

**“I’m Not Sure I Even Know”: Therapists’ Tentative Constructions of Autism**

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**Abstract:** Autism has historically been constructed within and through biomedical discourses and practices. Therapeutic interventions have focused on “treating” and “curing” the individual diagnosed with autism, with therapists positioned as the “experts.” In this paper, we report findings from a discourse analysis informed by discursive psychology of eight interviews with therapists of children with autism labels. While the therapists were frequently positioned as “experts” with presumed “stocks of knowledge,” they were reluctant to definitively name autism as something with clearly defined characteristics, thereby making evident the shifting nature of knowledge surrounding what autism “really is.” We discuss implications for practitioners and others, as well as point to the importance of engaging in social constructionist studies of the discourses surrounding autism.

**Keywords:** discursive psychology, discourse analysis, discourse, constructs of autism

### Introduction

Like most developmental disorders, autism has often been positioned as a disorder to be named and understood by professionals, often presumed to be the “experts.” Most definitions of autism describe it as being a biological fact comprised of a triad of deficits, which include: (1) impaired social interaction, (2) lack of or limited imagination, and (3) delayed and/or limited communication (Frith, 1989). The disorder is typically diagnosed when qualitative impairments in an individual’s ability to engage in social interactions and communicate are noted, alongside stereotypical behaviors (American Psychiatric Association, 2010). Even though the notion of autism was first discussed by Kanner in 1943 and Asperger in 1944, the biological “facts” that surround autism are often presumed to exist outside of the disciplinary knowledge that has made an autism diagnosis possible. In contrast, some scholars have suggested that the early constructions of autism are situated within and out of certain disciplinary practices and discourses (Nadesan, 2005), particularly the discourses of medicine, education, and childhood psychiatry. As Foucault (1972) 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. The discourses surrounding autism have also been tightly coupled with the professionalization of its treatment, with ideas related to how autism should be “fixed” resulting in the development of particular interventions and professionalization of interactions (Donnellan, Hill, & Leary, 2010). Yet, to date, little research has examined how professionals go about making sense of what autism means at the level of discourse.

Thus, in this paper, we share findings from a study focused on how therapists at a pediatric clinic constructed fluid meanings of autism in the context of a research interview. More specifically, we report on findings generated from a discourse analysis informed by discursive psychology (Potter & Wetherell, 1987) of eight interviews with therapists of children with

autism labels. As we analyzed the data, we were struck by the patterns and variations in how the therapists defined autism, and thus decided to focus a line of analysis on these definitions in order to better understand them. Further, in the larger data set, the participating parents frequently positioned the therapists as “experts” and presumed that they had “stocks of knowledge” that non-experts did not possess (Lester, 2012). Taking this into account, this study attended to the ways in which the therapists made relevant and talked about the construct of autism. We illustrate here how the therapists were reluctant to definitively name autism as something with clearly defined characteristics. Rather, the therapists negotiated the complexities and ambiguities of the social category of autism, making evident the shifting, fluid nature of knowledge surrounding what autism “really is.” First, however, we briefly discuss how autism has been historically constructed and made real in and through broader discourses and institutional practices. Further, we highlight how interventions designed for people with autism labels have been positioned as a practice for “fixing” and “correcting” symptomology.

### The Discursive Construction of Autism and Its Treatment

Situated within the public and professional discourses surrounding a “deviant” or “abnormal” child, as well as discourses around normative developmental patterns (Piaget, 1924/1928), Kanner’s (1943/1985) seminal article described 11 children who displayed what he believed was a “unique” syndrome (p. 41). Since Kanner’s seminal publication, there has been prolific work around autism; however, 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 in the diagnostic manual, with expansive changes to the criteria being made over the last few decades.

