Repositioning Disability in the Discourse of Our Times: A Study of the Everyday Lives of Children with Autism

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Abstract Autism is a global issue; yet, there has been little dialogue about how constructions of normality/abnormality in the context of autism are actualized. As such, in this chapter, we highlight the situated nature of the construction of autism, pointing to the economic, social, and institutional consequences of constructions of disablement. First, we offer a theoretical overview of how disability has been constructed in the field of disability studies, while also discussing the economic contexts within which disability and autism are situated. We then share findings from an ethnographic study focused on the discursive constructions of autism in a clinical context.

Keywords Abnormality • Autism • Disability • Disability studies • Discourse analysis • Discursive psychology • Education • Equity • Economy • Normality

1 Introduction

The field of disability studies has its roots in activism and a shared concern with issues of social justice (Grue 2011). Typically, disability theorists have focused on physical disabilities, giving far less emphasis to psychiatric disabilities (Mulvany 2000) or those disabilities presumed to have a neuropsychological or behavioral basis. In this chapter, we focus on neurodevelopmental difficulties as part of the critical disability paradigm, while taking up a social constructionist and discursive position. More specifically, we explore how children diagnosed with the childhood disorder of autism (an abbreviated term of Autism Spectrum Disorder) are constructed in disabling ways

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and how the normal/abnormal dichotomy is invoked to explain particular behaviors and narratives of (in)competence.

Autism is a global issue and has been described as occurring "…in every part of the world" both inside and outside of the U.S. and Europe (Bailey 2008, p. 145). However despite this global recognition, there remains relatively little dialogue about the ways in which these constructions of normality/abnormality in the context of autism are actualized. Throughout this chapter, we thushighlight the situated and contextual nature of autism constructions, while also pointing to the economic, social, and institutional consequences of these constructions of disablement. In doing so we explicitly take note of how such constructions generate systemic inequities for those diagnosed with the condition.

Within this chapter, we give particular attention to autism for several reasons. First, autism is the most widely researched childhood mental health disorder (Wolff 2004). Second, autism is a particularly contentious category in terms of being categorized as a disability, with some groups opposing the pathologizing of autism and others positioning autism within discourses of disease. Third, language and communication difficulties are part of the characterization of autism. This is particularly relevant in relation to schools, as schools have historically privileged certain types of communication (e.g., verbal, whitestream speech patterns). Fourth, the prevalence of autism is increasing and thus has become a focus for research funding (Singh et al. 2009). While autism has been argued by some to be an 'epidemic' (Eyal et al. 2010), others within the field of autism attribute the increases in diagnosis to the broadening of diagnostic criteria and greater public awareness (Frith 1989; Gernsbacher et al. 2005). Finally, autism is a diagnostic category that has global economic impact in terms of social care, education, health services, and familial outlay. Evidently, therefore, debates and conceptualizations of autism are grounded in a rich and complex history of psychiatry, critical psychiatry, psychology, and models of disability (Nadesan 2005).

Specifically, the chapter is divided into two sections. The first section provides a theoretical overview of how disability has been constructed in the field of disability studies, as well as how constructions of abnormality and normality have come to be. This provides an important context for our discussions of autism. Further, the first section presents a discussion of the economic contexts within which disability and autism more specifically, are situated. We thus begin the chapter by discussing the contexts that shaped and informed our empirical discussion, which is the focus of the second section of the chapter. In the second part of the chapter, we present findings from an ethnographic study focused on the discursive constructions of autism within a clinical context. We conclude the chapter by sharing a composite narrative, represented in an ethnopoetic form, aimed at reframing narratives of deficits as narratives of competence. We argue that these narratives of competence serve to counter discourses of deficit that generate, sustain, and perpetuate everyday inequities.

1.1 *Biomedical Understandings of Autism*

To provide a benchmark for our discussion and later empirical claims, we briefly introduce the biomedical conceptualization of autism, emphasizing the diagnostic characteristics associated with it. Generally, autism is considered a complex condition, which presents with several difficulties in the areas of daily functioning (Karim et al. 2014). It is often referred to as 'autism/autistic spectrum disorder' (ASD), which was a term coined by Lorna Wing (1981) and favored within the most recent diagnostic manual (DSM-5) (Swedo 2009). Considered by many to be a neurodevelopmental condition, autism is typically classified as a child mental health disorder. It has been classically defined as a 'triad of impairments' (Wing 1981, 1996), including:

1. Qualitative impairments in reciprocal social interaction;
2. Qualitative impairments in communication abilities; and
3. Repetitive patterns of behavior, activities and interests reflecting a rigid style of thinking.

As a mental health disorder, autism is defined behaviorally, and for a child to receive this diagnosis, the child must be judged clinically to demonstrate specific behavioral impairments across a triad (Muskett et al. 2013). Typically, assessments of the condition require multi-agency input with healthcare and education reporting on the behavior of the child. In clinical practice, there are specific diagnostic manuals, such as the International Classification of Diseases (ICD-10) and the Diagnostic Statistical Manual (DSM-5), which have historically provided official benchmarks for diagnosis.

