The Production of Autism Diagnoses within an Institutional Network:

Towards a Theory of Diagnosis

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ABSTRACT

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Autism is a neurodevelopmental disorder characterized by impairments in verbal and nonverbal communication and socialization, and behaviors that are restricted and repetitive in nature. As there is no cure, inherent in an autism diagnosis is a high degree of uncertainty, and prognosis is highly dependent on how the child responds to his or her individual treatment. Beginning with the empirical finding that all but two children undergoing assessment at an autism clinic received a diagnosis of the disorder, this dissertation argues for an institutional understanding of diagnosis. Parents and children are processed through a network of agents and organizations which eventually leads to the assignment of the diagnostic label of autism. Diagnosis is not an isolated act; rather, it is a prolonged process that is neither independent of the content of the diagnostic category itself nor its history. Based on participant observation, in-depth interviews and content analysis, I analyze the process through which parents and clinicians arrive at an autism diagnosis. I argue that the interests of parents and clinicians are not pre-conceived, motivational factors that direct their actions, but that their interests are constituted through interaction with the institutional matrix in which they are embedded. Parents do not enter this process wanting ambiguity about their child’s potential, they wish for a cure; clinicians do not want to dispense ambiguous diagnoses, but aim at providing definitive prognoses. However,
during the diagnostic process, the interests and actions of both are mutually adjusted to, and coordinated with, one another. From their initial interactions with Early Intervention therapists, parents learn how to identify the symptoms of autism in their children. They also learn how to find a physician who can diagnose autism, and how to obtain treatment services. In effect, children become patients-in-waiting, occupying a liminal state between health and disability, and parents enter a race against time to re-train aberrant neural pathways. In diagnostic interviews, clinicians alternate between narrative modes which frame autism as either a real disease, a performance, or a label with which to obtain services. Depending on parents’ needs, clinicians switch between these different frames in order to re-translate parents’ interests, ushering them from the temporality of cure to that of “one day at a time.” Ultimately, I observed that nearly all children received a diagnosis of autism as a result of the clinic’s positioning within the institutional funnel. Finally, this study describes the historical use of autism diagnostic instruments as they reveal the looping processes that have altered the autistic prototype as well as the alternating privileged status of parental and clinical expertise over time.
# TABLE OF CONTENTS

LIST OF FIGURES .................................................................................................................. v

LIST OF TABLES ...................................................................................................................... vi

ACKNOWLEDGMENTS .......................................................................................................... vii

A NOTE ON TERMINOLOGY ................................................................................................ xi

INTRODUCTION ....................................................................................................................... 1

PRELUDE .................................................................................................................................... 22

From Unique Syndrome to Spectrum Disorder ................................................................. 22

Autism in the Diagnostic and Statistical Manual of Mental Disorders ......................... 24

CHAPTER 1: THE MAKING OF THE AUTISM PARENT ...................................................... 28

The Significance of Early Intervention and the Moral Career ........................................ 29

Demand- and Supply-Side Accounts of the Increasing Prevalence of Autism .......... 34

The Study .................................................................................................................................. 36

The Parents ............................................................................................................................. 37

Facts and Narratives ............................................................................................................. 39

First Signs ............................................................................................................................... 43

Early Action ............................................................................................................................ 47

Diagnostic Careers .............................................................................................................. 52

Early Intervention Precedes Diagnosis (Careers A and B) ............................................ 53

Diagnosis Precedes Early Intervention (Career C) .......................................................... 62

Early Intervention Absent (Career D) ............................................................................. 65

Diagnosis after Early Intervention (Career E) ................................................................. 70
Autism Expectations................................................................. 74

CHAPTER 2: THE STRUCTURE OF THE CLINIC................................................................. 79

Methods ...................................................................................... 83

Site and Entry.............................................................................. 83

Sampling Procedure..................................................................... 84

Ethnographic Observations .......................................................... 85

Semi-structured Interviews ........................................................... 86

Data Analysis.............................................................................. 86

History of the Clinic ..................................................................... 87

The Space .................................................................................... 90

The Division of Labor .................................................................. 92

DAN!, the AMC, and the Biomedical Treatment of Autism ................. 94

Sources of Knowledge ................................................................ 96

Intake and Follow-up Forms .......................................................... 96

Standardized Tests and Scales ....................................................... 97

Physical Examinations .................................................................. 98

Other Formal Reports ................................................................... 99

Diagnostic or Follow-up Interview ................................................. 99

Established Routines and the Production of Knowledge in the Clinic .......... 99

The Clinical Mentality ................................................................ 105

Paradoxes of the Clinical World .................................................... 110

View of Parents ........................................................................... 119
# Conclusion

CHAPTER 3: THE DIAGNOSTIC INTERVIEW

The Autism Network

The Heterogeneity of Autism

Bridging Work

Structure of the Chapter

Case vs. Biography

Diagnosing Autism Spectrum Disorder at the Autism Medical Center

Translating Autism

Diagnosis and Prognosis

Autism, PDD-NOS, and Treatment Services

Summary: Narrative Variants in the Clinic

Treatment Variants in the Clinic

The Biomedical Treatment of Autism

Psychopharmacological Treatments

Responsibilization: Translating the Parent-Clinician Relationship

CHAPTER 4: DIAGNOSTIC INSTRUMENTS

Structure of the Chapter

Methodology

Participants

Workshop Goals

Workshop Protocol
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnostic Checklist for Behavior-Disturbed Children</td>
<td>183</td>
</tr>
<tr>
<td>The Autism Behavior Checklist</td>
<td>192</td>
</tr>
<tr>
<td>The Childhood Autism Rating Scale</td>
<td>203</td>
</tr>
<tr>
<td>The Autism Diagnostic Observation Schedule</td>
<td>208</td>
</tr>
<tr>
<td>History of the ADOS</td>
<td>209</td>
</tr>
<tr>
<td>The Structure of the New ADOS</td>
<td>211</td>
</tr>
<tr>
<td>The ADOS and the Performance of Autism</td>
<td>212</td>
</tr>
<tr>
<td>Coding the Performance</td>
<td>216</td>
</tr>
<tr>
<td>Scoring the ADOS</td>
<td>219</td>
</tr>
<tr>
<td>Black-Boxing the ADOS: Learning How to Code at an ADOS Workshop</td>
<td>220</td>
</tr>
<tr>
<td>The ADOS in Action</td>
<td>226</td>
</tr>
<tr>
<td>Functions of the ADOS</td>
<td>233</td>
</tr>
<tr>
<td>Conclusion</td>
<td>235</td>
</tr>
<tr>
<td>CONCLUSION</td>
<td>238</td>
</tr>
<tr>
<td>BIBLIOGRAPHY</td>
<td>248</td>
</tr>
</tbody>
</table>
LIST OF FIGURES

Figure 4-1: Observation Activities of Module 1 ................................................................. 214
Figure 4-2: Module 1 Items ............................................................................................... 217
Figure 4-3: ADOS Coding Scheme ..................................................................................... 218
Figure 4-4: Module 1 Scoring Algorithm .......................................................................... 221
Figure 4-5: Item A-6 of Module 3, Asks for Information .................................................... 226
LIST OF TABLES

Table 1-1: Characteristics of the Diagnostic Careers ................................................................. 53

Table 2-1: Diagnoses Observed at the AMC ........................................................................... 80
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A NOTE ON TERMINOLOGY

Parents, just as anyone new to autism, are often confused by the numerous acronyms that are used to label autism and related disorders: AD, ASD, PDD, PDD-NOS, and so on. As such, it is necessary to briefly clarify their referents as well as the way they will be used in this dissertation.

To begin with, the terms ‘autism spectrum disorders’ (ASDs) and ‘pervasive developmental disorders’ (PDDs) are synonymous, both referring to the entire class of disorders that make up the spectrum: Autistic Disorder, Asperger’s Syndrome, Rett’s Syndrome, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder – Not Otherwise Specified. However, confusion arises from the manner in which the term ‘PDD’ is used by both professionals and parents when they talk about a child’s diagnosis. Specifically, a diagnosis of PDD-NOS is rarely referred to by its full acronym but is instead shortened to ‘PDD’. To maintain consistency with my data, I stick to this tradition, though often in the text I will explicitly name PDD-NOS. Thus, when I refer to a diagnosis of PDD, I mean PDD-NOS and not the entire range of spectrum disorders. In an attempt to minimize confusion, to denote the complete set of disorders I use ‘ASD’ instead of the equivalent ‘PDD’. Matters are complicated further by the clinical use – or lack thereof – of the more technical term ‘autistic disorder’ to refer to this specific diagnosis, which is instead commonly referred to simply as ‘autism.’ And to further exacerbate the situation, parents (though not professionals) will often use the term ‘autism’ for ‘autism spectrum disorder,’ so that a mother of a boy diagnosed with PDD-NOS will say that her
son ‘has autism.’ In these situations, I will clarify which particular diagnosis is the referent, thought it should be noted that all mentions of ‘autism’ in the text refer to ASD.
INTRODUCTION

“I assume he’s somewhere on the spectrum if you’re here.”

So spoke Dr. Daly, a clinical psychologist at the Autism Medical Center (AMC), a hospital-based clinic which specializes in the assessment and management of Autism Spectrum Disorder (ASD). After almost one-and-a-half years of participant observation, only two patients at the AMC did not receive an ASD diagnosis. This I found surprising, not the least because autism – at least as presented in the medical literature – is a relatively complex disorder. A neurodevelopmental disorder, it characterized by a triad of impairments in verbal and nonverbal communication, reciprocal social interaction, and behaviors that are restricted and repetitive in nature (American Psychiatric Association 2000). Not only does autism overlap with many other conditions, and mental retardation in particular,¹ but there are numerous reports of the difficulty of obtaining an autism diagnosis, due in no small part to the lack of awareness amongst pediatricians of the disorder’s more subtle symptoms (see, for example, Goin-Kochel, Mackintosh et al. 2006; Dover and Le Couteur 2007).

In addition to these obstacles, the inventory of manifesting autistic symptoms is large and varied, ranging from the absence of eye contact to a lack of interest in others to stereotyped mannerisms such as hand-flapping. Consequently, and with a lack of any must-have symptoms to warrant a diagnosis, it is theoretically possible for each patient to have a unique symptom profile, and controversy still surrounds the notion of a broader clinical phenotype (Filipek, Accardo et al. 1999). This to me indicated that at the AMC, I would have the

opportunity to witness firsthand the “work” that is undertaken to separate children into their respective diagnostic categories. Many would get autism, of course, but some, as a co-diagnosis, would be deemed mentally retarded or speech-delayed. But not only did all but two children receive an autism diagnosis, none were co-diagnosed with mental retardation. What is more, clinicians rarely struggled when making their diagnoses – children were either obviously autistic or obviously not.

In stark contrast to my own surprise, the AMC staff were unmoved by the clinic’s high diagnosis rate. As one nurse put it, “With the prevalence of autism what it is today, I don’t understand why that’s so surprising.”\(^2\) She certainly had a point: autism today is so frequently diagnosed that the phrase “autism epidemic” has entered common parlance. Indeed, the number of cases of what was once considered a rare condition has risen dramatically in the last decades. The Center for Disease Control reckons that the prevalence of autism has risen from 4 per 10,000 in 1989 to 67 per 10,000 in 2000, with the most recent estimate reaching 1 in 110 (2009). Some believe the prevalence to be even greater than 1% (see, for example, Kogan, Blumberg et al. 2009).

This dissertation argues that this unusual finding – that almost all patients at the AMC received a diagnosis of autism – is best understood in relation to the clinic’s position within the “institutional funnel,”\(^3\) that network of agents and institutions through which children and their parents are processed, beginning at the moment when symptoms are first detected to when prescriptions for treatment and educational programs are made. Its central argument is that

\(^2\) Quotes, unless otherwise noted, are drawn from my fieldnotes and interviews.

\(^3\) I thank Gil Eyal for suggesting this term.
diagnosis is an institutional process, such that the placement of a child in a particular diagnostic category results not only from the manifesting symptoms, but the particular configuration of this institutional funnel.

I believe that the Dr. Daly quote I opened this introduction with has at least two major implications. First, although diagnosis is often defined as an act of classification in which the range of symptoms experienced by an individual are formally linked to a specific disease category, it is better understood as an ongoing process extending well beyond the precise labeling act, beginning with the instant symptoms are first recognized, continuing throughout the time when prescriptions for treatment and prognosis are made and persisting throughout the period when treatment ensues. Diagnosis is the end result of a longer series of events, as well as the beginning of an entirely new one. These events do not transpire in a social vacuum, but within the matrix of social institutions and practices that surround the actual classification.

Second, I am convinced that a new, alternative portrait of diagnosis can help us better understand why nearly every child visiting the AMC left with an ASD finding. Whereas the well-established sociology of professions interprets diagnosis as an interested act of professionals seeking to enforce their monopoly and jurisdiction (Freidson 1970; Abbott 1988), my approach, espoused in this dissertation, and drawing from the work of Bruno Latour, Ian Hacking and others, views diagnosis as an act of translation, accomplished by networks and embedded in institutions.

Few would question the value of medical diagnosis. Upon feeling ill, we visit our physicians who present us with the name of what ails us, which simultaneously gives us a
meaningful structure in which to understand our symptoms, as well as guides our doctors’
prescriptions for treatment and prognosis. Of course, it is not always this simple; sometimes
additional testing is necessary to rule out competing diagnoses. At other times, the exact
nature of the ailment eludes physicians, necessitating a succession of visits to various specialists
and exposure to an assortment of pokes and prods. Still, we acquiesce, for without a diagnosis
treatment can be difficult to determine. In these cases, as is common in medicine, physicians
may employ the reverse logic. They may begin not with a diagnosis but the treatment: if it
works, we will have discovered the diagnosis; if it is ineffective, we will know what the diagnosis
is not and adjust our strategy accordingly. Ultimately, we hope that the method of trial-and-
error prevails and the nature of the mysterious illness is revealed. Differential diagnosis,
therefore, may occur in an instant or may comprise a lengthier, more drawn-out process.

Diagnosis is a significant event, both psychologically and sociologically. It permits
patients – and their parents, in the case of autism – to gain some degree of personal and
emotional control in knowing what exactly is wrong (Brown 1995). It legitimates their suffering
and grants them the right to treatment; it offers a powerful narrative whereby patients can
construct a meaningful, organized account of what was a disorganized illness experience prior
to diagnosis; and it gives them a sense of direction about the future, particularly in terms of
expectations for prognosis and treatment that typically accompany diagnostic information.
Similarly, diagnosis offers physicians a roadmap for disease management: they now know which
treatments to administer and are thereby empowered to serve as the knowledgeable
ambassadors of medicine their patients expect.
Some scholars have called for the delineation of a sociology of diagnosis (Brown 1990; Jutel 2009). Such a discipline, it is argued, would constitute an important avenue for understanding the social framing of disease definitions, lay experience of illness, and how authority is conferred to medicine, among many other aspects of health and illness. Noticeably absent from this conversation is any discussion of a coherent theory of diagnosis. Both Jutel (2009) and Brown (1990) refer to Blaxter’s (1978) recognition of diagnosis as both a category, i.e., a list of diseases, and as a process, i.e., the act that the physician performs. Jutel’s review focuses more on the former, and though she does not deny that process is equally as important as category, her, Brown’s and Blaxter’s consideration of two independent facets neglects the possibility that category and process are acted upon simultaneously, and can act upon and change one another. This oversight is where this dissertation begins. How does category affect process, and how does process affect category? What is the influence of the broader social and institutional context in which a particular diagnosis is embedded? Through an analysis of the process by which children arrive at an autism diagnosis, I hope to further our understanding of how diagnosis actually works.

Scholars within the sociology of professions have emphasized the authority of the physician and dominance of medicine when reflecting on doctor-patient interaction. Simply put, the physician possesses expert medical knowledge that the lay patient does not. With diagnosis, a cluster of behaviors is medicalized and thereby brought under the purview of the medical profession which, as Freidson (1970) notes, has first claim to jurisdiction over anything that relates to the functioning of the body. By defining a problem as a medical one, this profession – with its prestige and connection to science – then functions as its sole proprietor, a
knowledge monopolist: it effectively removes the problem from public debate and places it on a platform from which only medical experts can discuss it (Conrad 1975). As a consequence, by claiming jurisdiction not only does medicine reserve the right to diagnose deviance but it also holds exclusive title to its prognosis and treatment. Rosenberg has referred to this as the “tyranny of diagnosis” (2002). Accordingly, diagnosis can be seen as an exercise of professional power: relaxing the diagnostic criteria for autism to include a broader range of behaviors becomes a means for medicine to increase its jurisdiction. In part, this is accomplished by attaching the individual experience of illness to the abstract, academic knowledge of the disease entity, and diagnosis constitutes the ritual through which this is realized (Abbott 1988; Rosenberg 2002). Both the disease entity and the profession’s right to treat it are simultaneously justified. At the level of interaction, the physician’s identification of the category to refer to when dealing with the patient – with a solid foundation in scientific research and cultural values – convinces both that intervention is legitimized (Rosenberg 2002). The physician’s authority is therefore justifiably imposed on the patient.

Diagnosis, however, encompasses more than just the doctor-patient interaction. Not only are children passed from professional to professional in order to arrive at an autism diagnosis; but they are processed through a network of organizations: schools, pediatricians’ offices, hospitals, and other institutions such as Early Intervention. Medical professionals do not act alone as entrepreneurs, but as members of organizations, and “it is the organizations that attract the clientele, attempt to control both supply and demand, and provide resources, not the professionals as individuals” (Freidson 1986: 71). Because professionals rely on these institutions in order to survive economically, they attempt to exercise some control over the
employment practices of these institutions. One strategy is institutional credentialing, i.e. mandating that certain positions or jobs be only provided to members or particular occupational groups (Freidson 1986). For example, a professional association of physicians requires that certain conditions are met before certifying a hospital with their endorsement. Through such action professionals partake in “gatekeeping,” the institutionalized control over desired resources. Situated between parents and an autism diagnosis, physicians become gatekeepers opportunistically positioned between the client and a benefit the client seeks.

The sociology of professions recognizes knowledge monopolies and gatekeeping as the two dominant sources of professional powers. Its representation of expertise is primarily top-down oriented: medical professionals assert that a problem is a medical one and devise a strategy for treatment, and barring any revolt of public opinion, their description holds. This concept has proven illuminative as it allows for an appreciation of how external institutions may create demand for a professional service, such as autism diagnoses being provided by a physician and not a psychologist. In New Jersey, for instance, the Early Intervention System (EIS) implements that state’s particular method for providing assistance to developmentally delayed infants and toddlers. While EIS policy recognizes psychologists as appropriate providers of counseling for children or consultation on child development, only licensed physicians are recognized as appropriate providers of diagnoses. Through such political practices, physicians are sheltered from the jurisdictional competition that psychologists and other autism specialists might otherwise present.

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There are two principal differences between a theory of diagnosis as understood through the sociology of professions and one from the perspective of translation espoused here. First, as Heritage and Maynard (2006) argue, the asymmetry in the doctor-patient relationship is not imposed but interactively achieved. Though the medical setting (for example, the physician’s office, medical degree and clinical experience) certainly provides solid grounding for the physician’s authority, patients – and this is certainly true of autism parents – are not passive recipients of diagnostic labels. They do not, as Freidson suggests, “acquiesce to the physician’s perspective and advice, whether they agree with it or not, because of the physician’s gatekeeping monopoly over such matters as therapy, surgery, prescriptions, insurance, and sick leave” (1970: 116-7). Maynard (1989) has suggested that diagnosis is product of patient-clinician interaction, in which the clinician is aware of and responsive to the ways in which the patient perceives the diagnostic category. The communication of diagnostic news is not a simple labeling process, but involves strategic action by participants (Gill and Maynard 1995), both of whom use their knowledge of the social environment as well as the diagnostic category and all that it implies (treatment, stigma, insurance coverage, etc.). Gill and Maynard (1995), working in the tradition of Conversation Analysis, have shown how diagnostic informing appears more like a negotiation than an instance of top-down labeling. Using data of physician-parent interactions from a diagnostic clinic for developmental disabilities, they reveal how clinicians employ different conversation strategies depending on the parent’s response to the diagnosis: they might give parents some authorship of the news or otherwise adjust their approach in order to obtain agreement. The point is that clinicians are cautious in their actions, and retain a battery of techniques which permit them to deal with contingencies such as
parental resistance. For instance, clinicians sometimes referred to the diagnostic criteria to account for the diagnosis, whereas at other times they focused on the access to services that the label would provide. According to Gill and Maynard, a clinician’s chosen presentation appeared to result as much from the parents’ concerns as those of the clinic.

This last point underscores the second difference between the sociology of profession’s perspective of diagnosis and one based on the notion of translation: namely, the manner in which interests and agency are construed. For the former, it is preconceived interests which dictate the action of professionals in jurisdictional competition. In other words, professional interests determine the diagnosis, which is essentially treated as a labeling process. I argue that interests are not just responsible for the shaping of a diagnosis but are themselves shaped by the diagnosis; the diagnosis works to translate and coordinate the interests of all actors, professional or otherwise. The resulting configuration of interests thus hinges on the particular matrix of institutions in which they are embedded. Consequently, actors’ interests are more than just motivational factors: they are “attempts to define the institutions, groups or organizations that exist from time to time in the social world” (Callon and Law 1982: 622), and in my view they continue to enforce these institutions, and are themselves shaped by these institutions. Any theory of diagnosis, then, would be wanting without accounting for the role diagnosis plays in structuring relationships between individuals and institutions, and facilitating their organizational coherence.

In a refutation of the argument that we are in the midst of an autism epidemic, Grinker (2007) discusses several of the social and institutional changes that have led to the increased
prevalence of autism in recent decades. He credits the “epidemic” to better awareness of the
disorder amongst pediatricians and teachers, the diagnosis of children at younger ages (which
can be credited in part to the fact that more children attend daycare and preschool, and are
therefore more likely to be compared to other children; no doubt initiatives like Early
Intervention have also contributed to earlier diagnosis), the broadening of the concept of
autism as represented by the changing diagnostic criteria in the DSM, diagnostic substitution
from mental retardation and learning disabilities, as well as changes in epidemiological
methods and the use of instruments such as the ADOS. Changes in prevalence are thus rooted
in changes in diagnostic practices which, as I have argued above, have both institutional and
interactional moorings. As Grinker points out, “the growth of child psychiatry as a field of
inquiry and area of practice, the decline of psychoanalysis, the rise of advocacy organizations,
greater public sensitivity to children’s educational problems, and changes in public policy ...
have together changed the way autism is diagnosed and defined” (2007: 4).

With respect to a theory of diagnosis, the sociology of professions certainly contains
useful insights. Ultimately, however, it cannot explain why most children at the AMC received
the diagnosis they received, because it does not attend to the content of professional
knowledge and of diagnostic categories and what both accomplish in practice. Why is this
important? The observation that the definition of autism has changed since it was first
described nearly seven decades ago emphasizes that the disorder’s diagnosis cannot be
envisioned as a static process in which the rules of interaction are constant over time. Autism is
an example of what Hacking (1999) refers to as an “interactive” kind, a classificatory type that
can change by means of interacting with what is classified. An autism diagnosis interacts with
individuals and their actions and behaviors. The diagnosis can change the way people experience their identity by altering the way they imagine themselves as well as the way they are treated by others. The modified self-perception leads people to envision a different range of possibilities for actions and behavior. This does not only have a significant impact on the life of a single person, but is also highly consequential when applied to an entire class of individuals, who may be led to acquire a set of behaviors by nature of being classified. Thus, over time, “kinds may become false because people of that kind have changed in virtue of how they have been classified, what they believe about themselves, or because of how they have been treated as so classified” (Hacking 1999: 104). Hacking refers to this as a “looping effect.” It offers a mechanism through which we can understand how the diagnosis of autism changes over time, and more importantly, how the diagnostic category and process can interact with one another. Experts create or modify classifications that are assigned to individuals who subsequently internalize them and make them their own. At the same time, the new behavior of the classified persons creates a reality that the experts must contend with in terms of their classifications. This means that the act of diagnosis is not solely the deployment of medical power, because the diagnosis already contains within itself a history of looping effects, of the actions of patients (and in the case of autism, their parents), and thereby acts within a pre-existing network.

Chloe Silverman (2012) has investigated how the definition of autism and its key diagnostic features have changed over time. As she shows, new directions in research – and consequently, in the definition of autism – have sometimes resulted from the popularity of certain areas of research (such as genetics) or were reflective of new research technologies. Her
point — and this is congruent with current thought in the sociology of science — is that new knowledge about autism has not always resulted from new evidence or the solid refutation of older theories, but rather from new practices. Thus, diagnostic instruments can alter the shape of diagnostic criteria: Silverman suggests that tests such as the ADOS can promote the behaviors that it elicits as the identifying characteristics of the disorder, arguing that this has resulted in autism acquiring the identity of a set of core deficits as opposed to a syndrome that can manifest such deficits. Treatment practices, too, can impact diagnostic criteria. For instance, Silverman shows how the Defeat Autism Now! organization — with both physician and parent membership — has brought new meaning to symptoms that are part of the autistic prototype, such as gastrointestinal issues and food intolerances. These symptoms have become legitimate targets or treatment even outside of the DAN! movement and have led to a reframing of autism as a medical disorder. Certainly at the AMC, which does not acknowledge any affiliation with DAN!, shares with the organization its recognition of autism as a medical disorder.

To reiterate, this dissertation argues for an alternative understanding of diagnosis: as the node in a broader network through which the interests of several different actors — children, parents, doctors, schools, clinics, laws, the state, treatment therapies, etc. — are translated. From this perspective, expertise is not simply the possession of the powerful, but distributed across actors and ultimately the product of negotiation between them. In the following chapters, I explore the “meaning” of autism as it is revealed by the process in which the diagnosis is obtained. I analyze the diagnosis of autism as a set of practices through which people make sense of children’s symptoms and social behavior, as well as of their treatment
regimens, education, and selves. I argue for an institutional understanding of diagnosis whereby parents and children are processed through a network of agents and organizations, an institutional funnel which eventually leads to the diagnosis of autism.

Why, then, did all but two patients get an autism diagnosis at the AMC? I suggest that this is in part due to the position of the AMC within the institutional funnel. Children who arrive at the AMC have, in one way or another, been flagged to receive the diagnosis. As I discuss in Chapter 1, most likely the parents noticed some developmental delays and the child was subsequently enrolled in Early Intervention in order to undergo therapy – speech therapy, physical therapy, occupational therapy, etc. – to address these delays, and one of the therapists suggested that the child be assessed for autism. Or perhaps a parent, while searching the internet for information about normal developmental milestones, read about autism and felt that it described their child perfectly, located the AMC and made an appointment specifically requesting a diagnostic assessment. Alternatively, there may have been no suspicion of autism whatsoever: since the AMC shares a space as well as administrative staff with the Child Development Institute (CDI), referrals to the AMC often result from the telephone screening procedure of the CDI, which involves the administration of the Modified Checklist for Autism in Toddlers (M-CHAT). Children who screen positively are directed to the AMC whereas negatives are assessed at the CDI. In consequence, the children who reach the AMC are not a random sample of the developmentally delayed population but a group that has already been pre-screened by therapists, parents, or a nurse on the other end of the telephone line.
Such pre-screening offers only a partial explanation; the observed phenomenon of diagnosis is as much due to the future as it is to the past. As I discuss in Chapter 2, there is a degree of uncertainty built into the diagnosis of ASD.\(^5\) For one, inherent in the notion of a spectrum disorder is the possibility of differing degrees of impairment; knowing that a child is on the spectrum could mean that she is severely disabled and profoundly mentally retarded, or she could be “high-functioning” and hence on the border of socially-awkward neurotypicality.\(^6\) But there is another, perhaps even more important ambiguity which concerns the notion of potential and the response of the child to therapy. As there is no “one size fits all” treatment for children diagnosed with Autism Spectrum Diagnosis, each child’s therapy regimen is individually tailored to his or her specific deficits and is drawn from a wide range of possibilities. There are educational therapies such as speech therapy and applied behavior analysis therapy; biomedical therapies such as chelation and the gluten-free, casein-free diet; all these therapies are applied with the goal of helping the child ‘catch up’ developmentally to his or her neurotypical peers. As a result, the ASD label is not always permanent; it can change over time and depends on how the child responds to the therapies.

Children at the AMC were either diagnosed with Autistic Disorder (AD) or Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS), the latter being a milder variant of the ASDs. Children diagnosed as PDD-NOS are said to show some of the symptoms for AD,

\(^5\) As I explain in the Prelude, though Autistic Disorder was originally thought to be a unique syndrome, it is now just one of several disorders that constitute Autism Spectrum Disorders. Unless otherwise noted, all references to “autism” imply Autism Spectrum Disorder.

\(^6\) “Neurotypical” is a term used to refer to people who are not on the autism spectrum and therefore have neurological development that is commonly perceived as normal.
but not enough for that diagnosis.\textsuperscript{7} In addition, as I describe in Chapter 2, the PDD-NOS label implies that improvement is possible; as one clinician explained, while PDD-NOS can become AD, it can also remain PDD-NOS or even be dropped altogether should the child’s deficits be overcome. AD, on the other hand, tends to be more permanent – though not as permanent as mental retardation, which implies little or even no potential for development. While children diagnosed with AD might show some improvements with therapy, they are unlikely to lose a diagnostic label. As I show in Chapter 3, it is precisely this underlying notion of potential – as seen in the child’s response to current therapies – which determines whether the AD or PDD-NOS diagnosis is given. Here is yet another reason why everyone at the AMC received an autism diagnosis: it allows clinicians to provide therapies while suspending judgment about potential and improvement until the critical window of development has passed.

In Chapter 4, I show how the use of autism diagnostic instruments contribute to the looping processes that have altered the autistic prototype, and how the structure of each instrument is reflexive of the dominant concerns at that particular moment in autism’s history. The analysis of these instruments also provides a window into the alternating privileged status of parental and clinical expertise over time. Rimland’s Form E-2 adhered strictly to Kanner’s diagnostic criteria and therefore maintained the rarity of the diagnosis. Based entirely on parent feedback, Rimland recognized parents as experts of their children though not as diagnosticians (he himself scored each test). The Autism Behavior Checklist (ABC) was similarly based on Kanner’s criteria, though having been constructed by a professor of Special Education,

\textsuperscript{7} PDD-NOS was sometimes described more specifically as deficits in communication and reciprocal social interaction that are \textit{not} accompanied by restricted or repetitive behaviors.
it goal was to facilitate growing concerns over the placement of special needs children within
the school system. Like the ABC, the Childhood Autism Rating Scale (CARS) can be completed by
anyone familiar with the child and necessitates no expert analysis. In addition, the CARS depicts
a spectrum definition of autism and was the first scale of offer diagnoses based on varying
degrees of severity. This practice continues with Autism Diagnostic Observation Schedule,
though this scale once again privileges clinical opinion in that it may only be administered by a
trained professional. The ADOS is unique in that it elicits behaviors that are the targets of
Applied Behavioral Analysis and other therapeutic interventions.

The sociology of professions essentially treats diagnosis as labeling process, looking only
at one side of the doctor-patient interaction and ignoring the feedback loop that could modify
the diagnosis and the content of medical knowledge itself. An account of diagnosis as
translation, accomplished by networks and embedded in institutions and itself part of the
historical process of looping, can meaningfully enhance the theory of diagnosis implied by the
sociology of professions. With respect to the diagnosis of Autism Spectrum Disorder, the
interests of both parents and clinicians are not preconceived. Parents do not want prognoses
for their children that are couched in ambiguity; they want a cure. Similarly, clinicians do not
want to dispense indefinite diagnoses or prescribe treatments that may work for some children
but not for others; they wish to mete out more parsimonious prescriptions for treatment and
prognosis. However, the autism diagnosis works best to accommodate both sides, clinicians as
well as parents and their children, by teaching them to construe their interests in some degree
of accordace and adjustment to one another. The diagnosis emerges as a crucial point of
intersection which serves to translate the interests of all actors and coordinate supply and
demand in a way that promotes cohesion. As a result, a stable network of mutual interdependency is established.

It should be emphasized that all the institutional conditions that create the epidemic within the walls of the AMC are not scope conditions for drawing inferences about the broader phenomenon of increased autism prevalence. The findings reported in this dissertation – the fact that almost all children at the AMC received a diagnosis, the diagnostic practices institutionalized at the AMC, together with the ways in which diagnostic instruments work and are historically shaped – explain only the “epidemic” as it occurred at the AMC. Even if we were to restrict consideration to the diagnosis of autism alone, institutional conditions are not identical across the myriad clinics, pediatrician offices and schools with which autism patients come into contact. Consequently, it is important to clarify that only the institutional theory of diagnosis proposed in this dissertation – and not the more specific findings – are generalizable. Other clinics will have different practices and therefore different results, though we can assume that in these settings diagnostic patterns will also depend on the specific location within the institutional funnel.

This dissertation is based on four different types of data and their analysis. First, from May 2007 to August 2008, I was a participant observer at the AMC. The AMC provides diagnosis and treatment recommendations for children and adolescents with autism and other pervasive developmental disorders. I was convinced that in order to understand how autism is diagnosed, I had to observe firsthand as it is taking place. The unique opportunity to discover the process of negotiation between parents and clinicians as well as the conflicts that arise reveals details
absent from after-the-fact (or after-the-diagnosis) explanations. At the AMC, I also observed private discussions between clinicians and became witness to the division of labor amongst professionals. All these experiences became invaluable resources for my understanding of how autism is conceptualized and how autism diagnoses materialize.

I gained entry to the AMC as a student researcher volunteer under the supervision of Dr. Michelle Baker, a pediatric neurologist. For the first couple of months, I shadowed Dr. Baker as she visited with her patients. I was soon introduced to the two other AMC clinicians who saw patients diagnosed as autistic, as well as a psychologist who regularly conducted the Autism Diagnostic Observation Schedule (ADOS). By the end of the summer, I was at the clinic every day that patients diagnosed with autism were seen, typically 2-3 days per week. When two clinicians had patients scheduled at the same time, I would prioritize based on whether a patient already had a diagnosis or not so as to maximize the chances of observing “new” diagnoses. I stopped visiting the AMC in August 2008, confident that after 15 months, I had gained a solid understanding of the inner workings of the clinic and the processes by which diagnoses were formulated.

Second, in light of the relative importance given to the ADOS at the AMC, in May of 2008 I attended a multi-day workshop dedicated to training clinicians and other interested parties in the administration of the scale in Philadelphia. The workshop consisted of an overview of the ADOS’ four modules and the joint coding and scoring of two of them as well as their live administration. Part of the appeal of the ADOS is tied to its claims of “high inter-rater reliability.” The scale is touted as the “gold standard” of diagnostic scales for precisely this

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8 The ADOS, discussed in detail in Chapter 4, is a standardized assessment of Autism Spectrum Disorder.
reason. Much of the workshop was dedicated to teaching clinicians how to code the ADOS’ items, therefore presenting the occasion to understand how clinicians understand autistic symptoms and how they define the autistic prototype. Particularly illustrative was how they discussed the more debatable symptoms. The workshop thereby offered a unique opportunity to observe “science in the making” (Latour 1987) and one of the key foci of this dissertation, the translation of interests: although promoters of the ADOS advertise the “ready-made science” of high-reliability scores to demonstrate the effectiveness of the ADOS and win supporters of the scale, the conflicts that arose amongst the clinicians at the workshop were both a demonstration of how the scale’s success was a result of its reinforcement through convinced followers.

Third, to supplement the data collected through observation, I conducted semi-structured interviews with both parents and clinicians. The parent interviews allow for the opportunity to determine the pattern of experts and institutions that families encounter en route to a diagnosis, and hence unearth any pivotal role that a particular expert or organization performs. While recounting their experiences chronologically, parents were asked to reflect on how each of their interactions with professionals altered their future behavior, the way they thought about their children as well as how they conceived of themselves and their role as autism parents. It is through this back-and-forth between self and society that the moral career emerges, the changes in perception and action that are entailed in becoming an autistic patient. Interviews with clinicians focused on how they as “autism practitioners” envisioned their role in the care and treatment of autistic patients, particularly with respect to establishing a diagnosis. These conversations included a discussion of what they considered to be their
primary responsibilities within the organizational structure of the hospital or clinic in which they function. I conducted a total of nineteen interviews: fifteen with parents who have visited the AMC and five with the responsible clinicians there. Through the larger project of which my research is a part, I also had access to another twenty-one similarly structured interviews with parents in the Northeastern United States.

Fourth and final, my discussion is informed by several different documents. In this dissertation I analyze the content, and where available the manuals, of three different autism diagnostic scales – the Diagnostic Checklist for Behavior-Disturbed Children, Autism Behavior Checklist, and Childhood Autism Rating Scale – in order to compare the different autism prototypes they reflect, as well as to learn about the goals and motivating factors as recognized by the test constructors themselves. I included journal articles and other writings of the checklist authors in my research, as well as the responses of others to the scales. This work comprised, but was not limited to, psychometric assessments. An e-mail exchange with David Krug, lead author of the Autism Behavior Checklist, offered additional valuable clues as to how the test had been produced and regularly updated.

In order to appropriately contextualize the findings reported in this dissertation, it is instructive to recount some major events in the disorder’s history. I therefore begin with a brief prelude describing autism’s development From Unique Syndrome to Spectrum Disorder and the changing profile of Autism in the Diagnostic and Statistical Manual of Mental Disorders. The four main chapters – The Making of the Autism Parent, The Structure of the Clinic, The

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9 This project, directed by Gil Eyal, included a socio-historical analysis of the origins of the autism epidemic, as well as ethnographic observation at therapy sessions and an autism school. Brendan Hart, Emine Onculer and Neta Oren were the other members of this group.
Diagnostic Interview, and Diagnostic Instruments – already briefly addressed above, are followed by a conclusion in which I summarize key findings of this dissertation, explore how these might contribute to the development of a “sociology of diagnosis,” and make some suggestions for future research.
PRELUDE

FROM UNIQUE SYNDROME TO SPECTRUM DISORDER

Autism was first described by psychiatrist Leo Kanner in 1943. In a detailed case analysis of eight boys and three girls, Kanner documented a number of “essential common characteristics” that formed a “unique ‘syndrome’” (Kanner 1943: 242). According to Kanner, the “fundamental disorder is the children’s inability to relate themselves in the ordinary way to people and situations from the beginning of life” [emphasis in original]. He phrased this extreme autistic aloneness, a quality present at birth that was evidence of the child’s desire to be alone. This state induced the child to disregard any external stimuli that risked disrupting his or her aloneness. As Kanner saw it, many of the symptoms of Early Infantile Autism (EIA) were related to a notion of ‘intrusions.’ For instance, several of the children in his study were afraid of loud noises, and others “anxious to keep the outside world away” (244) had difficulties feeding. Other commonalities also presented among the children in Kanner’s study: the children were seemingly obsessed with the maintenance of sameness, often echoed phrases and words in a parrot-like fashion, and their behavior could generally be described as having a repetitive quality. The combination of these characteristics – extreme autism, obsessiveness, stereotypy, and echolalia – were the central features of Kanner’s autism. Their simultaneous presentation was evidence to Kanner that EIA represented a unique syndrome distinct from others, especially childhood schizophrenia, which was the most common form of childhood psychosis at the time.
Kanner believed that EIA was extremely uncommon, affecting only approximately 150 of the 20,000 disturbed children he estimated to have seen over the course of his career. In fact, Kanner often expressed concern over the laissez-faire use of the label for children who did not manifest the full syndrome, but were instead afflicted by conditions that were “autistic-like.” This apprehension with over-diagnosis was echoed in the work of Bernard Rimland. Rimland, father of an autistic child and a staunch believer in autism’s rarity, would devote a significant portion of his career to advocating for a biomedical model and corresponding treatments for autism. He devised a scale that would identify autism from amongst its impostors and authored the seminal work that established autism as a biomedical – and not emotional – disorder (Rimland 1964). Though Rimland enjoyed much support for delineating a biomedical etiology for autism, to his dismay this unique disorder would eventually lose its distinction amongst other, similar syndromes, and the collection of conditions would come to be known as the Autism Spectrum Disorders.

The idea of a spectrum of disorders is first evident in an article by Lorna Wing and Judith Gould (1979). Dissatisfied with the then-current state of classification of developmental disorders, Wing and Gould studied the prevalence of symptoms, not syndromes. Their goal was to develop a system of classification that would be usefully both clinically as well as with respect to disorder management and the children’s education. They emphasized that many independently-named syndromes shared several symptoms with one another – and with mental retardation as well. In particular, Wing and Gould found that the majority of children diagnosed with autism were either mildly or severely retarded. Because of the great overlap in symptomology, they questioned the usefulness of distinctly labeling developmental disorders,
especially autism. Disorders can be classified in a number of different ways, they argued, depending on the purpose of the classification. Wing and Gould’s suggestion was that the classificatory system be functional with respect to clinical ends as well as its consequences for education, treatment and management. They demanded the diagnosis of developmental disorders to have eminent practical relevance, providing parents and clinicians with direction as to how the child is to receive treatment and an education.

The ultimate push leading to the creation of autism as a spectrum disorder resulted from Lorna Wing’s article on Asperger’s Disorder (Wing 1981; 2005), a condition originally described by Hans Asperger in 1944. Though Asperger himself believed that the two afflictions were unrelated – for him, autism denoted psychosis, whereas Asperger’s Disorder was considered a personality trait – Wing felt that the variation between the two could be distinguished simply in terms of severity. The evidence of a relationship, according to Wing, was apparent in the fact that the triad of impairments occurs in both autism and Asperger’s Disorder, as well as in other conditions such as childhood schizophrenia. Moreover, Wing found that classifying Asperger’s Disorder as a personality trait provided no direction with respect to treatment or educational implications, whereas it was clear that all children on the spectrum would benefit from the same kind of rigidly-structured educational approach.

Autism in the Diagnostic and Statistical Manual of Mental Disorders

The disagreement and confusion surrounding the diagnosis of autism is reflected in the ever-changing diagnostic criteria in the various editions of the DSM. In both the first (DSM-I; 1952) and second (DSM-II; 1968) editions of the manual, autism and autistic symptoms were subsumed under the category of childhood schizophrenia. It was not until third edition (DSM-III;
that autism appeared as a unique disorder that could be differentiated from schizophrenia. In this volume, Infantile Autism (IA) was characterized by a lack of responsiveness to others, significant deficits in language, odd speech behaviors (if speech was at all present), a resistance to change, and an unusual interest in objects. In addition, IA was defined by an age of onset prior to 30 months. The DSM-III also marked the first appearance of diagnostic criteria for Pervasive Developmental Disorder (PDD). While, like autism, it was to be distinguished from childhood schizophrenia, PDD was characterized by an age of onset after 30 months, impaired social relationships, and several other more specific symptoms such as inappropriate affect, anxiety, resistance to change, and abnormal speech behaviors. Thus in 1980, unlike today, because of the age of onset criterion and despite the similarity in symptoms, there could be no overlap between Infantile Autism and PDD.

This would change with the arrival of the revised third edition (DSM-III-R) in 1987, when the age of onset criterion was relaxed from “before 30 months” to “during infancy or early childhood.” Moreover, this was no longer a required criterion for the diagnosis of IA, which was now called Autistic Disorder. But the changes in the DSM-III-R were much more significant than just a new name and less relevance given to the age of onset. For one, autism was now represented as a triad of impairments in social interaction, communication and imagination, and restricted activities and interests. Each category of impairments contained between five and six items (or symptoms), with several examples listed in parentheses alongside each item. Secondly, the criteria were now presented in a format more reminiscent of a prix-fixe dinner menu than a medical handbook: a diagnosis of Autistic Disorder required that eight out of the total sixteen symptoms be present, with at least two from the social interaction category and
one each from the remaining two categories. Even more interesting was the way in which the behavioral examples given in parentheses next to most items were organized. Specifically, those first listed were said to be more likely to apply to younger or more disabled children. Take the abnormal nonverbal communication item as an example:

Markedly abnormal nonverbal communication, as in the use of eye-to-eye gaze, facial expression, body posture, or gestures to initiate or modulate social interaction (for example, does not anticipate being held, stiffens when held, does not look at the person or smile when making a social approach, does not greet parents or visitors, has a fixed stare in social situations).

Thus, a younger or more disabled child might not anticipate being held or stiffen when held, whereas an older or less disabled child might not greet visitors or have a fixed stare in social situations. Finally, the specific symptoms for PDD listed in the DSM-III were eliminated. Instead, in the DSM-III-R, a short paragraph describes a new diagnosis of PDD-NOS (Pervasive Developmental Disorder – Not Otherwise Specific) and suggests that this diagnostic code be used for children who display some impaired social interaction and communication, but do not meet enough of the criteria for Autistic Disorder or any other PDD, i.e. Schizophrenia, or Schizotypal and Schizoid Personality Disorders. Children with PDD-NOS may or may not show repetitive behaviors and restricted interests. As a consequence, the DSM-III-R not only allowed for more variations across different children diagnosed with Autistic Disorder, but the PDD-NOS diagnosis opened the door to a milder, more high-functioning variant. Though autism was not yet considered a spectrum disorder, the diagnostic criteria of the DSM-III-R certainly appeared to lean heavily in that direction.
The autism spectrum ultimately became a diagnostic reality with the publication of the DSM-IV (1994) and DSM-IV-TR (2000). The list of Autism Spectrum Disorders (ASDs, confusingly also referred to as PDDs) now included Asperger’s Disorder, Autistic Disorder, Rett’s Disorder, Childhood Disintegrative Disorder and PDD-NOS.¹⁰ Thus, over time, the DSM criteria for autism have broadened and, coupled with greater public awareness of the disorder, are believed to have contributed significantly to the increasing prevalence rates observed today.

