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# **Risk as Social Context: Immigration Policy and Autism in** California<sup>\*</sup>

#### Christine Fountain and Peter Bearman

Paul F. Lazarsfeld Center for the Social Sciences, Columbia University

# Abstract

Motivated by the dramatic increase in autism diagnoses in recent years, research into risk factors has uncovered substantial variation in autism prevalence by race/ethnicity, SES, and geography. Less studied is the connection between autism diagnosis rates and the social and political context. In this article, we link the temporal pattern of autism diagnosis for Hispanic children in California to state and federal anti-immigrant policy, particularly ballot initiative Proposition 187, limiting access to public services for undocumented immigrants and their families. Using a population-level dataset of 1992–2003 California births linked to 1992–2006 autism case records, we show that the effects of state and federal policies toward immigrants are visible in the rise and fall of autism risk over time. The common epidemiological practice of estimating risk on pooled samples is thereby shown to obscure patterns and mis-estimate effect sizes. Finally, we illustrate how spatial variation in Hispanic autism rates reflects differential vulnerability to these policies. This study reveals not only the spillover effects of immigration policy on children's health, but also the hazards of treating individual attributes like ethnicity as risk factors without regard to the social and political environments that give them salience.

#### Keywords

Autism; Immigration Policy; Hispanic/Latino; Social Epidemiology

# INTRODUCTION

The process by which autism is identified and diagnosed has changed over the past three decades. Public awareness of autism has increased, and the stigma associated with autism – arising from the mistaken belief that autism was a psychogenic disorder – has decreased. Against this background, autism prevalence has risen dramatically, if unevenly. In this article we show how attitudes and social policies toward immigrants contribute to the uneven diagnosis of autism among Hispanics. Specifically, we consider how immigration policy has significant spillover effects on health outcomes such that Hispanic children experiencing a wave of legislation putatively designed to control state budgets or combat terrorism turn out to be disadvantaged with respect to service access. This has implications for our understanding of risk, risk factors, and the proper identification of the drivers of increased autism prevalence.

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Address all correspondence to Christine Fountain (cf2337@columbia.edu) or Peter S. Bearman, (psb17@columbia.edu), Paul F. Lazarsfeld Center for the Social Sciences, CB3355, Columbia University.

There is a robust body of work in medical sociology and social epidemiology that has identified the role of social conditions in shaping health and health outcomes (Link and Phelan 1995; Marmot et al. 1997; Ross and Wu 1995; Williams and Collins 1995). Researchers repeatedly observe a socioeconomic gradient for health, such that morbidity and mortality are higher for the disadvantaged, across a wide variety of outcomes. This relationship is seen to arise from multiple overlapping causal mechanisms, including the environment, access to health care, treatment disparities, and health behaviors. The "fundamental cause" argument in sociology posits that social conditions are not mere proxies for direct causes, such as nutrition and health behavior, but are fundamental, if distal, causes of these intervening variables as well as health outcomes (Link and Phelan 1995).

Autism, a developmental disorder characterized by deficits of social interaction, communication, and repetitive behavior (and/or restricted interests), appears to provide a counter case, as not only are diagnoses increasing at a remarkable pace but the socioeconomic gradient has historically been reversed: autism is more common among children with educated parents, living in wealthier areas, and among non-Hispanic whites (King and Bearman 2010). The reason for this peculiar pattern, however, lies in the distinction between autism and the diagnosis of autism. Diagnoses for autism have increased rapidly in recent decades, and although the relative contribution of increased ascertainment versus increased incidence is contested (Rutter 2005; Fombonne 2001), at least some of the increase in measured prevalence (now reported to be nearly 1 in 100 [ADDMN 2009]) is due to changes in the diagnostic process. Several processes are at play simultaneously. First, diagnostic criteria for autism have changed, becoming broader and therefore including more children. Specifically, about a quarter of the increase in California is attributable to diagnoses among those who in previous years would have received diagnoses of mental retardation (King and Bearman 2009). Second, screening for young children is becoming a standard part of pediatric care, thus exposing more children to the opportunity for ascertainment (Johnson et al. 2007). Third, as autism has become more prevalent it has also become more visible, and so parents, teachers, caregivers, and physicians are more likely to recognize it (Liu et al. 2010).

Several studies have shown racial and ethnic variation in autism rates (ADDMN 2007; Liptak et al. 2008; Centers for Disease Control and Prevention 2006; Mandell et al. 2009; Shattuck et al. 2009). Although it is possible that racial and/or ethnic groups have differential risk of autism due to variations in allele frequency there is no current evidence for this. Rather, most researchers consider race and ethnicity to be a proxy for other socioeconomic variables, including wealth and income, education, and culture (Burchard et al. 2003; Link et al. 1998).

There are many candidate theories as to the cause of autism, with varying degrees of scientific support, including genetic expression (Freitag 2006), older parents (King et al. 2009), *de novo* mutations (Liu et al. 2010), toxicants (Roberts et al. 2007; Lawler et al. 2004), vaccines (Parker et al. 2004), pregnancy and birth complications (Croen et al. 2002; Hultman et al. 2002), and of course television (Waldman et al. 2008). There is no consensus – autism is a heterogeneous disorder with what are likely multiple, sometimes interacting, causes. We are agnostic as to the biological cause(s) of autism. Instead, we focus on administrative prevalence in a population-level database of autism diagnoses in order to show how social policies can influence diagnosis and therefore our understanding and expectations about risk factors.

Autism is a spectrum disorder with a wide range of symptom presentations that can sometimes overlap with other developmental disabilities and communication disorders.

There is no biomarker, so diagnoses are made solely on the basis of behavioral expression, typically at an early pre-school age. This provides a clue to the logic of the reverse socioeconomic gradient. An autism diagnosis requires two main ingredients: a child with developmental symptoms consistent with autism, and the knowledge, resources and incentives to negotiate the diagnostic process. In this article, we show one way in which autism may be unevenly ascertained as a result of social policies that induce differential access to the diagnostic machinery.

