain transparency about my choices of data collection, analysis, and the construction of the findings, I acknowledge that there are indeed lapses in the ways in which I have made sense of the data and crafted the findings. I am only just beginning to learn how to produce research that questions its own interpretations. As I continue to learn, I work to question daily my own authority, privilege, complicity, and to always ask: Who benefits when certain discourses, including my own, are privileged over others? As this study comes to

an “end,” it is my relationship with the participating children, parents, and therapists that I carry with me.

I do not desire to conclude with a definitive list of all the things that I have learned, as indeed there were many lessons learned, ranging from methodological insights (as discussed in Chapter IV, V, and VI, to some extent) to everyday interactional practices, with much yet to be learned. So, instead I acknowledge that I am left with layered and tension-filled understandings, as the participants’ discourses and everyday practices now remain a part of my story (Krog, 1998). I conclude with an entry from my research journal that speaks to much that I have learned in and through this work, and all that I hope remains a part of my story and journey as a researcher, practitioner, and friend.

> June 12, 2010 5:46 pm
>
> Yesterday, I had the joy of observing a little boy feel music deep, deep, deep in his body. His little shoulders moved like waves as his feet did a beautiful polka-like dance all around the room. I’ll never forget it. He brought a smile to my face, a smile that felt so new to me. And I wished that there were more spaces, even just one more space, where kids were told often, perhaps several times a day, “show me how you feel today...show me with your body, with your words, with whatever. I don't care how. Just show me. I want to know you.”

Chapter Summary

In this chapter, I first highlighted the ways in which this study’s findings are situated in relation to the broader body of literature. I then transitioned to discuss the implications of this

research for practitioners, dis/ability policy makers, and researchers. Finally, I put forth conclusions, revisiting my positionality and discussing this study's next steps.

Epilogue

In the Prologue to this dissertation text, I began with the words of Kanner and Asperger, considered by many to be the fathers of autism (Grinker, 2007). Now, I end with a response, one constructed primarily with the words of this study's participating parents.

Twelve children named so many things:
Humorous
affectionate
picky
loveable
predictable
delightful
brilliant.

He's somebody you need to experience
He has feelings
just like everyone else.

He thinks outside the box.
I hate calling it a disability.
Has a hard time seeing grey.
Capable of functioning.
It's a social deficiency.
It's an advantage.
Trapped inside his body.
She's more than meets the eye.

Diagnosis:
Autism.
Classification:
Don't care what you call it.
Principal Issue:
I don't worry about him
I worry about other people,
the way they interpret him.

She wants to play with kids,
but if they approach her

she can't talk
and then
it's like she's just out to them.
A lot of people don't know how to react.
Twentieth century disorder produced.
Autism:
defined
described
assumed
reified?

Years will pass.
Explanations will proliferate.
What stories will we tell?

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Appendices

Appendix A

Diagnostic Criteria from DSM-IV-TR for Autistic Disorder

(American Psychiatric Association, 2000, pp. 59-61)

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

(1) qualitative impairment in social interaction, as manifested by at least two of the following:

(a) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction

(b) failure to develop peer relationships appropriate to developmental level

(c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)

(d) lack of social or emotional reciprocity

(2) qualitative impairments in communication as manifested by at least one of the following:

(a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)

(b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others

(c) stereotyped and repetitive use of language or idiosyncratic language

(d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

(3) restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

(a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

(b) apparently inflexible adherence to specific, nonfunctional routines or rituals

(c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)

(d) persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

Appendix B

Institutional Review Board Approval Letter

THE UNIVERSITY of TENNESSEE KNOXVILLE

Institutional Review Board
Office of Research
1534 White Avenue
Knoxville, TN 37996-1529
Phone: 865.974.3466
Fax: 865.974.7400

DATE: April 21, 2010

IRB #: 8216 B
TITLE: The Discursive Construction of Autism

Lester, Jessica
Educational Psychology & Counseling
A529 Bailey Education Complex
Campus - 3440

Paulus, Trena
Educational Psychology & Counseling
A515 Bailey Education Complex
Campus - 3440

The points of clarification you submitted to this office regarding the above-captioned project, satisfied the concerns of the reviewers and the IRB thus, your project has been granted approval.

Approval is for a period ending one year from the date of this letter. Please make timely submission of renewal or prompt notification of project termination (see item #3 below).

Responsibilities of the investigator during the conduct of this project include the following:

1. To obtain prior approval from the Committee before instituting any changes in the project.
2. To retain signed consent forms from subjects for at least three years following completion of the project.
3. To submit a Form D to report changes in the project or to report termination at 12-month or less intervals.

The Committee wishes you every success in your research endeavor. This office will send you a renewal notice on the anniversary of your approval date.

Compliances

Enclosure

Appendix C

Parent Demographic Survey

Please answer the following questions. Your responses will be kept confidential.

Parent/Guardian Name: _____

Parent(s)'/guardian(s)' self-selected pseudonym(s): _____

Child's Name: _____

Child's self-selected pseudonym: _____

Child's Age: _____

Child's Gender: _____

Child's Race: _____

Phone Number: _____ Cell Number: _____

Email address: _____

Does your child have a diagnostic label? Yes or No (circle one)

If yes, what is/are the diagnostic label(s)? _____

Appendix D

Parent Semi-structured Interview Protocol

1. What things might you want someone who has just met your child to know about him/her?
2. Describe the ways that others describe your child.
3. Describe what your child does while h/she is at the clinic.

