Essays in the Sociology of Autism Diagnosis

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Abstract:

My dissertation examines the social and organizational processes that influence the diagnosis of autism spectrum disorder (ASD). The diagnosis of ASD, as a research setting, presents a number of empirical puzzles which I investigate using organizational, economic and medical sociology and which generate theoretical insights with broad applicability to the management of organizations. Two sets of analyses are included.

The first analysis is motivated by sharp differences in diagnostic rates across three specialized ASD clinics at Allied Health (pseudonym), a large health maintenance organization in the United States. I show that this difference is stable over time and cannot be explained by patient and pediatrician characteristics. Leveraging observation and interview data at each of the clinics, I characterize different approaches to diagnosis at each clinic, which originated in the training conditions of the initial clinic directors. These findings support developments to theory that explain how field-level changes typically expected to lead to adaptation and isomorphism can be moderated unintentionally by prior locally-institutionalized practices and result in stable practice variation.

The second analysis examines the role of patients in medical diagnosis. Patients are increasingly taking an active role in medical decision making and exerting subtle influence on the decisions of their health care providers. While a greater balance of power and knowledge between patient and provider can be beneficial in many ways, there is a risk that the shifting balance may fail to leverage the subject-matter expertise of medical professionals. With the goal of better characterizing the influence of patients, I draw on data from two systems of care – Kaiser Permanente Northern California and the California Department of Developmental Service – to examine the role of patients in the diagnosis of ASD. Findings are consistent with prior research in identifying patient influence, but illustrate several new boundary conditions: (a) assertive and influential patients may represent only a fraction of the total population and (b) the magnitude of a patient’s impact varies by the knowledge and role of the health care provider, and by institutional arrangements that create particular incentives.

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Essay 1: Imprinting variation

The diagnosis of autism spectrum disorder at two specialty clinics
**Introduction**

How do organizations respond when a new practice becomes popular in the organizational field? Several strands of literature suggest that organizations generally respond by adapting to field-level changes. Whether motivated by legitimacy (DiMaggio and Powell 1983; Meyer and Rowan 1977) or by efficiency (Strang and Macy 2001; Tolbert and Zucker 1983), organizations have been found to replicate what is prevalent in the field, and often come to be isomorphic with other organizations. On the other hand, several strands of literature emphasize organizational inertia and the inability or unwillingness of organizations to adapt to environmental pressures. Existing organizational practices may become infused with value (Selznic 1949), accepted as social fact (Zucker 1977), too complex to be changed (Levinthal 1997), defended by powerful organizational actors (Westphal and Zajac 2001), or the outcome of a selection (Hannan and Freeman 1984) or imprinting process (Baron, Hannan, and Burton 1999). These two sets of literature offer contradictory predictions yet have largely spoken past each other. Presumably, processes for adaptation and inertia work towards opposite ends: when inertial forces are relatively weak, organizations adapt and, when inertial forces are relatively strong, they do not adapt.

In this paper, I examine a case that demonstrates that pressures for adaptation and pressures for inertia are not necessarily competing and can in fact be complementary. I describe what happens when a large staff-model health maintenance organization (HMO), *Allied Health*, adapts to field-level changes in the diagnosis of Autism Spectrum Disorder (ASD). In 2001, in response to a legal change governing HMOs and a changing professional sensibility about appropriate ASD diagnosis, Allied Health initiated organization-wide changes to its process for diagnosing ASD. The number of ASD diagnoses at Allied increased, consistent with regional diagnostic trends. The actions of and outcomes at Allied are consistent with theories predicting organizational adaptation and isomorphism.

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1 *Allied Health* is a pseudonym.
However, a closer look at diagnostic outcomes within Allied reveals a puzzling pattern that cannot be reconciled with existing theory. Across the three specialized ASD clinics in Allied Health, I find remarkable variation in ASD diagnosis rates. In Alpha clinic, patients referred for evaluation have a 66% probability of ASD diagnosis, while at Bravo clinic and Charlie clinic, the rates of diagnosis are 39% and 35%, respectively. This variation does not appear to be explained by differences in patient characteristics or physician characteristics.

Prior research posits two primary reasons for variation in practices prompted by field-wide change: resistance (Fiss and Zajac 2004; Meyer and Rowan 1977; Westphal and Zajac 2001) and customization (Ansari, Fiss, and Zajac 2010; Tolbert and Zucker 1983; Westney 1987; Westphal, Gulati, and Shortell 1997). Neither applies in this case. Evidence indicates that Allied earnestly sought to adapt and establish uniform practices across the organization by designing new processes and allocating resources to improve ASD diagnosis. Senior managers at Allied did not deliberately attempt to resist or alter the field-level practices, yet variation across clinics emerged nonetheless.

In this study, I trace the origin of intra-organizational variation to the influence of imprinting processes at each clinic. According to imprinting, behavior is shaped by environmental factors during a relatively brief sensitive time period and this behavior persists over time (Johnson 2007; Marquis and Tlsty 2013; Stinchcombe 1965). I explain how clinic-level differences in diagnosis were shaped early on in each clinic’s history by key individuals and have persisted over time even as these individuals have left or took reduced diagnostic roles. Diagnostic differences appear to remain stable because of the team-based structure of evaluations, in which clinicians are continually negotiating the tacit rules for diagnosis with colleagues in their clinic. The key insights of this theory-building paper are (1) field-level changes typically expected to lead to adaptation and isomorphism can be unintentionally moderated by prior imprints which create unexpected practice variation as organizational actors enact change and (2) the stability of new practices post-adaptation can come from a new set of imprints, the exact form of which is

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2 Alpha, Bravo and Charlie are pseudonyms.
determined by seemingly minor organizational decisions during adaptation. I call this *imprinting variation*. The role of inertial forces, particularly imprinting, in adaptation has been overlooked by previous research, which has instead tended to focus on either adaptation or inertia, not both.

This paper also lends additional insight into the sociological forces partially responsible for the recent “autism epidemic” (Grinker 2008; Liu, King, and Bearman 2010). Given the central role of the health care provider in the diagnosis of ASD, it is surprising that medical and organizational sociologists have not yet studied the pediatricians, psychologists and psychiatrists responsible for diagnosing ASD. The empirical findings at Allied Health illustrate organizational processes that are likely common (if not more potent) at other ASD clinics throughout the country, and suggest a new explanation for the increase in and geographic clustering of ASD diagnoses.

The remainder of the paper is organized as follows. After a brief review of the relevant theories predicting adaptation and inertia, I introduce my research setting: ASD diagnosis in Allied Health. I then show how, as one would expect given current theories of adaptation, field-level changes impacted the diagnostic practices and outcomes at the organizational level. Next, I present evidence of diagnostic variation within Allied, and rule out alternative explanations for this variation including differences in patient characteristics across clinics. An examination of qualitative evidence indicates that each clinic has a distinct orientation towards diagnosis that was seeded by diagnostic approaches of key individuals years earlier but were rendered stable over time. I then describe how this process can be understood as *imprinting variation*, drawing on the concept of imprinting in a way that develops the theoretical relationship between imprinting and organizational adaptation. Finally, I conclude by discussing the importance of these findings for organizational scholars and policy-makers.
Theoretical foundations

Organizational adaptation induced by institutional change

Organizational adaptation in response to field-wide institutional change is expected – with few exceptions – to lead to homogeneity and isomorphism at the field level. Accounts of isomorphism are organized along two general lines (Colyvas and Jonsson 2011). According to neoinstitutional theory, organizations may adopt the structures and practices of similar organizations in the pursuit of legitimacy and organizational survival (Meyer and Rowan 1977). Increasing rationalization encouraged by the state, professions and competition lead to widespread use of the organizational practice (DiMaggio and Powell 1983). Institutional accounts of new practice adoption point to a legitimacy benefit independent of technical rationality (Baron, Dobbin, and Jennings 1986; Guler, Guillen, and Macpherson 2002; Staw and Epstein 2000; Tolbert and Zucker 1983; Westphal, Gulati, and Shortell 1997). Organizations adopt practices widely considered appropriate and worthy (Deephouse 1996; Guler, Guillen, and Macpherson 2002; Ruef and Scott 1998; Westphal, Gulati, and Shortell 1997), which leads organizations to look increasingly similar.

According to theories of social contagion, adaptation occurs because of the diffusion of information throughout networks (Burt 1987; Centola and Macy 2007; Coleman, Katz, and Menzel 1957; Davis 1991). Accounts vary in terms of the theorized mindfulness of the actors (Argote and Todorova 2007; March 1994), with some treating adoption as relatively automatic and mechanical (Centola 2010) and others treating adoption as a fairly calculated (Still and Strang 2009; Strang and Macy 2001), but the end result of homogeneity is the same. Common to both neoinstitutional theory and theories of social contagion is the prediction that an organization observes changes in the organizational field and initiates change, often adopting newly popular practices and coming to resemble other organizations in the field.

Exceptions to predictions of isomorphism outline conditions in which field-induced change may lead to organizational heterogeneity, and emphasize either a conflict or customization perspective.
Conflict may arise when external actors impose objectionable expectations on organizations. Organizations are biased towards inertia for many reasons (Hannan and Freeman 1984; Levinthal 1997; Selznick 1957; Zucker 1977) and may employ strategies to resist external expectations (DiMaggio and Powell 1983). Conflict can also arise among parties within organizations, leading to an unpredictable or ambivalent organizational response (Kellogg 2009; Zbaracki 1998). In conflict-based accounts, the organizational outcome may be largely a function of the power and effectiveness of the resisting party (Henisz, Zelner, and Guillén 2005; Westphal and Zajac 2001).

Customization accounts highlight the interpretive role of actors inside organizations. Individuals perceive field-level changes and formulate a corresponding organizational response *ex ante* (Ansari, Fiss, and Zajac 2010; Still and Strang 2009; Westney 1987; Westphal, Gulati, and Shortell 1997) or in response to varying institutional demands (Fligstein 1990; Lounsbury 2007; Thornton and Ocasio 1999). Actors may also vary in their ability to respond “rationally” to field-level changes (Edelman 1990; Tolbert and Zucker 1983).

I will demonstrate that neither conflict nor customization accounts adequately explain the variation I observed at Allied Health. Instead, I find the best explanation draws on the concept of imprinting.

**Imprinting in organizational adaptation**

Organizational sociologists have used the concept of imprinting to explain the persistence of organizational features. Stinchcombe (1965) observes that differences among organizations in the same industry are related to the timing of organizations’ foundings. He speculates that, because organizations experience different environmental conditions at birth, different organizational features would be developed and persist into the present day. The central predictions of imprinting are that (1) actors are shaped by the environment during a short sensitive time period and (2) actors’ behavior persists over time (Johnson 2007; Marquis and Tilesik 2013). In most empirical work, scholars emphasize the outcome of
imprinting, for example, the persistence of organizational structure, practices, or relationships, rather than the process of imprinting itself. As such, imprinting is commonly associated with organizational inertia.

Conceptually, however, imprinting is not necessarily incompatible with organizational adaptation and change. First of all, imprinting may not occur exclusively at the founding period of the organization. Organizational practices can be rendered stable even if those practices are introduced after birth. Organizations often experience dramatic episodes of change interspersed within long periods of stability (Tushman and Romanelli 1985). During major periods of transition, actors are re-establishing how they will carry out work and are effectively selecting the historically specific features that will adhere through time (Carroll and Hannan 2004). New rationales for current practices can be constructed by members of the organization at times besides founding (Selznick 1957; Zilber 2002).

Second, the form in which organizational change occurs may be subtly affected by pre-existing practices. Organizations do not develop from scratch, but rather from the materials that are available to them. Describing adaptation, Meyer and Rowan (1977) write that “the building blocks for organizations come to be littered around the societal landscape; it takes only a little entrepreneurial energy to assemble them into a structure” (p345). Similarly, Stinchcombe (1965) explains “the organizational inventions that can be made at a particular time in history depend on the social technology available at the time” (p153). Existing structures and practices in the organization may similarly serve as building blocks for new practices as the organization adapts. Moreover, actors working with locally-available building blocks may not be fully aware of or may discount alternatives when formulating new practices. If existing practices are locally institutionalized (Berger and Luckmann 1967; Zucker 1977), actors may incorporate existing practices into future practices unintentionally.

In this paper, I examine the role of imprinting in organizational adaptation and propose a new explanation for practice variation in face of otherwise homogenizing field-wide trends. I call this *imprinting variation*. 
Research setting and data

Medical diagnosis is an excellent setting for studying organizational adaptation to field-wide change because, in medicine, knowledge is both abundant yet ambiguous. Individuals and organizations know enough knowledge to theorize advantages and disadvantages of certain practices, but the optimal set of practices is difficult to assess, particularly as medical science and technology advances continuously. Indirect signs of effectiveness therefore carry substantial weight. Medical practice variation is tolerated in general (Wennberg and Cooper 1998), but may be even more pronounced in the case in the diagnosis of Autism Spectrum Disorder (ASD). Lacking a biologically-based test, diagnosis is often based on clinical impression or, at best, psychological instruments requiring professional interpretation and judgment. Despite the considerable level of ambiguity around ASD diagnosis, immense public and scholarly attention on ASD places substantial pressure on health care organizations to respond in a way deemed appropriate.

Autistic Spectrum Disorder

ASD is a highly variable disorder that impairs the normal development of social and communication skills in young children. Children with autism have difficulty socializing with peers, caring for themselves, and integrating into social institutions such as play groups and schools. As adults, individuals with autism often have trouble leading independent and economically self-sufficient lives. There is no cure for autism but individuals with autism can be taught necessary life skills through years of continual therapy. The impact on families can be substantial (Cidav, Marcus, and Mandell 2012; Herring, Gray, Taffe, Tonge, Sweeney, and Einfeld 2006); in addition to the emotional burden, families must endure stigma and structure their daily lives around care for their child (Marcus, Kunce, and Schopler 1997). Economically, the total direct costs of caring for a child aged 3 to 7 with autism, over and above the care costs for a child without autism is estimated at $46,220 per year (Ganz 2006).
ASD is controversial primarily because of the way it is diagnosed (Grinker 2008). Like many other disorders presenting as mental or behavioral rather than immediately physiologic, there is no known biomarker for ASD; diagnosis is made on the basis of interpretation against a set of qualitative behavioral criteria in the Diagnostic and Statistical Manual of Mental Disorders (DSM). The challenge is that a symptom, such as lack of eye contact, may be indicative of ASD as well as other psychiatric disorders. Health care providers must make a logical inference based on empirical evidence of patient behavior using professional judgment. Because the process of inference is opaque, it is unclear whether too few, too many, or simply the wrong people are being diagnosed.

These concerns are amplified by unsettling trends in the estimated prevalence of ASD, which has increased steadily over the past two decades. Between 1993 and 2011, the number of new autism cases recorded in the California Department of Developmental Services increased by 688%. Substantial scholarly effort attempts to explain this increase, focusing attention on environmental toxins (Larsson, Eaton, Madsen, Vestergaard, Olesen, Agerbo, Schendel, Thorsen, and Mortensen 2005; Lathe 2006; Newschaffer, Croen, Daniels, Giarelli, Grether, Levy, Mandell, Miller, Pinto-Martin, and Reaven 2007) and genetic factors (Baron-Cohen 2006; Neale, Kou, Liu, Ma’ayan, Samocha, Sabo, Lin, Stevens, Wang, and Makarov 2012; Sebat, Lakshmi, Malhotra, Troge, Lese-Martin, Walsh, Yamrom, Yoon, Krasnitz, and Kendall 2007). A single satisfactory explanation has yet to be found. One emerging line of thought advanced by social scientists draws a distinction between the true-but-unobserved prevalence of ASD and the social factors that affect the diagnostic process itself (Grinker 2008; King and Bearman 2009), though no prior research has examined how organizational context affects autism diagnosis rates.

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3 It is also controversial for pathologizing what is arguably unusual but normal behavior. The effect of the autism “label” can cause harm in and of itself (Link, Cullen, Struening, Shrout, and Dohrenwend 1989; Scheff 1966). This aspect of the autism controversy is interesting and important and raises questions of the social construction of autism historically. However, for the purposes of this paper, we treat ASD as “real” in the sense that ASD exists in the abstract but the distribution of autism in the population is determined (in part) by social forces.
Allied Health

The data for this study come from Allied Health, a well-known staff-model health maintenance organization. An HMO is an advantageous research setting because per capita reimbursement encourages the organization to operate efficiently. Allied has incentives to continually seek out the best set of medical practices and implement them uniformly throughout the organization. (Scott, Ruef, Mendel, and Caronna 2000) and, consequently, we should expect diagnostic practice variation to be minimal. A second benefit of studying a staff-model HMO is the comprehensiveness of the data. People insured through Allied only see health care providers from Allied⁴ and Allied health care providers see only people insured by Allied. Medical records therefore provide a fairly complete medical history of each patient. Lastly, Allied is a good setting because of its size. Allied serves one in four individuals with health insurance in the local metropolitan area. Even leaving questions of generalizability aside, research findings based on Allied are ipso facto significant for many health care administrators and patients.

The Allied data consist primarily of highly-detailed, confidential electronic medical records of eight complete birth cohorts (2000-2007, n = 276,395) between 2000 and 2012. Of the 276,395 patients, 3,181 (1.15%) children have been identified with ASD. At the patient level, these data include date of birth, race, sex, parent education, and place of residence among other fields. At the level of the health care provider, these data include occupation, specialty, and office address. At the medical encounter level, they include fields for patient, health care provider, and medical diagnosis. These fields are used to precisely characterize the differences across clinics and rule out alternative accounts for the diagnostic difference.

In addition, I have collected qualitative data to better understand the organizational and historical context of diagnosis at Allied. Quantitative and qualitative data were combined in an iterative manner (Genn 2009; Miles and Huberman 1994). Qualitative findings motivated precise quantitative analyses.

⁴ Exceptions are possible —say if patients pay out of pocket or if Allied does not offer a particular service. But the general rule at Allied sharply distinguishes it from other types of HMOs and types of health insurance.
and, to understand and interpret the results of these analyses, I conducted further qualitative inquiry. Based on a theoretical sampling logic (Yin 1994), qualitative data collection and analysis focused on two clinics – Alpha and Charlie – which represented the extremes in diagnostic outcomes and which I believed a priori would best illustrate the underlying processes at work.

These data include 28 interviews with a cross section of Allied health care providers with direct experience of ASD: pediatricians, psychologists, psychiatrists, social workers, speech therapists, and occupational therapists. I also conducted 60 hours of observation of clinicians at Allied’s three specialized ASD clinics where I shadowed psychologists and psychiatrists conducting full day ASD assessments with patients and their families. For these observations, I was seated either directly in the room or behind a one-way mirror. Using internal documents – emails, memos, presentations, spreadsheets – I was able to triangulate and add detail to interview and observation data. These documents were essential for establishing the historical timeline of ASD diagnosis at Allied. Finally, I had open access to staff at Allied Health’s headquarters, allowing me to continually discuss my emergent findings with key informants who could provide contextual information and point me to supplemental data sources.

**Environmental pressures for change at Allied**

**Field-level changes in the diagnosis of ASD**

Although autism had been identified as far back as 1943 (Kanner 1943) and listed in the DSM starting in 1980 (Grinker 2008), autism did not emerge as an “epidemic” until the turn of the 21st century. Andrew Wakefield and colleagues brought the spotlight on autism in a 1998 paper that claimed to linked autism to the measles-mumps-rubella (MMR) vaccine (Wakefield, Murch, Anthony, Linnell, Casson, Malik, Berelowitz, Dhillon, Thomson, Harvey, Valentine, Davies, and Walker-Smith 1998).\(^5\) Shortly

\(^5\) In 2009, he was accused of manipulating the study data. By 2010, the Lancet formally retracted the Wakefield’s article and, in 2011, it was revealed that Wakefield had engaged in deliberate fraud. (Deer 2011a; Deer 2011b; Deer 2011c)
after, a report using California Department of Developmental Services (DDS) data deepened and broadened the mystery. The DDS is mandated by state law to provide assistance to individuals with mental retardation, cerebral palsy, epilepsy and autism; the state’s administrative data is possibly the largest single dataset of individuals with autism. The 1999 report documented a drastic increase in DDS enrollment of individuals with autism between 1988 and 1998 (California Department of Developmental Services 1999). ASD, it seemed, was a bigger problem than had been recognized previously, and medical researchers seemed to know little about ASD etiology.

This prompted high-profile questions about causes of the increase and the link between enrollment and the underlying number of autism cases. The US Congress held hearings about autism, its prevalence and potential link to the MMR vaccine (US House of Representatives 2001). The California legislature commissioned a study to investigate possible explanations for the upward trend in enrollment. Media references to autism increased precipitously around this time (Blakeslee 2002), as did scientific articles related to autism.6

The medical community increasingly sought to improve the quality of autism diagnosis around this time. Consistent, high-quality diagnosis was seen as a fundamental first step to understanding autism and ensuring children who met criteria for ASD would receive the appropriate treatment (Filipek, Accardo, Baranek, Cook, Dawson, Gordon, Gravel, Johnson, Kallen, Levy, Minshew, Ozonoff, Prizant, Rapin, Rogers, Stone, Teplin, Tuchman, and Volkmar 1999). The National Research Council conducted a review of research literature to establish guidelines for educating children with autism (National Research Council 2001). In California, motivated by the 1999 DDS report and ensuing public discussion, the state legislature called for the development of tools and methods to “ensure consistency and accuracy of diagnosis of autism disorder [sic]” (California Department of Developmental Services 2002: p VIII)

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6 A search of the New York Times in Lexis Nexis shows the number of autism-related articles per year increased by a factor of 4.5 between 1995 and 2005. A keyword search of academic articles in Pubmed over the same 1995 to 2005 time period shows the number of annual autism-related publications increased by a factor of 9.
and assembled a series of advisory panels to develop best practice guidelines (California Department of Developmental Services 2002). The Autism Diagnostic Observation Schedule (ADOS), broadly considered the “gold standard” diagnostic instrument used by scientists research settings, was made commercially available for use in clinical settings (Lord, Rutter, DiLavore, and Risi 1999). A common conception of proper diagnosis began to emerge.