¹⁰ More significant changes are planned for the DSM-V. In this edition, the current list of spectrum disorders (Asperger’s, Rett’s, PDD-NOS, etc.) will be dropped and replaced by Autism Spectrum Disorder. This change in conceptualization is not specific to the ASDs alone, but represents a broader conceptual change for all categories of psychiatric disorders. This move is explained by two factors. First, the high levels of comorbidity reported for different syndromes has become apparent. Second, treatment response – in particular with the selective serotonin reuptake inhibitors – became less specific, such that a single treatment was found to be effective for several different syndromes. What is happening to autism, therefore, is also happening to depression and anxiety. Regier, D. A., W. E. Narrow, et al. (2009). "The conceptual development of DSM-V." The American Journal of Psychiatry 166(6): 645-650.
CHAPTER 1: THE MAKING OF THE AUTISM PARENT

The drastic increase in diagnostic rates over the last decades means that continually more and more families are living with autism, as both patient and parent. Will my child get better? What treatments are recommended? How will they be funded? Will special education be necessary, or will he enroll in a mainstream kindergarten classroom? Will he get married and have children of his own? These are just a few of the many questions that face those newly anointed to the role of the autism parent, as they struggle to make sense of their predicament and navigate the unknown territory of this new world. For with the diagnosis of autism comes not only a new way to understand their child’s behavior, but fluency with a new vocabulary (including words like “stimming” and a myriad of acronyms such as ABA, RDI and PDD), a new lifestyle including schedule-filled days shuttling from one therapy to another, a revamped home that has become a laboratory-type setting, and a double-role as advocate, all of which after several years may amount for some to divorce and declarations of bankruptcy. For these parents and their children, the diagnosis of autism is a major transition point demarking a point-of-no-return with serious implications for the trajectories of individual lives. It also serves as an engine for what Hacking (1999) refers to as “making up people,” providing the conditions of possibility for the creation of a new form of personhood.

This chapter is concerned with the social and moral transformation parents experience as their child is diagnosed with an Autism Spectrum Disorder (ASD) and attempts to uncover the forces – agents, institutions, etc. – through which both the autism parent and autistic child are gradually constituted. It asks, what is the sequence of changes that parents and their children
undergo – in terms of the framework they use for understanding themselves and others – in becoming autism parents and patients? To address this question, I rely on Goffman’s (1961) strategy of tracing the circuit of agents and agencies that parents and children navigate as they become autism parents and patients, identifying those events along the way which alter the life course and transition parents from one moral experience to the next and ultimately affect their social fate. The concept of career is particularly useful, for it allows a back-and-forth between the sentimental education of parents and the institutional matrix within which it is embedded (Goffman 1961). Similar to the process by which one becomes a mental patient, to become an autism patient one must pass through the predetermined steps of the moral career within a given institutional matrix, and diagnosis is an essential component of these career contingencies. It is a primary switching point, the moment at which the condition is deemed existing and legitimate by the medical profession – and hence to other relevant parties such as schools and insurance agencies – and not least of all to parents.

**The Significance of Early Intervention and the Moral Career**

The argument I put forth in this paper is succinctly stated by Howard Becker:

[The analysis of the genesis of marijuana use shows that] the individuals who come in contact with the given object may respond to it at first in a great variety of ways. If a stable form of new behavior toward the object is to emerge, a transformation of meanings must occur, in which the person develops a new conception of the nature of the object. This happens in a series of communicative acts in which others point out new aspects of his experience to him, present him with new interpretations of events, and help him achieve a new conceptual organization of his world, without which the new behavior is not possible. (Becker 1953: 242)
Although here Becker speaks of the experience of becoming a marijuana smoker, it parallels that of becoming an autism parent. As we shall see, parents have a variety of responses to their child’s initial symptoms, but with the assistance of Early Intervention and medical professionals, they learn how to interpret these symptoms as being constitutive of autism. Through these interactions with therapists and physicians, parents pick up on concrete behavioral referents and apply them to their own children. The key point is that this redefinition of experiences does not transpire in isolation, but through interaction with others. In the case of autism this is accomplished in conjunction with an autism expert (be it a therapist, teacher or physician), who teaches parents not only how to “see” the symptoms, but that these are symptoms of autism (and not, for instance, a speech disorder). This relearning is a crucial contingency in the moral career of the autism parent.

We will see that in the early stages of the moral career parents suspect that something is wrong with their child but most have difficulty obtaining confirmation from a medical specialist. But through Early Intervention, parents learn where and how to get a diagnosis for their child. Diagnosis is the most salient aspect of the career, both as a contingency point and a moral experience, as it transitions parents from this suspicion phase into the role of “patient-in-waiting” (Timmermans and Buchbinder 2010). This is because of the inherent uncertainty built into the diagnosis when given at a young age, when symptoms are more ambiguous and the ability to determine a prognosis is poor. The “patient-in-waiting” phase ends with one of two possible realizations: the child “loses the label” and is mainstreamed in school as his behavior becomes indistinguishable from that of his neurotypical peers, or the diagnosis stays and the child remains on the special education track. Throughout this chapter I allude to the sense of
urgency that the autism diagnosis imposes on families. Physicians cannot predict future outcomes, and so parents enter a race with the “ticking kindergarten clock,” mobilizing every possible resource that might help them reach the goal of a mainstreamed education.

The term “patient-in-waiting” was introduced by Timmermans and Buchbinder, who suggest that infants testing positive for genetic markers of disease, while remaining asymptomatic, “inhabit a liminal state between sickness and health, or more specifically, between pathology and a state of normalcy” (2010: 417), requiring continued medical surveillance but still evading diagnosis. As with genetic screening, Early Intervention places families in this liminal state, though with autism it is not continued medical surveillance but rather the initiation of treatment services that is the major consequence. Unlike infants testing positive for a particular genetic mutation, some children do receive an autism diagnosis at the outset, though just the indication of delay is sufficient to merit the provision of treatment services. For instance, in the state of New Jersey, the only requirement for early intervention is that the child tests at least 25% delayed in two areas of development. In other states, such as Massachusetts, some providers require a diagnosis in order for therapies to begin. The motivation behind Early Intervention is to provide children the opportunity to ‘catch up’ to their normal peers before the critical window of development is permanently shut and disability endures. In this sense, the concept of a patient-in-waiting forces a rethinking of the social understanding of diagnosis. While some children may have a diagnosis of autism and others just the indication of developmental delay, this status can be revised any number of times, and may include the sought-after goal of “losing the label.” Contrary to a more traditional social
understanding of diagnosis, with autism there is not always a clearly discernible junction between illness and disease (Jutel 2009).

Timmermans and Buchbinder’s second observation is that “patients-in-waiting face externally imposed uncertainty about the nature of disease” (418). The patient-in-waiting is a by-product of surveillance medicine (Armstrong 1995). Early Intervention, Child Find, and Infants & Toddlers all identify children who are developing more slowly or differently than normative standards indicate, but the final diagnosis is deferred until this window of developmental intervention firmly closes. Until then, it is precisely these institutions which mediate the uncertainty in diagnosis, teaching parents not only how to identify the symptoms of autism but how, as part of a team with therapists, they can intervene in order to alter the trajectory of development. Early intervention defines the moral duty of parents – they must act if they wish for their children to ‘catch up’ to the neurotypicals. To a lesser extent, the medical specialists who diagnose autism are also a part of this process even though they are not directly involved in the therapies. Parents may still gravitate to the authority of the physician, even when they provide few definite answers.

The third characteristic of a patient-in-waiting is that the experience is “marked by a lengthy trajectory of medical gate keeping to establish or relinquish a diagnosis” (418). Patients are kept under observation for long periods during which they undergo repeated testing and meetings with clinicians and therapists. The prototypical diagnose-treat-cure process is turned on its head, yet rather than weaken medicine’s grip on power the ambiguity of diagnosis functions to strengthen the entire matrix of institutions that initially created the patient-in-
waiting (Timmermans and Buchbinder 2010). With autism, this means not only medicine but also subordinate professions like speech and occupational therapists that work to keep the patient-in-waiting under their jurisdiction. Again, diagnosis is less about identifying the precise moment of transition from healthy to ill; instead, it is an object which translates the interests of all involved parties – parents, child, clinicians, therapists, and teachers – while simultaneously reinforcing the institutional matrix which produced it (Callon and Law 1982; Latour 1987). In other words, both the diagnosis and those who encounter it each take shape and adjust to one another in the same movement. Autism allows parents to enroll their children in Early Intervention, and Early Intervention as well as clinicians are justified in their continued surveillance. At the same time, parents are comfortable with the constant observation with which they feel they are receiving the best possible care as well as regular feedback about their child’s progress, which the diagnosis itself cannot provide.

Finally, and perhaps most significant for the current chapter, the experiences of a patient-in-waiting may “shape illness identity profoundly, leading to a shared if not always collectively expressed political consciousness“ (Timmermans and Buchbinder 2010: 419). When the child becomes an autism patient, the parent is gradually transitioned into the multifaceted role that is at once advocate, therapist, clinician and parent. While parents are already well-aware that they are responsible for their children, they now learn that they are responsible for their children’s neurological development – in short, for their brains. Through this process of responsibilization (O’Malley 1992; Rose 2001), parents learn that they should not passively accept what is provided to them, be it a diagnosis, treatment services, or school placement. Rather, they themselves must determine which therapies to use, learn to administer the
therapies and assess their impact, and are often forced to advocate for these therapies or school programs with school districts, doctors, insurance companies, and the like. The circuit of mediators – and especially Early Intervention – defines this situation for parents, as well as their moral duty to the child. Through Early Intervention, parents learn that they are primarily responsible for managing the risk of abnormal neurological development. It responsibilizes parents by emphasizing that they are in charge, they are the experts of their own children, they are the managers of the intervention team. In short, they are told that no improvement can occur without their effort, and the greater the effort, the greater the improvement. This is the most salient aspect of the moral career, both as a contingency point and as a moral experience. In this way, the very forces that drive the quest for new knowledge about autism – the search for effective treatments; the broadening of the spectrum to include new behaviors; the struggles over diagnostic criteria and the provision of services – are also the engines which produce the conditions of possibility for new ways of being human: autistic personhood and parenthood (Hacking 1999).

DEMAND- AND SUPPLY-SIDE ACCOUNTS OF THE INCREASING PREVALENCE OF AUTISM

Some media accounts have insinuated that the rise in autism diagnoses is in part due to demand-side forces: “pushy parents” who strategically navigate the system, visiting one professional after another until they locate someone who is willing to diagnose their child with autism. The preference for a diagnosis of autism and not some other developmental disorder, the story goes, is driven by the wealth of resources that autism brings parents, including more state-funded therapy hours and access to a well-organized network of parents and advocacy groups. On the other side of the debate surrounding the increase in autism prevalence are
social constructivist arguments positing that jumps in diagnostic rates fall hard on the heels of changes to the definition of autism in the DSM (Gernsbacher, Dawson et al. 2005). Evidence for this view is provided by several studies documenting diagnostic substitution from other categories of special education to autism. Shattuck (2006) found that as the administrative prevalence of autism in U.S. special education increased, there were corresponding decreases in the prevalence of both mental retardation and learning disabilities. Croen et al. (2002) too found a decreasing prevalence of mental retardation coinciding with an increase in autism, and King and Bearman (2009) estimate that almost 27% of the increased autism caseload is California is a result of diagnostic substitution from mental retardation to autism. These sources seem to imply that the hypothesized direction of influence is top-down, i.e., it is physicians and psychiatrists who are responsible for diagnostic change, and families are passive recipients of labels. More recent, however, is the suggestion in the academic literature that the diffusion of new knowledge about autism amongst parents could be an important contributor to increased diagnostic rates. For instance, Liu, King and Bearman (2010) found that children are more likely to receive an autism diagnosis when they live in close proximity to a child already so diagnosed. Moreover, parents’ proximity to a child with autism within the same school district increased the chances that their own child would be diagnosed with autism. After discounting the possibility that their finding is due to environmental toxicants, a virus, or an artifact of neighborhood selection, these authors suggest that the increased odds of an autism diagnosis are the result of an underlying social diffusion mechanism, through which, for example, parents of the yet-to-be diagnosed learn about the more subtle symptoms of autism, where to find a
doctor who specializes in autism, and how to advocate successfully for treatment services. Thus, social influence is posited as a major contributing force in increased prevalence rates.

Hence there is some debate concerning the direction of influence through which autism becomes an official label. Some propose a top-down (or “supply”) process whereby diagnostic change has spurred the prevalence, while others suggest a bottom-up (or “demand”) course of action, in which parents’ agency is instigated by contact with other autism parents. Why is this important? Surely this dissertation does not attempt to enter the debate about the causes of the autism epidemic. It does, however, suggest a new way to theorize diagnosis and by implication one direction that such research can take, as a coherent theory of diagnosis must precede any explanation of increasing diagnostic rates. As we shall see, the data I present here identifies a blind spot in demand- and supply-side accounts as well as the social influence theory. This is not to say that changing DSM-IV criteria do not affect the diagnostic process, nor that parents might prefer an autism diagnosis over others once they learn of the benefits it accrues. And though the possibility of parent-to-parent interaction as playing a major role in the pre-diagnostic period could be challenged, the structure of Liu et al.’s data renders it impossible to ascertain the exact nature of the proximity effect. But what is evident from the data presented here is that each of these explanations is only partial. Diagnosis involves a redefinition of experiences, and in this chapter I demonstrate the importance of institutional factors, Early Intervention, and the shaping of parental identities in the diagnostic process.

THE STUDY

The data used in this study derive from a larger project intended to provide a sociological account of the autism epidemic through a multi-faceted analysis of the
contemporary experiences of parents of children with autism. A collaborative effort between five researchers, a convenience sample of parents was approached in four different states – Maryland, Massachusetts, New Jersey, and Virginia – and the District of Columbia. Parents were primarily recruited in person, while visiting a clinic or therapy center with their child. Over 100 parents of children diagnosed with an Autism Spectrum Disorder participated in the larger study, and thirty-seven\textsuperscript{11} of these parents participated in the interviews reported on here. Four different researchers conducted the interviews using the same interview schedule. Thirty-three of the interviews were recorded on audiotape and transcribed verbatim. Due to a voice recorder transcription, two of the interviews were only partially recorded, and data collection for one interview was only possible through note-taking. All names are pseudonyms. While there exists no surefire method of determining the truth of parental reports during the interviews, whenever possible interview data was corroborated with that collected via participant observation. Detailed notes were taken during the course of the interviews, and parents were asked to clarify any seemingly contradictory claims. While the analysis undertaken here is influenced by participant observations made in the clinical setting, those observations were not systematically compared with the results obtained in the interviews.

**The Parents**

Parents of thirty-seven children diagnosed with an ASD were interviewed.\textsuperscript{12} Typically, it was the mothers who were interviewed, except for four cases in which both parents

\textsuperscript{11} One interview was eliminated from the analysis because the child in question had not, by the time of the interview, secured an autism diagnosis. Naturally, it is presumed that one can only be considered an autism parent if one’s child has been diagnosed with an Autism Spectrum Disorder.

\textsuperscript{12} Data for the variables reported on in this section were not available for all families. When percentages or fractions are reported, they are based on the number of cases for which data was available. The sample sizes for
participated. Two-thirds of the respondents described themselves as White, one-eighth as Hispanic, one-twelfth each as Black and Asian, and one person as bi-racial. In terms of socioeconomic status, the sample is predominantly middle-class. At the time of the interview, only one parent reported her highest educational credential to be a high-school diploma. Three parents (9%) had earned an Associate’s degree, thirteen (40%) a Bachelor’s degree, four (12%) had completed some graduate work, and seven (21%) were in possession of a graduate or professional degree. Five parents (15%) had completed some college but not earned a degree. In the eleven cases where this information was available for the other parent, five were found to be in possession of a Bachelor’s degree, three a graduate or professional degree, and two were conducting graduate work. Thirteen mothers (42%) were at home full-time, one was retired and one unemployed, with the remainder working part- or full-time in various occupations ranging from a fitness instructor to an X-ray technician, nurse, lawyer and professor. Seventy-five percent of respondents were married, 14% were divorced, 7% single, and 4% separated. Sixty-three percent had at least one other child living in the house. Eight respondents reported that one of their other children was also diagnosed with an ASD (n=3), Attention Deficit Disorder (n=1), or speech delay (n=2). One parent indicated that one of her other children was currently being assessed for an ASD, and another described her teenager as having learning difficulties in school but no formal diagnosis. Sixteen (44%) of the families interviewed resided in New Jersey, seven (19%) in each of Massachusetts and Virginia, three (8%) in Maryland, and one (3%) in each of Georgia, New York, and the District of Columbia. In

these variables is as follows: highest educational credential, n=33; current occupation, n=31; marital status, n=28; number of other children living in the house, n=33; race or ethnicity, n=24.
abstract, the modal respondent was a white, married woman with a Bachelor’s degree working at home full-time. She had one other child living at home, in the state of New Jersey.

FACTS AND NARRATIVES

An important aspect of every career is the view the person constructs when he looks backward over his progress; in a sense, however, the whole of the pre-patient career derives from this reconstruction. (Goffman 1961: 145)

Before proceeding to the data analysis, a disclaimer pertaining to my analytical approach is warranted. The analysis undertaken below walks a delicate line between the interpretation of interview data as factual versus its interpretation as narrative. Or, as others have termed it, the naturalist versus constructivist interpretation of qualitative interview data (Elliott 2005). At times, parents are taken at their word, their answers given the presumption of truth subject to the ordinary errors of recall or social desirability bias with which any social scientist relying on human reports must contend. At others, their responses are examined not for their content, that is to say, not with respect to what parents said they did, but in terms of how they narrate life events to tell a story about themselves and their children. But on what logic does such a methodological strategy rely, permitting one to conveniently shift between interpreting answers as unaltered declarations of fact, or representations of reality ultimately shaped by the ending of the story (i.e., an autism diagnosis), as a reality produced by the interview process itself?

The student of quantitative data analysis soon learns that there is a limit to how many times one can put their hand into the cookie jar: with each additional comparison to be analyzed from a single data set, a valuable ‘degree of freedom’ is lost, a discipline-imposed limit
to the frowned-upon practice of data mining. Here I face not a numerical limit, but a logical one: if I choose to analyze my data as narrative, then I implicitly acknowledge that my respondents do not necessarily report events as they happened, but make adjustments in order to construct a meaningful and coherent reality, or plot, from them. Events may be misrepresented, exaggerated or even omitted in order to preserve this plot to present oneself in a particular way. Moreover, the meaning of a past event can be changed by way of what happens in the future: an event may be encoded in a particular way as it transpires, but when recounted at a later point, is interpreted differently because of some intervening event (Bearman, Faris et al. 1999). Take, for instance, the accounts parents give of what signs they noticed when they first suspected that something might be wrong with their child. It is highly conceivable that a future event, namely the autism diagnosis, shapes responses to this question so that they provide answers such as “he didn’t make eye contact” but not “he had frequent ear infections.” Parents, as they encounter autism and become familiar with its symptoms, learn that the former is a common symptom of autism while the latter is not.

In the extreme view, the naturalist (or positivist) and constructivist analysis of interviews should be mutually exclusive practices: either interview data is seen as a “mirror reflection” of social reality, or as a narrative which is produced through the interviewer-interviewee interaction.13 I choose a different strategy, one espoused by Miller and Glassner (2004), located outside of this dichotomy rather than along it and which takes seriously both the criticism and goals of each. As they put it:

All we sociologists have are stories. Some come from other people, some from us, some from out interactions with others. What matters is to understand how and where the stories are produced, which sort of stories they are, and how we can put them to honest and intelligent use in theorizing about social life. (Miller and Glassner 2004: 138)

What is most essential for this chapter is the significance of these events for the ways in which parents narrate their own and their children’s lives. Miller and Glassner (2004) fully acknowledge that in-depth interviewing cannot provide the sort of data that positivists strive for, but that it can “provide access to the meanings people attribute to their experiences and social worlds” (126). But they argue that this does not imply that interviews cannot yield information about realities outside of the interview context, for to assume so is to “grant narrative omnipotence” (129).

Still, analyzing the meaning of events presumes that said events indeed occurred. To be sure, I make no attempt to contribute to the growing pool of research reporting on variables such as ‘age at diagnosis’ or ‘timing of first suspicion,’ a task not only beyond my scope but certainly my sample size. But most of the argument forwarded here rests on the processes by which a child comes to be labeled as autistic, the actual events around which moral experiences are structured. In other words, I need to be confident that these events actually took place. Thus, there is good reason to examine what information may be more or less truthful from parents’ accounts.

Psychological research on human memory shows that the likelihood of parental recall of an event that did not take place is small (Khazzoom 2010), and it is difficult to imagine why anyone would lie under the relatively innocuous circumstances of these interviews. Yet while
there is no obvious reason to doubt whether or not an event transpired at all, the exact timing of events reported by parents must be taken with a grain of salt. Parents are not unlike social scientists in that they have a theory about how they arrived at an autism diagnosis, and in explicating this theory, they will emphasize some experiences (or “findings”) while minimizing others considered less central to the plot (or “theory”). What this suggests is that while we should take care in relying heavily on the details of events (such as exact dates), we can be confident that the gist of the story adequately mirrors actual events. The risk, then, is less of false memories than of flawed ones. Even then, the circumstances surrounding the events parents experience en route to an autism diagnosis put us on relatively solid ground. For one, we know that emotion enhances memory, and the diagnosis of a incurable neurological condition for their child was indeed an incredibly affecting experience for parents. Second, rehearsal enhances memory. All of the parents we spoke to had repeated the same events time and again to the various physicians, therapists and teachers they encountered throughout the diagnostic process. Autism parents – and probably all parents who interact with the health care and educational system with such regularity – accumulate a library of dated documents that include diagnostic letters, enrollment forms and the like, all constituting a reliable basis for their reconstructions of the past.

Thus, while for the most part my analysis focuses on the way parents narrate themselves, I am confident that the events reported did indeed transpire and consequently I can make some inferences regarding objective careers. Nevertheless, I have tried to corroborate my findings on these variables with the results of larger studies asking similar questions.
**First Signs**

As portrayed by Goffman (1961), the initial moral experience of the mental patient involves the recognition that one is essentially failing at being human. It was this self-observation that transitioned one into the pre-patient phase of not-quite meeting the requirements for intervention on behalf of the medical profession, but no longer beyond its gaze either. The corresponding episode in the case of autism occurs at the moment when parents first suspected that their child might not be developing normally. Like the mental pre-patient, at this point the child is beyond the purview of medical treatment but becomes a blip on the radar of the system of surveillance surrounding child development.

To have their child diagnosed with autism, parents must first recognize symptoms of abnormal or delayed development in their child and act on that information to bring it to the attention of a medical professional who associates the symptoms with autism. In the interviews, parents typically reported that they themselves were the first to notice a problem, though on occasion either a family member or schoolteachers raised concern. Generally speaking, the more recent the child’s birth year, the younger the child when a problem was first suspected. This is in line with recent observations that the age of diagnosis – and hence presumably, the age of suspicion – is decreasing (Rogers and Laraine Masters 2000; Mandell, Novak et al. 2005; Hertz-Picciotto and Delwiche 2009), and is corroborated by the plethora of websites geared towards the early detection of autism, which list the developmental milestones parents are to watch for beginning as early as three or four months of age.14

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Accordingly, half of the parents first noticed symptoms when the child was 18 months old or younger, with a few parents indicating that they had been aware of a problem since birth. Of the parents who noticed symptoms after 18 months of age, only two became concerned after 2½ years, at each of 4 and 5 years (born in 1990 and 1996, respectively). Other studies have reported an average age at suspicion of just over 20 months, with 93% of parents noticing symptoms before a child’s third birthday (Howlin and Moore 1997), close to 17 months (Smith, Chung et al. 1994), and approximately 15 months (Chawarska, Paul et al. 2007).

Far more variability was apparent when parents described exactly which behaviors had initially raised suspicions. Taken together, they reported a myriad of symptoms as the first indication of a problem; in fact, there were more distinct symptoms mentioned that there were children being described. These symptoms varied over a wide range of deficits, from delays in language, social and physical development to problems sleeping, gastro-intestinal and other medical issues, hyper- or hypo-sensitivity, to odd behaviors like head-banging and staring into the television. In general, however, these symptoms were mobilized as evidence of one of four classes of problems. First, and most common of all, were symptoms representing a failure of the child to reach a normative standard of child development, a “milestone.” The term delay best describes this category. Speech delay was the most frequently reported symptom, but physical delays (walking, rolling over, etc.) and social or social-communicative delays were

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15 It should be noted that both of these children have somewhat atypical trajectories even beyond the age of suspicion. Most notably, in each case it was the school – and not a parent – who first suspected that something might be wrong with the child. In the case of the 5-year-old, the child was already enrolled in a regular kindergarten class when the teachers noticed that he didn’t play with toys or other children, and often spent time in the class coatroom for bad behavior. This was followed by an assessment by the school psychologist, and the subsequent chain of events led to this child being diagnosed with Asperger’s Disorder, the only such case in this study. The other case of late suspicion was a child first diagnosed while his family still lived in the Phillipines. During a first-grade entrance examination, the school recommended the child be evaluated by their educational diagnostician, who diagnosed high-functioning autism.
frequently indicated as well. When describing the latter, parents were most likely to employ the language of autism awareness campaigns, as though reading from a brochure: lack of eye contact, does not respond to name, does not extend arms to be picked up, does not engage with other children. Second, about one-quarter of parents described a course of regression, typically with regard to speech, in which the child had seemingly acquired the age-appropriate skills but then lost them suddenly. In this sense, speech spanned both of these categories, described either as a gradual process with the child continuing to miss milestones, or as an abrupt change in which the child was using some words but then suddenly ceased to exhibit any verbal behavior. Third, the child was sometimes described as exhibiting an excess of problem – albeit normal – behaviors, such as crying, screaming, biting, misbehaving, and not sleeping. Fourth, and least common of all, parents accounted for the presence of odd or unusual behaviors, including stimming, head-banging, toe-walking, spinning, obsessive staring at the television, and lining up toys. Thus, in describing the pre-autistic phase of the child's moral career, parents employ a multi-dimensional representation of the abnormal. What is significant is that the classic symptoms of autism – stereotypy, echolalia, head-banging, etc. – are the least common category of signs mentioned by parents, a finding not unique to this study. Howlin and Asgharian (1999) found delays in language development to be the problem most commonly reported to raise initial concern in parents, followed by delays in social development and play, but obsession with routines and rituals were the least frequently

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16 While regression was most commonly described in terms of the loss of the use of speech, some parents also reported the loss of other skills, such as the ability to make eye contact and pointing.

17 The term “stimming” is short for “self-stimulation,” which refers to behaviors that are hypothesized to stimulate one’s own senses, such as hand-flapping or rocking. Retrieved from http://www.iancommunity.org/cs/glossary_term;jsessionid=aexfryR3i9G52t5XOb?glossary.id=212&letter=S, last accessed November 17, 2010.
reported. Howlin and Moore (1997) reported similar findings in an earlier study, where only 4% of parents reported obsessional and ritualistic tendencies as a primary reason for their anxieties. Smith et al. (1994) too found these behaviors to be reported by only 5% of parents. Perhaps more telling is the Chawarska et al. (2007) finding that stereotyped behaviors were reported to raise initial anxieties in 17.6% of parents whose child received an autism diagnosis, but none of the parents whose child was diagnosed with PDD-NOS. This latter diagnosis is said to be appropriate when a child shows some, but not all, characteristics of the triad of impairments. In practice, this usually means that there are delays in communication and reciprocal social interaction, but no repetitive or stereotyped behaviors.

As in these studies, the symptoms most frequently mentioned by parents are those that have been adopted by early childhood surveillance programs, formulated in the language of delay and evidenced in places such as parenting manuals and announcements of organizations like the American Academy of Pediatrics\(^\text{18}\) that have become the targets of developmental surveillance and screening programs. For the most part, these are the signs of communication and social delays, and to a lesser extent, physical delays. The diversity of symptoms and their age of onset in the current sample of children opens the question as to whether there initially exists any obvious reason to group all of these children together under one diagnostic umbrella. This is reflective of the fact that the autistic prototype has expanded beyond the characteristics described by Leo Kanner (1943), who first described autism to the then-emerging field of child psychiatry. Kanner’s autism was an extremely rare condition that he believed to affect only 150

\(^\text{18}\) See, for example, the 2001 statement issued alerting pediatricians (and indirectly, parents) to the more “subtle” signs of autism: Committee on Children with Disabilities, American Academy of Pediatrics (2001). "Developmental Surveillance and Screening of Infants and Young Children." \textit{Pediatrics} 108: 192-196.
of the 20,000 troubled children he saw over the course of his career (Rimland 1964). More importantly, all of the children in Kanner’s initial case study displayed at least one odd or unusual behavior, such as echolalia or head-banging. As described in the introduction, today there exists an entire subset of autism diagnoses – PDD-NOS – for which this particular class of symptoms are entirely absent, exemplifying rather concisely how what was once necessary is now, in a sense, optional. This reporting pattern also indicates that parents had little previous knowledge of this expanded or spectrum definition of autism. As we shall see, parents were mostly unfamiliar with autism and especially unaware of the autism spectrum until they encountered surveillance programs such as Early Intervention, a finding that poses a particular challenge to proponents of demand-side explanations.

**Early Action**

In the interval between the initial detection of a problem in their child’s developmental trajectory and addressing their concerns with a medical professional or other child specialist, parents’ own hunches of the cause – usually speech delay – were for the most part a far cry from the diagnoses they would come to adopt. To get a sense of how this wide expanse was traversed, I delineate the course of action that was followed once it was acknowledged that the child was not developing “normally.” The complainants – those voicing the first official grievance to a child development specialist – were most often the parents themselves and

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19 Early Intervention, Child Find, Infants & Toddlers and similar programs have been a part of the Individuals with Disabilities Education Act (IDEA) since 1986. Part C of IDEA requires states to identify, locate and evaluate all persons with disabilities, from birth through to age 21, in need of early intervention or special education services.

20 Since Child Find and Infants & Toddlers perform the same function as Early Intervention, I use only the term Early Intervention to denote all three entities.
almost always the mother, but occasionally both parents or the parents together with other family members. One parent described this phase as happening as an open dialogue in conjunction with the pediatrician carried over several office visits, although this was as much an anomaly as the one occasion in which a pediatrician first suggested that something might be wrong. The widespread absence of this latter experience, it will be argued, has significant implications for the moral career.

Not surprisingly, almost four-fifths of parents initially raised their concerns at the next regular visit with their pediatrician, as they were typically the medical professional most familiar with the child, and one parent took her concerns directly to a pediatric neurologist. Half of the other children were already under medical surveillance for another problem, or were already enrolled in Early Intervention. Three parents were alerted to a potential problem by the school in which their child was enrolled. Of the parents who first approached a pediatrician, two-thirds were told that their concerns were unwarranted. The doctors’ responses were strikingly similar, and parents were given some slightly modified version of the script described by this mother:

The pediatrician gave me a lot of, ‘he’s the third [child], he’s a boy, he doesn’t need to communicate because everybody does it for him, some kids aren’t as attentive as others, they’re not all the same, you have to understand.’ (NR 001)

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21 That the mother was most often the primary complainant could be an artifact of the interview process, since mothers were the interviewees 95% of the time. Thus, a sufficient answer to the question, “Who noticed these signs?” would have been “I did,” and a more complete response was often not prompted. However, several other investigators have found mothers to be the primary managers of their children’s illness. See, for example, Leiter, V. (2007). ""Nobody's just normal, you know": The social creation of developmental disability." Social Science & Medicine 65(8): 1630-1641.
Other studies have also indicated that parents are often told either that nothing is wrong with the child or that no immediate action is necessary, ranging from 25% of respondents to almost 50% (Smith, Chung et al. 1994; Howlin and Moore 1997). Most of the other, more responsive pediatricians in this study either referred the child for a hearing test \(n=4\), immediately to Early Intervention or a similar organization \(n=3\), or initially took a wait-and-see approach only to later refer the child to a specialist \(n=1\). Only once did a pediatrician immediately diagnose autism.

About half of the parents whose complaints were initially brushed aside continued to raise their concerns with the pediatrician. These physicians eventually responded in a manner similar to their more responsive counterparts, either by ordering a hearing test or making a referral to Early Intervention or a specialist. When these parents were asked about how they were referred onwards, they sometimes explained how they demanded referrals from their pediatricians, with one mother telling me that she refused to leave the office without one.\(^{22}\) Parents whose persistent complaints failed to elicit action by the pediatrician either self-referred to Early Intervention or a specialist, or were pointed in that direction by a third party such as a teacher or therapist.

Some parents expressed that they experienced feelings of relief when their pediatricians told them that nothing was wrong with the child, that they wanted to believe that the doctor was correct and that they, the parent, were just overly anxious. But these parents grew

\(^{22}\) In a study of the search for diagnosis in parents of children with movement difficulties, Ahern found that parents who asked a vague, nonspecific question were more likely to have their concerns invalidated than parents who approached the professional with a more specific request. While not specifically addressed in the data analysis reported on here, a similar patterns appears to be indicated. Ahern, K. (2000). "Something is wrong with my child": A phenomenological account of a search for a diagnosis." Early Education & Development 11(2): 187-201.
increasingly concerned when their own perceptions of their child’s development diverged more and more from the pediatricians’ opinions. While this appears to also be the case when a condition other than autism is later diagnosed (Ahern 2000), the finding that parents of children with autism are more likely to be told that nothing is wrong with their child begs the question as to whether this is indeed more common with autism. Certainly the fact that the American Academy of Pediatrics has urged its members to take greater care in identifying the symptoms of autism is testament to this (Committee on Children with Disabilities 2001).

In a certain sense, it seems to make little difference whether or not pediatricians act on the parent’s complaint, since in either case, most parents eventually find their way to Early Intervention or a specialist (usually a developmental pediatrician or pediatric neurologist) regardless. Thus, visits with pediatricians do not function as transition points in the sense that the interaction propels parents one step closer towards the autism diagnosis. They do not directly participate in the passage of the child from “normal development” to an official status as “developmentally delayed.” Yet in denying the presence of a delay or other problem, pediatricians position themselves as the initial barrier to the acquisition of treatment services and legitimization of parents’ suspicions: they are the first medical professionals to provide resistance against parents, the first of many obstacles that parents of children with autism must overcome along the path to diagnosis and provision of treatment services. This was explicitly acknowledged by one parent, who when asked if the diagnosis changed the way she interacted with her son, replied:

Having the diagnosis, not really, because I had worked through it at that point [...] it was really just a reassurance to me to say, you know what, you did good.
Good thing you followed your gut, good thing you followed your instinct, good thing you called EI [Early Intervention], good thing you kept calling them to get him into speech [therapy], good thing you kept calling them to get re-evaluated by the supervisor to get this ABA. [...] because I kept pushing on, saying no, my son needs more help. (NR 001)

The path leading toward autism is a great struggle for parents, who must persist in order to obtain the diagnosis (Smith, Chung et al. 1994). And the more professionals that parents consult en route to diagnosis – between four and five in at least one study – the less satisfied parents were with the experience (Goin-Kochel, Mackintosh et al. 2006). Thus, from another perspective, pediatricians do serve as a significant career contingency – essentially a rite of passage – as parents are transitioned from a state of viewing the medical profession as an ally, to one where they question the expertise and opinions of physicians and begin to decide for themselves – and often in conjunction with teachers and therapists – what is and what is not an appropriate diagnosis or treatment regimen for their child:

So at two-and-a-half years old they [Early Intervention] sent me a supervisor from EI who sat with my son and said to me, ‘Do you have a diagnosis? We don’t have a diagnosis on record.’ And I said, ‘Well, they told me initially upon contacting you that I didn’t need a diagnosis.’ [...] And she said that she’d like to get him started on ABA. She said, ‘I want to treat him as though he’s on the spectrum, because from what I’m seeing, he should have a diagnosis.’ (NR 001)

That fighting medical professionals is central to the experience of the autism parent was most evident when parents were asked what they had learned from their experiences with autism. This “fighting” was not only an issue with pediatricians, but also involved therapy-administering institutions such as schools, and even autism itself:

And I think having James the way he is actually allowed me to realize that I really have to push for what I want, especially with him. Fighting with the school to get
him what he needed, it’s not like I could sit back and have everything drop on my lap. I actually have to go out and physically fight for what I want, you have to have a voice and you can’t just sit there and assume that something is going to go the way you want it to go. You have to fight for your kids and you have to fight for everything that you want. (NR 022)

And I think that what you have to do is persevere. And to always... you can’t just leave the kids alone, because that’s one thing about autism, they go into their own world, and they don’t let anybody in. But you have to fight to get in. You have to always be... that’s why my husband was always in their face. (NR 032)

As this latter parent articulates, adopting the identity of the fighting parent is critical to the child’s prognosis, for if parents are to yield or even concede defeat, they risk the child retreating into themselves and thereby compromising improvement. Interestingly, parents who did not find themselves having to advocate on behalf of their child to obtain more services consider themselves to be amongst the lucky few. Thus, fighting professionals appears to be a crucial component of becoming an autism parent. It also appears to contradict the supply-side suggestion that doctors are handing out autism diagnoses: not only did most parents need to go elsewhere for a diagnosis, but their interactions with pediatricians did much to detract them from that path.

**DIAGNOSTIC CAREERS**

Upon suspecting a problem in their child’s development, parents were most likely to approach their pediatrician for advice but would eventually need to seek assistance elsewhere before arriving at a diagnosis. Typically, this meant visiting Early Intervention, a developmental specialist, and/or the school district. But not all diagnostic careers are created equal. While there was a distinct set of institutions and professionals that parents tended to encounter, they
did not always do so in the same order or with the same results. Table 1 summarizes the five different careers discovered in the parent interviews. I now consider each in turn.

**TABLE 1-1: CHARACTERISTICS OF THE DIAGNOSTIC CAREERS**

<table>
<thead>
<tr>
<th>Career</th>
<th>n</th>
<th>Description</th>
<th>Children</th>
<th>Typical Characteristics</th>
<th>Mean Parental Education (years)</th>
</tr>
</thead>
</table>
| A      | 12 | Early Intervention Precedes Diagnosis | Anthony, Sebastian, Peter, Tim, Craig, Charles, John, James, Jason, Daniel, Marco, Ryan | • Diagnosis before 2½ years of age  
       |     |                                      |                                  | • Early Intervention the first to suggest autism                                      | 15.27                          |
| B      | 7  | Early Intervention Precedes Diagnosis | Stefan, Stevie, Tyler, Matthew, Noah, Elijah | • Diagnosis before 2½ years of age  
       |     |                                      |                                  | • Parents suspected autism before encountering Early Intervention                     | 15.33                          |
| C      | 6  | Diagnosis Precedes Early Intervention | Dominic, Joshua, Clarissa, Troy, Carlo, Joey | • All parents well-educated  
       |     |                                      |                                  | • Decision-tree route to diagnosis                                                    | 17.83                          |
| D      | 9  | Early Intervention Absent            | Michael, Galen, Melanie, Christina, Adam, Billy, Barry, Marla, Elias | • Diagnosis after 2½ years of age  
       |     |                                      |                                  | • Autism never suspected  
       |     |                                      |                                  | • Teacher, therapist, or physician raised possibility of autism                       | 16.71                          |
| E      | 3  | Early Intervention Precedes Diagnosis | Nicolas, Amanda, Mark           | • Received Early Intervention for other diagnoses prior to the first suggestion of autism | 15.33                          |

**EARLY INTERVENTION PRECEDES DIAGNOSIS (CAREERS A AND B)** Approximately half of the parents interviewed had enrolled their children in Early Intervention before receiving a diagnosis, after which they continued to receive Early Intervention services until transitioning to
the jurisdiction of the school district on the child’s third birthday. All of these children were diagnosed before 2½ years of age. Career B parents typically became suspicious of their child’s behavior between 10 and 18 months of age, whereas Career A parents sometimes did not suspect a problem until the child approached his second birthday.

Upon arrival at Early Intervention, the child is evaluated by a Child Study Team, typically consisting of a speech therapist, occupational therapist, and developmental therapist. In almost every case the parent is told that their child is delayed – either in terms of developmental age (e.g., their two-and-a-half-year-old functions at a one-year-old level) or as a percentage of normative standards (e.g., their child is 33% delayed in speech and 25% in motor development) – and qualifies for state-funded services. Early Intervention therapists are not certified diagnosticians: while they are responsible for assessing current developmental level, this leads only to the suggestion of Developmental Delay, a vague description that does little provide parents with a deeper understanding of their child’s difficulties, or what can be done to alleviate them. As one website describes it:

Developmental Delay is when your child does not reach their developmental milestones at the expected times. It is an ongoing major or minor delay in the process of development. If your child is temporarily lagging behind, that is not called developmental delay. Delay can occur in one or many areas—for example, gross or fine motor, language, social, or thinking skills. (University of Michigan Health System 2011; emphasis added)

Of course, the difficulty lies in determining whether or not the delay is temporary, which can only be resolved retroactively. Developmental Delay is, in effect, a placeholder diagnosis, the clarification of which requires continuous follow-up with a medical specialist, such as a pediatric neurologist or developmental pediatrician. Thus, even though Early Intervention
therapists cannot diagnose autism, they play a crucial role in transitioning the child into the patient-in-waiting phase.

Perhaps most significant for these parents is that these interactions with Early Intervention therapists provide the first confirmation from a child development professional that something is wrong with their child and probably has been all along, and further proof that they were correct to doubt their pediatrician’s judgment. But the significance of this interaction with Early Intervention goes beyond the mere validation of parents’ suspicions. It is here that many parents first heard the term “autism” mentioned in relation to their own child. It is in fact this mention of autism that is the primary distinctive feature between the careers I have denoted A and B. Specifically, for twelve of the eighteen parents who visited Early Intervention before receiving a formal diagnosis, it was an Early Intervention therapist who first suggested that their child might have autism, either during the child’s initial assessment or while she was receiving treatment services. As two parents recount the event:

I: Who then first raised the possibility that James had autism or something similar?
P: Two of the people who came to evaluate him. One of them, she wasn’t very... from what I understand, she’s no longer working for EI, but the other one, who I value every second of everything that she says now, since she was James’ therapist, she had said that he shows very good characteristics of being on the autism spectrum. (NR 022)

I: Who first raised the possibility that Charles had autism or a similar condition?
P: He was receiving Early Intervention services because of his physical delays. He didn’t walk until he was over two [years old]. He was 26 months old. So he received physical therapy and occupational therapy, and they mentioned it. Unofficially mentioned it.
I: The therapists?
P: Yes, the physical therapist and the occupational therapist. (NR 015)

Since Early Intervention does not provide diagnostic services, these exchanges about autism are always conducted unofficially; the child continues to receive treatment services but no diagnostic code – beyond the purposely indistinct Developmental Delay – is assigned that is communicated to other agents such as schools or physicians.

Prior to this encounter with Early Intervention, Career A parents had not suspected that their child was autistic, either because they possessed no prior knowledge about autism (including not even having heard the word previously), or because they simply did not see the symptoms in their child. During the course of my observations at diagnostic interviews between parents and physicians, some parents even seemed to be frightened of the diagnosis, prompting one physician to ask if the parents were “okay with the autism diagnosis.” In line with this observation, many parents told me that initially they did not believe that the autism diagnosis could be correct. In retrospect, they attribute this to their lack of understanding about the meaning of autism. For instance, a few parents thought that their child could not possibly be autistic since he was so affectionate, and autistic kids are not affectionate. Similarly, others described how their “very social” child could not be autistic, since he would never be found sitting in the corner by himself:

I: And were you thinking about autism at this point?
P: You know, I had thought about it because I had read. He was always so, and still, so attached to my husband and I, especially me. I always felt like autism… I thought it was that you can’t tell the difference between a person and an object, you know, and I was like, that’s not him. He’s so loving, he’s always so snugly, he’s always kissing and hugging, although that got less frequent as he got closer to two [years of age]. I was open to it. I remember specifically thinking I should
be open to everything but I didn’t and I think there’s a lot more information out there now about the different types of autism. But I’d compare him to *Rain Man* and think no, that’s not him. (eo03300808)

These same parents later admitted that they had been mistaken, that after having spent some time learning about autism, about the spectrum, about how “every child is different,” that they came to see how the diagnosis did, in fact, describe their child accurately:

We didn’t even have a clue and even when the school district said it, we disagreed with them and they actually, fortunately the school district had like a… they were just starting a parent’s seminar [...] of how to work with kids with, specifically with autism [...] you know, and then hearing other parents talk about “my kid will only wear one shirt ever,” you know, and then to hear sensory issues could be also if he’s staring at lights or clapping [...] so as I learned more about it through the workshop I started [...] oh you know, he kinda does fall into a lot of these categories. (eo04210807)

I: So you knew something about autism before that, because…
P: A little bit. But again, I only thought autism, not *spectrum* autism. Because if you look at autism, it’s *not* my son. But when you look at the spectrum of autism, everything that was listed was my son. (NR 022)

It could be said that the diagnostic criteria for autism are like the prophecies of a fortune cookie or horoscope: broad behavioral descriptors for which concrete referents in the child are easily discovered. Understanding autism as a *spectrum* of impairments renders this all the easier, encompassing both the hyper- and hypo-sensitive, affectionate and unresponsive, reticent and garrulous. Most parents, as we shall soon see, do not connect symptoms to diagnosis independently, but are taught this through Early Intervention as they undergo education in becoming autism parents. They simultaneously learn of this wider definition of autism as well
as how to identify it in their own child’s behavior. Consider the following mother as she struggled to understand her son’s behavior:

So they [Early Intervention] came in when he was about 16 months old by the time I made the phone call and we made the appointment, and by about 17 months they started the early intervention with just the DI [developmental intervention], and one of the girls who came here, who I… she was the one I cared the least for. He had three separate therapists at that point, and when he was, during a session, screaming, and I said, ‘But why is he so upset?’ And she said, ‘Well, that’s the autism.’ (NR 001)

By identifying the behavior as symptomatic of autism, Early Intervention offers parents a way to make sense of their child.

Physicians frequently direct parents to Early Intervention, but they themselves do not offer much advice on treatment or school placement, and prognoses are conspicuously absent from the parental reports of these interactions. Rather, it was Early Intervention that filled in these blanks, and parents such as Julia felt indebted to the Early Intervention therapists:

P: But you know, she [the developmental pediatrician] didn’t give me much information. It wasn’t like… because I remember going home to my husband and saying, so now what, what do we do? Where do we go? Am I supposed to go get more speech therapy, outside of what the state’s giving me? Do I call the insurance company? You know, none of that. It was just, yes, he’s got ASD, and she told me to make an appointment to come back in 6 months.
I: So not really any instructions in terms of next steps?
P: No. It wasn’t…
[...]
I: You said you talked about ABA, so now you would get the ABA?
P: Because the [Early Intervention] therapist I was working with, they were waiting for me, they knew I was going to the doctor. Once I got the diagnosis, then they’re the ones who helped me out more, they are the ones who explained more of what was going on, what I should be doing, teaching me to
handle my child. The doctor doesn’t teach you how to handle this. They diagnose, but how do I deal with this kid who’s screaming and throwing himself on the floor? They don’t teach you that. So the therapists that were here, they were very helpful, walking me through things, teaching me different techniques. (NR 024)

Thus, not only does Early Intervention responsibilize parents for their children’s neurological development, they also provide them with the necessarily arsenal of skills. Additionally, shortly before children age out of Early Intervention, Early Intervention case workers act as advocates in securing an appropriate school placement. Both Early Intervention therapists and case workers figure prominently in the design of the children’s Individualized Education Program, and hence the effects of their actions continue to reverberate even after the child ages out of Early Intervention.