Appendix E

Therapist Demographic Survey

Please answer the following questions. Your responses will be kept confidential.

Therapist Name and Professional Title: _____

Self-selected pseudonym(s): _____

Age: _____

Gender: _____

Race: _____

Phone Number: _____ Cell Number: _____

Email address: _____

How many years have you been working at the clinic? _____

How many years/months have you been working with each of the participating children/families? _____

Appendix F

Therapist Semi-structured Interview Protocol

1. What things might you want someone to know about the children you work with?
2. Describe your role at the clinic.
3. Describe each of the participating children.
4. What kinds of things do you do in the group therapy sessions?

Appendix G

Transcription Conventions

The transcription conventions utilized were developed by Jefferson (2004) and adapted for use within the context of this research study.

↑	Upward arrows represent marked rise in pitch.
↓	Downward arrows represent a downward shift in pitch.
> <	Text encased in 'greater than' and 'less than' symbols is hearable as faster than the surrounding speech.
< >	When turned 'greater than' and 'less than' symbols encase speech, the speech is hearable as stretched or slower than the surrounding speech.
=	Equal signs at the end of a speaker's utterance and at the start of the next utterance represent the absence of a discernable gap.
Cu-	cut-off word or sound
e	Underlining represents a sound or word(s) uttered with added emphasis.
° °	Text encased in degree symbols is quieter than surrounding speech, with double degree signs indicating whispered speech.
(laugh)	Description of what can be observed and/or heard
[ ]	Extended square brackets mark overlap between utterances.
(7)	Numbers in parentheses indicate pauses timed to the nearest second. A period with no number following (.) indicates a pause which is hearable, yet too short to measure.

Appendix H

Handout Used With Participants: Meeting One

Focus of Study

Within this study, I had multiple aims. While the overarching purpose of this research was to explore how autism is performed as an interactional event among children with autism labels, the therapists who work with them, and their parents, I also worked to interrogate how this "talk" was shaped, and perhaps, at times, constrained by the social and political institutions that often work to define autism and the related, official "plans of treatment." So, as I sought to explore the everyday talk of children with autism labels, as well as those of their parents and therapists, I positioned their talk within and, at times, against the broader institutional contexts that the participants made relevant in their social practices (e.g., insurance requirements). Further, as I attended to how the participants managed the meanings of autism through talk-in-interaction, I interrogated the ways in which "problematic" moments with and/or "concerning behaviors" of the participating children with autism labels were made relevant and "worked through" in the context of waiting room conversations, occupational and speech-pathology therapy sessions, and hallway conversations among therapists, children, and their parents and/or caretakers.

Overview of Discourse Theory

- Discourse includes all interactional moments—verbal/nonverbal. Discourses—ways of talking and the doing of social practice—are assumed to construct a particular version of the world.

- Discourse theory investigates the ways in which identities have been constructed historically and socially—focusing on how language constructs what we name as our reality, our "truth".

Therapists Interviews/Parent Interviews/Advocate Interview

- Broader discourse/socio-political frameworks—social conditions that make possible and also constrain
    - Insurance—the State Advocate—Medicaid
- Tension across institutional spaces
- Resisting definition of DISability (therapist interviews)—"more than meets the eye"
- Fluid, contradicting, and negotiable meanings of "autism"—"It's So Defined, It's Undefined"
- Accounting for autism (parent interviews)
- Explanations of behavior institutionally bound (parent interviews)

Therapy Sessions/Waiting Room Parent Conversations (the "doing" of therapy)

- "Problem" constructed as outside child (e.g., I've seen you defeat Glassman before)
- Positioning of therapist and child—"same team" (B and T) (pronoun use)
- Saving face—therapist works to keep the child positioned as knowledgeable, capable, and able to deal w/ the relevant "problem" or "issue" of focus
- Indirect "no" (negotiation)
- Accounting for the "behavior"/ "concern" (hard to work w/ sensitive people)
- Functionality—what parents make relevant—not a move toward normalizing necessarily—it is not that simplistic, it is layered, filled w/ complexity

Recasting Autism and Dis/ability

- What if your place in the world was always already occupied by the public's imagination/myths/dominant discourses of autism?
- Father Participant: "I don't worry about him as much as I worry about other people and the way they interpret him"
- **June, 2010 (research journal entry)**

  Yesterday, I had the joy of observing a little boy feel music deep, deep, deep in his body. His little shoulders moved like waves as his feet did a beautiful polka-like dance all around the room. I'll never forget it. He brought a smile to my face; a smile that felt so new to me. And I wished that there were more spaces, even just one more space, where kids were told often, perhaps several times a day, "show me how you feel today...show me with your body, with your words, with whatever. I don't care how. Just show me. I want to know you."

Next Steps??

- Send site's and participants' (children) descriptions for your review/consideration by October 14th.
- Share next layer of "interpretations" in December. Date?
- Skype in January 2011 (end) to talk through "final" iteration. Date?
- Workshops/Community events?
- Ideas?

Appendix I

Handout Used with Participants: Meeting Two

Focus of Study

The purpose of this research was to explore how autism is performed as an interactional event among children with autism labels, the therapists who work with them, and their parents.