Improved ASD diagnosis was understood as more sensitive diagnosis, i.e., more likely to identify true cases of ASD. While improvement is not logically tantamount to sensitivity, it was the case for ASD, as it is for many medical conditions for which diagnostic technology improves the ability to detect subtle signs and symptoms (Grob and Horwitz 2009). The upward trend evident in the DDS data, special education data (US Government Accountability Office 2005) and epidemiological studies of autism (Fombonne 1999; Fombonne 2003; Wing and Potter 2002) raised questions about the widely-held understanding of ASD. Autism was once understood as a relatively severe and relatively rare disorder (Weintraub 2011; Wing and Gould 1979), but its true prevalence (while still unknown) was almost certainly higher than earlier estimates. For clinicians, this implied that past procedures for screening and diagnosis overlooked individuals who would meet the current criteria for ASD if examined using new diagnostic technology (Grinker 2008). This possibility was particularly unsettling to clinicians because overlooking a diagnosis was known to lead to delayed intervention and inferior development outcomes (Baird, Charman, Baron-Cohen, Cox, Swettenham, Wheelwright, and Drew 2000; Cox, Klein, Charman, Baird, Baron-Cohen, Swettenham, Drew, and Wheelwright 1999; Dawson and Osterling 1997; Lovaas 1987).

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7 Clinicians outside the research setting could purchase an ADOS “kit,” which included booklets and equipment, and enroll in training courses to develop the latest skills in autism diagnosis.

8 Epidemiologists consider sensitivity as the ability of a diagnostic test to identify positive results. Sensitivity is calculated as the number of “true” positives identified by the test divided by the total number of “true” positives in the sample.
Organizational adaptation to field-level change at Allied

The changing scientific and professional understanding of ASD carried immense weight with health care organizations. Medicine is an applied practice that maintains a close though independent relationship with basic science (Freidson 1970; Rosenberg 1995; Starr 1982). Science imbues medicine with legitimacy, certifying medical practices and separating doctors from competing occupations. Clinical practice often aspires to be evidence-based and on the cutting edge of findings in the scholarly research community (Sackett, Rosenberg, Gray, Haynes, and Richardson 1996). Developments in the scientific understanding of ASD altered the normative image of a well-run organization to include a more sophisticated system for diagnosis.

At Allied, these changes were precipitated by the passage of a state Mental Health Parity Law in the late 1990s. Prior to the law, health insurers often limited benefits for mental health patients, e.g., a cap on outpatient visits, high deductibles and copayments. Under the new law, insurers had to offer benefits comparable to benefits for physical health ailments, which meant that insurers had to provide all services that were “medically necessary,” and to make available services to mental health patients if those same services were available to other insured patients.

Despite the law change, the necessary organizational changes were not clear to senior managers at Allied. As is often the case with new regulation (Dobbin, Sutton, Meyer, and Scott 1993; Edelman 1992), Allied needed to translate the legal mandate into a new set of organizational practices. It was in this translation that managers were guided by the emerging field-wide understanding of autism. A task force dedicated to ASD was assembled in 2001 to identify what services Allied would offer and how Allied would deliver them. This initiated more than a decade of efforts to develop and implement a new system of diagnostic practices.

Central to the new diagnostic approach was the establishment of three specialized ASD centers exclusively dedicated to conducting ASD evaluations. The task force examined well-known specialty
clinics in the nearby metropolitan area. Consistent with best practices promulgated in the scientific literature, the clinics would perform a team-based ASD assessment and coordinate care for children across and outside Allied. In a team-based assessment, several healthcare providers see the patient in a single visit (rather than a sequence of separate visits) and then work jointly to formulate an accurate diagnosis and comprehensive treatment plan. This degree of specialization is not common in clinical settings (Skellern, McDowell, and Schluter 2005). Furthermore, health care providers would use the ADOS diagnostic instrument (Lord, Rutter, DiLavore, and Risi 2000), which is widely considered the gold standard instrument for ASD but is used infrequently outside of research settings because of high training requirements.

The plan to develop the clinics was approved in 2002 and funds were allocated to open the three clinics in sequence. Alpha clinic opened in 2004, Bravo clinic in 2006 and Charlie clinic in 2008. According to the Allied director who oversaw the clinics, “The plan was to have the three ASD centers perform the same evaluations with the same tools and have consistent trainings.” The choice to create three centers represented a balance between gains from specialization and accessibility to families spread across a wide geographic area. In addition to the three centers, a permanent organizational-level ASD office and a council of ASD “champions” were established to govern the clinics and coordinate with the rest of the Allied Health organization.

These changes appear to have had an effect on diagnostic outcomes. The number of new ASD diagnoses increased, largely tracking the regional field-wide trend of a factor of six increase between 9

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9 There are other proposed explanations for the field-wide increase in autism diagnosis – the changing definition of autism (King and Bearman 2009), increasing parental age (Liu, Zerubavel, and Bearman 2010), and social influence among parents (Liu, King, and Bearman 2010). Even if we take this at face value, there is ample room for changes in health care organizations to also account for part of the field-wide autism increase. The authors of previous sociology-based studies of ASD argue that these explanations account for up to 50% of the autism increase. Given the drastic changes at Allied, the concomitant rise in diagnoses is suggestive of the influence of organizational factors. This paper provides evidence of this.
1993 and 2011 (Figure 1). The percentage of each birth cohort diagnosed with ASD by the age of 5 increases as does the proportion of ASD diagnoses relative to all child psychiatric disorders (Figure 2).

**Figure 1: New ASD diagnoses in Allied Health, 1994-2012**

*Source: The state’s Developmental Services agency.*

While costly, clinician managers at Allied believed these diagnostic changes to be worthwhile. From a legitimacy standpoint, these changes satisfied the regulatory mandate in a way that incorporated contemporary insights about autism. Organizations that consider themselves industry leaders, like Allied, may also experience strong positive pressure to live up to their reputations and be among the first to adopt new practices (Burt 1987; Staw and Epstein 2000). Clinicians at Allied were proud of the ASD centers for making high quality ASD evaluations available to a large patient population. Even university-based
ASD clinics, on the forefront of autism research, could not offer the same level of integration with other health services.

**Figure 2: Percent of cohort diagnosed with ASD by age 5**

![Graph showing percentage of children diagnosed with ASD by birth year, with a trend line indicating an increase over time.](image)

- **ASD prevalence**
- **Ratio of cohort percentage diagnosed with ASD to cohort percentage diagnosed with any child psychiatric disorder**

From an efficiency standpoint, improving ASD diagnostic practices offered a way - using language from internal Allied presentations - to improve “quality of care” and “increase member satisfaction.” There was also a cost minimization rationale; Allied would provide some degree of care *anyway* to children with developmental delays regardless of ASD diagnosis, and a correct and timely diagnosis would save resources spent on prolonged diagnosis and inappropriate treatment.
Differences in diagnostic outcomes

Intra-organizational variation

Despite these organizational changes, I found a surprising degree of heterogeneity across the three ASD centers at Allied. Figure 3 shows the observed percentage of children diagnosed with ASD at each of the three clinics. Alpha clinic diagnoses at 66%, while Bravo clinic diagnoses at 39% and Charlie clinic diagnoses at 35%. While Bravo and Charlie diagnose at roughly the same rates, their 27 to 31 percentage point difference from Alpha is both striking and statistically significant.

Figure 3: Observed rates of diagnosis at three clinics

![Diagram showing the observed rates of diagnosis at three clinics: Alpha (66%), Bravo (39%), Charlie (35%).](image)

Note: 95% confidence intervals shown.

In addition to the large differences in the diagnosis rate between clinics, there is also remarkable consistency in diagnosis rate among individual clinicians within each clinic. Figure 4 shows the distribution of diagnostic rates among clinicians; the vertical axis is the percentage of cases in which ASD...
was diagnosed, while the horizontal axis is a randomly-assigned index variable. There is little overlap in the diagnostic rates of individuals across clinics. The clinicians at Charlie generally diagnose ASD in 30% to 40% of their cases, the clinicians at Bravo diagnose ASD in 35% to 55% of their cases, and the clinicians at Alpha diagnose ASD in 50% to 90% of their cases. The average differences across clinics, along with the consistency within clinics, suggests the diagnostic heterogeneity at Allied is a clinic-level phenomenon.

**Figure 4: Diagnosis rates of individual clinicians**

![Graph showing diagnosis rates of individual clinicians](image)

Note: The index variable is based on an underlying randomly assigned number drawn from the uniform distribution between 0 and 1. Observations are sorted in value and assigned an ordinal rank. This rank is the index variable.

To scholars of organizations, these patterns are surprising because the three clinics were opened by and report to the same ASD director at Allied, all have a team-based diagnostic approach, and use the
same set of psychological instruments including the ADOS.\textsuperscript{11} It was an organization-level, not a clinic-level, decision to implement organizational change, so why are there differences at the clinic level?

To scholars of ASD, these patterns are familiar and provocative. The increased number of diagnoses resembles broader trends throughout the country (Boyle, Boulet, Schieve, Cohen, Blumberg, Yeargin-Allsopp, Visser, and Kogan 2011) as does clustering of autism cases (Van Meter, Christiansen, Delwiche, Azari, Carpenter, and Hertz-Picciotto 2010). Many attempts have been made to explain these patterns, but no study has drawn a connection to organizational processes among health care providers. What is the organization’s role in the current case?

\textbf{Regression analysis}

Before attempting to answer these questions, it is critical to rule out a number of alternative explanations for the observed diagnostic pattern. In establishing evidence of a difference between clinics using only observational data, the major challenge to overcome is confounding by unobserved patient characteristics that may be unevenly distributed geographically and correlated to the underlying risk of ASD. The three ASD clinics are located in different geographical areas and patients are assigned to clinics based on the location of their primary care provider. Given the potential spatial correlation between patient characteristics and risk of ASD, unobserved patient characteristics may be responsible for the observed diagnostic differences between clinics. Put simply, clinics may be seeing different types of patients.

Prior research has established geographic clustering of ASD cases (Van Meter et al. 2010) and enumerated three general explanations: localized environmental toxins, clustered demographic characteristics of patients (Mandell, Novak, and Zubritsky 2005; Mandell, Wiggins, Carpenter, Daniels, DiGuiseppi, Durkin, Giarelli, Morrier, Nicholas, and Pinto-Martin 2009b), and social influence from

\textsuperscript{11} It is even possible to claim that we should expect to see the opposite of what was observed, i.e., that Charlie ought to have the highest rate and Alpha the lowest. The scientific-consensus in the field continued to see ASD as even more common. Because the clinics were opened at different times, they were exposed to slightly different institutional conditions.
children already diagnosed with autism (Liu, King, and Bearman 2010). Clustering could also be related to “schools of thought” among local physicians that can lead to locally homogenous medical practices (Epstein and Nicholson 2009; Grytten and Sørensen 2003). Ruling out these possibilities would require patients to be drawn from a common geographic area.

A second related-but-distinct problem stems from variation in the referral patterns of primary care providers. Because patients need a referral to be seen at an ASD clinic, local referral practices affect the composition of patients seen at each clinic. Systematic differences in the referral decisions of primary care providers across geographic areas can alter the risk set at each clinic; primary care providers who are more conservative will lead to a risk set with a greater proportion of positive diagnoses, while less conservative primary care providers will lead to a risk set with a lower proportion of positive diagnoses. Ruling out this possibility would require patients to be drawn from a common referral area.

I address these concerns using regression analysis, controlling for patient demographic factors and exploiting externally-imposed changes in clinic catchment areas. I model the probability that a patient receives an ASD diagnosis when visiting an ASD center. First, I include controls for age, sex, race, parent education, parent age. Second, I include the visit number as a control variable. Most patients are seen at an ASD clinic only once, but occasionally are seen a second time (26.3% of visits) at the same or a different clinic (1.7% of visits). Typically, this happens because the family wants a second opinion or new symptoms emerged.

Third and most importantly, the key to addressing differences in patient composition across clinic is the inclusion of fixed effects for the medical office of each patient’s primary care provider and for the zip code of the patient. Fixed effects exploit changes in clinic catchment areas that are unrelated to the diagnostic practices at each clinic. Allied generally assigns patients to pediatricians and pediatricians to

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12 This raises the possibility of selection bias driven by patients. However, I believe this is a minor problem because it only accounts for 1.7% of total visits and relies on a very strong set of assumptions which I discuss in the Appendix.
ASD clinics, typically based on geographic proximity. However, the assignment between pediatricians and ASD clinics changes over time as the Bravo and Charlie clinics were opened and as the clinics continually adjust to changes in patient demand and clinician availability (e.g., maternity leave). Models with medical office fixed effects exploit within-office variation in clinic use, and directly address differences in referral patterns. Models with patient zip code dummies are used to rule out explanations directly correlated geographically. I estimate the following linear probability model:

\[
Y_i = \alpha_1 I[\text{Alpha clinic}] + \alpha_2 I[\text{Bravo clinic}] + Z_i + X_i + \epsilon_i
\]

The unit of analysis, \(i\), is patient visit. \(Y_i\) is the probability that the patient is diagnosed with ASD at the clinic visit. \(I[\text{Alpha clinic}]\) and \(I[\text{Bravo clinic}]\) are indicator variables for each clinic. \(Z_i\) is a vector of indicator variables specifying the medical office of the primary care provider, or patient zip code. \(X_i\) is a vector of control variables that includes indicators for sex and race, patient age, maternal and paternal education, maternal and paternal age, and visit number.

Table 1 lists descriptive statistics for patients. Patients in the data are overwhelmingly male but include a wide distribution by race. Whites account for 55%, Asians 21%, Blacks 6%, and Hispanics 14%. The average age of parents at birth is 31.6 years for mothers and 34.5 years for fathers. The average parent has completed some college. There have been 3,957 outpatient visits to the three centers, out of which a diagnosis of ASD was given at 2063 (52%) visits. First to open, Alpha clinic accounts for 51.2% of patient visits. Bravo clinic, second to open, accounts for 34.1% and Charlie clinic accounts for 14.7%.

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13 Because an ASD evaluation may involve encounters with multiple health care providers over several days, I define a visit as the entire set of patient interactions at a particular clinic within a seven day period. At the end of the visit, health care providers typically come to a decision over the diagnosis of the patient.

14 Education is measured on a seven point scale: 1 for less than an 8th grade education, 2 for some high school, 3 for high school graduate/GED, 4 for some college, 5 for an associate degree, 6 for a bachelor's degree, and 7 for a graduate degree.
Table 2 shows four models of the probability of ASD diagnosis during a clinic visit. Model 1 includes only the indicator variables for the two clinics, with Charlie clinic serving as the reference category. The coefficients correspond to the values shown previously in Figure 9. The coefficient of Alpha clinic is 0.305 and significant at the 0.001 level, while the coefficient of Bravo clinic is 0.041 and significant at the 0.1 level. The model indicates that the probability of diagnosis is 30.5 percentage points higher at Alpha clinic than at Charlie clinic. Model 2 includes the vector of controls including patient characteristics and visit number. In this model, the magnitudes of the Alpha clinic and Bravo clinic coefficients decrease slightly, but Alpha clinic remains statistically significant with a value of 0.281. The probability of diagnosis is higher for males, with a coefficient of 0.047 but other demographic controls do not affect the probability of diagnosis. Visit number does increase the probability of diagnosis as expected. Model 3 adds fixed effects for year and for pediatric office. The coefficient of Alpha clinic is still significant and actually increases to 0.317. The interpretation is that children - from the same pediatric office, in the same year, holding demographic characteristics constant - are still 31.7 percentage points more likely to be diagnosed with ASD at Alpha clinic than at Charlie clinic.

Model 4 includes fixed effects for five-digit zip code. This directly addresses the possibility that the difference between ASD clinics is driven by localized environmental toxins or other factors that are not explicitly controlled. The coefficient of Alpha clinic in this model is 0.355 and statistically significant. Patients living in the same zip code, but going to different ASD clinics still have substantially different chances of diagnosis. Remarkably, demographic controls, medical office fixed effects and zip code fixed effects do not diminish the magnitude of Alpha clinic coefficient. Overall, regression analysis provides strong evidence of a difference across clinics that is independent of patient characteristics.15

15 I find the substantive finding holds regardless of whether linear probability models or logit models are used.
<table>
<thead>
<tr>
<th></th>
<th>Mean Full sample</th>
<th>Std Dev Full sample</th>
<th>Mean with ASD</th>
<th>Mean without ASD</th>
<th>Mean Alpha patients</th>
<th>Mean Bravo patients</th>
<th>Mean Charlie patients</th>
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Table 2: Regression results

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+ p < 0.1, * p < 0.05, ** p < 0.01, *** p < 0.001

Conventional organizational accounts for diagnostic variation

Organizational sociologists offer two general accounts for this difference – resistance and customization – but neither resonates in the case of Allied Health. An organization-level resistance interpretation of events is not appropriate because the fact that the clinics were established in the first place indicates an earnest effort on the part of Allied to change ASD diagnosis. The process of
diagnosing ASD was fundamentally changed by the establishment of the clinics. Before reform at Allied, diagnosis was ad hoc and carried out on a sequential basis by individual health care providers. In the creation of the clinics, office space was leased, new health care providers were hired, and diagnostic work was centralized. Allied elaborated its formal structure (c.f. Edelman 1992), committed substantial resources and changed work processes. Mere symbolic compliance in this case may have been achieved by much less - perhaps the creation of ASD guidelines or even the creation of a central office that advised existing departments (e.g. pediatrics, psychiatry, neurology) about diagnosis.

A customization interpretation of events at Allied is not appropriate either because at no point did managers identify differences between parts of the organization and tailor diagnostic practices to each unit’s needs. Because the ASD organization and the three clinics were created ex nihilo, there was no existing organization or organizational sub-unit that could resist or customize the change. More importantly, Allied’s goal was to establish three clinics that would be equally effective at diagnosis, consistent with the behavior expected of a well-run HMO. According to internal documents, “adherence to the model....screening, referral, evaluative and case management processes and tools” was a “pre-requisite to open shop.” Alpha clinic - the first to open – was to be the prototype that would be replicated by future clinics.

Furthermore, it was not even clear to many clinicians that Alpha, Bravo and Charlie were diagnosing differently which suggests, a fortiori, that they did not intend to produce that difference through customization. Very few people have directly observed the work processes at more than one clinic and systematic data was not presented until an internal report was produced in September 2010. Even then, there was no attempt at Allied to disentangle (as my regression models do) the impact of diagnostic practices from the impact of patient characteristics.
Imprinting in organizational adaptation

The explanation advanced in this paper articulates a role for imprinting in organizational adaptation to field-level change. Professionals are known to develop rationalized, coherent approaches when exercising judgment (Bittner 1967; Huisling and Silbey 2011; Iyengar, Van den Bulte, and Valente 2011) which can remain stable over time (Barley 1986; Zucker 1977). The same can generally be expected for the clinicians at the Allied ASD centers but what makes this case interesting and informative are a number of key details. Where did the approaches come from? How do they explain the diagnostic differences across clinics? What is the mechanism for persistence?

In this section, I explain how (1) each clinic has a different diagnostic orientation that relates to diagnostic outcomes, (2) these diagnostic orientations were shaped by key individuals early in the history of each clinic, and (3) diagnostic orientations likely persist over time because of the team-based structure of ASD evaluations. Consistent with the theoretical sampling approach mentioned previously, the empirical evidence in this section is drawn from two clinics - Alpha and Charlie.

A framework for contrasting diagnostic approaches

Health care providers at both Alpha and Charlie clinics try to make what they consider to be correct diagnoses, but conceive of correct diagnoses in philosophically different ways. Diagnostic practices at each of the clinics reflect different points of resolution along two fundamental tensions in medicine: (1) standardization versus clinical judgment and (2) sensitivity versus specificity.

The first tension is between standardization of care versus clinical judgment (Dawes, Faust, and Meehl 1989; Sackett et al. 1996; Timmermans and Berg 2003). On one hand, it is well known that medical practices for the same medical problems can differ substantially (Wennberg and Gittelsohn 1973) and many health care providers are not using the most up to date diagnostic and treatment methods (Berwick 2003). This suggests a substantial opportunity for improved medical care by simply standardizing medical care. On the other hand, professional knowledge cannot be fully distilled into a set
of guidelines for diagnosis. The job of the professional is to apply abstract knowledge to specific cases and it is unrealistic to expect the standardized procedures to anticipate all patient contingencies. Moreover, when professionals apply their knowledge to unusual cases, they learn from observing the outcome and the knowledge of the entire profession can be expanded.

The second tension is whether to prioritize sensitivity or specificity in diagnosis. The ideal diagnostic test would identify all individuals with the condition and only those individuals, but all tests exhibit some error. The test may not detect some individuals who truly have the condition (i.e., a false negative), and might indicate some individuals have the condition when they truly do not (i.e., a false positive). The fundamental dilemma is in deciding which error is worse. Emphasis on sensitivity prioritizes detection of all individuals with the condition, which can be critical for initiating medical treatment, but risks over-diagnosis. The urge for sensitivity can be particularly powerful in the case of children, possibly to a fault (Timmermans and Buchbinder 2012). Emphasis on specificity prioritizes detection of only individuals with the condition, which reduces the unnecessary emotional and economic burden of an erroneous diagnosis, but risks under-diagnosis.