The prevalence of autism is unclear, particularly with the recent changes to and the publication of the DSM-5 (2013), which has functioned to redefine its diagnostic criteria. However, it has been estimated that one in 88 children born in the United States will be diagnosed with autism (CDC, 2012), and approximately 540,000 people have been diagnosed with autism in the United Kingdom, with one fifth identified as children (Knapp et al., 2007). Researchers suggest that the scientific taxonomies used to diagnose autism remain in flux (Rosenberg et al., 2009). Not surprisingly, then, there exists great controversy and inconsistency regarding the diagnosis of autism. For instance, Mayes and Calhoun (2004) reported a lack of evidence for the DSM’s assertion that Asperger’s was distinct from the autistic disorder. Further, Sanders (2009) suggested that Asperger’s and an autistic disorder are not qualitatively distinct, but are instead “different quantitative manifestations of the same disorder” (p. 1560). With the recent revisions of the DSM, many autism-related diagnoses, including Asperger’s syndrome, are now included within a single diagnosis of autism spectrum disorders.

Despite these ongoing debates, autism remains a common topic in the media (e.g., Trilling and Massin, 2010, *ABC* television series “Parenthood”), and the most prolifically researched childhood mental health disorder (Wolff, 2004). The vast majority of the research related to autism has focused on identifying the etiology, neurological differences, genetic markers, and appropriate treatment for those with autism. More importantly, the majority of the research has assumed that the “experts” who work with people with autism labels know (or at

least should know) what it means to be labeled autistic, and how to “treat” and “remedy” the presumed condition (Biklen et al., 2005; Glynne-Owen, 2010). Some researchers have even argued that professionals working with children with autism labels should have an understanding of what autism really is and how to address the needs of diagnosed individuals (Cascella & Colella, 2004).

In many ways, knowing what autism is has been implicitly related to the ability to effectively treat autism. How does one treat what one cannot define? This very question is played out in the diagnostic manuals within which symptomology is outlined in a very detailed way. Yet, clinical practice has long been described as a subjective process (Karim, Cook, & O’Reilly, 2012), one whereby particular norms may or may not be imposed on the identity of another. In fact, a common characteristic of autism interventions has been the focus on changing people with autism labels to fit within the norm (Brownlow, 2010). Such interventions have rested upon assumptions related to the normal-abnormal binary, with the professionalization of the “interactions with people with autism” often being bound within interpretations of “what happens in terms of simple, binary views of behavior (i.e., good/bad or positive/negative)” (Donnellan et al., 2010, p. 2). Accordingly, particular professions have defined the bounds between normal and abnormal behavior and thereby generated practices around how to make “normal” or “treat” those constructed as falling outside the expected. As Becker (1963) suggested it is “social groups” that “create deviance by making the rules whose infraction constitutes deviance, and by applying those rules to particular people and labeling them as outsiders” (p. 9).

Yet, while biomedical discourses have shaped how autism has been defined and treated, some individuals diagnosed with autism have resisted the pathologizing of their bodies, positioning society as the disabling entity (Oliver, 1996) and disability as a social construct (Gilson & DePoy, 2000). One such group, the Aspies, which includes individuals diagnosed with Asperger’s, have advocated for viewing autism spectrum disorders in relation to its positive qualities (Bagatell, 2007). In an ethnographic study of adults diagnosed with Asperger’s, Rosqvist (2012) found that many of her participants expressed ambivalence towards those interventions used to treat them, as they viewed such interventions as requiring them to “be someone other than who they are” (p. 5). Rosqvist suggested that interventions should be informed by the neurodiversity movement, and thereby conceptualized in relation to positive understandings of autism.

Along with the assumption that professionals “know” what autism is and how to treat it, has come the notion 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 (e.g. therapists) owning these stocks of knowledge, while others do not. Discursive research has shown that the relationship between expert and commonsense explanations is often ambiguous (Gilbert & Mulkey, 1984; Horton-Salway, 2004). Rather than a generalized, concrete knowledge base, expertise is, instead, locally produced in the process of building up one’s account. As such, in this study, we sought to unpack how therapists, the presumed “experts,” made sense of the varied constructions of autism.