Findings

1. With a focus on the interview data of the therapists, parents, and state advocate, I described the varied meanings of autism, while pointing to the related political and social conditions that make the naming, performing, and treating of autism possible.
2. I also draw upon data from the therapy sessions, presenting the noted patterns across the participants' discursive practices and highlighting the ways in which the therapists' and children's interactions worked to discursively reframe "behaviors of concern" and to move beyond normative communication patterns.

Data Analyses/Findings Excerpts

1. **Excerpt One**:

   Bria: Um I think <I've (.1) grown to almost>have such a broad definition of autism that I >don't even have one anymore< um and I'm not even sure I know=

   Jessica: =mm hm=

   Bria: =<u>specifically</u> what I would call autism anymore because to me it's <u>such</u> a spectrum like if someone says oh well this child has autism like I don't think that that necessarily >means↑ <u>any</u>thing to me < anymore↓ because I it because it could mean so many things=

   Jessica: =mm=

Bria: =it could mean that they just have some sort of social problems or have a little bit of um the Asperger type traits or it could be someone who is totally nonverbal or absolutely anywhere in between=

Jessica: =mm hm=

Bria: =so (.3) I don't know I think it's at this point so defined that it's undefined [laughs] (.2)

2. **Excerpt Two**: In response to my first interview question, "what things might you want someone who has just met your child to know about him," Amelia made relevant the need to "be patient" and wait for her son (The Emperor) to respond after posing a question.

   Amelia: um wow that's a good question um (4) eh (1) y- I guess i-i-it's to be patient [with him↑ I think

   Jessica: hm]

   Amelia: a lot of people ask him questions and then (1) it takes him it will take The Emperor a good thirty seconds sometimes to think of the answer but it's in↑ there=

   Jessica: =mm hm=

   Amelia: =I mean he knows what you're saying to him and he knows the answer to what you're asking him↑=

   Jessica: =mm hm (1)

   Amelia: sometimes it comes out and sometimes it doesn't so most of it is patience most of it is you know (1) don't expect >even though he looks< like he should react↑=

   Jessica: =mm hm=

Amelia: like everybody else's kid (1) he's not gunna react [like

Jessica: mm hm]

Amelia: everybody else's kid um (2) but he's (.) he's smart I mean he knows (1) he knows what's going on he knows (2) everything anybody else's child that age knows he [just can't

Jessica: mm hm]

Amelia: just can't get it out so

3. **Excerpt Three**:

Jennifer: I think I'm ready↑ (3) (Jennifer kneels down, positioning herself in front of The Emperor. She holds The Emperor's left hand with her right hand. She slowly moves The Emperor's left hand to her right cheek, holding it there for the entire interaction)=

The Emperor: =(looks directly at Jennifer, making eye contact with her)=

Jennifer: =hi The Emperor (5)

Amelia: hello (1)

The Emperor: (looks directly at Jennifer, making eye contact with her)=

Jennifer: =hi The Emperor (4) hi (2) can you [tell me hi

Amelia: °the lights are on°] [the lights are on but nobody's home

The Emperor: (looks out the front door of The Green Room)] duh duh duh=

Jennifer: =(Laughs) boo=

Amelia: =Who is this (4) The Emperor=

Jennifer: =(Laughs)=

Amelia: =Say hello (2) who is that (2) who is it=

Jennifer: =Am I George↑(1)

Amelia: Who is this (2)

The Emperor: halfie (1)

Amelia: Who is [that

Jennifer: Look]

The Emperor: (Looks directly at Jennifer, making eye contact with her)=

Jennifer: =Hi The Emperor (3)

The Emperor: Hi Jennifer (.)

Amelia: [oof

Jennifer: (laughs)]=

Amelia: =Made me break a sweat there↑=

Jennifer: =(Laughs) we got there right↑

Practical Implications

- How do you see the findings impacting (self and other) therapists, parents and children as they go about "doing" therapy?

Transcription Symbols

- What was it like to read the excerpts with the transcription symbols included?

↑ Upward arrows represent marked rise in pitch, with two arrows representing a more significant rise in pitch.

↓ Downward arrows represent a downward shift in pitch, with two arrows representing a more significant downward shift in pitch.

> < Text encased in ‘greater than’ and ‘less than’ symbols is hearable as faster than the surrounding speech.

< > When turned ‘greater than’ and ‘less than’ symbols encase speech, the speech is hearable as stretched or slower than the surrounding speech.

= Equal signs at the end of a speaker’s utterance and at the start of the next utterance represent the absence of a discernable gap.

e Underlining represents a sound or word(s) uttered with added emphasis.

° ° Text encased in degree symbols is quieter than surrounding speech, with double degree signs indicating whispered speech.

[ ] Extended square brackets mark overlap between utterances.

(7) Numbers in parentheses indicate pauses timed to the nearest second. A period with no number following (.) indicates a pause which is hearable, yet too short to measure.

Next Steps

- Parent gatherings in April and May of 2011?
- Working and meeting with the participating children in June-August of 2011?
- Community workshops: What aspects of the findings are relevant? Who is the target audience?

Appendix J

Map of Iterations/Levels of Analysis (to be read from bottom up).