Because having a child with autism is enormously challenging there are strong incentives to obtain a diagnosis. Many states require that insurance companies cover behavioral services for people with autism; autism is included under the Individuals with Disabilities Education Act (IDEA) that mandates publicly funded special education services; and many states provide developmental services directly to children and families with autism. California, where our data were collected, provides free services to children with autism through its Department of Developmental Services. Thus, for a family with a child manifesting autistic symptoms, diagnosis provides access to publicly funded services which can otherwise be quite expensive, and which may not be available for other psychiatric or behavioral disorders. To the extent that some children with autism symptoms are less able to acquire a diagnosis, they will also have less access to treatment.

Prevalence rates for populations can differ because of actual differences in the prevalence of a condition, or because of differences in the rate at which the condition is diagnosed. In this article, we provide evidence that autism was systematically under-diagnosed among Hispanic children born in 1990s California, in part because of the effects of the ballot initiative Proposition 187 (hereafter, Prop 187) and other anti-immigrant legislation. The pattern of under-diagnosis, relative to non-Hispanic white children, is particularly informative: it rises and falls in concert with changes in the political climate with respect to immigration. Although these policy changes were aimed at enforcing immigration rules and keeping undocumented immigrants from using public services, their effect in this case was to discourage some families of citizen children from seeking diagnosis of and services for their developmental disabilities.

Along the way we show that estimating risk on samples pooled over time, a common practice in epidemiological research, ignores the impact of history and social policy and is thus deeply problematic. This is particularly relevant in the case of a disorder such as autism, for which the diagnostic criteria and frequency have changed so rapidly and markedly. In such cases, pooling disparate temporal samples can result in a sample that represents no population, yields misleading risk estimates, masks consequential social, demographic, and epidemiological changes and leads researchers to believe a risk factor exists when it does not (or to miss one that may be important). Further, the concept of a "risk factor" as an attribute of individuals, separable not only from other individual attributes but from social and historical context, is called into question.

We illustrate this problem using a large data set on the population of births in California between 1992 and 2003, linked to autism case records from the Department of Developmental Services (DDS) from 1992 to 2006. The size of this data structure, collected over a period in which the autism caseload increased by 598%, allows us to observe the consequences of failing to take time seriously when estimating risk. Focusing on the changing pattern of risk of autism for Hispanic children, we show a spike and subsequent decline in risk of being diagnosed with autism. Observation of this temporal patterning of risk would have been muted by an analysis strategy that pooled across cohorts, yet the temporal pattern we observe tells us about the drivers of risk – in particular how relative rates of autism diagnosis for Hispanic children change in response to the political

environment in which they lived. We link autism risk for Hispanics to legislation on immigration and social services that occurred in California during this period, particularly Prop 187, which restricted access to public services for undocumented immigrants and their children. Observing such a strong relationship between social policy regimes and "risk" suggests that much of our thinking about risk factors – as developed within the epidemiological literature – is problematic.

#### Roadmap

We first review the research on racial and ethnic disparities in diagnosis for autism, with a special focus on Hispanic children. Next, we describe Proposition 187 and other legislative developments pertinent to immigrants and their families in California during the 1990s and early 2000s, and explain the connection between immigration policy and service utilization by families of mixed immigration status. Then, we elucidate the role for sociological thinking – about social conditions as well as about time – in epidemiological problems. We show how autism prevalence among Hispanic birth cohorts has fluctuated along with changes in immigration policy, and how in particular two policies – Prop 187 and the post-9/11 transfer of immigration enforcement to the department of Homeland Security – sharply shifted the odds of diagnosis for Hispanic children of immigrant mothers relative to White children of native-born mothers. We also illustrate spatially how these policies shifted the geographic variation in and concentration of autism births. Finally, we discuss the implications of these results for understanding the unintended consequences of social policy and the practice of social epidemiological research.

# BACKGROUND

#### Autism among Hispanics in the US and California

National surveys such as the National Survey of Child Health (NSCH) and the National Health Interview Survey (NHIS) show that Hispanics have lower rates of self-reported autism, although they report more severe symptoms (Centers for Disease Control and Prevention 2006; Liptak et al. 2008) Similarly, evidence from the Centers for Disease Control and Prevention's Autism and Developmental Disabilities Monitoring Network (ADDMN) shows that for the 1994 birth cohort, autism prevalence was lower for Hispanics than for non-Hispanic whites (Mandell et al. 2009; ADDMN 2007). This same data set shows that Hispanics tend to be diagnosed at slightly older ages (Shattuck et al. 2009). School districts with higher percentages of Hispanic students have fewer autism diagnoses (Palmer et al. 2009).

Most scholars argue that where observed, the lower risk to Hispanic children is due to under-diagnosis (Centers for Disease Control and Prevention 2006) in part arising from limited access to health care. NSCH data show that Latinos, along with Blacks and the poor, are disadvantaged in access to health care (Liptak et al. 2008), although access to public programs like Medicaid or SCHIP mitigates this disadvantage. Under-diagnosis may also stem from lower utilization of medical and mental health services by Latinos, even when access is available. The process of seeking help for a health condition can be complex, and highly constrained by institutional and social structures (Pescosolido 1992). Minority and poor families may wait longer than others to seek care and can have an especially difficult time obtaining a specialist referral (Liptak et al. 2008). Finally, the challenges associated with obtaining quality health care for poor families can be exacerbated for the Spanishspeaking by language and/or cultural barriers. These can include differences in developmental expectations, uncertainty about language delays for bilingual children, and a preference for keeping private problems inside the family (Liptak et al. 2008; Overton et al. 2007). For immigrant families, these issues may be particularly acute (Portes et al. 2009). Hispanics appear to have lower autism prevalence nationwide and this pattern holds in California, where Hispanic mothers account for more than half of all births (Center for Health Statistics 2007). However, pooling observations across all available years and adjusting for demographic attributes (especially education) and known risk factors for autism, the risk of autism among Hispanics is *higher* than for non-Hispanic whites1. This would suggest – and has led scholars to assume – that Hispanics are at greater risk for autism as a consequence of unmeasured environmental conditions, for example greater exposure -- or genetic expression in response -- to neuro-developmental toxicants. We show that to make sense of risk that we need to understand the institutional and legal context in which health services are organized. Absent these considerations, identifying such environmental or genetic risk factors is problematic.