While clinicians at Alpha and Charlie agree on the importance of accurate diagnosis, clinicians at Alpha clinic place greater emphasis on standardization and on sensitivity, while clinicians at Charlie clinic place greater emphasis on professional judgment and on specificity. These differences in positions lead to different biases, different tacit rules in diagnosis, and different diagnostic outcomes.

The origins and impact of diagnostic orientations

The differences in diagnostic approaches are unexpected because the clinics were opened by the same ASD regional office and there was little precedent for how these clinics, prior to ASD diagnostic reform, should run. As the clinics opened, diagnostic practices developed along different paths at each clinic, leading to different diagnostic orientations and different diagnostic outcomes. How did this unfold?
Diagnostic orientations seemed to have been shaped early in the history of each clinic by key individuals who served as a kind of raw material that seeded the subsequent development of diagnostic approaches of each clinic. The key individual at Alpha clinic is an external consultant from an elite research university in California who was closely involved in contemporary autism research, while the key individual at Charlie clinic is the initial director who had become an autism expert in the early 1990s under the tutelage of a conservative mentor.

The consultant at Alpha clinic

When the plan to establish Alpha clinic was approved in 2002, it was a generalist child psychiatrist who was chosen both to develop Allied’s system for ASD diagnosis and to lead the first ASD clinic, Alpha. As a child psychiatrist, she was familiar with ASD, but had to learn much more to diagnose ASD confidently. She contacted a former colleague - with whom she completed her residency - for guidance. This former colleague was actively involved in an ASD research at an elite nearby university, closely followed contemporary research, and was informed by the nascent scientific bent towards diagnostic sensitivity. A clinician at Alpha spoke about the influence of the consultant in the following way:

“The first few years were us learning through our mistakes and slowly developing a very sharp eye of just how subtle autism can be. There were no experts in [Allied] to say ‘This is autism. This is how you assess it.’ We had to bring in someone from the outside, from a research institution...to train us. Until she came in, we were in a period of stumbling. [The consultant] only stayed with us for a couple years before she went back to [her university]. She got us on the right track.”

The consultant was influential because of the clinic director’s desire to develop a well-respected, research-based model for ASD diagnosis at Allied, and the consultant had the clinician-researcher qualifications to guide Alpha clinic along this path. The following quote illustrates the director’s admiration of research:
"I’m not an epidemiologist, or any other type of researcher, but I’ve been involved in research projects because, like you, I feel very fortunate to work in [Allied], and I know this is a gold mine, where we can educate the field."

As part of establishing a respected ASD clinic, the director also sought to become involved in the broader autism community in the region and engage with scientists in Allied’s research division. She participated in statewide efforts in 2002 to establish a set of ASD diagnostic best practice guidelines and in other expert panels organized by the state legislature. She organized trainings and workshops for psychologists in Allied, staff in the state’s Department of Human Services, and local school districts.

Achieving a research-level diagnostic standard was key part of the director’s plan. Clinicians maintained close ties with a group of autism epidemiologists at Allied’s research division. Research subjects were frequently recruited from patients who were seen at Alpha clinic, and Alpha clinicians would conduct ASD evaluations as part of research studies. Research-quality evaluations are considered superior to “clinical” evaluations because of the high degree of effort in achieving reliability both within the research site and with other research sites across the ASD scientific community.

**The initial director at Charlie clinic**

Unlike the Alpha clinic director, the Charlie clinic director had prior experience diagnosing autism and therefore she, not an external consultant, served as the local subject matter expert. She was shaped by her medical training at one of the top medical schools immediately prior to joining Allied Health in the early 1990s. Her psychiatry fellowship included a six month rotation at an ASD clinic run by a notable, conservative autism expert.

This training gave Charlie director assurance in her knowledge of ASD. Even before the opening of Charlie clinic in 2008, she went out of her way to conduct team-based (i.e., higher-quality) ASD evaluations. For several years before the clinic opened, she coordinated schedules with a local Allied psychologist and a behavioral pediatrician, and carved out time from her regular child psychiatry duties to conduct joint ASD evaluations.
Charlie director’s fellowship experience was integral to her orientation towards diagnostic specificity. When I asked Charlie director via email about a possible intellectual link to her fellowship, she wrote, “The local clinic I developed here [at Charlie] in 2003 very much reflected the training I’d had years before at [my fellowship]...of course I used the same model in my regional clinic once I agreed to open and direct one here.”

The model was developed by Charlie director’s former mentor, who has a distinct reputation as a conservative, no-nonsense clinician who pulls few punches with families. In the media, USA Today quotes her as saying that she does more “un-diagnosing” than “diagnosing” of Asperger’s disorder (Leigh 2007b), and on blogs, she has been called the “Ann Coulter of autism experts.” SFGate writes:

“Others parents have been antagonized by her [Charlie director’s mentor] apparent stinginess with dispensing autism diagnoses. [The medical school], like many other high-ranking universities, is conservative with its labeling of autism, and [Charlie director’s mentor] is dismissive of psychologists who ‘see autism in everyone.’ She attributes this to a desire to show competence in recognizing the condition as well as bowing to pressure from...parents.” (Leigh 2007a : p1)

One thing Charlie director learned from her mentor was to emphasize the importance of professional judgment acquired over time through master-apprentice training. This emphasis is revealed by an internal controversy at Allied. Soon after Charlie opened, Allied researchers noticed that rates of diagnosis at Charlie seemed different from those in Alpha. This suggested for the first time the possibility that Charlie, Alpha, or both might not be diagnosing appropriately. Charlie’s response is illustrative. Wanting to check her approach to diagnosis, the Charlie director contacted her former mentor and asked her to conduct an independent review of Charlie clinic’s practices. The former mentor largely approved, affirming the professional judgment of the Charlie clinic director. Alpha clinic, by contrast, received and continues to receive affirmation from their participation in research studies and formal tests of diagnostic reliability. With a belief that a good diagnostician uses her own professional judgment, the

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Charlie clinic director was less swayed by post-1998 field-level developments calling for greater diagnostic sensitivity.

**Key individuals and the development of tacit rules**

These key individuals were influential in shaping diagnostic outcomes at their respective clinic because staff clinicians lacked a pre-existing diagnostic orientation and well-developed prior beliefs about diagnosis when they joined. Most clinic staff were newly-hired psychologists who had recently received their PhD or PsyD in clinical psychology and completed a post-doctoral fellowship. Some clinicians at Alpha worked part-time at the clinic and part-time at mental health departments elsewhere in Allied. Because ASD diagnosis is highly specialized within psychiatry,\(^\text{17}\) nearly all clinicians had to learn both the formal psychological instruments and the informal rules for diagnosis (i.e., clinical judgment). The effect on staff clinicians is exemplified by a psychiatrist, who worked part-time in Alpha clinic and part-time in a mental health department. Here, she describes how her experience at Alpha broadened her definition of autism as compared to her definition acquired during her residency years before:

“For about two years I went down [to Alpha] once a week and worked actually in the diagnostic center as one of the clinicians, and then worked here the other three days a week. Really, really enjoyed that. And it really helped me further develop my understanding of autism, which has changed a bit since my [residency] training. It’s almost a completely different thing, now it’s a little more broad-based umbrella, what we call autism these days.”

Clinicians do not openly express a preference for diagnosing one way or the other. All clinicians I spoke to were concerned first and foremost with getting the diagnosis correct and might even take offense at the idea that their individual beliefs might affect their clinical evaluations. However, because staff clinicians started with few prior beliefs about ASD diagnosis, they were sensitive to the diagnostic

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\(^{17}\) One mental health care provider told me: “You’re gonna find that most mental health departments - the clinicians - don’t want to work with autism.” When I asked why, she continued “That’s a specialty. That’s an area all in itself. That’s not a mental health category that really responds to traditional psychotherapy. So clinicians that come to psychiatry are trained in traditional mental health therapies and traditionally autism was just never one of them.”

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orientation and tacit rules for diagnosis present during their training. The tacit rules promoted originally by the key individuals later came to be internalized by individuals throughout each clinic.

Tacit rules refer to clinicians’ scripts for interpreting evidence and are an essential part of diagnosis because, even using formal criteria, professionals must interpret idiosyncratic patient behaviors in abstract terms (Rosenberg 2002). Medicine conceives of disease and other conditions as ideal types, abstracted away from specific individuals. The application of general medical categories like ASD to specific individuals with idiosyncratic symptoms requires a degree of judgment. Unlike medical conditions such as tuberculosis or HIV, there is no definitive, specific test for diagnosing ASD.

Diagnosis of ASD is made on the basis of behavioral criteria in the DSM; out of the 12 criteria (see Table 3) for ASD, patients must meet a threshold number to be positively diagnosed.18,19,20 Accurately determining whether a patient meets these criteria requires the reliable application of tacit diagnostic rules.21

An example of the gap between formal criteria and patient idiosyncrasies is DSM-IV-TR criterion A3 which reads:

“A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people, (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people).”

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18 The official version used during the study period (2000-2012) was DSM-IV-TR. The next version, DSM 5, was released in May 2013. DSM 5 removes the five “subcategories of ASD” and uses only a single diagnosis of “ASD.” To diagnose ASD according to DSM 5, the social and communication categories have been combined and include three criteria, all of which must be met. Children must still meet the criteria for stereotyped behavior, but must now meet two of four criteria.
19 Children diagnosed with ASD need only meet some but not all of the criteria. For Autistic disorder, the individual must meet six of the 12 criteria with at least two from the first category (i.e. social), one from the second category (i.e. communication) and one from the third category (i.e. stereotyped behavior).
20 I describe the diagnostic process at Allied further in the Appendix.
21 Even though the “gold standard” diagnostic instrument - the ADOS - provides a sharp lens for identifying social, communication and behavioral deficits in children and improves reliability, the ADOS does nothing to change the fundamental nature of the diagnosis decision.
Table 3: DSM-IV-TR Criteria for ASD

A. Qualitative impairment in social interaction, as manifested by at least two of the following:

1. marked impairments in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction
2. failure to develop peer relationships appropriate to developmental level
3. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people, (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
4. lack of social or emotional reciprocity (note: in the description, it gives the following as examples: not actively participating in simple social play or games, preferring solitary activities, or involving others in activities only as tools or "mechanical" aids)

B. Qualitative impairments in communication as manifested by at least one of the following:

1. delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
2. in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
3. stereotyped and repetitive use of language or idiosyncratic language
4. lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

C. Restricted repetitive and stereotyped patterns of behavior, interests and activities, as manifested by at least two of the following:

1. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
2. apparently inflexible adherence to specific, nonfunctional routines or rituals
3. stereotyped and repetitive motor mannerisms (e.g. hand or finger flapping or twisting, or complex whole-body movements)
4. persistent preoccupation with parts of objects

Given this criterion, it is easy to conjure image of extreme cases that qualify, e.g., a child who never initiates conversation or interaction with another person, even a parent. However, many cases are not so extreme and can cause disagreement among clinicians pursuing precision. In criterion A3, the part that causes difficulty is the word “lack.” Because the level of “seeking to share enjoyments, interests, or achievements” can vary in degree, this criterion defies a simple yes-no distinction. One psychologist explained:

“I’ve had debates with people about what the word ‘lack’ means. Does it mean a hundred percent, total absence of social or emotional reciprocity, or is it just a deficit? I’m of the personal belief that it doesn’t have to be a complete absence. That seems a little rigid to me, but I know that there are staff who feel differently.”
Making a judgment about this criterion requires that the clinician develop an unstated threshold for deciding when the observed symptoms of the patient fit the criterion. This psychologist refers to an interpretation of “lack” that she believes is appropriate, and notes that other clinicians may have different ways of interpreting “lack.”

It is in the space between formal criteria and idiosyncratic patients that tacit rules are necessary. Clinicians develop tacit rules for maximizing reliability in this space but, without an external reference point, can be susceptible to subtle biases (Gawande 2002). Consistent with research showing that biases can unconsciously influence professional decision-making (Castilla 2008; Greenwald and Banaji 1995; Reskin 2000), even the most dedicated ASD clinicians may diagnose differently from one another without being aware. In this setting, tacit rules may include a list of symptoms known to be equivocal, alternative explanations for each symptom and thresholds of evidence for ruling out alternatives.

Systematic differences in tacit rules can produce different outcomes in diagnosis at the clinic level. In the previous example of DSM-IV criterion A3, differences in the rules for interpreting symptoms have a clear influence over the probability of diagnosis. The quoted clinician would conclude that the criterion is met even if the patient had a mere “deficit” in reciprocity, while other clinicians would only consider the criterion met if the patient has a “total absence” of reciprocity. Ceteris paribus, this clinician will be more likely than other clinicians to give a diagnosis of ASD.

More generally, relevant tacit rules seem to relate to the search for alternative explanations besides ASD. As a first step, the clinicians must gather evidence of social, communication and behavioral deficiencies and then decide whether they are severe enough to meet the DSM criteria. As a second step, clinicians must decide whether the child’s unusual behavior can be explained by alternative psychiatric disorders besides ASD (e.g. speech delay, attention deficit hyperactivity disorder).
The first step is easy, but the second task is extremely difficult: A child’s behavior can be consistent with the DSM-IV criteria for ASD and the ADOS, but the etiology of that behavior may not be ASD. Relative to other psychiatric conditions, ASD is marked by a complex set of symptoms. If only a subset of symptoms are identified, clinicians may diagnose another, more narrowly-defined disorder (Gallo 2010).

**Diagnostic orientations at Alpha and Charlie**

With clinicians lacking strong priors about ASD diagnosis and key individuals providing contrasting guidance at each clinic, the tacit rules that emerged at Alpha and Charlie were different. These tacit rules appear to have a certain coherence, which I refer to as a diagnostic orientation. The diagnostic orientation at Alpha clinic places greater emphasis on **standardization** and on **sensitivity**, while the diagnostic orientation at Charlie clinic places greater emphasis on professional **judgment** and on **specificity**. Clinicians do not state their positions overtly but their orientations are revealed by the way they discuss matters related to ASD diagnosis.

**Diagnostic orientation at Alpha clinic**

At Alpha clinic, emphasis on standardization is reflected in clinicians’ attitudes towards scientific research and use of the ADOS diagnostic instrument. Clinicians at Alpha clinic work alongside Allied researcher scientists on studies of autism, carrying out clinical evaluations for ASD on research subjects. They believe that participating in research keeps them on the cutting edge of clinic practice. Interactions with full-time research scientists present opportunities to learn about the latest developments in ASD and challenge their current knowledge. When I arrived at Alpha clinic to shadow a psychologist as part of the fieldwork, he was given a tall stack of research papers about the diagnosis of ASD. This clinician told

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22 This task is analogous to disentangling causation from correlation. Correlation is easy to observe but it is often driven by a multitude of factors besides the hypothesis of interest. Substantial effort is therefore required to rule out alternatives.
him that research was a major selling point and, if she were not allowed to participate in research, she would probably leave. 23

Alpha clinic takes pride in the skilled use of the ADOS instrument and is uncompromising about its reliability. The ADOS is considered the “gold standard” psychological instrument for the diagnosis of ASD (Lord, Rutter, DiLavore, and Risi 1999; Lord, Rutter, Goode, Heemsbergen, Jordan, Mawhood, and Schopler 1989). Standard training is normally at the “clinical” level and involves a two to three day workshop with a certified instructor. Alpha clinic pursues a “research reliable” rating, which entails substantially more training 24 and is a de facto prerequisite to participate in a research study. One clinician explained:

“[Alpha clinic] is trained to a research level, so maybe we do have a different threshold from everyone else. [Alpha clinic] has always been interested in research. Whereas the other clinics were asked to be involved in research and they declined. They are ‘clinically reliable’ but not ‘research reliable.’ ”

Alpha clinic’s emphasis on sensitivity is reflected in clinicians’ concern about the burden autism poses for families. Speaking to a clinician at Alpha clinic, I asked about the overall upward trend in autism prevalence estimates and whether she was worried about over-diagnosis. The narrative she gave

23 Readers may be concerned about the possibility that biased hiring and turnover processes may lead to systematically dissimilar clinicians at Alpha and Charlie, which then drives the diagnostic difference. For example, conservative clinicians hire other conservative clinicians and drive away non-conservative clinicians. However, this is unlikely to be the case because (1) most clinicians are hired with little prior ASD diagnostic experience and have no apparent diagnostic proclivities to be selected on and (2) evidence from the only clinicians to work at more than one clinic shows that the clinic difference persists even in the same individuals (compare Figure 6 with Figure 9). Moreover, the moving of the group of clinicians was exogenous to their experience at Alpha because the move was planned when they were first hired into Allied, before working at Alpha and Charlie.

24 “Research reliable” training qualifies clinicians to identify individuals with ASD at an acceptable standard for research studies (e.g. to evaluate the effectiveness of treatment), for which researcher must be certain research subjects truly have ASD (e.g. Dawson, Rogers, Munson, Smith, Winter, Greenson, Donaldson, and Varley 2010). Research-level training consists of three additional days of training working with certified instructors. After the course, the trainee must videotape herself conducting six independent administrations of the ADOS, send in those tapes to a certified trainer and achieve 80% inter-rater reliability at the item-level. Amazingly, clinicians in Alpha clinic not only undertake research-reliable training but even go a step further as part of their research. They test their inter-rater reliability among themselves every three months and regularly test their inter-rater reliability with other research sites.
in response emphasizes the plight of the parent and illustrates how sensitivity to ASD can be a way to lessen parents’ burden. A positive diagnosis opens the door for the family to receive supports from the state, the school and the medical system. She explained:

“Actually a bigger problem is under-diagnosis...parents go through this horrible period of blaming themselves. ‘What if I didn’t do this, or if I did that?’ It’s really terrible. We reiterate to them that they didn’t do anything. And we try to take out the blame. It can really be heartbreaking. But when parents connect with the diagnosis, they can really do some amazing things.”

The clinic’s emphasis on early diagnosis is another indicator of its commitment to diagnostic sensitivity. Another clinician explained: “When someone is diagnosed late, they lose a lot of the opportunity to improve. It’s really best to diagnose at 2 years old and we’ve been getting better about diagnosing kids earlier.” To diagnose at earlier ages, clinicians must attend to a new set of subtle signs and symptoms which, by definition, require clinicians to be more sensitive to ASD than they had been in the past.

**Diagnostic orientation at Charlie clinic**

At Charlie clinic, the emphasis of professional judgment is illustrated in clinicians’ idealized image of a good clinician, discounting of the ADOS instrument, and approach to training new psychologists. A good clinician is one who has an extensive amount of experience and has developed a broad understanding of many psychiatric disorders. This understanding allows the clinician to carefully sift through patient information and behavior, consider possible alternative diagnoses, and arrive at a diagnosis of ASD once alternatives have been ruled out. A senior clinician at Charlie clinic explained:

“You’re not a good internist unless you know the differential diagnosis of chest pain. If you don’t know that chest pain can be due to esophageal problems, or all sorts of other things, then you can’t do the full diagnosis.

Autism is a psychiatric disorder. Especially as they get older, you have to really know typical development, its minor aberrations that can affect functions but be below the threshold. You need to know what other things that can present within psychiatry that can lead to aberrant social development. It’s much harder to teach this than it is to teach one single test.”
The single test the quote refers to is the ADOS. While the ADOS is considered essential at Alpha clinic, it is explicitly considered secondary to clinical judgment at Charlie clinic.

This is reflected in Charlie clinic's use of standardized instruments when the clinic first opened in 2008. At first, the approach to evaluation at Charlie was unstructured – to simply interview the parents about their concerns and observe the child in free play. Standardized psychological instruments were used, but were used in different combinations and were used selectively. Clinicians were to be sensitive to signs and symptoms of a range of psychiatric disorders, and to allow those signs to direct the clinician to the appropriate instruments and diagnosis.

Although this clinic now uses the standardized protocol of instruments, the emphasis on clinical judgment persists. The ADOS is now used at every Charlie clinic evaluation, though it is still described as only one part of a complete assessment. One clinician recounted explained that, during an ADOS training session with one of original developers of the ADOS, the instructor acknowledged the instrument’s limitations:

“[The instructor] admitted it up front that the reliability of the ADOS - for ASD versus typically developing [children] - is high. But the reliability of ADOS for ASD versus other child psychiatric disorders...the reliability is low. No matter how high it is, it’s still a test.”

Charlie clinic’s approach to training is consistent with an evaluation approach that relies on good professional judgment. Training at Charlie clinic emphasizes learning-by-doing under the tutelage of a more experienced clinician, rather than training in specific psychological instruments like the ADOS. A senior clinician at Charlie explained “a good psychologist can just learn another test. Much more important is whether they truly understand the differential of ASD.” Relationships among new clinicians

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25 Interestingly clinicians at Alpha say the same thing and we have observed ASD evaluations at both clinics in which the ADOS results were combined with the results of other psychological instruments. What is suggestive of different clinician orientations is that they emphasize different points.
and established clinicians at Charlie were described as hierarchical, while relationships among clinicians at Alpha were described as egalitarian. New clinicians at Charlie conduct evaluations only with experienced clinicians and meet with a senior mentor on a regular basis.

Charlie clinicians emphasize specificity in their clinical evaluations. Clinicians at Charlie agree with clinicians at Alpha that a diagnosis would allow families to initiate treatment, but are more concerned with the potential drawbacks of making a positive diagnosis. A diagnosis of ASD initiates an often dramatic response by the family, health care providers, and the school system. A false positive error may lead unnecessarily to severe distress in the family, be a permanent part of the patient’s medical record, and possibly affect health insurance premiums. Given a truly borderline case of ASD, clinicians at Charlie clinic would choose not to make an ASD diagnosis. One clinician expressed it this way:

“I am definitely more comfortable being conservative if I’m not sure about an autism diagnosis, I’d much rather not make the diagnosis versus make it and then be, you know, incorrect, and have to take it away later. Because I think that’s unfair to do to a family.”