## Theoretical and Methodological Perspectives

While some research within the field of disability studies has emphasized the socially constructed nature of disabilities (Corker & French, 1999; Oliver, 1990) and the voices and perspectives of people with autism (e.g., Rubin et al., 2001; Mukhopadhyay, 2008; Savarese, 2007), relatively fewer studies have specifically attended to the situated, discursive ways in which caretakers of children with autism labels perform and make relevant their own understandings and representations of autism. As such, with a commitment to insider perspectives, we took up a social constructionist orientation to discourse theory and analysis, situating this study within a discursive psychology framework (Potter & Wetherell, 1987). As a broad framework, discursive psychology is underpinned by social constructionism and attends to how “psychology” and “reality” are produced, dealt with and made relevant by participants in and through interaction (Hepburn & Wiggins, 2005, p. 595). Like Osteen (2008), we do not deny the bodily realities of impairment. However, in lieu of assuming bodily (physiological) or psychological states to be an underlying explanation for why people act as they do, discursive psychology views physiological states, such as autism, to be constructs which are situated and made real in discursive practices.

How facts are constructed at the level of discourse is of particular interest in discursive psychology (Potter, 1996), and we considered in our analysis how therapists went about constructing their accounts of autism as factual or not. Factual claims often function to construct credible accounts that may be difficult to challenge. Specifically, when describing a position, people, including therapists and other professionals, rhetorically organize their descriptions to make their accounts seem believable to others and not easily challenged. 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 possible alternative explanations. Such constructions are built to provide “norm-oriented accounts and justification for” actions and beliefs (Edwards, 1997, p. 9). Such factual claims often function to disguise personal interests, and are presented as “just telling it how it is” (Edwards & Potter, 1992, p. 3). As such, a discursive psychology orientation to fact construction does not treat a participant’s account as a way of discovering their internal experiences, but rather views the account as actively constructing a version of the world. Thus, as we attended carefully to the ways in which the therapists talked about the meanings of autism, we presumed those meanings were always contingent, negotiable, and made visible in discourse.

## Methodology

We situated our discourse study within discursive psychology (Potter & Wetherell, 1987), also drawing upon conversation analysis (Sacks, 1992) and critical orientations to disability (Thomas, 1999). Drawing from a larger ethnography of the everyday practices of children with autism labels and their parents and therapists (Lester, 2011), this study focused more specifically on the ways in which therapists went upon negotiating, at the level of discourse, meaning(s) of autism. The research question of focus was: How do therapists discursively construct the meaning(s) of autism?

### Site and Participant Description

Prior to conducting the study, we acquired Institutional Review Board approval. After approval, the first author traveled to the research site, The Green Room (self-selected pseudonym). The Green Room was a pediatric clinic located in a mid-sized city in the Midwestern region of the United States, and served approximately 80 families of children with developmental disabilities in a bi-state area. The clinic offered individual occupational, physical, and speech therapy, as well as group social skills therapy and sibling support programs.

Upon arrival at The Green Room, the first author worked closely with the directors of the clinic to identify and contact parents whose child (1) had a diagnostic label of autism, and (2) participated in at least one of the clinic's therapeutic activities, ranging from group social activities to speech therapy to occupational and physical therapy. A total of 12 children clinically diagnosed with autism spectrum disorders and 14 parents (11 mothers and 3 fathers) agreed to participate in the larger study.

The directors identified the therapists and clinic staff who worked with the participating children/families and invited them to participate in the study. Through purposeful sampling, the first author recruited the participation of three speech and language pathologist (two of whom were also the directors of the clinic), two occupational therapists, one physical therapist, one teacher/social group facilitator, and one medical secretary/sibling support group facilitator. The occupational therapists, speech and language pathologists, and physical therapists held master's degrees. The teacher/social group facilitator held a bachelor's degree. The therapists all had varying levels of clinical experience, ranging from ten years to less than a year. Table 1 provides a summary of the participating therapists' and clinic staff's demographic information, including the number of years they had been at the research site. All of the participants selected pseudonyms that were used to maintain their anonymity. From here on, we refer to all participants as "therapists."