#### Anti-Immigrant Policy in the 1990s in the US and California

In 1994, California voters passed Proposition 187 with broad support, denying access to social services and public benefits, including health and education, to undocumented immigrants. Specifically, Prop 187 required that law enforcement agencies, hospitals, and schools verify the citizenship status of all arrestees or persons seeking services and report them to the INS if they were suspected of being illegal residents. Likewise, public school districts were required to verify the citizenship status of all enrolled children as well as new enrollees and, if illegality was suspected for a student *or their parents or guardians*, report them to immigration authorities. While Prop 187 was beset by legal challenges and was overturned in 1998 (in part due to its inconsistency with 1996 welfare reform legislation, also strongly influenced by anti-immigrant sentiment), it had an unsettling effect on the immigrant community in California, and encouraged similar initiatives in other states, including Illinois, Florida, New York and Texas. Proposition 187 resulted in a decline in use of social services by undocumented residents (Fix and Zimmerman 2001).

California anti-immigrant politics resonated at the federal level as well. In the mid-1990s, the California State Department of Health shared information on non-citizens' Medicaid usage with the Federal Immigration and Naturalization Service (Baumeister and Hearst 1999). In thousands of these cases, immigrants were warned that their and their children's benefits would be considered public charge expenditures, threatening future immigration status unless repaid. The INS uses public charge determinations to identify immigrants who appear likely to become dependent on public aid in the future. These determinations can block permanent residence applications, keep immigrants from returning to the US after travel abroad, threaten the ability of relatives to immigrate, and in extreme cases result in deportation (Baumeister and Hearst 1999). California officials used this mechanism to discourage immigrants, including legal permanent residents, from obtaining Medi-Cal benefits. This program was not officially dismantled until 1999. This, alongside Prop 187,

<sup>&</sup>lt;sup>1</sup>Relevant to this finding is as the "Hispanic Paradox" in epidemiology. The "paradox" is that, on average, Hispanics in the US and Canada have better health than would be expected given their socioeconomic status (Franzini et al. 2001; Markides and Coreil 1986). Two main explanations for this paradox have been proposed. The first is selection: under this theory successful migrants, particularly those without legal status, will tend to be relatively healthy. The border crossing is difficult, dangerous and costly, so families strategize to send the person with the best chance of success and the highest expected remittances, and those who succeed are the healthiest and most motivated of potential migrants. In addition, immigrants in poor health are more likely to return home -- the so-called "Salmon bias". The second explanation is rooted in cultural differences. Recent immigrants, particularly those in Hispanic enclaves, are seen to retain many cultural elements of their homeland, including diet, lifestyle and close-knit social networks. As immigrants assimilate these advantages disappear. The Hispanic Paradox only appears when socio-demographic factors are controlled – that is, Hispanics have better health than we would expect given their low education and economic status, relative to non-Hispanic whites. With respect to autism, which has a reversed socioeconomic gradient we observe that Hispanics in California have more autism *than would be expected given their relatively low educational levels*. However, our population was born in California and is very young at diagnosis, and so the conventional explanations for the Hispanic Paradox are unlikely to account for the bulk of the association, nor can they account for the temporal pattern we observe.

There have been few systematic studies documenting the effect of these sorts of policies on service utilization by immigrants. However research by the Urban Institute provides two relevant examples. Based on administrative data from the LA County Department of Social Services, they show that after the 1996 federal welfare reform law, applications for AFDC/ TANF and Medi-Cal by noncitizens dropped dramatically, although their eligibility for these services did not change (Zimmerman and Fix 1998). Further, the number of citizen children applying for these services also declined significantly: if citizen children of non-citizen parents had applied in late 1996–1998 at the same rate as in early 1996, then about 25,000 additional children would have been approved for TANF and Medi-Cal. National trends in service utilization among immigrants show a similar pattern. Use of welfare and Medicaid by noncitizens, including noncitizens with children, dropped much more steeply than use by citizens, in spite of the fact that there was little or no change in eligibility for these groups (Fix and Passel 1999). These cases illustrate the depressant effect on service utilization arising from increasing anti-immigrant sentiment, encoded in either legislation or institutional practices. Fear and confusion about eligibility and risks to family members' immigration status cause declines in use of public services, even when there has been no actual change in eligibility.

Although our dataset includes only children born in California, and thus US citizens *jus soli* with full attendant rights, many of them reside in families of mixed citizenship status. Data from the Current Population Survey indicate that in 1998 30% of California children, and 47% of children in Los Angeles, lived in mixed-status families (Fix and Zimmerman 2001); and this number was much higher for Hispanic children. During the same period, 85% of noncitizen households with children include at least one citizen child (Fix and Passel 1999). Thus, policies that disadvantage undocumented immigrants will also affect citizen children who live with them.

The downward pressure on the use of services by the citizen children of non-citizens described here may have been especially salient in the case of Prop 187, which would have required health providers to report citizenship status for children and their parents to immigration officials. Immigrant parents would be hesitant to seek services, or even health care, for their children for fear that their own undocumented status would be revealed. Although this may not have been the main purpose of the legislation, the result was to diminish the use of services by citizen children in mixed-status families, as occurred with welfare and Medicare benefits both in LA County and nationally (Fix and Passel 20021999; Zimmerman and Fix 1998).

#### Taking a Sociological Approach to Epidemiology

The central project of epidemiology has been to identify and quantify risk factors for disease. In this important undertaking epidemiologists have had much success, yet for the most part they have focused on identifying proximate risk factors, rather than explaining the causes of disorders (Palloni and Morenoff 2001). A typical study design, particularly in the case of rare disorders like autism, is case-control, where a sample of affected persons is compared with a sample of controls, in an attempt to assess differences while eliminating confounders. Factors such as race, age, and socioeconomic status are, as much as possible, held constant in order to focus on behavioral and other risk factors. Of course, we live in a world where these "confounders" are frequently distal causes, inseparable from the risk factors of interest. Social epidemiologists pay more attention to these social and demographic factors, but in most cases they are still mainly proxies for the more direct

causes, such as nutrition or health behavior. In any case, the ways that the political context affects risk is rarely, if ever, examined.