This is nearly the opposite of what is said at Alpha. Wondering how psychologists could hold such different views, I pressed and prompted the clinician with what I had heard from Alpha clinic.

**Interviewer:** I’ve heard people sort of argue the opposite, that, “Hey, you know, if these kids might have ASD, we want to get them in speech therapy, or what-not, ASAP. Let’s not worry too much about what we call it, so long as they get the therapy that they need.

**Respondent:** No, I totally understand that. I get that. Usually...I would say for a response...the kids where this has been an issue, we’re not suggesting that they go away and get no treatments. We’re suggesting options. Could be a social skills group, or it could be treatment with a psychologist, that sort of thing. And we’re usually asking that whoever’s working with them at [Allied], to kind of keep an eye on them, see what they think, and reevaluate as they go along.

It turns out that there is general agreement on the gravity of an ASD diagnosis and the importance of seeking treatment, but clinicians at Charlie consider the drawbacks of not diagnosing to be less severe than the clinicians at Alpha. Emphasizing specificity over sensitivity, they were more reluctant to give a positive diagnosis.
The effect of diagnostic orientations and tacit rules on diagnosis

A consistent application of formal technology across multiple sites requires consistency in tacit rules (Collins 1974) and diagnostic differences across clinics reflect differences across the tacit rules at each clinic. Emphasis on sensitivity makes clinicians less likely to find alternative explanations for symptoms consistent with ASD, while specificity makes clinicians more likely to find alternative explanations for symptoms consistent with ASD. Emphasis on standardization makes clinicians more receptive to the wider public and scholarly discussions about autism, which during this time period advocate more sensitive diagnosis. Emphasis on professional judgment rather than standardization means clinicians are less aware and receptive to public and scholarly discussions advocating sensitivity.

Figure 5: Distribution of diagnosis in Alpha and Charlie clinics

Note: Visits with multiple diagnoses are omitted. The individual bars from left-to-right correspond to the list from top-to-bottom. For example, the leftmost bar is Autism Spectrum Disorder, the next bar is Specific delays in development, etc. The small width of some bars made differentiation through fill patterns difficult.
Figure 5 and Table 4 show how these differences manifest at Alpha and Charlie. Figure 5 illustrates the distribution of psychiatric diagnoses at each clinic. Particularly notable is the finding that both clinics diagnose a non-psychiatric disorder at about the same rate—19% at Alpha, 25% at Charlie—which suggests that clinicians largely agree on whether a disorder is psychiatric or non-psychiatric, but disagree in differentiating among psychiatric disorders.

### Table 4: Regression models for other diagnoses

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Coefficient of Alpha indicator</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism Spectrum Disorder**</td>
<td>0.32***</td>
</tr>
<tr>
<td>Autistic disorder</td>
<td>0.23***</td>
</tr>
<tr>
<td>Asperger's disorder</td>
<td>0.09*</td>
</tr>
<tr>
<td>Pervasive development disorder - NOS</td>
<td>-0.00</td>
</tr>
<tr>
<td>Specific delays in development (e.g. language disorder)</td>
<td>-0.13***</td>
</tr>
<tr>
<td>Neurotic disorders (e.g. obsessive-compulsive disorder)</td>
<td>-0.06**</td>
</tr>
<tr>
<td>Hyperkinetic syndrome (e.g. ADHD)</td>
<td>-0.09***</td>
</tr>
<tr>
<td>Emotional disturbance (e.g. selective mutism)</td>
<td>0.00</td>
</tr>
<tr>
<td>Other mental retardation</td>
<td>0.00</td>
</tr>
<tr>
<td>Episodic mood disorders (e.g. bipolar disorder)</td>
<td>0.00</td>
</tr>
<tr>
<td>Disturbance of conduct not classified</td>
<td>-0.04**</td>
</tr>
<tr>
<td>Mild mental retardation</td>
<td>-0.01*</td>
</tr>
<tr>
<td>Moderate to profound mental retardation</td>
<td>-0.00</td>
</tr>
<tr>
<td>Other mental retardation</td>
<td>0.00</td>
</tr>
<tr>
<td>No psychiatric diagnosis</td>
<td>0.00</td>
</tr>
</tbody>
</table>

+ p < 0.1, * p < 0.05, ** p < 0.01, *** p < 0.001

Note: Models are the same as M3; they include controls for patient characteristics, year dummies and pediatrician office fixed effects, but use different outcome variables. Autism spectrum disorder is an umbrella term that includes several more specific disorders including: Autistic disorder, Asperger’s disorder, and Pervasive development disorders – NOS (not otherwise specified).

Table 4 confirms this pattern, presenting results from linear probability models of other common clinic diagnoses, with controls for patient characteristics, year dummies and pediatrician office fixed effects. The coefficient of Alpha clinic is nearly zero in the model predicting No psychiatric diagnosis, is
notably higher in the models predicting *Autistic disorder* and *Asperger's disorder*, and is notably small in models predicting *Specific delays in development, Neurotic disorders, Hyperkinetic syndrome, Disturbance of conduct* and *Mild mental retardation*. My argument suggests that the symptoms interpreted as ASD at Alpha are interpreted as other psychiatric disorders at Charlie.

**Persistence of clinic differences**

The final piece of the empirical puzzle is the remarkable persistence in differences across clinics. One might expect that these differences ought not to persist because the very premise of an HMO is to provide health services efficiently. Allied should be proficient in developing optimal medical care policies and implementing them throughout the organization, or at least disseminating the knowledge from one part of the organization to another. However, Figure 6 shows the trend of diagnostic rates at Alpha and Charlie, exhibiting little convergence over time. Why did the differences between the clinics, which were established initially by key individuals, persist even among general staff years into the future?

Although the founding director orientation and the receptiveness of new staff may explain initial differences between the clinics, the persistence of clinic differences over time requires additional explanation. Persistence and homogeneity of clinic diagnosis, I contend, is shaped by the internal organizational structure of autism evaluations, which are team-based and have a rotating membership.

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26 Readers may interpret the decline in diagnosis rates at Alpha as evidence of convergence, but this pattern is actually an artifact of the study sample. Figure 6 is based on data from eight birth cohorts and, by 2010, many of the children with ASD have already been identified. Thus the observed diagnosis rate confounds the diagnostic practices of clinicians with the cumulative number of past ASD diagnoses within the cohort. Figure 7 uses supplemental data that helps to tease these apart. Data from all evaluations at Alpha from 2009 to 2012 introduces new children to the risk set which offsets the diagnosed children who leave the risk set. Using these data, the rate of diagnosis remains stable.
Figure 6: Rates of diagnosis at Alpha and Charlie clinics, 2005–2012

![Graph showing rates of diagnosis at Alpha and Charlie clinics, 2005–2012.]

Note: 95% confidence bands shown

Figure 7: Evaluations and diagnosis rates of Alpha clinic

![Graph showing evaluations and diagnosis rates of Alpha clinic.]

Note: My main analyses are based on data of eight birth cohorts, but this does not represent all Allied patients seen at Alpha clinic. The data used to produce this figure is based on all patients seen at Alpha, which was drawn from a proprietary database maintained at Alpha clinic.
Influence of internal organizational processes

ASD evaluations at Allied involve two or more clinicians who administer psychological instruments, interview parents, and observe the child throughout the day. The clinicians gather and interpret data jointly, deliberate and come to a consensus diagnosis. This means that the informal rules for interpreting evidence in terms of the formal ASD criteria are not developed and accessed on an individual basis, but are intersubjective. Joint-interpretation requires a common basis for recognizing critical evidence and inferring meaning. At every ASD evaluation, the tacit rules of each clinic are renegotiated, re-enacted and reinforced by clinicians.

To illustrate the negotiation of tacit rules, I show an excerpt of dialogue between two clinicians who are interpreting the results of the ADOS diagnostic instrument. The ADOS involves a series of standardized play interactions between a clinician and a patient. During the test, clinicians observe the behavior of the child for symptoms of ASD. After the ADOS interactions are completed, the clinicians go into a separate room and (in their language) “score” the ADOS. They work through a booklet with about 30-35 questions about the nature of the interactions. Depending on how the child responded during the interactions, a certain number of points will be given for each item and, at the end, the points will be

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27 An example of a standardized interaction involves an ordinary balloon, blowing it up slowly and then releasing it, causing it to zip around the room. This sound and sight of the flying balloon typically captivates and delights the child who may smile, clap her hands and squeal in amusement. Having captured the attention of the child, the clinician will then pick up the balloon, blow it up again and release it. This continues several times. The balloon is used to create a situation where the child should interact socially with the clinician or a parent. The clinician will look to see whether the child makes eye contact with the clinician, or with a parent in the room, as evidence that the individual is “sharing enjoyment” (c.f. DSM-IV criterion A3 from before). After blowing up the balloon a few times, the clinician will ask the child if she should release it before actually releasing it. Here the clinician is looking for the way the child responds to the question, e.g., does the child respond in a socially appropriate way? Does the child make eye contact?
added to generate a composite score indicating whether the child has autistic disorder or ASD. In the exchange below, two clinicians are assessing the patient's score for the social skill of "giving."

**Clinician 1:** I gave a zero for giving.

[A higher score is more suggestive of autism.]

**Clinician 2:** Yeah. I gave a one and thought I should’ve given a zero. She gave the flower to the Dad and put it to his nose. So it was kind of functional sharing.

[Here, the clinician is referring to an interaction when the child took a toy flower and gave it to her father. By putting the flower to the father's nose, it suggests that the child is aware that the father would enjoy smelling the flower. This does not suggest a social deficit.]

**Clinician 2:** But she also used his lap as a table, put the toy on his lap even when the Dad tried to be responsive.

[The clinician is referring to another earlier interaction when the child wanted to play with a toy and placed it on the lap of her father who was sitting in a chair. If this action is interpreted as "sharing" than it would not be suggestive of ASD. If this action is interpreted as serving only the interests of the child, who needed a table for the toy, then it would be suggestive of ASD.]

**Clinician 2:** Yeah but she didn’t seem to observe what happened with the object and Dad after she gave it. The frequency of sharing seemed age appropriate, but not the quality of sharing.

[In a good social interaction, the child would have put the toy on Dad’s lap and then made eye contact with Dad to see how he would respond to the toy. By not paying attention to Dad or the toy, this action suggests a social deficit consistent with ASD. In the end, the clinicians gave a score of one on this item]

This exchange illustrates the first organizational ingredient of clinic-level diagnostic stability—the constant team-based renegotiation and reinforcement of tacit rules. The two clinicians were initially unsure about how to evaluate the patient’s behavior, but came to a consensus that distinguishes between the frequency and quality of sharing behavior. Assuming clinicians learn from their experience, they should apply this improved understanding, i.e., an updated tacit rule, to similar patient evaluations in the future.

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28 The ADOS is not used exclusively to grant a diagnosis. Clinicians consider its composite score as one of several pieces of information when making a diagnosis.
The second ingredient of diagnostic stability is rotation in team-membership. Every clinician works with most if not all other staff clinicians on a regular basis. This provides stability because a single clinician cannot drift in their own judgment nor can a clique of clinicians develop their own tacit rules. Clinic-level change in tacit rules is more difficult because it would require simultaneous, compatible shifts among all clinicians. Figure 8 displays the network of joint-evaluations at Alpha clinic. The first panel shows the evaluation network for a typical week, the week of May 3, 2010. All clinicians work with at least two others in that week, with some working with as many as seven different clinicians. Panels 2 through 6 show the evaluation network each day of the week. The fact that each network is different indicates constantly-shifting team membership. Finally, Panel 7 shows the evaluation network for the entire year of 2010 and, in all but two nodes, clinicians are well-integrated into a single component.

The effect of team-based, rotating evaluation can be powerful. This is best illustrated by a group of clinicians who moved from Alpha clinic to Charlie clinic in 2008. When they started at Alpha clinic in late 2006, they were trained initially according to the rules of Alpha clinic and, when they moved to Charlie clinic, they were not merely blank slates (as most clinicians are) but were in fact predisposed to diagnose ASD in a diametrically different way from Charlie clinicians. Their rates of diagnosis while at Alpha are consistent with the clinic average - a 69% chance of diagnosing ASD in 2007 and a 71% chance in 2008 – but, once they moved to Charlie clinic, their diagnostic outcomes changed dramatically.

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29 This may explain why diagnosis rates are stable over time, while the rates of diagnosis in the broader organizational field increase.
30 These were the only clinicians in the data who switched clinics.
Figure 8: Evaluation networks at Alpha clinic

Panel 1: Week of May 3, 2010
Panel 2: Monday, May 3
Panel 3: Tuesday, May 4
Panel 4: Wednesday, May 5
Panel 5: Thursday, May 6
Panel 6: Friday, May 7
Panel 7: Year of 2010

Note: Tie represents joint evaluation of a single patient; square node is the founding director
Figure 9 presents the probability of diagnosing ASD for these clinicians between 2007 and 2012. In 2007 and part of 2008, when they were at Alpha clinic, their average diagnosis rate of ASD was about 70%, consistent with the Alpha clinic average (see Figure 6). However, starting in October 2008 and continuing through to 2012, their rate of ASD diagnosis dropped precipitously by about 30 percentage points to within the Charlie clinic average.

*Figure 9: Average probability of diagnosing ASD for the “movers” by clinic*

Note: 95% confidence bands shown

**No evidence of coercion by clinic directors**

One may wonder if persistence is driven by direct coercion of the clinic directors. My data suggest that this is not the case. In general, coercion is unlikely in this setting because all providers are governed by professional medical ethics and have a primary organizational role in diagnosing their patients. Yet, as an empirical check, if coercion were to occur, it would be strongest in evaluations in which the director directly participated (and could actively shape the interpretation of evidence) and would be weakest in evaluations in which the director did not directly participate (and had no firsthand knowledge of patient symptoms). However, Figure 10 shows there is little difference between evaluations with and evaluations without directors. In Panels 1 and 2, the lines in Figure 10 indicate the
rates of ASD diagnosis with and without directors. While diagnosis with directors is noisier (as would be expected given fewer observations), the probability of diagnosis appears the same.

Directors have also become less influential over time. Figure 10 shows that the proportion of evaluations with founding directors is small and, in the case of Charlie, decreasing. The Charlie founding director is currently focusing considerable attention to new ASD-related projects (i.e. the development of ASD treatment programs at Allied) while the founding director of Alpha stepped down in 2008 and works in the clinic without a formal leadership role.

Panel 3 of Figure 10 best illustrates the dynamic by which the behavior of clinicians take on the behavior their new clinic, independent of any possible coercion. The figure shows the diagnosis data of the group of clinicians who moved from Alpha to Charlie. From 2006 to the first half of 2008, they diagnosed about 70% of their cases with ASD. From the second half of 2008 through to 2010, their rate of diagnosis decreased and rates of diagnosis with the Charlie director matched rates of diagnosis without the Charlie director. After 2010, they largely stopped working with the Charlie director but their rates of diagnosis remained stable relative to the 2008 to 2010 time period. This suggests that, whatever their approach to diagnosis between 2008 and 2010 (when they sometimes worked with the director), it persisted even without director intervention.31

**Little influence from outside each clinic**

My argument is that internal processes at each clinic contributed to stable differences in diagnostic practices and outcomes, but one might ask why the clinics were not influenced by external parties. For example, the clinics might be expected to learn from one another (Darr, Argote, and Epple 1995). Knowledge transfer (Argote 1999) should lead to homogenous practices across clinics, especially within the same organization (Kogut and Zander 1996). As a second possibility, the central ASD office at Allied has authority over each clinic and it was the central office that imposed uniformity in the use of

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31 In the Appendix, I argue that this difference does not reflect coercion by more senior staff at Charlie.
psychological instruments, team-based evaluation structure and rules for referral. Why did the central office not modify the practices at Alpha and/or Charlie (especially once Allied researchers noticed differences in diagnosis rates)? I argue that external stability was provided by the difficulty of transferring tacit knowledge and by the overwhelming shroud of uncertainty over ASD.

Knowledge transfer across clinics does not attenuate the differences in the diagnostic outcomes because the knowledge that generates the diagnostic differences is tacit and therefore difficult to transfer (Argote, McEvily, and Reagans 2003; Hansen 1999; Nonaka 1995). Staff clinicians rarely interact with other ASD evaluators outside their clinic, though clinic directors do see one another more often when attending meetings. However, discussion is far too vague and abstract for clinicians and directors to reach consensus on diagnostic approaches. Clinicians are taught to put patient symptoms in a broader context and consider the family situation, comorbidities, and other evidence gathered during the evaluation. Tacit rules shape how these symptoms are interpreted for or against an ASD diagnosis. Although information may be exchanged (e.g., in a short conversation after unrelated meeting), the recipient does not have sufficient contextual information for that knowledge to be meaningful (as would be the case in a shared evaluation). Communication may be simply too thin to convince clinicians that a particular symptom should be interpreted differently, that they should update their tacit rules.
Figure 10: Clinic evaluations involving founding director

Panel 1: Alpha clinic

Panel 2: Charlie clinic

Panel 3: Movers at Alpha and Charlie clinic
Senior managers outside the ASD clinics did not impose corrective actions because of the substantial uncertainty over ASD. While the Alllied researchers did suspect that differences in diagnostic approaches lead to different rates of diagnosis, they did not have enough independent evidence to motivate an intervention. Clinicians themselves speculated that, because Alpha and Charlie clinics cover largely different geographic areas, it was quite possible that the differences were attributed to different patient compositions, localized environmental factors, and referral patterns of primary care providers. They were unsure whether different diagnostic rates result from consistent practices with dissimilar patients, or inconsistent practices with similar patients. For example, one clinician at Charlie speculated that families in an area north of the clinic were more “loosey goosey” than those south of the clinic.

Even if senior managers at Allied were convinced that practices across the clinics were inconsistent, they would still be confronted with the larger mystery surrounding ASD prevalence. Because the true prevalence of ASD is unknown and estimates continually change in scholarly research, it is unclear which clinic required intervention. Senior managers did not know which clinic was most accurate in diagnosing true ASD cases: Alpha might have been over-diagnosing while Charlie might have been under-diagnosing, both might have been over-diagnosing, or both may be under-diagnosing. When a gold standard outcome is unavailable and there is no benchmark against which to assess performance, practitioners often strive to enforce the integrity of processes (e.g. Lind and Tyler 1988). Accordingly, the formal aspects of the diagnostic process are the same across clinics, but formal aspects alone are insufficient for ensuring similar diagnostic outcomes.

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32 They had not done the calculation presented in this paper shown on Table 2 using medical office and zip code fixed effects. Also, this is why the external review of Charlie clinic by the director’s former mentor did not prompt intervention. Her conclusion was consistent with the possibility that diagnostic practices were uniform, while patients were different. The belief in uniform practices has a certain appeal because acknowledging differences raises uncomfortable questions about service quality which cannot be easily resolved.
Discussion

Imprinting variation in organizational adaptation

Let me summarize the empirical findings of this study. Allied Health initiated organizational change in response to the passage of the state Mental Health Parity law and did so in a way consistent with the contemporary scholarly conception of ASD. Three clinics were established but, unexpectedly, diagnostic outcomes varied considerably across clinics. Evidence indicates these differences are not driven by different patient populations but instead, are driven by different clinical orientations towards diagnosis. Alpha clinic emphasizes standardization and sensitivity, while the Charlie clinic emphasizes on professional judgment and on specificity. These orientations were the consequence of a combination of factors – the degree of interpretation required in apply of formal diagnostic criteria, the lack of pre-existing conceptions of ASD diagnosis by clinicians, and influential individuals at each clinic with contrasting approaches to diagnosis. These orientations appear to persist over time because of the rotating, team-based structure of evaluations. While each of these empirical details may seem unsurprising and even prosaic, together they provide considerable theoretical insight.

These events teach us about the theoretical relationship between imprinting and organizational adaptation to field-level change. The case of ASD diagnosis at Allied demonstrates the concept of imprinting variation, which is an organizational outcome consisting of: (1) the shaping by prior imprints of a particular distribution of new practices and (2) the locking-in of these practices at a sub-unit level.

To elaborate on the first element, while neoinstitutional theory and social contagion can explain Allied’s formal commitment of resources and increased ASD diagnosis organization-wide, they offer little to explain the precise pattern of diagnosis at Allied, namely variation in diagnostic rates across clinics. Variation in ASD diagnoses across clinics is driven by an adaptation process that

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In the Appendix, we consider two other theoretical accounts – institutional logics and translation – but argue that neither explains my empirical findings as well as imprinting variation.
unintentionally incorporated existing elements from the organization—directors and their ASD mentors—and generated a set of diagnostic practices that became imprinted at the clinic level.

Differences in the diagnostic orientation of each clinic were seeded by differences between the initial directors, their training, and prior relationships to ASD experts. Acquired during a sensitive time period and persisting over time, the diagnostic approach of Charlie director reflects an individual imprint shaped by early educational experiences (e.g. Ding 2011; Tilesik 2010). Similarly, the relationship between Alpha director and the consultant at Alpha developed during a formative stage in psychiatric education and can be understood as part of a network imprint (e.g. Marquis 2003; McEvily, Jaffee, and Tortoriello 2012); it was this social tie that led to the consultant’s involvement and influence at Alpha. The imprints on the initial directors in turn shaped the diagnostic orientations at each clinic. The new theoretical insight is that, when field-level changes prompt the organization to adapt, the distribution of prior imprints can shape the pattern of new practices.