Table 1. *Participating Therapists' Demographic Information.*

Pseudonym	Professional Title	Total Years at the Site
Bria	Occupational Therapist	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/Sibling Support	½

Seth

Occupational Therapist

½

### Data Sources

The interview data from the eight therapists was the primary data used for this analysis. The interview data was part of a larger corpus of data that included 14 interviews with the parents of children with a clinical diagnosis of autism, 175-hours of audio and video data (e.g. from group and individual therapy sessions and waiting room conversations), 650 pages of field notes made during observations at the clinic, audio recordings of two meetings with the participants focused on discussing the findings, a corpus of e-mail correspondence with the therapists, and artifacts/documents that were used within the therapy sessions. This larger data set informed the analytical understandings we report here.

The first author, who collected all of the data, interviewed the participating therapists at The Green Room. The interviews ranged from 10 minutes to 42 minutes, averaging 22 minutes. The interviewer followed a semi-structured interview protocol (Appendix A), with the bulk of the time spent on exploring meanings of autism. Throughout, we did not assume that the therapists were trained or taught to conceptualize autism in a similar way. Rather, we presumed that the therapists would likely vary in how they talked about autism, as discourse is variable and functions to construct multiple social realities (Potter & Wetherell, 1987); we were interested in examining this (potential) variability. Further, even though the therapists were aware that they were invited to participate in the study because they worked with children with autism labels, we did not assume that the therapists necessarily took up “expert” identities; rather, this is what we hoped to explore at the level of discourse. We recognized that “identity inscription of any kind,” whether by academics, therapists or parents, is “occasioned by some interactional or institutional circumstance” (Rapley, Kiernan, & Antaki, 1998, p. 825). As such, during the course of the interviews, the first author only used the word “autism” after the therapists made it relevant in their talk. Indeed, all of the therapists spoke of autism at some point during their interview at which point the interviewer asked: “When you say autism, what does that mean to you?”

### Data Analysis

During the data analysis process, we took an interpretive and emergent approach to data analysis. More specifically, we conducted a discourse analysis from a discursive psychology perspective (Edwards & Potter, 1993), drawing upon conversation analysis (Sacks, 1992) and poststructural understandings of discourse (Derrida, 1981; Foucault, 1971). We sought to move our analysis between the micro-level of the conversation (interview talk) and macro-level discourses (e.g., what is culturally “known” about autism), while remaining committed to staying close to what the participants made evident in their talk.

Similar to other discourse studies (see Lester, 2012), we carried out six phases of data analysis, including: (1) repeated listening; (2) transcription and creation of modified Jeffersonian transcripts; (3) intensive reading and re-listening of the synchronized transcripts; (4) selection, identification, organization, and analysis of patterns across the discourse segments; (5) generation of explanations/ interpretations; and, (6) reflexive and transparent sharing of findings.

Transana, a computer application often used for discourse analysis and the creation of Jeffersonian transcripts (Fassnacht & Woods, 2005), was used for transcribing the audio and video data. Beyond the transcription process, we used ATLAS.ti 6 (Muhr, 2004), a computer-assisted qualitative data analysis software package, to organize and systematize the analysis process, primarily using the coding, memoing, and other annotating features. ATLAS.ti has been used in discourse analysis studies of talk (e.g., Lester & Paulus, 2014), and described as a tool that can be used to support the micro-level analysis typical of discourse analysis informed by conversation analysis (Lester, in press; Paulus & Lester, 2013).