Label/"Code" Mapping for Data Set (Anfara, Brown, & Mangione, 2002)

Final Iteration/Level of Analysis Applied to Data Set

Recurring Discursive Events/Broad Patterns

1. Contingent and fluid meanings of autism (Chapter VII)

2. Reframing and accounting for non-normative behavior (Chapter VII)

3. Accounting and Re-accounting for "Problematic" Behaviors and Events (Chapter VIII)

4. Redefining acceptable communication patterns (Chapter VIII)

- Accounting
- Agency/responsibility
- Attributions
- Autism definitions (meanings)
- Body as discourse
- Broader discourses of "autism"
- Category work
- Economy of autism
- Emotional discourse/states
- Extreme case formulations
- Face-saving
- Impairment effect
- Institutionality of talk
- Insurance
- Justifications
- Laughter
- Mitigation
- Non-normative
- Outsider's Interpretations
- Participants' responses to findings

- Performing competence/normality
- Performing dis/abled/pathologized
- Popular knowledges of autism
- Pronoun use
- Reframing behaviors
- Reframing identity
- Silence
- Turn-taking sequence
- Unavailable resources

Second Iteration/Level of Analysis Applied to Data Set

- Advice giving
- Autism meanings
- Bodily "realities"
- Broader discourses
- Doing accountability
- Economy of autism (e.g., insurance)
- Emphasis
- Extreme case formulations
- Face saving
- Functionality of therapy
- Initiation-Response-Evaluation
- Institutionality of talk
- Laughter
- Medicalized notions of autism
- Mitigation
- Negotiation
- Nonverbal communication approaches
- Normative language constructions
- Other institutions (e.g. schools/schooling)
- Parents' constructions
- Popular knowledges of autism
- Pronoun use
- Reframing behaviors and identity
- Repairs
- Reported speech

- Silence
- Site description
- Strategies
- Technical vocabulary
- Therapists orientation to their work
- Therapists orientations to my work
- Therapists' constructions of child participant
- Three reasons/list of three
- Topic nomination
- Turn-taking sequencing
- When/how dis/ability is (is not) made relevant

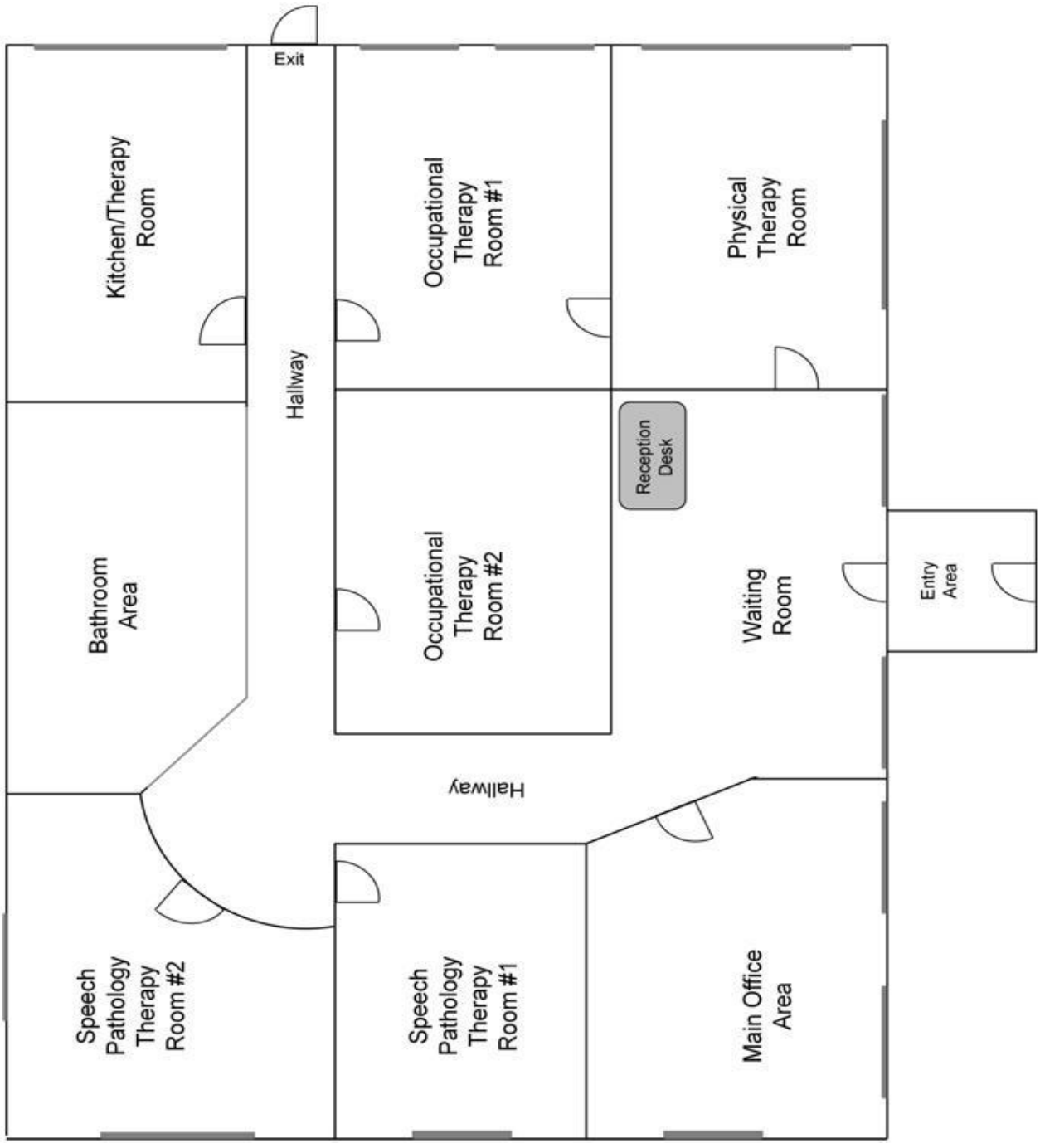
First Iteration/Level of Analysis Applied to Data Set