Time is another nuisance variable that is often set aside, except as a measure of exposure, which can lead to the masking of important patterns. A typical strategy for dealing with time would be to draw a sample of cases with an autism diagnosis at a point in time, and then to select a control group matched on age (e.g. Larsson et al. 2005; Hultman et al. 2002). Although this might seem to "control for" the effects of age, under some conditions it may treat a potentially heterogeneous group of children who were born and diagnosed under very different diagnostic regimes as homogenous with respect to risk of diagnosis.2 A conventional epidemiological approach views time (when not a measure of exposure) as a confounder, while a more sociological approach to time can reveal important social processes – history -- affecting the diagnosis of children with autism.

A more sociological approach would focus on elucidating the causal pathways between risk factors and disease outcomes, taking the health differences as a starting point, and then examining the social, cultural, and institutional contexts that produce the differentials. For example, medical sociologists have long been interested in how factors such as racism, socioeconomic inequality, acculturation and assimilation, access to medical care, and health behaviors interact with race to produce health disparities (Williams and Collins 1995). There is also attention to how these processes play out over time, and over the life course.

An important strand of medical sociology considers social conditions, rather than proximate attributes and behaviors, as "fundamental causes" of health and illness (Link and Phelan 1995). Low SES is associated with every one of the International Classification of Disease's major cause of death categories, and this relationship has been very stable over time. Link and Phelan show that this association is extraordinarily robust and enforced by a multitude of intervening mechanisms. Perversely, educational campaigns and attempts to remedy disparities through the spread of information can actually amplify the SES gradient, as information and the ability to use it effectively are also disparately distributed. Thus, the social conditions themselves deserve attention: although proximal risk factors may present obvious opportunities for intervention, these interventions are likely to be ineffective if salient aspects of the underlying social conditions are not addressed.

Setting aside autism's idiosyncratic SES gradient, our approach focuses on social conditions. Although it is possible that ethnicity might be a risk factor for autism at the genetic level, there is as of yet no evidence in support of this idea (Freitag 2006). In contrast, there is strong evidence for differential levels of diagnosis between ethnic groups, and change in these levels over time and space. In the case of Hispanic children in California, we attempt to understand the social and political conditions that have created uneven diagnosis for autism, as well as change over time.

In this article we show that the passage of Prop 187, against the background of national welfare reform, shaped the willingness of immigrant and mixed-status families in California to utilize the public services for developmental disabilities to which their children were entitled. Specifically, we consider how state and federal policies toward immigrants are visible in the pattern of diagnosis for autism in California administrative data. By examining ten consecutive cohorts of children, we reveal not only the effects of immigration policy on the health of California's children, but also the hazards of treating attributes such as

 $<sup>^{2}</sup>$ An important exception is the sample design of the ADDM group at the CDC is intended for surveillance over time. Eventually, this will be a useful data set for identifying temporal patterns.

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ethnicity as risk factors without regard to the social and political contexts that make these attributes salient.

# METHODS

#### Data

For the bulk of the analysis, we utilize birth and diagnostic records for the 4,937,363 children born in California between 1992 and 2000. Of these births, 16,681 were identified as receiving a diagnosis of autism by 2006. To identify diagnoses, we matched birth records from the California Birth Master Files to the autism caseload records from the California Department of Developmental Services (DDS), from 1992, when the DDS began to maintain electronic records, through 2006. Although later birth cohorts had a shorter time window for ascertainment, this does not bias our results as age of diagnosis fell from 5.9 years ( $\pm$  2.9) among the 1992 birth cohort to 3.8 years ( $\pm$  0.9) for the 2000 birth cohort, and the difference in diagnostic timing between whites and Hispanics was greatly diminished. For some analyses we include an additional 1,590,052 births and 4,411 autism cases born from 2001 through 2003. These cases were included in order to extend the analysis, however there is likely under-ascertainment of autism in these cohorts, so we limit analysis of autism to diagnoses before age four.

In California the DDS system is responsible for coordinating diagnoses, services, and support for persons with developmental disabilities including autism. The DDS provides services to patients with full syndrome autism (DSM-IV code 299.0), but not to those with other spectrum disorders or pervasive developmental disorders unless they have another qualifying condition or substantial disability. The vast majority of persons with autism in California are enrolled with the DDS, making it the largest administrative source of data on autism diagnoses (Croen et al. 2002). The key dependent variable was a binary indicator for whether the child was ever listed on the DDS caseload with a diagnosis of autism during our study period.

Demographic information was obtained from the linked birth and DDS records; 85 percent of DDS files for children ever diagnosed with autism were successfully linked to birth records. Since demographic variables came from birth records, and these are by definition missing for the unmatched DDS cases, we cannot make a thorough comparison of matched and unmatched cases, but the unmatched group likely includes some children born outside of the US in addition to those born outside of California. Variables extracted from birth records included maternal and paternal age at birth, education, and ethnicity; maternal place of birth; child's sex, birth weight (less than 2,500 grams was considered low birth weight), duration of gestation (less than 35 weeks was considered pre-term); and parity (used to generate a dummy variable for firstborn). A child was considered to be of Hispanic origin if at least one parent was recorded as being of Hispanic origin on the birth record, and mothers who were born outside of the US and its territories were considered immigrants. Descriptive statistics are reported in Table 1.

#### Analytic Strategy

Using logistic regression, we compare the odds of diagnosis for autism for Hispanic and non-Hispanic children, adjusted for demographic and other known risk factors. Models estimated separately on each birth cohort are presented along with a pooled analysis to illustrate the consequences of pooling in the context of changing risk. Next, we unpack the pattern of autism among Hispanics by including an interaction between Hispanicity and immigrant status in our models, showing how the probability of autism diagnosis for these groups shifts over time, in concert with the rise and fall of Prop 187. Finally, we use

difference-in-differences methods to estimate the size of the relative changes in odds of autism diagnosis for the group most vulnerable to the chilling effect on developmental services use – young children with Hispanic immigrant parents. We compare the pattern of change for two groups – Hispanic children with immigrant mothers and non-Hispanic white children with US-born mothers – as Proposition 187 is passed and overturned, and as the post-9/11 crackdown on illegal immigrants began, a dynamic which lagged 9/11 by two years, when the new Immigration and Customs Enforcement agency began policing the border (see Figure 1).