2 Part I: Autism Within the Field of Disability Studies

2.1 *Definitions and Models of Disability*

Within the field of disabilities studies, there have been many emergent models of disability. While these models share some central characteristics, several important differences exist between them. At present, there is no dominant school within disability research, with research perspectives being underpinned by a range of theoretical frameworks. Yet, there are several distinct models of disability, which are generally perceived as incompatible (Grue 2011). Nonetheless, while there are some important differences between the models, there are some similarities in aim and scope, and many scholars agree that a more critical approach to the study of disability is needed (Mulvany 2000), with defining characteristics of this orientation, including that:

1. Writers who take up this view should challenge the conventional deficit view of disability (Barton 1993).

Table 1 Medical model of disability

Model	Description
The medical model of disability	The medical model of disability is one that views disability as a permanent biological impairment and has its focus on the physical, behavioral, cognitive, sensory, and psychological tragedy (Gilson and DePoy 2000). This model has been the dominant view of disability, with the solutions to problems encountered by the disabled presumed to lay with the medical profession (Mercer 2002). From this perspective, the problem has been positioned as an individual one, and as such those that cannot be 'fixed' positioned by medical intervention as deficient (Gilson and DePoy 2000). In terms of mental health difficulties, a biomedical understanding offers a scientific development framework for understanding and treatment (LaFrance and McKenzie-Mohr 2013)

2. Impairment and disability should be differentiated (Mulvany 2000), with disability referring to a disadvantage of activity caused by a social organization (Oliver 1990), and impairment referring to a bodily defect (Barnes et al. 1999).
3. Critical disability theorists should focus on the rights of those with disabilities, and on the consequences of the development of a collective identity for social change (Mulvany 2000).

These critical approaches are also important for the study of mental health, and particularly autism, as there are differences regarding the ways in which autism is experienced by those diagnosed with it. For example, some individuals with autism struggle with the difficulties associated with their condition (Huws and Jones 2008) and may desire a cure for their problem (Bagatell 2010), whereas others celebrate autism as being inseparable from their identity (Baker 2011) and demonstrate opposition towards a cure (Brownlow 2010). Some self-advocates even fear that seeking a cure will lead to the genetic prevention of autism (Pellicano and Stears 2011).

An important aspect of these critical approaches is that in some way they all oppose or critique the dominant biomedical discourses and practices advocated by the medical model of disability. Yet, autism is typically conceptualized as a neurodevelopmental disorder, and therefore is grounded within a biomedical frame. We briefly outline this model in Table 1.

Despite remaining dominant, it is questionable whether the biomedical model actually is a model or whether instead it is a series of examples of medicalization, in that it promotes the reduction of various elements of disability to medically recognizable phenomena (Grue 2011). More importantly, this model has received extensive criticism from scholars who take up a range of perspectives. For example, it has been argued that this view condemns the disabled as second-class citizens and segregates them from mainstream society (Mercer 2002). For example, historically children with difficulties were commonly segregated into special education schools, and while there has been some movement towards inclusion, the appropriateness of inclusion has been challenged. In this way, the biomedical model is an ideological framework that positions normalization as the goal and denies the agency of those identified as disabled (Eyal et al. 2010; Grue 2011). In terms of mental illness, the medical model has underscored the severity of people's difficulties, which in turn casts judgments of weakness, laziness, or belligerence on those identified as disabled (LaFrance and McKenzie-Mohr 2013). It is further problematic that single cause models rely on a conceptualization of psychiatric disorders as comparable to physical diseases (Muskett et al. 2010).

Notably, however, in contemporary medicine, the medical model has tended to be replaced with the biopsychosocial model. This is a general model that recognizes that biological, psychological, and social factors all play an important role in the context of disorder or illness (Santrock 2007). Although this biopsychosocial model is more closely related to care and considers the social components of illness, many thinkers still view this model in terms of causation and orient to the cause of illness as stemming from an individual's body. Furthermore, it has been argued that there has been a co-existence of perspectives rather than a genuine integration, as this model has been pushed back into the 'shadows' with the re-ascendancy of biomedical perspectives (Pilgrim 2002).

The critical perspectives on disability, therefore, have resulted in several alternative models. In Table 2, we present some of the common alternative models of disability, acknowledging that this description is limited in scope and simply a brief overview to provide context for our discussion.

Notably, none of these models have succeeded in providing a full account of disability (Grue 2011), but the theoretical perspectives underpinning them shape and direct the assumptions made and research produced (Mulvany 2000). In both our writing and empirical analysis for this chapter, we do not specifically subscribe to any particular model. Rather, we adopt a broad theoretical framework by taking up

Table 2 Emergent models of disability

Model	Description
Social model	The social model of disability was developed mostly within the UK and oriented to Marxist sociology (Grue 2011). For this model, disability is explained as a form of political and economic oppression enacted on those whose bodies fail to conform to the needs of industrial capitalism (Oliver 1996). In other words, this model of disability takes an alternative perspective whereby the incapacity to function is positioned within a hostile environment in which barriers clash against personal choice (Gleeson 1997). From the perspective of the social model of disability, disability is seen as a diversity of the human condition as opposed to something that requires 'fixing'; thus, disability is positioned as being socially constructed (Gilson and DePoy 2000). It is also argued that definitions of disability are based on non-disabled assumptions of disabilities and thereby fail to reflect the personal realities of those with disabilities (Oliver 1983). While this model has been valuable in focusing our attention on the systemic factors that shape the meaning of disability (Grue 2011), it has been criticised for various reasons. First, some have argued that this model fails to fully include culture in its analysis of disability (Shakespeare 1994). Second, others have suggested that this model has been slow to embrace the intrinsically embodied phenomenon of 'being disabled' (Grue 2011). Finally, it has been claimed that this model's conceptualisation of disability ignores the differences across gender, age, class, and sexual orientation (Barton 1993)