- Accounting
- Action
- Agency
- Assistive technology
- Attributions
- Autism made relevant when needed
- Behavior made accountable
- Behavior/problem as outside individual
- Body/Impairment effects
- Broader discourses
- Category/Identity Work
- Causes of autism
- Children descriptions
- Community/local needs
- Competent (or not) assumptions about child
- Curriculum/objectives
- Definitions of autism (meanings)
- Diagnostic process
- Dietary issues
- Disability
- Discursive resource (unknown)
- Doing of research

- Doing therapy
- Economy of autism
- Factual claims
- Functionality
- Gaining access to site
- Imagined community/stood witness to
- Institutional restraints
- Institutionality
- Insurance
- Insurance claims
- Interventions vs. social relational approach to disability
- It's like family
- Justifications
- Labeling/naming
- Look at me
- Meanings of autism
- Media's story of autism
- Medicalization of autism
- Methodological theoretical concerns
- More than meets the eye
- Normality/"He's just like…"
- Parent constructions of child
- Participant description
- Popular knowledges of autism
- Poststructural/anti-foundational notions of autism
- Potential
- Researcher's orientation to "behaviors"
- Researcher's relationship to site and participants
- Safety concerns
- Schools/schooling
- Site description
- Theories of "autism"
- Therapy practices/approaches
- Turn-taking sequence
- Validated research sources
- When dis/ability is made relevant/when it is not

Appendix K

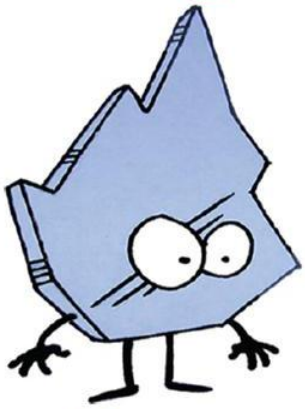
Floorplan of The Green Room



Appendix L

Glassman Handout

Beware of glass!!!



Glass Man, that is!!

One of the most common unthinkables who can make someone shatter – if he gets into his brain.

He lets a person be flexible to some extent, but then all of a sudden he just breaks. He doesn't melt down slowly; he quickly starts getting very upset, often over "tiny" problems.

Glass Man usually thinks things aren't "fair."

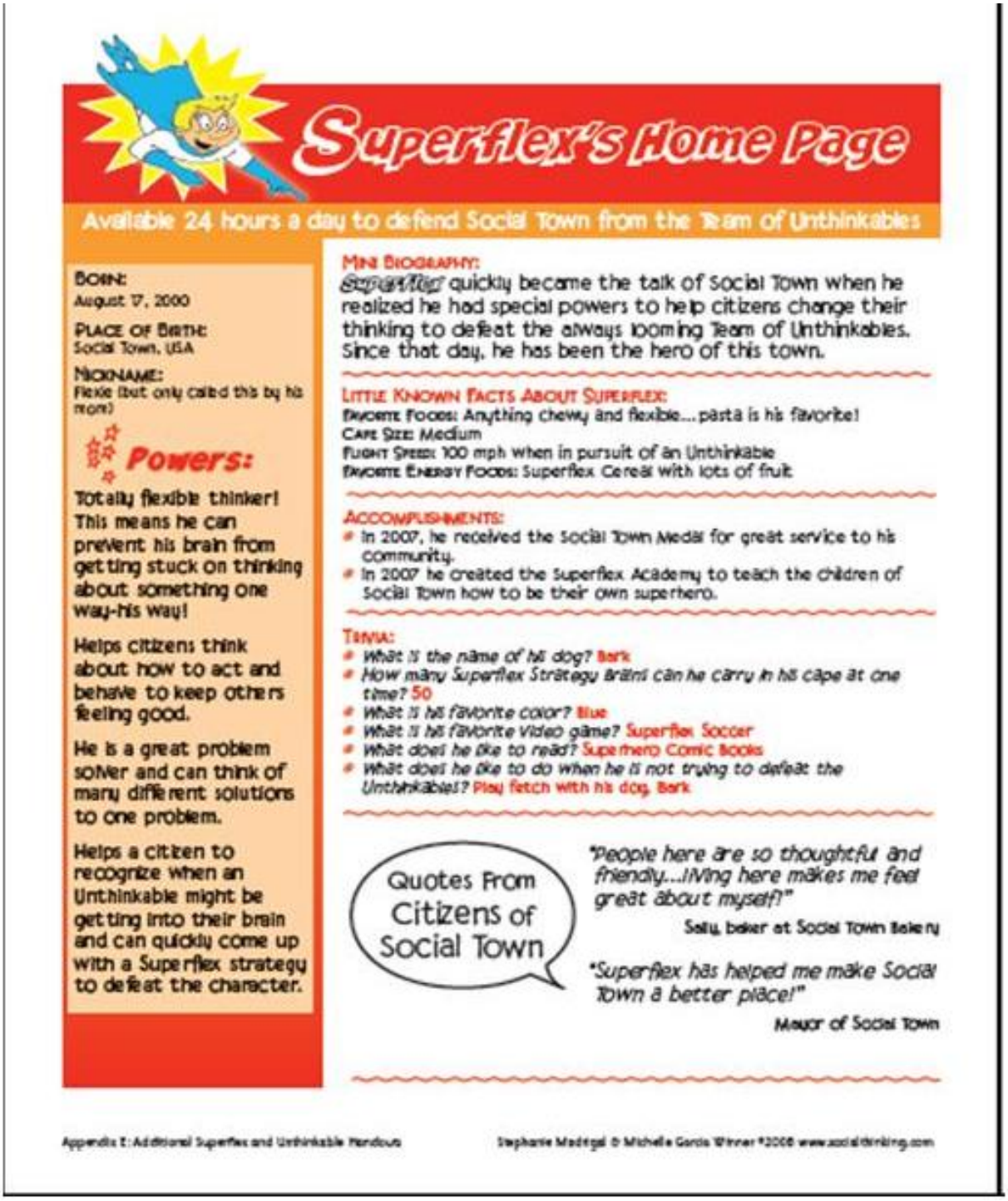
Does this sound familiar? Do you know someone who gets invaded by **Glass Man**? Do you think **Glass Man** is on your team of unthinkables? If so, do not worry because **Superflex** can help.