To elaborate on the second element, as the organization undertook change, a second set of imprints emerged at the clinic level. The orientations of initial directors were particularly influential because almost none of the newly hired staff had prior experience diagnosing autism and learned on-the-job at each clinic. These differences persisted because the team-based nature of evaluations served to lock-in the informal diagnostic rules that are continually negotiated and reinforced at each team-based evaluation.

This study demonstrates the importance of imprinting under a strict set of conditions under which homogeneity would be expected. While prior research has argued that imprints can persist in the face of market selection pressures (Baron, Burton, and Hannan 1999), markets are rarely perfectly competitive and firms, given some distinctive capability, may survive despite deviating on some dimensions from homogeneity. This paper shows that imprints can also persist even in the face of direct intervention by organizational actors. That imprinting still matters under conditions where institutional and internal
organizational factors promote homogeneity is evidence that imprinting is a more powerful and more ubiquitous organizational process than has been previously recognized.

This work also offers insight into the organizational mechanisms of imprinting. With few exceptions, previous scholars infer imprinting based on a correspondence between initial conditions and present-day organizational behavior. The act of imprinting is left a conceptual black box. Prior work understates the degree of organizational work involved in the formation of an imprint, essentially relegating the act of imprinting to a conceptual black box. It is deceptively easy to use imprinting to explain an observed empirical pattern post hoc.

By offering further insight into the mechanisms of imprinting, this paper provides leverage for unpacking boundary conditions. Seemingly minor decisions had a startling effect on the nature of new practices. The decision to select particular individuals to serve as the initial directors set into motion a sequence of events that amplified pre-existing individual differences into clinic-level differences. While the individual-level imprints had already been in existence in the organization, they effectively remained latent until Allied decided to reform its diagnostic practices for ASD. Paradoxically, it was the effort to adapt and conform to field-level changes that in a sense “activated” these imprints and led to clinic differences.

Counterfactual scenarios are illustrative here. Consider the Allied health care providers who were not selected for the initial director position; whatever their background with ASD and their diagnostic orientation, it was essentially irrelevant in shaping the clinic- and organization-level practices. In effect, the decision not to choose these individuals neutralized the effect of any prior imprints they may have had. A similar logic applies to staff clinicians; as illustrated in the group of clinicians who moved from Alpha to Charlie, any prior imprints on newly-hired staff were negated.

Alternative ways of staffing the evaluation teams may have led to drastically different diagnostic patterns. Diagnostic orientations persist at the clinic level because of the way ASD evaluations are
staffed – on a rotation basis with other members of the same clinic. If Allied had decided to establish a single large clinic or rotate individuals between clinics, it would likely eliminate variation (and the Allied case could have been seen as a standard case of neoinstitutional theory). Similarly, if membership in evaluation teams was not rotated and clinics worked with a long-term partner, my argument suggests that diagnostic variation would be at the team, rather than the clinic level. The decision to structure clinic staffing in a particular way made diagnostic variation a clinic-level, not an individual-level or an organizational-level, property.

Where else might there be imprinting variation?

This paper describes how imprinting variation arises at a large health care organization. While the prevalence of imprinting variation is ultimately an empirical question, there is reason to believe that it is fairly common. First, imprinting variation is likely to occur when organizations adapt in response to field-level change regardless of the level of resistance or attempts at customization. In the Allied case, I ruled out the usual explanations of resistance and customization as drivers of diagnostic variation, which was essential for identifying a new source of variation. However, there is no reason to expect that imprinting variation is limited to cases when organizations neither experience resistance nor pursue customization. It is instead likely that the effects of prior imprints co-occur with other drivers of practice variation but have simply not been recognized by prior research.

Second, imprinting variation should be possible wherever organizational actors have some degree of discretion, which includes many professional settings. The case of health care may at first seem unusual in that clinicians have advanced degrees and a great deal of autonomy within the organization. However, there is no reason to expect imprinting variation is limited to only cases with a high degree of discretion. Elements of prior practices may infiltrate adaptation efforts because new practices are ultimately developed and implemented by individual actors who have come to embrace the assumptions of prior imprints. Individuals are the top of the organization may envision a uniform set of practices in the abstract but they are divorced from practices on the ground and must rely local actors to implement
new practices. So long as local actors are left to formulate some portion of the organizational response to field-wide change, prior imprints practices should shape organizational adaptation.

Implications for medical variation and autism epidemiology

This paper also offers insights for healthcare scholars and policymakers. The literature on small area variation attempts to explain substantially different rates of health care expenditures and surgical rates among nearby geographic areas (Wennberg and Gittelsohn 1973). A major explanation is the development of physician-specific practice styles (Epstein and Nicholson 2009; Grytten and Sørensen 2003) that affects the use of surgical procedures, spending, and ordering of tests. Evidence shows that these practice styles can be stable, even after moving to a new work location.

My findings suggest that, in the case of team evaluations of very difficult-to-diagnose disorders, practice styles may be a property of the workgroup rather than the individual. Most poignantly, this is illustrated by the groups of clinicians who moved from Alpha clinic to Charlie clinic. Along with Wennberg (2010), I point out how tacit forces at the local organizational level can constrain physician-specific behavior. This paper however goes further by articulating a sociological account of the behavior of health care providers and resulting clustering of medical practices.

For epidemiologists and policy-makers focused on autism, this paper can help explain two puzzling patterns in observed cases of ASD. First is the drastic increase in the number of ASD cases in recent decades, with the autism caseload in California increasing by more than 600% (Croen, Grether, Hoogstrate, and Selvin 2002; Fombonne 2003; Newschaffer et al. 2007). Second is the clustering of autism cases in select geographic hot spots, where local autism incidence is approximately twice that of surrounding areas but cannot be satisfyingly explained by known localized risk factors (Hagberg and Jick 2010; Hertz-Picciotto and Delwiche 2009; King and Bearman 2009). This paper proffers a new explanation for both patterns.
Geographic clustering of ASD cases may reflect the distribution of clinicians with particular diagnostic approaches. The differences between Alpha clinic and Charlie clinic likely reflect of diagnostic uncertainty in the broader community of health care professionals. If anything, one would expect variation to be attenuated within a single organization, Allied Health. The roughly 30 percentage point difference found within Allied likely underestimates the diagnostic variation at large.

Similarly, increased ASD diagnosis may be driven by the distribution of health care providers who have specialized in ASD in recent years and have been affected by recent public and scholarly debates. Although it is common wisdom that autism awareness has led to the increase in ASD diagnosis, the mechanisms are unclear. This work suggests that the ASD increase may in part reflect a rise in a new generation of diagnosticians who have been shaped by the current progressive orientation towards diagnosis.

**Future Research**

These findings suggest several areas for future research. First, because this study uses retrospective accounts, the description of past events may be incomplete and inaccurate (Christensen-Szalanski and Willham 1991; Golden 1992; Podsakoff, MacKenzie, Lee, and Podsakoff 2003). I attempted to mitigate these concerns by relying on the testimony of multiple respondents and triangulating accounts with historical documents and quantitative data, e.g., patterns in the electronic medical records. The argument laid out in the paper is based on a constellation of quantitative and qualitative evidence from which a coherent account is weaved. Future research could use data collected in real time as an organization adapts to environmental changes.

Second, my data collection efforts deliberately focused on Alpha and Charlie because they represented the most extreme outcomes. Based on a logic of theoretical sampling, I believe this choice offered the greatest theoretical insight given a finite amount of research resources. From my current understanding of Bravo, there is nothing inconsistent with the grounded account of the differences
between Alpha and Charlie and, more importantly, there is no evidence that contradicts the broader theoretical findings of this paper. Future research could examine a larger number of intra-organizational units, from which an even richer research findings might be extracted.

**Conclusion**

Adaptation and inertia appear to be two sides of the same coin: pressures for adaptation seemingly compete with pressures for inertia and one or the other dominates in any given case. The finding in this paper is surprising because it demonstrates a more complex and complementary relationship between the two. Imprints, typically associated with inertia, can play two roles during organizational adaptation to field-level change. First, existing imprints on key individuals can serve as the raw materials for new practices as organizations implement change. Meyer and Rowan (1977) write "the building blocks for organizations come to be littered around the societal landscape; it takes only a little entrepreneurial energy to assemble them into a structure" (p345). This paper takes this insight a step further by showing that the building blocks of new practices can be found not only in the societal landscape, but also in the existing practices and network ties of the organization. The effect of existing practices can be unintentional and emerge only during efforts to adapt.

Second, existing imprints can play a role in locking in the new practices post-adaptation. As new practices take hold within organizations, practices can become stable and persist despite limited managerial oversight. Organizational decisions, seemingly-minor, can shape the way that new practices are imprinted. In these ways, imprinting plays a subtle but significant role in shaping and lending persistence to organizational adaptation to field-level change.
Essay 2: Warrior parents and the diagnosis of autism spectrum disorder

Characterizing patient influence on the decisions of health care providers
Introduction

Since the mid-twentieth century, patients have been taking on an increased role in medical decision making by actively shaping the decisions of their health care providers. This has been hailed as a positive development, a way for individuals to be involved in a critical arena once the exclusive jurisdictions of physicians. Yet it has also been seen as problematic, with some policymakers concerned that this trend may have gone too far, for example, in the direct-to-consumer marketing of pharmaceuticals and the autism epidemic. While it is widely accepted that patients do have influence of the medical decisions of their health care providers, the mechanisms of patient influence in medical diagnosis have yet to be made clear.

For example, recent research in sociology articulates a role for patients – namely parents - in explaining the apparent epidemic of autism (Liu, King, and Bearman 2010). Autism spectrum disorder (ASD) is a highly variable developmental disorder that impairs the normal development of social and communication skills in young children. Autism has traditionally been understood as a biological, genetic disorder (Folstein and Rutter 1977), suggesting some fixed proportion of the population should be affected with the condition. It is therefore deeply puzzling that, over recent years, the number of individuals diagnosed with autism has increased dramatically (Baio 2014).

More knowledgeable parents are theorized to be more motivated and better equipped to navigate a health care system whose complexity in effect discourages diagnosis (Liu, King, and Bearman 2010). This is consistent with the epidemiological research on autism, which has used the same interpretation to explain observed associations of autism prevalence with socio-economic status (SES) and with race (Bhasin and Schendel 2007; Mandell, Wiggins, Carpenter, Daniels, DiGuiseppi, Durkin, Giarelli, Morrier, Nicholas, and Pinto-Martin 2009a). This argument also has theoretical support among medical sociologists have argued more generally that patients play an increasingly active role in diagnosis as medicine (Conrad 2005; Donohue, Cevasco, and Rosenthal 2007; Lupton 1997).
This example raises a series of questions relevant to patient influence over health care providers more generally. Perhaps patients exert their primary influence during their interactions with physicians and other health care providers? This might play out as bringing more knowledge, perhaps obtained from the Internet or marketing efforts of commercial firms, to the medical encounter that sways otherwise-agnostic physicians. Physicians might be intellectually agnostic, worried about the potential loss of patients or simply concerned with appeasing a troublesome patient. Or perhaps patients are influential in shaping their assignment process to physicians? This might play out as “doctor-shopping” or as a consequence of unobserved factors like SES or health insurer policies that are associated with assignment to more (or less) sympathetic physicians.

Unpacking the mechanisms of patient influence is immensely important. Using ASD as an example, while it is undoubtedly surprising that parents can affect the prevalence of a biologically-based medical condition, it is not clear whether it is problem. On one hand, this finding might be interpreted as concerned and knowledgeable parents being more likely to raise their concerns to their pediatricians and other medical professionals, who then rule autism in or out. The autism increase may reflect an increase in parents pointing out the signs of autism in their child, a child who might have been overlooked or misdiagnosed by the medical system in times past. Parent influence is useful for ensuring that all children with signs of autism are evaluated thoroughly. In this view, the health care system contains too many barriers that prevent patients who require medical attention in some objective sense from actually receiving that care. A greater balance of power and knowledge between patient and provider leads to a more thorough medical assessment.

On the other hand, this finding might be interpreted as parents having greater ability to manipulate – either sincerely or cynically - the health care system. Parents may believe that their children are best served by investing time and effort in obtaining the maximum level of autism-related resources available from the state, schools, and health care providers. They may be skeptical of medical conditions lacking distinct biomarkers, viewing a diagnosis as merely a label that can artificially lead to social
stigma or access to material resources. In this view, the health care system is flawed and must be at times corrected by interested and influential parents. There runs the risk, however, that parents may have too much influence and may crowd out the subject-matter expertise of medical professionals in the decision-making process.

In this paper, I draw on empirical data from Kaiser Permanente Northern California (KPNC) and the California Department of Developmental Services (DDS) to unpack the mechanisms of patient influence in medical decision making. I focus analysis in three directions. First and foremost, I parse the diagnostic process of autism spectrum disorder into two conceptual stages: I refer to the first stage as initial suspicion of ASD and the second stage as formal evaluation (conditional on suspicion). The diagnostic process can be idealized as an extended period of diagnostic uncertainty initiated by the identification of signs and symptoms indicative of a medical condition and resolved by a formal diagnosis that resolves this uncertainty. During the period of uncertainty, ASD may be raised as a diagnostic possibility and, once raised, may be confirmed, ruled out, or reinterpreted as another medical condition.

This distinction is useful because the role of parents should be different at each stage. In raising the initial suspicion of ASD, health care providers are assessing whether behavior is within some normal range of variability and they should “wait and see” how the patient fares in the future, or whether behavior is sufficiently unusual to warrant immediate further investigation. Parents contribute primarily by voicing their concerns and conveying observations of unexpected behavior to health care providers. In formal evaluation, health care providers are aware that the patient likely has a medical condition of some sort, but the challenge lies in differential diagnosis, i.e., selecting the most appropriate diagnosis given available evidence. Parents may contribute by consciously or unconsciously providing selective evidence to health care providers, or may propose (or even demand) a specific diagnosis.

This paper's insight into the patient influence process comes from examining the impact of parents at each stage in the diagnostic process. Should parents be found to influence diagnosis in the
suspicion stage, it would suggest that their influence comes from raising the concern of ASD to a health care provider. Should parents be found to influence diagnosis in the formal evaluation stage, it would suggest that their influence comes from the selective provision of evidence or from an explicit demand.

Second, I compare the impact of parent influence on diagnosis in two distinct institutions: Kaiser Permanente North California (KPNC) and the California Department of Developmental Services (DDS). These distinct institutions provide special analytical leverage in disentangling the motivations of parents, who have several potential reasons to be inclined towards the diagnosis of ASD. Traditionally, medical diagnosis has been viewed as offering a concrete terms for understanding and dealing with poorly understood personal problems (Pescosolido 1992; Woodward, Broom, and Legge 1995) but in the case of ASD substantial public resources are available to children with the condition. From the perspective of a parent, the California DDS represents a direct source of material assistance in the care for their child while KPNC primarily represents a medical solution to a perceived problem and is of limited benefit in securing material assistance. I analyze the same set of patients as they pursue recognition of ASD in both systems.

Third, I examine the relative impact of parent influence across the entire population of patients (and parents). Previous arguments for patient influence suggests that it applies to patients as a general class. This argument has been used in the case of ASD (Liu, King, and Bearman 2010) in a very large sample of parents with evidence that parent influence affects diagnosis on average across parents. However, the degree of parent influence almost certainly varies across the population and it is unclear whether prior evidence should be interpreted as a roughly constant level patient influence of parents on average, or as high levels of patient influence among only a minority of parents.

The remainder of the paper is organized as follows. In the next section, I provide context by reviewing prior research related to ASD and to patient influence in medical decision making. Next, I describe by empirical strategy, research setting and measures. Results from discrete time event historical
analysis are presented in section 4 and discussed in section 5. I then conclude by articulating this paper’s contribution to understanding patient influence in medical decisions.

Prior literature

Making sense of the autism increase

Autism spectrum disorder (ASD) is a highly variable developmental disorder that impairs the normal development of social and communication skills in young children. Children with autism have difficulty socializing with peers, caring for themselves, and integrating into social institutions like schools. As adults, individuals with autism typically have trouble leading independent and economically self-sufficient lives. There is no cure for autism but individuals with autism can be taught necessary life skills through years of continual therapy. The impact on families can be substantial; in addition to the emotional burden, families must alter their daily life activities and arrange for care from professional care providers. Economically, the total direct costs of caring for a child aged 3 to 7 with autism, over and above the care costs for a child without autism and borne by families, schools, insurance companies and state agencies is estimated at $46,220 per year (Ganz 2006). Since autism was first identified in 1943, prevalence estimates have steadily increased (Fombonne 1999) - from a 1 in 2200 estimate in the earliest epidemiological study of autism (Lotter 1966) to 1 in 68 in the most recent ASD estimate from the United States Centers for Disease Control (Baio 2014). Because ASD has been traditionally understood as a genetic disorder (Bailey, Le Couteur, Gottesman, Bolton, Simonoff, Yuzda, and Rutter 1995; Constantino, Zhang, Frazier, Abbacchi, and Law 2010; Folstein and Rutter 1977), the increased prevalence ASD has been vexing to medical and public health researchers.

Research efforts in the search for a cause can be classified along two primary lines. The first line emphasizes the role of environmental factors that either alone or through a genetic interaction lead to autism (Hallmayer, Cleveland, Torres, Phillips, Cohen, Torigoe, Miller, Fedele, Collins, and Smith 2011; Palmer, Blanchard, Stein, Mandell, and Miller 2006; Roberts, English, Grether, Windham, Somberg, and
Wolff 2007; Windham, Zhang, Gunier, Croen, and Grether 2006). More relevant to sociologists, the second line emphasizes the importance of social, institutional processes that have altered the way that children are assigned diagnostic categories (Croen, Grether, Hoogstrate, and Selvin 2002; Grinker 2008; Shattuck 2006; Shorter 1992). According to this explanation, children who are diagnosed with ASD today would have been either not diagnosed or been given a different psychiatric diagnosis in years past. Autism has indeed evolved from being initially a narrowly-defined condition (Kanner 1943) to now being understood as a “spectrum” (Folstein and Rutter 1977; Wing and Gould 1979) and even a “broader autism phenotype” (Piven, Palmer, Jacobi, Childress, and Arndt 1997) encompassing a wide range of symptoms and severity levels, and scholars have documented diagnostic substitution of mental retardation with autism (King and Bearman 2009).

Sociologists have traditionally viewed mental illness as a socially constructed account for deviant behavior (Lupton 2012; Scheff 1966). By accounting for deviant behavior as “illness” and discounting it, prevailing norms and the social order can be maintained (Parsons 1951a). The emergence of specific disorders can be highly dependent on the contemporary cultural context (Foucault 1964; Hacking 1995; Shorter 1992). Anorexia, for instance, has been argued to emerge from conditions where food is abundant, thinness is a valued norm, and outward appearance takes precedence over inner character (Brumberg 1989; Horwitz 1999). As Western society has become increasingly interdependent (Durkheim 1997 [1893]), extroversion has become a valued norm (Cain 2011), and legitimacy now depends on the scientific rationality of accounts (Kirk and Kutchins 1992), the increase in mental illnesses may reflect a growing means for explaining asocial behavior. Indeed, recent increases have been found across many other mental disorders besides autism: bipolar disorder (Moreno, Laje, Blanco, Jiang, Schmidt, and Olfson 2007), attention deficit-hyperactivity disorder (Conrad 2007; Getahun, Jacobsen, Fassett, Chen, Demissie, and Rhoads 2013), depression (Klerman and Weissman 1989), and social anxiety (Lane 2008).
Social actors often have a direct interest in expanding the boundaries of medical conditions (Friedson 1970; Szasz 1961; Zola 1972). Physicians may seek to expand their professional domain and commercial actors may seek to expand their markets by redefining non-medical problems as medical ones, or even creating new medical problems entirely (Conrad 2005). Patients, traditionally viewed as subordinate in power to the health care professional, may also have an interest in defining problems as medical (Lane 2008; Lexchin 2006; Payer 1992). For patients, a medical diagnosis can help make sense of distressing experience (Woodward, Broom, and Legge 1995), provide a legitimate account to third parties, and grant access to medical resources for treatment (Conrad 2007, Ch 1).

Liu, King and Bearman (2010) argue for the role of patients - namely parents - in the diagnosis of ASD. After addressing three competing explanations - demographic homogeneity resulting from self-selection into a neighborhood, geographically-localized toxicants, and diffusion of a virus - the authors argue that the macro level trends increased autism diagnosis can be explained in part by the actions of parents.34

The warrior parent hypothesis

The influence of patients on the decisions of physicians has been of considerable interest to medical sociologists, health services researchers and policymakers. Historically, physicians had immense power, the doctor-patient relationship was largely a paternalistic one (McKinlay and Stoeckle 1988; Parsons 1951b) and sociologists were wary of professional claims expanding the scope of medical problems (Conrad 1992). A shift towards consumerism and a market logic complicated the doctor-patient relationship, justifying the idea that patients could be demanding of their physicians and that these demands might lead to different medical decisions (Haug and Lavin 1983). The energetic debates around the direct-to-consumer marketing of prescriptions drugs imply (Donohue, Cevasco, and Rosenthal 2007) that patients have some influence over doctors’ prescription decisions (Kravitz, Epstein, Feldman, and et al. 2005).