## RESULTS

#### New Diagnoses of Autism

In Figure 2 we plot the time series, based on quarterly enrollments, for the proportion of all new autism and mental retardation enrollments (from the 1992–2000 birth cohorts) who are Hispanic children of immigrant mothers. On the same chart we plot the similar statistic for new mental retardation diagnoses. The basic pattern is common to both DDS populations. Note that a child can have diagnoses for both autism and mental retardation at the same or different times, so persons may appear in both time series. There is an initial drop in Hispanic enrollments around 1994, when anti-immigrant feeling was intense and Proposition 187 was passed. Enrollments remained relatively low, rising when Prop 187 was repealed. This peak is consistent with what we would observe if a sizeable number of parents had delayed enrolling their children with the DDS until after Prop 187 was repealed. We also see a dip around 2003, when the Department of Homeland Security sharply increased immigration enforcement. Due to small numbers we cannot see the pattern for autism in the earliest years, although the shapes of the time series are consistent.

#### **Cohort Analysis**

Here, we estimate odds of autism diagnosis for Hispanic children versus non-Hispanic whites, by birth cohort. Figure 2 reports the odds ratios for risk of autism for Hispanic children, relative to non-Hispanic whites, controlling for known risk factors for autism and demographic variables. Models are estimated separately on each birth cohort from 1992 to 2000, so each odds ratio comes from an identically specified model on children born in California in the indicated year only. The cohort estimates in the top panel show that for most of the years in this period, the odds of a Hispanic child being diagnosed with autism are about the same or slightly higher than a white child, adjusting for known autism risk factors and socioeconomic correlates. For the 1997 and 1998 birth cohorts, the odds ratios jump so that Hispanic children have 25–30% greater odds of autism; this starts to decline back toward the previous levels in 1999.

A common analysis strategy for a dataset like this would be to pool observations across years, combining these birth cohorts into one group. The advantage of this strategy is to maximize sample size for a rare condition by including all available data points up to the current moment. However there is also a trade-off. In the bottom panel of Figure 3 we demonstrate the effect of ignoring history by pooling samples cumulatively across cohorts. Thus, the 1994 sample would include the 1992, 1993 and 1994 birth cohorts, while the 1998 sample includes all observations from the 1992–1998 cohorts. The 2000 sample is equivalent to pooling across all available birth cohorts. Here it is clear that pooling cohorts, particularly across a long period of time can obscure patterns and result in mis-estimation of effect sizes. First of all, the inclusion of the outlier years, 1997 and 1998, in the pooled samples pulls the estimates higher than they are in any of the other years, inflating the odds ratio. Second, the pooled estimates mask the temporary spike in risk for Hispanics. If this increase is important, and we argue below that it is, we would never have found it using a

conventional analytic strategy. Finally, the cumulatively pooled samples suggests a slow but relatively steady increase in the odds of Hispanics being diagnosed with autism over time, which is incorrect. In fact, the cohort estimates show us that excluding 1997 and 1998, all the estimates hover between about 1 and 1.1.

#### **Children of Hispanic Immigrants**

If autism risk for Hispanics is due in part to immigration policy, then this effect should be especially strong for children of undocumented immigrants. From the birth records, we know whether mothers were born inside or outside the United States. As a second test, we estimate a model with an interaction between hispanicity and maternal immigrant status. We use the joint status of Hispanic and having a mother born outside the US as a proxy for having undocumented or mixed-status families. Although not all of these foreign-born Hispanic mothers are necessarily in the country illegally, and some families with US born mothers have other undocumented members – so our assessment in necessarily conservative -- we should still expect this population to be most affected by immigration policy.

Using these cohort models, we calculate the predicted probabilities of autism diagnosis by Hispanic and maternal immigrant status separately for each cohort, adjusted for risk factors and demographics. Aside from the key interaction variables all categorical variables are set to the omitted (modal) category, and both parents are assumed to have a high school education in the prediction model.

Although the analysis in the previous figure is based on year of birth, the diagnostic event happens several years later. For most children autism symptoms have begun to manifest by around 18–24 months. In the DDS data, the modal age at diagnosis is three, and diagnoses after six are quite rare. Thus, there is a critical period, beginning around age two and extending until the child enters school, where diagnosis (and services) depends on parents and physicians to recognize symptoms. It follows that for children born in 1992, the crucial period for autism diagnosis starts in 1994, and ends when they enter kindergarten in 1997. So we should expect the effect of the political climate on service utilization to matter most during the 2–5 year old age range, centered at age three.

We then plot the ratio of predicted probabilities by year, to illustrate the rise and fall of the risk of autism for Hispanic children. This procedure is repeated for risk of diagnosis before age four, to ensure that all children had equal time for ascertainment. Figure 4 illustrates the complex relationship between age, period and cohort for this process. The light gray region contains the population of children born 1992 through 2001, over the observation period from 1992 through 2006. The calendar year is on the X-axis, and age is on the Y-axis. Each cohort proceeds diagonally across the graph, and the darker shaded bar shows their location at age three. Periods relevant to immigration policy are marked. We expect that children who are approximately age three between passage and repeal would have experienced the strongest suppression effects. And it is among the children who turn three after the repeal of Prop 187 that we should expect to see an increase in DDS enrollment among Hispanic immigrant children.

The curves plotted on the graph represent the relative probabilities of autism diagnosis for children of Hispanic immigrants relative to children of US-born non-Hispanics. The solid line, which ends with the 2000 birth cohort (who turn three in 2003) shows this ratio for lifetime (by 2006) probability, while the dashed line contains ratios for diagnosis by age three. Both lines show more or less the same story: The probability of autism was about equal for these two groups while Prop 187 was on the books, then it rose fairly rapidly around the time of repeal, peaking with 1997 birth cohort, which would have turned three in

2000, the year after its final defeat. After this peak the probability of autism for Hispanics began to decline again.