Unlike the parents I denote as Career A, Career B parents did suspect that their child might have autism, although none of these parents reported being told by Early Intervention that autism was a possible diagnosis for their child, even when parents specifically asked therapists their opinion on the matter. Take, for instance, the following parent:

Q: Okay. And they [Child Find] did the evaluation and --
A: Yes they did. They did evaluations and they did all these different testing to see how he scored but nobody would come out. They would always say we are not a doctor. They would not say that he had autism. They would not say that, they would just say that he had delays. After he was diagnosed for a very long time with having a developmental delay in speech and in his motor skills. But pretty much that is what we were told but at that point when I began to see characteristics I just felt that okay there is something with this autism here.

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23 An Individualized Education Program (IEP), required for all children who qualify for special education, is mandated by the Individuals with Disabilities Act (IDEA). Among other elements, it includes the specific services and accommodations to be provided to the child, as well as a set of measurable academic and functional goals.
The presumption is that when parents are already tuned into the possibility of autism – which would include more up-to-date knowledge on the spectrum or at least the expanded definition – the Early Intervention therapists themselves remain silent on the suggestion. This finding is substantiated by an observation made at the AMC. When Martha, the nurse who conducted intake interviews with parents before scheduling an appointment for them at either the Autism Medical Center (AMC) or the Center for Child Development (CCD), explained how she determined who would get the AMC appointment and who would be directed instead to the CCD, she described how she refrained from mentioning the word ‘autism’ at any point during the interview. She repeatedly emphasized that she did not want parents to be influenced in any way by her own words or suspicions. In the end, parents who suspected autism and specifically mentioned this during the intake were immediately scheduled to see a physician at the AMC. Those who did not refer to this particular diagnosis could end up at either clinic, depending on Martha’s own impression at the end of the interview. It is difficult to overestimate the significance of this finding, for in observing almost fifty families as they visited the AMC, only three children were not diagnosed with either autism or PDD.

While no official diagnosis is made at Early Intervention or its counterparts, and regardless of whether or not parents suspected autism themselves (i.e., followed Career A or B), it is here where parents learn that to get such a diagnosis, they need to visit a developmental pediatrician or pediatric neurologist, from whom approximately two-thirds of the children in this study received an autism diagnosis. In fact, parents often reported that it

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24 As will be discussed in Chapter 3, not only was the AMC only concerned with autism, but except for the sharing of some administrative positions, it had its own clinical staff that operated independently from that of the CDD.
was an Early Intervention therapist who referred them to the particular specialist who eventually gave them the autism diagnosis:

I: So he was almost two when he was evaluated by EI and they suggested it [autism]?
P: And they suggested I see a developmental pediatrician. (NR 022)

I: And who first raised the possibility that he had autism or a similar condition?
P: Well after those two [Early Intervention therapists] came in... actually, maybe it was before he was 28 months old, because they had come and evaluated him and then they suggested a behavioral specialist come and evaluate him, and that took a little bit, and then they just suggested that I have him evaluated by a developmental pediatrician. (NR 024)

Through these discussions with therapists, parents also learn that an autism diagnosis will get them more therapy hours than they currently receive with only the indication of delay:

They [Early Intervention] suggested, there’s a real backlog for getting in to see people for diagnosis in Boston and so they suggested a study that was being done by Boston University and they could get us in within a couple of weeks [...] it was just a piece of paper that we needed to get services started [...] I needed the diagnosis to get this group called Building Blocks, which I really wanted. (eo03300808)

And naturally, by this point parents are also well-versed in the mantra that “the best thing you can do for your child is get him as much therapy as possible.” Since Early Intervention also provides assistance to families in the transition to the education system, parents learn too that the autism diagnosis will also permit them to register their child in an autism-only classroom (or even an autism-only school):

By the time they’re three years old, they age out of early intervention, and then it becomes a school district [‘s responsibility]. So in that time, I’d say from like 2-
3 years [of age], when I had to take him to EI, the mothers who brought the children, we all had to sit around. It was more like therapy, it was mandatory that the parents sat with a social worker and talked about things. At first I was very hesitant, [...]. But that’s where I learned a lot, from all these parents that were about to age out of early intervention, and they were talking about autism and special schools. And the woman that was the social worker [for Early Intervention], she was very knowledgeable, and she’s the one who said, ‘You’ve gotta get things rolling here. You’ve got to get him in a school that deals with kids with autism.’ [...] The social worker [at Early Intervention] was the one who more or less educated us. And she said he needed to go to a special school for kids with autism, and there were far and few. She said he needed to have one-on-one, ABA, discrete trails. They were talking about 40 hours a week. (NR 020)

Both parents and professionals consider the autistic-only classroom the best placement option for autistic children, with promises of more therapy hours, teachers with more specialized knowledge about autism and its treatment, and a lower teacher-to-student ratio than the comparative multiple-handicapped classroom. Thus, Early Intervention is a significant transition point which serves not only to explicitly direct parents to where they can obtain an autism diagnosis, but also to provide the initial coaching on how to be an autism parent.

**Diagnosis Precedes Early Intervention (Career C)** Six of the children in our study received Early Intervention services only after receiving a diagnosis of autism or PDD. While their parents, like their Career A and B peers, typically became suspicious before two years of age, were shunned by pediatricians, and received diagnoses before 2½ years, they differ in that their children received diagnoses prior to enrolling in Early Intervention. Thus, unlike their undiagnosed counterparts, these parents needed no diagnostic guidance from Early Intervention therapists. To the contrary, they were referred to Early Intervention by the diagnosing physician.
The most striking difference between parents who received a diagnosis before Early Intervention and those who received it afterwards was the amount of parental education. Career C parents were well-educated: at least one parent in each family possessed a Master’s degree or higher, and in all but one case both parents had at least a Bachelor’s degree. As is shown in Table 1, on average Career C parents possessed almost eighteen years of schooling, approximately equivalent to a Master’s degree. This amounts to more than one year more than the next highest average (Career D at 16.71 years) and about 2.5 years more than the remaining three careers.25 While parental education or socioeconomic status are no longer considered risk factors for autism (Larsson, Eaton et al. 2005), parental education and family income have been linked to a lower age of diagnosis and greater satisfaction with the diagnostic process (Goin-Kochel, Mackintosh et al. 2006). Kogan et al. (2009) found a negative correlation between parental education and the severity of the ASD, as well as a lower prevalence of ASD in families with lower parental education and decreased severity in parents with higher education. These authors speculate that families with less education have fewer resources from which to draw upon in the search for information about their child’s behavior or for a diagnosing physician. More educated parents, on the other hand, might possess an increased capacity to navigate the system and make certain demands on the professionals, who in turn might view these parents differently because of their elevated status. It may be that these parents, many of whom are professionals themselves, place greater importance on the meaning of the diagnostic act and are therefore more motivated to complete this ritual before

25 Of course, with such a small sample size these results were not tested for statistical significance. But this finding does indicate that parents following other careers were not as well educated as Career C parents.
moving into the treatment phase. Of course, another possible explanation is that parents with more education are pushier, and diagnosis is a response to their demands. This would help explain not only the increased satisfaction of these parents with the diagnostic process, but also why milder cases of ASD have a lower prevalence in families with less parental education.\footnote{This finding, should it be confirmed in future research, may also help explain Kanner’s observation that autistic children tended to have highly educated parents. Certainly a better education would have helped such parents locate Kanner to begin with.}

The upshot is that more education affords parents diagnosis at an age young enough to enable the child to enroll in Early Intervention, and in at least some states the autism diagnosis qualifies the child for a greater number of therapy hours. Of course, already possessing a diagnosis means that, for these families, Early Intervention does not play a significant role in directing parents to diagnosing physicians. But it does offer a new way in which to regard Early Intervention, as a sort of equalizer that cancels out the effects of higher education. For while parents with more education were the only ones to get diagnoses without the assistance of Early Intervention, parents with less education were still able to get the same diagnoses within the same time frame as their more educated counterparts. As several studies have pointed out that lower socioeconomic status was correlated with diagnosis at a later age (see, for example, Mandell, Novak et al. 2005), this is no small achievement. Moreover, here we see that Early Intervention allows parents to bypass the decision-tree route to diagnosis, where a series of tests are conducted in order to rule out other disorders. Instead, with Early Intervention parents are immediately directed to services focused on development. Even without assisting in the diagnostic process, Early Intervention nevertheless proves itself an essential resource for these parents. One mother emphasized the importance of Early Intervention for any child who
has any kind of a delay, and regretted what she considered the fear of many parents to have their child labeled with a diagnosis and receive services.

_EARLY INTERVENTION ABSENT (CAREER D)_ As significant as Early Intervention is for parents who encounter it, about one-quarter of the children in our study did not receive any such services. Except for three cases (described below), these children were diagnosed after 2½ years of age. In fact, in most cases the first symptoms were not even noticed by this point. I mention 2½ years as this is the age at which Early Intervention begins to organize a child’s transition to school. When diagnosed after this age, professional advice is for parents to begin seeking proper school placement rather than Early Intervention services.\(^{27}\)

Children in this category were more likely to come into contact with and/or be diagnosed by a psychologist, or be identified by the school in which they are enrolled. About 20% were directly referred to a pediatric neurologist by an audiologist after a negative hearing test. Others were directed to a specialist by the school district (27%) or another physician (30%), occasionally passing through a circuit of specialists en route. The remaining 20% were seen by a psychologist or psychiatrist. Overall, these children tended to have more responsive pediatricians, with less time elapsing between initial suspicions and diagnosis. This is likely due to the older age at which the first symptoms appeared. After two years of age, speech delays are more apparent and taken more seriously by pediatricians. In fact, only two children who showed symptoms after two years of age had non-responsive pediatricians. It was also more likely for these children’s symptoms to be noticed by someone other than a parent, such as a

\(^{27}\) This is yet another domain in which the fighting parent is evoked. Under IDEA, states _must_ provide services to all children under three years of age who qualify. At least one parent I observed at the AMC told of how she insisted that her son receive services despite the fact that he was just a few months away from his third birthday.
health professional or teacher in school. Certainly the latter has the advantage of directly comparing the child to his or her neurotypical peers.

It would seem, then, that after a certain age – approximately 2½ years – both the medical and school systems more readily confront the possibility of an autism diagnosis, without the assistance of Early Intervention. Still, what Career D families show is that Early Intervention allows one to bypass the tradition medical decision tree – first rule out the obvious (usually a hearing problem), then begin testing for the most likely problem, etc. – and immediately begin focusing on developmental issues. For parents visiting one specialist after the other, the process can endure for months. On the other hand, Early Intervention and similar institutions conduct all of their testing in one day, giving parents an immediate answer from which they can begin strategizing the subsequent course of action. Early Intervention also gives parents details about their child’s specific challenges in terms of a percentage – 25% delayed in speech, 30% in motor development, and so on. Not only do these figures put the vague notion of delay into concrete terms, they also provide parents with intervention targets and help structure the course of treatment. At the same time, parents learn how suppress the desire for a cure and to instead work on small goals and derive satisfaction from them.

Three children in this category were diagnosed early enough to qualify for Early Intervention, but still did not receive them. Melanie’s family was preparing to move out of the country, hence her parents willingly withdrew altogether from the process. Christina and Andrew, on the other hand, were certainly diagnosed young enough to benefit from Early Intervention services (both prior to their second birthday), yet neither did. Accordingly, their
parents expressed feelings of guilt or anxiety. Christina’s mother, Frances, said she was confused when the neurologist instructed her to go to the school district.\textsuperscript{28} Thinking that at 18 months, Christina was much too young for school, she waited one year before following the doctor’s advice. She explained:

\begin{quote}
P: Now, looking back, me not knowing things the way I know now, I feel really upset that I allowed that [lack of services] to go on in her young years. Because the young years, I realize now, was the years she needed the most services. And those were the years that she got no services practically.

[...]

I: So even though she was diagnosed at about 1½, they still said...

P: Right. [So they told me] to go look on the internet. I didn’t really realize about all that stuff, and go talk to your school district. I just felt she was young so I didn’t pursue it then. And then about two years old, I started looking into what they told me. And then at two, when I started looking into it, they’re like, well, she’s 2½, she’s kind of too old to do this early intervention because at three you become part of the school district. And I believed it all. And when she went to the school district, they just had her in like a handicapped program with high-functioning kids. She never had any kind of ABA or any of that stuff that she should have probably had. (NR 021)
\end{quote}

In this case, Frances did not assume the role of the fighting autism parent after Christina was diagnosed, and this lead to feelings of guilt. Michael’s mother did not experience guilt so much as anxiety as she tried to decipher the diagnosing doctor’s instructions regarding treatment:

\begin{quote}
P: But really we couldn’t find an audiologist who could test him either so it was very unclear if it was his problem or the testers problem and no one wanted to commit at that point too and so for the next four or five months it was just gobbledy-gook which is completely not what it’s like now. If you have any issues or problems people pretty much know where to send you. But nobody knew where to send us or if they did you had to wait months and months to get an appointment and the months and months were vital pieces of time we found out
\end{quote}

\textsuperscript{28} In some states, Early Intervention is provided by the school district.
as we went along. So, we saw Dr. Jameson [...] So, he saw Michael for like five or ten minutes and he just said, ‘Your kid’s retarded.’ Which wasn’t, you know, or he’s got autism, take him home, stimulate him and then come back in a year. I thought, what is that? And then he called, I called him back later cause I said you know I really had to clarify this, this seemed a little much to me, and I didn’t, I needed to understand it a little bit better and, he gave me the name of some social worker in Manhattan on the west side and I could go talk to her. And by the time –
Q: So he didn’t like make any official diagnosis in the charts or anything, he just--
A: No, he just said autism or mentally retarded, doesn’t really matter right now, you’ve just got to stimulate him. Which is pretty open, right?
Q: Yeah.
A: A little loose. And get a speech therapist. There was no speech therapist to be had. I mean it was just incredibly vague. (BH.12.12.07)

As his mother points out, when Michael was diagnosed in 1994 there were far fewer resources available to parents. The absence of this infrastructure or even more detailed instructions lead to a desperate scramble to put together a treatment regimen that was sufficiently stimulating, without feeling confident about what exactly that meant. It is precisely this gap that Early Intervention fills today.

The observation that more educated parents (i.e., Career C) are more likely to get a diagnosis for their child at a young age before Early Intervention begins begs the question, are Career D parents, who receive the diagnosis at an age too late for Early Intervention or do not enroll in EI earlier, less educated than other parents? According to Table 1, the mean education for these parents is 16.71 years, somewhere between a Bachelor’s and Master’s degree. In fact, one parent in this group possessed a doctoral degree, and another was a Ph.D. candidate in – strikingly – Special Education. This is a curious result that demanded a closer look, for the only other parents with this degree of education fell into Career C. Moreover, if these two parents
are removed from the calculation the mean years of education in Career D drops from 16.71 to 15.20 (which, consequently, would be the lowest observed average across all career types). Though we surely cannot draw any firm conclusions, it is interesting that both of these families are unique in that the parents are foreign born. Barry was actually diagnosed in the Philippines and did not arrive in the United States until he was thirteen years old. Melanie’s family was Kuwaiti and in the process of moving to England when she was diagnosed, so there was little time to enroll in Early Intervention. Foreign nationality might also help explain why these parents, despite their education, did not initially suspect autism. For one, there may exist different cultural expectations of child development. Also, autism awareness was low outside of the United States in the late 1990s. And even if these parents had suspected autism, they may have been challenged while attempting to navigate a new medical infrastructure. They might have also struggled to have clinicians take their claims seriously.29

Perhaps another way to regard the differences between diagnostic careers is in relation to the decreasing age of diagnosis. In the sphere of developmental medicine, the current understanding is that there exists a critical window in which certain skills must develop; otherwise, the chances of acquiring that particular skill rapidly diminish. On the other hand, it is difficult for clinicians to determine whether developmental delays are minor or symptomatic of something more serious such as autism. For instance, many parents explained that they received a PDD diagnosis because it was too early for autism to be diagnosed. As pressure mounds to diagnose autism younger and younger, and with the evidence that this is already

29 For example, on several occasions at the AMC, Dr. Daly doubted the word of parents who spoke English as a second language, insisting that they could not know whether or not the child could actually understand English.
happening, presumably more parents will find themselves navigating the careers I have denoted A and B, and consequently fewer parents missing Early Intervention (and so following Career D). With time, then, Early Intervention increasingly bears the greater burden of mediating this uncertainty in prognosis.

**Diagnosis after Early Intervention (Career E)** A small subset of children in this study tracked careers which resisted categorization in the present scheme. Three received Early Intervention services for problems that were not related to autism, including seizures, physical delays, and deafness, and so were already involved with the system of childhood surveillance before autism was suspected. These parents reported becoming suspicious of a problem as early as five (and no later than seven) months of age, yet only one child received an ASD diagnosis before his fourth birthday (and was, coincidentally, also the only child born after 1994, the year in which the DSM-IV was published). All of these children received the autism diagnosis after aging out of Early Intervention, meaning that schools and physicians played a more significant role in the labeling process for these children.

Two of these children – Mark and Amanda – were amongst the oldest in the sample, born in 1989 and 1994, respectively. Mark’s mother was the only parent to describe the moment she first thought about autism as a possible diagnosis for her son as a sudden revelation, a *Eureka!* moment. Meredith, who holds a Master’s degree in Public Health and was working within the Early Intervention system when Mark was born, attended a conference on

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30 For instance, in California 12% more children were diagnosed before age five years in the 1996 birth cohort as compared to the 1990 cohort. It is estimated that later birth cohorts will show a 24% rise in the proportion of diagnoses by age five. Hertz-Picciotto, I. and L. Delwiche (2009). "The rise in autism and the role of age at diagnosis." *Epidemiology* 20: 84-90.
autism and developmental disabilities when Mark was three years old. Here she attended a session in which the presenter spoke about the new, expanded (or spectrum) definition of autism. As she recalls:

I was sent to a conference where Barry Prizant was the speaker and he was speaking about language and specifically autism and the DSM-IV criteria and I remember, that was like my *Eureka!* moment, I sat there and I left the conference and called my family who was babysitting and I said, “I think Mark has autism.” He fits all the characteristics, but nobody has ever put that together. (NR 003)

Here Meredith provides a supply-side account for Mark’s subsequent diagnosis: the new DSM-IV criteria for autism described her son perfectly. In a climate where there were few autism experts, Meredith sought out a neurologist who specialized in autism and Mark was diagnosed with PDD-NOS. Since he had already aged out of Early Intervention, Meredith mobilized her own expertise of developmental disabilities to eke out what she felt were the most appropriate services and educational plan for her son. Like that of most mothers we spoke to, Meredith’s story is replete with rich descriptions of how her own agency determined her child’s educational fate.31

Amanda, who was enrolled in Early Intervention to help with physical delays, was not diagnosed with autism until she was eight or nine years old. At the time, her mother Jackie recalls that she already had four other diagnoses, including mental retardation and ADHD.32 Because of these pre-existing conditions, Amanda regularly visited a neurologist, and it was during one of these visits that she was diagnosed with autism. Up until this point, Amanda’s

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31 I thank Neta Oren for drawing my attention to this observation.

32 Jackie could not recall the other two diagnoses.
educational setting had always been in a special needs classroom or school. The new diagnosis, which Jackie describes as mild autism, did not spur any changes in Amanda’s schooling or treatment regimens, perhaps because the mental retardation diagnosis had already solidified a poor prognosis. In fact, the only change resulting from the diagnosis seems to be a recasting of Amanda’s earlier childhood:

I: Did it change the way you understand Amanda, and the way you interacted with her?
P: No, the only thing was that when I started going back to when she was two or three, certain things... when it came to brushing her teeth, as an example, that they hate the toothpaste or whatever, like stuff like that where I started to realize that she was showing all of these signs since she was a kid, a little baby. So going back, reading and stuff like that, it helped me understand her more. (NR 006)

Again, Amanda’s story seems to emphasize supply-side forces: changes in the DSM criteria coupled with rising awareness amongst clinicians. Her case is quite possibly one of diagnostic substitution from mental retardation to autism (Shattuck 2006; King and Bearman 2009), initiated by her neurologist. As she was one of only two children who was also diagnosed with mental retardation at some point in the career, it is not possible to generalize to other children who were similarly reclassified.

Nicolas, the third child falling into this category, is a rather special case. At birth, Nicolas was diagnosed as deaf and began receiving treatment services as a toddler which were provided by a specialized school for deaf children. A teacher and speech therapist at this school were the first to suggest that Nicolas was autistic. A clinical psychologist observed Nicolas but,

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33 This seems to be readily accepted by Jackie, who when asked what she hoped the therapies would accomplish for Amanda, replied, “I hope the behavioral problems with the biting and the tantrums will stop.” (NR 006) In contrast, other parents had hopes that their children would become indistinguishable from their peers.
unsure of the diagnosis, insisted on continued monitoring until ambiguity could be further reduced. When Nicolas was two years old, the school suspected that he had autism and refused to continue his services, leaving his mother no option but to home school. At this point the psychologist diagnosed Nicolas with PDD-NOS so that he might receive services, but the school still refused to accept him, even with a state-provided individual aide. Home-schooling continued for over one year, until at 3½ years when he was enrolled in an autism program at a public school.

Thus, excluding Nicolas, whose story is particularly unique, what the Career E paths are most demonstrative of are supply-side arguments. Neither Meredith nor Jackie were shopping for an autism diagnosis; rather, it resulted from their position within the institutional matrix. Recall from the introduction that in 1989 – coincidentally, the year in which Mark was born – the prevalence of autism was estimated at just 4 in 10,000. At this time, there was little public awareness of the condition such that even someone like Meredith who worked in Early Intervention essentially found out about autism by chance. Had she not been employed within Early Intervention she would not have attended the conference at which she heard Barry Prizant speak, and it is likely that Mark, like Amanda, may have waited several more years to receive his diagnosis (if he would have received one at all). That Amanda was diagnosed at such a late age is illustrative of the rising awareness of autism amongst clinicians of the broadened diagnostic criteria. Because Amanda was already under medical surveillance for other conditions, particularly mental retardation, she had regular contact with a neurologist at a time

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34 Some of the symptoms of autism parallel those of children born without the ability to hear. Consequently, an autism diagnosis cannot be confirmed until a child has had a hearing test. That Nicolas is both deaf and autistic justifies excluding him from this argument.
when the prevalence had grown to more than 67 in 10,000. Thus, the diagnoses of Mark and Amanda appear to result from the changing diagnostic criteria of the DSM-IV and the increasing awareness amongst providers with which it was coupled.

**AUTISM EXPECTATIONS**

Given the evidence presented here, what is to be made of the notion that the diagnosis of autism is an artifact of supply- and/or demand-side forces? There appears to be at least some evidence for both types of explanations. For one, we saw that the diagnostic process for Career E parents seems to point to the significance of changes to the autism criteria in the DSM-IV as well as rising awareness of the disorder amongst clinicians. But the main strike against these theories is the behavior of pediatricians: rather than accelerate the diagnostic process, they function as retardants that actually prolong the practice. We have already seen that for most parents, the first mention of autism did *not* arise in the pediatrician’s office. In fact, while never asked specifically about the helpfulness of their pediatricians, several parents voluntarily reported that their pediatricians were extremely *unhelpful* during the diagnostic process, primarily through their reluctance to acknowledge that the child had a problem, or that it was anything more significant than “normal” late development.35 In effect, the conduct of pediatricians equips parents with the fighting instinct and teaches them to be suspicious of doctors. In part through their interactions with pediatricians, parents learn to follow their own interpretations of what is wrong and become prepared to battle for them.

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Does this imply that demand-side explanations offer a better account of the autism diagnosis? We saw that at least one mother demanded a referral to a specialist from her pediatrician. At the very least, the fact that parents’ initial suspicions demonstrated unfamiliarity with symptoms of autism should give us pause. For one, several parents told us that they suspected that their child was either deaf or was only speech delayed, whereas others claimed that they initially took their pediatrician at their word that nothing was wrong with their child. And only two of the parents interviewed claimed that they knew a lot about autism before hearing it mentioned in relation to their child. One had worked in a developmental disabilities center for a semester as a psychology major and had been exposed to the disorder then; the other explained that she had a neighbor with an autistic child, and also had several friends whose children were diagnosed with PDD-NOS. The latter was the only parent to express familiarity with the notion of the autism spectrum. But most parents admitted to barely knowing anything about autism previously, such as John’s mother:

I: And what did you know about autism before that?
P: None. Nothing. I’d never even heard of it. I had no knowledge. I had, I guess like anybody else, no reason to know about it, because I didn’t know anybody that suffered from it, I didn’t know anybody that had... well, my first son had these issues with his speech and all. That was like the first of anybody that I know, though. No friends who had... anybody with disabilities. (NR 020)

Moreover, when asked what previous knowledge they possessed about autism prior to hearing it first mentioned in relation to their child, the majority of parents indicated that they either knew very little about the disorder or nothing at all, with some parents admitting that they had never before even heard the word ‘autism.’ When these parents elaborated on the

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36 This observation appears to support the social influence theory, and will be discussed below.
little knowledge they had, they tended to refer to the characteristics that comprise what is now referred to by clinicians as “classic” autism, such as hand-flapping, head-banging and toe-walking. More up-to-date knowledge, including of higher-functioning forms of autism, was rare – recall that only one mother showed previous familiarity with the autism spectrum. This was especially evident as parents sometimes cited the film *Rain Man* (1988) as either a source of their knowledge, or the embodiment of it. Accordingly, when describing what they knew, they were more likely to refer to the “classic” symptoms as opposed to the spectrum symptoms, such as the following mothers:

I had my girlfriend’s son [with autism who] was a toe-walker, a hand-flapper, a lot of these very awkward, obvious signs [...] I think everyone’s typical thought is *Rain Man*, you think that severe. [...] So it was basically all of those signs, that there’s a language delay, that they’re socially... some kind of social... missing something, it’s just that they can’t really blend in. I always thought autism – just the root of the word – was that a child or person who was autistic was kind of into themselves, and pushed themselves outside of the world and the people around them... (NR 001)

I knew autism to be a kid that banged their head against the wall and their hands up in the air and shaking them. (NR 016)

The imagery of a child “in his own world,” of severe social withdrawal and self-isolation, is reminiscent Kanner’s (1943) original description of “autistic aloneness,” referring to the child’s seeming preference for solitude from his external environment and inability to relate to other

37 Clinicians today use this term in reference to the cluster of characteristics that were first described by Kanner, before autism was understood as a spectrum disorder. While the classic symptomology would still be diagnosed as autism today, it no longer represents the “typical” case that it did in the 1940s and 1950s. Kanner, L. (1943). *Autistic disturbances of affective contact*, Nervous Child 2 1943, 217-250.

38 Raymond, Dustin Hoffman’s character in the film, would today be classified as having “classic autism.” The character was based on Bernard Rimland’s son.
people. It resonates too with Bruno Bettelheim’s (1967) “refrigerator mother” hypothesis, which claimed that autism was a psychogenic disorder caused by cold and distant mothering. According to Bettelheim, as a result of the child’s frustration in his ability to have his needs met, “he withdraws to an inner redoubt in an effort to survive,” to an “inner fortress” (1967: 78).

That the “own world” metaphor was a recurrence in the parent interviews suggests not only that the imagery of the “empty fortress” still permeates today, but also that parents’ prior understanding of autism was indeed “classic” in more than one sense of the word.\(^\text{39}\) That such limited knowledge of autism was the common state of affairs for these parents prior to diagnosis suggests that, despite popular convictions, the diagnosis of autism is not driven by demand-side factors alone. One could also argue that in states where treatment services are offered even in the absence of a diagnosis, there are less incentives for parents to be aggressive. Rather, consonant with the argument put forth in this dissertation, it is institutional factors which shape parental responses: parents do not fight by innate instinct, but because they were coached to do so by Early Intervention.

Finally, some observations appears to support the social influence model. Tyler’s mother reports that she had a neighbor with an autistic child, as well as several friends who children had been diagnosed with PDD-NOS. It was through these channels that she learned about autism and the spectrum of symptoms. Another parent suspected autism because of a strong family history – three cousins with autism and an older son with Asperger’s Disorder. Still, this theory has limited purchase, as this sort of interaction was not commonly reported in this

\(^{39}\) In a telling example, one mother, observed during a diagnostic assessment, described to the clinician how she had thought that perhaps her son was ignoring her because as a tax accountant, she was probably “not ‘mommy’ enough.” She subsequently quit her job in order to devote herself completely to motherhood.
sample of parents. Most notably, not once did a parent report that another autism parent made the initial suggestion. In fact, parents report little communication with other parents until after the autism diagnosis is already secured. When they were reported, exchanges between parents tended to be mediated by a third party, such as a social worker, as described by John’s mother above.

So how do parents account for the way in which the possibility that their child had autism was introduced into the narrative of their child’s problem? Few parents seem to raise the possibility themselves, and more importantly, autism was not always a welcomed diagnosis. When parents were initially confronted with it, many resisted or even rejected the label and expressed shock upon hearing of it. As they describe it, they were unable to “see” autism in their child, it did not seem to be a valid description of their child’s symptoms and behaviors. We saw above how one mother thought that her child could not possibly have autism since he was so affectionate. Other parents – and this was usually in states where the provision of services was contingent on a diagnosis – began by referring to the diagnosis as only a “piece of paper,” but eventually they too came to identify and accept it. It is primarily through Early Intervention or a medical specialist, i.e., representatives of the system of developmental surveillance, that parents are introduced to autism as a possible diagnosis. These institutional actors – those affiliated with Early Intervention, schools, clinics, etc. – are the key mediators between parents and the autism diagnosis.
CHAPTER 2: THE STRUCTURE OF THE CLINIC

When I first set out to conduct my fieldwork at the AMC, I was most intrigued by the opportunity to witness differential diagnosis in action. How were “normal” kids – or as I would learn to refer to them properly, neurotypicals – distinguished from autistic kids? I expected to see a lot of ADHD, and maybe even a little bipolar disorder. After having read so much about diagnostic substitution from mental retardation to autism, I wondered too how this distinction was acted upon in practice, and how much work went into either separating the two diagnostic categories or co-diagnosing them. But to my surprise, none of this would I regularly witness at the AMC. Instead, all but two of eighteen patients – almost 90% – seeking a diagnosis did in fact receive a diagnosis of either Autistic Disorder or PDD (see Table 2-1). 40 I did see one ADHD patient, though this turned out to be purely by accident: he was supposed to be scheduled at his neurologist’s other office, not at the AMC. Moreover, on only one occasion was the mental retardation diagnosis even mentioned. And the latter was raised by the parent and subsequently denied by the clinician. How could my expectations – based primarily on the medical literature and accounts in the media – been so far off base?

Supply-side theorists would surely snicker at my naïveté: clearly, they would argue, you were witnessing the frivolous disposal of autism diagnoses to any child who showed up to get one. You saw no differential diagnosis because there is no differential diagnosis, there is only

40 Enrica, an eight-year-old girl, was diagnosed with significant communication impairment and secondary emotional and social impairment. Dr. Johnson was adamant that she just didn’t “see that it’s autism at all.” Rachel was a 23-month-old girl whose older brother is diagnosed with ASD. Given her son’s diagnosis, Rachel’s mother was concerned that her daughter might already be showing signs of autism. Both Dr. Johnson and Dr. Jenkins examined Rachel and felt that she did not appear to be showing early signs of autism. Rachel was the only patient to leave the AMC without any diagnosis.
autism and the access to therapies and other benefit that its diagnosis provides. Even one of
the AMC nurses was confused when I wondered aloud as to why I witnessed so little
differentiation. With the autism prevalence what it is today, she replied, I don’t think there’s
anything to be surprised about.

**TABLE 2-1: DIAGNOSES OBSERVED AT THE AMC**

<table>
<thead>
<tr>
<th>Name</th>
<th>Age*</th>
<th>Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Luis</td>
<td>29 months</td>
<td>Autistic Disorder</td>
</tr>
<tr>
<td>Robert</td>
<td>26 months</td>
<td>PDD-NOS</td>
</tr>
<tr>
<td>Marla</td>
<td>5 years</td>
<td>Autistic Disorder</td>
</tr>
<tr>
<td>Nelson</td>
<td>29 months</td>
<td>PDD-NOS</td>
</tr>
<tr>
<td>Melvin</td>
<td>29 months</td>
<td>PDD-NOS</td>
</tr>
<tr>
<td>James</td>
<td>30 months</td>
<td>PDD-NOS</td>
</tr>
<tr>
<td>Tyler</td>
<td>22 months</td>
<td>PDD-NOS</td>
</tr>
<tr>
<td>Parker</td>
<td>26 months</td>
<td>PDD-NOS</td>
</tr>
<tr>
<td>Lucas</td>
<td>3 years</td>
<td>Autistic Disorder</td>
</tr>
<tr>
<td>Dylan</td>
<td>21 months</td>
<td>Autistic Disorder</td>
</tr>
<tr>
<td>Andy</td>
<td>3 years</td>
<td>Autistic Disorder</td>
</tr>
<tr>
<td>Murray</td>
<td>3 years</td>
<td>PDD-NOS</td>
</tr>
<tr>
<td>Rachel</td>
<td>24 months</td>
<td>(No diagnosis given)</td>
</tr>
<tr>
<td>Emma</td>
<td>4 years</td>
<td>PDD-NOS</td>
</tr>
<tr>
<td>George</td>
<td>5 years</td>
<td>PDD-NOS</td>
</tr>
<tr>
<td>Nathan</td>
<td>3 years</td>
<td>Autistic Disorder</td>
</tr>
<tr>
<td>Sean</td>
<td>3 years</td>
<td>PDD-NOS</td>
</tr>
<tr>
<td>Enrica</td>
<td>8 years</td>
<td>Communication Impairment</td>
</tr>
</tbody>
</table>

* Given in months for children under 3 years of age and years otherwise.

In hindsight, I should probably not be too shocked by my finding, but for reasons other
than the presumed supply-side mechanisms. We have already seen in chapter one how
approximately half of the parents interviewed were directed to a diagnostician via Early
Intervention or a similar institution, so some parents were already prepared for the possibility
of autism. And at the AMC, as I describe below, children who are most likely to receive a
diagnosis of autism were preselected by means of the clinic’s intake routine. I was to learn that
I would not observe “pure” differential diagnosis at the AMC because it is an institutional process which transcends any specific chronological or geographical location.

In the previous chapter I recounted the struggle of parents and their search for an explanation of their child’s perceived difficulties. Diagnostic careers could take various forms, but what they all have in common is that the child eventually came to be diagnosed with an Autism Spectrum Disorder even though parents were at first highly suspicious that this could be the right diagnosis. It is through interactions with therapists and clinicians, I argued, that parents are made aware of the autistic symptoms their child displays and coached on how to be an autism parent. In chapter three, I will examine the parent-clinician interactions in more detail. This chapter is about the clinic, or more specifically, the institutionalized routines and practices through which the patient-in-waiting is funneled at the AMC. As I will show, this process extends well beyond the walls of the clinic. We have already seen how it begins with Early Intervention, where ‘at-risk’ children are flagged and directed to physicians specializing in autism. Next, at the AMC, patients are pre-selected based in part on their results on the Modified Checklist for Autism in Toddlers. But diagnosis is more than Early Intervention and the M-CHAT – for one, the latter has a tendency to drastically overestimate the number of children who merit a diagnosis, so it alone cannot explain the observation that most children visiting the AMC receive a diagnosis. Rather, these children are further funneled towards the autism diagnosis through the assumptions built into the clinic’s routines and procedures. As Dr. Daly told one mother before her son was diagnosed, “I assume he’s somewhere on the spectrum if you’re here.” Clinicians are looking for autism – after all, it is an autism clinic. Data on each child is reconstructed in the clinic through its practices, which in effect amount to a ‘test until find’
approach in which testing for autism continues until the child has duly earned the label. Even in the face of uncertainty the culture of the clinic favors diagnosis over non-diagnosis, with the belief that it is better to diagnose the well than to leave the unwell untreated.

Crucial to the institutionalized differential diagnosis performed by the clinic is the PDD-NOS diagnosis. It is through the use of this label that the children who have the potential to improve are distinguished from those who do not. This is the diagnosis that parents want, for it communicates that the child is not currently “all he will ever be,” but that he has the potential to occupy a seat in a mainstream kindergarten class. It is indeed the notion of potential that underlies the distinction between mental retardation, Autistic Disorder, and PDD-NOS. Children with PDD-NOS are the exemplary patients-in-waiting. These are the children who might eventually lose the label. This helps to explain why physicians often delay the decision to diagnosis Autistic Disorder until the child is closer to five years of age, and PDD-NOS is used as a placeholder until the final diagnostic decision can be made. Thus, the PDD-NOS diagnosis constitutes a crucial part of the meaning of parents’ experience of dealing with a diagnosis of developmental delay.

It is also through institutionalized clinical practices and routines that the diagnosis of autism by prototype becomes possible, for unless the flows and channels of the clinic are stabilized, this skill, the hallmark of medical expertise, cannot work. As more and more children outside of the ‘classical’ prototype arrive at the clinic, clinicians learn to expect these deviations and recognize them immediately. Thus, diagnosis-cum-prototype is shaped by looping processes, and so is not independent of the institutional funnel in which one is operating. The
differential diagnosis of autism is the totality of these institutional processes. This means that diagnosis is more than just the interplay of supply and demand forces: it is produced by this institutional funnel.

Hence, in this chapter I examine more closely the characteristics of the institution and those who populate it, setting the stage for chapter three in which parents encounter the clinic in the diagnostic interview. After a description of the methodology, I describe the history of the AMC, the physical space, and the daily activities that take place there. Next, I relate the routine practices of the clinic to the fact that almost every child assessed there receives an autism diagnosis. Finally, I take a closer look at the organization of clinical perception at the AMC and how clinicians perceive their own role as well as the role of parents, while paying special attention to the ways in which the notion of the autism spectrum facilitates interactions in the clinic.

**Methods**

*Site and Entry*  Over the fifteen month period from May 2007 until July 2008, I became a participant observer at the Autism Medical Center, a clinic specializing in the diagnosis and management of Autism Spectrum Disorders. The center is situated within the outpatient psychiatry division at a university hospital, which I have dubbed University Medical School, located in the tri-state area. Entry to the clinic was negotiated by my dissertation supervisor, Gil Eyal, who met with Dr. Michelle Baker, a pediatric neurologist and the clinic’s founding director, in November of 2006 and obtained her permission. While the conditions of my entry (as well as the title on my identification badge) stipulated that I was a volunteer at the clinic, no physician (or other employee, for that matter) ever requested that I act in that capacity at any time
during my residency. Thus, I was free to spend my entire time conducting observations. This proved to be particularly advantageous after I learned that the clinicians only met with patients on Wednesdays, though beginning in October 2007 one physician began seeing patients on Thursdays as well.

**Sampling Procedure** By necessity, my sample was one of convenience. For the first two days at the clinic, I observed all of Dr. Baker’s appointments. Parental consent was obtained before any observations were collected. In the periods between appointments I was introduced by Dr. Baker to two other staff pediatricians at the clinic, Drs. Michaels and Johnson, both of whom consented to my presence during their appointments. Dr. Johnson brought it to my attention that the staff psychologist, Dr. Daly, frequently conducted the ADOS for her patients and suggested I make a direct request via email to observe these sessions. Dr. Daly consented, and by the third week I was began observing Dr. Daly and the ADOS. Within a few months I had established my modus operandi. As my research is most concerned with the diagnosis of autism, I prioritized appointments in which a diagnosis was being made. In practical terms, this meant that I most often tried to observe families visiting the AMC for the first time, and were either seeing one of the pediatricians for a primarily interview-based diagnosis or the psychologist for an ADOS. This information was easily obtained from the secretary, whom I would call on Monday mornings for the doctors’ weekly schedules. When it became apparent that most of the older children visiting the AMC for the first time already had an autism diagnosis, I began to ask the secretary about patients’ ages and aimed to recruit patients less than five years of age. It soon became evident that new patients without prior diagnoses or those seeking a second opinion were always seen by Dr. Johnson. In many cases, Dr. Johnson
would have these patients see Dr. Daly for an ADOS, sometimes prior to her examination, but more often afterwards. Although Drs. Michaels and Baker also saw younger patients, these patients always had previous diagnoses. Thus, when at the AMC, I would prioritize new appointments with Dr. Johnson, then new appointments with Drs. Baker or Michaels, and then follow-up appointments for patients I had seen previously, and finally, any other type of appointment.

**Ethnographic Observations** Once enrolled in the study, I would observe patients whenever they had an appointment at the AMC. In total, I recruited 50 patients and four clinicians in the study. I sat in the corner of the room to observe the interactions during appointments or ADOS administrations, and did not initiate any interaction unless the doctor was not in the room. Notes were taken in plain sight. Presumably, this did not come across as unusual since the clinicians were often taking notes themselves. If the clinician left the room for any reason, I typically made small-talk with the parents, often keeping to autism-related topics. During these casual conversations, I would not take notes openly but would later jot down what I could remember during the bus ride home, or in the adult waiting room if I was waiting for another appointment. With regards to the physicians, I would try to ask as many clarification (i.e., “why?” or “how?”) questions about the appointment once the patient had left. Drs. Michaels and Baker regularly spent a few minutes clarifying things for me, but Dr. Johnson seldom had time between patients and her administrative responsibilities (although she once told me to call her later that evening). After administrating the ADOS, Dr. Daly would sit with me and score the test while thinking out loud, allowing me to jot down the scores and follow her train of thought. I was able to ask her questions as they came to me, to which she immediately
responded. Again, notes were always taken in plain sight when talking to clinicians, unless of course we were walking and talking, in which case I would jot down the conversation during the journey home. There were never any objections to my open note-taking, only the occasional joke about my having more information about the appointment than the doctors themselves.

**Semi-Structured Interviews** In addition to brief question-and-answer sessions I tried to maintain in the field, I conducted semi-structured telephone interviews with the four clinicians I regularly observed at the AMC. All interviewees were females. The length of the interviews ranged from eighteen to fifty-six minutes. The interview questions touched on four general topics: how they became interested in autism; their general views about its etiology and treatment; how they diagnose and treat autism, and their views on the role of parents in diagnostic and subsequent sessions.

**Data Analysis** An alternating inductive-deductive approach was used to analyze the interview and ethnographic data. To begin, I wrote summaries of the various activities I witnessed and based on these summaries, developed a coding scheme in line with the patterns I observed. The initial iteration of the analysis involved coding the data according to this scheme, as well as introducing new codes and categories for patterns that arose and recurred as I read through the entire set data in close detail. At the end of this iteration the coding scheme was revised accordingly, and I incorporated the new categories as well as discarded those that proved nonviable. At this point, I consulted the medical sociology and sociology of science literature for salient themes and consequently restructured the coding scheme. I then reanalyzed the data

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41 In fact, during the period of my observations, only three males appeared regularly at the clinic: the psychiatrist, the behaviorist, and the project coordinator (administration). Judging by the clinic’s website there were several more, but I encountered none of them in my fourteen months.
using this new coding scheme, and continued to do so until general agreement was reached between my coding scheme and the raw data. Thus, the resulting analytical framework is equally rooted in both theory and data, and as such serves as the basis for the argumentation of the dissertation.

**History of the Clinic**

The Autism Medical Center (AMC) opened its doors to the public in April of 2002, though the seeds of its founding were sown as early as 1999. At this time, the University Medical School (UMS) had a new dean who wished to establish two new centers for two ‘important’ conditions at the University. One was to be a cancer center, but the second had yet to be determined, and the dean sought input from his colleagues. Dr. Baker, a pediatric neurologist, along with Drs. Jenkins and Krumov (a psychiatrist and psychologist, respectively), met with the dean in one of the university cafeterias. Autism had been on the dean’s mind, though he was not yet sure if this was the right choice, so a meeting with several parents of autistic children was arranged. As Dr. Baker recounts the event, the dean saw that these parents tended to be wealthy and he imagined that they would constitute a reliable source of endowments for the center. He thus decided that the second center would indeed be an autism center.

Dr. Baker became the first director of the AMC. The center was intended to establish autism as a *medical* disorder, not psychiatric or behavioral, and in this sense would differ from its contemporaries in that it went beyond mere diagnosis and psychological testing. As she recalls, theirs was the first – or at least among the first – centers to adopt this perspective. The idea underpinning this approach is that several physical symptoms and conditions like allergies,
sleep problems and gastrointestinal disorders are common in children with autism and hence probably related to its pathology. Since all behavior is controlled by the brain, these physical ailments might parallel some of the processes that have gone awry in children with autism. In keeping with its theoretical foundation, when the center was staffed Dr. Baker insisted on a multidisciplinary team: in addition to the standard psychologists and psychiatrists, she wanted an immunologist, a gastroenterologist, geneticist and developmental pediatrician on board. Dr. Baker, herself a pediatric neurologist, lobbied aggressively for this team which included putting pressure on the president of UMS. In due time, her efforts were rewarded and the team was created. This essentially established a one-stop shop for parents, for whom more centralized care accrued benefits above and beyond a reduction in commuting time. As one parent put it, being able to address most medical issues in one place means at least “one less doctor to go to.” Even beyond medical concerns, parents would receive greater oversight for their children and be able to consolidate advice on medical, alternative and educational treatments under the care of a single physician.

The next challenge was to find a physical space in which to house the center. Dr. Baker negotiated an agreement with the University Neurological Institute (UNI) in which they would provide space for the autism team to see patients for one day of each week. The AMC doctors would meet with patients at the UNI each Tuesday, and hold a staff meeting at the end of the day to discuss the cases as a group and with a social worker. This arrangement lasted for about one year, until the UNI neurosurgeons decided that they wanted to expand their own operations and were in need of the space. At this point, frustrated with workplace politics and juggling her time between the dean, her administrative responsibilities and her own research
and clinical work, Dr. Baker quit as director of the AMC but remained on its staff. This was a rather weak point for the center, as she recalls, as there was neither a director nor a permanent home. The only alternate building under consideration was badly in need of renovations. Some funds were available, but not enough, and parents were becoming impatient with the university, which they had wanted to match their own financial contributions.