34 Autism epidemiologists have long speculated a role for “increased awareness” (Fombonne 1999). From this perspective, studying the role of parents in autism diagnosis can be viewed as unpacking the notion of “awareness.”
While it is difficult to argue that patients have no influence over physician decision-making, it remains an open question exactly how and under what conditions patient influence happens. A purely consumerist view of the patient evokes the image of a demanding individual confident in what he wants and unabashedly asking for it. Concerned with maintaining a good doctor-patient relationship, which physicians might care about for several reasons, doctors may concede. Yet, in contrast to this idealized image, qualitative fieldwork has shown that patient "demands" are typically expressed in subtle rather than overt ways (Morgan, Jenkins, and Ridsdale 2007; Stivers 2002) and, even then, patient influence may apply to only a subset of medical-decisions: those for which the scientific evidence is equivocal and otherwise-agnostic doctors may be more willing to defer to patient preferences (Wennberg, Fisher, and Skinner 2002). Murray, Lo, Pollack, Donelan, and Lee (2003) for instance find that patients affected physician prescription behavior in their study, but physicians did not consider the altered behavior to be harmful to the patient.

In the case of ASD, existing literature suggests that parents have substantial influence over the decision to make a positive diagnosis. There are a number of reasons to believe that parents may take an active and effective role in directly persuading health care providers of the suitability of the ASD diagnosis. Acting on behalf of their children, parents may be less willing to relinquish responsibility and more likely to assume shared authority with a physician (Roter and Hall 1992). Being a "good parent" may mean being assertive in the medical encounter (Stivers 2007). In addition, parents have been successful historically in shaping health care institutions to accommodate autism. Parent advocates were certainly hugely influential in shaping educational and health care services for disabled children in the 1960s and 1970s (Eyal 2010; Leiter 2004) and even today there are accounts of some parents being immensely successful in securing services for their children (Zarembo 2011).

Finally, the successes of past parent advocates have created conditions in the present that may encourage help-seeking behavior. The social stigma of ASD has declined, which may lower parents' apprehension over approaching medical professionals, and public services and supports for affected
children has increased, which may act as a twisted incentive to pursue an ASD diagnosis. Recent research finds consistent evidence, arguing “facing likely strong incentives for an autism diagnosis, parents seeking to provide benefits to their children would have reason to deploy their resources for an autism diagnosis” (Liu, King, and Bearman 2010: p1393) and parents might “observe behavioral symptoms consistent with autism...learn how to effectively identify and reach a physician, and...learn how to access and subsequently navigate services and service agencies” (Liu, King, and Bearman 2010: p1389). Physicians may even cooperate with assertive parents; as one doctor explained, “I’ll call a kid a zebra if it will get him the educational services I think he needs.” (Grinker 2008: p 131).

I borrow an evocative term used in the popular media (Zarembo 2011) to refer to the stylized image of the highly influential parent: the warrior parent hypothesis. Prima facie, this hypothesis is compelling. It squares with the macro trend of a shifting balance of power between the doctor and patient, with the personal experiences of scholars and other highly-educated individuals, and with the active historical role of parents of developmentally disabled children.

Still, there are reasons to believe the influence of parents is more limited, that is, to doubt the warrior parent hypothesis. First, health care providers may prove resistant to the demands of patients. Physicians are not necessarily receptive to patients concerns and do not necessarily engage in supportive talk (Street, Gordon, Ward, Krupat, and Kravitz 2005). Financial incentives may discourage the diagnosis of ASD, as the cost of treating ASD is high (Croen, Najjar, Ray, Lotspeich, and Bernal 2006; Kogan, Strickland, Blumberg, Singh, Perrin, and van Dyck 2008) and physicians are known to be influenced by financial incentives (Gruber and Owings 1996; Houle, McAlister, Jackevicius, Chuck, and Tsuyuki 2012).

Second and more importantly, research in the area of special education paints a different, less assertive image of parents. Research finds that many parents fail to fully participate in the special education Individualized Education Program (IEP) process (Silverstein, Springer, and Russo 1992), are
largely passive in IEP meeting (Garriott, Wandy, and Snyder 2001) and lack the information necessary for making informed decisions (Brantlinger 1987). The majority of parents receiving special education services for their children are actually satisfied with what was received (Plunge and Kratochwill 1995). Parents are often reluctant to challenge the expertise of professionals and, even when they do, are reluctant to challenge too vigorously for fear of jeopardizing their necessarily ongoing relationship with school personnel (Turnbull and Turnbull 1990).

**Research Approach**

The empirical goal in this paper is to better characterize the nature of parent influence over ASD diagnosis. My strategy is to first replicate the findings of prior research that suggests a link between parents and diagnostic outcomes, then test the scope of the *warrior parent hypothesis* by focusing empirical inquiry along three substantive directions. First, I decompose the diagnostic processes of ASD into two stages – suspicion of ASD and diagnosis of ASD – to examine the relative impact of parent influence along the diagnostic process. Patient influence in medical decisions undoubtedly occurs to some extent, some of the time, but as patients and parents are directed to increasingly specialized health care providers along the diagnostic process, it is unknown whether and how patient influence will be attenuated. The *warrior parent hypothesis* suggests that patient influence will extend across the entire diagnostic process.

Second, I compare the impact of parent influence on diagnosis in two distinct institutions: Kaiser Permanente North California (KPNC) and the California Department of Developmental Services (DDS). KPNC a large Health Maintenance Organization (HMO) that provides comprehensive health care to more than 3 million individuals in California. The California DDS is a state agency that provides educational, work, and living assistance to individuals diagnosed with autism and other functionally similar conditions. These distinct institutions provide special analytical leverage in disentangling the motivations of parents. From the perspective of a parent, the California DDS represents a potential direct source of material assistance in the care for their child while KPNC primarily represents a medical solution to a

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perceived problem and is of only secondary, indirect benefit in securing material assistance. With the instrumental benefits for a diagnosis being slightly different, we might imagine that the impact of parents might also be slightly different. The warrior parent hypothesis, in its strongest form, suggests that patient influence will substantively similar across both institutions.

Third, I examine the relative impact of parent influence across the entire population of patients (and parents). Previous arguments for patient influence suggests that it applies to patients as a general class. Empirical evidence in the case of ASD (Liu, King, and Bearman 2010) has been interpreted as affecting diagnosis on average across parents. However, the degree of parent influence almost certainly varies across the population and it is unclear whether prior evidence should be interpreted as a roughly constant level patient influence of parents as a general class, or as high levels of patient influence among only a minority of parents. Existing research consistent with the warrior parent hypothesis does make any claim about the prevalence of “warriors” throughout the population, therefore giving us little reason to expect this should not be a general finding. I thus take as a baseline expectation uniformity in parent influence across the population.

**Data and methods**

Data for this study come from Kaiser Permanente North California (KPNC) and the California Department of Developmental Services (DDS). KPNC a large Health Maintenance Organization (HMO) that provides comprehensive health care to more than 3 million individuals in California. The KPNC dataset consists of highly-detailed, confidential electronic medical records between 2000 and 2012 for eight birth cohorts of children born within the Kaiser system between January 1, 2000 and December 31, 2007 (2000-2007, n = 276,395). A subset of these children have qualified for services from the California DDS.
The California DDS assists people diagnosed with autism, mental retardation, epilepsy, cerebral palsy or a condition with the similar functional impairments lead as self-sufficient lives possible. The DDS contracts with non-profit organizations to run 21 regional centers which provide case management and provide an array of services including community care, behavioral therapy, respite care, and work programs to eligible individuals. Data from the California DDS come from two specific files. The Client Diagnostic Evaluation Report (CDER) contains the diagnostic data of individuals considered eligible for services and the Client Master File (CMF) contains data about each individual who has been at least evaluated for eligibility by the regional centers. The CMF includes people who are ultimately deemed eligible as well as people who applied but were not found eligible for regional center services. These data include all children applying for and receiving services for autism in California between 1992 and 2011 (n = 74,275), a subset of which have KPNC as their primary health care provider.

**Conceptualizing ASD diagnosis as a two-stage process**

The diagnosis of ASD can be understood as occurring in two qualitatively-different stages. Initial suspicion of ASD (or a similar condition) begins when initial suspicion is raised by parents, teachers, family friends, and health care providers and concludes when a health care provider begins to investigate ASD as a likely possibility. Parents play a necessary, though not sufficient role in diagnosis. Without their cooperation, the evaluation cannot ethically or practically occur but many other actors may be instrumental in bringing developmental concerns to parents. A health care professional such as a family pediatrician may suspect ASD on the basis of well-child visit through direct observation or on the basis of reports of parents whose suspicions are not fully formed. An educational professional like a teacher or school psychologist may also notice unusual behavior during school activities.

Initial suspicion need not be limited to concerns about ASD. Attention-Deficit/Hyperactivity Disorder (ADHD), for example, has received just as much attention as ASD (Schwarz and Cohen 2013) suggesting that unusual behaviors may also be attributed to ADHD, not necessarily ASD. Similarly,

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35 Mental retardation is now known as *intellectual disability*. 

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symptoms of speech delays and learning disorders can also be recognized by many parents. These and other unusual behaviors or developmental delays can trigger investigation by health care providers, who have experience with other childhood disorders besides ASD. Once the child comes under the scrutiny of an experienced health care provider, ASD is considered a possibility ipso facto.

The second stage, formal diagnosis of ASD, refers to the sequence of activity initiated by suspicion, leading to diagnosis of ASD and the provision of treatment. The first health care provider seen by a concerned family is typically a generalist. Although a generalist physician can legally make a diagnosis of ASD, he or she will often defer (as a matter of ethics) and refer the patient to a specialist. Several types of specialists may be relevant: speech therapists, neurologists, developmental pediatricians, or child psychiatry. The first referral will generally be from generalist to specialist but, depending on how quickly the child is diagnosed, there may be multiple additional referrals from specialist to specialist as the sequence of investigation proceeds. During the medical encounter with a specialist, the specialist draws on a deeper body of knowledge to examine the patient in a more focused way. Parents consequently have a smaller formal role and may be more likely to be deferential to a medical professional with such deep knowledge.

**Measuring each stage of ASD diagnosis in KPNC and the California DDS**

The outcomes of interest – initial suspicion and formal diagnosis – are identified from the detailed electronic medical records from KPNC and the specialized files from the California DDS.

**Formal diagnosis in KPNC** - This outcome is registered based on the first date when an autism spectrum disorder is recorded, for the 3,181 children identified by the Kaiser Permanente Autism Research Group. ASD is indicated based on ICD-9-CM codes 299.0 (autistic disorder), 299.8 (other specified pervasive development orders – including Asperger’s syndrome), and 299.9 (unspecified pervasive developmental disorder). The Autism Research Group maintains a database of all children with ASD at KPNC. Children are identified based on the presence of the ICD-9 diagnostic code in their electronic medical
record and confirmed based on a manual record review. The manual review is helpful in identifying and excluding “rule out” diagnoses, that is, cases in which a clinician suspects but cannot confirm ASD but notes the suspicion by recording the ICD-9 code in the record.

**Formal diagnosis in DDS** – This is measured based on the appearance of a child in the DDS CDER data. The CDER data includes diagnostic information recorded after the clinical evaluation by a DDS-sponsored psychologist. Because the CDER file is intended by the DDS to record data about clients, the very appearance of a child in the CDER data indicates that the child has been evaluated and has qualified for DDS services. DDS eligibility is measured as the first year that an individual appears in the CDER file as an autism client. I identify children from Kaiser Permanente who receive services from the DDS by merging the two datasets based on patient name, date of birth, sex and, when available, mother’s name and mother’s date of birth. The number of children from Kaiser Permanente who appear in the CDER files for autism is 1,391.

**Initial suspicion in KPNC** – This is identified based on patient’s health care provider notes. Many health care providers record notes during or after the patient’s visit documenting the patient’s concerns, findings from the appointment, and actions to be taken. Notes are open-ended and often take the form of incomplete sentences. However, health care providers from child psychiatry, one of the most relevant specialties for children with ASD, are especially detailed and write in full sentences and paragraphs. The average provider’s note is 200 words, a typical intake child psychiatry note is more than 1000 words, and the longest note in my data is 19,370 words.

Notes from the child’s first visit to child psychiatry, known as an intake, have a standard set of sections which are designed to efficiently elicit the patient’s history and parent concerns. Sections include: identifying information/referral source, chief complaint, history of present illness, review of symptoms, patient’s prior psychiatric history, developmental history, psychosocial history. This structure and level of detail is useful for drawing out autism-related concerns in many cases when ASD is not
formally diagnosed. Table 5 presents several excerpts from provider notes where a diagnosis of ASD came to be suspected:

### Table 5: Excerpts from providers’ notes related to ASD

<table>
<thead>
<tr>
<th>Suspicion raised by parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>They [parents] are unsure about his correct diagnosis. They know he has a great deal of difficulty with reading, and often reverses letters or says phrases backwards (like &quot;4 or 3 times&quot; instead of &quot;3 or 4 times&quot;). They suspect that he might have dyslexia. His mother read an article about the emotional effects of dyslexia and she says it &quot;fit him to a T.&quot; They also wonder if he has ADHD, and have wondered in addition about the possibility of autism. His parents have requested an evaluation by the school district, which will begin shortly.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Suspicion raised by provider</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient has an IEP for Expressive Language Disorder. Patient has a one on one aide to help patient a couple of hours a week. IMPRESSION: Patient has many symptoms indicative of an ASD diagnosis. The school has also discussed this with parents. Patient needs to be evaluated by the ASD to refine the diagnosis to help qualify patient for services in the school and possibly SARC [DDS regional center]. Parents will gain education on Autism be connected with community services.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Suspicion by provider; parent disagrees</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pt is here for ADHD evaluation per mom’s request…. [Mom] does not have an understanding how greatly disabled pt is with current impulsivity and hyperactivity…He currently has problems learning in a regular school environment and mom is working on getting an IEP for him. He has not had psychological testing. Other risk issues: Mom appears unable to hear the possibility of any other diagnosis than ADHD. Discussed need for psychological and cognitive testing at school and mom appeared to disregard these requests as not necessary. This writer made a referral to the ASD Clinic.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Suspicion by parent; provider disagrees</th>
</tr>
</thead>
<tbody>
<tr>
<td>[April 3, 2008] - 8 Y male who returns for medication follow-up visit [for ADHD medication] … Other concerns: Poor social skills, stereotypic activities (pacing, turning), language delay in the past. Mother asks for evaluation at ASD clinic. Parents are divorced, the relationship is strained, cannot agree on visitation schedule for patient, will go to court.</td>
</tr>
<tr>
<td>[April 4, 2008] - [patient]’s medication was changed and the family was put in contact with the ASD Clinic given mom’s concerns about [patient]’s poor social skills and the fact he didn’t speak until age 2. They have a screening phone interview next week to see if evaluation is appropriate at their facility.</td>
</tr>
<tr>
<td>[April 25, 2008] - Mom will be resuming more custody time with [patient] soon which affects his Father negatively but might help in giving him respite from full-time fatherhood. Mom is really pushing for ASD diagnoses. They will meet with ASD next week at STR and learn whether he will be accepted for services. Unlikely based on this evaluator’s read.</td>
</tr>
</tbody>
</table>

I run a case-insensitive search for the following strings - “asd,” “autistic,” “autism,” “asperger,” “asberger [sic],” “pdd,” and “pervasive development.” These strings appear fairly unique to ASD, as suggested by a manual review of records.\(^{36}\)

\[^{36}\text{There were a few exceptions that required special consideration. One exception was “asd” which could also refer to an atrial septal defect, i.e., a hole between two chambers of the heart. To eliminate recorded referring to an atrial septal defect, I ignored any records that also had any of the following strings which often co-occurred with “ASD” in the second context – “heart,” “cardi,” “septal,” “secundum,” “VSD.”}\]
Initial suspicion in DDS – This is measured based on the appearance of a child in the DDS CMF data. Parents may apply for services from the DDS but must first be deemed eligible, and a key criterion for eligibility is the medical diagnosis of autism. For the DDS, the CMF is meant to store basic data about each individual (e.g., birth date, sex, mailing address) and a record is entered for each child at the time of application. Consequently, appearance of a child in the CMF indicates that the family had applied to the DDS for services. These children may (or may not) then go on to be deemed eligible for services and their data recorded in the CDER file.

Initial suspicion in the DDS is measured based on the date when the family first applied for DDS services, which is recorded as the date of each child’s first CMF. I identify children from Kaiser Permanente who apply for services from the DDS by merging the two datasets based on patient name, date of birth, sex and, when available, mother’s name and mother’s date of birth. The number of children from Kaiser Permanente who also appear in the CMF is 11,600.

“PFO,” and “PDA.” Another possible issue is proper names which may not follow standard conventions of English words. For example, if the patient’s name is “Jasdeep” for example, my search would pick up on the “asd” in the middle of the name. To mitigate this possibility, I ignore “asd” if it appears in the middle of a word.

To mitigate this concern even further, I supplement the search of the open-ended text field of the provider’s note with another field in the patient’s record: reason for visit. This field is much shorter, typically only a phrase, and it is recorded by KP staff when the patient makes the appointment. While the field is shorter and therefore lacks the richness of the provider notes, this field has the advantage of being available for the full time period, 2000-2012. Examples of visit reasons are shown on Table 6. Similar to the search of the open-ended provider’s notes, I measure suspicion of ASD based on the presence for certain keywords: “ASD,” “PDD,” “ASPER,” “AUT.” To minimize false positives, I exclude records if they include others keywords suggesting that the visit is not related to ASD (viz. “CAUT,” “AUTO,” “AUTH,” “NAUT,” “LAUT,” “SAUT,” “VSD,” “PFO,” “PREOP,” “CLOSURE,” “RASD,” “EKG,” and “PDDM”).

37 Eligibility in the DDS is given only to children with autistic disorder, which is a subcategory within the broader autistic spectrum disorder (ASD) that reflects the classic autism first described in 1943.
Table 6: Examples of appointment reasons used to measure suspicion of ASD

<table>
<thead>
<tr>
<th>Autism related</th>
<th>Not autism related</th>
</tr>
</thead>
<tbody>
<tr>
<td>AUTISM/PDD</td>
<td>SHOW TIME: 09:30A WELL CARE VISIT</td>
</tr>
<tr>
<td>12:30 W/PKT ASPB ASD EVALUATION</td>
<td>VOMIT/DIARRHEA</td>
</tr>
<tr>
<td>NSPB ASD CLINIC</td>
<td>PERSISTENT URI</td>
</tr>
</tbody>
</table>

Table 7: Measurement of first and second stages of diagnosis in KP and DDS

<table>
<thead>
<tr>
<th>Children at risk (full KPNC sample)</th>
<th>Stage 1: Initial suspicion</th>
<th>Stage 2: Formal diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kaiser Permanente</td>
<td>ASD mentioned in record</td>
<td>ASD listed as diagnosis</td>
</tr>
<tr>
<td>276,395</td>
<td>N = 11,659</td>
<td>N = 3,181</td>
</tr>
<tr>
<td>DDS</td>
<td>Application for services</td>
<td>Deemed eligible for services</td>
</tr>
<tr>
<td>276,395</td>
<td>N = 3,065</td>
<td>N = 1,391</td>
</tr>
</tbody>
</table>

Measuring parent influence

One further step is necessary to identify the children who applied to the DDS for autism-related services. The DDS serves individuals not only with autism but also individuals with mental retardation, cerebral palsy, and epilepsy. The CMF does not indicate why the family applied for services and which condition is the basis for possible eligibility. To identify individuals likely to have applied based on suspicion of autism, I compare the list of DDS applicants to the list of individuals suspected of ASD in KPNC (i.e. with an ASD-related string in their medical record) and exclude children who were not suspected in KPNC. This leaves 3,065 children. A limitation of this approach is that it may be an

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38 W/PKT – refers to questionnaire packet parents are asked to fill out and bring to the appointment; ASPB – a department code used by KP
39 NSPB – a department code used by KP
40 URI – Upper respiratory infection
underestimate. Table 7 provides an overview of the children who experience each outcome in KP and DDS.

**Spatially-based measures**

Parent influence poses a measurement challenge and no study to my knowledge has attempted to construct a measure. Health services researchers typically infer patient influence by surveying patients before and after a medical encounter, and comparing the patients stated objectives for the visit with the eventual outcome of the visit (e.g. diagnosis, prescription, referral) (Kravitz, Epstein, Feldman, and et al. 2005). Others identify patient influence through a close examination of conversation patterns between doctors and patients (Stivers 2007). Neither of these approaches scales up to large-n datasets which, unfortunately, are precisely the type of dataset necessary for characterizing the scope conditions of patient influence. My strategy is to use multiple measures for parent influence and assess its impact based on consistency across multiple measures.

The first measure is based on the distance between the address of KP children and address of children receiving DDS services (Liu, King, and Bearman 2010). Liu and colleagues use this as a measure of social influence among parents on ASD diagnosis, with the logic being that social influence among parents leads parents to be more assertive and effective in navigating the health care system. I redeploy this logic in a slightly different way. By arguing for an effect of social influence, which is theorized to shape parent-doctor encounters, Liu, King, and Bearman (2010) make the case *a fortiori* for using the same measure for parent influence.

