Health Care of Latino Children with Autism and Other Developmental Disabilities: Quality of Provider Interaction Mediates Utilization

Susan Parish, Sandra Magaña, Roderick Rose, Maria Timberlake, and Jamie G. Swaine

Abstract

This study examines access to, utilization of, and quality of health care for Latino children with autism and other developmental disabilities. We analyze data from the National Survey of Children with Special Health Care Needs (N=4,414 children with autism and other developmental disabilities). Compared with White children, Latino children with autism and other developmental disabilities had a consistent pattern of worse health care access, utilization, and quality. We then test mediation models to determine if health care quality mediates the relationship between ethnicity and health care utilization disparities. Three of four quality indicators (provider does not spend enough time with child, provider is not culturally sensitive, and provider does not make parent feel like a partner) were significant mediators. These analyses suggest that interventions targeted at improving providers' cultural sensitivity and behavior during the clinical encounter may reduce disparities in the health care utilization of Latino children with autism and other developmental disabilities.

Key Words: health care disparities; Latino children; health care quality; health care access; cultural competence

Racial and ethnic health care disparities in the United States have been well documented across multiple domains, including access to care and use of services, prevention and population health, health status, chronic diseases, special health care needs, and quality of care (Flores, 2010; Strickland et al., 2009; Weinick & Krauss, 2000). Although the focus of the existing research has primarily been adults without disability, there is some evidence to suggest that children's patterns of care mirror those of adults with the same racial or ethnic identities (Javier, Huffman, Mendoza, & Wise, 2010; Liptak et al., 2008).

Ethnic health care disparities have been shown to exist for Latino children, but the nature and magnitude of the disparity for Latino children with autism and other developmental disabilities are not understood. Ethnic disparities in health care for children with autism have been difficult to study for two reasons. First, autism lacks a

definitive epidemiology, and measured prevalence rates have been growing (Liu, Zerubavel, & Bearman, 2010). Second, most of the national studies that collect data on health care access and service utilization have sample sizes that are insufficient to support research about ethnic disparities for children with autism.

The focus of this article is on disparities between Latino and non-Latino White children with autism and other developmental disabilities. Latinos are the largest and fastest-growing ethnic minority population in the United States (Fry, 2008) and are therefore an important population to consider. Although studies of this specific population are few, we expect disparities in health care access and quality for Latino children with autism and other developmental disabilities as other researchers have found evidence of disparities on our dimensions of interest (Latinos, autism, and health care) separately. Indeed,

Krahn, Hammond, and Turner (2006) have aptly characterized the health care access of people with developmental disabilities as a "cascade of disparities," which emerge from poverty, lack of education, lack of adequate attention from health care providers, high rates of comorbidities, and inadequate focus on health promotion. Overwhelming evidence indicates a pattern of similar health inequities in the United Kingdom (Emerson & Baines, 2010) and elsewhere in the European Union (World Health Organization, 2010). In this article, we are particularly interested in understanding the experiences of children with autism and other developmental disabilities because of the growing evidence that Latinos experience daunting inequities in receiving appropriate health care in the United States (Flores, 2010; Strickland et al., 2009; Weinick & Krauss, 2000).

The terms Latino and Hispanic are often used interchangeably, and in our review of the existing research, we use the term employed by the authors of each study we cite. Since 2001, the health care access and utilization of children with special health care needs have increased, although gaps in access and utilization persist (Strickland et al., 2009). Despite general access increases, however, Latino families consistently face greater barriers to care and have worse health outcomes (Liptak et al., 2008; Strickland et al., 2009). In one national analysis, Hispanic children had the lowest rates of high-quality care compared with White children. Hispanic children were more likely to lack a usual source of care, more likely to lack a personal doctor, and less likely to receive family-centered care (Strickland et al., 2009).

English proficiency is a significant predictor of health care quality and access for children. Families who do not speak English as their primary language were more likely to lack a usual source of care, a personal doctor, and familycentered care (Yu & Singh, 2009). The relationship between English proficiency and health care access has been reported in other studies as well (Strickland et al., 2009; Yu, Huang, Schwalberg, & Nyman, 2006). Children in non-English-speaking households were more likely to lack insurance, less likely to visit an emergency department, and lived in families with higher poverty and less education. Non-English-speaking families were less likely to report delayed or foregone care but more likely to have gone outside the United States to obtain health care. Among families in this study that reported speaking English not well or not at all, most were Hispanic (Yu et al., 2006).

Yu and colleagues (2006) found that children without insurance were more likely to lack a usual source of care and to be without a doctor in the past 12 months. Hispanic families had the highest percent without insurance coverage, without a usual source of care, and without any doctor visits in the past year compared with White, Black, and Asian families. These results are consistent with earlier findings in which Hispanic children were three times more likely than White children to lack a usual source of care (Weinick & Krauss, 2000).