The center sat in a state of limbo from about six months to one year. Dr. Jenkins, a psychiatrist, was then named acting director of the AMC. At the same time, the Department of Psychiatry acquired a new building on campus and part of this space was allotted for the AMC. But Dr. Jenkins’ conception of the center differed from Dr. Baker’s, and he was less keen on the multidisciplinary approach. While the same staff members continued to see patients and shared the same physical space, the group meetings were dropped and there was little – if any – integration amongst the different physicians. Each clinician cared solely for his or her own patients. Apart from the pediatric neurologists and the developmental pediatrician, it appeared as though the other medical specialists do not hold their patient consultations at the AMC but rather within their own departments. Dr. Baker believed that the problem was rooted in the lack of independence afforded the AMC. The clinicians hold only an affiliation with the center, but are housed in different departments. The AMC does not compensate its staff, and as a result the director has little power. For her own part, Dr. Baker eventually found it difficult to see her autism patients in this new space. As several of her patients were also enrolled in her research studies, she often needed to draw blood or collect urine samples, and the AMC had neither the staff nor the physical resources. By the end of 2007, she had begun to see all of her patients (autistic or otherwise) from her office within the Neurology Department. While now
not even physically integrated with the AMC, she still considers herself a staff physician with the center.

**THE SPACE**

The AMC sits on the third floor of the Psychiatry Building, behind a set of glass double doors just in front of the elevator. Passing through the doors one immediately encounters the front desk whose angular layout encloses the receptionist in a triangular space. The walls in this area are a dusty blue and decorated with several small pieces of artwork. The paintings are bright-colored oil paintings with abstract designs of mostly vertical brush strokes, but sometimes different shapes. The two walls behind the reception desk were windowed, with the one on the left facing the adult waiting room and the one on the right the family waiting room. Autism is visible from the moment one steps out of the elevator. The center’s name and logo are on display behind the reception desk, which itself is littered with pamphlets of various sorts – one advertising the local autism advocacy group, another listing upcoming seminars, and a small informative booklet. Even the artwork, I would later learn, was made by autistic children.

The paintings disappear and blue walls turn eggshell white as the main hallway is traversed past the family waiting room to the first intersection. The walls are completely bare as are the doors of the offices and examination rooms along this hallway. No signs indicating directions, no family pictures to decorate office doors; ‘bland’ is perhaps even an understatement. Autism is no longer visible but now audible as the occasional vocalization escapes from within the rooms along the first intersecting hallway, where I would conduct most of my observations over the next fourteen months. I would seldom venture past this crossing – not more than fifteen yards from the reception desk – except to observe the occasional ADOS
or grab a coffee from the conference room at the third such intersection. To the right are two rooms used for medical examinations, equipped with a gurney and blood pressure recorder, as well as the office that Dr. Michaels uses to see her patients, equipped only with an empty desk, several chairs and some toys. To the left is the office used by Drs. Baker and Johnson during their appointments. This was the only room with any personal items – namely, Dr. Johnson’s many diplomas on the east wall – but after time this seemed more an oddity than anything else. Dr. Johnson was never to be found in this room outside of her consultations with autism patients, and always transported the necessary items – files, copies of scales, even a pen – into the room when she used it. ADOS examinations were conducted in a room split with a one-way mirror (though the other half was never utilized), located off of the second intersection.

Several weeks into my ethnography at the clinic, I noticed a number of staff members who were seeing patients, but to whom I had never been introduced. I asked the receptionist, Carla, if they were also seeing patients with autism. It was then that I learned about the Center for Child Development (CCD). The CCD operated in the same space as the AMC, but while there was some slight overlap in administrative staff, the two centers functioned entirely independently of one another. Moreover, and almost metaphorically, to the unexpecting eye the CCD was completely overshadowed by the AMC: no logo was hung in the reception area, there were no pamphlets, and Carla always answered the phone with, “Autism Medical Center, how may I help you?” Indeed, had I not been so eager to observe as many diagnostic sessions as possible as well as explore the boundaries of the center, its presence might have easily escaped me as well. The CCD, I was to learn, served to evaluate children with developmental problems other than autism. It consists of a staff of physicians, psychologists, speech
pathologists and occupational therapists who evaluate children on a one-time or continuing basis in order to provide a report of the child’s abilities and needs, and serve as a recommendation for necessary services to be provided by the schools. Like the AMC, the CCD does not itself provide treatment services.

THE DIVISION OF LABOR
Over the course of fourteen months at the AMC three clinicians emerged as the face of the clinic, sharing the responsibility of accommodating the new patient load: Dr. Johnson, a developmental pediatrician; Dr. Baker, a pediatric neurologist; and Dr. Michaels, also a pediatric neurologist. Over time it became apparent that Dr. Johnson performed the majority of the new diagnoses for patients who had not yet been diagnosed or were seeking a second opinion. In fact, I did not observe any other clinician conducting the initial diagnostic testing for a patient. I also did not witness Dr. Johnson performing the ADOS herself, though she sometimes worked in conjunction with clinical psychologist Dr. Daly who had been trained in the administration of the ADOS. Dr. Daly’s specialization is not autism but Fetal Alcohol Syndrome, though she does work with children who have developmental problems. Typically, a new, undiagnosed patient would be scheduled to see Dr. Johnson for an interview in which she would ask parents questions and spend some time herself interacting with the patient. The latter could last anywhere from a few minutes to several hours, and seemingly depended on how difficult it was to categorize the child. Often these “tricky” cases were immediately directed to Dr. Daly for an ADOS and would return weeks later for an appointment with Dr. Johnson, who would then

42 Sometimes, the child would have only seen Dr. Johnson after the ADOS.
interpret the ADOS results in light of her own observations and present the patient’s final diagnosis.

The multidisciplinary team at the AMC also included a geneticist, gastroenterologist, and an immunologist. These physicians are affiliated with the clinic but only see patients by referral on the part of the three primary physicians. Only the geneticist took autism patients at the AMC, the other physicians presumably worked out of their usual office. When any of these physicians see patients, they prepare a report for the referring primary physicians which is then discussed with the family. Two nurse coordinators, who were not on staff when I joined the clinic, were hired during the observation period to lessen the burden for Dr. Johnson. They are responsible for the physical examinations of patients and completion of progress reports for follow-up patients. Drs. Baker and Michaels perform these examinations themselves. Dr. Jenkins usually saw adolescent patients for counseling therapy, sessions which I was not granted permission to observe. However, on occasion he was asked to offer his opinion on a few of the more complicated cases, which I was able to observe.

Three non-medical autism specialists also work with the AMC. Melissa Jones assists parents with outreach and advocacy. She provides parents with information on social programs, community events, as well as the various school programs in the different counties. She has also helped parents dispute service provisions they did not agree with, and on occasion has even accompanied some families to court. Sara Goldstein is the Director of Outreach and Education at the AMC, though I rarely encountered her during my visits. Steve, a behaviorist,
was the only therapist working with the center (which was on a contractual basis). In my observations, only Dr. Michaels consistently referred patients to Steve.

Every new diagnosis or ADOS that I observed – of which there were eighteen – was conducted or ordered by Dr. Johnson. Thirteen of these were preceded by an ADOS with Dr. Daly. Dr. Michaels was occasionally consulted by parents for a second opinion on diagnosis, but typically saw follow-up patients or parents seeking her opinion regarding treatment. During the first five weeks of observation Dr. Baker screened patients for her new research study; otherwise, she normally saw follow-up patients. The doctors worked independently of one another and I witnessed little formal discussion over patients among them, as results from the ADOS or other tests were always communicated by means of a formal report. However, clinicians did on occasion consult one another on more complicated diagnostic cases. Still, in all of my observations, while both Drs. Baker and Johnson would refer patients to other specialists on staff, only Dr. Michaels presented the center to parents as serving more than just medical needs, telling parents not only of the other physicians on staff but the behaviorist and outreach personnel as well, whom she referred to as the “most important people at the center.”

DAN!, THE AMC, AND THE BIOMEDICAL TREATMENT OF AUTISM

The Defeat Autism Now! (DAN!) project was created by the Autism Research Institute, which was founded by Bernard Rimland. The project is “dedicated to educating parents and clinicians regarding biomedically-based research, appropriate testing and safe and effective

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43 Since Dr. Johnson’s new patient time slot overlapped with that of the ADOS, I often had to choose between the two options. If Dr. Johnson was seeing a patient whose ADOS I had observed, I would join her appointment. Otherwise, I would observe the ADOS.
interventions for autism.”⁴⁴ DAN! challenges the notion that autism is an incurable, lifelong disorder, and its proponents speak of “cures” and “recoveries” from the disorder. As mentioned above, the AMC was established as a center for the *medical* treatment of autism. Though both the AMC and DAN! practitioners contend that autism is caused by an interaction between genetic and environmental factors, because of the controversial nature of DAN! treatments, it is important to distinguish the practices employed at the AMC from those of the DAN! movement, a task which I turn to now.

There is certainly some overlap between the treatments prescribed by physicians at the AMC and DAN! physicians. For instance, I witnessed the frequent prescription of elimination diets (especially the gluten-free, casein-free diet), and nutritional supplements on occasion. However, as Silverman (2012) reports, these treatments, while originating with DAN! and the ARI, are becoming more commonly accepted in the broader medical community. As Dr. Johnson put it, the diet is not the “voodoo science” it used to be. Knowledge of DAN! theories and treatments is not foreign to Dr. Johnson - indeed, she was the one clinician at the AMC who was known to attend DAN! conferences. This, she claimed, was in part to better understand the totality of practices her patients might be engaged in outside of the AMC, several of whom were regularly visiting DAN! practitioners. Dr. Johnson does not consider herself to be a DAN! practitioner: by her own telling, she claims she does not have enough scientific evidence to engage in many of the DAN! treatments. In several instances, I witnessed her explaining to patients interested in chelation and hyperbaric oxygen chamber therapies that these

techniques had not been proven effective. She also does not believe – as is not uncommon amongst DAN! doctors – that vaccines cause autism. Finally, I did not find the name of any of the AMC clinicians on a searchable database for DAN! practitioners. Thus, despite the similarities among etiological theories and prescribed treatments between DAN! and AMC physicians, I believe this stems more from a broader acceptance of these ideas by the medical community at large, as opposed to any specific allegiance to DAN!

**Sources of Knowledge**

Medical diagnosis makes for a challenging ethnography. This is especially true when all the symptoms of a condition are behavioral. Though I could make note of the questions clinicians asked and the answers parents gave, I had no special access to information that was thought but not verbalized. What was the clinician looking for when she watched a child play? And how much weight did that observation carry in the grand scheme of diagnosis? As I will describe in the next chapter, my attempts to ask clinicians these questions directly – when time allowed – yielded few definitive answers. But failed attempts at mindreading can be partially overcome by taking stock of the various sources of information which clinicians both consume and produce (often at the same time) within the clinic. This sort of formalized information assumed five different forms at the AMC. Except for the administration of the ADOS, most were incorporated into the diagnostic interview.

**Intake and Follow-up Forms** Parents could receive an appointment at the AMC through two possible channels, either by calling the AMC directly or being directed their after a telephone
intake with the CCD.\textsuperscript{45} Once granted an appointment they are required to mail in a set of completed intake forms, including the standard demographic and insurance details as well as acceptance of the hospital’s privacy practices typically required of any medical clinic. But the main component of the intake is a detailed, eleven-page patient history form organized into seven sections,\textsuperscript{46} and the bulk of the information collected is based entirely on parent recall and opinion. While one parent told me that she was frustrated when Dr. Johnson seemed not to have read the information she had so laboriously provided, all doctors often referred to this data during the diagnostic interviews. Indeed, a rehashing of the intake information during the initial interview was routine practice at the AMC. Only Dr. Daly did not refer to the intakes during her sessions, though she did inquire about several developmental milestones as she conducted the ADOS. Parents who are not new to the AMC are asked to complete an analogous, follow-up form to record any progress or changes in the child since the previous visit. This is the place to indicate any changes – improvements or otherwise – in the child’s behavior. Parents are also asked to indicate here whether they have made any changes to the child’s treatment regimen.

\textit{STANDARDIZED TESTS AND SCALES} The ADOS, described in detail in chapter four, was the only standardized test that was conducted with any regularity at the AMC. The Gilliam Autism Rating Scale (GARS), based on the DSM-IV-TR criteria for autism, was designed to differentiate between individuals with autism and those with severe behavioral disorders, as well as

\textsuperscript{45} I will describe the CCD’s telephone intake process in greater detail below.

\textsuperscript{46} These are: birth history, family history, medical history, diet (including food allergies/intolerances, supplements, and attempted dietary treatments), developmental history (including dates milestones were achieved and details on the child’s use of language, socialization, and emotional/behavioral control) school history, and the child’s history of evaluations and therapies.
neurotypicals. Unlike the ADOS (which was always conducted separately from the diagnostic interview), the GARS can be completed in an unstructured setting by anyone who knows the child well, including parents. Despite this flexibility, I only witnessed the GARS being used once. Similarly, the Childhood Autism Rating Scale (CARS) was never performed in my presence, though one follow-up appointment Dr. Johnson remarked on how much the patient had improved since they did the CARS on his first visit, on which he was classified as ‘mild autism.’ Speech and language assessments were the only other tests conducted that were not autism-specific. Again, they were rarely used, and only by Dr. Johnson. More common was less structured testing of the patient, such as having him put a puzzle together or stack several blocks, or asking him to hand over a particular toy.

**PHYSICAL EXAMINATIONS** Each child underwent a physical examination during their appointment, usually after the interview if performed by the physician herself, or before it if performed by a nurse. These exams were often the only portion of the experience that followed a script most like a ‘normal’ doctor’s appointment, except of course that it can prove quite challenging to look inside the ears of a child with autism. Measurements of height, weight, blood pressure, and standard neurological and motor skill assessments were all part of the program. Physical exams also allowed physicians to assess any of the side effects associated with the medications they frequently prescribed, especially weight gain and breast formation. Blood testing was regularly ordered to monitor liver function for one commonly-prescribed medication in particular.

47 In her interview Dr. Michaels, a pediatric neurologist, told me that with respect to diagnosis neurologists do not rely heavily on structured tests.
**OTHER FORMAL REPORTS** In addition to their own observations, clinicians make use of data and observations provided by other physicians, teachers and therapists. Children with digestive problems were often referred to the staff gastroenterologist, Dr. Chang, and this information was incorporated into the treatment recommendations for these children. The staff geneticist, Dr. Artuso, could be called upon to rule out genetic abnormalities such as Fragile X Syndrome, which causes symptoms akin to those of the Autism Spectrum Disorders.¹⁴⁸

**DIAGNOSTIC OR FOLLOW-UP INTERVIEW** One could say that all roads lead to the interview: it is here where the various information sources converge and together culminate in the diagnostic act. Here was the opportunity to ask parents to expand on or clarify the data on the intakes, but also observe the child and interact with him or her. The interview constituted my primary unit of observation at the clinic, and consequently will be the subject of chapter three. Typically, diagnostic or new patient interviews lasted between forty-five minutes to one hour but on occasion could last the better part of the day. Follow-up interviews lasted about thirty or thirty-five minutes. No clinician followed any written questionnaire during the interviews though they all appeared to adhere to the structure of the intake forms and the manner in which they processed new patients was remarkably similar.

**ESTABLISHED ROUTINES AND THE PRODUCTION OF KNOWLEDGE IN THE CLINIC**

In part responsible for the high proportion of autism diagnoses at the AMC was the fact that the segregation of ‘autistic’ from ‘other’ had begun to be processed before the children were assessed at either center. While many parents visiting the AMC were self-referred and

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¹⁴⁸ In fact, children who test positive for Fragile X Syndrome may retain their ASD diagnosis. Current clinical opinion is that Fragile X Syndrome is one possible cause of autism, though not all children with Fragile X are autistic.
suspected autism in particular, they called this center directly. But since many parents know nothing (or at least very little) about autism before their own child is diagnosed, and since several suspected either speech delay or a hearing loss to be likely, it seemed possible that these parents might have first come into contact the CCD. To help me understand how these parents might be directed to the AMC and not to the CCD, I spoke to Martha, the intake nurse who was primarily responsible for making these distinctions.49

Martha would use the Modified Checklist for Autism in Toddlers (M-CHAT; Robins, Fein et al. 2001) when conducting telephone intakes. The M-CHAT consists of twenty-three yes/no questions that can be answered by parents of toddlers 24 months or older over the telephone. The questionnaire is an extension of the Checklist for Autism in Toddlers (CHAT) developed by Baron-Cohen et al. (1992), but has the added benefit of successfully screening not just for Autistic Disorder (as with the CHAT), but the larger population of children with “autistic features” (including PDD-NOS) who are in need of intervention. In other words, as a screening device the M-CHAT is intended to maximize the pool of positive results because, if effective, it will identify at-risk toddlers, including some who will later be diagnosed with autism and some who will not. In one study, in which 4797 toddlers were screened at a well-child pediatric visit, 466 (9.7%) children screened positive on the M-CHAT. Of the 362 children who were then given a follow-up interview, only 61 were still found to be at risk (Robins 2008). Leviton et al. (2009) found that children born preterm were more than twice as likely to screen positive on the M-

49 Martha explained that before Dr. Johnson left the UMC, Martha would complete the intakes and review them together with Dr. Johnson in order to decide who would be seen at the AMC and who at the CCD. This would have been the case during my time at the AMC, as I ended my observations before Dr. Johnson’s departure. At the time of my interview with Martha, however, she was still completing the forms but Dr. Daly had taken sole responsibility for these decisions.
CHAT, and that the odds of a positive screen grew to as much as twenty-three times more likely of the child was unable to sit or stand independently and eight times for children with major vision or hearing impairments. Even when the M-CHAT is supplemented by a follow-up interview, the positive predictive value of the questionnaire is only 0.57 (Robins 2008). Nevertheless, the M-CHAT attempts to address the same need as does the AMC: to minimize the gap between the initial detection of symptoms and the formal diagnosis of an ASD. Pediatricians rarely identify autism before a child reaches three years of age, though this is long after parents first become concerned and research shows that some early signs of autism can be detected at 18 months (Baron-Cohen, Allen et al. 1992; Rogers and Laraine Masters 2000). As shown in chapter one and elsewhere (McLaughlin, Sices et al. 2004), parental expression of concern to pediatricians does not necessarily result in a referral for diagnosis. Not only does this cause a good deal of stress in families, but delayed diagnosis means delayed intervention, and early intervention has been shown to improve prognosis for these children (Rogers 1996). Thus, “time is of the essence” to identify those at-risk as quickly as possible and bring them into the rubric of developmental interventions.

When I pressed Martha for details about her interviews with parents, she immediately declared – without my prompting – that she never mentions the word ‘autism.’ As she described it, “I don’t want to put ideas in their head, you know. I don’t want to prejudice them in any way.” This sentiment was repeated at least five times in a conversation lasting no longer than five minutes. Sometimes the parents are not aware that it is probably autism, sometimes the referring doctors do not tell them, but her job is to “make sure they’re coming to the right place.” To that effect, she asks parents about the behaviors they are concerned about and what
diagnosis they are thinking about, but never whether or not they think their child has autism. This, she insisted, would be too suggestive. Martha was not unlike her colleagues at the AMC in that during her interview with me, she worked to establish a sense of objectivity with respect to the children and parents she encountered and the autism diagnosis. Though it was never articulated by any one practitioner, their responses sometimes had the effect of establishing the “reality” of the autism epidemic, as if to ensure that I did not get the impression it was being created in the clinic by its staff. This was not unlike responses of clinicians to questions regarding how they first came to work with autistic patients, which I discuss below. The autism epidemic happened to them — that is to say, more and more autistic patients presented at the clinic — and not the other way around — i.e., doctors did not change their diagnostic practices so as to produce more autism cases. And not only does the increase in diagnoses produce the epidemic, but the epidemic serves as the legitimizing narrative for this practice, for one could not justify diagnosing almost all patients with an ASD if there were not an epidemic.

As commendable as Martha’s efforts may be, her vigilance is perhaps less necessary than she realizes. As we saw in chapter one, parents often start hearing about autism before the child is diagnosed, often at Early Intervention. If one of these parents had spoken to Martha, they certainly would have mentioned autism and obtained an appointment at the AMC whether Martha herself had mentioned it or not. Earlier steps in the diagnostic career delineate the space of the subsequent sequence. Thus, while differential diagnosis is ultimately formalized in the physician’s office, it is a process which begins sometimes long before the diagnostic interview, and certainly has consequences for the future. The point is that the diagnostic interview occurs in a setting which pre-structures its course towards the production
of an autism diagnosis. Even the belief that we are in the midst of an autism epidemic has its role. As Bloor (1976) describes a study by Bakwin (1958) of 1000 New York schoolchildren undergoing assessment for tonsil-adenoidectomy:

Sixty-one percent of these children had already lost their tonsils, the remaining 39% were assessed by a group of school doctors who recommended that 45% of the children should undergo 'T's and A's' and rejected the rest. The rejected children were then sent to a second group of doctors who recommended surgery for 46% of them. Those children twice rejected were sent to a third group of doctors who recommended surgery for 44% of them. At this point only 65 of the original 1000 children had not been either operated upon or had the operation recommended for them. (44)

Though the results of individual assessments by these doctors is not reproduced from one group to the next, the expectation that about 45% of children require the operation is. As Martha replied when I wondered aloud how nearly every child at the AMC received and ASD diagnosis, I should not be so surprised given the high prevalence of autism today.

As Berg (1992) has shown in his analysis of how physicians construct medical disposals, the presumption that biomedical knowledge directs the physicians actions simply does not hold. To the contrary, the data confronting the physician in the diagnostic interview is not so much “uncovered” as “(re)constructed” in the diagnostic process. As he puts it, the “type of questions a physician asks, the way she asks them and her interpretation of the answers shape the symptoms of the patient” (157). Thus, while routines can be useful in facilitating medical action, they can also have the effect of pre-structuring the clinician-patient interaction so as to produce one diagnosis more favorably than others as it is already embodied in the diagnostic process. Consider the general routine at the AMC. As mentioned above, the M-CHAT – which maximizes the number of children identified as ‘at risk’ for autism – was used in the telephone
intakes. The patient history form, which serves as the basis for the in-person interviews solicits information specific to an autism or PDD diagnosis. Children who by this point could not be given the diagnosis were tested with the ADOS, a scale with a propensity to overdiagnose PDD-NOS in neurotypical children (Lord, Rutter et al. 2002). All children tested with the ADOS received at least a diagnosis of PDD-NOS. Furthermore, not once did I witness the administration of a test for a non-ASD disorder. In other words, other than reliance on clinical intuition, no systematic effort was made to eliminate the possibility of false positives. Instead, diagnostic work at the AMC appeared to follow what Mehan (1986) refers to as a ‘test until find’ approach.

Similarly, the choice of the standard to which the patient’s symptoms are compared shapes whether or not they are considered as part of the autistic prototype or external to it. For instance, an estimated 44-83% of children with autism suffer from various sleep disorders (Richdale 1999), and this issue is routinely discussed in the diagnostic interview and queried in the intake form. Still, when Henry’s mother complained that he has troubles staying awake during the day and falling asleep at night, Dr. Baker insisted it was not related to autism and noted that compared to normally developing children as represented on a graph of sleep hours by chronological age, Henry sleeps for an adequate amount of time. Likewise, when Henry’s mother expressed her concern about his weight and eating habits, Dr. Baker referred to a similar chart:

Dr: So 34 pounds, that’s about the 25th percentile. That’s not bad. 
[...]
Mom: It takes about an hour everyday to get him through dinner, and then another hour to get him to sleep at bedtime. Is there any way to find out about that, about how to improve it?
Dr: A lot of children are like that, not just those with autism. Do you think it’s a medical problem?
Mom: I don’t know, I’m not the expert.
Dr: I think it’s more behavioral. The 25th percentile is not bad. *(Fieldnotes, 06/13/2007)*

The point is that the tests administered or the standard forms utilized can delineate which pieces of information are relevant to the diagnosis, and which are not. I will explore this further in chapter four when I discuss the ADOS. For the remainder of this chapter, I look at the specific ways that the clinician’s mode of thinking effects behavior in the clinic.

**The Clinical Mentality**

During my tenure at the AMC only three clinicians provided patients with diagnoses of autism, and one psychologist performed the ADOS. Still, despite the small overall sample size, they are the population of diagnosticians at the AMC and as the main interface between parents and the autism diagnosis, their perspectives merit further analysis. We have seen in the previous chapter how parents understand their own actions, but what is the frame of mind of those they encounter when they visit the AMC, and what kind of structure does it impose on the parent-child-clinician exchanges that take place there? I begin with how the clinicians came to work at the AMC and then discuss how they understand the autism spectrum and the role of parents in the diagnostic process.

Despite the strategic action taken to establish the AMC, this mode of thinking was noticeably absent when clinicians described how they began working with autistic children. Nor was it characterized as a calling or vocation, or even a decent domain in which to apply their
own unique set of skills. Instead, a rather accidental quality possessed their explanations: they had not purposely sought out this specialty, engrossed by the mysteriousness of the disorder, it had simply ‘happened’ to them. As one clinician put it, “people knock on your door:”

> It’s just that autistic patients came more [into the clinic]. You know, more proportion of the patient came in. Everyone calls in, you have an equal chance of making an appointment, and there happens to be a lot more autism. Dr. Baker, pediatric neurologist.

Even Dr. Johnson who, after practicing in general pediatrics for several years, was prompted to return to undergo fellowship training in developmental pediatrics after her son was diagnosed with autism, admitted that the disorder was barely on her radar at that time and that she would not have returned for more specialized training had her son been diagnosed with something else. Autism, she explained, was not something that she thought much about as a practicing pediatrician, and certainly not something that she saw very often in her patients. When she did see it, the cases were rather severe and the children behaved very differently from the way her son eventually presented. In this way, Dr. Johnson was not unlike her colleagues, who also knew little about autism – and in particular, the spectrum – before they began working with autistic patients. Dr. Baker, who completed her training in pediatric neurology under a supervisor whose primary research interest was autism, admitted that even in this setting they saw very few cases, and consequently she is essentially self-taught on the disorder. And Dr. Daly’s initial impressions sounded very much like that of the parents participating in the interviews:

> I knew it was a developmental disability. I knew there was a range of issues but many people felt that it was a horrible, one of the most horrific disability
diagnoses you could give a person, because the old model used to be the child in the corner, kind of rocking back and forth in his own little world. You know, refrigerator parents type of thing. Dr. Daly, clinical psychologist.

Clinicians’ knowledge about autism before they specialized, it seems, was not so different from that of parents before their child became affected: either there was little familiarity with the disorder, or their knowledge was that of the classic variety.

Familiarity with only the classic symptoms of autism is thought to be one of the ills plaguing early detection by pediatricians. Because they are likely to be the only medical professional to have regular contact with a child, these physicians constitute the first line of detection for autistic symptoms. When parents recounted their path to obtain an autism diagnosis, many spoke of the struggle to have their pediatrician even acknowledge the existence of delay. The general failure of pediatricians to recognize the symptoms of autism – particular in toddlers – has been well-documented (Howlin and Moore 1997; McLaughlin, Sices et al. 2004; O'Connor 2004), and in recent years the American Academy of Pediatrics has conducted an outreach campaign counter this problem and facilitate the diagnostic process for parents (Committee on Children with Disabilities 2001). What is interesting is that once parents reach a specialist, autism seems to be an easy condition to diagnose. In my interviews with clinicians, some spoke of the need to differentiate autism from other disorders, but despite the generous overlap of autistic symptoms with those of, say, mental retardation, no clinician

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50 The DSM-IV-TR defines mental retardation as follows: A) Significantly subaverage intellectual functioning: an IQ of approximately 70 or below on an individually administered IQ test (for infants, a clinical judgment of significantly subaverage intellectual functioning); B) Concurrent deficits or impairments in present adaptive functioning (i.e., the person’s effectiveness in meeting the standards expected for his or her age by his or her cultural group) in at least two of the following areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety; and C) The onset is before age 18 years. Differential diagnosis is most challenging in toddlers, in which only
admitted to having any difficulty in distinguishing autism from amongst the rest. To the contrary, autism was immediately visible as if by instinct:

I: What do you know about your patients when they arrive?
C: I don’t know them, which is why I spend a lot of time [with them]. I don’t know what they have, but a lot of times I can kind of guess what their diagnosis is.
I: Before they enter your office?
C: No, when I see them in the office, before I start to interview the parents, I can tell they’re autistic. I seldom make mistakes on that. Somehow this is a... I guess it’s a gut feeling or something [laughs]. Once you get into it you just... they look different. [...] when they come, and it’s the new patients I’m talking about, I just somehow... somehow I just know. Dr. Baker, pediatric neurologist.

This subjectivism is not an uncommon occurrence in the diagnosis of psychiatric disorders. In her study of the training of psychiatric residents, Luhrmann (2000) discovered that residents move from recognizing symptoms in line with diagnostic criteria to recognizing prototypes, a cluster of traits that constitute the “best example” of a class of objects. Prototype theory, popularized in cognitive science, defines a mode of graded categorization whereby an object is classified not in terms of whether or not it meets certain criteria but whether it resembles the best example – i.e., the prototype – of that class. The theory is based on Wittgenstein’s notion of family resemblance, which he used to explicate how things which are thought to be linked by a single common feature are actually linked by a group of features, with not one of the said features being common to all members of the group. As Luhrmann describes, although psychiatrists are taught to formulate diagnoses of patients by comparing what they observe to a set of objective criteria, this proves to be a very difficult and confusing task for first-year communication and social skills deficits (which overlap with the criteria for autism) can be assessed. American Psychiatric Association (2000). Diagnostic and statistical manual of mental disorders: DSM-IV-TR. Washington, DC, American Psychiatric Association.
residents. It is particularly mystifying with respect to differential diagnosis, as there is typically much symptom overlap amongst the different mental disorders. First-year residents will read the DSM criteria for two conditions and conclude that the patient seems to manifest some, but not all, symptoms of both; the boundary between the two categories does not at all appear straightforward. But within a year, the same residents learn to think – and consequently diagnose – by using prototypes. Residents become adept at teasing out the information in a case presentation that corresponds to the prototype and effectively ignoring what does not. There is no need to consult the DSM as the difference between two disorders is obvious, and a diagnosis can be made within seconds (Luhrmann 2000).

The AMC clinicians too diagnosed patients within seconds, and those who acknowledged using the DSM-IV criteria when they diagnosed autism had no need to consult the text itself, or at least not in my presence. Why is this important? For one, clinical intuition, the tacit knowing, is indeed the ‘art’ of medicine, the foundation of its power and prestige which can only be based on firsthand experience. One could argue that diagnosis by prototype – a practical skill based on academic medical knowledge but not wholly dependent on it – is an exercise of this power. Second, and more important for autism in particular, it opens up a means through which physicians can include treatment considerations within the diagnostic process. If a child “looks like” the standard treatments can help him, then the physicians can legitimately include him within the rubric of autism. But while the autism diagnosis may be self-evident to clinicians, it still has to be established as real for parents. As I will begin to argue below and elaborate in chapter three, this is primarily achieved through deployment of the concept of the autism spectrum.
PARADOXES OF THE CLINICAL WORLD

What are the needs of the clinical world? Medical practice is rooted in the tradition of science, which values the unbiased, objective observer and the general laws of human behavior he discovers. Variables are manipulated to control for undesired effects and subjectivity is most unwelcome, a weakness of the “soft” sciences to be avoided at all costs. But the rules of the laboratory are an impossibility in the clinic, where the variability in the human patient can be in no way controlled. A great epistemological gap separates medical knowledge from clinical practice, the theoretical from the empirical. Clinical medicine is indeed a “science of individuals” (Montgomery Hunter 1991). What, for instance, should a clinician do with the information that 75% of patients with autism also suffer from mental retardation? Or that 10% of autistic patients improve with a gluten-free, casein-free diet? A known value for the population becomes an unknown for the individual, and the pragmatic clinician attends less to the 10% population value than to the fact that the patient before her suffers from gastrointestinal issues that could indicate a gluten allergy or intolerance.

Uncertainty is the name of the game in clinical medicine, and broader scientific generalizations are of limited value in determining a course of action for the individual patient (Freidson 1970). The abstract, formalized knowledge that is medicine’s foundation thus creates a dilemma for the practitioner, who must somehow bridge the epistemological divide in order to successfully perform his duties as a practicing physician. In this way, the clinician is a sort of “interface manager” who administers the space between the individual patient and the disease category (Rosenberg 2002). Obviously, they have enjoyed quite some success, as few of us hesitate to seek the profession’s advice in cases where our bodies appear to fail us. But to do
this, he must work to minimize the uncertainty that inevitably arises in the clinic where individual cases present, but generalized principles prevail. Rosenberg argues that this heavy reliance on specific disease categories is one of the great paradoxes of our tendency in the 20th century. On the one hand, the physician’s status is enhanced as she alone can provide access to knowledge of the disease and its treatment. But on the other hand, she becomes ever more vulnerable by the very ambiguity that knowledge creates.

One way in which uncertainty is mediated is through the culture of individualism that pervades the clinic. Individualism was indeed the overarching theme that emerged from the interviews with clinicians, and Freidson (1970) argues that this is a dominant component of the clinical mentality. The individualist orientation places the burden of proof on the particular as opposed to the general, thereby downplaying the role of generalized, scientific knowledge. The notion of the autism spectrum itself emphasizes the particularistic and the individualistic in each patient, so the friction between the individual case and general theory is lubricated through deployment of the concept in the clinical setting. As I describe below, the spectrum also rationalizes the prescription of different treatment options for the same disorder.

Uncertainty in the clinic may arise not only with respect to the various autism therapies, but in considering whether a patient should be treated at all. In other words, for some patients the ambiguity lies in whether or not they should be diagnosed with an autism spectrum disorder. Thomas Scheff (1984) has argued that certain decision making norms have developed in the clinic in order to deal with uncertainties of this sort, such that action is facilitated and not stifled. In medicine, he avers, it is much graver to leave an ill person undiagnosed than it is to
diagnose a person who is not ill: “when in doubt, diagnose illness” (80). Serious illness, loss of limb or life, contagion – such irreversible effects are the potential consequences of undiagnosed illness from the medical practitioner’s point of view. On the other hand, she sees little harm in diagnosing that which might not exist or manifest with any negative health effects. The pressure to diagnose is not universal, and there are other decision rules that may counteract it, like “when in doubt, delay your decision” (78). This norm might take precedence when diagnosis implies more aggressive treatment, such as major surgery. Still, says Scheff, both the physician and the public are so heavily biased towards diagnosis and treatment that not only legal but also moral condemnation may result, something that is rarely observed when doctors err on the side of caution. Even in the field of autism, with no shortage of accusations of overdiagnosis, public rebuke tends to target pediatricians who find “excuses” because they are “afraid” to mention that a child might have autism (see, for example, O’Connor 2004).

Of course, from the sociologist’s perspective the social consequences of diagnosing the healthy can be rather extensive. In psychiatry diagnosis is often accompanied by stigma, which is not easily erased by simply removing the diagnosis. Diagnosing a psychiatric non-illness can be rather harmful to the patient’s social status (Scheff 1984). Timmermans and Buchbinder’s (2010) findings take this one step further. Based on their research at a clinic for metabolic-genetic disorders, they describe how having their newborn test positive for a genetic mutation requires parents to take any number of precautions with the infant, including waking them every hour and adhering to a strict, limited diet. This period was marked by great anxiety on the part of the parents. Thus, even just being at risk of disease, of screening positively for risk factors but showing not a single symptom – and so not being cleared as ‘normal’ – has serious
moral consequences for the patient-in-waiting. Even after geneticists assured parents that they no longer needed to follow the previously recommended precautions, some continued with these practices. As these cases indicate, clearly the physician’s interpretation of the Hippocratic oath is more like, “first, do no physical harm.” But diagnosis puts a person into the “sick role” regardless of whether or not illness develops.

Thus, a culture of individualism and overdiagnosis has developed in the clinic in order to mediate the inherent uncertainty of medical practice, and there is little evidence to suggest that these same norms do not also operate at the AMC. In fact, one could argue that the coerciveness of these norms is even stronger in a clinic specializing in the treatment of autism, and this is what helps to make autism such a successful diagnosis. This is because the notion of the autism spectrum, and in particular the category of PDD-NOS, is especially tailored to this climate of uncertainty. The PDD-NOS diagnosis – casually referred to by one clinician as a ‘catch-all’ category – identifies those children exhibiting symptoms from some, but not enough, of the triad of impairments to qualify for an autism diagnosis. These are children who are not so easily diagnosed with Autistic Disorder (AD). They lie at the periphery of the autistic prototype, failing to meet the criteria for AD but also those for neurotypicality. It is at this boundary where proponents of supply-side explanations of autism diagnosis voice their objections loudest: the 1 in 110 number, they argue, is merely an artifact of the change in DSM criteria that introduced the category of PDD-NOS. Clinicians also recognize that the spectrum enlarges the diagnostic pool and thus is responsible for the breakdown of diagnosis-cum-prototype. Thus, it is here where diagnostic tools like the ADOS come in, for the “tricky kids” straddling the boundary of neurotypicality. Uncertain of a diagnosis, clinical intuition is suspended and awaits the results of
a battery of tests, tests which have been closely modeled on the DSM criteria and themselves rigorously analyzed.

Like parents, clinicians came to embrace the idea of the autism spectrum, each emphatically expressing their belief in the construct and its validity. On the one hand, the spectrum definition of autism is validated by the range of disability they see in their patients. As Dr. Michaels explained:

I truly believe that there is a spectrum, and that each... even each particular category such as speech issues, socialization issues. I think that each category itself is also a spectrum. For instance, when we talk about speech, we have some kids that don’t speak at all, and we have some kids that speak almost as good as you and I do. Same thing goes for socialization. Some kids are really introverted and kind of stay to themselves, and other kids that want to be social but just may be a little bit socially awkward. So I think not only is autism itself a spectrum, but almost every facet of the disorder is a spectrum unto itself. Dr. Michaels, pediatric neurologist.

Thus, the spectrum is real because clinicians bear firsthand witness to it in the clinic. At the same time, but in the other direction, the notion of the spectrum justifies grouping such a diverse cluster of children under the same diagnostic umbrella, a point I will return to in chapter three. Dr. Johnson – perhaps drawing on personal experience – takes this one step further: the spectrum, she insists, is useful for persuading disbelieving parents that their child is autistic. This resonates with the way parents described their reaction to the diagnosis when it was first presented to them. As we saw in chapter one, many parents were not convinced that the diagnosis was correct until they learned about the spectrum, and about how their child could manifest different symptoms than another child with autism, yet qualify for the same
diagnostic classification. Diagnosis requires cooperation between parents and clinicians. On the one hand, clinicians have to reconcile the presentation of a particular patient with their clinical imagination, the entire history that constitutes their ‘clinical experience:’ they need to know that they are making the right diagnosis, and they do this by comparing the child with the prototypical case that has emerged over the course of their training. Parents, on the other hand, want the correct diagnosis because only then will they receive the correct treatment. The behaviors they perceive in their child have to match those they see in other children undergoing the same treatment, or placed in the same special education category. And they need to detect a coherent association between symptoms and treatment, if only because of the exorbitant costs. The autism spectrum, in all of its heterogeneity, simultaneously reconciles each actor’s dilemma of meaning. As a boundary object, it is flexible enough to meet the individual needs of the differing social worlds of parents and clinicians, yet robust enough to maintain a common identity across all arenas of its use (Star and Griesemer 1989).

Despite the ambiguity brought in by the category and the wide-ranging diversity of the children who fall within it, clinicians at the AMC insisted on the utility of a category they all believed to rightfully belong on the autism spectrum. I argue that this is in large part due to the fact the PDD-NOS diagnosis offers clinicians a way to rationally treat patients who are not so obviously autistic, a way to diagnose and treat the as-of-yet unclassifiable. More to the point, it lets them diagnose when in doubt. Practically speaking, PDD-NOS means not autism, at least for now, and a more permanent diagnosis can be postponed until the therapies have run their course. If intervention is timely and intensive, there is hope that the patient might “catch up” to his neurotypical peers and even “fall off the spectrum.” Of course, this could mean that the
child was not autistic to begin with, but no one would suggest conducting a randomized clinical trial to find out. And while the uncertainty of medical intervention might characterize the PDD-NOS diagnosis, *ethically* the physicians stand on firm ground as it enables them to care for patients they feel would benefit from intervention, but who might otherwise fall through the cracks. As we saw above, in clinical culture it is considered far worse to judge an sick person well than to label a well person sick. But the real power of the PDD-NOS diagnosis is that it allows clinicians to simultaneously abide by two opposing norms: when in doubt, do you diagnose or do you delay your decision? With PDD-NOS the practitioner does *both*: she postpones a decision about autism specifically but at the same time the child is allowed to benefit from the same care and treatment afforded autistic patients. Not everyone who could benefit from the therapies fits the criteria. As one clinician put it: “we need something.”

The benefits of the PDD-NOS diagnosis for clinicians is by now obvious. It offers the ability to provide care without settling on a determinate diagnosis, it alleviates the clinician of any sort of moral quandary, and – at least from the physician’s perspective – it does not harm the patient. But PDD-NOS is also beneficial for parents. As we learned in chapter one, most parents were searching for some recognition that their child was not well and the persistent lack of legitimization of their concerns induced anxiety. Parents *knew* something was wrong, and they wanted *someone* to agree with them so they could figure out a way to help their child. PDD-NOS, while typically confusing for parents at first, not only legitimized their concerns but brought them under the purview of the medical profession which offered not only treatment strategies but simply the feeling that everything possible was being done to help the child, that they were receiving the best possible care. The same is true of the parents studied by
Timmermans and Buchbinder. While it was disconcerting that their newborn tested positive for a genetic defect, and even though the babies displayed no signs of illness, parents were relieved to remain under medical surveillance. For autism parents, while the spectrum diagnosis might have been a shock initially, the therapies and the care that came along with it brought them much relief. Generally speaking, living without a clinical diagnosis in the presence of medically unexplained symptoms is more unsettling, leaving patients to struggle with uncertainty and illegitimacy (Nettleton 2006).

To be sure, there is a corollary to this sense of relief. Parents are yanked out of what Corbin and Strauss (1985) call ‘diagnostic limbo’ and are thrown into the fight: against schools, therapists, insurance companies and even other parents. But the greatest battle is that against time, as parents race against the “ticking kindergarten clock” to alter the trajectory of development before the critical window is shut for good. At this point, PDD-NOS elapses and autism begins. But despite the complete rearranging of life this entails, no parent opts to remain undiagnosed, to “wait and see.” Though PDD-NOS may account for a large proportion of the increase in autism diagnoses, this “creation of illness … may go hand in hand with the prevention and treatment of disease in modern medicine” (Scheff 1984: 78). PDD-NOS is mutually beneficial to parents and clinicians, as it reassures each that the best course of action is taken.

Because it occupies this interstitial space between autism and neurotypicality, PDD-NOS conveys different information about severity and prognosis than does the diagnosis of Autistic

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51 One parent told me that good – or rather, any – speech therapists were so hard to come by that parents would not share the names of their therapists with other autism parents, for fear of initiating a bidding war between them.
Disorder. It is often used to denote milder, higher-functioning cases with a better prognosis. As Dr. Daly explained:

If I see PDD-NOS on a report, I know, number one, he’s on the spectrum; number two, he’s not as severe as autistic; and number three, there’s still mild disabilities similar to, you know, that would be expected of autism. *Dr. Daly, clinical psychologist.*

But although the notion of a spectrum of autistic behaviors resonated well with what clinicians saw in the daily life of the clinic, as a diagnostic label it communicates too little information to be of practical (read: therapeutic) use. Even the more specific diagnosis of Autistic Disorder was of little guidance. Both the PDD-NOS and AD diagnoses draw from the same pool of therapies: speech, occupational, physical, ABA, etc., but it is the particular combination of therapies that is individualized. Not everyone needs occupational therapy, or will benefit from a gluten-free, casein-free diet. Even the same therapies might be shaped differently for different children. As clinicians explained when asked what therapies they recommend:

It’s individualized, yeah? I mean usually they all get speech therapy, but then it’s a different speech therapy. There is articulation, pragmatic, language therapy, social use of language. It’s all different, receptive or expressive, then there’s oral-motor apraxia, motor therapy. So it depends, it’s individualized. *Dr. Baker, pediatric neurologist.*

Again, it depends on what the kid is presenting. I don’t automatically say, ‘Oh, he’s autistic, therefore he needs blah blah blah.’ *Dr. Daly, clinical psychologist.*

While clinicians do not find that the notion of the spectrum plays a significant role in the way they formulate diagnoses, it is extremely useful when prescribing a treatment regimen. Every child is different, so there is no “one-size-fits-all” with respect to treatment. Now the dual role
of the spectrum is especially evident. On the one hand, it explains how one diagnostic label can account for the vast heterogeneity of symptoms. On the other hand, it permits great diversity in treatment strategies for children carrying the same diagnostic label. More to the point, the spectrum and the individualism go hand in hand.

**VIEW OF PARENTS**

Whereas at one point in time parents – particularly mothers – were seen as the cause of autistic tendencies in their children, they have since come to occupy a role that clinicians deem invaluable, that of key informant of their child’s behaviors and abilities. The physicians at the AMC ascribed a great deal of validity to the information provided by parents in both the intakes and the diagnostic interview, and felt that they place more weight on the information from parents than on their own observations as they formulate diagnoses and prescribe treatments. Still, physicians were careful not to ascribe this to a unique form of parental expertise or possession of special knowledge:

> Sometimes they [the children] don’t always act the same at the office as at home, so it’s difficult to judge if it’s just a young kid with speech delay. [...] Even though I spend a good amount of time with patients, one hour to one and a half hours, parents live day to day with these kids. Not all behaviors are going to be displayed in the office. Dr. Michaels, pediatric neurologist.

Thus, parental knowledge is one of convenience, less of quality than of quantity, a simple consequence of being the child’s primary caregiver. It holds the bulk of its value in operating as a second set of eyes.

The parental eye, however, was seen by clinicians as highly susceptible to bias. A parent may not be a “proper informant” for several reasons. They might think the child is more
impaired than he actually is, or less impaired and therefore not meriting the autism diagnosis.

As Dr. Baker described after I asked her to expand on some of the problems she has encountered with the validity of parental reports:

Oh you know, the ‘oh, you know, he can do it himself, he doesn’t need to communicate.’ You know, they will find an excuse for [their children], they don’t... you know ‘he’s pretty talented, his brother would have to ask you for everything, he doesn’t have to ask me, he does it himself.’ And I have to tell them, well you know, there’s something wrong, he doesn’t communicate with you. **Dr. Baker, pediatric neurologist.**

Thus, in order to use parent-provided information effectively, clinicians have to work to separate the action denoted in the observation from the parents’ *interpretation* of that action.