We should not expect the policy effects of Prop 187 and its repeal to follow a clean discontinuity pattern, but rather to rise and set over several years. The first reason for this expectation is that diagnosis happens at different ages for different children, and even within a single birth cohort the diagnostic event could happen in several different years. Second, obtaining a diagnosis of autism is a complicated process that does not happen immediately. It often begins with suspicions by parents or caregivers, who then discuss symptoms with neighbors and other parents they know, relatives or a pediatrician, who may provide a referral to a child psychiatrist or other expert. Then, parents contact the DDS, and the enrollment process can take months while diagnosis is confirmed and the child is evaluated. This process is fraught with starts, stops, and additional appointments and meetings with physicians, teachers, educational administrators and lawyers, among others. There are many points along the way at which this process involves points of contact with state and federal public services or the legal system which are likely to create additional barriers for children with undocumented or mixed-status families.

Finally, history is always messy. There is substantial ambiguity as to the period in which Proposition 187 itself was in effect. It passed after a heated campaign, and during a period of strong anti-immigrant feeling. We might expect the impact to begin on the date the laws were to come into effect, January 1, 1995; or on November 9, 1994, the day after the election; or some earlier date when it became clear to the immigrant population that California citizens were becoming less tolerant of their presence. Further, the law was challenged in court almost immediately after passage, and was never strongly enforced. The uncertainty over when and whether it applied may have contributed to immigrant families' confusion over eligibility. Thus Prop 187, rather than marking a crisp policy change, symbolizes a shift in the climate for families of mixed legal status. Complicating matters further, the end of Prop 187 is also ambiguous; while overturned by the US District Court in late 1997 it was not finally dead until mid-1999, when the new governor declined to further pursue appeals. Thus, the policy effect of Proposition 187, rather than turning cleanly on and off, would be expected to rise and fall more gradually.

#### **Difference-In-Difference Estimates**

Now, we turn to quantifying the impact of these climate and policy changes on groups of children (age 3–5) at greatest risk for autism diagnosis at the time of the policy change. To produce the difference-in-differences estimates, we estimate a logistic regression model, adjusting for relevant risk factors, with terms for the interaction between those children expected to be most affected by the policy change (i.e. Hispanic children with immigrant mothers) and the relevant period.

We assume that the relevant age for autism diagnosis begins at age three. Estimates in Figure 5 represent the odds ratios, with confidence intervals, for Hispanic children born to immigrant mothers before and after the policy change, compared to those not affected by Prop 187, controlling for demographic and autism risk factors. The first panel shows that our affected group had 13% lower odds of autism during the Prop 187 period than they would have if their risk changed at the same rate as the control group. After the events of 9/11, diagnoses for children of Hispanic immigrants similarly dropped, although the difference did not reach significance at the 5% level.

The middle panel examines at finer resolution the timing of change after the events of 9/11. There may have been a negative effect on service utilization during the post-9/11 immigration crackdown, but there was a delay: the significant effect began for those

children who turned three in 2003 and 2004. Here the climate change in California with respect to immigrants was shaped by the institutional response to 9/11 – the transfer of antiimmigrant enforcement from the INS to Homeland Security after the passage of the 2002 Patriot Act.

Finally, the last panel contrasts groups of children who were age 3 one year before and after three significant events: the repeal of Proposition 187, the September 11 attacks, and the Department of Homeland Security's assumption of immigration enforcement on March 1, 2003. Both Proposition 187 and the DHS takeover have significant effects, while 9/11 does not. The difference-in-differences estimates suggest that Prop 187 reduced the odds of a child of a Hispanic immigrant being diagnosed with autism by about 16%, relative to others. Similarly, this group's odds of diagnosis were reduced by about 17% after the DHS assumption of immigration enforcement, relative to the children of US-born non-Hispanic whites. The significant effect for the 2003 increase in immigration enforcement, alongside the lack of an effect for 9/11, suggests that families wished to avoid drawing special attention to members whose immigration status may have been in doubt.

## **Changing Age of Diagnosis**

The analysis of probabilities of diagnosis above suggests that there may have been a suppression effect during the pre-1997 birth cohorts, so that some of the children who, in the absence of the effect of Prop 187 on service utilization, would have enrolled with DDS never did. There may also have been some postponement. If parents were delaying enrollment with DDS in the wake of Proposition 187, we should see evidence that children who should have been diagnosed during the 187 period were diagnosed later. This is the case. Through 1996, children of native-born non-Hispanics were diagnosed earlier than Hispanic children of immigrants. This difference was significant in most years, largest for the 1996 birth cohort, and disappeared after that. This pattern is consistent with what we would expect to see if children born under the Prop. 187 regime tended to delay diagnosis.3

#### Spatial Variability over Time

Because we can observe the effect of political changes on Hispanic autism rates in the aggregate, it is reasonable to expect that the impact should also express itself spatially. Figure 6 reports how changes in institutional context affect the ratio of Hispanic autism over non-Hispanic autism by county in California. Panel A considers the repression effect of Prop 187, while Panel B considers the post 2003 border enforcement. In each, the county is shaded by whether it experienced an increase (white), decrease (gray), or no change (diagonal lines) in the relative prevalence of autism in the Hispanic immigrant population relative to others between the analysis periods. If the change in relative prevalence for a county after Homeland Security assumed control of the border,

HI Prevalence<sub>2000-1</sub>/Non – HI Prevalence<sub>2000-1</sub> HI Prevalence<sub>1997-8</sub>/Non – HI Prevalence<sub>1997-8</sub>

is greater than 1.25, we consider it an increase, and if it is less than .80 we consider it a decrease, while values close to 1 are considered to be no change. Counties with fewer than 30 cases total in the analysis periods are also classified as no change, in order to comply with our data protection agreement.

<sup>&</sup>lt;sup>3</sup>Results available by request from authors.

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On one hand, we might expect to observe that repeal of Prop 187 induces increased autism cases amongst Hispanics in counties where the Hispanic population is the smallest, since it is in these areas where Hispanics are likely more vulnerable to both formal and informal discrimination. On the other hand, research and theory on the vulnerability of minority populations in other contexts finds that discriminatory actions are more likely to occur when the minority group is large or growing (Beck and Tolnay 1990; Lyons 2007). This suggests a curvilinear relationship between ethnic composition and discrimination: anti-immigrant actions should be most common in places where immigrants are rare, and thus visible and vulnerable, and when they are common, and thus perceived as a threat by the native-born population.