Throughout the analysis, we took multiple measures to attend to the authenticity of our claims (Antaki et al., 2003). First, with the participants' discourse surrounding autism being understood as having shifting meanings, we intentionally sought out alternative cases and explanations. We also attended to inconsistencies and diversity in the participants' talk (Potter, 2004). Second, the first author shared these findings with the participating therapists and the parents. Seven of the eight participating therapists and one parent shared their responses to these findings over several weeks and even months, sending the first author emails, calling by phone, or sharing via face-to-face gatherings. We share some of these responses within the findings section, illustrating the ways in which they build upon the initial impressions generated in the early stages of the analysis process. Finally, in lieu of simply reporting our interpretation of the data and pointing to an excerpt to illustrate a particular point, we demonstrate how a given excerpt of the data has been analyzed and thus how our interpretations were reached (Wood & Kroger, 2000). Jeffersonian symbols included in the excerpts are in Appendix B.

### Findings

Overall, we noted that rather than working up a factual account of a "true" technical and/or medical definition of autism, the therapists positioned their definition of autism as tentative and still unfolding. While all of the participants named some of the characteristics often associated with autism (e.g., social challenges), they never constructed autism as something that could be fully known. Rather they produced a meaning of autism that was contingent and difficult, if not impossible, to define. We found that all of the participating therapists mitigated their own knowledge claims when constructing the meaning(s) of autism, frequently highlighting the variation and "spectrum" of autism, while displaying reluctance to define autism conclusively. We highlight below three representative excerpts that illustrate how the therapists went about building and even mitigating their own expert status on the "facts" surrounding autism. Then, we offer a discussion around how the participants, including one participating parent, responded to this study's findings.

#### The "Spectrumed" Conundrum

In Excerpt 1, Drew, a speech and language pathologist, constructed autism in relation to a "spectrum," evoking an image of autism referring to more than one thing.

## Excerpt 1

- 1 Jessica: when you say autism what are you referring to what do you mean  
 2 Drew: like my definition=  
 3 Jessica: =mm [hm  
 4 Drew: mm] (.1) I think er (.2) it's so spectrumed out that it's hard now to like define  
 5 it in actual words >I think for me< it's it's it's essentially and I don't even really like  
 6 the word disorder because that kind of indicates that at some point there was order  
 7 and I don't think for them that that there was so I think like a total mm (.1)  
 8 unavailability of processing=  
 9 Jessica: =mm hm=  
 10 Drew: =so they're not processing (.) language or social language or nonverbal  
 11 language or even really kind of the relationship component [um  
 12 Jessica: mm hm]  
 13 Drew: and (.2) so I guess that's kind of you know from the super high functioning  
 14 who (.2) don't get that there's like a social you know ramifications and perspective  
 15 taking they don't process that information um and not that they don't that the brain  
 16 doesn't actually process but like for them they just don't (.2) they just don't get it↑  
 17 Jessica: mm hm  
 18 Drew: to like super low functioning where really (.) um words in general aren't super  
 19 meaningful [so  
 20 Jessica: mm hm]  
 21 Drew: I guess for me that's kind of what I (.) think of

Here Drew evoked “spectrum” as her first response to being asked to define autism (line 4). She stated, “I think er (.2) it's so spectrumed out that it's hard now to like define it in actual words,” emphasizing that the spectrum itself makes it hard to define what it is “in actual words” – as opposed to just knowing it when you see or experience it. 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 to talk about autism. In the case of Drew, such a focus perhaps functioned to justify her claim that it is “hard now to like define it” (lines 4-5), as it encompasses a variety of symptoms.