The performance of this sort of work, according to clinicians, is necessary primarily because parental denial of the degree of their child’s impairment render these observations less reliable. Parental denial was, in turn, seen by clinicians as the principal source of conflict that might arise at the center, a source which was always described as external to both the clinician and her clinic. To the contrary, the basis of disagreements were often narrated as though they were inherent characteristics of parents, whose emotions or lack of knowledge about the diagnosis or prognosis led them to challenge the physicians. Clinicians almost portrayed themselves as victims:

C: It’s not easy, practicing autism specialty. It’s actually a high-risk practice.
I: Why is that?
C: There are a lot of children with autism who [...] may have behavior problems that can lead to secondary injuries [...]. And then there are parents. Parental satisfaction is difficult to obtain for children with autism. [...] I have to say, I have less satisfied patients than dissatisfied, because, you know, they come in with high expectations so even though you make a difference, they don’t see it. [...]

You know studies show co-morbidity of problems in the family, even though this is the only child with autism. So sometimes, I tell you, I got into difficulties. It’s much easier to treat a headache or even a seizure patient than to treat autism. 

*Dr. Baker, pediatric neurologist.*

In this example, Dr. Baker insinuates that difficult parents may share some of the social deficits of their children. Even when clinicians were asked how these conflicts could be avoided in the future, they did not view this as an area in which they could exercise their own agency. Change, if at all possible, could only occur outside of the clinic – for instance if treatments become more effective in the future thereby satisfying parent expectations.

In light of the discussion in chapter one, it should be noted that clinicians did not voice any indication that parents were requesting a diagnosis of autism. To the contrary, Dr. Baker made it clear that this was specifically *not* her impression, and that the opposite was in fact true, that parents felt their child was less impaired that the diagnosis suggested. Parents may have heard about autism as a possible diagnosis, but either they still hold out hope that the physician will dismiss it and offer something less severe or they do not make the association based on their own child’s behavior. As we saw above, it was in these situations where knowledge of the autism spectrum was effectively deployed to diminish conflict.

**CONCLUSION**

In his *Genesis and Development of a Scientific Fact*, Ludwik Fleck (1979) illustrated how stylistic bonds, conditioned by cultural-historical factors, can exist between concepts. Specifically, he revealed how early on, syphilis was associated with the blood and mystical-ethical overtones of “bad blood”, but it was only with the discovery of the disease agent in the blood that the association became scientifically sound. Any fact is possible, he argues, so long
as it fits the accepted thought style of the community. One of the goals of this chapter has been to highlight this fit between the “fact” of the autistic spectrum and the thought style of the medical clinic. Uncertainty, focus on the individual, and the tendency to overdiagnose are all accounted for through deployment of the spectrum. Doctors fulfill their moral obligation to treat, and parents receive the treatment they feel their children require. As a result, Autism Spectrum Disorder is a stable, successful diagnostic category.

I have also tried to show that the clinic is not merely a place to apply established medical knowledge, but through the work of clinicians becomes a site of knowledge production. There are several dimensions in which this took place at the AMC. First, it is here where children become subjects of the clinical gaze. Their behaviors are scrutinized and documented, their bodies poked and prodded. At times they are subjected to further testing, both medical and behavioral. Parents are routinely questioned, notes are jotted down and the sum of all observations is realized in the patient medical file, essentially an intricate case study.

Second, the work at the AMC establishes autism as a medical disorder. Though Leo Kanner was a psychiatrist, the biomedical model of psychiatric disturbances had in his day not yet taken hold. The disorder, presumed to be emotional in nature, was studied largely by psychiatrists and psychologists. Still, already in 1964, Bernard Rimland’s *Infantile Autism* argued for a theory of biological causation, and speculated on the underlying mechanisms that led to the manifestation of the disorder. But by and large, *treatments* for autism originate outside of the medical field. Clinicians at the AMC would certainly not deny that ABA, speech therapy,

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52 This is especially true of the services provided by Early Intervention. However, groups like Defeat Autism Now!, which was begun by Bernard Rimland, advocate for biomedical treatments in particular.
occupational therapy and the like can be effective treatments for autism. But at the same time, they are acutely aware of the potential to systematically treat autism with biomedical therapies in addition to the behavioral ones. For instance, when Dr. Baker and I were discussing the goals for therapy that might be feasible in the near future, she recounted of an article she had recently published on the co-morbidities of autism that could benefit from medical intervention. By her own telling, parents applauded her for producing this research, praising how she had done a “huge service for the autism community” where most parents face “older doctors” who deny that autism can in any way be treated medically. Still, she lamented that currently they could only do symptomatic treatment, because at present “everyone studies everyone with autism, the subject selection is based on diagnosis, which will be heterogeneous.”

The ASD diagnosis is so well matched to the structure of the clinic that it acts to enforce the institution as well as the diagnosis itself. It therefore thrives in the clinic. In the first chapter we saw how the notion of the spectrum textures the patient experience. In the next chapter, I show how clinicians translate parent experiences of their children using the language of the autism spectrum. In doing so, they moderate the transition of parents from a position of disbelief to the multi-faceted role of parent-activist-therapist-researcher.
CHAPTER 3: THE DIAGNOSTIC INTERVIEW

In Chapter 1, I described how parents were initially suspicious at the suggestion of autism as a descriptor of their child’s delayed development. Not only did they perceive that their child acted differently from autistic children, they simply did not believe that whatever it was that ailed the child could be something so severe. Clinicians, of course, were reasoning on the basis of a much broader and milder autistic prototype than parents, using the children themselves as proof of the reality of the spectrum. Interestingly, no clinician I spoke to challenged the unity of the autism diagnosis, despite the varying presentations of different patients. The children all look different because they are different, they contend. That is the very nature of a spectrum disorder, and it is so compelling and so real that it structures much of the activity that transpires in the AMC.

By the time of the interviews, parents were as convinced as clinicians of the reality of the autistic spectrum. They neither expressed discomfort with symptom variability nor questioned whether the autism diagnosis was indeed the correct one. Throughout the discussions, they often made reference to the fact that “every child with autism is different” and when asked if their opinion about autism had changed since their journey began, it was the idea of the spectrum that emerged as one of the most important lessons learned. Similarly, in Chapter 2 we saw that the PDD-NOS is crucial to the institutionalized differential diagnosis performed by the clinic. More precisely, as will be explicated below, it is the attribution of potential that underlies diagnostic gradations between mental retardation, Autistic Disorder, and PDD-NOS. The latter is an indication that the child has the utmost potential to overcome
his deficits – if they must receive one, this is the diagnosis parents want, for it communicates the greatest likelihood of improvement. On the other extreme, though 75% of children with autism are thought to also be mentally retarded, the MR designation was never raised at the AMC (at least not by clinicians). Implicit in this diagnosis is the absence of potential. This is the child who, at diagnosis, was “all he is ever going to be.” In a sense, the Autistic Disorder designation is a modern-day euphemism for mental retardation, for as we shall see, this diagnosis was given when the child demonstrated little progress with his current therapies, and therefore little potential for improvement. Still, with AD, but not with MR, the child is given the potential for potential; namely, almost double the therapy hours he would have with a diagnosis of PDD-NOS.

In this chapter I ask how, in the face of such behavioral variability among the children diagnosed with an autism spectrum disorder, and in the absence of biological markers to assist in the process, autism maintains its coherence as a single, unitary diagnosis acceptable to both parents and clinicians. I argue that this is accomplished in part through the practices and narratives that structure parent-clinician interactions. In these exchanges autism is variously and simultaneously constructed as something real, as a performance, and as a label to procure services. Through the use of bridging work to connect these narratives into a coherent whole, autism becomes a boundary object that performs multiple functions simultaneously in various social worlds.

THE AUTISM NETWORK

Autism, in a manner of speaking, is a successful diagnosis. By this I do not mean evolutionary success, that as a disease entity similar to a virus or bacterial infection it has
thrived because of a natural symbiosis between its reproductive behaviors and biological environment, allowing it to win out over similarly constituted entities. As we well know, in the absence of any specific causal entity for autism scientists are far from able to make any such claims. But the evolutionary model is perhaps a decent enough metaphor for what I mean when I say that autism is a successful object. Historically, amongst a number of rivals, it has won out over its competitors. Thus, today we find ourselves in the midst of an *autism*, and not childhood schizophrenia or mental retardation, epidemic (Eyal, Hart et al. 2010).

As discussed in chapter one, supply-side arguments alone are insufficient to account for this success. For this would assume that parents are passive recipients of diagnostic labels, and we have already seen that they are not. Besides, as Latour (1987) reminds us, the ultimate fate of an object is in part dependent on the behavior of others, i.e., not only those who create – or in the case of autism, label – the object. Take, for instance, the removal of homosexuality from the DSM, which nicely exemplifies how social advocacy on behalf of the labeled can effectively disqualify a diagnosis from the medical lexicon. The reign of medicine – and especially psychiatry – is not so absolute as to completely determine the path of its subjects. A clinician can diagnose a child with autism, but then what do the child and his parents do from there? Many parents initially rejected the label. But even if it is not rejected completely, an object or in this case a classification scheme can be modified as it adopted by more and more actors. This has certainly been the case with the diagnostic criteria for autism, which some have suggested might change more towards the way the diagnosis is used clinically than clinical practices
following diagnostic change. This is because autism is an example of what Hacking (1999) refers to as an interactive kind: a classificatory type that can change by means of interacting with what is classified. This means that the autism diagnosis can interact with individuals and their actions and behaviors. It can change the way people experience themselves by altering the way they imagine themselves as well as the way they are treated by others. This modified self-perception leads people to envision a different range of possibilities for actions and behavior. While this may be of little impact in reference to a single person, it is of no small consequence if it applies to an entire class of individuals, who may be led to acquire a set of behaviors by nature of being classified as such. Thus, over time “kinds may become false because people of that kind have changed in virtue of how they have been classified, what they believe about themselves, or because of how they have been treated as so classified” (Hacking 1999: 104). This is what Hacking refers to as a looping effect, and it offers a mechanism whereby we can understand how the diagnosis of autism can change over time. Experts create or modify classifications that are assigned to individuals who subsequently internalize them and make them their own. At the same time, but in the other direction, the autonomous behavior of the classified persons creates a reality that the experts must contend with in terms of their classifications. Thus, autism is not an empty label assigned to patients, but is collectively constituted by them (Latour 1987; Hacking 1999). But herein lies a dilemma: if autism is to succeed as a diagnosis it needs other actors to participate, but in so doing the nature of the object may change based on the behavior of these actors. To escape this quandary, autism

53 Arguably, the current proposal for the DSM-V criteria for Autism Spectrum Disorder coincides nicely with current practices at the AMC, where “autism” and “PDD” are understood as synonyms.
must be tailored to the interests of all actors, *translated* in a way such that the needs of each are realized.

What exactly are these interests? Diagnosis permits patients – or parents, in the case of autism – to gain some personal and emotional control in knowing what exactly is wrong. It legitimates their suffering and grants them the right to treatment. It offers a powerful narrative whereby patients can construct a meaningful, organized account of what was a disorganized illness experience prior to diagnosis. It gives them a sense of direction about the future, particularly in terms of expectations for prognosis and treatment that typically accompany diagnostic information (Brown 1995). An autism diagnosis is particularly empowering because it grants access to a wide range of state-funded services as well as activist and advocacy groups – an entire community of like sufferers which not only provides families with information and expectations, but also a language with which to express and understand themselves. Clinicians want to take care of their patients by addressing their medical problems and providing appropriate and effective treatment. Schools need public funds, insurance companies diagnostic codes, and so on. In the near seven decades since it was first described, autism has emerged as a crucial point of intersection between these various actors. It effectively translates the needs of each and by so doing coordinates supply and demand in a way that promotes cohesion, so that a stable network of interdependency is established.

Without a doubt, autism has been successfully translated and the very existence of the spectrum is intricately bound up with this network. But translation is not a given fact; it is an endeavor that is only sometimes achieved (Callon 1986). Difficulties can arise when actors from
differing social worlds interact and attempt to reconcile the meaning of a given object. We saw in chapter two that a central tension that arises in the clinic is the negotiation between generalized, medical knowledge and the application of this knowledge to the individual patient. I argued in that chapter that this tension is managed through deployment of the notion of the autism spectrum. In this chapter, I borrow Star and Griesemer’s (1989) concept of boundary objects and Timmermans and Buchbinder’s (2010) notion of bridging work to illustrate how the translation of multiple viewpoints is managed in the autism clinic, as manifest in the diagnostic interview and maintained in patient follow-ups.

According to Star and Griesemer, boundary objects manage both diversity and cooperation. They

... inhabit several intersecting social worlds ... and satisfy the informational requirements of each of them. Boundary objects are objects which are both plastic enough to adapt to local needs and the constraints of the several parties employing them, yet robust enough to maintain a common identity across sites. They are weakly structured in common use, and become strongly structured in individual-site use. These objects may be abstract or concrete. They have different meanings in different social worlds but their structure is common enough to more than one world to make them recognizable, a means of translation. The creation and management of boundary objects is a key process in developing and maintaining coherence across intersecting social worlds. (1989: 393)

It is clear that the meaning of autism varies across different social groups. For clinicians, autism legitimizes the medico-psychiatric gaze. It exemplifies the relationship between the brain and behavior. It connects abstract medical knowledge to concrete behaviors. Autism gives parents a way to make sense of their child’s behavior and the series of events that brought them to the moment of diagnosis. It gives them a plan for action and hope for the future. For therapists,
autism provides a discrete set of behaviors on which to work. Autism is a directive for schools on to how to educate the child and what sort of classroom environment is suitable, as well as a means for schools to appropriate state funds. Autism, then, easily adapts to local needs, but through the triad of impairments also preserves a common identity.

Still, it is important to recognize that the idea of a concept like autism having variants in different social worlds stands as a threat to the unity of the concept as a whole. Herein lies a second paradox of translation, as it is the existence of variants themselves that makes the concept “work” to begin with. Why does autism – or any other boundary object, for that matter – not fracture into its constituent parts? For instance, several parents indicated that the autism diagnosis offered them little with respect to a more detailed understanding of the struggles of their own child. The spectrum was too general a construct for that; the “problem” of autism is constructed differently in different children. For some, their bodies could not process certain proteins which led their brains to “starve,” for others it was an improperly wired sensory system that was the heart of the matter. For some parents like these, the unity of autism was more disconcerting than constructive. Why, they asked, was autism considered a unitary disorder? Would it not be more helpful if children were grouped according to their specific deficits? The point is that work has be to be done in order to minimize this fracturing. The success of any translation endeavor depends on the work done on behalf of all actors to both achieve and maintain a common understanding. If autism is to succeed as a diagnosis, to persist as a useful concept, it has to maintain a shared meaning amongst all groups. This does not just happen naturally, or by accident: rather, actors work to maintain this common identity. This chapter is about the work that is done – specifically, the bridging work by clinicians – to
maintain this common autistic variant and hence autism’s success as a diagnostic category. I argue that the maintenance of autism as a boundary object is accomplished by the performance of bridging work, which connects the different meanings of autism across the different social worlds.

Part of what I want to demonstrate with this chapter is that the arguments put forth by both the supply-side and the demand-side theorists are all at least partially true. On the one hand, better detection techniques sharpened through the development like instruments like the ADOS and the implementation of Early Intervention programs greatly increases the number of children suspected of having autism. Similarly, as autism awareness spreads through the work of advocacy organizations such as Autism Speaks, the disorder not only receives greater funding but also becomes less stigmatized, prompting the trends towards diagnostic substitution from MR to autism that have been observed. The work at the AMC shows not only that there is some truth to all of these claims, but that the different dimensions all converge in the diagnostic situation. It can be argued that supply-side theories treat autism as a reality, whereas demand-side theories see it as a label. Thus, one way to understand why neither side can work in isolation is because autism is mostly neither real nor a label, but a performance. Parents are unsatisfied when physicians attribute autism as an all-or-nothing reality – they prefer to see that the diagnosing clinician has conducted some tests on the child or otherwise made some effort to elicit the performance of autism from him. At the same time, clinicians are uncomfortable with the idea of merely handing out a label – they too must see evidence of the reality in the performance. Instead, it is precisely the ability to switch between the three
different frames that permits the institutional funnel to function smoothly and so effortlessly manage the concerns of all actors.

For instance, in the early stages of the moral career, parents are in search of a diagnosis and cure for whatever it is that ails their child. But as we saw in Chapter 1, learning that their child had autism, a condition for which there is no cure, offered parents little direction in terms of treatment and management. In other words, the presentation of autism as a real entity was a dead-end of sorts for parents. It is perhaps no surprise, then, that few parents believed that their child was indeed autistic. However, by switching to a narrative of autism as a performance, clinicians could not only point out the concrete behaviors that were indicative of autism, but they could also usher parents into a new temporality of “one day at a time.” This is because the distinction between a reality and a performance is also the distinction between an illness and a disability, and each are marked by different temporalities: the temporality of the cure as compared to the temporality of “one day at a time.” What was originally a concern with diagnosis and cure, then, is translated into the concrete task of getting the child to perform differently, focusing not on the ultimate goal of neurotypicality, but on making small steps toward improvement every day.

**The Heterogeneity of Autism**

The triad of impairments that characterize autism seem straightforward enough: the disorder is marked by deficits in communication, impairment in social interaction, and repetitive behaviors and restricted interests. But as I have emphasized throughout these pages – to the point of being repetitive myself – is that the manifestation of the disorder varies across the individual children it affects. Thus far, I have spoken freely of the inherent variability in the
autism spectrum, how “every child is different,” while offering the reader little evidence of this diversity. To contextualize the argument of this chapter I now describe in detail the cases of two children, Charles and Matthew, both diagnosed with an autism spectrum disorder. The descriptions are based both on the parent interviews as well as my observations at the AMC.

Charles is a 2½ year old boy. Though he is nonverbal he does make the occasional vocalization and babbles frequently. During the interview at the clinic, Charles spends most of the time playing by himself at the opposite side of the room from where his parents and the doctor are sitting. He engages in a few different activities and rotates between them. At one point he is playing with jumbo-sized plastic blocks, one in each hand, banging them together and vocalizing. In the next instance, he is playing with a large toy truck which he has turned upside down and is spinning the wheels. He often tries to put things in his mouth, including one of the blocks, at which point mom and dad loudly say, “Charles, no mouth!” Charles’ parents first noticed a problem when he was only three days old. As an infant, he constantly needed to be held and slept only about six hours per day in spurts of ten to sixty minutes. As his parents put it, Charles has “never been normal” and never met any of the developmental milestones on time. He did speak about ten words at one point, but subsequently lost the ability to use them. Charles’ pediatrician insisted that there was nothing wrong with the child, but after several visits his mother insisted on a referral for physical therapy and an ophthalmologist, and Charles was later diagnosed with hypotonia and mystagnis. The autism diagnosis came later – from a developmental pediatrician at about twenty-two months – and was spurred by a comment from his Early Intervention therapists. His mother admits that she had thought about autism because of Charles’ inability to look at people, but claims that he simply did not fit any of the
checklists she had attempted online: Charles *loves* to cuddle, she explained, which was evidence enough that he was not on the spectrum. When the autism diagnosis did come, Charles’ parents expressed relief that they “finally had one.” He was subsequently enrolled in a full-day autistic program and received ABA, occupational, physical and speech therapy. In addition, melatonin was used to help manage some sleep issues and the GFCF diet to help with the later-diagnosed ADHD and yeasty gut. His parents hoped to eventually enroll Charles in music therapy, as they felt that he possessed a keen ability to discriminate high-quality music.

Though Charles exhibits many of Kanner’s original autistic symptoms – like repeatedly spinning objects – he also “loves to cuddle,” which falls more in line with the disorder’s modern symptomology. Still, he lies closer to the classic prototype than does Matthew, a three-year-old patient of Dr. Johnson at the AMC. According to his mother, Matthew was developing normally until he was eighteen months old, at which point he began to lose some skills. Within one month, Matthew had stopped talking, no longer responded to his name, and screamed much more than previously. He also began having between numerous bouts of diarrhea every day. The changes in Matthew’s behavior was most striking when a home video taken at Halloween was compared to one made at Christmas. His parents were convinced that Matthew’s vaccination regime was responsible for the regressive behavior. During the December holidays, a cousin who worked in special education suggested that Matthew be formally evaluated for his delays. The pediatrician hesitatingly complied and offered the telephone number of Early Intervention. Out of fear, Matthew’s mother procrastinated in making the call, but eventually had her son evaluated when he was 28 months old. Matthew tested at the one-year-old level. Eventually, Matthew was brought to Dr. Johnson at the AMC, who diagnosed him with Autism
Spectrum Disorder. His mother recalls her shock and disbelief at the diagnosis. At the first of Matthew’s appointments that I observed, he spoke little but did interact with his family, if only to request his diaper be changed. His parents had him on several biomedical therapies and were considering chelation. At the next appointment six months later, and after having begun chelation therapy, Matthew was regularly using three-word sentences and happily playing with his sister (including asking her if she was okay after falling down). His behavior had improved to such an extent that Dr. Johnson had to ask, “So what do you need me for now?”

Both Matthew and Charles are diagnosed with Autism Spectrum Disorder, but in the details you find not only two different sets of symptoms, but two different illness narratives. Charles had been affected since birth, whereas Matthew was developing normally until 18 months of age and then lost many of his skills. Charles was nonverbal; Matthew used conversational speech. Charles flitted about and showed little enjoyment in any one particular activity; Matthew enthusiastically engaged in play with his younger sister. Charles had many other diagnoses (mystagnis, hypotonia, and ADHD); Matthew only showed symptoms in line with the triad of impairments. Charles’ mother was relieved when she received the autism diagnosis, happy to finally have one; Matthew’s mother was devastated.

Behaviorally, as accounted for by the notion of the spectrum, autism is a disorder of extremes. As I explicate in later sections and will support with evidence throughout this chapter, clinicians have methods with which to manage these difficulties, to reduce the indeterminacy that exists between the individual and his diagnosis. Some children, like Charles, are mute whereas other talk incessantly. Impaired social interaction at times appears as
complete avoidance or disregard of others, but at others emerges as the inappropriate hugging and kissing of strangers. Some children are hand-flappers or toe-walkers, others do not exhibit any such odd behaviors. And perhaps the most striking paradoxes of all materialize in the reaction to sensory stimuli. On the one hand is the hyper-sensitive child who is intolerant to certain sounds – covering his ears in an auditorium or at the flush of a toilet – who cannot wear certain materials and will only eat foods of a particular texture. On the other hand is the child who is seemingly oblivious to loud sounds and the sensation of pain, who simply picks up and carries on after what seems to his parents as a bad fall. These inter-individual differences are further complicated by the intra-individual differences that may manifest over time. For instance, in adults with autism childhood stereotypies may persist in a less obtrusive and manner, such as finger-rubbing (Rapin 1997). Rimland himself noted that the apparent similarities among children with autism were only statistically significant until the age of 5½, after which point their developmental trajectories diverged. Of course, autistic children may also respond differently to therapies, so that some may reach a higher degree of functioning later in life, while others improve little. To complicate matters even further is autism’s co-morbidity with several other disorders, including mental retardation, epilepsy, obsessive-compulsive disorder, ADHD, and several communication disorders.

The obvious fallout from such great phenotypic variation are thwarted attempts on the part of geneticists to uncover a common autistic genotype. Though some studies have shown autism to be highly heritable (Rutter and Folstein 1977), the absence of a common phenotype

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54 One mother of three-year-old twin boys had to puree all of their meals and feed them from baby-food type jars. Another complained that not only would her child only eat five or six different items, but the chicken nuggets had to come from McDonald’s.
has hindered the identification of causal genes. Moreover, studies that have been able to identify a possible causal gene have been found difficult to replicate. What has emerged from years of research is the discovery of over twenty-five different loci that may be considered “autism susceptibility candidate genes” (Bill and Geschwind 2009). Taken together, these findings have lead geneticists to believe that autism is marked by genetic heterogeneity. This heterogeneity is two-sided: there are many genes than can render an individual susceptible to autism, but these genes also make individuals susceptible to other disorders, including mental retardation, schizophrenia, and epilepsy. In addition, a more recent study has estimated heritability at 19% for males and 63% for females (Liu, Zerubavel et al. 2010). With approximately 4 in 5 autism diagnoses belonging to males, heritability estimates such as these put the search for the culpable gene on very shaky ground.

**Bridging Work**

The heterogeneity of the autism spectrum can be traced to at least two major events. First, the expansion of the diagnostic criteria from a unique syndrome to a spectrum of impairments inevitably increased the pool of diagnoses and clinical phenotypes. Complicating matters further is the fact that the clinical picture for a particular individual can change as a person ages. Thus, not only is every child different, but one child may manifest a different symptom profile at different points in the life span. Second, the implementation of developmental screening of infants and toddlers introduces a more systematic strategy to identify at-risk children with developmental delays. In 1997, the definition of disabled children in the Individuals with Disabilities Education Act (IDEA) was expanded to include developmentally delayed children between the ages of three and nine years. Under IDEA, public
school districts are required by law to identify all children with disabilities within their jurisdictions. These children are then required to either receive early intervention services (if under age three years) or be provided a free and appropriate public education (if between age three and twenty-one years). As with most types of surveillance, when implemented the pool of potentially diagnosed inevitably increases.

Thus, in an environment in which both the pool of potentially-diagnosed and the diagnostic criteria are expanded, autism proliferates. And not just the administrative prevalence of autism, but the observed clinical phenotypes. Consequently, questions arise as to what constitutes “real” autism. Even the permanency of the condition is called into question: some clinicians believe that a child can lose the diagnosis with improvements, whereas others insist that “if they ‘fall off the spectrum’ then they probably weren’t autistic to begin with.” Comments such as these illustrate the awareness amongst clinicians of how problematic the notion of the spectrum can be in clinical practice with respect to a common phenotype. The difficulties in identifying clinical subtypes also leads to questions about whether autism is best considered many syndromes as opposed to a unitary one. This is a much less trivial challenge than it may appear. Already in the 1960s, long before Lorna Wing formally proposed the idea of the spectrum (Wing and Gould 1979; Wing 1997), Bernard Rimland made an impassioned call for autism to “be rescued from the nosological oblivion toward which it is daily being pushed by careless and indiscriminate diagnosis” (1968: 146).55

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55 To remedy this, a great deal of Rimland’s efforts were directed towards creating a diagnostic test that would differentiate “true autism” from the non-autistic syndromes. I return to this discussion of Rimland in chapter four.
For Rimland, autism was a specific constellation of symptoms, an idea inconsonant with the notion of the spectrum. This spectrum definition, in combination with expanded screening procedures, took what was once a homogeneous disease – or at least rarer and more narrowly defined – and greatly unsettled it, creating not only multiple variants but introducing variability in prognosis and prescriptions for treatment. As screening procedures are implemented in new institutions and by new agents in pediatrician’s offices, schools, Early Intervention, and the like (i.e., different social worlds) the pool of the potentially diagnosed, those red-flagged for further testing and observation, inevitably increases. Through looping, not only will the new label change the behavior of these newly-identified individuals, but their symptoms and behaviors will modify the diagnostic label in return. Uncertainty arises upon the execution of these new practices because the diseases no longer behave as the medical experts anticipated, and so previous understandings of the condition are now insufficient. Bridging work is a term for the various activities that clinicians must perform in order to reconcile the consequences of the implementation of screening and diagnostic practices with the contradictions they create in the clinic (Tiemermans and Buchbinder 2010). Every autistic child is different, yet the absence of a common autistic phenotype has not led to the dissolution of the condition into various distinct disorders. I argue that this is because clinicians work to maintain a common identity across the various manifestations of autism that they face in the clinic. Instead of narrowing in on specific symptom profiles, they adhere to the broadly defined “triad of impairments” to reconcile the diversity of symptoms and treatments with a common disease identity.
STRUCTURE OF THE CHAPTER

From the clinician’s perspective, at least three tasks must be accomplished during the diagnostic interview and later in follow-up sessions. First, they must determine if the child falls on the autism spectrum and recommend appropriate treatments, whether they be educational (such as ABA) or medically-based therapies (such as the GFCF diet). In the previous chapter we saw how diagnosis is usually easily achieved via the clinician’s “gut instinct.” Second, they must connect-the-dots for parents by helping them to identify the symptoms their child presents and understand why the prescribed treatments are appropriate. Parents are not only in search of a diagnosis, but one that makes sense of their experiences thus far, one that can provide a logical connection between the child’s therapies, schooling and prognosis. Finally, they have to situate themselves as gate-keepers of the autism diagnosis, as the point of access not only to alleviated symptoms but to more therapy hours and an improved school environment. The AMC is not only a diagnostic center, but manages patient cases throughout childhood and adolescence. In other words, clinicians have to not only translate the symptoms of autism, but also the parent-clinician relationship. Once achieved, translation has to be maintained, for as Blaxter has pointed out, diagnosis is not just a category but also a process (1978). That is to say, diagnosis does not only imply a classification scheme but is also something a physician does and must continue to do to legitimately keep patients under medical care. This is especially true with respect to the autism spectrum, where the uncertainty inherent in both development and diagnosis needs to be constantly reassessed. As will be shown below, the provisional nature of the PDD-NOS diagnosis necessitates continual reassessment. Children change quickly with or without autism, and development is continuously scrutinized.
This chapter is organized into four main parts. I begin by examining a central tension in the parent-clinician interaction: while clinicians search for general symptoms that link the child to the diagnostic category, parents work to assert the individuality of their children by referring to their special talents or unique personality traits. In the following section I describe the diagnostic process as it was witnessed at the AMC. Diagnostic testing and interviewing comprised about 36% of my observations and applied to 34% of the patients I followed. In the third part of this chapter I document my impressions of the remainder of appointments I observed at the AMC. These consisted of either the follow-up sessions of those previously diagnosed, intakes of new patients who were already diagnosed, and follow-up appointments for patients who already visit the AMC regularly. In keeping with the discussion above, in the remaining sections I will focus on how clinicians translate both autism and the clinician-parent-child relationship in the interviews while they simultaneously bridge the uncertainty inherent in clinical work. At the same time, I demonstrate the multi-faceted nature of the autism diagnosis as evidenced by the different narrative styles that are assumed in the talk which surrounds it. Finally, I conclude with an examination of how two different types of therapies, biomedical and psychopharmacological, are thought of as treating different aspects of the disorder – core versus peripheral symptoms, respectively.

**CASE VS. BIOGRAPHY**

The focus of what follows leans more towards the ways in which clinicians act to direct or shape parent behavior. But parents are not passive recipients of diagnoses and translations
behaviors (this is why the supply-side is wrong). Instead, they actively engage in the performance of their child’s identity, offering alternative explanations for behaviors that are not framed in terms of a deficit but as an expression of personhood. The central tension is one of descriptions of the child as either a “thick” or “thin” person. Diagnostic assessment strategies and tools, and this is particularly true of the ADOS, parse a child’s overall behavior into the smallest possible elements that are still capable of conveying a clinically meaningful distinction. Does he respond to his name when called? Does she use eye contact to show you something? Can he follow simple commands, like “go get your shoes”? Answers to these questions constitute the child as a thin person, a patient whose particular set of deficits are at the forefront. These characterizations, while useful for directing parental attention to the child’s therapeutic needs, are insufficient for parents who view the same individual as a child and not a patient, a “thick” person who possesses not just a certain set of deficits but a personality and his own interests.

The medical practitioner compares a patient to all the other cases she has seen before him and attends to the ways in which they are the same. Routinely asking questions like those above helps clinicians isolate the similarities between patients, ignore the features that make them different, and ultimately facilitate decision-making as to whether or not what presents before her is a case of autism. When clinicians do ask about the child’s interests, it is always immediately followed by an inquiry into their possible repetitive nature:

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56 That patients cannot be assumed as passive recipients of diagnostic labels is understood to be the ultimate undoing of the labeling theory of diagnosis, which gave way to the negotiated order and other theories which proposed that a diagnostic label must be acceptable in light of the patient’s beliefs, or it might be rejected. Madden, S. and J. Sim (2006). "Creating meaning in fibromyalgia syndrome." Social Science and Medicine 63(11): 2962-2973.
Dr: Does he have any other interests? Does he like to watch TV, or listen to music, anything?
Dad: He likes TV. And if there is a song playing that he likes on TV, he’ll run from another room to come and listen.
Dr: Does he have to watch the same TV program or videos?
Dad: No, he likes different things.

Thus, the physician’s curiosity about a child’s interests is motivated by a desire to determine whether these interests are repetitive or otherwise odd and subsequently characteristic of autism.

Parents, on the other hand, often refer to the quirks and behaviors that depict their child not as a case but as a person. They highlight biographical details that make their child unique. I observed two primary strategies they employed to accomplish this at the AMC. First, parents would offer alternative explanations for a child’s autistic behaviors or developmental delays. They conceived of the deficits noted by clinicians as not deficits at all, but as resulting from the child’s personality. For example, after four-year-old Henry had demonstrated his remarkable ability to read, Dr. Baker inquired after his ability to comprehend what he had easily read. Henry’s mother reasoned that his level of reading comprehension was not low but that Henry was simply shy:

Dr: Does he understand, or just read?
Mom: I think he does understand, he just doesn’t want to communicate it. [To Henry:] What’s on the plate?
Henry: Orange.
Mom: That’s the plate in the center. What’s on the plate in front of her?
Henry: Bacon.
Dr: What does she ask grandma for?
Henry: Juice.
Mom: No, you ask grandma for juice.
Dr: Yeah, see, he can’t answer questions about the content.
Mom: I think he’s shy because of his personality.
Though parents never disputed the autism diagnosis, in this fashion they indirectly challenged the clinician’s interpretation of the autistic nature of some of the child’s behaviors. They might also preemptively offer explanations of how what would normally be considered a symptom of autism does not impair their child at all. For instance, Charles’ mother insisted that her son did not need to make coordinated eye contact:

Dr: Does he understand when you speak to him?
Mom: Everything. He doesn’t have to look at you to understand. He understands everything, at least when he wants to.

Like both Henry’s and Charles’ mothers, parents regularly referred to the fact that the child did not want to do something, thereby rephrasing a deficit as pure stubbornness. This most often occurred when a parent was asked if the child responded to his or her name when called: “when he wants to” was a common response to this question. Parents thereby communicated that their child was just like any other (neurotypical) kid, at times behaving badly and ignoring his parents because he’s engaging in an activity that interests him, or because “he’s got that teenage attitude.” They present a child that while autistic, still possesses intellectual and social competencies as well as a sense of humor:

Dad: He does show some protective qualities towards the baby. One time he offered her a cheerio because she was crying. He’s never offered me a cheerio.
Mom: Yeah, and he also mocks her when she cries. He’s got a really strange sense of humor.

Parents also spoke of their children’s exceptional creative talents. Lucas’ mom recounted how her son enjoyed painting and would often return to look at an older piece, tilt his head in thoughtful reflection, and add to the work. Charles was said to have a special ear for music:
Mom: The music he likes is very complicated jazz, like [names several artists]...
Dad: Yeah, [artist], he introduced me to that. He pointed out the CD. He likes music an awful lot. I was a music major, and when I look at him when he listens, the look on his face, he smiles at the right moment, you know, when he should smile.

Thus, parents focus on the unique characteristics of their children to create biographical narratives. They are not passive recipients of the autism diagnosis, but actively work to establish the identity of their child. Clinicians, on the other hand, construct cases from these narratives, culling the relevant information about patients that makes them similar to all the others diagnosed. I now turn to the ways in which clinicians argue the case for autism to parents.

**Diagnosing Autism Spectrum Disorder at the Autism Medical Center**

Some parents bringing their children to the AMC for diagnostic testing have already received confirmation – either by a pediatrician or other specialist, but probably Early Intervention – that something is amiss with their child’s development and they suspect that autism might be the cause. Others have already received a diagnosis, usually of PDD-NOS, and are seeking a second opinion. Almost all children are already receiving Early Intervention services, and parents have accepted the fact of their child’s atypical developmental trajectory. The question that remains is whether or not the problem is indeed autism, and if so, what more can be done to help. As it turns out, in my observations of diagnostic sessions it almost always was autism. In only one instance was the child *not* diagnosed with an Autism Spectrum Disorder: eight-year-old Enrica was diagnosed with significant communication impairment, with secondary emotional and social impairment. In no case did diagnostic testing lead to a confirmation of neurotypicality. Twenty-three month old Rachel did not receive an ASD
diagnosis but was “kept on” (Latimer, Featherstone et al. 2006) for further observation, even though doctors claimed to “like what they see” with respect to her social development. But with the exception of these two girls, all children undergoing assessment at the AMC were found to fit the criteria for either Autistic Disorder or PDD-NOS.

Though this finding may be shocking at first glance, there are many reasons why this result is not so unusual. For one, as Martha suggested, autism is becoming more and more common, so it is to be expected that an autism clinic commonly diagnoses autism. But is this enough to explain a diagnostic rate near 100%? In chapter one I argued that the autistic career began long before the child was actually diagnosed, and that early career events served to shape the identity of the autism parent. Prior to their arrival at the AMC, parents had already learned about autism, be it through Early Intervention therapists or from their own research. Young children without a prior diagnosis were screened using the M-CHAT, so clinicians already expect to see autistic-like symptoms. As a result, the children who visit the AMC – even those without a prior diagnosis – enter the clinic with plenty of “autistic baggage”: most were already undergoing Early Intervention therapies, from where child development professionals directed them to a specialized clinic. These children were already identified as different, their disability identity had already begun to be formed. Furthermore, most of the standardized testing conducted at the AMC was with autism-specific instruments. In this way, the referral process to the clinic also functions as a confirmation process, and the autistic identity is shaped through it (Goffman 1961; Mehan 1986). The symptoms of autism are by no means specific to an ASD diagnosis alone, but the means by which they are “discovered” can lead to some conclusions being more probable than others. For instance, in an examination of the testing procedures of
school psychologists for learning disabilities, Mehan (1986) found that a “test until find” approach based upon the referral reason was commonly utilized. Thus, if a child was referred for reading comprehension difficulties, the examiner would administer the complete battery of reading comprehension tests until the child could be labeled as reading-challenged. Similarly, it can be argued that the expectation of autism increases the possibility of an autism diagnosis. As Dr. Daly expressed to one parent during ADOS testing with regard to her son: “I assume he’s somewhere on the spectrum if you’re here.”

TRANSLATING AUTISM

Parents visiting the AMC are sometimes anxious to receive a diagnosis for their child. From their perspective a suitable treatment strategy, and hopefully recovery, can only be achieved once a diagnosis is made. The greatest challenge to proponents of demand-side explanations of the diagnosis of autism is the finding that parents neither expect nor want (at least explicitly) an autism diagnosis. As the AMC clinicians reported, the problem is less of parents shopping for a diagnosis than of convincing them that their child is more impaired than they would like to think. Parents usually suspected a different developmental difficulty, be it speech delay or a hearing problem. Thus, clinicians need to demonstrate the degree of severity to parents and communicate that the problem is not going to go away with a little bit of speech therapy. The emotionally-charged nature of parent-clinician interaction in the diagnostic interview renders these exchanges more complex than what one might typically expect from a doctor-patient exchange. Parents want proof of autism, and clinicians have no biological test results to support their opinions. As we saw in chapter two, autism is often diagnosed by prototype or ‘gut instinct,’ as is perhaps the case all disorders whose symptoms manifest only
behaviorally. Clinicians at the AMC readily acknowledged their own capability to diagnose in an instant, which they understand as deriving from an amassed amount of clinical experience.

When they describe this particular manifestation of their clinical intuition, clinicians talk about autism as something real, a genuine disease entity, that the trained eye can identify within seconds. Autistic kids stand out amongst both their neurotypical peers and children with other disabilities. But parents and lay observers like myself clearly cannot “see” autism so easily. After observing the first ADOS administration I asked the clinician how she could tell the difference between autism and something like Attention Deficit Disorder (ADD). In response, she offered no details of differentiating symptoms but only explained that children with ADD “are very connected” and that I would learn how to spot autistic symptoms when I see them, and that until I see them, I could not really know what I was looking for. My own inexperience with children was taken as the reason why I could not distinguish autism:

Dr: So what did you think? Do you know about autism?
NR: Well yeah, I’ve read about it but this is the first time I’ve seen the ADOS done. One thing that strikes me is how you can distinguish this from other disorders, like for example ADD.
Dr: Oh, well ADD is very different. They [children with ADD] are connected [to other people]. It’s completely different. Well, I mean, autistic kids can be hyperactive also, and he was clearly overactive, but... are you around kids? Do you have kids?
NR: No.
Dr. Yeah, see. ADD kids are connected, they’re interacting with you.
NR: I see. (Fieldnotes, 06/06/07)

Thus, recognizing the autistic prototype is not a skill exclusively reserved for those who have been medically trained, but can be acquired by anyone who has had enough experience with children and/or autism itself. According to Dreyfus and Dreyfus (2005), “intuitive judgment is
the hallmark of expertise” (779). Expertise is a skill that is acquired through the accumulation of experience, which continually refines the ability to make more and more subtle discriminations until the expert is able to immediately categorize what is before her. Of course, it is precisely the institutional funnel that determines the range of experience clinicians have. For example, Dr. Johnson referred to the fact that she has “seen a lot of kids” when I pressed her for a more comprehensive explanation of why she had settled on the PDD-NOS for a certain child. As described in Chapter 2, she has seen a lot of kids who have already been flagged as probably autistic. One might argue that the “gut feeling” is the connection between what the practitioner sees and the formal medical knowledge she has internalized over the course of her training. As such, this feeling confirms the diagnosis and obviates a symptom-by-symptom analysis of each and every individual patient. It effectively erases any discrepancy between the definition of the disease and what qualifies as a diagnosis.

In the course of my fieldwork, I frequently asked clinicians how and why they had arrived at the diagnosis for a particular child. However, they proved rather adept at dodging my persistent questioning for more detailed, symptom-based clarifications of their diagnostic behavior by deferring to this tacit sort of knowledge. Experts need not make recourse to decision rules – those are for beginners (Dreyfus and Dreyfus 2005). Take, for example, the following situation in which I urged Dr. Johnson to offer me a more formal understanding of their diagnostic reasoning, as in:

NR: What about the regression? What role did this symptom play when diagnosing Andy?
Dr: Regression shows up in about 25% of patients, maybe less.
NR: Does that mean it’s a good indicator of whether it’s autism?
Dr: Well, not really. Like I said, it shows up in about 25% of cases. (*Fieldnotes*, 11/25/07)

Here, Dr. Johnson did not articulate whether or not Andy’s reported course of regression after several days with an extremely high fever was an argument for or against his particular diagnosis. As Dreyfus and Dreyfus (2005) warn, “[i]f one asks an expert for the rules he or she is using, on will, in effect, force the expert to regress to the level of a beginner and state the rules learned in school” (788). References to the statistical averages of medical research were littered throughout the diagnostic interviews. Clinicians would frequently place a child’s individual symptoms into this broader context, as Dr. Johnson does with Andy’s sensory-seeking behaviors:

Mom: He’s *constantly* seeking sensory stimulation. He likes to roll things between his hands a lot.
Dr: I think he’s seeking input. There is a small subset of autistic kids who seem to need higher input. [...] Some kids just have a very high tolerance for pain. (*Fieldnotes*, 11/25/07)

To physicians, the gut instinct is proof that the diagnostic category is real; autism exists because it can be “seen” in the child. Abstract, medical knowledge is thereby connected to patient behavior by a visceral reality. But clinical intuition alone cannot legitimize medical intervention. Clinicians must work to present their own interpretation of the patient’s troubles as the natural conclusion that any physician would have drawn based on the presentation of symptoms at hand. They have to connect-the-dots between the child’s concrete behaviors and the current understanding of autism. They must do this not only for observers like myself but for parents as well, and not only to explicate what *is* autism but what is decidedly *not* autism. Recall from chapter one that for parents, “autism” was understood as *Rain Man*. 
To this effect, clinicians regularly pointed out autistic behaviors to parents during diagnostic sessions at the AMC. Dr. Baker, in sleuth-like fashion, would ask a question and subsequently re-phrase parents’ answers by thinking out loud:

Dr: [referring to how Dad has been trying to get Dylan to respond to his name] So he doesn’t respond quickly to his name?
Dad: No.
Dr: What about before the change [in Dylan’s behavior], at 11 months?
Dad: Yes, he did.
Dr: Hmm, interesting... even though his comprehension would have been less then. So he’s okay without interaction, he just sits there as he does now. Because other [neurotypical] kids his age, they won’t sit there like this.

Mom: In the summer, when we go to the playground, he will pick up a rock, or play with the wood chips on the ground. But he doesn’t have any interest in the slide, or the swing. We have to take him to it. But then when we do, he’ll enjoy it lots. But he doesn’t show any interest in it on his own.
Dr: So he doesn’t imitate.

Through this sort of talk, Dylan’s parents learn to recognize the specific behaviors that make their son autistic: he does not respond to his name, he does not seek out social interaction, and he does not imitate others. While for the most part Dylan’s parents accepted Dr. Baker’s assessments without question, other parents would counter the physician’s declarations by clarifying the situations in which the child does exhibit the behavior assumed to be lacking. For instance, the following exchange occurred after Dr. Daly had conducted the ADOS with Nathan and diagnosed him Autistic Disorder:

Dr: Well, he has lots of the symptoms associated with autism. He doesn’t talk, he doesn’t make gestures like clapping or waving goodbye.
Dad: He will if prompted.
Dr: Right, but I’m looking for spontaneous action. He gets caught, really stuck on stuff, like the Play-Doh and the Goldfish. And he’s got lots of sensory stuff. So he’s got lots of stuff you see with autism.
In this example, Nathan’s father suggests that the boy can clap or wave goodbye. But Dr. Daly takes the parent’s understanding the behavior and rephrases it as deficit as opposed to a skill: Nathan will only perform the behavior if he is prompted and not on his own initiative; neurotypical kids perform these behaviors *spontaneously*. In this manner parents learn that autism is not only marked by the absence of certain social behaviors, but also the contexts in which they arise. What is interesting is that Dr. Daly explicitly employs the language of the ADOS, where the “spontaneous use of at least two different gestures” is coded as normal (or better, ‘not abnormal’) in the Language and Communication section. The language of the ADOS was used even in the interview setting, whether or not the child had done the ADOS. For instance, when Lucas brought his grandmother a Ziploc bag of crayons for her to open for him, Dr. Johnson commented, “So I see that he’ll take something to you, but there’s no coordinated gaze.” Coordinated gaze and integration of eye contact, as it were, are indicated in many ADOS items pertaining to Reciprocal Social Interaction.57

In all of these cases, autism is talked about as though it is something exhibitable, something that the child can present to others. Here, I borrow Goffman’s definition of performance as “all the activity of a given participant on a given occasion which serves to influence in any way any of the other participants” (1990: 15). It is in part through the child’s performance in the clinic that autism comes into existence and the autistic identity is assumed. An emphasis on performance is a means to teach parents not only what autism looks like, but exactly which skills the therapies should target for development. In the interviews, parents

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57 One researcher has noted on her blog that clinical diagnostic practices conform much to standardized instruments such as the ADOS. (Dawson, M. (2010). Proposed new autism criteria: the DSM-V. *The Autism Crisis: Science and Ethics in the Era of Autism Politics*. 2011.) I will return to this idea in chapter four.
explained that it was especially in the course of Early Intervention, but also through their interactions with specialists, where they learned about the autism spectrum and how to recognize the features of autism in their child. Autism is immediately visible to clinicians; but at the outset, parents do not see autism as a “real thing.” Sometimes they do not see autism at all but rather suspect either a speech disorder or deafness; many suspected that autism was misdiagnosed. The point is not only that the identification of autism is a learned skill acquired with the assistance of therapists and clinicians, but that this is done through the deployment of a performance-type narrative that makes explicit reference to the discrete behaviors that qualify the child for the autism diagnosis.