During the post-repeal period, relative Hispanic autism prevalence increased, as is evident by the predominance of white counties in the map. This is especially true in the Central Valley of California, where a relatively high proportion of Hispanic agricultural workers live. In contrast, the heightened immigration enforcement in the post-2003 period is associated with a decline in relative autism prevalence for Hispanics, as can be seen by the preponderance of black counties. The closing is especially noticeable in the southern part of the state and near the border. By tabulating counties by the change in relative prevalence of autism Hispanic immigrant children versus others for both periods, and partitioning counties into tertiles by the proportion of all births to Hispanic immigrant mothers, we can test whether or not change disproportionately occurs in the counties in the upper and lower tertiles of Hispanic immigrant births. This is the case (p = .002).

# DISCUSSION

In this paper, we show that declines and spikes in risk of autism diagnosis for Hispanics mirror shifts in the California political environment. Observing how political changes shape observed risk for autism in this instance helps inform our understanding of risk across diverse social demographic factors in other contexts.

#### Immigration Policy and Utilization of Autism Services

We observe that adjusted autism rates for Hispanics between 1992 and 1996 are comparable to whites (OR 1.0 to 1.1). Children born in these years would have begun to be eligible for diagnosis and entry into the DDS system in the 1994–1998 period, when anti-immigrant legislation was at its height. Proposition 187 was overturned by the Ninth Circuit Court of Appeals in 1998, and in 1999 Governor Gray Davis dropped further appeals. At the same time, naturalization rates were rising dramatically, particularly among Mexican immigrants, perhaps in part in response to state and federal legislation restricting the rights and benefits of both illegal and legal immigrants (Fix et al. 2003). Thus, the 1997 and 1998 birth cohorts, who would turn two just after Prop 187's demise, are the first cohorts whose non-citizen parents would have felt free to seek the services to which their children were entitled without threat to their own or their families' immigration status. Autism rates rose dramatically for those years, as Hispanic children, particularly those with immigrant mothers, entered the system at an accelerated rate.

Looking at the other side of the coin, the sharp declines in risk to Hispanic children in two birth cohorts in the late 1990s is consistent with chilling effects of the waves of antiimmigrant political environment of the 1990s and early 21<sup>st</sup> century. Results from a difference-in-differences analysis also suggest that the newly created Department of Homeland Security had a similar effect. The increased scope of immigration enforcement activity arising from the 2002 Patriot Act resulted in a crackdown on illegal immigrants. Aimed at combating terrorism, the new rules had a spillover effect on garden-variety immigrants, and their families. Although our initial expectation was that Hispanic

immigrants in California might have been affected by anti-immigrant sentiments immediately after 9/11, the evidence does not support this. Until anti-immigrant sentiment crystallized into institutions and became policy with real effects, the incidence of autism amongst Hispanic children remained comparable to those of native-born children. It was not until 2003 when both apprehensions along the southwest border and deportations began to increase – an enforcement program that had little if anything to do with eligibility for developmental services, particularly for children who are US citizens – do we observe increased vulnerability of Hispanic immigrant families, making them less likely to apply for services.

It follows that the 1997–1998 spike reflects change in utilization of services, rather than an actual change in the risk of autism. Our administrative data can only document entry into the DDS system. To the extent that a group is systematically excluded, whether intentionally or not, from access to such services, their risk may appear artificially low. The most direct interpretation of the results reported in this article is that changes in the political environment can have significant effects on the lives of children with autism and their families. Without taking time seriously by examining these data by birth cohort, this fact would not have surfaced.

Although the impact of political repression on the use of services by children in immigrant families is not specific to autism, this disorder might be particularly susceptible, because of marked ambiguity in diagnoses based solely on behavioral symptoms. These ambiguities are especially large for the youngest and those at the edges of the spectrum: the high-functioning, those with subsets of symptoms, and those comorbid with other developmental, intellectual or physical disabilities. Further, the inequalities inherent in the US health care system contribute to the potential for underdiagnosis among children whose parents have few resources. For those children who might qualify for diagnosis but are relatively high-functioning – meaning they are verbal and have few serious behavioral problems – the benefits to enrolling with the DDS might seem outweighed by the risks during a period of political repression.

An interesting but untested possibility is that the 1992–1996 and post 2001 birth cohort rates for autism amongst Hispanics are artificially low, therefore masking environmental drivers of increased risk, for example exposure to neurotoxic pesticides. Observation of pooled data alone, ignoring the impact of legislation on Hispanic utilization would mask this possibility entirely. Yet there is evidence that such exposures do increase risk for autism (Roberts et al. 2007) and that biomarkers for exposure to particularly neurotoxic pesticides like DDT (banned in the US since 1972 but in Mexico since only 2000) are more common among women of Mexican origin (Eskenazi et al. 2008). The spatial expansion of autism diagnoses by residence at birth following the repeal of Proposition 187 provides some indirect support that exposure to pesticides could play a critical role in autism etiology. Our spatial analysis, though purely descriptive, provides an illustration of the disproportionate "opening" of autism diagnoses to Hispanic children in California's agricultural Central Valley. Although our data set does not permit us to test this hypothesis, the question of why Hispanics have an elevated adjusted risk of autism - even if it appears that they do not as a consequence of the political climate -- deserves further study. Consideration of the temporal and spatial pattern of autism amongst Hispanics suggests that we would be well advised to consider whether pesticides used either for agricultural purposes or simple yard care are more salient than the extant scientific work would indicate.

#### **Alternative Explanations**

Clearly, this evidence is indirect. The possibility remains that the temporal association between autism diagnostic patterns and immigration politics is spurious. One idea is that a

recessionary economy could spur both anti-immigrant feelings as well as cutback in developmental services and outreach disproportionately affecting the less advantaged. Although the recession in the early 1990s may have contributed to the passage of 187, the unemployment rate peaked in California in 1993 and fell steadily throughout the Prop 187 period. Further, although the DDS did face deep budget cuts during the 1994–1995 fiscal year, it also expanded its population served at a faster pace than the statewide population, and particularly expanded among groups with non-white ethnicities (DDS Information Services Section 1998). Although an independent effect of the DDS budget on Hispanic enrollment cannot be ruled out, the fact that this pattern is stronger for children of Hispanic immigrants than for US-born Hispanics points to a mechanism affecting immigrants in particular rather than just vulnerable populations in general.