Drew then engaged in several false starts/self-repair, with “>I think for me< it's it's it's essentially” (line 5) before defining it as what it is *not* – a disorder. False starts often function to mark something as a source of trouble (Lamerichs, 2003). In this case, perhaps the trouble is in defining autism. After these false starts/self-repair, Drew described what autism is not, revealing in this way what it is: “I don't even really like the word disorder because that kind of indicates that at some point there was order and I don't think for them that that there was”. She went on to define autism as a processing problem (repeating a variation of “processing” four times), though with hedges and mitigating devices such as, “so I think like a total mm (.1) unavailability of processing=” (lines 7-8). Mitigating devices often function to display hesitancy and uncertainty around what is being shared (Pomerantz, 1984). Here, Drew restated that “they,” that is people with autism labels, are not processing language, social or nonverbal cues. As such, Drew coupled the meaning of autism with common characteristics that are frequently listed in diagnostic

manuals (e.g., social language challenges). Drew went on to say, “or even really kind of the relationship component” (line 11), positioning an understanding of human relationships as even more basic than language processing, neither of which the person with autism presumably “gets” or “has.” She then distinguished between the “super high functioning” person with autism, who “just don’t get it,” and the “super low functioning” person with autism, for whom “words in general aren’t super meaningful” (lines 13-16). Drew ended her definition with a mitigating sentence, “I guess for me that’s kind of what I (.) think of (.) when I think of it.” The words “I guess” perhaps functions to again point to the tentative and contingent ways in which Drew constructed the meaning of autism.

We noted in Drew’s talk a contrast being made between the “types” of autism, which is common in talk surrounding the meanings of autism (Lester & Paulus, 2012). Historically, the very term “high functioning” has become code for an individual who is perceived as being highly verbal and more accomplished than those labeled “low functioning.” Further, as Osteen noted (2008), even within the autism community there is a rift between those individuals labeled “high functioning” and those identified as “low functioning” (p. 6), particularly as much of the popularized writing around autism position “higher functioning” individuals as being a step forward or even more desirable. Such individuals (e.g. Temple Grandin) are often described as savants and/or worthy of public attention, gaining a great deal of media attention and becoming the “voice” of and even dominating representations of autism. Some recent literature has begun to question and critique this assumption, illustrating the slippery nature of naming an individual “high” versus “low” functioning and presuming that verbalness equates to success or intellectual potential (Biklen et al., 2005). For instance, Rosetti et al. (2008) conducted a study exploring the actions and/or performances of individuals labeled with autism during communication “training” sessions. All of their participants typed to communicate. The researchers suggested that the participants in their study performed agency through their nonverbal actions, with these nonverbal and presumably “low functioning” actions frequently misinterpreted by non-autistic professionals as moments of incompetence or purposeless behavior. Nonetheless, the discourse of our times continues to position autism as that which is experienced in extremes, resulting in “low” and “high” functioning forms (Osteen, 2008).

### The (Im)possibility of Defining

In Excerpt Two, Bria, an occupational therapist, responds to the question, “When you say autism, what does that mean to you?” by providing an account for why she no longer knows what it means when someone says autism. Bria’s response was particularly intriguing, as she took up the idea that autism is not definable.

#### Excerpt Two

- 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*: =specifically what I would call autism anymore because to me it’s such a
- 5 spectrum like if someone says oh well this child has autism like I don’t think that
- 6 that necessarily >means anything 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 absolutely 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

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” implies that in the past she had a more absolute and narrow definition of autism (lines 1-2); yet, as time has passed and with more experience, she has grown to orient to autism as an indefinable entity. Bria claimed not to know what to “specifically” call autism and then moved to account for her inability to answer the question. While many of the parents in the larger study located the meaning of autism in their individual, day-to-day experiences (Lester & Paulus, 2012), Bria did not. She positioned autism as a “spectrum,” like the majority of the participating therapists, with multiple meanings and degrees of seriousness (lines 5-7).

Bria's choice of the word “spectrum” emphasized her focus on the idea that what comes to be named autism includes a wide range of possibilities (lines 4-5) – so many possibilities that they are difficult, if not impossible, to delineate. She then moved to name 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. In other words, autism does not have one unitary definition. She further complicated the meaning of autism by stating that its meaning could be located “absolutely anywhere in between.” By defining autism, she claimed, it remains “undefined” (lines 11-13), positioning autism as a floating signifier.