Why might parents experience difficulties perceiving autism in their children, and what might autism-as-performance do to resolve these difficulties? Parents of children who are only mildly affected are usually shocked to learn that their child shares a diagnosis with the character from *Rain Man*. Many had expectations of a speech disorder that could be remedied with a few years of speech therapy, or that their child would simply “grow out of it.” But the use of these performance-type narratives and tools such as the ADOS serve both parents and clinicians. In practice, clinical intuition is not 100% reliable, and clinicians sometimes deferred to performance-based measures such as the ADOS in order to clarify a diagnosis when the child was thought to present very mild symptoms. This was routine practice with the “tricky kids.” More common practice was the clinician’s switch from a reality- to a performance-type narrative in order to clarify a diagnosis for parents. If either a parent was thought to express any doubt about the diagnosis, further testing (typically in the form of an ADOS) was ordered or at least suggested, as with the following parent:
Mom: He’s still very self-directed. When he wants to do something, he does it.
Dr: Do you want him to do the ADOS?
Mom: Well, what does it do?
Dr: It’s used a lot for research.
Mom: Maybe we should...
Dr: Well, what are you most concerned about?
Mom: Mostly his language.
Dr: Do you want to do more developmental tests?
Mom: What will it do for us?
Dr: Well, do you have a hard time believing he’s on the spectrum? (Fieldnotes, 09/05/07)

This last question could be rephrased as, “If you don’t believe he’s on the spectrum, we can get him to perform it for you.” Parents (and in this other cases, patients themselves) like diagnostic tests and are more comfortable with the results of tests than a reliance on clinical intuition (Nettleton 2006). In the interviews, parents expressed frustration when they felt a physician had made a quick diagnosis solely on the basis of appearance without having done any testing, and they praised physicians who had really “taken the time to get to know” their child. In a sense, both clinicians and parents rely on the same strategy. Clinicians turn to performance when the prototype method fails or is inconclusive. Parents, or anyone who lacks the ability to “see” autism, rely directly on test results. For both, uncertainty is reduced by the bridging work of clinicians to bring objective, medical knowledge – in the shape of formalized scales and questionnaires – to bear on diagnostic decisions.

The threatened permanency and severity of autism is frightening and overwhelming for parents, and the diagnosis itself offers little information with respect to prognosis and a course of action through which improvement is actualized. As one parent whose son was diagnosed with PDD put it, “I got an umbrella [term] handed to me.” Rephrasing the diagnosis as a set of...
behaviors to be modified puts the diagnosis is a more digestible format for parents. They want to know what it means to have “impaired social interaction,” and what they can do about it. Talking about improving eye contact and learning how to point provides parents with short-term, manageable goals as well as a strategy – often ABA therapy – with which to achieve them. There is no cure for autism, but there are therapies for improving speech, learning how to point, and replacing hand-flapping with a more appropriate behavior. No doubt this alleviates some anxiety for parents, as concerns about the distant future (Will he make his own friends? Get married someday?) are exchanged for something more proximate and obtainable. When asked about how autism had changed their lives, a common response among parents was that they learned to slow life down and take “one day at a time.” In this sense, the delineation of discrete behaviors is a form of bridging work which simultaneously connects the manifesting autistic behaviors with the specific therapies that are prescribed. Furthermore, with tests like the ADOS modeled closely on the DSM criteria, it is also a bridge to the abstract disease entity itself.

DIAGNOSIS AND PROGNOSIS

The specific disorders that comprise the autism spectrum are conspicuously absent from the proposed DSM-V criteria. Instead, Autistic Disorder, Rett’s Syndrome, Asperger’s Disorder and the all-important PDD-NOS are exchanged for the unitary but inherently multidimensional Autism Spectrum Disorder. While the important debates surrounding these proposed changes are beyond the scope of this chapter, one implication for clinical practice is obvious: all of the

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clinical work performed to distinguish AD from PDD-NOS is obviated. But while the job of the 
clinician might become easier in one respect, subsuming all these disorders under one heading 
also introduces new challenges. Namely, parents want to know where there child is on the 
spectrum; they want some indication of the degree of severity they are up against. Knowing 
whether they are dealing with autism, Asperger’s or PDD is informative. It provides parents 
with a more acute sense of the degree of impairment, and it offers clinicians a way to 
communicate it.

The PDD-NOS/Autistic Disorder distinction has some degree of clinical utility at the 
AMC. Though a symptom-by-symptom comparison of patients was not possible – clinicians did 
not always ask the exact same questions, nor could I always jot them down – two differences 
between AD and PDD-NOS sessions did emerge from the data. First, the children diagnosed 
with AD possessed no expressive language at the time of the interview, though some parents 
had reported the use of words at one point followed by a course of regression. On the other 
hand, the children diagnosed with PDD-NOS were at the very least capable of labeling some 
objects with words, and others could speak in full sentences. Second, and undoubtedly related 
to the first, parents of the AD children reported very little to no progress with the current 
therapies the child was receiving. The one commonality amongst the PDD-NOS children, 
however, was that they were all progressing with the educational therapies. Though some of 
the parents interviewed told of how pediatricians hesitated with the autism diagnosis because 
it could not reliably be made at a very young age, this was not a rule of thumb strictly adhered 
to at the AMC. In fact the youngest patient to be diagnosed, at just twenty-one months, was
said to have Autistic Disorder, whereas patients as old as seven years were diagnosed with PDD-NOS.

The importance of language and markers of progress in the PDD-NOS diagnosis is perhaps best exemplified through a comparison of two patients, James and Dylan. James was two months shy of his third birthday when he was diagnosed with PDD-NOS by Dr. Johnson. James lacked several of the skills that a typical child his age possessed. He did not babble as a baby and did not respond to his name if called. At present, he could not follow simple commands (e.g., ‘Get your shoes’) nor express his wants or needs. He was not interested in other children nor did he engage in imaginative play, and he was unable to recognize if another person was angry. He also displayed many of the unusual and stereotyped behaviors that characterize classic autism: he toe-walked, stimmed, was echolalic, lined up toys and turned toy cars upside down to spin their wheels. On the other hand, with the aid of speech therapy James was now beginning to build two-word phrases. Dr. Johnson reasoned the PDD-NOS diagnosis as follows:

So the [Early Intervention] program seems remarkable. He’s gone from no speech to putting words together. He uses the word “I”, which is all very good. His behavior can still be described as on the autism spectrum. The ADOS looks at severity of symptoms; he came out as PDD-NOS. Some kids lose the diagnosis.  

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59 There was some debate amongst clinicians at the AMC about whether or not a child could “lose the label” if the therapies were sufficiently successful such that he became indistinguishable from his neurotypical peers. Some argue that the diagnosis is for life, that even if a child – with the help of the therapies – can learn to point and make eye contact, she is still autistic precisely because she had to learn these skills. For others, the diagnosis was viewed more as a descriptor of current functioning. If the child showed no communication or social deficits, and was not in need of special placement in school, then the label was unnecessary. This is essentially a dispute between two frames: the former of autism as a real illness, and the latter of autism as a performance. From the perspective of the argument presented in this chapter, this is primarily an academic debate. In practice, what is most important is the capacity of clinicians to switch frames when it is most appropriate for parents and the child.
Kids are a work in progress. I wouldn’t classify him as autism; it seems as though he’s improving.

Dr. Johnson hedges her verdict with a quick synopsis of the “remarkable” progress James has already made in Early Intervention. And while she feels that PDD-NOS is an appropriate descriptor, she adds that this label is only provisional and might be dropped later on, should the current success of the therapies continue. The fact that James has responded well to therapeutic interventions is understood as evidence that his impairments are more mild and possibly surmountable. The positive overtones of this talk was typical of PDD-NOS diagnoses. The “nice skills” the child possessed were annotated and followed by a statement that the child nevertheless manifests behaviors that put him on the spectrum. In contrast, Dylan’s diagnosis was communicated as follows:

Dr: I would probably put him as autism [Autistic Disorder], not PDD. Do you know the difference?
Dad: No.
Dr: It’s a large spectrum. [I cannot say?] much with respect to prognosis. His communication is a lot less than what we expect with a kid at this age. You really have to push him, but he doesn’t look at you. He’s mad but he doesn’t push me away, or go to you for help. I’m going to put autism [AD] in his report and recommend more services. [...] When you don’t engage him, he goes off. He goes away. So we want more therapy to engage him.

Twenty-one-month-old Dylan was brought to the AMC by his father, who was concerned with his development as Dylan’s older brother, Noah, was diagnosed with PDD-NOS. Dylan had no language and did not react to any of the social overtures initiated by his father or the physician. He did not initiate contact with others or engage in imaginary play. He did a lot of visual stimming. Dylan was not improving on the GFCF diet, and he was making little progress with the ABA. Though his father insisted that Dylan was much more advanced than Noah had been at
the same age, Dylan had yet to make any breakthroughs. Thus, in contrast to the more optimistic tone used with James, Dr. Johnson spells out exactly which behaviors Dylan is not exhibiting to show what makes autism the appropriate diagnosis. Speaking in more general terms, Dr. Johnson explained the difference between the PDD-NOS and AD diagnoses as follows:

PDD[-NOS] is sort of a middle category. As kids get older, PDD[-NOS] can become autism, it can remain PDD[-NOS], or it can turn out to be nothing [i.e., the child loses the label, is ‘neurotypical’]. It’s really variable. But if a kid gets an autism [Autistic Disorder] diagnosis at a young age, it usually stays. It usually means that the deficits are more significant.

Thus, diagnosis is not independent of prognosis. Both are enveloped in uncertainty, but PDD-NOS even more so than AD. Here again autism is something real, a graded degree of impairment in which more severe deficits are more difficult to overcome. Notably, these conversations were not about whether the primary diagnosis was to be designated as autism or, say, mental retardation. And rarely was the choice between Autism Spectrum Disorder or nothing at all. Rather, the choice was between Autistic Disorder and PDD-NOS. The key to understanding these exchanges is with respect to prognosis. After I observed Dr. Daly administer the ADOS to Luis, who was classified as autistic (and not PDD) on the scale, she remarked that he “should blossom.” When I asked why she thought so and if it had anything to do with the diagnosis, she replied:

The key to improvement is EIP [Early Intervention Program]. The diagnosis is only for the classification. Essentially, it’s all about the EIP. Some parents even ask for the autism diagnosis in order to get better services for their kids. With the diagnosis, you automatically get [4? 5?] hours per week of EIP. (Fieldnotes, 06/06/07)
There may not be a cure for autism, but the question as to how much a particular child can improve is always an open question. At the same time, there exists no one-to-one mapping of diagnosis and prognosis. For not only does every child respond differently to the treatments, but the provision of services itself confounds the relationship between diagnosis and prognosis. and it is common knowledge amongst parents and practitioners that a child’s potential is maximized to a similar extent as his or her therapy hours.

**Autism, PDD-NOS, and Treatment Services**

For some, autism is less a rapidly-spreading disease than an artifact of changing diagnostic criteria and practices. Part of the appeal, it is argued, is that an autism diagnosis – unlike mental retardation, learning disabilities or other developmental problems – yields a far greater number of publically-funded services. Parents are demanding the diagnosis, and clinicians are complying. While the evidence presented in the first chapter clearly rules this out as the full story, there is certainly truth to the claim that an autism diagnosis will grant a child more services. In some states the number of therapy hours almost doubles with the diagnosis, or it may be that the diagnosis brings broader insurance coverage. We have already seen how formal medical knowledge about autism, best exemplified in the DSM-IV criteria, enter the diagnostic situation through the clinician’s instinct and the use of standardized tests like the ADOS. We have also seen how diagnosis is not independent of prognosis and the children’s response to the therapies they receive in Early Intervention. I now consider a third way in which autism is narrated to parents: as a label to obtain services.

During the diagnostic interviews, neither parents nor clinicians at the AMC hesitated to openly negotiate the diagnostic label a child would receive in the resulting report. For instance,
on one occasion Dr. Johnson asked the parents if they were “okay with the autism diagnosis.” When I later asked what she meant by this, she replied:

Well, he had a PDD-NOS diagnosis [from his previous assessment at a different clinic]. If I say this [PDD-NOS] in my report, it’s often confusing for parents. Sometimes I’ll use it for kids who will meet the diagnosis later on. But with this diagnosis, it’s not as easy to get services, whereas the autism [AD] diagnosis will help them get services. *(Fieldnotes, 10/25/07)*

Thus, the autism label is used as a means for children to obtain the greatest possible amount of services and the optimal placement with respect to schooling environment. Within these discussions a third narrative style arises, one in which autism is a completely pragmatic category for assigning children to services. Here, autism is no longer something that really exists or is at least exhibitable, but a means to group together the entire range of atypical children who need services. In a reversal of the standard diagnostic logic, it is treatment that determines diagnosis, which here becomes an assessment of need. This is by no means an unusual or new practice: arguably, diagnosis by treatment almost always defines how physicians operate.

That the severity of ASD was sometimes exaggerated in the diagnostic code given to a particular child could be used to comfort parents for whom the actual (as opposed to administrative) diagnosis is Autistic Disorder. For instance, when Dylan was diagnosed at the AMC his father explained that the neurologist they had seen previously reckoned that on a scale of severity ranging from 1 to 10, Dylan was a five. Dr. Johnson disagreed: she thought that Dylan was closer to seven. But immediately thereafter, in the face of the father’s obvious grief, she softens this calculation:
Dr: I see babies a lot worse than him that do very well. I don’t want to take away your hope.
Dad: No, I know...
Dr: It's just that we can qualify for more services [with the AD diagnosis] and we want to be as intensive as possible.

Thus, there is a “bright side” to the AD diagnosis: it will support more intensive treatments somewhere in the vicinity of twenty to forty hours per week, which the research has shown to be most effective. To the same effect, another parent was told to “forget about the scores” and instead “focus on the treatments.” The use of the autism label as a means to obtain services thereby communicates to parents the urgency of intervention. States and insurance companies both recognize this urgency and judge it to be within their economic interests to treat the child as intensely and early as possible. Improvement now means a lower likelihood of special education, assisted living and therapy bills later in life. It matters little to anyone whether it is called autism or PDD; what is important is to secure as many therapy hours as possible, as soon as possible.

The exigency of services and importance of potential is further emphasized, though indirectly, through the labels that are not discussed during diagnosis. For instance, though approximately 75% of autistic patients are thought to also be affected by mental retardation (Rapin 1997), this was rarely discussed at the AMC. In fact, during the entire course of my observations, the possibility of a child being mentally retarded in addition to autistic arose on only one occasion. Notably, it was the parents and not the clinician who raised the issue. In this case, the parents of 13-year-old Ethan were in search of a physician who specialized in autism, as they were frustrated that their current neurologist did “not seem to understand what to expect” from Ethan. They were also unsure whether or not they should base their current
dissatisfaction with Ethan’s school in the school itself, or whether Ethan was suffering from more severe impairments that were responsible for his failure to make more notable progress.

Dr. Michaels thought that the school was the more likely culprit:

Dr: Just because he’s got autism, it doesn’t mean he’s not smart. I think for Ethan, he should be learning more at school and I’m going to recommend that in my report. Maybe the people at his school just haven’t realized his potential. Autism is a spectrum, and for something like language, it’s not that these kids can’t speak, it’s that they don’t know what language is for. They don’t know how to make friends, even if they want to. So we have to teach them how to do these things that come naturally to us. But having problems with these things doesn’t necessarily affect intelligence.

Mom: Well, two years ago the neurologist said that he was more affected, she said that he was on the more severe side of autism and that he was mentally retarded.

Dr: No! From what tests?

Mom: I don’t know.

Dr: No. I would say that Ethan’s somewhere in the middle of the spectrum. He’s got some independent skills. He’s not severe. He’s not screaming, or lining up toys. Now we haven’t done any tests here so I can’t make any inference on Ethan’s intelligence other than from what you tell me. But he’s using the VCR, he’s making piña coladas, he knows his directions. He’s not retarded. I can’t tell you his IQ, but he can learn. (Fieldnotes, 10/25/07)

The DSM-IV-TR (American Psychiatric Association 2000) defines three diagnostic criteria for mental retardation. First, sub-average intellectual functioning as indicated by an IQ of 70 or lower, to which Dr. Michaels makes explicit reference. Second, age of onset before age eighteen years, to differentiate from dementia. Third, impairments in adaptive functioning in at least two areas among the following: communication, self-care and home living, social skills, use of community resources (such as public transportation), self-direction (independent completion of day-to-day tasks), functional academic skills, work, leisure, health issues and safety (ability to recognize dangerous situations). Ethan’s lack of independence or self-direction – he was unable to dress himself, use the bathroom, take a bath, or tie his own shoes – was
obvious. He was also unable to speak, did not spontaneously interact with others, and his parents were deeply concerned about his safety after a recent episode in which he ran out of the house and down the street. Nevertheless, even without the results of an IQ test Dr. Michaels quickly dismissed the suggestion that Ethan could possibly be mentally retarded, which she implicitly equated with being on the more severe side of the spectrum. Ethan was not retarded, she insisted, because he could learn.

There is nothing obvious in the definition of mental retardation (MR) that indicates an inability to learn. Persons with Down’s Syndrome, for example, learn to speak and interact with others, live independently, and sometimes maintain employment. There are several reasons why Dr. Michaels might have preferred to avoid any association with MR. First, for reasons in part related to the activism of autism parents in the 1970s (King 2008), autism is perhaps a less stigmatizing diagnosis than MR, so parents are reassured when they hear that their child does not have MR. Since its inception, autism has been – and it still remains – enveloped in mystery, a curious disorder that hides a unique person from the rest of the world. Second, and related to this first point, because of the notion of the spectrum and the understanding that low-functioning or severe autism already implies MR, there is no need for the co-morbid diagnosis. As a diagnostic label, MR is redundant alongside autism. The individualized prescriptions for treatment should not differ, and the diagnosis would not yield more therapy hours, so from a purely pragmatic perspective the MR diagnosis could do no good – though quite possibly harm. Third, and arguably most significant, the MR label is avoided because what it implies with

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60 In an unrelated conversation with Dr. Johnson, she explicitly indicated that a lack of independent skills was suggestive of severe autism.
respect to a child’s potential is grossly incongruent with that of the autism diagnosis. Mental retardation is permanent – we do not hear stories of persons who overcome a diagnosis of MR get PhDs, write books, or go on inspirational speaking tours. The autistic (as exemplified by Temple Grandin) have this potential, but the mentally retarded do not. In fact, many parents expressed in the interviews that this potential was something they had learned about persons with autism:

I thought it was a condition that had no hope in the beginning. I thought that what Charles was when he was diagnosed was all that he was going to be. And now I know that’s not true. Because he grows every day. There’s something new every day, and I know that he’s capable of learning. You just have to ask him questions in a different way.

We saw above that the notion of potential embodied in the autism diagnosis is also evident in the distinction that is made between Autistic Disorder and PDD-NOS. The former is associated with a higher degree of impairment and, accordingly, more treatment services. On the other hand, PDD-NOS connotes less impairment and an unknown outcome. Thus, when a clinician tells parents that the child has PDD-NOS but she will diagnose AD, she simultaneously attributes greater potential to the child and communicates how this potential is best maximized.

That autism is at times narrated as a currency, a meaningless label to exchange for services, is not meant to imply that there is anything phony or artificial about the diagnosis. It is significant that in none of the exchanges I witnessed was autism one-dimensional in this fashion: not once did a clinician offer to diagnose a child with autism without also indicating her own self-conviction that the ASD label was appropriate. On the whole, clinicians do believe that they are dealing with a unique disease entity, something that they really do see in their
patients, something that is distinctly different from other disabilities. When this is not the case, but the diagnosis is given, clinicians are dissatisfied. For instance, twenty-two month old Tyler was described to his mother as being “mildly on the spectrum.” He was given a diagnosis of PDD-NOS “because he’s already had an autism [spectrum] diagnosis.” I later asked if the diagnosis would have been given without this diagnostic history:

Dr: I probably would have, because he still has some sensory issues. But he does interact and share. A PDD[-NOS] diagnosis in kids this young is always provisional. Development is on a trajectory. I’m going to guess that given my experience – and I’ve seen a lot of kids – he’ll end up in a normal preschool.

Upon further reflection, Dr. Johnson later admitted that she was “not really impressed with the PDD diagnosis” that Tyler had received previously. She rhetorically asked one of the medical residents present during the session, who worked in a clinic for children with learning disabilities, “you wouldn’t have really picked out this kid in your clinic, would you?”

**SUMMARY: NARRATIVE VARIANTS IN THE CLINIC**

The central tenet of this dissertation revolves around the idea that the diagnosis of autism is multi-faceted in nature. We have seen some evidence testifying to this already in chapter one: while there is some truth to arguments purporting either a biological or social motivations for diagnosis, neither is sufficient on its own. In this chapter, I have shown how the talk that takes places in the diagnostic and follow-up interview reflects the multi-faceted nature of autism. Most crucial is the interlocking nature of these narratives, how they tie into one another and constitute the diagnostic situation collectively. Autism is not only a set of diagnostic criteria; it is also the performance of discrete behaviors, a label to obtain services, and an optimistic prognosis for parents. As such, it is a boundary object that not only inhabits
multiple, intersection social worlds simultaneously but maintains coherence and interdependency across them.

**TREATMENT VARIANTS IN THE CLINIC**

The translation of autistic symptoms does not end after the diagnostic interview. In fact, *diagnosis* does not even end at the diagnostic interview. Rather, both continue after the initial meeting and throughout the follow-up interviews. These follow-up sessions are also an assessment of treatments: which are working, which are not, what should be tried next, and so on. To the extent that diagnosis is a process that continues as long as clinicians at the AMC monitor their patients, treatments are a part of differential diagnosis. For instance, as we saw above, response to the treatment regimen is an indication of whether a child is labeled with Autistic Disorder as compared to PDD-NOS.

In this section, I analyze the narratives that surround the treatment therapies. Because the AMC does not provide educational treatments, this discussion is limited to the use of biomedical and psychopharmacological therapies. At the AMC, biomedical treatments were narrated as though targeting the actual *cause* of autism’s symptoms. In contrast, psychiatric treatments are described as being limited to the management of autistic *behaviors*. They cannot treat autism’s core deficits, but they can help make the child amenable to the educational therapies. Thus, the distinction between biomedical and psychiatric treatments is reflective of that between autism as a reality and autism as a performance.

**THE BIOMEDICAL TREATMENT OF AUTISM** The founders of the AMC pride themselves on its status as a *medical* center and they firmly believe that autism can be treated medically. Still,
while certain medications have been approved for use with autism, there is of yet no breakthrough medical treatment for autism. Physicians at the AMC always prescribed educational-type therapies chosen from a relatively small pool of options, including speech therapy, ABA, occupational therapy, physical therapy, and social skills training. But parents rarely rely on these recommendations alone. In an internet survey of treatments used by parents of children with autism, Green et al. (2006) found that almost all of the 111 therapies included on his survey were used at least once by some parents, and that on average parents were using seven treatments at any one time. Supplementing the more mainstream therapies recommended at the AMC are a myriad of others, many of which are not empirically validated and thus fall into the broad category of alternative treatments, such as the gluten-free casein-free (GFCF) diet, vitamin supplements, and chelation therapy. The trouble for the clinicians at the AMC is that these alternative therapies sometimes work, but no one knows why; or, more importantly, no one can predict beforehand which children might benefit and which will likely not. As of yet, medical research has not provided an answer, neither to the question of why the therapies are effective for some children but not others, nor to that of the underlying mechanism. As Dr. Johnson admitted, when it comes to trying these therapies with various children, “it’s a lot of trial and error.”

In chapter two I indicated that uncertainty in the clinic often arose from the incompatibility between generalized research findings and the individual patient. With respect to alternative therapies for autism, the uncertainty stems from the absence of consensus regarding their efficacy in the medical literature. Some AMC clinicians were trying to change this; Dr. Baker, for instance, was conducting research on the efficacy of fish oil (DHA) in
reducing oxidative stress, part of a larger attempt to identify the differing clinical subtypes of autistic patients that she considered the optimal place to begin searching for the as of yet unknown biomedical subtypes. But parents need to know now whether they should try a certain alternative therapy or not, and at the very least they need to know if these attempts are safe for their child. At the AMC, parents continually asked doctors their opinions on a particular alternative therapy, be it the GFCF diet, the methyl-B\textsubscript{12} shots, chelation or hyperbaric oxygen chamber. Physician responses to these queries tended to be of two sorts. First, if parents asked if they should try a specific therapy for their child, doctors would offer parents a medically-rational decision:

Mom: Would you recommend that they be on a special diet?
Dr: Some kids do well with the diet. But they [the twins] don’t really have the GI symptoms.
Mom: Would it maybe help with the stimming?
Dr: I think their stimming is just immaturity of the nervous system.
[...]
Dr: I can give you a prescription for blood work to look for any food allergies, but I don’t think the diet will do much for them. Fieldnotes, 10/24/07.

In this example, the diet is not recommended because the patients, 2½ year old twins, do not suffer from gastrointestinal problems such as diarrhea, constipation or excessive vomiting. Dr. Johnson instead recommends allergy testing to quell any concerns about the boys’ diet. Thus, when advising patients on unproven, alternative treatments, doctors still adhere to basic medical principles. For instance, they want to check for a B\textsubscript{12} deficiency before recommending the B\textsubscript{12} shots, or for high levels of heavy metals in the blood in the case of chelation. And they are surprised to learn on occasion that these principles might not hold:
Dad: At 17 months we started him on the gluten-free, casein-free diet. Then he started to change.
Dr: Really? Even without bowel problems?
Mom: But when we switched him from formula to milk, then he started waking up during the night.
Dr: Oh yeah, maybe he was a little gassy. Was it a milk- or soy-based formula?
Mom: It was milk-based. But then after we stopped giving him milk, he started sleeping through the night again.
[...]
Dr: So the diet seems to help. Fieldnotes, 11/21/07.

In this case, Dr. Baker is surprised to hear that the patient responded to the diet despite not having previous gastrointestinal problems, and later presumes that the boy must have had less noticeable GI issues. Overall, however, they still make use of the individualized nature of the spectrum to recommend a certain therapy for some patients but not others. If a parent was curious about chelation therapy, physicians would first ask whether that child had tested for high heavy metals.

Another manner in which clinicians respond to parents requesting information on alternative therapies is to refer to abstract medical knowledge and scientific procedures, and in particular to the lack of supporting evidence for the therapies in the research literature. For instance, when Matthew’s parents voiced that they would only try chelation if it had been proven safe, Dr. Johnson commented:

But then that means you won’t do it, because we’re only just starting to study it now. [...] The problem with the chelation is that their haven’t been any controlled studies published on it yet. That’s the problem with that stuff, there’s no real evidence that it works.

One way to understand this is as a safeguard for clinicians against therapies that are attempted and fail to elicit any change, or worse, harm the child in some way. Still, clinicians would
attribute the success of a biomedical treatment to the presence of an underlying medical problem, but attribute failure to the unstudied nature of the treatment. More importantly, and a point I will return to at the end of this section, clinicians were more open to accepting the medical problems that are the targets of biomedical interventions as the cause of autistic symptoms as opposed to a correlate. Psychiatric treatments, on the other hand, were understood solely as the latter.

**Psychopharmacological Treatments** To date, only two medications are FDA-indicated for use with autism, Risperdal and Abilify. Both are classified as atypical antipsychotics and are also indicated for use with schizophrenia, mania and bipolar disorder. Their approval for use with autism is specific to symptoms of irritability, mood swings and aggressive behaviors (such as self-injury) that are common in children diagnosed with an ASD. Seraquel, another atypical antipsychotic, is used similarly though it has not received FDA approval for ASD. In addition to the three atypical antipsychotics, I saw nine other drugs in use at the AMC. Six of these (Ritalin, Adderall, Concerta, Strattera, Clonidine and Tenex) were indicated for ADHD, and the remaining three (Wellbutrin, Luvox and Xanax) are used primarily for depression, obsessive-compulsive disorder, and anxiety disorders.

In my observations, no child younger than age six years received pharmacological therapies. Clinicians were clear that no pharmacological treatment exists for autism per se. There are treatments for associated behaviors like hyperactivity and obsessive-compulsive tendencies, but no medication will give a child speech and social skills. Unlike an antibiotic which is used only as long as needed to kill the target bacteria, the psychoactive drugs used
with autistic patients only have their effect so long as they are continually used by the patient. The proper analogy is a drug used for hypertension: blood pressure lowers with use of the drug, but resumes its higher value upon cessation. The same holds for autism. Take away the Risperdal, and aggressive behaviors return. Some autistic symptoms can be alleviated with psychiatric medication, but the disorder itself is treated through other means. Accordingly, when clinicians recommended medications, they couched their suggestions in one of two narratives, sometimes both. First, medications could be helpful in managing problem behaviors, especially sleep troubles, impulsivity or hyperactivity, and self-injury or other aggressive behaviors. For instance, one child was given Clonidine because he had a habit of suddenly leaving the house and running into the street. This use of medication was often connected to concerns with safety, both the child’s and those around him. But what was clear was that the medications, while relieving certain symptoms, were not treating the core autistic deficits. As Dr. Baker told one mother:

\[
\text{Unfortunately there’s nothing we can do medication-wise to help with the social stuff. But we have medication to help the anxiety and paranoia so as not to inhibit him.}
\]

Clearly, Dr. Baker believes that using medication to alleviate Michael’s anxiety would help with the “social stuff,” just not the autism social stuff. Instead, she believes that in addition to autism, Michael suffers from an anxiety disorder. Both conditions affect Michael’s ability to socialize, but only the component related to the anxiety disorder is treatable with medication. The social deficits that result from autism, on the other hand, are treatable only through the educational-type therapies. This brings us to the second manner in which the use of psychoactive medication is narrated: it removes any behavioral barriers to the “true” autism
treatments. The drugs may not treat the core deficits, but they can facilitate the therapies that do. For instance, six-year-old Jonathan’s parents were looking for a medication that could help with their son’s hyperactivity but that was in a form that he would tolerate as he disliked large capsules and skin patches. During one appointment, Jonathan exhibited quite acutely the behaviors his parents were speaking of: he was incessantly vocalizing and moving about, constantly climbing onto chairs and other objects and jumping off of them. Dr. Baker wondered how typical this hyperactivity was of Jonathan:

Dr: In school, is he like this?
Mom: Sometimes he’s good, sometimes bad. They give him breaks when he needs one.
Dr: Yeah, the therapy can’t be effective if he’s so hyper.

Dr. Baker later explained to me that she did not approve of prescribing medication for the purpose of improving scholastic achievements, but in a case like Jonathan’s it was necessary to exercise some control over the behavioral symptoms if the therapies he received in school were going to have any effect.

Unlike the various biomedical treatments, the efficacy of psychiatric medications to change behavior is unquestioned. Randomized controlled trials are the paragon of medical truth-finding. But unlike biomedical treatments, these drugs are only understood as helping to alleviate the more peripheral symptoms of autisms, or those caused by other, co-morbid disorders. Despite the guessing-game strategy of the biomedical treatments, however, when they do work are understood as treating autism itself, directly affecting core symptoms like eye contact, speech, and social interaction. Parents spoke of a “completely different child” emerging after these treatments, one who had only had a few words in his lexicon but began
speaking in full sentences within three days of starting the GFCF diet. On the other hand, no parent expressed a similar degree excitement about the reduced anger outbursts after beginning the Risperdal. To the contrary, many parents questioned whether the psychiatric medications were working at all, and it was not uncommon for parents to realize only after taking their child off of these medications that they were indeed having a therapeutic effect.

The translation of autistic versus non-autistic symptoms, it would seem, continues well past the initial diagnosis. Autism is consistently translated as a medical, and not psychiatric, disorder. This practice likely extends beyond the walls of the AMC. For instance, Siegel (1996) notes her clinical impression that self-injurious behaviors are less common now than in previous decades, as these symptoms has responded well to both behavioral treatments and medication. Though looping, then, these behaviors fall to the periphery of the diagnosis and are understood as consequences of the core deficits: the child becomes frustrated because he is unable to communicate his wants and needs.

**RESPONSIBILIZATION: TRANSLATING THE PARENT-CLINICIAN RELATIONSHIP**

In chapter one I suggested that as parents traverse the steps of the diagnostic career, they are responsibilized for their child’s brain. Here I want to expand on this idea to argue that clinicians restructure the parent-clinician relationship so as to responsibilize parents for their child’s treatment regimen. During the diagnostic interview and throughout the follow-up appointments, clinicians continually clarify their own role as well as imbue parents with a solid sense of theirs. Parents learn that they cannot passively accept the care or education that is offered to them. It is their own responsibility to learn about different treatments for autism, to provide clinicians and therapists “good data” on the child’s behavior and abilities, and to
continually expose the child to as therapeutic an environment as possible. As Dr. Baker told one mother:

Dr: You know, you have to take him to as many social events as possible, like the YMCA, Chuck E. Cheese. The more the better. It does make a difference. In ten years [as a clinician working with autism] I’ve really seen the difference it can make. It’s not enough to rely on the school and the therapy, it’s what you do that makes the difference.

When this same parent asked how she was to secure the various recommended treatments for her son, Dr. Baker responded, “with a lot of fighting.” A neurologist’s report can only go so far on its own; parents must advocate strongly on their child’s behalf. Through interactions like these, parents are transformed from primary caregiver to the multi-faceted role of parent-activist-therapist-researcher (Eyal, Hart et al. 2010).

It should be pointed out that clinicians are indeed the gatekeepers of the autism diagnosis and consequently control access to many of the therapies (or at least state-funding for them). Though schools may administer the autism label for the purposes of special education, and Early Intervention therapists are familiar enough with the disorder to correctly identify autism, only a clinician’s word will carry weight with the state, insurance companies, and the school district. Physicians at the AMC did indeed conduct some medical testing and prescribe medical treatments, but this proved to be only a small piece of the child’s overall treatment schedule. With autism, the physician’s role is greatly reduced after diagnosis, and arguably they play only a supporting role in overall treatment. Clinicians provide documentation of the diagnosis, recommendations for educational therapies and prescriptions for medications, but the ultimate responsibility of deciding which treatments are appropriate
and should be administered, and see to it that they are, falls in the hands of parents. In the words of one parent:

Everything that I've done, everything has been parent-driven for our son. I certainly check in with different doctors and stuff [...] We'll say were doing this, this, and this and she'll say you might try a little more of this or a little less of that or don't worry about this. But there's no one who... you're the captain of your ship. It's something I've discussed with a lot of parents where again, it feels like the early days of cancer where doctors coming in and going, well we can do this experimental stuff, chemotherapy, we can give him a little bit, we can give him a lot, what do you think? And you're sitting there as a parent going, I think you're the professional and you tell me what you think. They don't know yet and so you are part of the process and you're one of the best people to know your kid so you need to be part of the team.
"Our preserved theories and the world fit together so snuggly less because we have found out how the world is than because we have tailored each to the other." Ian Hacking, *The Self-Vindication of the Laboratory Sciences* (1992: 29)

Any account of the diagnosis of autism would be wanting without consideration of the various checklists, scales, and other instruments that have been devised as diagnostic aids. Commonly used by clinicians and school psychologists alike in the assessment of children with developmental delays, these devices are an important component of the diagnostic enterprise, and consequently, a significant part of this story. Yet they are more than just passive pawns to be manipulated, using simple formulae to yield quick answers to the complex question of whether a given presentation of symptoms is or is not autism. Each diagnostic scale that enjoyed prosperity at some point in the history of autism diagnosis is like a snapshot in time, a representation of the meaning of autism at that particular moment in time. Taken together, they represent the development of the autism prototype and help recreate the social and historical context from within which our current practices evolved. The diagnosis of autism does not transpire in a social vacuum, but within a matrix of social institutions and practices that are historically situated.

There are two motivations for charting the history of diagnostic instruments. First, these scales are an important site of calibration and looping. Looping, it will be recalled, describes the mechanism by which a classification can change by means of interacting with what is classified, implying that an autism diagnosis can interact with individuals and their actions and behaviors. Similarly, the autonomous behavior of the diagnosed persons creates a reality that the experts
must contend with in terms of their classifications. While they may be useful for organizing people into categories, this very act may result in a reaction by the classified to the category, such that the diagnostic label – as well as the instrument – as originally applied is longer relevant. As a result, either the classification has to change, or the instrument, or both. Diagnostic instruments, therefore, can have implications for the dominant autistic prototype at a given historical time.

Over time, the autistic prototype has transformed from Kanner’s specific symptomology to a spectrum disorder encompassing a broad range of symptoms with varying degrees of severity. Though an analysis for the causes of this change is beyond the scope of this dissertation, the role played by looping is evident. The success of autism therapies marginalized some of the key features of Kanner’s syndrome. For instance, self-injurious behaviors were exceptionally amenable to change (Siegel 1996). At the same time, the activism of the National Society for Autistic Children (NSAC) and autistic self-advocates like Temple Grandin attracted to the spectrum ever more parents of children who were not classically autistic, thus further contributing to looping processes (Eyal, Hart et al. 2010).

Calibration refers to the means by which new diagnostic instruments are standardized, the fine-tuning that occurs between old instruments, current clinical opinion, and the new instrument. Calibration is not independent of looping: all new diagnostic instruments are calibrated before they enjoy common usage, but because of looping processes, exactly what a scale is calibrated on can have a significant impact on its longevity. Tools like the Autism Behavior Checklist (ABC) and the Childhood Autism Rating Scale (CARS) were calibrated on a
population of children that were produced by earlier instruments and prototypes. The ABC, for instance, was constructed from Rimland’s Form E-2 as well as Kanner’s original criteria. But as the symptoms associated with the autistic prototype broadened in scope, and especially after the DSM-III-R criteria were released, the ABC became less and less relevant as it had been calibrated on a population produced by earlier instruments and prototypes. In other words, the ABC could not keep up with looping and ultimately fell out of step with time. On the other hand, the Autism Diagnostic Observation Schedule (ADOS), which defines autism as a very broad spectrum, is calibrated on clinical judgments. It therefore identifies performances that confirm clinical opinion and so participates in the looping process by validating the underlying prototype.

Second, the history of diagnostic instruments also contains a story about the expertise on autism and the fluctuating movement of credibility within this network. From the outset, amidst the dominant etiological theory held by clinicians that pinned the cause of Early Infantile Autism on mothers, parents possessed little credibility within the autism sphere. Rimland, however, attacked the credibility of clinicians and elevated that of parents. Form E-2, for example, circumvented clinicians completely, and parents could receive both a diagnosis and recommendations for treatment from Rimland himself. This was an environment in which the expertise of parents was of the highest reliability, and it was in this milieu that the ABC and the CARS operated. At the same time, these scales introduced new agents of expertise: teachers
and therapists, respectively. The ADOS, however, is unique not only for introducing a new, interactive format, but it resurrects clinical expertise and elevates it above that of parents.\textsuperscript{61}

**STRUCTURE OF THE CHAPTER**

From Bernard Rimland’s Form E-2 to Catherine Lord and colleagues’ Autism Diagnostic Observation Schedule, each diagnostic instrument was designed with specific goals and motives in mind. Through an analysis of these intentions and the social contexts in which they arose, we can uncover the diverse set of interests that the construction of these tests served. Though different factors may have been considered important over time, all play a role in the way in which autism is conceived of today.

The first part of this chapter is an analysis of the three major diagnostic instruments that have been used in the history of autism. I begin with Bernard Rimland’s Diagnostic Checklist for Behavior-Disturbed Children (Rimland 1964), which sought to both limit the diagnosis of autism and raise the status of parents who, according to the dominant psychoanalytic theory, were thought to be the cause of autistic symptoms in children. Next, I take up the Autism Behavior Checklist (Krug, Arick et al. 1980), which was developed primarily for use by teachers of special education as a class placement aid. Finally, I discuss the Childhood Autism Rating Scale (Schopler, Reichler et al. 1980) whose application was open to a wide variety of professionals. This scale, it will be shown, reflected an ever-growing tendency to view autism as a spectrum of disorders.

\textsuperscript{61} Still, while the ADOS reafﬁrms clinical expertise, it should be noted that this expertise is still deployed over a prototype that has was part created though the intervention of parental expertise.
The epigraph of this chapter, while made in reference to the instruments of the laboratory sciences, applies equally nicely to the scales that have been devised to diagnose autism. Similar to the scale that came before it, the Autism Diagnostic Observation Schedule (ADOS) has become the “gold standard” of all diagnostic scales not because of its superior detection capabilities, but because what it means to have autism in terms of the ADOS, and what autism looks like, have simultaneously shaped one another. In the second part of this chapter I focus solely on the ADOS. Unlike any of its predecessors, the ADOS is an interactive scale in which the clinician and child engage in an elaborate performance. Though designed to offer clinicians a means to incorporate systematic observations into the diagnostic process, I will show how the ADOS nevertheless leaves room for the inclusion of subjective opinion under the mask of objectivity. I conclude this chapter with a discussion of the various functions that the ADOS accomplishes for a number of actors, and clinicians and parents in particular.

**Methodology**

My discussion of the Diagnostic Checklist for Behavior-Disturbed Children, Autism Behavior Checklist, and Childhood Autism Rating Scale is informed by several different sources. First, for each scale I analyzed the content of the checklists. Second, if available I studied the manuals in order to learn of the goals and motivating factors as recognized by the test constructors themselves. Third, I looked at journal articles and other writings of the authors, as well as the responses of others to the scales (including, but not limited to, psychometric assessments). Finally, I conducted an e-mail interview with David Krug, lead author of the Autism Behavior Checklist.
To complement my observations of the administration of the ADOS at the AMC, in May of 2008 I took part in a two-day ADOS clinical workshop in Philadelphia, PA. The workshop was hosted in a large conference room of a hotel. Participants sat along eight rows of rectangular tables draped in white linens. The instructor stood at the front of the tables, and behind her was a small stage approximately two feet high where the live administrations of the ADOS were performed.

**Participants** Approximately 90 individuals participated in the workshop, most of whom were practicing psychologists. By a count of hands, three participants were medical doctors, six speech therapists, three special education specialists, three occupational therapists, and one physical therapists. All others were psychologists (about 74 in total). Approximately fifteen of the participants were male and 75 female. Some participants were repeat attendees. The instructor was also a clinical psychologist (though not one of the original developers of the test). By her own admission, her daily work consisted of 70% clinical assessment and 30% research.

**Workshop Goals** The goal of the workshop was to introduce participants to the ADOS and its theoretical underpinnings, as well as to the administration and coding of the test. It was explicitly declared that the workshop was not equivalent to full preparation for clinical use of the ADOS, nor was it a replacement for reading the manual. Rather, it was designed to provide the background information necessary for further training for both clinical and research use.

**Workshop Protocol** After a brief (one-hour) introduction to the scale on the first day, the first part of each morning was spent on a lecture detailing two of the four ADOS modules
(Modules 1 and 2 on Saturday, Modules 3 and 4 on Sunday). After a short break, the instructor demonstrated the use of one of the modules through a live administration. Participants independently scored the module, and after lunch the administration and scoring were discussed with the group. Each day ended with a review and discussion of the day’s modules. In order to ensure visibility of all participants, I sat in the middle of the last row of tables. The only exceptions were during the two live administrations of the ADOS, where I sat in a chair close to the stage. I recorded my observations openly, as it was not unusual for participants to be taking notes during the course of the workshop.

DIAGNOSTIC CHECKLIST FOR BEHAVIOR-DISTURBED CHILDREN

The Diagnostic Checklist for Behavior-Disturbed Children (Rimland 1964), known simply as Form E-2, was one of the first attempts to quantify autistic symptomology. It was devised by Bernard Rimland who, while holding a doctorate in psychology, had no training in either child or abnormal psychology, having “carefully avoided such irrelevant courses” during his studies in psychometrics (Rimland 1981: 201). However, upon learning that his son suffered from autism, Rimland abandoned his position as director of personnel measurement with the US Navy in San Diego and fully devoted himself to the study of the disorder. He found the state of research on autism at the time to be “chaotic” and plagued by “abysmal” scholarship, and consequently set out to arrange a comprehensive review of the topic (Rimland 1981). This research led to his publication of Infantile Autism: The Syndrome and its Implications for a Neural Theory of Behavior (1964). The book was an instant classic and the first of several achievements that

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62 This was encouraged by the instructor, as it was difficult to both see and hear the on-stage activity from afar.
would eventually earn Rimland the designation as “father of modern autism research” (Maugh 2006).

Rimland accomplished two principle goals with the book. First, he successfully refuted the “refrigerator mother” hypothesis – initially formulated by Kanner and further developed by Bruno Bettelheim⁶³ (1967) – which claimed that autism was a psychogenic disorder caused by cold and distant mothering. Second, through arguing for a theory of biological causation, the book encouraged biological research on autism, in terms of both etiology and the search for treatments. Yet one goal remained elusive. The first chapter of the text had been devoted to establishing that autism was a unique diagnostic entity, distinct both from mental retardation as well as childhood schizophrenia, the latter being the most common form of childhood psychosis at the time. The problem, according to Rimland, was that the term “autism” was being carelessly overused, applied to cases that, while possibly sharing some symptoms with autism, were clearly not – at least according to Rimland – real cases of autism, but other, “autistic-like” syndromes.⁶⁴ Thus, one of Rimland’s objectives with Infantile Autism was to rein in the over-diagnosis of autism and bring clarity to the confused manner in which childhood psychoses were being labeled at that time. To assist in the untangling of the muddled mass of childhood disorders, he included a multiple-choice questionnaire on the symptoms of autism as an appendix to the book. Parents with children who had been diagnosed as autistic, autistic-like, or with a similar designation, were requested to complete the questionnaire and return it.