The American Psychiatric Association released its Diagnostic and Statistical Manual IV (DSM-IV) in 1994, including significant revisions to the diagnostic criteria for autism and related pervasive developmental disorders. Criteria for autism spectrum disorders were expanded. Although this event is coincident with the passage of Prop 187, it strains credulity to imagine how they might be directly related. The revised criteria were adopted by the DDS for use in establishing eligibility for services, and the caseload rose rapidly in following years. Here we observe that the explosion of autism diagnoses following the release of the DSM-IV (King and Bearman 2009) was not observed among the children of Hispanic immigrants, at least not until several years later. Conceivably, diagnostic expansion resulting from the DSM-IV was suppressed or delayed in this group by the passage of Prop 187.

# CONCLUSIONS

It is not being Hispanic *per se* that helps predict risk of diagnosis for autism, but being Hispanic in California at a particular point in time that matters. Individual attributes are salient in particular social and historical contexts. Autism diagnoses depend to a great degree on access to information, expertise, medical care, and public services. In California, during a period of rapid change in access to these resources for immigrants and their families, lack of access for a vulnerable group of children was manifest in under-diagnosis for autism. The brief period of widening access, after the repeal of Proposition 187 and associated state and federal restrictions but before the 2003 offensive against illegal immigration, provides evidence that service utilization for autism did respond to increased access.

Without taking the role of time seriously, this pattern could not have been uncovered. Further, a sociological approach to explaining risk factors, rather than just estimating their size, is crucial to understanding the autism "epidemic." Much has changed over the past few decades, as autism prevalence has increased. Parents, physicians, and teachers are more aware of the symptoms. Stigma has decreased as persons with autism have become more visible and diverse. And treatments are more numerous and available. As the process through which autism is identified and diagnosed has changed we should expect prevalence to change as well, and to have uneven penetration. With respect to autism, we show how policy toward the public service eligibility of immigrants can have unintended consequences, contributing to the uneven diagnosis of autism among a particular group of children.

With respect to social policy, we show that seemingly health-neutral policy has significant spillover effects. Here, Hispanic children experiencing a wave of legislation putatively designed to control state budgets or combat terrorism turn out to be disadvantaged. If, as is widely thought, early identification of autism is critical for subsequent development, the effect we document of the moods and policies of natives towards immigrants achieved little

but wasted opportunity. In light of recent anti-immigration legislation passed in Arizona and threatening to spread to other states, the California experience described in this article appears to be of more than just historical interest.

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#### Figure 1.

Deportable Aliens Removed or Returned from the US, fiscal years 1992–2008. Source: United States. Department of Homeland Security. 2009. Yearbook of Immigration Statistics: 2008. Washington, D.C: U.S. Department of Homeland Security, Office of Immigration.



#### Figure 2.

Quarterly Time Series of Hispanic Immigrant Representation Among New DDS Enrollments by Diagnosis. (Data are smoothed by 4-quarter moving average.)





Odds Ratios for risk of diagnosis with autism for children of Hispanic parents relative to non-Hispanic whites, from cohort and successively pooled models



**Figure 4. Relationship between social policy in the period in which a child turns three and risk of autism diagnosis. Birth cohorts progress through the life course on the diagonal** Ratios of adjusted probabilities for male children of Hispanic immigrants relative to male children of US born non-Hispanic White children.



# Figure 5. Difference-in-differences estimates for policy changes on children of Hispanic immigrants relative to children of native born white mothers (Odds ratios and 95% confidence intervals

Panel A contains estimates for effect of Proposition 187 (relative to after repeal) and September 11 (relative to period after 187 but before 9/11). Panel B breaks the 9/11 period into five annual periods. Panel C contains comparisons between children who are age three one year before and after the relevant event. Models are adjusted for individual-level socioeconomic characteristics and autism risk factors.



**Figure 6.** County-Level Change in Relative Autism Prevalence for Children of Hispanic Immigrants versus others, 1994–5 to 1997–8 (Panel A) and 1997–8 to 200–2001 Panel B) Counties labeled "Opening" increased in relative prevalence by at least 25% relative to the reference period, and counties labeled "Closing" decreased by at least 20% relative to the reference year.

#### Table 1

Descriptive Statistics on Population of California Births and Matched Autism Cases, 1992-2000.

	All Births		Autism Cases	
	Ν	%	Ν	%
Total	4,937,363		16,681	0.34
Male	2,525,578	51.15	13,786	82.64
Birth Cohort				
1992	600,964	12.17	1,418	8.50
1993	584,490	11.84	1,493	8.95
1994	566,870	11.48	1,621	9.72
1995	551,232	11.16	1,702	10.20
1996	538,607	10.91	1,836	11.01
1997	524,293	10.62	2,004	12.01
1998	521,452	10.56	2,141	12.83
1999	518,076	10.49	2,170	13.01
2000	531,379	10.76	2,296	13.76
Low Birthweight	261,060	5.91	1,093	7.52
Firstborn	1,898,744	38.46	6,964	41.75
Pre-term	670,101	13.57	2,566	15.38
Race				
White	3,668,298	74.30	11,719	70.25
Black	298,251	6.04	1,140	6.83
Native American	6,102	0.12	а	
Asian	345,253	6.99	1,693	10.15
Pacific islander	13,276	0.27	а	
Hispanic	2,421,339	51.50	6,539	40.82
Foreign-Born Mother	2,197,663	44.51	6,745	40.44
	Mean	(SD)	Mean	(SD)
Parental Education (total yrs)	23.75	(6.66)	26.40	(5.69)
Maternal Age	27.29	(6.24)	29.48	(6.10)
Paternal Age	30.09	(7.03)	32.45	(7.11)
Age of First Diagnosis			4.71	(1.93)

 $^{a}$ Cells with fewer than 30 cases are not reported in accordance with our confidentiality agreement.