### The “Troubles” with Defining

In Excerpt 3, Jennifer, a speech and language pathologist, displayed “trouble” in her talk, hesitating when asked to talk about the meaning(s) of autism. This “trouble” or difficulty in making sense of the meaning(s) of autism was displayed through a variety of conversational features (e.g., laughter).

#### Excerpt Three

- 1 *Jessica*: so how (.) for you then what what is autism  
 2 *Jennifer*: U:h (laughs) (2) [smacks lips together] (2) °autism° what is autism (4)  
 3 [smacks lips together] (6) I I really think of it as like a brain based developmental (.)  
 4 disorder I [guess  
 5 *Jessica*: mm hm]  
 6 *Jennifer*: um (. 3) with those those three things that I said [before  
 7 *Jessica*: mm hm]  
 8 *Jennifer*: the social needs and the communication needs and then the behav- and the

- 9 stereotypic behavioral needs um (3) something that really doesn't have a cure but  
 10 something that can really be managed (.)  
 11 *Jessica*: hm (.)  
 12 *Jennifer*: it's different for every kid↑ (.) I think I think of the spectrum whenever I  
 13 think of it there's some kids that you might see on the street and you'd never  
 14 know  
 15 *Jessica*: mm hm

In Excerpt Three, Jennifer did not respond immediately with an official definition of autism; rather, she hesitated through the use of “uh”, laughter, lip smacking, repeating the question, and a self-repair (“I – I”) in line 3. This hesitation pointed to trouble in the talk – specifically the troubles that are part of defining a construct that is “slippery” or “difficult” to unequivocally make “real”. Her use of “really”, in her statement “I really think of it”, implied a contradiction between what she should think and what she “really” does think, or what she used to think, and what she currently thinks, perhaps similar to Bria’s use of “I’ve grown almost to have” in Excerpt Two. She used pauses and phrases such as “I guess”, as she names her definition “brain based developmental (pause) disorder I guess”, making visible the uncertainty or hesitancy around offering an “official” definition.

Bria then used a three part list to complement the definition “with those, those three things that I said before”, defining autism in terms of the needs of the person with autism (social, communication and “stereotypic” behavioral needs) (lines 8-9). Three part lists are often used to establish the completeness of a claim (Heritage & Greatbatch, 1986). Further, the list that she provided mirrors the official diagnostic criteria that are used in the DSM to diagnose autism. Yet, Jennifer did not solely construct autism with medicalized language or according to the official diagnostic criteria; instead, she positioned autism in relation to “needs” (line 8). Needs are something that can be met, and she chose to define autism in terms of needs rather than other kinds of static linguistic, physical, or emotional symptoms. Perhaps this functions to highlight Jennifer’s membership category as a therapist – an individual who is asked to meet needs through intervention. She acknowledged that autism is “something that really doesn’t have a cure”, yet it is “something that can really be managed” (lines 9-10).

She, similar to the other therapists interviewed, in line 11 highlighted “it’s different for every kid” – emphasizing the uniqueness of children diagnosed with autism, thereby evoking the notion of the “spectrum” as opposed to what could be seen as the same syndrome or symptoms across those with the diagnosis. She closed by saying that in some “kids” you would never know that they had autism just by looking at them, highlighting that the spectrum includes not only physical manifestations but other more “hidden” symptoms as well. This notion of hidden symptoms raises the possibility that when you cannot see something, its very truth or existence is potentially called into question.

### Participant Responses to the Varied Constructions of Autism

The participating therapists and parents were all invited to respond to the analysis presented above, with seven of the eight therapists offering responses in the form of emails and face-to-face interactions and one parent offering a response during a face-to-face meeting. While

the therapists, in response to the findings presented above, reiterated the ways in which the meanings of autism were untenable, again positioning its very meaning as always shifting and unfolding. Maria, the participating parent, stated 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 Two 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 also offered her own definition of autism, stating 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.”