⁶³ According to one journalist, Rimland had “blown Bettelheim’s theories to hell” (D. R. Katz, The kids with the faraway eyes. Rolling Stone, 8 March 1979, p. 48-53).

⁶⁴ Rimland often mentioned these non-autistic syndromes, but never defined them more explicitly.
to Rimland, who would subsequently score the form and return the result, along with an analysis of the child, back to the parents.

Rimland devised the 80 multiple-choice questions of Form E-2 to be consistent with Kanner’s (1943) original behavioral descriptors. While a few questions address pre- and perinatal conditions and behaviors during the early months of life, the majority of items are concerned with behaviors exhibited by the child between the ages of three and five years. Included were items on the lack of affect, echolalia and other odd speech behaviors, stereotypy, obsessiveness and resistance to change, ritualistic behaviors, repetitive behaviors, and nonresponsiveness. The final three items ask about the education level of the parents, as well as the family’s history of mental illness and mental retardation. Each response can receive one of three possible codes: +1 for behaviors which are characteristic of autism, -1 for symptoms not associated with autism, or a code of zero for item options which do not fall into either of these categories. Subtotals of the autism (+1 codes) and “non-autism” (-1 codes) scores are calculated, and their simple sum yielded the total score. A score of +20 was said to be indicative of autism; lower scores were designated as non-autism.

Since Rimland never published the scoring key for Form E-2, the positive-scoring item responses indicative of autism cannot be ascertained. This renders it nearly impossible to

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65 An earlier version of the checklist, Form E-1, appeared in the first edition of the text. Form E-2, a revised version of E-1 based on responses from parents, was included in the appendix of the second edition of Infantile Autism. Results of data collected through Form E-1 were never published, and Rimland himself admits that the checklist was an “armchair” instrument (B. Rimland, On the objective diagnosis of Infantile Autism, Acta Paedopsychiatrica, 1968, 35, 146-161). Hence, the discussion which follows concerns the second version of the checklist.

66 For example, a “Don’t know” response, or for options like “Too little speech to say” on items assessing speech behavior.
reflect on the prototypical behavior pattern that Rimland thought was exemplary of a child with autism. But since he so frequently and forcefully restated the belief that only those children manifesting the symptoms described by Kanner warranted a diagnosis of autism, and given that in one publication he did disclose the coding scheme for six items (Rimland 1971), one can surmise that Rimland’s “autistic symptomology” would include the following: nonresponsive behavior, such as appearing aloof, remote, indifferent, acting as though deaf, appearing to “look through” people or be “lost in thought”; lack of affect, such as showing displeasure at being held, not being cuddly, failure to assume an anticipatory posture when being picked up; stereotypical in behavior, including rocking oneself, whirling oneself, self-injurious behavior, spinning objects, and other repetitive behaviors; ritualized behavior, including insistence on particular routines and resistance to change; odd and/or repetitive speech patterns, including pronoun reversal, echolalia, use of repetition to answer questions; and the possession of specialized knowledge or special abilities in one area, such as remarkable memory or exceptional fine motor control.

Thus, from Rimland’s perspective, Form E-2 was a means to quantify Kanner’s syndrome, or Early Infantile Autism (EIA), with the ultimate goal of limiting the number of children diagnosed. Rimland had come to despise the way in which the terms “autism” and “autistic” were so carelessly used by clinicians that it could not be assumed they were being applied correctly. Differential diagnosis became somewhat of a crusade for Rimland, and was closely coupled with his search for biological treatments. Indeed, not only was Form E-2 constructed to yield accurate diagnoses for the purposes of scientific research (while sidestepping clinical judgment), but Rimland also wanted to defend the notion that that autistic
children had the potential to be highly intelligent, a potential that could be accessed through early and intensive intervention (Rimland 1984). Rimland emphatically reiterated Kanner’s original observation that the parents of autistic children tended to be of high intelligence, which to him was strong evidence that autism was not related to mental retardation.\(^{67}\) Thus, in a clever move, Form E-2 circumvented the finger-pointing clinicians while elevating the status of parents as reliable witnesses. And since the scale was embedded in the same scientific values that the clinicians abided by, it was duly protected from accusations of “unscientificness.” Throughout the later years of the 1960s and early 1970s, Rimland continued his scathing indictment of clinical psychiatry that had begun with *Infantile Autism*. He made an impassioned call for autism to “be rescued from the nosological oblivion toward which it is daily being pushed by careless and indiscriminate diagnosis,” arguing that “the existence and identification of a syndrome … is actually … a mathematical and statistical problem, and not simply one of intuition and judgment” (Rimland 1968; 146, 157). A psychometrician by training, who better to investigate the relationship between a latent variable – here, autism – and responses on a multiple-choice scale than Bernard Rimland?

A few years after the publication of Form E-2, Rimland conducted an analysis of over 2,200 checklists that he had received from parents. He first reported that of all the checklists he received, only 9.7% had scores of +20 or higher and could therefore be classified as true cases of EIA. Not only did this justify setting the cutoff score at +20, he argued, but it was remarkably close to Kanner’s estimate that only about one in ten of all cases referred to him as autism were true cases of EIA. Furthermore, upon inspection of the breakdown of responses to the

\(^{67}\) The savant skills that autistic children possessed could also serve as evidence to this effect.
individual items, the true EIA cases were much more likely to fall into the positively coded option, whereas the non-autistics were more likely to be evenly distributed across all item options. In Rimland’s opinion, these results indicated that, first, EIA is “a unique clinical entity and not merely a synonym for childhood psychosis;” and second, Form E-2 is a useful tool for differentiating EIA from other diagnoses (Rimland 1971, 170).

Analyses of Form E-2 by other investigators were less optimistic, and Rimland’s decision to withhold the scoring key from publication effectively shielded the checklist from undergoing further assessments or critiques. The checklist was criticized for relying heavily on parental recall, and not providing for any observation of the child, and there were many open questions about of the scale’s reliability and validity. Morgan (1988) notes that while the scale effectively differentiates between psychotic (i.e., schizophrenics and autistics) and non-psychotic children, it could not separate the autistics from the schizophrenics. Others still questioned whether the syndrome of early infantile autism existed at all, since Form E-2’s ability to detect it was not significantly better than the base-rate prediction (Masters and Miller 1970). To be fair, Rimland himself was more interested in relating the results of Form E-2 to biological variables, which would not only provide support for his hypothesis of biological etiology but assist in the search for reliable treatments for EIA. He published several studies of the sort, including one which reported that children with high E-2 scores responded better to a multivitamin treatment.

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68 Consider Item 33 as an example. For this item, option 1 is coded +1, and the remaining three options as -1. In this case, 73% of EIA cases (i.e., total score of +20 or greater) selected option 1, 8% option 2, 12% option 3, and 8% option four. In comparison, the distribution of the non-EIA cases (i.e., total score of +19 or less) was 33%, 23%, 33%, and 11%, respectively. Whereas the EIA cases tend to cluster in the +1 coded option, the non-EIA cases are more evenly distributed across all options.
regimen than did those with lower scores (Rimland 1971). Yet even these studies were found difficult to replicate (Morgan 1988).

Despite these replication failures, Rimland’s Form E-2 was successful in several other ways. Perhaps even too successful: while the initial challenge for autism was to be recognized as a unique syndrome distinct from schizophrenia and mental retardation, by the very act of writing the book, autism became susceptible to being over-applied, even if carelessly, to other disorders of childhood. Thus, the next order of business was to prevent the overuse of the diagnosis. Rimland had effectively carved out a niche for autism, distinct both from childhood schizophrenia and mental retardation. However, by his alliance with NSAC and the therapies this space was inadvertently extended, enjoying so much popularity as to become an attractive diagnosis; the pendulum had swung too far in the opposite direction. In fact, the checklist was originally derived from one whose function was to differentiate autism from childhood schizophrenia, mental retardation, and brain damage (Polan and Spencer 1959). Yet by the time of the checklist’s second edition, the more pressing task was to isolate true cases of EIA from other, similar cases, “autistic-like” but nevertheless “non-autism.” The uniqueness of autism had been established, and now its presumed rarity needed to be protected.

Rimland’s checklist was also instrumental in banishing the “refrigerator mother” hypothesis, and it was in part through the checklist that Rimland was able to recruit a crucial ally for his fight against parental blame: namely, the parents of children with autism. At the time when *Infantile Autism* was published, the psychogenic hypothesis was the leading etiological theory amongst clinicians: parents themselves were thought to be responsible for
bringing into being their child’s deficits. Rimland offered parents an alternative explanation, one free from moral judgment and feelings of guilt. Thus, not only were parents exonerated of personal responsibility, but they were empowered with a new, higher status in the hierarchy of credibility: while it was not uncommon for clinicians at the time to cast serious doubt on parental reports of the child’s behavior, including with Form E-2, Rimland defended parents. Not only was the record of reliability and validity of clinical diagnosis extremely poor, he argued, but parents know their child best, especially the parents of the sick who must pay greater attention to their children, which in all likelihood increases the accuracy of their observations (Rimland 1971).

Rimland went to great lengths to nurture the bond he had created with parents. For each completed checklist Rimland received, parents would receive a score as well an explanation of what the answers indicated about the child. He was known to speak at length with parents over the telephone, as much as two or three hours at time with just a single parent. At the same time that the status of parents was elevated, clinicians were circumvented altogether and rendered somewhat useless: parents no longer needed them for a diagnosis, nor for recommendations for treatment, both of which could be obtained from Rimland, and free of blame. This allowed Rimland to secure for himself a prominent position within the network of autism expertise while excluding from it the parent-blaming clinicians. There was no role for the clinician in Rimland’s exchange with parents.

Despite the mutual benefits of these exchanges with parents, Rimland remained committed to keeping autism rare. Part of the problem of over-diagnosis, he declared, was that
“the unique symptom pattern which Kanner described ‘shuts off’ at about age 5½, and each child thereafter follows a path which is very much his own” (Rimland 1968, 156). Indeed, when parents mailed their completed E-1 forms to Rimland, he found that an overwhelmingly high number of them had noted in the margins that the child had indeed exhibited the behavior in question, but only before the age of 5½ years. The major difference between Forms E-1 and E-2 was that the former instructed parents to answer the questions with respect to the child’s behavior between ages three and seven, whereas this was modified in the latter to ages three through five. With such a broad age window, neither the syndrome (at least as understood by Rimland), nor the instrument designed to identify it, were coherent objects, and the upper age limit was adjusted accordingly.

The use of Form E-2 by researchers other than Rimland appears to have dwindled significantly after 1980. There could be several reasons for this. For one, autism was beginning to be understood as less distinct from other, similar conditions: not discrete disease entities, but a continuum of impairments (Wing and Gould 1979). Yet Rimland insisted that the sharing of symptoms did not disprove the existence of a syndrome, and certainly did not prove a spectrum of disorders. He referred to this style of thinking as the “continuum fallacy,” and insisted that the problem of the existence of separate syndromes was not a rhetorical question that needed to be thought out, but a mathematical and quantitative one. Form E-2 was designed to do exactly that: differentiate amongst different disorders through the use of different scoring algorithms.69 Ironically, the structure of Form E-2 – and, arguably, most scales

directed at differential diagnosis – offers more evidence for the existence of a spectrum than against it. For one, it suggested that all of the conditions drew from the same pool of symptoms: while he never did develop scoring rules for other conditions, the fact that one scale collected enough information on all of these symptoms meant that to begin with, they had several symptoms in common. Besides, it does not seem likely that any of these symptoms were necessary for a diagnosis of autism.\footnote{However, it is possible that Rimland considered the intelligence level of parents a necessary symptom, though he never made this explicit.} Furthermore, by basing diagnostic categories on the total score alone (as opposed to, for example, requiring particular configurations of symptoms), Form E-2 permitted different combinations of symptoms in different children with the same diagnosis, although Rimland might not have been aware of this, since he never met most of the children from whom he collected data.

Form E-2 likely fell in to disuse also because scales such as the Autism Behavior Checklist and Childhood Autism Rating Scale began to populate the landscape, with both scales demonstrating greater discriminative ability than Form E-2. Furthermore, without publishing the score rule, Form E-2 could not easily become a widely used diagnostic tool, but was limited to its intended use in building a detailed database on autism symptoms and behavior. To the present day, Form E-2 can be found on the Autism Research Institute’s website, and parents are still encouraged to download the form and mail it in upon completion.\footnote{See \url{http://www.autism.com/pro_e2description.asp}, Last accessed August 15, 2011.}

**The Autism Behavior Checklist**

The Autism Behavior Checklist (ABC; Krug, Arick et al. 1980) is one of five instruments of the Autism Screening Instrument for Educational Planning (ASIEP), with the other four scales...
addressing vocal behavior, interaction skills, educational skills, and the child’s learning acquisition rate. The ASIEP was designed to evaluate children with developmental disabilities in terms of their specific deficits and assist professionals in developing appropriate instructional programs. The ABC assesses autistic behavior in particular, but can also be used in differential diagnosis, in particular to identify differentiate with autism from those with other disabilities. For the purposes of diagnosis the ABC is typically used independently of the other scales of the ASIEP, and was in fact introduced in a separate article in the same year the complete inventory was published, justifying its consideration in isolation here.

Like Form E-2, the ABC coincides closely with Kanner’s core symptomology. In fact, the scale’s 57 behavioral descriptors\textsuperscript{72} were selected from both Kanner’s original criteria and Rimland’s Form E-2, as well as from other definitions and scales dating mostly from the 1960s. In total, the original ABC was comprised of criteria from seven different sources, a reflection of just how muddled and controversial the field of autism diagnosis was at the time. In fact, one of the sources – Creak’s Nine Points (Creak 1964) – was even an inventory of diagnostic criteria for childhood schizophrenia, and not autism, although by this point many psychiatrists were calling for the dissolution of the former, as it had well-outlived its usefulness as a diagnostic category.\textsuperscript{73} Still, the claim was that the ABC could detect what is referred to today as “classic autism” (Kraijer 1997).

\textsuperscript{72} Like E-2, the ABC measures deviance. The items describe deviant behavior and the higher the item score, the more deviant the behavior is considered to be.

The ABC has several practical advantages over Form E-2, the most obvious being the ease of administration and scoring which render the scale amenable to widespread application and discussion. It also has a slightly more sophisticated psychometric structure than Form E-2. For one, each item has a weight ranging from one to four, with the higher weights indicating that the behavior item is more indicative of autism, as compared to the less common behavioral descriptors with lower weights. These ‘weights’ are actually the number of points that a child receives if he or she is accurately described by the behavior in question. If the child does not exhibit the particular behavior, a score of zero is given for that item. The total score is a sum of these weights, and can range from zero to 158. A score above 67 is considered autistic, below 54 non-autistic, and scores between 54 and 67 are said to be “difficult to interpret”.

Furthermore, unlike the uncategorized items of Form E-2, the items of the ABC are grouped into five areas: Sensory, Relating, Body and Object Use, Language, and Social Self-Help. Both the Sensory and Language subscales are straightforward, the former consisting of items describing odd or unusual sensory responses to stimuli (e.g., “covers ears at many sounds”), the latter basic comprehension and expression, as well as linguistic peculiarities (e.g., “speech is atonal and arrhythmic”). Social Self-Help seems to be more of a “garbage can” category, encompassing items that are not easily comprehensible within any of the other subscales and addressing developmental delay, savant abilities, self-care abilities, as well as aggressive and infantile behaviors. The Relating items assess the child’s capacity for social interaction, and the

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74 While Rimland occasionally reported relationships between behavior and speech scores on E-2 (for example, Rimland 1971), he did not attempt to define any more meaningful categories of behaviors.
Body and Object Use items are mostly descriptors of stimming\textsuperscript{75} behavior, as well as several rigid and stereotyped behaviors. Of these subscales, the most points are available in the Relating and Body and Object Use categories, together amounting to almost half of the maximum number of points possible. This is due primarily to the disproportionate amount of high-weighted items in those two subscales: 11 out of the total 16 items with a weight of four belong to one of these two subscales. In comparison, the Language subscale accounts appropriately for about one-fifth of the total possible points, whereas the Sensory behaviors and Social Self-Help together account for about one-third of the total (about one-sixth each). Thus, many of the stereotypical behaviors that are today referred to as “classic autism” receive the heaviest weights on the ABC: whirling oneself, odd speech intonation, rocking oneself, hand-flapping, savant skills\textsuperscript{76}, covering ears at sounds, echolalia, ritualistic behaviors like lining up toys, toe-walking, staring into space for prolonged periods of time, and the like. Interestingly, there are only two descriptors on ABC with a weight of four that the Autism Diagnostic Observation Schedule – the current “gold standard” in terms of diagnostic instruments – considers relevant today: eye contact and the failure to develop friendships, constituting further evidence that the ADOS, unlike its predecessors, defines autism as a broad spectrum.

The weighting scheme of the ABC is a distinct departure from Rimland’s Form E-2, in which items were scored in an all-or-nothing manner. In a sense, the ABC’s weighting scheme

\textsuperscript{75} From “stim”, a more recent “term for behaviors whose sole purpose appears to be to stimulate one’s own senses” (http://www.autism-resources.com/autismfaq-glos.html, last accessed 9 April, 2009). Examples include rocking one’s body, hand-flapping, toe-walking, spinning, and echolalia. Also referred to as stereotypy.

\textsuperscript{76} Item 19, “Has special abilities in one area – seems to rule out mental retardation” is the only item that explicitly addresses other possible diagnoses.
primes for the notion of an autistic spectrum, in that it designates some behaviors as ‘core’ symptoms (with a weight of 3 or 4), and others as ‘peripheral’ (worth only 1 or 2 points). Of course, the most important difference between Rimland’s Form E-2 and Krug et al.’s ABC was what each had devised their scales to do. For one, Rimland was arguing against the idea of a spectrum. To the contrary, he strove to identify distinct syndromes, so the items on his scale need only determine whether a behavior is present or absent. On the other hand, Krug and his colleagues, while theoretically not in favor in one way or another (and quite possibly, not even cognizant of the debate) with respect to a spectrum of behaviors, were more interested in how to place these children in the correct educational program. Thus, not only the character but the severity of their problem behaviors would have been of concern. In the classroom, it is more important that children be grouped according to the similarity of their symptoms, rather than the actual diagnosis. To this same effect, Lorna Wing argued that diagnostic criteria should reflect pragmatic and educational considerations: “It soon becomes clear in the field of communication problems how pointless it is to draw sharp lines between autistic and ‘not really autistic’ in educational practice, even if this distinction is of great theoretical interest. The question to ask about each child is – what are his handicaps, what are his skills and what can we do to help him?” (Wing 1971: 118).

Psychometric assessments of the ABC have focused mostly on the discriminant validity of the scale and the accuracy of the cutoff scores. The results of these studies have varied widely, and offer some insight into changing perceptions of autism in the 1980s. Teal and Wiebe (1986) found the ABC, when combined with two other scales of the ASIEP (IA and EA), to correctly classify 100% of the autistic children in their sample and 95% of the trainable mentally
retarded. Volkmar et al. (1988) found that only 57% of the children with autism in their study were classified as probably autistic and 23% were classified as questionably autistic. The test was only 62% accurate in discriminating the non-autistic children. Wadden et al. (1991) reported that only 49% of their children with autism had scores that indicated a high probability of autism, 27% fell within the questionable range, and 24% fell in the unlikely range. The non-autistic group, however, was correctly classified with 100% accuracy. Sevin et al. (1991) found that 50% of their subjects who fulfilled the DSM-III-R criteria were misclassified as non-autistic by the ABC.

The last point is particularly telling: with the advent of the DSM-III-R criteria in 1987, which reflected a broader definition of autism, the ABC began to underestimate the prevalence of autism. This is evident in the studies by Sevin et al., Volkmar et al., and Wadden et al., which all suggest that the cutoff score recommended by Krug and his colleagues is too high and thus may not identify a large proportion of individuals with autism. In comparison to the recommended cutoff of 68, Nordin et al. (1996) found that children with autism could be reliably identified when the cutoff score used was lowered to 45. When Wadden et al. adjusted the cutoff score to 44, they found that the ABC correctly classified 87% of the children with autism and 96% of the non-autistic group. These authors did admit that the definition of autism they were using – new criteria recommended by Denckla (1986) – yielded much higher prevalence rates than those reported previously. But the broader implication is that the scope of the autism label was widening dramatically, and Krug and his colleagues set the cutoff score to 47 in the second edition of the ASIEP.
Evidently, the authors of the ABC were backward-looking in terms of how the behavior items of the checklist were selected. Of all the sources from which they derived the items, the most recent criteria was Lotter’s checklist of 1974, by this point already six years old in a rapidly-changing field. Even more strikingly, all of the other sources date from the 1960s, so it could have hardly been expected to produce classes of children coherent with the then-current clinical understanding of autism. But the harking to the past should by no means be taken as an attempt to restrict the diagnosis of autism to children exhibiting Kanner’s syndrome. The ABC was not even meant to diagnose autism at all, but to provide “a tool which is accurate, easily used, and can facilitate placement of these children into programs with specialized curriculums and reduced student-teacher ratios,” such that “local educational administrators … [could] provide appropriate services” (Krug, Arick et al. 1980, 221). It was intended as an initial screening device that was short and parent and teacher friendly. The checklist developers were not psychiatrists or clinicians, or even autism researchers, but an ambitious young professor of Special Education and two of his master’s students. In other words, the ABC was not a call – in tune with Rimland – to keep autism rare; rather, it was evidence that a new set of actors had arrived on the scene – teachers, schools, and the special education system – that would subsequently offer new information about autism, as a new site of looping. In a sense, it suggested that Rimland’s efforts might have been in vain: autism, while not yet a spectrum, was getting bigger. So big, in fact, that it had enough visibility in schools so as to demand special attention there. The prescience of the co-authors can be seen in their reflections on the instrument even before it was published and widely available: “it is possible that the behaviors
on the checklist, when differentiating between autism and mental retardation, are measuring the severity of involvement of the same pathology” (Krug, Arick et al. 1980).

David Krug had received his doctorate in Special Education at the University of Washington in 1972, and his first appointment at Portland State University in the Department of Special Education included an assignment as Director of the Practicum Clinic. The clinic offered students at the master’s level practical experience working with elementary school students with learning disabilities, which was the “hot area of the day” (Krug 2009). Autism, on the other hand, was not only considered rare, but also unteachable and even untestable by special education experts. Not surprisingly, then, when one parent – who had been turned down even by the public schools – sought placement for her autistic son at the clinic, Krug told her that they “didn’t work with that disorder.” But the mother insisted, and challenged Krug and his clinic to help her child. Intrigued by the challenge, and what in retrospect appears as a critical switching point, Krug wrote a proposal for establishing an experimental classroom for children with autism. The proposal was funded, and with the assistance of graduate students Joel Arick and Patricia Almond, the program was set up after conducting research and observations across the country. Within three years, it was taken over by the Portland Public School system (Krug 2009). It soon became evident to Krug and his colleagues that the testing and screening instruments available at the time were “not teacher friendly and did not lead the teacher towards developing effective IEPs [individualized education programs]”. Consequently, the group decided to develop their own test and materials, which eventually became the ASIEP.
Since no publisher was willing to take on the ASIEP in 1980, the authors established their own company. But just three years later, the ASIEP Ed Company had enjoyed enough success to be bought out by another, larger business. What had changed so drastically, that the visibility of autism had increased in schools? At the time that the ABC was published, the institutionalization of mental retardation was undergoing a massive reversal, meaning that more and more children who would have previously been institutionalized were now living at home with their parents (Eyal, Hart et al. 2010). Also at this time, NSAC was fiercely advocating to have autism included within the definition of “developmental disabilities” (Akerley 1979). This put increasing pressure on schools and especially special education. Particular emphasis was placed on the early detection of developmental disabilities, and efforts to mainstream special needs children educationally emphasized appropriate placement in schools. As more and more children with special needs were landing in schools, so increased the need to better classify them and devise education plans accordingly. The ASIEP and the ABC, then, were in the right place at the right time. As the popularity of the ASIEP increased, by extension so to would the visibility of autism, and so the ABC contributes to the looping process: a child enters the school system, the teacher administers the ABC and suspects autism, the parent brings the child and the diagnosis to the doctor’s office, and so on. As others have noted, the autism label was also becoming less stigmatized and applied across a wider variety of social classes at the same time that prevalence rates were increasing (Holzman 1982). In fact, estimates of the prevalence of autism doubled from the 1970s to the 1980s, from 5 in 10,000 to 10 in 10,000.

Obviously, I do not wish to claim that the increase in prevalence during this time was in large part due to the ABC, but only suggest that it mirrored a rapidly changing autism landscape
within which the ABC was intertwined. The system in place for the surveillance of childhood
was undergoing an immense overhaul, pushing a large mass of previously undifferentiated
children with special needs into a school system that was hardly prepared to handle them. The
implication is that the education system now had a large stake in the diagnosis of autism, and
the ABC is itself evidence of this, as can be seen in the types of professionals it engaged. For
one, the ABC was intended for use by teachers and psychologists as well as the more traditional
psychiatrist. But perhaps more striking is the fact that it was calibrated on the judgments of
professionals in the field of special education: the initial data on the ABC, which was used to
determine the cutoff score, came from members of the American Association for the Education
of the Severely/Profoundly Handicapped and teachers of the so-called ‘trainable mentally
retarded.’ Psychiatrists and clinicians played no role in the standardization of the scale. It was a
new node in the network of expertise on autism.

There is evidence that the ABC might also have fallen out of favor for its inability to
distinguish between autism and other disabilities (including mental retardation) in some
groups, and for not allowing for the identification of finer gradations of impairment. For
instance, using the DSM-IV criteria to identify a group of autistic children, Rellini et al. (2004)
found that the ABC correctly identified only 54% of them as autistic. Of the 25 autistic children
that were false negatives, the ABC labeled 19 of them as mentally retarded. The authors
recommend that the ABC not be used for formulating diagnoses – clearly it was not aligned
with the prototype indicated by the DSM-IV – although it could be useful for screening
purposes. But the nail in the coffin for the ABC seems to have been its underperformance in
comparison to the Childhood Autism Rating Scale (CARS). There were a number of studies in the
early 1990s that compared the CARS to the ABC, all of them concluding that the CARS was a better predictive tool. Compared to the ABC’s misclassification of 50% of their subject, Sevin et al. (1991) found the CARS to be accurate 92% of the time. Rellini et al. (2004) found an accuracy rate of 100% for the CARS. Nordin et al. (1996) too found the CARS to outperform the ABC. In fact, the Teal and Wiebe (1986) study that found the ABC to accurately discriminate 100% of the children with autism also found that it was outperformed by the CARS.

One explanation is that by the 1990s, the ABC had lost face validity with what most clinicians and researchers believed to be true about autism. In their own psychometric assessment of the ABC, Miranda-Linne et al. (2002) explains the divergence of their results from those of Krug and his colleagues by the fact that the latter group’s standardization sample contained a narrower range of autism spectrum disorders. Ultimately, the ABC could not keep up with the very changes that it helped create. Because it was calibrated on a population that had been created by earlier tools, the ABC could not accommodate the concept of an autism spectrum. The American Academy of Pediatrics advises that because of its low sensitivity the ABC is not useful for diagnosis, but that it is still useful for research on intervention strategies (Baron 2004). To be fair, this is in fact how the ABC was intended to be used. On the other hand, the CARS is intended for the purposes of diagnosis, equally easy to administer, based on more recent diagnostic criteria, and able to distinguish between different degrees of severity of autism. But the subscale structure of the ABC did reflect that people were now starting to think about autism in terms of categories of deficits, as evidenced by the four distinct subscale scores of the scale, each referring to a unique combination of impairments. This feature of the
prototype would appear in the American Psychiatric Association’s 1987 version of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III-R).

**THE CHILDHOOD AUTISM RATING SCALE**

The Childhood Autism Rating Scale (Schopler, Reichler et al. 1980) developed out of the Treatment and Education of Autistic and related Communication-handicapped Children (TEACCH) program, which provides services and therapies for children with autism and their families. TEACCH was founded in 1966 by child psychologist Eric Schopler at the University of North Carolina at Chapel Hill, and was unique in its explicit recruitment of parents as co-therapists in the treatment of children with autism and other developmental disorders (Schopler and Reichler 1971). In the beginning, Rimland’s Form E-2 was completed for all children evaluated at TEACCH, but the authors “had the clinical impression that very few of our children were autistic according to Kanner’s criteria,” and developed the CARS “in response to the limitations of existing classification systems.” The resulting scale was originally referred to as the Childhood Psychosis Rating Scale (CPRS), avoiding the word “autism” to minimize confusion with Kanner’s syndrome since the CPRS reflected a broader conceptualization of disorder. The decision to change the name to CARS came “in light of increasing evidence that the definition of autism has expanded and is no longer restricted to Kanner’s use of the term” (Schopler, Reichler et al. 1980: 91-2).

The CARS consists of fifteen scales each scored along a 7-point continuum: a score of 1 denotes normal behavior; 2, mildly abnormal; 3, moderately abnormal; and 4, severely abnormal. There are also three half-point scoring options to be used when the child fits neither the higher nor lower rating. The ratings are based on observations of the child’s responses to
various structured activities (such as behavior in the classroom) and situations related to each scale. Summing the 15 individual ratings yields the total score, which may range from 15, when the child’s behavior is rated as normal on all scales, to a high of 60, when the child’s behavior is rated as severely abnormal on all scales. Children with scores below 30 are categorized as non-autistic, those with scores from 30-36 as mildly to moderately autistic, and those with scores exceeding 36, and with a rating of three or higher on at least five of the fifteen scales, as severely autistic.

The structure of the CARS is markedly different from that of the ABC. First, the CARS employs *scales* instead of items, which are scored to reflect a certain *degree* of impairment, whereas deviant behaviors are either present or absent on the ABC. Even more significant is the shift from *items* of autistic behavior as the objects of focus to *categories* of behavior. On the ABC, each item was a description of a behavior (e.g., “Strong reactions to minor changes in routine/environment”) whereas on the CARS, each scale is a category of behavior (e.g., “Impairment in Human Relationships”). Although the ABC score could be broken down into different subscales, most researchers and clinicians tended to use the checklist as a whole, focusing only on grand total score and whether or not it exceeded the single cutoff score (Miranda-Linne and Melin 2002). Consequently, the categorization of symptoms and behaviors fell below the radar of those using the scale. Both of these innovations in the CARS reflected changes in the way which autism was understood. Unlike the instruments before it, the CARS

77 The other 14 scales of the CARS are: Imitation; Inappropriate Affect; Bizarre Use of body Movement and Persistence of Stereotypes; Peculiarities in Relating to Nonhuman Objects; Resistance to Environmental Change; Peculiarities of Visual Responsiveness; Peculiarities of Auditory Responsiveness; Near Receptor Responsiveness; Anxiety Reaction; Verbal Communication; Nonverbal Communication; Activity Level; Intellectual Functioning; and one item of General Impressions, for which 1=No autism, 2=Mild autism, 3=Moderate autism, and 4=Severe autism.
forced practitioners to think of autism as affecting certain categories of behaviors, as opposed to the appearance of a small subset of symptoms. Different degrees of impairment in different aspects of behavior meant that the question of whether it is autism was now one of what kind of autism. While still a relatively crude categorization, the CARS’ breakdown of autism into two levels of severity was revolutionary for its time.

In addition, the shift from specific symptoms to broader categories creates a space for a wider variety of symptoms. For instance, the category of “Bizarre Use of Body Movement and Persistence of Stereotypes” (CARS) can encompass many ABC behaviors – whirling oneself, toe-walking, rocking oneself – but also any other unusual or inappropriate bodily movements. At the same time, the CARS changed the relationship between the different dimensions of autism to one another; many of the ABC behaviors that would be classified as “Body and Object Use” on the ABC carried the maximum weight of 4. But on the CARS, exhibiting all of these behaviors would only add a maximum of four points to the child’s CARS score, as opposed to a possible 25% of the ABC total. Thus, while making space for more types of body movements to be counted as a symptom of autism, the CARS also severely restricted the importance of this category for a diagnosis of autism, and put it at par with fourteen other categories. Similarly, categories that were given less weight on the ABC have been upgraded on the CARS. One example is the scale for “Imitation”, of which there is only one corresponding item (with a weight of 3) on the ABC.

Schopler and his colleagues made no effort to hide the fact that the CARS included more behaviors under its scope and would consequently increase the number of children diagnosed
with autism. To the contrary, they celebrated it. When they tested the CARS on 537 children who had visited the TEACCH clinic, they found about half of the children to be autistic (27% severe and 23% mild to moderate). When 450 of these same children were also administered Rimland’s Form E-2, only 8 (1.8%) were found to be autistic, and the CARS even labeled 3 of these 8 as non-autistic. Not only was autism more broadly defined on the CARS, but it also produced a different type of autistic person than Form E-2.

What kind of a different person? Certainly one that distorted the traditional boundaries between mental retardation and autism, a boundary which Rimland had taken great pains to enforce. Schopler and his colleagues found a positive relationship between the degree of autism and the degree of intellectual functioning. It is possible, they explain, that the Kanner syndrome children are considered to be of higher intelligence not on the basis of standardized intelligence tests, but because they possess savant skills in one area. Or it could be that the Kanner-type autistic child is recognized as mildly or moderately autistic on the CARS. Either way, what is certain is that the CARS somewhat blurred the distinction between autism and mental retardation. It accomplished this in part by raising the status of certain categories – Verbal Communication, Resistance to Environmental Change, Inappropriate Affect – that overlapped significantly with behaviors associated with mental retardation.

How did this blurring take place, if so many prominent autism researchers had labored to maintain the division between autism and mental retardation? The key is the TEACCH program itself. The real innovation of the CARS was that it brought the therapies and therapists into the game, as new engines of discovery. While Schopler and Reichler remained heavily
involved in the academic debate over the definition of autism, they were also heavily immersed in the therapies. Yet they were not dealing exclusively with autistic children, but those with other developmental disabilities as well. We saw above that only about 50% of the children visiting the clinic were even considered autistic, even given the CARS’ apparent generosity with the label. Thus, any child exhibiting symptoms that could be worked on by the therapies offered at TEACCH – and the clinic employed various types of professionals – was seen there. This meant that Schopler and his colleagues were continually presented with children with many different diagnoses but much overlap in symptomology, and who were constantly changing in response to the therapies. They therefore had to contend with a new type of autistic patient, one that might exhibit a different pattern of behaviors after several months of therapy, thus leading to new ideas about what were the “core” symptoms of autism, and which were peripheral and treatable. Thus, it is no surprise that the old definitions were inadequate for the CARS.

Schopler and colleagues’ updated understanding of autism and its connection to the TEACCH program is perhaps nowhere more obvious than in their explanation of the change in name of the Journal of Childhood Schizophrenia to the Journal of Autism and Developmental Disorders (Schopler, Rutter et al. 1979). Here they argued that autism was not a “unitary disease entity” but was indeed linked to other developmental disabilities. Since there were some symptoms occurring in some autistic children but not in others, successful treatment depends on factors which are unique to each child. It was not the similarity of symptoms that defined the category of autistics, but the similarity of treatment. Thus, they argued that a re-
understanding of autism as overlapping with other developmental disabilities would prove beneficial to research as well as treatment.

THE AUTISM DIAGNOSTIC OBSERVATION SCHEDULE

There are at least three reasons which justify a more in-depth examination of the ADOS as compared to the scales discussed earlier. First, in both the literature and at the AMC, the ADOS is constantly referred as the ‘gold standard’ of current diagnostic tests. This was also emphasized at the workshop, where the instructor informed participants that in terms of autism research, it would be difficult to publish any results that were not based on the ADOS. Second, the ADOS is unique in its mode of administration, which follows a very specific script and must be executed by an autism specialist. Thus, unlike the development of the CARS in which newer editions became less reliant on administrator expertise, the ADOS requires professional training and the accumulation of numerous ‘administration hours’ before one is certified to perform the test reliably. Finally, the ADOS is important because its terminology has become the common language through which autism is explained, acted upon and understood. It structures the set of goals established for the child as well as the treatment plan with which to reach them. As autism researcher and blogger Michelle Dawson has noted in response to the proposed DSM-IV criteria, “in many ways DSM-V autism is autism altered to conform to the current ‘gold-standard’ autism diagnostic instruments (see the role of Catherine Lord in both), whose predominance, weaknesses and limitations have come to determine what autism is and isn't.”

I focus solely on the ADOS for the remainder of this chapter. First, after a brief discussion of the scale’s history, I demonstrate how the ADOS narrates autism as a performance. Second, I examine how through a complex process of administration, coding and scoring, the ADOS adds an air of scientific legitimacy to the diagnosis of autism. Yet there is ample space within the structure of the scale for subjective opinion to affect the results of the ADOS. As a result, through the use of the scale these beliefs are granted the authority of science. Next I discuss how this faith in the ADOS persists despite the fact that when clinicians are initially trained to use the scale, they express much discontent over the coding scheme. I conclude the chapter with a discussion of the various functions that the ADOS serves for both parents and clinicians.

** history of the ADOS **

The ADOS was created by clinical psychologists Catherine Lord, Pamela DiLavore and Susan Risi, and psychiatrist Michael Rutter. The current form of the ADOS is a combination of two earlier instruments: the 1989 version of the Autism Diagnostic Observation Schedule (Lord, Rutter et al. 1989) and the Pre-Linguistic Autism Diagnostic Observation Scale (PL-ADOS; DiLavore, Lord et al. 1995). The development of the original ADOS was intended to solve a specific problem in the clinic: while clinicians often wanted to incorporate their own observations of the child’s behavior into the diagnosis, there existed no way in which to standardize these observations, neither with respect to the context in which they occurred nor the behavior of the clinician herself. Thus, the ultimate purpose of the ADOS was to provide a standardized context in which to observe the social and communicative behavior of persons with autism. In addition, the then-current autism scales were not particularly effective at
identifying high-functioning autism, which had become more visible in the 1980s when self-advocates like Temple Grandin arrived on the scene. In contrast, the ADOS aimed to differentiate those behaviors that were specific to autism from those that could be exacerbated from MR.

The creators of the 1989 ADOS claimed that the new scale was innovative in two ways. First, it is an interactive schedule in which both the context and examiner behavior are standardized. It incorporates a series of what the creators refer to as “social presses,” along with toys and other props to serve as contextual presses, that are designed to elicit specific social and communicative behaviors. As written on one of the PowerPoint slides at the ADOS workshop, the schedule “creates a ‘social world’ in which behaviors related to the autism spectrum can be observed.” Second, the scale allows for ratings of the quality of social behaviors, not only their presence or absence. Thus, the examiner has to have significant experience with autism in order to qualify to administer the test.79 This marks the return of clinical expertise which, after having been marginalized by Rimland and remaining unnecessary with the ABC or the CARS, is reasserted on a new, higher level: unlike the CARS or the ABC, parents or other non-specialists are not permitted to administer the ADOS. Consequently, the scale cannot be used as a screening instrument but is specifically intended as a diagnostic aid.

The original ADOS was intended for use with both children and adolescents at least five years old and with language skills that were at a minimum equivalent to the level of a three-year-old. The PL-ADOS, on the other hand, was intended for use with children who had limited

79 Training requirements for examiners is more stringent for those doing research than those providing clinical assessments.
or no language skills. Its development reflected a growing need and interest to diagnose autism in children younger than three years of age. According to its creators, instruments like the CARS overdiagnosed autism in two-year-olds and children without phrase speech. Like the ADOS of 1989, the purpose of the PL-ADOS was to provide a set of standardized observations that could assist in a formal diagnosis of autism based on the DSM-IV/ICD-10 diagnostic criteria. However, the context for the presses was modified so as to accommodate younger children. For instance, it used shorter activities with fewer of them requiring the child to sit at a table for significant periods of time.

THE STRUCTURE OF THE NEW ADOS

While the PL-ADOS effectively discriminated the autistic from the non-autistic, it tended to be under-inclusive for children who were thought to have autism but possessed some expressive language. In other words, there was a discontinuity between the PL-ADOS and the original. Furthermore, neither of the schedules consisted of activities appropriate for the assessment of autism in older adolescents and adults. Modifications were therefore needed to address these issues. The current ADOS provides a means to standardized observations of persons suspected of having autism who range in age from toddlers to adults. It consists of four different modules from which the examiner may select, based on the expressive language abilities\(^80\) and chronological age of the child or adult: pre-verbal/single words (Module 1); phrase speech (Module 2); fluent speech in child or adolescent (Module 3); and fluent speech in adolescent or adult (Module 4). Each module can be administered in 30 to 45 minutes. While the protocols for each module differ, all consist of three parts: observation, which describes the

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\(^80\) The ADOS is not appropriate for non-verbal adolescents or adults.
different activities and behaviors that are to be performed and observed; coding, which explicitly lists and describes the behaviors that are to be graded, with each behavior typically accompanied by three or four different coding options; and finally the algorithm, which instructs the examiner on how to aggregate the codes in order to arrive at a diagnostic classification. The examiner takes notes during the administration of the ADOS (there is space specifically allotted for this purpose in the booklets), and the ratings are completed immediately after administration. Neither child nor parent is present during the coding process. The ratings are then plugged into the algorithm and a diagnostic classification is derived. Each module has two cut-off scores: a lower score for the autism spectrum cut-off, and a higher score that corresponds to a “traditional, narrower conceptualization of autism” (Lord, Rutter et al. 2002: 110). At the AMC, these were in practice referred to the PDD and autism cut-offs, respectively.

The ADOS and the Performance of Autism

Out of a total of eleven ADOS observations at the AMC, Module 1 was used on all but one occasion. This was not surprising, since the majority of children given the ADOS were three years old or younger. For this reason, and in order to portray a more vivid picture of the ADOS, I will describe the administration of this particular module in greater detail. Module 1 of the ADOS is based on the PL-ADOS. The observation phase consists of ten activities, with 29 ratings in the coding section (see Figure 4-1). It is intended for children who are pre-verbal or do not yet consistently use phrase speech.

The administration of the ADOS is best understood as a staged performance (Goffman 1990). In an odd reversal of Goffman’s notion of impression management, the stage is set such that the
child – the performer – responds in the way in which the audience – or examiner – intends, such that the behaviors most salient for an autism diagnosis are elicited. According to the manual, since the ADOS focuses on social and communicative behavior, the activities are intended to create a standard social setting in which interactions naturally occur, and the creators claim to wanting an “imposed structure as invisible to the subject as possible” (Lord, Rutter et al. 2002: 2). The goal of the activities is to “present tasks that are sufficiently intriguing so that the child … being assessed will want to participate in social interchanges” (Lord, Rutter et al. 2002: 2). To this effect, Module 1 includes several materials and activities that are presumed to be of interest for young children, such as an electric bunny than can be animated, a balloon, bubbles, and the simulation of a birthday party. Before the child enters the room, the examiner assembles the stage of the testing environment with all the requisite props. The layout is always the same: the birthday party materials are set on a table and covered with a blanket so as not to attract the attention of the child before the intended presentation of the activity; a variety of toys are laid out on the floor in such a location that they can immediately be seen by the child as he enters the room; the electric bunny is also on the floor, but covered with a blanket. A toy truck is placed atop a bookcase so that it is visible to yet unreachable for the child.

Once the child enters the testing room, he is directed towards the cluster of toys on the floor. Testing begins with an activity referred to as ‘Free Play:’ the child is given time to adjust to the environment, but the examiner also assesses his use of the toys, interaction with the caregiver, and the presence of any repetitive behaviors. Free Play is the least controlled of the
## FIGURE 4-1: OBSERVATION ACTIVITIES OF MODULE 1

<table>
<thead>
<tr>
<th>Activity</th>
<th>Focus of Observation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Free Play</td>
<td>Whether and how child spontaneously seeks interaction with caregiver; child’s symbolic or functional exploration of materials; attention to a particular activity and repetitive behaviors.</td>
</tr>
<tr>
<td>2. Response to Name</td>
<td>Consistency of response to a hierarchy of auditory stimuli.</td>
</tr>
<tr>
<td>3. Response to Joint Attention</td>
<td>Child follows shift of gaze alone or with pointing.</td>
</tr>
<tr>
<td>4. Bubble Play</td>
<td>Child’s affect, initiation of joint attention, shared enjoyment, requesting, and motor behavior while bubbles are present.</td>
</tr>
<tr>
<td>5. Anticipation of a Routine with Objects</td>
<td>Child’s affect, initiation of joint attention, shared enjoyment, requesting, and motor behavior.</td>
</tr>
<tr>
<td>6. Responsive Social Smile</td>
<td>Consistency of smile in response to examiner smiling; caregiver smiling; caregiver smiling and implying physical contact; being touched.</td>
</tr>
<tr>
<td>7. Anticipation of a Social Routine</td>
<td>Child’s affect and attempts to initiate repetition of the routine. Extent to which child integrates gaze, facial expression, vocalization, and gesture in actions.</td>
</tr>
<tr>
<td>8. Functional and Symbolic Imitation</td>
<td>Child’s use of miniature objects and a placeholder in imitation of familiar actions with social awareness and shared enjoyment.</td>
</tr>
<tr>
<td>9. Birthday Party</td>
<td>Child’s interest and ability to joint in the “script” of a doll’s birthday party.</td>
</tr>
<tr>
<td>10. Snack</td>
<td>How the child indicates preference and requests food.</td>
</tr>
</tbody>
</table>


Module 1 activities: all other activities are highly structured so as to provide the appropriate prompt or cue for the child when the performance of a specific behavior is desired. Consider as an example the examiner’s instructions for the ‘Response to Name’ activity:

> When he/she is involved with a toy or other activity of interest, make sure that you are positioned so that he/she has to turn in order to look at you. From a distance of 3 to 5 feet, call the child’s name once or twice. Pause and watch for
him/her to look toward you. If he/she does not respond, or lifts his/her head without orienting toward you, repeat the press for a total of four attempts. If the child still does not clearly respond, the parent/caregiver should be asked to call the child’s name in an attempt to get his/her attention without physical contact. If the child does not respond to two of these presses, ask the parent/caregiver, “Is there any way you can get him/her to look at you without touching him/her?” If the child still does not respond, encourage the parent/caregiver to use any method to get a response, including touching the child. (Lord, Rutter et al. 2002: 10)

Thus, not only are vocal cues highly structured, but the examiner must also position herself in a certain region of the stage when she offers the cues. At other times, the examiner’s body must be controlled in an even more specific way in order to function properly as a prompt for a certain behavior. For instance, in the Response to Joint Attention activity the examiner tries to direct the child’s attention to a toy without pointing or touching the child. Instead, she calls out “Look, [child’s name]!” while turning her head and eye gaze towards the toy. This gesture was always performed at a slower pace than one would naturally use, in an almost exaggerated manner. While it would have likely seemed odd if viewed out of context, in the testing room this cue appeared appropriate amongst all the other calculated motions.