Some ways that **Superflex** suggests taking on **Glass Man**:

- **Identify the size of the problem** (1-10) and what would be an expected reaction to match the size of the problem.
- **Self-Talk:** "I'm starting to get mad. I need to move away and take a break."
- When getting frustrated, **tighten** all of the muscles in my body **and** then **relax** them.

Appendix M

Superflex Handout



Superflex's Home Page

Available 24 hours a day to defend Social Town from the Team of Unthinkables

BORN:
August 17, 2000

PLACE OF BIRTH:
Social Town, USA

NICKNAME:
Flexie (but only called this by his mom)

Powers:

Totally flexible thinker! This means he can prevent his brain from getting stuck on thinking about something one way-his way!

Helps citizens think about how to act and behave to keep others feeling good.

He is a great problem solver and can think of many different solutions to one problem.

Helps a citizen to recognize when an Unthinkable might be getting into their brain and can quickly come up with a Superflex strategy to defeat the character.

MINI BIOGRAPHY:

Superflex quickly became the talk of Social Town when he realized he had special powers to help citizens change their thinking to defeat the always looming Team of Unthinkables. Since that day, he has been the hero of this town.

LITTLE KNOWN FACTS ABOUT SUPERFLEX:

FAVORITE FOODS: Anything chewy and flexible....pasta is his favorite!
CAPE SIZE: Medium
FLIGHT SPEED: 100 mph when in pursuit of an Unthinkable
FAVORITE ENERGY FOODS: Superflex Cereal with lots of fruit

ACCOMPLISHMENTS:

- In 2007, he received the Social Town Medal for great service to his community.
- In 2007 he created the Superflex Academy to teach the children of Social Town how to be their own superhero.

TRIVIA:

- *What is the name of his dog?* Bark
- *How many Superflex Strategy Brains can he carry in his cape at one time?* 50
- *What is his favorite color?* Blue
- *What is his favorite video game?* Superflex Soccer
- *What does he like to read?* Superhero Comic Books
- *What does he like to do when he is not trying to defeat the Unthinkables?* Play fetch with his dog, Bark

Quotes From Citizens of Social Town

"People here are so thoughtful and friendly....living here makes me feel great about myself!"

Sally, baker at Social Town Bakery

"Superflex has helped me make Social Town a better place!"

Mayor of Social Town

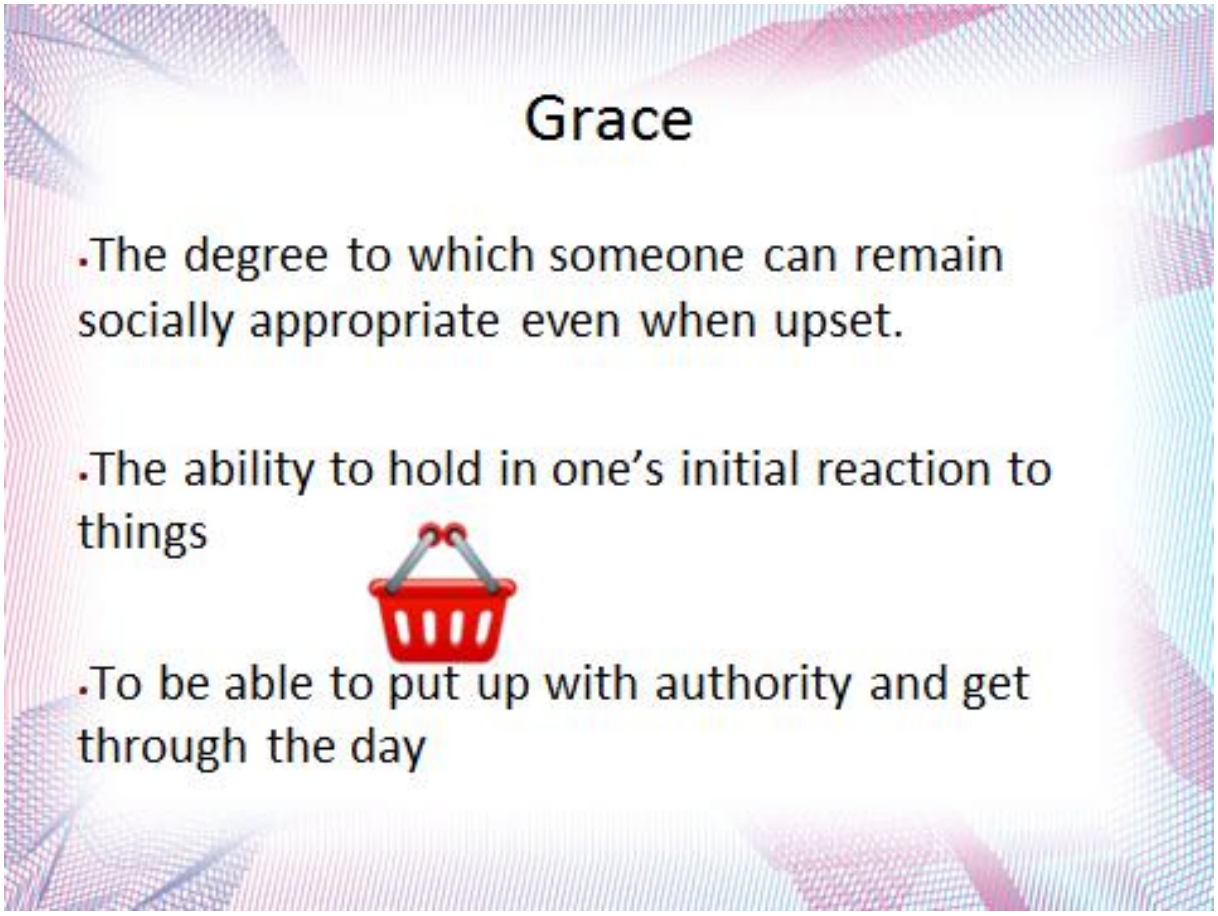
Appendix I: Additional Superflex and Unthinkable Handouts