Measure one: \( \text{parent influence}_{t,t} = -\ln(d_{t,j_{t-1}}) \) where \( d_{t,j_{t-1}} \) is the minimum \( d_{ij} \forall j \)

This measure is constructed using the spatial distribution of children at risk relative to children who have already been diagnosed with autism. Spatial proximity is known to increase the likelihood of social interactions (Festinger, Back, and Schachter 1963) and Liu, King, and Bearman (2010) find that spatial proximity between children with autism and children as risk of diagnosis is related to the
likelihood of diagnosis in the next time period. For each KPNC child at risk, the distance to the nearest child already diagnosed with autism in the DDS is calculated, logged and negatively coded.41

As a complement, I develop a second spatially-based measure that captures the potential effects of more than one child with autism. The logic of this measure is that influence of parent \(i\) in time \(t\) on health care providers is correlated to the social influence exerted on individual \(i\) by individual \(j \in J\), where \(J\) includes every child within 5 kilometers receiving services from DDS in December of the prior year. Social influence is a function of the distance, \(d_{ij}\), between dyads \(i\) and \(j\). Children at smaller distances will exert greater social influence on individual \(i\), while children at larger distances will exert nearly zero influence. Social influence is exerted by all children receiving services in the DDS, which includes both KP and non-KP children.

\[
\text{Measure two: } \text{parent influence}_{i,t} = \sum_{j, \text{s.t. } d_{ij,t-1} < 5\text{km}} \frac{1}{1 + \frac{d_{ij,t-1}}{500}}
\]

Besides the spatially-based measures, I will also pay attention to the relationship between parent influence and race. Epidemiologists who have observed a correlations between race with the likelihood of diagnosis (Mandell, Novak, and Zubritsky 2005; Street et al. 2005; Van Meter et al. 2010). The consistent empirical finding is that white children (often more educated) are more likely to receive an ASD diagnosis. The standard interpretation is that this reflects greater skill and knowledge in navigating social institutions in general, and medical institutions in particular.42 My regression analysis will include Black, Hispanic, Asian and Other (non-Whites) indicator variables.

41 Using the set of DDS children is more complete than using only children from KP. Recall that the DDS data include both KP and non-KP children.
42 This could also be interpreted as differences in the cultural norms of parents. Help-seeking behavior may be prompted from incongruence of a child's behavior with the behavioral expectations held by parents.
Geocoding using ArcGIS

Geocoding requires fairly complete address data. The DDS Client Master File contains addresses in December of each year. Kaiser Permanente maintains records of address changes starting in 2004 and, for every year after 2004, the address data are nearly complete. For years before 2004, I infer addresses where possible by leveraging California Birth Certificate data. Birth Certificate data are available with personal identifiers after approval from the California Committee for Protection of Human Subjects and the California Vital Statistics Advisory Committee, and these data include name and mother’s address at birth. For children with the same name, date of birth, and mother’s name, I compare the birth certificate address to the earliest address in Kaiser Permanente records. If the addresses match, then I infer continuous residence at that address. If the addresses do not match, I make no inference and I exclude person-years without addresses in subsequent analyses.

Addresses are geocoded using ArcGIS 10 and Euclidean distances are calculated between the address of child \(i\) at time \(t\) and the address of child \(j\) at time \(t-1\). The addresses of 77% KP person-years are matched successfully at the street address level using the ESRI Street Maps and Census TIGER/Line All Lines Shapefile reference data.\(^{43}\) Another 2% of person-years have no address, 7% of person-years have an address that cannot be geocoded, and 13% of person-years have an address that can only be matched at the 5-digit zip code level. The parent influence measures are calculated only from DDS addresses matched at the street address level (87%) or at the 5-digit zip code (4%). 8% of DDS person-years do not have an address and 0.5% person-years have an address that cannot be matched. Any out-of-state addresses are excluded from analysis. I only include Kaiser Permanente addresses that can be matched at the street address level and DDS addresses that can be matched at the street address or zip code level.

\(^{43}\) Typically, the percentage of successfully matched addresses ranges from 50% to 99% (Kurland and Gorr 2012).
Control variables

Two critical control variables are population density and the ASD experience of the KPNC health care provider. Population density is a key control because the parent influence measure is confounded with the general population density in the area, i.e., Kaiser Permanente children living in high-density areas will have higher values in the spatially-based measures of parent influence. Conceptually, parent influence should be correlated with the likelihood of encountering and sharing information with a parent of an autistic child, independent of the population density of the area. Population density is measured at the Census tract level and is calculated as the natural log of the tract population of children aged zero through nine in thousands divided by land area of the tract.

ASD experience of the KPNC health care provider offers a means of adjusting for the diagnostic inclination and capability of the health care organization. It has been shown in many cases that medical knowledge can diffuse among physicians via social ties (Coleman, Katz, and Menzel 1957; Iyengar, Van den Bulte, and Valente 2011) and that social ties are correlated with spatial proximity (Festinger, Back, and Schachter 1963). Because patients likely see pediatricians who are close to their homes, measures of parent influence may be correlated with pediatrician factors which are themselves spatially correlated. I construct a measure of ASD experience of the patient’s primary care provider based on the number of children with ASD seen by the provider prior to time $t$.

Other control variables include: age, sex, socioeconomic status, and parent age. I include a range of control variables that are known for or suspected of affecting the risk of ASD. I include dummy variables for three age periods, 0-3, 3-6, and 6 or older. The three age periods which represent qualitatively different regimes of diagnosis: children typically stay at home between 0 and 3, begin to enter pre-school and school settings between 3 and 6, and are well into the educational system after the age of 6. I include an indicator for males because boys have been found to be 4.3 times more likely than girls to be diagnosed with ASD (Fombonne 2005; Newschaffer et al. 2007). The link between sex and
ASD is assumed to be genetic, thought scholars are only now identifying some direct evidence (Strom, Stone, Ten Bosch, Merriman, Cantor, Geschwind, and Nelson 2010 is an exception).

Family socioeconomic status has long been associated with increased prevalence of autism, likely because of ascertainment bias (Stahmer and Mandell 2007; Van Meter et al. 2010; Wing 1980; Yeargin-Allsopp, Rice, Karapurkar, Doernberg, Boyle, and Murphy 2003). From the birth certificate data, education is measured on a seven point scale: 1 for less than an 8th grade education, 2 for some high school, 3 for high school graduate/GED, 4 for some college, 5 for an associate degree, 6 for a bachelor's degree, and 7 for a graduate degree. Because increased family resources have been argued to help families better able to navigate the medical and DDS systems in seeking services (Bhasin and Schendel 2007; Lareau and Shumar 1996), I also include family income as a measure of socioeconomic status. Family income is not known directly but is estimated using the median family income of the 2010 Census tract using 5-year estimates from the 2011 American Community Survey.44

Finally, because prior research shows the risk of autism increases with parental age (Croen, Najjar, Fireman, and Grether 2007; Durkin, Maenner, Newschaffer, Lee, Cunniff, Daniels, Kirby, Leavitt, Miller, Zahorodny, and Schieve 2008), I include paternal and maternal age at time of childbirth as a control. This is calculated using father and mother date of birth from California birth certificates. Results

These data are structured as patient-year dataset and the primary method of analysis is discrete-time event history analysis. Three outcomes will be examined: the diagnosis process overall (which includes both stages), initial suspicion of ASD, and formal diagnosis of ASD.

44 My choice to use 5-year tract level data reflects a strategy to exploit primarily cross-sectional variation across tracts. The Census-tract level is the most finely grained level in the Census data, each tract consisting of approximately 4000 people. There are 8057 census tracts in California, compared to 478 cities and 58 counties. Tract-level data thus give the greatest variation of any Census unit. The Census Bureau defines tracts so that they are internally homogenous in terms of demographics, economic status and living conditions. Five-year estimates pool data from multiple years of the same tract. Compared to one-year estimates, it is more precise but obscures variation across time.
Descriptive Statistics

There are 276,395 children born in Kaiser Permanente North California between 2000 and 2007. Of these, 3,181 (1.15%) have been identified as having ASD in KP which is consistent with national averages (Baio 2014). The number of children with autistic disorder, a specific disorder within autism spectrum disorder, is 1,854. The number of males is 2,588 and the number of females is 593 for a male-to-female ratio of 4.36:1, consistent with prior literature. Table 2 summarizes the data by sex and diagnostic status. The overall sample is approximately 51.2% white, 18.9% Asian, 7.7% black, and 17.6% Hispanic. These proportions are consistent with the racial distribution of the San Francisco and Sacramento metropolitan areas which is 21.1% Hispanic, 46.8% non-Hispanic white, 19.2% non-Hispanic Asian, and 7.7% non-Hispanic black. Among children with ASD, whites are slightly underrepresented relative to their proportion in the sample while Asians and Blacks are slightly overrepresented. Table 8 shows the race distribution of all children, children with ASD and children with autistic disorder. Table 9 lists the values of these control variables for the entire sample and the subsets of children suspected of ASD, diagnosed with ASD, applicants to the DDS and service recipients from the DDS.

45 The primary difference is stems from how to count Hispanic whites. Birth certificate data, which is used to determine race in this sample, counts these people difference from the Census data. Including both Hispanic and non-Hispanic, whites make up 56% of the population which is greater than the 51.2% in the sample. The percentage of non-Hispanic whites is 46.8%, which is less than the 51.2% in the sample.
Table 8: Distribution of sample by race and sex

<table>
<thead>
<tr>
<th></th>
<th>Total sample</th>
<th>ASD</th>
<th>Autistic disorder</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N = 276,395</td>
<td>N = 3,181</td>
<td>N = 1,854</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>141,136</td>
<td>1,615</td>
<td>867</td>
</tr>
<tr>
<td></td>
<td>(51.16)</td>
<td>(50.91)</td>
<td>(46.92)</td>
</tr>
<tr>
<td>Asian</td>
<td>52,143</td>
<td>673</td>
<td>420</td>
</tr>
<tr>
<td></td>
<td>(18.9)</td>
<td>(21.22)</td>
<td>(22.73)</td>
</tr>
<tr>
<td>Black</td>
<td>21,312</td>
<td>251</td>
<td>163</td>
</tr>
<tr>
<td></td>
<td>(7.72)</td>
<td>(7.91 )</td>
<td>(8.82)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>48,611</td>
<td>490</td>
<td>319</td>
</tr>
<tr>
<td></td>
<td>(17.62)</td>
<td>(15.45)</td>
<td>(17.26)</td>
</tr>
<tr>
<td>Other</td>
<td>12,682</td>
<td>143</td>
<td>79</td>
</tr>
<tr>
<td></td>
<td>(4.6)</td>
<td>(4.51 )</td>
<td>(4.27)</td>
</tr>
<tr>
<td>Missing</td>
<td>550</td>
<td>10</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>(0.0)</td>
<td>(0.0)</td>
<td>(0.0)</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>134,619</td>
<td>593</td>
<td>332</td>
</tr>
<tr>
<td></td>
<td>(48.71)</td>
<td>(18.64)</td>
<td>(17.91)</td>
</tr>
<tr>
<td>Male</td>
<td>141,773</td>
<td>2,588</td>
<td>1,522</td>
</tr>
<tr>
<td></td>
<td>(51.29)</td>
<td>(81.36)</td>
<td>(82.09)</td>
</tr>
<tr>
<td>Missing</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(0.00)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

In the KP data, I find the trends of increased ASD prevalence and earlier ASD diagnosis. The mean and median age of diagnosis have decreased over time from 3.57 and 3.59 respectively for the 2000 cohort, and 3.08 and 301 for the 2007 cohort. Prevalence has also increased over time. Prevalence by age 2 and age 5 were 1.8 and 46.2 respectively for the 2000 birth cohort and 9.1 and 92.5 for the 2007 birth cohort. The decrease should not be interpreted as a decrease in autism incidence and, rather, should be seen as a mechanical consequence of the cohort structure of the data. No new children are included in the data after the 2007 birth cohort.
Table 9: Descriptive statistics of full sample, the subset suspected of ASD and the subset diagnosed with ASD in both systems

<table>
<thead>
<tr>
<th></th>
<th>All KP children</th>
<th>KP children suspected of ASD</th>
<th>KP children w/ ASD</th>
<th>DDS Applicants</th>
<th>DDS Recipients</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean</td>
<td>Mean</td>
<td>Mean</td>
<td>Mean</td>
</tr>
<tr>
<td>Parent influence (measure 1)</td>
<td>14.06 (9.22)</td>
<td>24.32</td>
<td>23.59</td>
<td>19.01</td>
<td>19.44</td>
</tr>
<tr>
<td>Parent influence (measure 2)</td>
<td>-5.84 (1.03)</td>
<td>-5.83</td>
<td>-5.29</td>
<td>-5.59</td>
<td>-5.48</td>
</tr>
<tr>
<td>Sex (Male)</td>
<td>0.50 (0.50)</td>
<td>0.71</td>
<td>0.81</td>
<td>0.75</td>
<td>0.82</td>
</tr>
<tr>
<td>Age at Birth - Father</td>
<td>32.71 (6.86)</td>
<td>34.07</td>
<td>34.33</td>
<td>34.36</td>
<td>34.27</td>
</tr>
<tr>
<td>Age at Birth - Mother</td>
<td>29.84 (5.95)</td>
<td>31.11</td>
<td>31.40</td>
<td>31.42</td>
<td>31.20</td>
</tr>
<tr>
<td>Education - Father (1-7)</td>
<td>4.34 (1.77)</td>
<td>4.64</td>
<td>4.76</td>
<td>4.63</td>
<td>4.70</td>
</tr>
<tr>
<td>Education - Mother (1-7)</td>
<td>4.43 (1.74)</td>
<td>4.78</td>
<td>4.84</td>
<td>4.75</td>
<td>4.74</td>
</tr>
<tr>
<td>White</td>
<td>0.49 (0.50)</td>
<td>0.55</td>
<td>0.51</td>
<td>0.54</td>
<td>0.50</td>
</tr>
<tr>
<td>Asian</td>
<td>0.18 (0.39)</td>
<td>0.18</td>
<td>0.21</td>
<td>0.19</td>
<td>0.22</td>
</tr>
<tr>
<td>Black</td>
<td>0.07 (0.26)</td>
<td>0.07</td>
<td>0.08</td>
<td>0.08</td>
<td>0.10</td>
</tr>
<tr>
<td>Hispanic</td>
<td>0.18 (0.38)</td>
<td>0.14</td>
<td>0.15</td>
<td>0.13</td>
<td>0.14</td>
</tr>
<tr>
<td>Family Income (tract median, 1000s)</td>
<td>81.44 (33.25)</td>
<td>87.92</td>
<td>88.54</td>
<td>84.91</td>
<td>84.41</td>
</tr>
</tbody>
</table>

The number of children receiving autism services from the DDS has been drastically increasing. In 1993, there were 1,324 new DDS clients and in 2011, that figure jumped to 9,103. The mean age at which a child receives services from the DDS is 3.8, slightly greater than the average age of diagnosis in Kaiser Permanente. The mean age at which a child first applies to the DDS is 1.84, significantly smaller than the average age of diagnosis at Kaiser Permanente.

---

46 Families often apply to the DDS under the federally funded Early Start program, which is a related-but-separate program for children at risk of disabilities under the age of three. The disability threshold for
Discrete time event history analysis

The event history model used is shown below. The dependent variable is the log-odds of provider \( j \) diagnosing patient \( i \) at time \( t \). In addition to the constant, \( \alpha \), there are two main terms on the right hand side of the equation. The first term captures the effect of social influence; the variable \( D \) is the measure of social influence on patient \( i \). The second term includes control variables in the vector \( X \). Positive values of \( D \) provide evidence of social influence effects. Note that, because all children in my sample were born within Kaiser, I do not have the problem of left-censoring.

\[
\ln\left( \frac{p_{it}}{1 - p_{it}} \right) = \alpha + \beta D_{it} + \gamma X_{it},
\]

- \( p_{it} \): Probability of patient \( i \) being diagnosed KP, considered for DDS services, or considered for an ASD evaluation in KP \( r \) in year \( t \)
- \( D_{it} \): Parent influence measure
- \( X_{it} \): Vector of controls, including patient covariates
- \( \alpha, \beta, \gamma \): Parameters to be estimated; \( \beta \) measures the effect of social influence \( \alpha \) is the constant, \( g \) is the vector of control variable coefficients

Analysis of DDS data

Event history models with the same covariates will be used to predict outcomes in the DDS and Kaiser Permanente diagnostic processes. Table 10 lists the results of analysis on ASD diagnosis in the California DDS using the first spatially-based measure of parent influence. Model 1 is the baseline model for the diagnostic process overall (both stages) and many of the variables that are expected to influence diagnosis are significant. Children with health care providers more experienced with ASD are more likely to be diagnosed in the DDS system. Males are 4.3 times more likely than females of being diagnosed. Race does not seem to be an influential factor. Paternal education is associated with a

the Early Start program is substantially lower and, unlike the normal DDS services mandated by the Lanterman Act, does not require a medical diagnosis. Early Start only requires that children are developmentally delayed without regard to the medical causes of those delays. Children entering DDS in the Early Start program are re-evaluated at the age of three for eligibility for Lanterman Act mandated services.
higher likelihood of diagnosis, as is increased maternal age. Model 2 adds a parent influence measure (measure one) to Model 1. The odds-ratio of the key independent variable parent influence is 1.156 and significant. The coefficients of the other variables change very little from Model 1 to Model 2 with the exception of population density; this is consistent with intuition that population density is correlated with parent influence and the fact that the coefficient of population density changes increases confidence in the spatially-based measure of parent influence.

Model 3 estimates the log-odds of initial suspicion while Model 4 estimates the log-odds of formal diagnosis. The odds-ratio of parent influence is 1.071 in Model 3 (p < 0.001) and is 0.939 (p < 0.05) in Model 4. This suggests that parents have some degree of impact at the first stage of diagnosis in the California DDS system. The odds-ratio less than one in the second stage suggests that children with higher levels of parent influence and who make it past the first stage will actually have lower odds of being formally diagnosed. Similarly, the odds-ratios of the race variables - Asian, Black, and Hispanic - are significantly less than 1 in Model 3 but significantly greater than 1 in Model 4. In conjunction with the largely non-significant odds-ratios in Model 2, this suggests that these minorities are just as likely to be diagnosed overall (controlling for other factors) but suffer from a disadvantage in initial screening. The fact that they are more likely to be diagnosed in the second stage is suggests that the non-White children who do make it beyond the first stage, may have more severe ASD symptomology.
Table 10: Event history analysis results of California DDS

<table>
<thead>
<tr>
<th></th>
<th>Discrete time event history (logit) models</th>
<th>Diagnostic outcomes in California DDS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Model 1: Both stages (baseline)</td>
<td>Model 2: Both stages</td>
</tr>
<tr>
<td>Parent influence</td>
<td>1.156***</td>
<td>1.071***</td>
</tr>
<tr>
<td>(measure 1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ASD experience</td>
<td>1.009***</td>
<td>1.009***</td>
</tr>
<tr>
<td>Age</td>
<td>1.107***</td>
<td>1.107***</td>
</tr>
<tr>
<td>Male</td>
<td>4.321***</td>
<td>4.318***</td>
</tr>
<tr>
<td>Race - asian</td>
<td>1.027</td>
<td>1.004</td>
</tr>
<tr>
<td>Race - black</td>
<td>1.233+</td>
<td>1.205</td>
</tr>
<tr>
<td>Race - hispanic</td>
<td>0.944</td>
<td>0.932</td>
</tr>
<tr>
<td>Race - other</td>
<td>0.976</td>
<td>0.962</td>
</tr>
<tr>
<td>Population density (ln)</td>
<td>0.980</td>
<td>0.943*</td>
</tr>
<tr>
<td>Age - Father</td>
<td>1.011</td>
<td>1.011</td>
</tr>
<tr>
<td>Age - Mother</td>
<td>1.023**</td>
<td>1.023**</td>
</tr>
<tr>
<td>Educ - Father (1-7)</td>
<td>1.085**</td>
<td>1.084**</td>
</tr>
<tr>
<td>Educ - Mother (1-7)</td>
<td>1.010</td>
<td>1.012</td>
</tr>
<tr>
<td>Median Income</td>
<td>0.997*</td>
<td>0.997*</td>
</tr>
<tr>
<td>Year FE</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Constant</td>
<td>0.0001***</td>
<td>0.0001***</td>
</tr>
<tr>
<td>N (person-years)</td>
<td>1410735</td>
<td>1410735</td>
</tr>
<tr>
<td>log-likelihood</td>
<td>-7130.18</td>
<td>-7119.91</td>
</tr>
</tbody>
</table>

***p<0.001 **p<0.01, *p<0.05, +p<0.1

Assessing parent influence across both stages using multiple measures

Because measurement of parent influence is challenging, my strategy was to use multiple measures and interpret regression results as a coherent whole. Table 11 (Panel A) summarizes the influence measures from many separate regression analyses of diagnosis in the California DDS. Overall, it appears that parents have a clear impact in diagnosis overall, and in the initial suspicion stage, but it is not clear whether they have influence in formal diagnosis stage.
The second measure of parent influence like the first measure was spatially-based but was constructed in a slightly different way. In regression models using measure two, *parent influence* is found to be marginally significant in diagnosis overall (both stages), which is consistent with prior research as well as the results from measure one. When parsing the diagnostic process into both stages, these models indicate parent influence at *initial suspicion* as well as in *formal diagnosis*.

**Table 11: Parent influence across both stages of ASD diagnosis**

**Panel A:**

<table>
<thead>
<tr>
<th>Measure</th>
<th>Diagnostic outcomes in California DDS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Both stages</td>
</tr>
<tr>
<td>1: −ln(dijt−1)</td>
<td>1.156***</td>
</tr>
<tr>
<td>2: Σj(1/(1+ditj−1))</td>
<td>1.008+</td>
</tr>
<tr>
<td>3a: Asian</td>
<td>1.027</td>
</tr>
<tr>
<td>3b: Black</td>
<td>1.233+</td>
</tr>
<tr>
<td>3c: Hispanic</td>
<td>0.944</td>
</tr>
</tbody>
</table>

**Panel B:**

<table>
<thead>
<tr>
<th>Measure</th>
<th>Diagnostic outcomes in KPNC</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Both stages</td>
</tr>
<tr>
<td>1: −ln(dijt−1)</td>
<td>1.218***</td>
</tr>
<tr>
<td>2: Σj(1/(1+ditj−1))</td>
<td>1.008+</td>
</tr>
<tr>
<td>3a: Asian</td>
<td>1.027</td>
</tr>
<tr>
<td>3b: Black</td>
<td>1.233+</td>
</tr>
<tr>
<td>3c: Hispanic</td>
<td>0.944</td>
</tr>
</tbody>
</table>

***p<0.001 **p<0.01, *p<0.05, +p<0.1
Regression models using Asian, Black, and Hispanic indicator variables without the spatially-based measures of parent influence indicate similar findings as those in Table 10. In diagnosis overall, race seems to make only a marginal difference. Provocatively, however, Asians, Blacks and Hispanics are less likely to be initially suspected of ASD but, conditional upon being suspected, were more likely to be formally diagnosed. What appears to be little to no difference across race belies striking differences once the process is parsed into qualitatively different stages.