(continued)

Table 2 (continued)

Model	Description
Labelling model	Labelling theory grew out of American (Chicago/California) ideas about deviance, stemming from the writings of Lemert and the symbolic interactionist perspective (Petrunik 1980). In his writing, Lemert (1948) differentiated primary from secondary deviance, with the primary being the attributes or experience of the person, and the secondary being the behavior that follows from the real/imagined response of others to the deviance. In other words, for labelling theorists, the focus is on the social reaction and not the perceptions of those who have been labelled (Mulvany 2000). This has been particularly influential in making sense of mental health difficulties. That is, the main argument of labelling theorists is that the role of those with mental health difficulties is consolidated by the social reactions of others (Goffman 1968); a mental illness label was presumed to have a powerful effect on the reactions of society towards the 'mentally ill' (Martin et al. 2007). Advocates of labelling theory argue that people in society learn a stereotyped imagery of 'mentally ill' people and grasp the negative language associated with it, such as 'nuts' and 'crazy', as a way of characterising people with mental illness (Weinstein 1983). This model has received considerable criticism, with some actively rejecting the model (see Petrunik 1980). Critics have argued that the adoption of a psychiatric definition of illness assumes the existence of a psychopathology, and through this view, the disorder is positioned as an abnormal condition (Weinstein 1983)
Minority model	The minority group model was developed mostly in the U.S. (Grue 2011). In many ways, this model is linked to a political model and based on a socio-political definition of disability (Hahn 1996). The minority group model suggests that the attainment of civil rights is an important solution to the challenges encountered by individuals with disabilities (Hahn 1987). This model was linked to the expansion of civil rights to include the needs of disabled people and the development of the cultural minority model of disability, which was applied through activism and led to the Americans with Disabilities Act of 1990 (Grue 2011). Thus, this model has resulted in important challenges to those studies shaped by the functional limitations paradigm (Hahn 1996). From this perspective, disability is explained as a form of cultural otherness, which has led to some rejecting particular conditions as being a disability (e.g., deafness and autism) (Grue 2011). However, this model has been subject to criticism for failing to account for the political and economic context of disability (Grue 2011)
The political model	The political model of disability has some connections with the minority model (Hahn 1996) and the social model of disability (Gilson and DePoy 2000). The socio-political approach defines disability as the product of interactions between individuals and the environment (Hahn 1985). This model moves disability into the domain of power and resources, whereby disabilities are viewed as conditions that interfere with the individual's capacity to work and make an economic contribution to society (Gilson and DePoy 2000). Therefore, through this perspective, disability can be empirically assessed by measures of visibility and labelling (Hahn 1993)

a social constructionist position (Burr 2003) advocated by the social model of disability, and assume that the language defining disability is central to understanding the experiences and worldviews of children with autism and their families. However, in our work, we differ in an ontological sense from the social model of disability, as it presupposes that particular power structures operate at different levels of society. Rather, we align our work with a discursive framework (Edwards and Potter 1992), and draw upon the premise of conversation analysis of 'unmotivated looking' (Hutchby and Woffitt 2008). In other words, we adopt a more relativist standpoint to explore how participants within a given interaction make relevant or resist issues of power, oppression, and socio-political identities as they draw upon discourses of disability and mental health.

2.2 Social Constructionism, Medicalization, and Mental Health

We take a micro-social constructionist (Grubrium and Holstein 2008), discursive approach to investigating autism. We recognize, though, that social constructionism is a broad term, with varied meanings. There are three main versions of social constructionism as described by Brown (1995):

1. The American perspective of Spector and Kitsuse (1977) is not concerned with whether health conditions are real or not, but rather focuses on the social definition. This version of social constructionism is grounded in ethnomethodology and symbolic interactionism.
2. The European perspective, based on European postmodern theory, originated with the early work of Foucault. This emphasized social actors, groups, and institutions and had central concerns with issues of power.
3. The sociology of scientific knowledge view grew from the work of Latour (1987) who argued that the production of scientific facts were the result of mutually conceived actions by scientists.

While social constructionism cannot be conceived of as a unified framework (Brown 1995), there are some core features that are important. Social constructionism is an epistemological position that conceives of psychological and social phenomena as constituted through interpersonal and social processes (Georgaca 2012). Scholars operating within this framework: (1) instill radical doubt in the taken-for-granted world; (2) argue that knowledge is viewed as historically, culturally, and socially specific and sustained by social process; and (3) argue that explanations and descriptions of phenomena are never neutral, but constitute social actions that serve to sustain particular patterns to the exclusion of others (Gergen 1985). In other words social constructionism takes a critical position against taken-for-granted knowledge and illuminates the cultural and historical specificity (Burr 2003). The central constructionist premise for mental health, therefore, is that professional practices of diagnosis and treatment are not based on objective or disinterested implementation of scientific practices, but are constructions linked to the context by social, institutional, and practical considerations (Georgaca 2012).