Parents of children with autism report greater difficulty than parents of children with other disabilities in accessing specialty care and have less access to insurance compared with parents of children with other disabilities (Krauss, Gulley, Sciegaj, & Wells, 2003). Among children with special health care needs, those with autism have exceptionally high health service use as well as greater unmet health needs. Compared with their same-age peers, children with autism have higher rates of comorbid health conditions and subsequently require increased health services as compared with their typically developing peers (Gurney, McPheeters, & Davis, 2006; Kogan et al., 2008).

The extent of the disparities in access and quality of health care for Latino children with autism and developmental disabilities is not fully clear. In one study, race, ethnicity, and poverty were associated with decreased access to health care (usual source of care, personal doctor) for children with autism. Net of age, insurance status, poverty, and condition severity, Latino children were less likely than White children to have a usual source of care and more likely to have difficulty obtaining advice and to have poor health status (Liptak et al., 2008).

In its exhaustive review of the evidence related to racial disparities in health care access, the Institutes of Medicine found that factors at three levels contributed to observed disparities. These include the individual level, the clinician level, and the system level. The clinical encounter, or the point at which the clinician and patient interact, has been shown to contribute to interaction between clinician and patient (Smedley, Stith, & Nelson, 2002), but few studies have examined clinician-level factors with this population. Our purpose was first to describe the extent of disparities in access to health care, utilization of health care, and quality of health care for Latino

children with autism and other developmental disabilities. Our second purpose was to examine the role of health care quality as delivered by the health care provider in explaining the relationship between ethnicity and health care utilization outcomes for Latino children with autism and other developmental disabilities. To the best of our knowledge, no research has either described ethnic disparities in health care access and utilization or examined the relationship between these and health care quality for children with autism and other developmental disabilities.

Method

Data and Sample

Child and family data were drawn from the 2005– 2006 wave of the random-digit-dialed National Survey of Children with Special Health Care Needs, conducted by the National Center for Health Statistics between April 2005 and February 2007 (Blumberg et al., 2008). The data are representative of the U.S. noninstitutionalized population of U.S. children with special health care needs. In the United States, children with special health care needs are defined as those children who either have or are at elevated risk for developing emotional, behavioral, physical, or mental conditions that increase their need for health care services, in comparison with typically developing children (Newacheck, Rising, & Kim, 2006). Detailed interviews about the child's condition and health care access and utilization were conducted with a knowledgeable parent or guardian. A five-question screening instrument identified households that included a child with special health care needs. In households that had more than a single child with special health care needs, one child was randomly selected for inclusion in the study. Details about the survey methods and identification of children with special health care needs are available elsewhere (Bethell et al., 2002; Blumberg et al., 2003). We limited our analytic focus to White and Latino children whose parents or caregivers indicated that they had been diagnosed by a physician with either autism or autism spectrum disorders, Down syndrome, cerebral palsy, or mental retardation. These decisions reduced the analytic sample to 665 Latino and 3,762 White children. When weighted, the sample represented 201,930 Latino children with autism and other developmental disabilities and 898,783 White children with

autism and other developmental disabilities (total = 1,100,713). As is evident in Table 1, which describes the sample, in comparison with White children, Latino children with autism and other developmental disabilities were significantly less likely to be diagnosed with autism, significantly more likely to have mental retardation, significantly more likely to be from families with total household income below poverty or below twice the poverty level, significantly more likely to be from families where neither parent graduated high school, significantly more likely to be from families headed by a single mother, and significantly more likely to have public health insurance. The difference for other boys present in the household was marginally significant.

Measures

Dependent variables. There were four measures of health care access: (a) child's needs were not met by insurance, (b) child does not have a usual source of health care, (c) child does not have a personal doctor or nurse, and (d) child was uninsured at any time in the past year. There were three measures of health care utilization: (a) needed health care was delayed or foregone, (b) difficulty using health care services, and (c) problems getting referrals. There were four measures of inadequate health care quality: (a) health care provider does not spend enough time with child, (b) provider does not listen carefully, (c) provider is not culturally sensitive, and (d) provider does not make parents feel like a partner. Each dependent variable was created as a binary indicator of the presence of a disparity. We note that these indicators are commonly employed health care outcomes in U.S. health services research for populations with and without disabilities because of the large proportion of the population that does not have health insurance or whose care needs are unaffordable even with insurance (U.S. Department of Health and Human Services, 2000).

Independent variable. Ethnicity was entered as a dichotomous independent variable indicating whether children were White or Latino. All children whose parents identified them as Hispanic were deemed to be Latino for our sample, regardless of their race. All children whose parents identified them as non-Hispanic White were identified as White for our sample. Children who were not White or Latino were excluded