Assessing parent influence in the California DDS and KPNC

Panels A and B of Table 11 summarizes the results of regression models in both the California DDS and KPNC. The results estimating the KPNC outcomes are generally those estimating outcomes in the California DSS. Using measure one, the odd-ratios for parent influence are greater than one and significant for diagnosis overall and initial suspicion, but not for formal diagnosis. As in the California DDS, the odds-ratio for parent influence in formal diagnosis is less than one. Similarly, race does not seem to be strong factor in the diagnosis overall, with Asians having lower odds of diagnosis relative to Whites, and neither Blacks nor Hispanics being different from Whites. At initial suspicion, all three non-White categories have odds-ratios less than one and, at formal diagnosis, odds ratios greater than one.

The pattern of results across stages of diagnosis are slightly different using measure two. In KPNC, the odds-ratio in formal diagnosis is not significantly different from one, but in the California DDS, the odds-ratio is still greater than one. By contrast, measure one and the race indicators exhibit a consistent pattern across stages of diagnosis and across diagnostic institutions. This finding indicates that in the California DDS, parents may indeed have some impact over the formal diagnosis stage and suggests the possibility that parents interact with KPNC and the California DDS differently. Further evidence of difference is also shown in the next part of the analysis.
Assessing parent influence across the patient sample in the California DDS and KPNC

Finally, I assess the uniformity of parent influence across the full sample. I first explore the distribution of parent influence by estimating regression models in which I remove the parent influence measure and substitute indicator variables of parent influence by decile. This essentially uses a step-function of parent influence rather than a smooth continuous measure of patient influence. If parent influence is fairly uniform, then we should expect the odds-ratios of the highest deciles to be the highest, followed by the odds-ratios of the second highest deciles, etc. If parent influence is not uniform, then we should expect to see the odds-ratios of most deciles to be near 1 and the odds-ratios of the influential deciles to be far from 1.

Table 12 lists the coefficients of decile indicators in regression models the California DDS and KPNC based on measure one. Across both, the top decile indicator variable is highly significant and exhibits the same pattern of odds-ratios greater than 1 in diagnosis overall and in initial suspicion, but less than 1 in formal diagnosis. A difference emerges outside the top decile. In KPNC, the odds-ratios of other deciles are not noticeably different from one, but in the California DDS, the odds-ratios of the lowest deciles appear to be less than one and the odds-ratio of the lowest decile is statistically significant.

This finding is confirmed using regression models in which I estimate parent influence on subsets of the full sample (Table 13). Including both the continuous measure one of parent influence First, I estimate the regression model in only the top quartile of patients by parent influence and find the pattern of odds-ratios to be the same as in the full sample. However, when I estimate the regression models excluding the top quartile, the pattern of odds-ratios looks substantially different. In KPNC, parent influence is only marginally significant in diagnosis overall and is not significant in initial suspicion and in formal diagnosis. In the California DDS, parent influence is significant in diagnosis overall and in formal diagnosis, but not in initial suspicion. These results suggest that parents are influential in KPNC only at the upper end of the distribution, i.e., parent influence matters only among the most influential.
parents. In the California DDS, patients are influential across the full distribution of parents, but the pattern of influence is different across the distribution of patients.

**Table 12: Parent influence across the patient sample**

<table>
<thead>
<tr>
<th>Decile</th>
<th>KPNC Both stages</th>
<th>Initial Suspicion</th>
<th>Formal diagnosis</th>
<th>California DDS Both stages</th>
<th>Initial Suspicion</th>
<th>Formal diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>10</td>
<td>1.625***</td>
<td>1.515***</td>
<td>0.707***</td>
<td>1.264*</td>
<td>1.193**</td>
<td>0.730**</td>
</tr>
<tr>
<td>9</td>
<td>0.903</td>
<td>1.007</td>
<td>0.959</td>
<td>0.759*</td>
<td>0.995</td>
<td>0.813</td>
</tr>
<tr>
<td>8</td>
<td>0.981</td>
<td>0.990</td>
<td>0.978</td>
<td>1.002</td>
<td>0.928</td>
<td>0.988</td>
</tr>
<tr>
<td>7</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>6</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>5</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>4</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>3</td>
<td>1.045</td>
<td>1.044</td>
<td>1.023</td>
<td>0.952</td>
<td>1.061</td>
<td>0.976</td>
</tr>
<tr>
<td>2</td>
<td>0.908</td>
<td>0.990</td>
<td>0.968</td>
<td>0.852</td>
<td>0.973</td>
<td>0.825</td>
</tr>
<tr>
<td>1</td>
<td>0.923</td>
<td>1.019</td>
<td>0.973</td>
<td>0.638*</td>
<td>0.967</td>
<td>0.677*</td>
</tr>
</tbody>
</table>

***p<0.001, **p<0.01, *p<0.05, +p<0.1

**Table 13: Parent influence in the top quartile of the patient sample**

<table>
<thead>
<tr>
<th>Quartile</th>
<th>KPNC Both stages</th>
<th>Initial Suspicion</th>
<th>Formal diagnosis</th>
<th>California DDS Both stages</th>
<th>Initial Suspicion</th>
<th>Formal diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>All</td>
<td>1.218***</td>
<td>1.153***</td>
<td>0.908***</td>
<td>1.156***</td>
<td>1.071***</td>
<td>0.937*</td>
</tr>
<tr>
<td>4th</td>
<td>1.444*</td>
<td>1.315***</td>
<td>0.829***</td>
<td>1.247***</td>
<td>1.172***</td>
<td>0.804***</td>
</tr>
<tr>
<td>1st-3rd</td>
<td>1.079+</td>
<td>0.987</td>
<td>1.063</td>
<td>1.292***</td>
<td>1.047</td>
<td>1.264**</td>
</tr>
</tbody>
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***p<0.001, **p<0.01, *p<0.05, +p<0.1
Discussion

The empirical findings suggest three conclusions. First, based on regression models run at different stages of the diagnostic process, it seems that patient influence is weaker in the second stage of diagnosis. Second, based on regression models run after splitting patients into quartiles and deciles, it seems that arguments in favor of patient influence do not apply across a wide distribution of parents. Third, based on regression models of diagnosis in KPNC and the California DDS, it seems that the strength of patient influence varies by institutional context. These three findings highlight new insights – specifically new boundary conditions – on patient influence across medical conditions and medical institutions.

Differential parent influence across diagnostic stages

Patients may have less impact in later stages of diagnosis because they increasingly deal with more specialized health care providers. Yet by contrast, almost all studies of patient influence in medical decisions focus on the general practitioner. My findings suggest it worthwhile to consider the differences between specialists and generalists to understand why generalists appear to be more receptive to patient influence.

Generalists operate under greater number of institutional constraints than specialists. Specialists are trained consider a wide range of information sources, based on specialized knowledge, which reducing the relative weight of patient testimony. In the case of ASD, specialists rely on a number of in-depth psychological instruments and direct observation of the child, and must be very careful in differentiating ASD from other child psychiatric disorders such as intellectual disability or oppositional-defiant disorder. Generalist pediatricians by contrast are highly time-constrained in a well-child visit, must attend to a wide range of potential health problems, and at best have only time to consult with high-level ASD diagnostic guides (e.g., Diagnostic Statistical Manual of Mental Disorders (DSM) or the Modified Checklist for Autism in Toddlers questionnaire). When the objective is to attend to a wide
range of potential medical conditions, the evidence for any one condition is consequently sparse and patient testimony comprises a larger proportion of evidence.

The different nature of generalist and specialist responsibilities may also play a role. A generalist pediatrician serves as the patient’s gateway into the medical system and therefore failing to suspect ASD could stymie an entire line of medical inquiry. This may be detrimental to patients’ health outcomes, depending on optimal balance of Type I and Type II error, but may also damage the doctor-patient relationship. A health doctor-patient relationship helps to maintain open lines of communication and can help the doctor identify potential health problems earlier. Moreover, some doctors even consider it ethical to permit the patient to have a level of control over his or her own care. These considerations are less important to the specialist because the specialist’s role is to evaluate the patient for a particular set of conditions like ASD. If they do not make a diagnosis, they can suggest visits to another type of specialist (e.g. an audiologist) or leave it to the generalist to decide the next step.

Future work might focus on the distinction between generalists and specialists, and might even focus on identifying the underlying mechanisms driving the difference between generalists and specialists. For instance, if the difference is about knowledge, then this could be investigated comparing the diagnosis of ASD to other child psychiatric diagnoses such as Attention Deficit/Hyperactivity Disorder (ADHD) which are simpler to diagnose. In the case of ADHD, there are fewer disorders with overlapping symptomology making the differential diagnosis easier; generalist pediatricians are likely more comfortable diagnosing ADHD themselves and forgo a consultation with a specialist.

**Differential patient influence across the full sample**

The overall finding is that patient influence is likely driven by a subset of patients who may be more motivated, more knowledgeable, or both. By contrast, there have been few large-scale studies of patient influence in medical decision making; most have been either ethnographic in nature, or have been survey-based and focused on relatively small number of physicians. My analysis of complete birth
cohorts in a very large health maintenance organization allows me to examine variation across a much broader population and identify new insights. In particular, prior research on parent influence in the diagnosis of ASD may have overlooked the possibility that their results reflect the disproportionate impact of a minority of parents, rather than a fairly uniform impact across the population of parents. More generally, my findings confirm the existence warrior parents, but suggest that most parents may not be “warriors.”

**Differential parent influence across institutions**

My results shows that the extent of patient influence may vary by institutional context. This is perhaps the most exciting result as well as the most provisional. The distinction between the California DDS and KPNC provides leverage for unpacking the motivations of the warrior parent. On one hand, previous studies have suggested that parents may be agnostic to the precise diagnosis, so long as the patient is offered services that will help him or her. This is consistent with model of patients implicit in research concerned over the direct-to-consumer marketing of pharmaceuticals. In an idealized sense, patients assume the role of consumers, who know what is best for them and who are willing to seek out what they consider appropriate. On the other hand, patients may simply be seeking a legitimate account of their problems, a way to render them meaningful, and a productive direction in which to focus coping and treatment efforts (Broom and Woodward 1996). Often, these two motives go hand-in-hand as patients seek medical help.

However, the California DDS and KPNC vary in the magnitude of services available to children diagnosed with autism. The DDS is not a healthcare organization, yet serves an important role in helping individuals with disabilities to participate in society. This is achieved through the provision of services, which are free of charge to those individuals who qualify. From the perspective of a patient, the California DDS is a source of concrete material benefit which that can pursue in parallel with a medical consultation. KPNC is a healthcare organization and, as such, appeals to parents seeking insight and alleviation of uncertainty. During the study period, however, KPNC offered minimal treatments for
ASD\textsuperscript{47} (instead referring parents to the DDS or to their school district) and thus appealed less strongly to parents seeking material resources for the management of ASD.

Using this theoretical lens, the differences in parent influence coefficients across the patient sample and between KPNC and the California DDS are provocative. It would seem that when the incentive is primarily material (i.e., in the DDS), a larger portion of the population exhibits patient influence but, when the incentive is less material (i.e., in KPNC), it is only a small minority that exhibits patient influence.

Further work is necessary to support this interpretation. One issue that must be addressed is role of \textit{motivation} and \textit{capability} as independent concepts embedded in patient influence. It is possible that all parents in my data were \textit{motivated} to pursue a diagnosis of ASD, but most of them lacked the \textit{ability} to influence the health care professionals in the DDS or KPNC. Alternatively, it is possible that only a minority of parents were even \textit{motivated} to pursue a diagnosis and therefore only a few parents even tried. The notion of capability also raises yet another interpretation: it might be about health care providers - not patients - who were less susceptible to influence attempts at KPNC than at the DDS.

More work is also required to conceptualize and measure parent influence. The measure in my analyses extended the spatially-based approach of previous work; while it is probably reasonable, it is not ideal. Textual-analysis and machine-learning could be applied to doctors' notes as a means of better characterizing and better measuring parent influence, or at least validating the spatially-based measure. Another issue is the functional form assumption of how influence varies over distance. Parent influence should almost certainly be monotone decreasing in distance, but little is known beyond that. Again, while the approach taken here is reasonable, it is likely not ideal and this may have implications for the way the distribution parent influence across the sample is interpreted.

\textsuperscript{47}At KPNC, services included case management and medication, but not the hands-on therapies widely considered essential for the treatment of ASD such as Applied Behavioral Analysis.
Conclusion

This paper is among the first to conduct a large-scale study of patient influence in medical decision making. Findings from this empirical setting are consistent with prior research in identifying patient influence in medical diagnosis, but illustrate several new boundary conditions. First, based on regression models run at different stages of the diagnostic process, it seems that patient influence diminishes in the second stage of diagnosis. Second, based on regression models run after splitting patients into deciles and quartiles, it seems that arguments in favor of patient influence do not apply across a wide distribution of parent. Third, based on regression models of diagnosis in two health-related institutions, it seems that the strength of patient influence varies by institutionalized structure of benefits offered. To wit, warrior parents are real, but they represent only a fraction of the population and the magnitude of a warrior parent’s impact varies by the knowledge and role of the health care provider, and by the level of material resources at stake.
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Appendix

A.1. Assessing the selection problem in regression models

It is worthwhile at this point to discuss one possible issue with this analysis: selection. It is well-known that fixed effects analysis can be undermined by the presence of selection (Ashenfelter and Card 1985). While clinics cannot pick and choose patients, patients have some latitude to select a clinic; patients are automatically referred to a clinic based on catchment area, but Allied would honor a specific patient request to go to a different clinic. Although much of the within-pediatric office variation comes from organizational changes to the catchment area, some may be driven by parent requests. This section assesses the magnitude of this problem and argues that this is ultimately a minor issue.

First, there are reasons to believe patient-driven selection is not common. The distance between centers (about two hours apart) makes it impractical for parents. Two hours may not seem very problematic for most people, but it is more difficult for parents who have a child with behavioral problems. It might also be possible to get some estimate of the number requesting particular clinics by looking at the number of patients who seek second opinions from another clinic. Of the 3112 patients seen at the clinic, 819 are seen at least one more time and only 53 patients (6.5%) go to a different clinic. Of the 53, up to 30 may be because the alternate clinic was not open at the time of the visit to the first clinic. If switching clinics is uncommon, then requesting a different clinic at initial referral is likely to be just as uncommon and almost certainly would not be frequent enough to drive a roughly 30% difference between the clinics.

The second reason selection is a minor issue is that, even if it did occur, the direction of bias is unclear and bias would rely on fairly strong assumptions about parents. It is unclear whether parents seek out or avoid ASD diagnoses. On one hand, government and school services are available to children with autism, giving parents some incentive for a positive diagnosis. On the other hand, autism carries life-long consequences for the family, and parents may defend and normalize their children’s behavior as
long as possible. Systematic bias requires a belief one way or the other by parents. Because it is unclear how many parents seek out a diagnosis, how many avoid a diagnosis and how many are neutral, it is unclear how parent selection would result in bias.

Even if we are willing to assume parents systematically seek (or avoid) an ASD diagnosis, other assumptions about parents are still necessary. Selection is only a problem when it changes characteristics of the treatment group and these characteristics are associated with the outcome variable, e.g., in estimating the economic returns to schooling, individuals with higher “ability” tend to choose more schooling. For it to be a problem here, we would have to be willing to make several assumptions about parents, without which there would be no bias. First, we would have to assume that enough parents have knowledge of each clinic’s reputation. If we do not assume this, then there can be no bias from parent preferences. Second, we would have to assume that enough parents have some estimate of their child’s likelihood of having ASD. If we do not assume this, then selection is essentially random with respect to ASD risk, i.e., high and low risk parents are going out of catchment area, leading to no net change in the clinic probability of ASD; there is no bias from parent preferences.

Even if we are willing to make the first two assumptions, then bias still depends on a third assumption, that parents’ decisions to seek (or avoid) an ASD diagnosis is correlated with their ASD risk estimate. If parents seek or avoid an ASD diagnosis but this is not correlated to their ASD risk estimate, then selection is also essentially random with respect to ASD risk. Even if it is correlated, then it must be correlated in a particular way. Parents seeking a diagnosis must be more inclined to choose Alpha when ASD risk is high (or parents avoiding a diagnosis must be inclined to choose Charlie when ASD risk is low). More likely, the opposite is true. Parents seeking a diagnosis will be more inclined to choose Alpha when ASD risk is low because it is when ASD risk is low when choosing Alpha confers the greatest benefit (or parents avoiding a diagnosis will be more inclined to choose Charlie when ASD risk is high because it is when ASD risk is high that choosing Charlie confers the greatest benefit). When the opposite is true, parent selection actually works against the regression results.
A.2. **The diagnostic process at Allied Health**

Autism is characterized by impairments in three general areas: impairments in social interaction, impairments in communication, and repetitive and stereotyped behavior. The DSM lays out four criteria for each area and requires patients meet a threshold number of criteria. At Allied, clinicians describe their work as first attempting to develop a complete picture of the child’s history and pattern of development, before reviewing and making a diagnosis based on the DSM-IV-TR criteria. Over one or more full days at the clinic, health care providers conduct a series of psychological tests (including the ADOS), interview the parent or guardian, and review the responses from standardized questionnaires as well as the patient’s medical and psychiatric history. A fairly typical set of psychological tests would include a speech test (e.g. Preschool Language Scales, Fifth Edition), an adaptive skills test (e.g. Adaptive Behavior Assessment System, Second Edition), a cognitive test (e.g. Mullen Scales of Early Learning), and an autism specific test (i.e. the ADOS). Standardized questionnaires would be completed beforehand and include the Child Behavior Checklist (completed by a parent) and the Teacher’s Report Form (completed by a teacher). The parent interview would be structured based on the Autism Diagnosis Interview (ADI-R) instrument.

After these data are collected, clinicians working in teams of two or more discuss the findings from each instrument and create a profile of the patient’s deficiencies and strengths. They then walk through each of the DSM criteria and make a diagnosis.

A.3. **Robustness check: senior clinicians and the movers**

One may worry that the new lower diagnostic rate of the moving clinicians may have been driven by coercion by not just the founding director but all senior clinicians. Although they joined Charlie when it was first started, there were three clinicians who had worked together in an informal mini-clinic. Consistent with the master-apprentice model of training at Charlie, they were treated as junior members
of the evaluation team and were almost always paired with a senior clinician, i.e., a clinician who had worked at the informal mini-clinic that was a precursor to Charlie. Therefore, the drop in diagnostic rates could just as easily be explained as the senior clinicians trumping junior clinicians.

However, Charlie clinic continued to hire new clinicians and senior clinicians participated on a smaller share of evaluations (See Figure 10). Even as the percentage of evaluations conducted with senior clinicians declined, the rates of diagnosis remained stable. It appears that the clinical judgment of the movers remained stable even as they were conducting evaluations with each other or newly hired clinicians. Figure 11 confirms this by showing that the rates of ASD diagnosis both working with and without senior clinicians remained the same. The overall interpretation is that movers’ informal rules for diagnosis changed once they moved to Charlie and, while it may have been though pressure from senior clinicians at the beginning (e.g., through dominance, persuasion, teaching, etc.), a new stable set of informal rules was established and drove consistent ASD diagnosis thereafter.

**Figure 11: Probability of diagnosing ASD for the “movers” with and without senior clinicians**

Note: 95% confidence bands shown.
A.4. Two alternative interpretations - institutional logics and translation

It is worth considering two other scholarly perspectives – besides resistance and customization – that might offer an alternative interpretation of the research findings. Some scholars might contend that the observed pattern could be explained by a translation interpretation. This interpretation highlights the socially constructed nature of adoption and contends that institutionalized meanings simply do not diffuse, but are actively reshaped by local actors (Czarniawska-Joerges and Sevón 2005; Sahlin-Andersson 1996; Zilber 2006). Actors construct idiosyncratic problems, solutions and rationalized myths which then drive adaptation. This interpretation is not incorrect but my explanation is more precise in identifying the role of imprints in the way the adaptation is enacted and the way that new practices come to exhibit persistence over time.

According to an institutional logics approach, variation in practices may be a consequence of overlapping and conflicting institutional orders (Friedland and Alford 1991; Greenwood, Raynard, Kodeih, Micelotta, and Lounsbury 2011). When multiple logics apply to a single organization, actors have latitude in choosing a justifiable response (McPherson and Sauder 2013). An institutional logics interpretation of ASD diagnosis at Allied might be that tension between conflicting institutions is resolved differently across clinics. However, it is not apparent what those conflicting institutions might be. There are certainly different approaches to the diagnosis of autism at the clinics, which reflect long-standing debates in medicine. Perhaps this part of the allied story could be explained in terms of the medical logics of science and care (Dunn and Jones 2010) along with a logic of professions (Thornton and Ocasio 1999), but such an account would still ultimately require an explanation for why logics were resolved differently across clinics and how the differences remained stable over time.