Social constructionist work in mental health began in the 1960s and examined psychiatric and community understandings of mental illness, exploring the impact of labels (Mulvany 2000). While there has been a significant focus on the power structures, asymmetry, and political aspects of disability, not all social constructionists take a political position in their research (Burr 2003), which reflects their particular ontological concerns as illuminated by differences between macro-and-micro versions. Macro-social constructionism tends to be concerned with the role that linguistic and social structures play in terms of shaping the social world, whereas micro-social constructionism tends to focus on talk, situated interactions, interactional order, and local culture (Grubrium and Holstein 2008). It is this latter position that we ourselves subscribe to given the theoretical framework that guides our approach to discourse analysis. Through our empirical analysis in Part II, we aim to illustrate the value of taking this theoretical perspective to understanding how autism is taken up in situated and discursive ways.

2.3 The Challenges for Families and Children with Autism

Given the broader context of disability studies and the social construction of mental health, we now consider the challenges that families and children with autism face. We first focus on the on-going negotiation of the normal/abnormal dichotomy. Second, we consider the issues of stigma associated with disability and mental illness. Finally, we examine the economic conditions in which families with children with autism currently live, highlighting the impact of economic austerity and the market economy that surrounds the labeling process.

The Normal/Abnormal Dichotomy

From a social constructionist perspective, mental health (including autism) is socially constructed. That is, it is set against a construction of normality as defined by the diagnostic manuals and clinical parameters of a given condition. From the medical model perspective, those with disabilities have aspirations of normalization and the elimination of conditions is focused on deficit and symptom reduction (Baker 2011). Such narrow interpretations of normality, however, can have a negative impact on those who do not and cannot conform to the prevailing standards of normality (Fisher 2007). In line with this promoted way of thinking, many parents of children with autism pursue treatments for their child with the hope of a cure, or at least a more normal appearance (Chamak 2008). This is not surprising, as autism has historically been positioned within a discourse of illness and deficit, characterized by medicalized language and a general societal/media discourse of cure and treatments (Broderick and Néeman 2008).

Children with autism and their families thus are required to engage in a daily negotiation of what constitutes normal or abnormal/autistic behavior. The conceptualization of normality and biomedical classifications construct children as developmentally delayed and assume a binary opposition between the categories of normal and disabled (Fisher 2007). With society presently organized around 'neurotypical' values, autism is often inevitably constructed as a deficit (Brownlow 2010). This is a perspective that seems to underlie the views of some people who are diagnosed with autism, and, who when talking about their condition in negative ways, link their condition to the notion of not being 'normal' (Humphrey and Lewis 2008).

When applying a social constructionist framework to notions of normality and abnormality, researchers are able to unpack the ways in which the discourses that make autism 'real' are legitimized by psychiatric rhetoric. Importantly, the social construct of normality is only possible via some comparison with something else (Lester and Paulus 2012). Normality is always compared to that which is constructed as abnormal/pathological, and the two constructs are thereby mutually constituted (Canguilhem 1989). It follows then that "the embodied performance of another is 'read' as *normal, non-autistic* in and through the process of cultural and discursive enactment" (Lester and Paulus 2012, p. 261). That is, an understanding of pathology needs to be based on a previous conceptualization of the corresponding state of 'normality' (Canguilhem 1989).

Stigma

Associated with the normal/abnormal dichotomy is the issue of stigma, which is at least in part linked to how mental health difficulties are viewed and judged by society. In other words, the dominant versions of mental distress have a profound effect on those individuals living with conditions in terms of the repercussions of being constructed as patients within the mental health system, and in terms of stigma (Georgaca 2012). While the medical model did not necessarily bring about the stigma associated with mental illness, it has contributed to it (LaFrance and McKenzie-Mohr 2013).

There are of course real consequences to the ways in which mental health conditions are constructed, and the abnormality construction associated with the symptoms and behaviors of autism. Those who are diagnosed tend to feel devalued, and because of stigma may avoid seeking help or attending services (Jones 1998). Further, the stigmatizing attitudes of the public towards medications may lead families to resist this course of treatment (Pescosolido et al. 2007). Additionally, the stigma may affect the way in which society interacts with children with mental health conditions and their families. For example, social contact with these children may be avoided (Martin et al. 2007), and the views of society may lead to social exclusion (Braddock and Parish 2001). It is important to recognize, however, that while mental illness in particular is stigmatized across cultures, variations do exist (Abdullah and Brown 2011). Rao et al. (2007), for instance, noted that, "diagnoses of mental illness are given based on deviations from sociocultural, or behavioral, norms. Therefore, mental illness is a concept deeply tied to culture, and accordingly, mental illness stigma is likely to vary across cultures" (p. 1020). In this way, stigma and the very process of being identified as 'disabled' is situated and culturally-bound. This is particularly pertinent for individuals with autism, with autistic persons themselves recognizing that a general ignorance of the condition leads to stereotypes and stigmatization (Davidson and Hendersen 2010). This is reified further by discourses of curing the condition, with the scarce resources being directed towards seeking resolution for autism as opposed to finding improvements and strategies to support quality of life (Pellicano and Stears 2011). This is occurring despite increases in funding for autism research in both the U.S. (Singh et al. 2009) and the U.K. (Pellicano and Stears 2011).