Maria’s response highlighted the presumed distinction between lay and expert knowledge, 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 (Horton-Salway, 2004). While we did not orient to Maria’s response as indicating that our interpretations were “right” or “wrong” (Tracy, 2010), we viewed her response as further highlighting the variable ways in which autism is made “real” in talk, as well as making evident how “experts” are positioned as people who should know what autism “really” is.

### Discussion and Conclusions

We suggest that much of the therapists’ talk in the interview data reinforces the idea put forth by many disability studies scholars (Altman, 2001; Biklen et al., 2005; Osteen, 2008) who argue that autism, as a disability 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 attempts to locate definitive differences between who is autistic and who is not autistic is a difficult and perhaps untenable task. Certainly, the therapists’ talk 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 (Barthes, 1973). In therapeutic and clinical practices more generally, this is further complicated by the lack of definitive diagnostic assessments and the subjective approach to determining whether an individual qualifies as autistic (Karim, Cook, & O’Reilly, 2012). Nonetheless, there has been a recent drive to increase the sensitivity of psychiatric diagnoses (Frances & Nardo, 2013), resulting in a broadening of diagnostic criteria and fears that as a result “the pool of ‘normality’” will “[shrink] to a mere puddle” (Wykes & Callard, 2010: 302).

While autism, like other diagnostic categories dependent upon subjective assessment processes, is often portrayed in the media and other contexts as a well-defined disorder that can be definitively diagnosed and treated by experts, our study questions these assumptions. Rather, as noted in our findings, the categories themselves are fluid in nature with the “experts” reluctant to define what counts and what does not count as an “autistic identity”. That all of the therapists in our study mitigated their own knowledge claims highlights the variation and “spectrum-ed” nature of autism. Further, the therapists’ reluctance to define autism in any strong, definitive way, other than naming some symptoms, may provide additional evidence for the socially and culturally-mediated nature of autism. That is, even the community of practitioners ostensibly

trained to “fix” the disorder, are reluctant to define it in a concrete way. Similar to Timimi Gardner, and McCabe (2011), the very value of a label of autism is perhaps questioned here, which itself is bound within the cultural, discursive, and economic practices that define it (Lester & O’Reilly, in press).

These findings offer insights to practitioners, parents of children with autism, and the public at large, to better understand the somewhat subjective nature of diagnostic categories such as autism and the associated treatments. That there is fluidity in how autism is described by the experts (in this case, therapists) should lead us to be more cautious in our own descriptions, as well as in our treatments, particularly in that treatments are commonly linked to diagnostic categories. Rather than being driven by diagnostic labels or visibility-based interventions, supportive treatments can and should be driven by the specific needs of the person (e.g. linguistic needs). Timimi, Gardner, and McCabe (2011) suggested that the “task of good clinical services is to take each individual and their family’s narratives into account and find creative possibilities for change” (p. 3). Indeed, autism as a construct is fluid, shifting and complex (Lester & Paulus, 2012), while simultaneously resulting in the emergence of bodily needs and interventions (Lester & O’Reilly, in press).

Finally, as Nadesan suggested, 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). This study’s findings provide opportunities to reimagine other identities for individuals labeled with autism, while pointing to the layered and contingent nature of the construct of autism. Dominant 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), like other scholars, have called for counter-discourses and narratives offering cultural critiques of medicalized notions of autism, thereby producing alternative possibilities for making sense of embodied differences. We suggest that the findings from this study offer new possibilities for making sense of the contingent meanings of autism, the process of being named autistic, and the very act of interpreting differences.

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#### Appendix A

##### 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 B

##### Transcription Conventions

The transcription conventions utilized were developed by Jefferson (2004) and adapted for this research study.

- ↑ Upward arrows represent marked rise in pitch.
- ↓ Downward arrows represent a downward shift in pitch.
- = Equal signs at the end of a speaker's utterance and at the start of the next utterance represent the absence of a discernible gap.
- e Underlining represents a sound or word(s) uttered with added emphasis.
- [ ] 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.