There is at least one ‘prop’ on this stage which the examiner cannot completely control: at the AMC, at least one parent was typically present during administration of the ADOS. To adequately manage this random element, parents are requested to refrain from prompting the child to participate in any of the activities unless specifically instructed to do so by the examiner. If a parent should prompt a child during the examination without the examiner’s request, he or she is quickly reprimanded. For instance, after Dr. Daly had placed the toy airplane in front of Luis, the following exchange occurred:

Mom: Make the plane fly, Luis!
Dr. Daly: No, Mom, don’t do that [talk to him]. I have to ask things in a specific way.
Mom: Oh, I’m sorry, I’m sorry.

The ADOS, then, is a tightly controlled and structured performance. Each of the ten activities has a specified purpose that is clearly delineated in the manual. The Birthday Party encourages symbolic and functional play; the Snack offers the child an opportunity to make requests; Bubble Play elicits eye contact, vocalization, and pointing to direct another’s attention.

**CODING THE PERFORMANCE**

There are twenty-nine items to be scored on Module 1, separated into five categories (see Figure 4-2). The coding scheme for the items of the ADOS, which is common to all four modules, is given in Figure 4-3. While all items allow for a score of zero to denote age-appropriate, neurotypical behavior, the other options may vary from item to item. Most items range from zero to two (‘definitely abnormal’ behavior) or three (‘markedly abnormal’ behavior). Occasionally there is an option for a score of seven or eight. The latter applies when the behavior in question did not occur (and so there was no opportunity to observe abnormality) such that the rating is inapplicable. For example, this option appears in the coding scheme for the item measuring immediate echolalia – obviously, if the child is nonverbal, one cannot observe instances of the repetitive use of language. A code of seven is used when a behavior is abnormal along a dimension that is not encompassed by codes one through three. In Module 1, this option is only available for the Overactivity item; a code of seven is given when the child is underactive.
FIGURE 4-2: MODULE 1 ITEMS

Section A: Language and Communication
1. Overall Level of Non-Echoed Language.
2. Frequency of Vocalization Directed to Others.
3. Intonation of Vocalizations or Verbalizations.
4. Immediate Echolalia.
5. Stereotyped/Idiosyncratic Use of Words or Phrases.
6. Use of Other’s Body to Communicate.
7. Pointing.
8. Gestures.

Section B: Reciprocal Social Interaction
1. Unusual Eye Contact.
2. Responsive Social Smile.
3. Facial Expressions Directed to Others.
4. Integration of Gaze and Other Behaviors During Social Overtures.
5. Shared Enjoyment in Interaction.
6. Response to Name.
7. Requesting.
10. Spontaneous Initiation of Joint Attention.
11. Response to Joint Attention.
12. Quality of Social Overtures.

Section C: Play
1. Functional Play with Objects.
2. Imagination/Creativity.

Section D: Stereotyped Behaviors and Restricted Interests
1. Unusual Sensory Interest in Play Material/Person.
2. Hand and Finger and Other Complex Mannerisms.
4. Unusually Repetitive Interests or Stereotyped Behaviors.

Section E: Other Abnormal Behaviors
1. Overactivity.
2. Tantrums, Aggression, Negative or Disruptive Behavior.
3. Anxiety.

FIGURE 4-3: ADOS CODING SCHEME

<table>
<thead>
<tr>
<th>Code</th>
<th>Behavior</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>No evidence of abnormality.</td>
</tr>
<tr>
<td>1</td>
<td>Mildly abnormal or slightly unusual, but not necessarily grossly abnormal.</td>
</tr>
<tr>
<td>2</td>
<td>Definitely abnormal.</td>
</tr>
<tr>
<td>3</td>
<td>Markedly abnormal such that it interferes with the interview, or so limited that judgments about quality are impossible.</td>
</tr>
<tr>
<td>7</td>
<td>Abnormal of a type that is not encompassed by the other ratings.</td>
</tr>
<tr>
<td>8</td>
<td>Did not occur and/or rating in inapplicable.</td>
</tr>
</tbody>
</table>


The coding process begins once the testing period is complete and the child and caregiver(s) have left the room.\(^{81}\) While one actor leaves the stage, another one enters: the idealized child,\(^{82}\) the neurotypical aptly represented by the set of ratings with a score of zero denoting the absence of abnormality. This is the child who “uses eye contact effectively with words or vocalizations or gestures to communicate social intention,” “rarely or never uses stereotyped or idiosyncratic words or phrases,” and “shows definite and appropriate pleasure with the examiner during more than one activity” (ADOS, Module 1). He plays appropriately with toys and does not turn cars upside down for the sensory stimulation of spinning its wheels. He smiles to express pleasure and does not try to injure himself. We have seen this same child

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\(^{81}\) At the AMC, Dr. Daly did not herself return the results of the ADOS to parents. Instead, she prepared a report for Dr. Johnson that stated the classificatory result of the ADOS as well as a description of the child’s behavior during the examination. Only the classification (autism or PDD) was shared with parents, not the final score.

\(^{82}\) During one of the coding sessions at the ADOS workshop, one participant asked why there was so much emphasis on the “typical” in the coding options. The instructor replied, “I don’t know, that’s just the way it’s written. ‘Typical’ just means the idea of what these things are.”
before: he manifests in the multitude of parenting handbooks and guidelines for developmental milestones. He points in order to get his needs met by twelve months of age, uses at least ten words by eighteen months, and by twenty-four months he enjoys being around other children his age.

Like the instructions the examiner follows to perform the ADOS activities, the rating descriptions too are highly specific. Consider again the rating for the Response to Name item. A score of zero is given only if the child looks at the examiner and makes eye contact immediately after his name is called on either the first or second attempt. If the child instead looks at the parent/caregiver after the first or second call of his name, or he looks at the examiner after the third or fourth attempt, he receives a score of one. A score of two is slightly more complicated:

Does not make eye contact with either the examiner or the parent/caregiver after his/her name is called in six attempts, but shifts gaze briefly (no eye contact), OR looks at least once when and interesting or familiar vocalization or verbalization is made (e.g., tongue clucking; “I’m gonna get you”).

A score of three means the child didn’t look at anyone after any type of attempt. Dr. Daly would rate the child’s responses according to these and other rating criteria and, presumably for my benefit, verbalize her thought process as she negotiated among the possible alternatives. Thus, post-performance I was permitted backstage, where I was privy to all the previously undisclosed observations and assumptions that would serve as input to the diagnostic algorithm.

**SCORING THE ADOS**

Although the particular items included in the scoring algorithms differ for each module, the general procedure for the computation of the scores are the same. In each case, a subset of
items from the Communication, Reciprocal Social Interaction, Play and Stereotyped Behaviors and Restricted Interests sections are subtotaled, after which the subtotals for the first two sections are combined to yield the final score. The scoring algorithm for Module 1 is shown in Figure 4-4. Thus, in the determination of the diagnostic classification, only a subset of twelve items from the Communication and Reciprocal Social Interaction sections are used. In other words, one dimension of the triad of impairments has no direct impact on the ADOS classification. The developers’ rationalize this significant omission by distinguishing between low- and high-threshold items. High-threshold are those which allow for a behavior to be observed repeatedly during test administration. Eye contact and facial expressions, for example, should occur with relatively high frequency throughout the duration of the observation period. In contrast, hand-flapping and other odd mannerisms are low-threshold behaviors which may not occur even once in the examiner’s presence. These items are therefore excluded from the algorithm, due to the floor effects that would occur if they were included. The few items that are included in the algorithm were selected on the basis of a factor analysis, through which they were found to be the best predictors of the correct diagnostic classification. Still, the developers argue that the other seventeen codes are nevertheless important because given their strong correspondence to the DSM-IV criteria, they help diagnosticians formulate their clinical judgments. In other words, these items complete the prototype.

83 In the scoring protocol, all scores of 3 are converted to 2, and all other scores other than 0-3 are treated as 0.
FIGURE 4-4: MODULE 1 SCORING ALGORITHM*

Communication
A-2 Frequency of Vocalization Directed to Others
A-5 Stereotyped/Idiosyncratic Use of Words or Phrases
A-6 Use of Other’s Body to Communicate
A-7 Pointing
A-8 Gestures

Communication Total ______
(Autism cut-off = 4; autism spectrum cut-off = 2)

Reciprocal Social Interaction
B-1 Unusual Eye Contact
B-3 Facial Expressions Directed to Others
B-5 Shared Enjoyment in Interaction
B-9 Showing
B-10 Spontaneous Initiation of Joint Attention
B-11 Response to Joint Attention
B-12 Quality of Social Overtures

Social Interaction Total ______
(Autism cut-off = 7; autism spectrum cut-off = 4)

Communication + Social Interaction Total ______
(Autism cut-off = 12; autism spectrum cut-off = 7)

Play
C-1 Functional Play With Objects
C-2 Imagination/Creativity

Stereotyped Behaviors and Restricted Interests
D-1 Unusual Sensory Interest in Play Material/Person
D-2 Hand and Finger and other Complex Mannerisms
D-4 Unusually repetitive Interests or Stereotyped Behaviors

*In the scoring algorithm, score of 3 on the protocol are converted to 2, and all scores other than 0-3 are treated as 0. Thus, each item on the algorithm is worth a maximum of 2 points.

BLACK-BOXING THE ADOS: LEARNING HOW TO CODE AT AN ADOS WORKSHOP

Thus far, the story of the ADOS reads like an open-and-shut case. It is a tool that functions like a well-oiled machine: the stage is set, the test is administered then coded and scored, all according to a very elaborate and specific set of instructions. With such detailed coding descriptions, there is little room for inter-rater differences across item scores. After only two or three observations of Dr. Daly administering the ADOS, I was impressed by how similarly she performed across the different instances, as if using the same script each time. Of course, I understood the inherent logic: if we wish to arrive at an objective result, we must administer the test in an identical fashion each time. Still, I was struck by how little she struggled when scoring the ADOS. How, for instance, did she know when to code a behavior as mildly as compared to moderately abnormal? What counted as a ‘gesture’ as opposed to a ‘behavior’? As a child development specialist, Dr. Daly has internalized the prototype of the ideal child to such an extent as to respond almost automatically when scoring the test. Of course, at the AMC I bore witness to ready-made science (Latour 1987), where disputes over what counts as a symptom of autism and what does not have already been resolved. But the ADOS workshop permitted access to science in-the-making. It was here where I witnessed the live administration of two of the ADOS modules, followed by a discussion of the coding for each module. In a room full of child development specialists there was a great deal of disagreement with respect to coding the modules. In fact, before the first live administration was coded, the instructor informed us that “most people usually get 50% of the codes correct the first time.” Thus, during the ADOS workshop, a large proportion of time was used to teach participants how to code the ADOS correctly. In the words of Latour, it was here where the ADOS was black-
boxed, where all of the conflict surrounding the instrument is isolated, silenced, and swept under the rug.

On the whole, coding instructions were not passively accepted by the workshop participants. To the contrary, there was much dispute over the codes and how they applied in a given administration. The determination of item scores could be problematic for several reasons. One type of disagreement arose when coders attempted to reconcile the overt behavior of the child with the sentiment it was assumed that the child was attempting to express. This difficulty seemed to be unavoidable, for while the ADOS is advertised as relying solely on overt behavior, several of the items require examiners to speculate on the intent which motivates the action. For instance, the first item of Module 2 – Overall Level of Non-Echoed Language – includes the following option: “All speech is echoed (immediate or delayed), with or without communicative intent.” In this case, the examiner must infer whether the child wanted to communicate something or whether the verbalization instead represented meaningless repetition. These types of inferences proved challenging, even confusing, for workshop participants. For instance, during the discussion of the appropriate code for the Gestures item for Megan, the instructor informed the group that the correct code was a one, as Megan only performed one gesture on one occasion. This item initiated a discussion that was lengthier than most, as participants tried to understand the difference between a gesture and a behavior:

Q: What is a gesture, other than pointing?
I: Holding the hand out [to receive or request something], clapping, motioning that something is this big, things like that. Clapping in the corner is not a gesture,
but during the birthday activity it is. I gave her credit for blowing out the candles. What else did we see?
C: She lay on the floor, turning her head away from the activity.
I: That’s a behavior, not a gesture.
Q: What about when she covered her eyes from the bubbles?
I: That’s not a gesture.
Q: What about waving bye-bye to the bunny?
I: Yes, but did she do that?
C: No.
I: So what do we end up with? She blew out the candles. So that’s a one, because it’s only one gesture, done only one time.

One factor of relevance is that to be included on this item, a gesture must be communicative.

This proved particularly problematic for participants:

Q: What’s communicative about blowing out candles?
I: We still just code it there. So that’s why you coming to the coding [workshop].
Q: Why isn’t jumping up for the balloon communicative?
I: She just wanted to get it [the balloon]. The birthday was more social.

There are at least two interesting aspects of this interaction. First, to continue the above discussion, at times the examiner must speculate on the child’s intention before a behavior can be coded. In this example, the instructor distinguishes between Megan’s jumping for the balloon in order to request that the activity be repeated and jumping to try to reach for the balloon for her own use. The former would indicate a gesture that communicated a social desire for the examiner to repeat the balloon activity, whereas the latter expressed more of an individual interest in the object itself. Second, not all coding disputes were reconciled during the workshop. In fact, in several cases the instructor closed the discussion by invoking because-I-say-so type argumentation, as she did when responding to a participants question about the

84 In yet another odd twist, sign language is coded not as communication but as a gesture. Apparently, this is because the creators of the ADOS did not themselves know sign language and therefore could not code it otherwise. (Fieldnotes, ADOS Workshop)
communicative nature of blowing out candles. The most heated dispute over coding occurred in the scoring of item A6 on Module 3 after five-year-old Jake’s live administration:

I: There was one question that he asked, and that’s how we code this item. I said, ‘I play games with my friend’ and he said, ‘What are they?’ So at least one clear example gets you to a [score of] one.
C1: But then what does ‘rarely’ [in the description of a code of three] mean?
I: That’s true. That’s why we have training.
C1: You gave him many chances [to ask questions].
C2: But [the code for option] one says “at least one clear example.”
I: Well, it’s true, but that’s what I’m telling you.
C3: It should be clarified in the next edition.
I: I can see that some of you are really upset with me, but he did ask.
C4: Rarely, never, occasionally... these really should be clarified in the next edition.

The coding instructions and options for this item, Asks for Information, is given in Figure 4-5.

What is interesting is that even though participants may not know exactly what gestures are, they did not question the fact that their absence can be a symptom of autism.

In other cases, participants did not ‘see’ autism at all, but surmised that something else was going on. For instance, when discussing Jake’s score for item A8, Conversation, the following exchange occurred:

C: The give-and-take is elaborate. He didn’t really talk about his own interests. The timing is good. His behavior was shy, maybe even depressed, but not necessarily autistic.
I: I understand what you’re saying, thank you. [To group:] Anything else?

Not everything about the ADOS – or even then autism diagnosis – is obvious to clinicians, even in a group dominated by child psychologists. Prototypes must be learned. Interestingly, though the appropriateness of the autism label was questioned at times, not one workshop participant
voiced a concern with the legitimacy of the ADOS itself, whether it be the symptoms that were coded or the items that comprised the algorithm.

**FIGURE 4-5: ITEM A-6 OF MODULE 3, ASKS FOR INFORMATION**

The focus of this item is on the participant’s spontaneous expression of interest in the examiner’s ideas, knowledge, experiences, or reactions. This should not be part of a preoccupation. When assigning a rating, exclude asking for information that is not related to the examiner, or about the ADOS materials, or about particular facts not specific to the examiner; include these instead when assigning a rating under “Conversation.” For this item, questions do not necessarily have to lead to a sustained conversation. Questions about relationships or possessions may be coded here if they refer to an activity rather than filling in a list.

0  Asks the examiner about his/her thoughts, feelings, or experiences on several occasions.

1  Occasionally (at least one clear example) asks the examiner about his/her thoughts, feelings, or experiences.

2  Responds appropriately to examiner’s comments about his/her thoughts, feelings, and experiences, but does not spontaneously inquire about them.

3  Rarely or never asks the examiner about his/her thoughts, feelings, or experiences, nor expresses interest in them.


**THE ADOS IN ACTION**

Of course, one cannot expect that even with the accumulation of ADOS training, all clinicians will code alike. As strict as the guideline in the ADOS manual may be, practice is never perfect. Clinicians are, after all, human beings. And surely the occasional smile is missed because notes were being taken in that moment, or the child was facing the opposite direction. We have already seen some of the challenges that arise when clinicians learn how to code. Still, the ADOS is considered to have high validity, and at the AMC it was often used with children who were otherwise difficult to diagnose clinically. Ultimately, however, every child given the
ADOS was diagnosed with Autism Spectrum Disorder. My observations at the AMC suggest that diagnostic classifications made by the ADOS rest on more than just the examiner’s observations during the twenty minute interaction with the child. As I now demonstrate, while the ADOS is meant to *supplement* clinical judgment, in practice the ADOS classification actually incorporates it.

With practice, clinicians quickly learn which items contribute to the diagnostic algorithm. For instance, while Dr. Daly was scoring Nelson’s ADOS, she admitted that “he’s probably got autism” after she had scored the Communication section but before she had begun scoring the Reciprocal Social Interaction items. Later, when she reached the final RSI question, she said:

> Quality of Social Overtures [item B12], that’s a two. There wasn’t much [quality] there. Even if he looked or smiled, it wasn’t really the *quality* you expect. Actually, I could give him a one. He’s gonna fit the criteria [for autism] anyway.

Item B12 is included in the ADOS algorithm. While Dr. Daly begins her reasoning with some certainty that “there wasn’t much there,” she allowed herself to be slightly more generous with this score on this item, as she had already calculated that Nelson was indeed going to meet the ADOS criteria for autism. This was not the only instance in which I observed Dr. Daly changing her mind about an item in consideration of its effect on the final score. For instance, when coding James’ behavior, she initially gave him a score of two for item A6 (Use of Other’s Body to Communicate) and a score of one for item A8 (Gestures), after which she said, “Yeah, he’s

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85 Quality of Social Overtures is a “summary item that focuses on the *quality* of the child’s attempts to initiate social interaction” (10). This item, intended to generalize across all aspects of the child’s behavior, offers clinicians an opportunity to insert into the ADOS score their overall feeling as to whether or not the child merits an ASD diagnosis, and therefore it can be easily manipulated to tip the balance in favor of the diagnosis or in opposition to it. Lord, C., M. Rutter, et al. (2002). ADOS: Module 1. W. P. Services. Los Angeles, Western Psychological Services.
probably gonna be PDD.” Later, after coding all of the items and moving on to summing the scores in the algorithm, she noticed that James’ total in Section A (Communication) surpassed the Autistic Disorder threshold. At this point, Dr. Daly paused and began to rethink her coding:

Well, Use of Others’ Body to Communicate, that’s really a one because he only did it once. He’s probably going to be autistic because of it. Gestures, I’m going to give him a zero here, because he made two different kinds of gestures. There was the clapping, which is an emotional gesture, and the blowing, which is a descriptive gesture. But he has at least spontaneous use of two of them, so that’s a zero. You see, sometimes I change things once I think about them. He’s probably going to be PDD. [She adds the scores.] Yes, you see, because he meets the criteria in one section [B: Reciprocal Social Interaction], but not the other [A: Communication]. Even if it were to be autism, then he would be really high-functioning. I know that Dr. Johnson won’t say autism when she sees him.

Of course, using the original codes Dr. Daly assigned, James did meet the ADOS criteria for autism, but the modifications she made had the effect of putting his Section A score below the autism cut-off, although he still met the threshold for Autism Spectrum Disorder. The adjusted codes are justified with reference to what is believed will be Dr. Johnson’s diagnosis. The objectivity of the ADOS, it would seem, is secondary to concerns about its agreement with more subjective clinical judgments. In its development and in practice, the instrument is shaped to coincide and thereby reaffirm clinical intuition. As the epigraph of this chapter suggests, the ADOS does not so much uncover a new reality as add credibility and further legitimacy to current practices. Clinical judgment and test results are mutually adjusted to one another, thereby becoming a ‘closed system’ that is essentially irrefutable (Hacking 1995).

There are consequences to this approach. For one, though the results are fairly reliable for those children with a clinical diagnosis of Autistic Disorder, the ADOS is more likely to
classify children with a clinical diagnosis of PDD-NOS as autistic.\textsuperscript{86} In fact, Module 3 of the ADOS is just as likely to correctly diagnose PDD-NOS as to diagnose a child with PDD-NOS incorrectly as Non-spectrum.\textsuperscript{87} But what is most interesting is that the ADOS is calibrated \textit{not} against other diagnostic instruments, but against clinical diagnoses. In other words, the ADOS has been constructed to conform to current diagnostic practices. As Hacking puts it, “[t]hrough calibration, a network of mutually consistent and self-confirming testing devices is set in place” (Hacking 1995: 100). Moreover, in part because of the rigorous psychometric testing that has been gathered to support it, the ADOS wears a badge of legitimacy that only rigorous statistical testing can provide. Therefore, in practice the ADOS – like other such tests – has the effect of bestowing scientific authority not only on the scale itself, but its object as well.

Also of particular note was the manner in which describing her intuition of the child’s behavior, Dr. Daly alternated between a presentation of her impressions as objective facts and one of subjective interpretation. To comprehend this, it is useful to distinguish between the expression that the child \textit{gave}, and the one that he \textit{gave off}. In everyday interaction, an audience attributes greater weight to the expression giving off – the unintended signs that are interpreted as indicating a performer’s true intentions (Goffman 1990). But during the ADOS, it is the \textit{intended} behavior, those actions the child \textit{purposefully} performed in order to convey information – the smile to indicate pleasure, the eye contact to indicate joint attention – that

\textsuperscript{86} If we allow ourselves to follow Michelle Dawson’s reasoning as mentioned above, we see that the proposed criteria for the DSM-V – which eliminate the distinct disorders like AD and PDD-NOS, replacing them with the all-inclusive Autism Spectrum Disorder – then we would find that one of the major flaws of the ADOS, the inability to clearly differentiate between AD and PDD-NOS, is eliminated.

\textsuperscript{87} This group included children diagnosed with impairments other than autism, including language disorders and mental retardation, as well as neurotypical children.
are the ones believed to indicate the child’s true intentions. Of course, with pre-verbal children one can never determine what the child intended to indicate with his actions. Thus, Dr. Daly used a lot of guesswork, as in the following instance:

Dr: Functional interaction, that’s the frog. I think he just didn’t want to do it. His mom said he didn’t like it but I don’t think that’s it, I think he just didn’t want to do it.
Me: I thought she meant that he didn’t like the material? That he didn’t want to touch it?
Dr: Maybe, because he’s very sensory, like with the balloon and the airplane propeller. But I think he just didn’t want to do it.

Dr. Daly is referring to the portion of the ADOS administration in which she pressed two-year-old Luis to imitate her previous action of hopping a small toy frog across the table. Luis did not reach for the frog when it was placed in front of him, and his mother explained that this was because he didn’t like the texture of the plastic material of which the frog was made. Even though Luis displayed other sensory symptoms throughout the testing period, Dr. Daly insists that he simply did not want to play with the frog. Through the interpretation of intent, one finds space to shape the ADOS to conform to the clinical impression.

Where is the danger in permitting clinical impressions to influence the ADOS classification? After all, as was stressed at the training workshop, the ADOS alone is not sufficient for diagnosis: it must be supplemented by clinical judgment. But systems of measurement can bring a new fact into being. For example, Hacking argues that the Dissociative Experiences Scale, in part constructed to better comprehend multiple personality disorder, brought about the “fact” that dissociation is a continuum. One can see how the rating scale for the ADOS items coincides with the notion of a spectrum, with some behaviors being only mildly abnormal and others extremely so. The codes of most Module 1 items range from
zero to two or three, with some also offering an eight. The one exception is the item which rates eye contact, for which there are only two coding options: zero for “appropriate gaze with subtle changes meshed with other communication” and two to denote eye contact that is “poorly modulated” and “limited in flexibility, appropriateness, or contexts” (Lord, Rutter et al. 2002: 7). Poor eye contact has become one of the most distinctive autistic symptoms. Parents often note its absence, or its improvement after trying a new therapy, and it is one of the targets of ABA therapy. In Module 1, it is one of the items that is included in the scoring algorithm. Yet it is not an easy quality to measure. During the ADOS training, the instructor revealed that the original options for this item were zero, two and one. But when the scale was tested by clinicians, the creators found that few clinicians were willing to give a child a rating of two. Rather, clinicians tended to avoid both extremes and only employ the middle rating of “mildly abnormal.” Interestingly, instead of removing the seemingly uninformative item from the scale, the developers dropped the one rating that clinicians considered the most appropriate behavioral descriptor. Since the zero option applies only to the appropriate use of eye contact, it is likely that what were previously ones are now twos. In other words, what was originally an item that offered little discriminatory power was transformed so as to give it more weight in the determination of a diagnostic classification. Calibration, therefore, can create a defining symptom out of a quality that is difficult to assess.

I do not want to claim that as in Hacking’s case, a new fact about autism – namely, eye contact – was created by the ADOS. Rather, I want to highlight the significance of the work that was done to keep the eye contact item as part of the scale. Why, for only a single item, deviate from the continuum of options that characterizes the coding scheme for all other items, a
scheme that so aptly mirrors the concept of a spectrum disorder? Because the ADOS is more that a means to separate the autistic from the PDD-NOS from the normal: the set of behaviors denoted by the items are constitutive of the autistic prototype. These behaviors, if not meaningful in terms of being included in the ADOS algorithm, therefore have a symbolic significance which justifies their inclusion. Indeed, in the ADOS manual the decision to include item in the modules that did not contribute to the scoring algorithm rested on whether “it was felt that they contributed to the possible assessment of improvement over time ... or the description of behaviors of clinical importance” (113). They provide what test constructors refer to as face validity: a scale must look like it measures what it claims to measure. Just as it would appear odd to include on the ADOS a item to measure the amount of affection the caregiver give the child, so too would it be questionable to exclude the eye contact item. The construction of diagnostic tests and scales is, after all, grounded in the common understanding of what it means to be autistic. This is further evidenced by the inclusion of a subset of the Stereotyped Behaviors and Restricted Interest Items in the scoring section, despite the fact that they are not included in the algorithm.

Of course, I also do not want to claim that the ADOS has not brought new facts about autism into being, only that an answer to this question falls beyond the scope of this dissertation and its methodology. To the contrary, my interviews with clinicians suggests that the structure of diagnostic scales can quite possibly influence the autistic prototype. For instance, when I asked clinicians to describe how they know when someone has autism, most described to me the triad of impairments in communication, social interaction, and stereotyped or restricted and repetitive interests. The exception was Dr. Daly, who answered:
I think it depends on what your individual feeling is, but I think what you’re really looking at is a lack of communication for the individual and social reciprocity, that in terms of social interaction, being able to read social interactions, being able to truly have a give-and-take socially. I’m not really into the stereotypic stuff.

Earlier in the conversation, Dr. Daly – who was the only clinician administrating the ADOS at the AMC – explained that one would use different diagnostic criteria depending upon whether one referred to the DSM or the ADOS. Note that the ADOS developers were not suggesting that this particular dimension of the triad was less important to the diagnosis. They are not included in the algorithm, it is explained, because they are high-threshold behaviors that may not occur in the short time span of the test administration even though the child does indeed flap his hands or bang his head. Naturally, this does not offer conclusive evidence that the ADOS works to shape the autistic prototype, but it does open the question to future research.

**FUNCTIONS OF THE ADOS**

Despite the imperfections of the ADOS, it continues to command respect from those who encounter it. One can assume that this is because several different groups serve to benefit from the scale. Obviously, the developers of the ADOS are one such group. At the very least, they have become an obligatory point of passage (Latour 1987) for anyone wishing to publish research on Autism Spectrum Disorder. Yet in order to reach this point, the scale’s creators must have successfully translated the interests of other groups such that they were enticed to adopt the ADOS for their own good. In this section I discuss those who benefit most from the ADOS, as well as the specific needs that it serves.

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88 These are contrasted to low threshold behaviors, such as eye contact or social smile, for which there are many opportunities to observe during the ADOS administration.
Obviously, clinicians are one such group. Not only does the use of the ADOS validate their research, but as we learned in Chapter 2, the ADOS can be strategically deployed by clinicians in order to convince parents that their child is on the spectrum and thus simultaneously legitimize medical intervention. Parents, in turn, like to have tests done on their children (at least to the extent that they are not harmful) so they can be confident that their child has been correctly diagnosed, and can therefore be appropriately treated. Moreover, the ADOS also teaches clinicians how to “see” autism; through it, symptoms are separated from the individual. It creates a ‘thin’ person and thereby reinforces the reality of the spectrum while still making room for clinical judgment. The significance of this goes beyond the mere jurisdictional claim to territory (Abbott 1988). Arguably the most important function of the ADOS is to outline a set of discrete behaviors that can be used both as evidence of illness as well as the targets of treatment. It is through such means that clinicians can displace parental hopes for a cure to a plan for treatment. Thus, through diagnosis, not only are parents responsibilized for their children’s brains, but they begin to learn how to alter the trajectory of development, and what their own role is in the process.

Autism is a devastating diagnosis for families. Unexpected by many, parents are overwhelmed with the news and the uncertainty that surrounds both treatment and prognosis. They quickly learn that there is neither a cure nor a “magic pill” to alleviate symptoms. Most do not know where to start in order to help their child, and doctors can offer no certainties. But the language of the ADOS facilitates the transformation of what is initially a great uncertainty, a mysterious disorder with unknown etiology and no known cure into a much less daunting – and perhaps even manageable – set of behaviors. The enormity of autism is broken down into a
tangible and attainable set of goals, giving parents the basis on which to manage the “ticking kindergarten clock” by “taking it day by day.” Though not all children are assessed with the ADOS en route to diagnosis, it nevertheless infiltrates the clinician-parent interaction, and especially the parent-therapist interaction. The behaviors delineated by the ADOS are the focus of the therapies as well as a means through which to mark a child’s progress.

CONCLUSION

Analyzing previous diagnostic practices, and in particular the administration of checklists and scales, is significant for several reasons. First, creating and applying a system of measurement can bring a fact into being (Hacking 1995). Items which are included in a diagnostic checklist for autism, as well as those excluded, tell us something about what it means to have autism, what does or does not count as a symptom at a given point in time. Different weights assigned to items both create and reinforce perceptions about which behaviors are core symptoms and more central to the autism prototype, and which are more peripheral. Scoring rules and the breakdown into subscales create sensitivities to particular clusters of symptoms, and facilitate the mapping of discrete behaviors to abstract disease categories and subcategories. In other words, checklists and scales produce and validate a mental image, or prototype, of the disorders they diagnose. They can bring a new type of object into being, or modify its properties. Consequently, this is also a site of looping.

Second, new instruments have to be calibrated not only against old instruments, but also against judgments, clinical or otherwise (Hacking 1995: 100). Sometimes calibration calls for the instrument to be changed. For instance, we saw that the cutoff score of the ABC was lowered in order to agree with clinical opinion. At other times, it is the prior judgments that
must be altered. Many clinicians initially struggled with the coding scheme of the ADOS, thus the workshop training serves to adjust clinical judgments to align with the scale. Calibration is significant because it is a means through which “a network of mutually consistent and self-confirming testing devices is set in place” (Hacking 1995: 100). While the ADOS purports to add a layer of objectivity to clinical diagnoses, in practice it actually incorporates subjective opinions. Yet at the same time, with its compendium of results of psychometric testing, it leads the clinician to believe that the tool is scientific. The ADOS validates clinical judgments, not just the other way around.

Finally, diagnostic tests offer a mechanism whereby an actor can gain credibility and be incorporated into the network of expertise on autism. For instance, When Krug et al. (Krug, Arick et al. 1980) created the ABC, calibrated it on special education professionals, and demonstrated that teachers could effectively administer the test, they were able to successfully insert themselves into the discourse on autism. More importantly, each of these instruments – Form E-2, ABC, CARS and ADOS – enjoyed success because they were able to recruit as allies the parents of autistic children. These relationships, of course, were mutually beneficial, as parents themselves initially had little to lose. Before Rimland, they were viewed as the least credible witnesses: not only did they cause their child’s disorder, but they could not even be counted on to reliably report on his behavior. Rimland offered parents a way out of this predicament, by scapegoating the clinicians and offering them a direct link to research on their children through Form E-2. The ABC answered parents’ demand that the school system adjust to the needs of their children. TEACCH would not have been possible without parents, who were needed as co-therapists to conduct therapy and establish the credibility of the program (Eyal, Hart et al.
Finally, the ADOS offers parents a means to understand the disorder such that it enables them to knowledgably manage their child’s treatment regime. It offers parents something attainable; a means to understand and begin to treat the disorder; a way in which to organize life “one day at a time.”
CONCLUSION

Why did nearly every child who visited the AMC leave with a diagnosis of ASD? I argue that this empirical observation can be best understood if diagnosis is viewed as a node in a network through which the interests of various participants in the diagnostic process are translated. This offers an alternative to the notion prevalent in the sociology of professions that professional interests are preconceived and thereby dictate the actions of professionals, whose primary interest is assumed to be the expansion of professional jurisdiction (Abbott 1988). Instead, as I show, the configuration of interests with respect to an autism diagnosis hinges on the particular matrix of institutions in which it is embedded. Interests are not rigidly predefined, but are constituted in the diagnostic process. Similarly, following Heritage and Maynard (2006), the current approach shows how professional dominance is interactionally achieved. The implication of this is a conception of expertise that is not primarily the possession of the powerful and dispensed in a top-down fashion, but distributed across actors and ultimately the product of negotiation between them. The emphasis on the importance of the institutional chain runs against most current discussions of the diagnosis of autism, which tend to focus on either supply- or demand-side factors.

This dissertation makes four contributions to the sociology of medicine. First, it brings to the fore the role played institutions such as Early Intervention and their agents in the diagnostic process. This is important because these institutions and their agents not only pass patients through the institutional funnel, but they also serve to shape the moral experience of patients and their families.
Second, it shows how institutionalized routines at a diagnostic clinic can favor one diagnostic outcome over others (Mehan 1986; Berg 1992). Thus, the “epidemic” – though attributed by clinicians to diagnostic changes in the DSM – is reproduced (and taken for granted) by the staff at the AMC. Yet this results as much by the clinic’s own practices as its positioning in the institutional network.

Third, this dissertation demonstrates that in the doctor-patient interaction, diagnosis is achieved through translation. Clinicians do not simply hand over labels to passive parents, but strategically deploy autism narrative variants based on parental responses. These translations are moored in the current institutional matrix in which autism is embedded: the medical community views autism as a real, biological entity; the ADOS parses the syndrome into the performance of discrete behaviors that are the targets of therapy; autism as a label ensures that services are funded by the state or insurance companies; and autism as set of symptoms justifies the use of psychoactive medications.

Fourth and final, the calibration of diagnostic instruments can modify both diagnostic category and process. This, along with the observation that the definition of autism has changed since it was first described nearly seven decades ago, emphasizes that diagnosis cannot be envisioned as a static process in which the rules of interaction are constant over time. With the DSM criteria as vague as they are and more definitive tests like genetic or blood screenings for autism being absent, and also because clinical intuition constitutes the foundational diagnostic logic, there is ample room for diagnostic change to happen over time. The implication of this is that with time, the looping process can yield a prototype that differs in
its core characteristics from the original, possibly suggesting that the increase in autism diagnosis numbers could simply reflect a broadening prototype.

It is worth reiterating that the findings reported in this dissertation do not offer an account for the increased prevalence of autism recorded in recent decades. While it does make the claim that the diagnosis of autism is a product of the institution matrix in which it is embedded, this work does not – and cannot – consider the question of how this particular institutional matrix came into being, or how we have come to think of it as natural and even necessary. In fact, one should not even generalize that the findings reported here would be replicated in another autism diagnostic clinic, or with respect to a different condition. We might expect some commonalities – for instance, similar clinical norms existing outside of the AMC – but whether or not a diagnosis will thrive or disintegrate will depend at least in part on its consonance with the supporting institutional culture. Furthermore, one cannot deny the significance of history: each condition is surrounded by its own set of institutions and entails its own looping processes. I see no need to assume that there exists a unique underlying structure according to which all diagnosis occurs. To the contrary, my interest has been in how diagnosis takes place day-by-day and within a specific institutional and socio-cultural structure. Looping, after all, depends on the clinical culture of today as much as that of the past, which renders it necessary to be a bit particularistic.

I hope that it is clear to the reader why a translation model of diagnosis is advantageous. Parents are not born “autism agents.” Before they come into contact with Early Intervention, therapists and clinicians, they do not know that they must learn how to fight to
tackle their children’s disorder. They do not know that they will forfeit any hope for a cure in exchange for a new temporality of ‘one day at a time.’ Suddenly, their concerns about whether their child will have good friends, go to college, find a good job, and get married are all pushed aside. They are less important than getting as much therapy, as intensely as possible, by the best therapists. Now, unexpectedly, they have to fight for the best school to accept their child; now, they have to turn their home into a makeshift laboratory; now, they hope for their child’s diagnostic label of autism to change before the critical window of development closes. Parents learn to change their priorities, their interests, and their behavior through diagnosis. They adjust to the content of the autism category, and the process through which the diagnosis and the prescribed treatment is formulated.

Few parents suspect autism in their children: he is not like Rain Man, he is very affectionate, he loves to cuddle; he just needs a little speech therapy and everything will be fine. But this changes with greater familiarity with the content of the autism diagnosis, and in particular the spectrum definition of the disorder. Rain Man is not my son at all, as they suspected; but the autism spectrum describes him perfectly. Of course, this change does not occur naturally, is not generated by themselves alone. It is mediated through the stories of others, through reading medical commentary, and then through exchanges with therapists, with clinicians, with professionals who point out concrete behaviors in the children and identify them with the symptoms of autism. Through these exchanges, parents learn to abandon the desire for a cure and begin to embrace uncertainty. The goal now is progress: what is important is that the child is always improving.
Parents are not only taught what it means to have autism, but they learn what their own role is to be, what their moral duty is as caregiver. It’s what you do that will make the difference. They discover that they are not only responsible for their children’s well-being, but also for their brains, and for their neurological development. To them, wait-and-see is not an option: either those typical neural pathways are going to be stimulated or the opportunity to develop them (and for their children to develop neurotypically) will be lost permanently.

There is no single treatment regimen appropriate for all children on the spectrum, so the search ensues for whatever works, for anything that helps the child’s development progress. Hence the motivation behind why parents use so many different therapies at one time, and are constantly on the lookout for new ones. Always moving forward feels like the best, or even the only, thing they can do. Thus, upon initial diagnosis, the children become patients-in-waiting, embraced by the uncertainty that characterizes surveillance medicine. Yes, they have a diagnosis, but it need not be permanent, at least while that developmental window is still open; the diagnosis is a classification that can be revised, and in some cases removed altogether. Children at the AMC undergo therapy daily, but only visit the clinic every six months for a progress update and, possibly, hopefully, diagnostic reassessment if enough improvement is noted. Feeling responsible for a patient-in-waiting, parents adjust to a new temporality – their interests are displaced from ‘cure’ to ‘improvement.’

Differential diagnosis, an institutional process apparent in the finding that most children at the AMC received an ASD diagnosis, actually begins long before the child steps foot in the clinic. It can already be seen at Early Intervention, where kids thought to have autism are
directed to the appropriate diagnosticians, and in the M-CHAT screening that was given to parents over the telephone, the results of which directed parents and child to the AMC (or the CDI if the test was negative). Thus, by the time the child arrives at the AMC, the decision to be made is less about whether it is autism or another developmental disability, but exactly where the child is on the autism spectrum, i.e., whether it is AD or PDD-NOS. *I assume he’s somewhere on the spectrum if you’re here.* Children presenting milder symptoms and those who show potential by responding to the prescribed therapies are labeled as PDD-NOS; AD is for more severe cases and those who have been less responsive to treatments – both are presumed to have a lower likelihood of ‘losing the label.’

The position of the AMC within the institutional funnel helps explain how clinicians are able to instantly “see” whether a new patient is on the spectrum. Children who have progressed to this point have passed several diagnostic pre-tests. They are not a random sample of disturbed children but a group sharing many similarities, even though individual symptoms may vary from one child to another. The clinician has “seen a lot of kids,” which from her perspective explains why she is able to diagnose by a glance. The institutional funnel shapes what she will see and ensures that the children who reach the clinic are a fit for the ASD diagnosis. Through a looping process, she learns to expect children that look different from the classic prototype, but who look the same (or at least similar enough) to the autism prototype.

Since it serves different needs in different social worlds, the autism diagnosis can be thought of as a boundary object. It is this characteristic which permits the diagnosis to effectively function as an entity of translation. At the AMC, three different narrative modes –
reality, performance and label – are deployed when communicating autism. Clinicians effectively switch between these different narrative frames according to the needs of parents. For clinicians, autism is a real thing which they can immediately see in the child. This is not so obvious for parents who must rely on clinicians and therapists to identify aspects of the child’s behavior and relate them to the symptoms on the spectrum. To accomplish this, clinicians must switch from a reality to a performance frame that will usher parents into a new temporality of “one day at a time.” Parents’ original interests in diagnosis and cure are translated into the concrete task of getting the child to perform differently, to improve if only incrementally. Diagnostic tools such as the ADOS are deployed not least to convince parents that their child is on the spectrum, to help them accept the label. At the same time, these instruments identify discrete performances that are to be worked on, and will be hopefully modified, by the therapies.

The various narrative frames also illuminate the distinction between biomedical and psycho-pharmaceutical therapies that are used in the treatment and management of autism at the AMC. Biomedical treatments, on the one hand, are narrated as though they target the root cause of autism’s core deficits and hence belong to the discourse in which autism is communicated as a reality. Psychiatric treatments, on the other hand, are described as being limited to the management of autistic behaviors and therefore view autism as a performance. The latter therapies, in contrast to the aforementioned, cannot alter the course of development (i.e. the reality, the existence of the disorder) but can only modify the presentation of symptoms (i.e. the performance of the child).
Throughout the history of autism diagnosis, several different diagnostic instruments have been devised to identify the disorder and differentiate it from others. These tools are an important object of this study because of their potential contribution to looping processes that can modify the dominant autistic prototype at a given point in time. Each of the instruments I discussed was the dominant model amongst its contemporaries, and therefore best represents what was considered the core autistic symptomology during the period of their prevalence. Of course, we would expect that these instruments are only accepted and put to regular use once they have been calibrated to previous measures and to clinical judgments. At times the scales had to change in order to ensure compatibility with clinical assessments. A scale like the ABC, for instance, was calibrated against former instruments (and the judgments inherent in them). But then diagnostic rates were rapidly increasing, and as a consequence the autism prototype was changing; rather suddenly, the ABC could not stand the test of time any longer. In other words, as a result of looping processes and the modification of the prototype, scales like the ABC (and later, the CARS) quickly fell out of favor. The ADOS is different in that regard. It is standardized on clinical judgments, so it actually serves to reinforce the current clinical prototype – it actually participates in the looping process.

The history of diagnostic scales also tells a story about the alternating movement of credibility. From the outset, amidst the dominant etiological theory held by clinicians that pinned the cause of Early Infantile Autism on mothers, parents possessed little credibility within the autism sphere. Rimland, as shown, attacked the credibility of clinicians and elevated that of parents through the development of a new tool. His Form E-2, for example, circumvented clinicians completely, and parents could receive both a diagnosis and recommendations for
treatment from Rimland himself. This was an environment in which the expertise of parents was of the highest reliability. At the same time, the introduction of new scales also introduced new agents of expertise: teachers and therapists, respectively. Ultimately, the ADOS resurrected clinical expertise and elevated it above that of parents.

Needless to say, there are several limitations plaguing the research presented in this dissertation. They are not uncommon to most ethnographies. My sample size is small; I regularly observed only four clinicians at the AMC. Though this represents the total number of clinicians operating at this clinic, I also only conducted observations at this one clinic. Though I found support for many of my observations in the literature, future research should extend the sample size to maximize generalizability.

There were some additional problems I encountered that may have been exaggerated by the choice of a clinic as an ethnographic site. The most significant of these problems was the limited insight I was able to obtain concerning the doctors’ perceptions of patients. Although it was clearly visible when the doctor was observing the child, I could not know what particular aspects of the child’s behavior she was paying attention to and their significance to her. To remedy this, I attempted to informally interview clinicians after each appointment to get a clearer idea of how they were assessing the child. Dr. Baker and Dr. Michaels were usually able to take three to five minutes to sit with me and answer my questions, but this was rare for Dr. Johnson. It appeared as though her administrative responsibilities interfered with her ability to treat her patients in a timely fashion, and this translated into my inability to spend a few moments asking her questions after an appointment. This was particularly unfortunate as it was
Dr. Johnson who was most often diagnosing new patients. Still, the most I could do was try to ask as many questions as possible whenever I found the opportunity to do so. What could also have been an important confounder in my research was the effect of my presence on the behavior of doctors and parents, as there was no way could I have avoided any social desirability effects. Although I do not have the means to estimate the extent to which this might have been true in the course of my research, such effects may have been minimized in that my research took place in the presence of doctors and other professionals. I refer here to the possibility that any pressure perceived by parents would emanate from the physicians and not me. Similarly, one limitation I feel I suffered from most was having to rely on what people were doing to infer what they were thinking, particularly in the case of the doctors. Informally interviewing clinicians to get a better understanding only seemed to introduce a new confounder: now I had to distinguish between what people did and the stories they told about themselves. Although I found it extremely helpful when Dr. Daly would “think out loud” while coding and scoring the ADOS, the fact that the behavior is inherently social implies that social desirability effects immediately come into play. Finally, though I made every effort to include all aspects of the interactions in my field notes, by virtue of being human I am of course subject to the same biases of perception that I attribute to my subjects. Just as clinicians “know” what autism looks like, I arrived at the clinic with several ideas as to what diagnosis would look like. It would be interesting to learn how other researchers portray the diagnostic process. Likewise, I would like to extend my research on autism to the creation of a theory of diagnosis, and compare it to the analysis of other disorders and medical curiosities.
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