2.4 Autism in an Age of Austerity

The construction of the child with autism and the stigma associated with it are contextualized against a backdrop of the cost to the global economy and to the individual families. More so than any other illnesses, child and adolescent mental health disorders have longstanding costs to society (Belfer 2008) with children who have disabilities being considerably more likely to live in poverty than their peers (Parish and Cloud 2006). We currently reside in a global austerity with the U.S. and the U.K. making cutbacks to services. For example, the U.K. budget deficit reached £178 billion in 2010 and tough choices have been made in terms of public cuts, particularly in maintaining the 11 % share of the health budget for mental health (McDaid and Knapp 2010). Despite assurances that cuts would not affect the vulnerable, in the U.K. there have been "unprecedented attacks" on every area of support for those with disabilities (Cross 2013, p. 719). U.S. children with disabilities were twice as likely to visit the physician and had five times as many visits to other services, such as nursing, psychology, social work, or physical therapy, with an average annual healthcare expenditure of $2669 per individual, compared to $676 for children without disabilities (Newacheck et al. 2004). Similarly, in the U.K. a total reported cost for poor mental health (for adults and children) was £33.75 billion, with 77 % falling outside of the healthcare system (McCrone et al. 2008).

The financial impact is not however just with society, but also falls to the individual's families. Up to 40 % of families of children with special healthcare needs experience financial burden (Kuhlthau et al. 2005), and the income of parents of children with disabilities on average tends to be 32 % lower than that of other parents (Parish et al. 2004). Potentially this is due to the fact that families who care for a child with a disability tend to be single income families with lower quality jobs and are more likely to be single parent families (Anderson et al. 2007).

While having a child with a disability induces significant costs for society and families, autism in particular results in significant costs. U.S. statistics suggest that the lifetime cost for an individual with autism is estimated at $35 billion for an entire birth cohort (Ganz 2007). U.K. estimates also show similar figures with estimates of £2.7 billion per year for children with autism and £25 billion per year for adults with the condition (Knapp et al. 2007). There is also a significant cost for families, with an average loss of income being $6200 (i.e. 14 %) (Montes and Halterman 2008). Families in the U.S. may spend an average of $2239 on home healthcare costs (Liptak et al. 2006) and have to pay for expensive therapies, supplements, and expensive equipment costs (Sharpe and Baker 2007). Furthermore, families spend an average of $613 annually simply in out-of-pocket expenses (Liptak et al. 2006), while having a child with autism is likely to result in lower savings and investments (Montes and Halterman 2008). Yet, this market surrounding autism shapes the very way that the construct is being defined. With first constructions of autism not occurring until the early 1900s, such economic impacts are connected to a particular historical context. Further, as the diagnosis of autism has increased, there have been increasing numbers of treatments and costs associated with it. From promises of a "cure" to the need for everyday supports that are only available through direct payment, families and children with autism are bound within a web of normality/abnormality woven around a growing economy that now surrounds disability and autism more particularly.

3 Part II: A Discursive Exploration of Autism

To contextualize the critical orientation to autism that we take, we share some of the findings from the analysis of data drawn from a larger ethnographic study of the everyday discursive practices of children diagnosed with autism, and their parents and therapists (Lester 2012). Our study was situated within a discursive psychology framework (Edwards and Potter 1992), which served to both theoretically and methodologically ground our work. Broadly, discursive psychology attends to how psychological matters are produced and made relevant in and through everyday interactions. In this case, we were particularly interested in examining how the constructs of autism and normality/abnormality were made evident in everyday discursive practices. While discursive psychology informed our analytical decisions, we also situate our work within an understanding 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).

3.1 Site Description

The study took place at The Green Room (pseudonym) – a pediatric clinic in the Midwestern region of the U.S. Eight therapists and 14 parents of children with autism participated. During the first year of the study, a total of 12 children with autism, aged 3 to 11 years, participated. All names are pseudonyms in what follows.

3.2 Data Sources

During the course of 1 year, Jessica collected several sources of data, including: (1) 175 h of conversational data within the context of the group and individual therapy sessions; (2) 14 parent interviews; (3) eight interviews with each of the participating therapists/The Green Room staff members; (4) an unstructured interview with the clinical directors regarding insurance claims; (5) an unstructured interview with the state disability advocate focused on qualifying for services and acquiring an autism diagnosis; and (6) email correspondence between the participants and Jessica focused on qualifying for insurance coverage and state-based services. In this chapter, we focus on presenting findings from the parent interview data, interviews with therapists and the state disability advocate, as well as observational notes taken during over 300 h of on-site observations.