Appendix N

Powerpoint Used during Diesel Weasel's Therapy Session

Slide One

Slide Two


Grace
•The degree to which someone can remain socially appropriate even when upset.
•The ability to hold in one's initial reaction to things
•To be able to put up with authority and get through the day

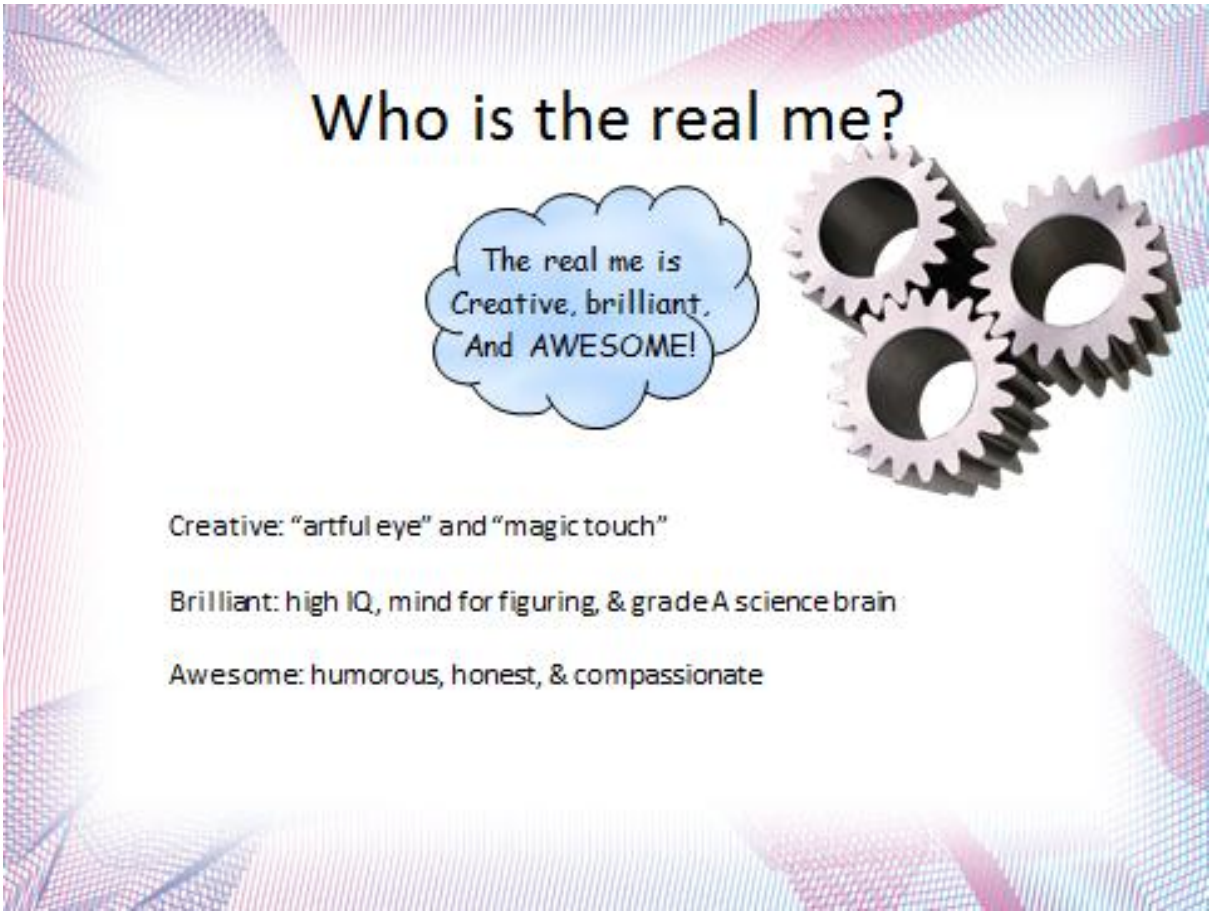
Slide Three

Authority

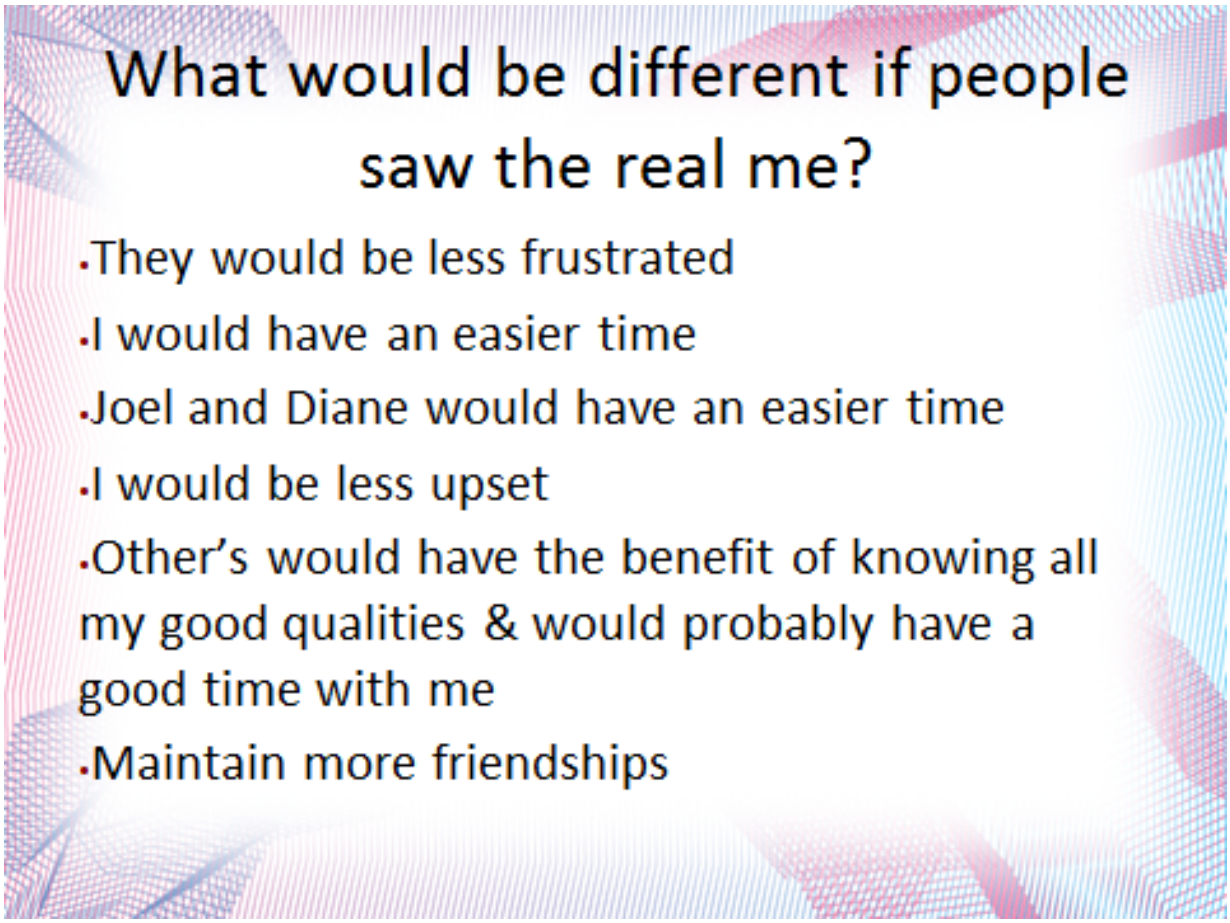
- Dealing with authority is sometimes difficult

- Definition of authority:
  - A hierarchical relationship between a boss-like figure and others in a group or team
  - Not a capacity…more like a relationship

Slide Four


Who is the real me?
The real me is Creative, brilliant, And AWESOME!
Creative: "artful eye" and "magic touch"
Brilliant: high IQ, mind for figuring, & grade A science brain
Awesome: humorous, honest, & compassionate

Slide Five


What would be different if people saw the real me?
They would be less frustrated
I would have an easier time
Joel and Diane would have an easier time
I would be less upset
Other's would have the benefit of knowing all my good qualities & would probably have a good time with me
Maintain more friendships

Vita

Jessica Nina Lester was born and grew up in Bismarck, North Dakota. She completed the requirements for a Bachelor of Arts in Biology in 2000 from Jamestown College in North Dakota. In 2003, she earned teaching credentials in elementary education and special education. She completed her Master's degree with a concentration in special education in 2005 at the University of Mary in North Dakota. In 2010, she completed a graduate certificate in Autism Spectrum Disorders at the University of North Dakota. She also completed a certificate in Qualitative Methods in Education, and a minor in Cultural Studies in Education at the University of Tennessee at Knoxville in 2009. She is currently employed at Psychoeducational Network in Knoxville, TN, and teaches and learns with and from children and adolescents with developmental dis/ability labels and their families. Upon acceptance of this dissertation, Jessica will have graduated with a Ph.D. in Educational Psychology and Research from the University of Tennessee at Knoxville in 2011.