3.3 Data Analysis

While Jessica collected the data and completed the fieldwork, we both participated in carrying out an inductive analysis, which included: (1) intensive listening (Wood and Kroger 2000); (2) transcription (Potter and Wetherell 1987); (3) repeated reading and listening (Potter and Wetherell); (4) selection, identification, organization, and further analysis of patterns across the data set; (5) generation of explanations/interpretations; (6) sharing of findings with the participants. In crafting our representation of findings, we aimed to present enough evidence to allow the reader to put forward alternative interpretations (Hammersley 2010), while also selecting excerpts and extracts from fieldnotes that showed the variability within the data set. Further, we shared some of our findings poetically, with the hope of representing the layered and multidimensional nature of this work (Anders and Lester 2011; Norum 2000).

Finally, we recognize that our descriptions and interpretations of the data are of a particular place. As such, we sought 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 1992, p. 154). Thus, in presenting the findings, we do not offer broad themes or patterns that function at the level of generalities or suggest that the patterns we share offer a complete picture of all therapeutic settings with children with autism labels. Rather, we work with and attempt to make sense of the data in local and always partial ways, and desire not to construct the participants and their practices as invariable and without contradiction.

3.4 Findings

We organize and share our findings around three prominent and overlapping patterns generated through the analysis process: (1) the market economies of disablement; (2) disability labels functioning to secure services; and (3) parental narratives of competence.

We begin by situating our discussion 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, a healthcare program within the U.S. typically for individuals "…with low incomes and limited resources" (Social Security Administration 2010, p. 16). Further, we position this discussion against the backdrop of schools, as all of the children who participated in this study attended public schools during the day and received additional therapies in the afternoon, as they were described as "needing more supports and being better understood at the clinic." This is a particularly relevant point, as children with autism quite often do not receive adequate services in school contexts, thereby necessitating the need to pursue additional clinical interventions (see, for instance, findings from Hess et al. (2008), highlighting the variability in the types of autism interventions in the state of Georgia's public schools).

The Market Economies of Disablement

Across the data, we noted that parents and therapists collectively wanted to provide access for children to receive the care they needed. However, upon closer investigation, we noted that both the insurance market and the government policy actors *both* permeated and defined the therapeutic setting in intriguing ways. Namely, across the data, we noted that: (1) therapists were hypersensitive to the use of discipline specific diagnostic codes; and (2) there was a shared sense between parents and therapists that the insurance company and government policy would likely overrule the decisions to provide services to the child unless aligned to approve disability labels. The permeation of both the governmental policy and insurance companies into the therapy setting therefore incentivized the diagnosis of children with disability labels. When a label of autism did not lead to approval to provide the requested and needed therapy hours, the therapists would then identify discipline specific labels that would prompt the insurance company to cover the cost of compensatory services. For instance, the insurance companies would pay for therapies for a child with an "expressive language delay", a label specific to speech-language pathology, with a child with only an autism label viewed as having too broad of a diagnosis. Consequently, therapists and parents were incentivized to seek out additional disability labels in order to secure therapies and services for the children.

Insurance Mandates Permeate the Therapy Setting

The very meaning(s) attributed to disability and autism, more specifically, were often associated with "treating" autism and the process of qualifying for primary insurance and Medicaid coverage. Early on in the data collection process, Jessica took note of the following in her observational/field notes:

> **June 2, 2010 8:30 pm**
>
> I have been struck with the ways in which the therapists moved from 30 minute sessions to filing documents to making insurance notes—their movements appear to be situated between

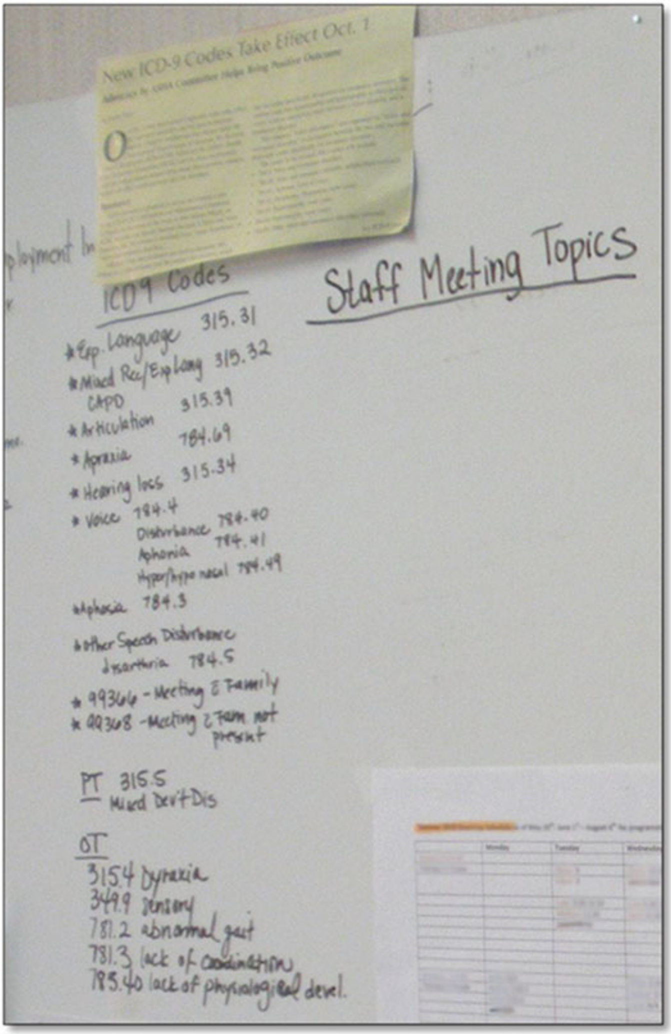
> therapy sessions with each child and the insurance note-taking/report-making. There were even discussions between the more experienced and the more novice therapists about how to perform differently for a parent, an insurance provider, and a doctor. The more experienced therapists often said to the new therapists, "You need to write this way when you are writing for an insurance company, but write this way when sharing something with a parent."

As such, we oriented to the meanings of autism as being bound up in those institutionalized practices that were explicitly tied to a family's insurance policy 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, 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). That is, 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 Fig. 1) of specific diagnostic labels and codes, based on The International Classification of Diseases-10 (ICD-10) (American Medical Association AMA 2010), that needed to be used when requesting insurance coverage.

While all of the participating children held primary insurance policies, only six of them qualified for Medicaid. Based on Jessica's 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 disabled, which is not explicitly linked to a diagnosis of autism, 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 took place, 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" and/or exhibited "significant" functional limitations. According to the participating therapists and state advocate, qualifying for Medicaid under the disability 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.

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



New ICD-9 Codes Take Effect Oct. 1

ICD9 Codes
* Exp. Language 315.31
* Mixed Rec/Exp Lang 315.32
CAPD 315.39
* Articulation
* 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
* 99366 - Meeting c̄ Family
* 99368 - Meeting c̄ Fam not present

PT 315.5
Mixed Dev't Dis

OT
315.4 Dyspraxia
349.9 sensory
781.2 abnormal gait
781.3 lack of coordination
783.40 lack of physiological devel.

Staff Meeting Topics

Fig. 1 ICD codes for diagnosis

Medicaid as "confusing" and "frustrating." Megan (pseudonym), one of the directors of The Green Room, in an email exchange in which Jessica 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 interviewing Ruth, the state family disability advocate, Jessica asked explicitly about the process of qualifying for Medicaid. Ruth 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, five conversations occurred 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. Drew and Megan, the directors of The Green Room, explained why this was important, talking explicitly about "who benefits when a family gets Medicaid coverage," Megan, in response to questions regarding this practice, responded:

> **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 actuallybill 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 "market" which surrounds treating children with autism labels, in this case 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.

Disability Labels Functioning to Secure 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, 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.

Parent Interview Excerpt

Jessica: Did they diagnose him?
Lily: They did I needed him diagnosed for him to be on Medicaid.
Jessica: okay
Lily: and the f- um the psychologist who did it wasn't very patient with him
Jessica: Mm hm
Lily: and you know he just kinda fifteen minutes and you know he had
figured out he was mentally retarded
Jessica: Mm that's what the psychologist said
Lily: yeah
Jessica: After fifteen minutes
Lily: Mm hm
Jessica: Mm
Lily: because he couldn't get answers and stuff from him you know and so I
did not like that assessment at all
Jessica: I would imagine not
Lily: because he is not
Jessica: Mm hm
Lily: I mean he can learn you know
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. 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". She reframed her son's failure on the official assessment as not being due to some intrinsic inability, but to the psychologist's impatience and the little time he spent with her son. After Jessica affirmed Lily's dislike of the assessment, 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. She worked up the construct "mental retardation" as being indicative of not capable of learning, an attribute from which she distanced her son.

While drawing upon symbolic interactionism and a Foucauldian-oriented analytical framework, Rocque (2007, 2010), who conducted a 2-year ethnographic study of autism, described how mothers of children with autism often act as mediators of selfhood, working to actively interpret their child's "odd" behaviors as reasonable and rational for those individuals who "typically are not equipped to understand what mothers believe are the self-expressions of their children" (p. 487). Like the participants in Rocque's (2007, 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.

Later Lily was asked, "*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 and Mann 2003, p. 639), and carries with it some level of stigma (Major and 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 et al. 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), we interpreted these institutionalized constraints as examples of barriers to doing, with disability 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).

3.5 Narratives of Competence

We conclude by offering an alternative narrative of autism, incorporating the perspectives of the parents/caregivers of children with autism labels. We present this narrative as a poetic representation, positioning it in contrast to the historical and present day descriptions of disabled voices, bodies, and minds. In doing so, we seek to highlight and explicitly critique the deficit-models that sustain inequitable access to education, clinical, and community contexts for children with autism. This representation also aims to challenge the "perceived wisdom of those at society's center," providing "a context to understand and transform established belief systems" (Solorzano and Yosso 2002, p. 156) about the very meanings of disablement and competence. Further, we draw upon the rich, methodological history of poetic representation (Marechal and Linstead 2010), which has served to privilege the participants' message so "it is not submerged in the researcher's analysis. It is allowed to stand alone inviting interpretation by the reader; the reader is invited into the research space" (Ward 2011, p. 356).

We begin first with a poetic representation that draws upon the words of Kanner and Asperger, considered by many to be the 'fathers of autism' (Grinker 2007). These words were drawn from the seminal texts used to define and delineate what was initially thought to make autism 'true'. We then end with an alternative narrative, structured as a response to the words of the fathers of autism, and constructed primarily with the words of this study's participating parents.

A "Unique Syndrome"
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 88 children diagnosed each year.

Medicalize
Pathologize
Essentialize
Spectacularize
Public imagination captivated.

He's Somebody
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?

4 Discussion and Conclusion

We situate our research findings in the body of literature most often associated with disability studies, as we position disability at the intersection of culture and biology and orient to the disabling effects of impairments as located in culture (Barnes et al. 2002). Like other studies that view disability labels as embedded within culture (e.g., Rocque 2007, 2010), our work points to how disability is not a discrete object, but rather a "set of social relations" (Davis 1995, p. 11). Abnormality is bound within the norms and practices of a given community, influencing all that comes to be named ordered and disordered. 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 constructions of autism and what comes to be named normal and abnormal functioning. Drawing upon a micro-social constructionism and discursive psychology position, we did not actively pre-assume the existence of these political, social, or economic constraints. Rather, aligning with our methodological position, we utilized a data-driven approach and explored if and how these constraints emerged through the narratives of the participants. Additionally, we recognize the value of the transferability of our findings. While ostensibly a small data corpus, the rich micro-attention afforded by the analytic approach allowed us to explore the pertinent issues as shaped and considered by the participants themselves. When these findings were contextualized against a history of disability theory and research and the core issues were considered against the evidence-base that we already have in the critical assessment of the language of disability, the messages provided from this chapter become more pertinent.

Indeed, for well over 100 years, disability policies have existed in Western societies, with the earliest policies typically equating disabilities with individual disadvantages (Baker 2006). These policies have significantly influenced institutionalized practices and structure in many countries, such as those that are frequently taken-for-granted in the everyday life of schools. At present, the theoretical bases for most disability policies fall somewhere in between a constructionist notion of disability and an individual, deficit orientation to disability, with a delicate balance being sought between "the extremes of individual or social responsibility for disability" (Baker 2006, p. 177). Yet, in practice, current policies in the U.S. and the U.K. tend to retain essentialist notions of disability, 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 in the U.S., like Medicaid coverage, maintain essentialized and static notions of disability categories, such as mental retardation and autism. Thus, acquiring supports for a child with autism is complicated and often filled with roadblocks. Of course, the global economic position has affected this further, with competition for resources and service provision in education, health, and social care all experiencing cuts to budgets. While some countries, such as the U.S., are served mostly by private institutions (e.g., insurance companies), others, such as the U.K., are served by government-funded institutions. Nonetheless, despite funding sources, countries across the globe are actively seeking more cost-effective ways to meet their obligations to children with autism and their families. This means that often families have to 'fight' for services to meet their 'duty of care' by illustrating that they are genuinely in need of such care. In schools, resources are carefully monitored so that cost-effective education may be delivered, and in healthcare, questions are being raised regarding most effective outcomes so that money may be more appropriately directed. However, the cuts are affecting children and their families, and, as we have noted in this chapter, are possibly damaging those individuals who most need support through service provision.

Findings from our research further point to the material consequences of economics driving definitions of disability, for example through government rhetoric and insurance companies or service restrictions. These different ways of defining conditions reflect tensions between the expressed needs of families of children with autism and what "official" governing bodies ultimately provide. What governments will provide to these families and their children rests therefore on how the condition is defined and whether the child meets particular criteria, and this is the case in the U.K., the U.S. and beyond. That is, the diagnosis, labels, and definitions of what is needed for that child is defined by "official" governing policies. More specifically, in this study, the challenges and conflicts of acquiring Medicaid coverage were made relevant again and again by the participating parents, highlighting how the very meanings of autism were inextricably linked to governmental and insurance-based definitions and assumptions surrounding disability. This study's finding, then, point to the ways in which narrow, static, and even inexplicable definitions of disability categories function to constrain and, at times, limit the degree to which children with autism are afforded opportunities to participate in meaningful therapies.

As such, we argue that in the ongoing development of disability policy, the culturally contingent nature of disability 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. 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). We suggest, 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, we argue that policy makers carefully attend to how 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.

In considering the connections between our research and the series’ themes of education, equity, and economy, we note that spaces, such as schools, clinics, and policy circles, often function to rearticulate deficit-laden, medical discourses, thereby locating the problem or “abnormality” within the individual. Through such a positioning, inequities are generated and sustained, often in relationship to economic gain for a few and losses for many. We argue here for taking up narratives of competence, recognizing that people with autism 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. (Nadesan 2005, p. 179)

We do not argue for a dismissal of “treatment,” rather we suggest that in lieu of simply accepting autism as that which is equivalent to a list of symptoms, we, as a society, 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. We argue that it is essential to understand the discursive construction of deficit and how the prevailing discourses of medicine contribute to the stigmatization of those diagnosed with autism. We further argue that there is room in society and the academic literature to listen to the voices of those individuals who live with the label of autism and account for how the construction of the condition has an impact on their lives, and those of their families. 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). We suggest that ultimately meaningful, respectful, and equitable societal responses “require a deep and local knowledge of the individual” with autism (Donnellan et al. 2010, p. 15).

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