Table 1
Description of the Sample

	White (n	= 3,762)	Latino (n	a = 665	Test statistic
Characteristic	n	%	n	%	χ^2
Child has autism	1,541	40	214	32	5.8*
Income <100% federal poverty level	523	16	245	40	37.7***
Income ≥100% and <200% federal poverty level	914	24	187	32	
Income <200% federal poverty level	1,436	41	432	72	66.4***
Other language spoken	15	0	214	42	89.8***
Child is female	1,217	35	229	35	0.0
Child has mental retardation	2,700	75	543	86	19.4***
Child has cerebral palsy	452	12	68	12	0.1
Child has Down syndrome	253	6	68	9	2.5
Parent did not graduate high school	163	6	123	23	31.0***
Child's health care needs are not stable	479	13	104	15	0.7
Child's condition or problem is not moderate or severe	709	17	140	8	0.4
Child's condition or problem is moderate	2,081	56	344	53	
Child's condition or problem is severe	973	26	181	29	
Parent is a single mother	870	25	272	43	21.0***
Child has public health insurance only	1,046	31	315	55	20.5***
Child has private and public health insurance	698	15	89	10	
Child has no insurance	120	3	58	10	
Other boys present in household	108	3	21	1	3.31+
Other girls present in household	109	3	29	4	0.4
	Mean	SD	Mean	SD	
Child's age	9.6	8.1	8.9	6.4	-1.9

p < .10.

from the analysis so as not to confound the estimation of the mediation effect.

Mediators. The four dependent variables of inadequate health care quality were tested as potential mediators of the relationship between ethnicity and health care utilization. As noted above, these were binary and included (a) health care provider does not spend enough time with child, (b) provider does not listen carefully, (c) provider is not culturally sensitive, and (d) provider does not make parents feel like a partner.

Covariates. The mediation models contained several covariates, including language (an indicator of whether the interview was conducted in a language other than English), family income (an indicator of whether the family had income below 200% of the federal poverty level, compared with families at or above 200%), parental education (highest parental schooling was less than high

school graduation, compared with high school graduation or higher), parental marital status (parent is a single mother, compared with single fathers and married or cohabiting parents), and severity of the child's condition (condition is severe, compared with moderate or mild).

Analytical Strategy

We used chi-square tests to describe the extent of ethnic disparities in health care access, utilization, and quality (Table 2). We then conducted a mediation analysis to test whether health care quality mediated ethnic disparities in health care utilization. A typical mediation model is represented in Figure 1 (MacKinnon, Lockwood, Hoffman, West, & Sheets, 2002). The effect of the independent variable ethnicity (X) on each health care utilization (Y) is shown to be composed of two parts: a direct effect representing the

 $p^* < .05. ***p < .001.$

Table 2
Bivariate Measures of Health Care Access and Utilization

	White (n	= 3,762)	Latino (n	a = 665	Test statistic
Outcome	n	%	n	%	χ^2
Utilization					
Care foregone/delayed	400	12	107	17	2.9^{+}
Difficulty using services	934	24	179	32	5.1*
Problems getting referrals	428	28	95	41	4.8*
Quality					
Provider does not spend enough time with child	794	21	237	36	17.9***
Provider does not listen carefully	519	14	128	18	2.4
Provider is not culturally sensitive	1,394	36	294	46	7.8**
Provider does not make parent feel like partner in					
child's health	548	15	154	24	8.57**
Access					
Needs not met by insurance	847	24	179	30	3.1+
Does not have a usual source of care	187	5	70	10	9.9**
Does not have a personal doctor/nurse	192	5	65	12	5.1*
Child has no insurance	120	3	58	10	9.8**

p < .10.

association between ethnicity and utilization unconfounded by the mediator and an indirect effect representing the association between ethnicity and utilization that occurs through covariation with the mediator.

The direct effect is represented by β' . In the present context, where the health care utilization outcomes are undesirable, the positive sign indicates that an ethnic disparity was present (i.e., Latino children had worse outcomes than White children). The indirect effect is calculated by taking the product AC, multiplying the effect of ethnicity on the mediator M (coefficient A) by the effect of M on Y(C), controlling for ethnicity (MacKinnon et al., 2002). In the present context, the signs of A and C should both be positive as well: effect A was hypothesized to be positive because the mediator is also a disparity, demonstrating a lack of (e.g.) cultural sensitivity to Latino families by the health care provider. Finally, C was hypothesized to be positive because as the mediator disparity increases in likelihood, the utilization outcome also increases in likelihood. For example, as the probability of cultural insensitivity increases, the probability of having difficulty using services is also expected to increase.

With these hypotheses about signs in mind, the mediation analysis was conducted in two parts. We first identified models consisting of combinations of dependent variables and mediators that demonstrated the potential for mediation. This was done by estimating two regressions, one consisting of the mediator regressed on ethnicity (providing effect A) and the other consisting of the dependent variable regressed on ethnicity and the mediator (providing effects β' and C, respectively). We then examined the signs of the three effects to determine if they conformed to the hypotheses. If any of the three signs in a model did not conform to the positive sign hypothesis, then the model was disregarded in further analysis. If all three signs were positive as hypothesized, we conducted a calculation and test of the mediation effect. All models used the same covariates as described above (MacKinnon & Dwyer, 1993).

The mediation models were conducted using logistic regression. There are three differences between mediation models with binary dependent variables and mediation models with linear dependent variables. First, model coefficients or log-odds were standardized to make the scale of the mediator (used as both a predictor and a

 $[\]hat{p}$ < .05. **p < .01. ***p < .001.

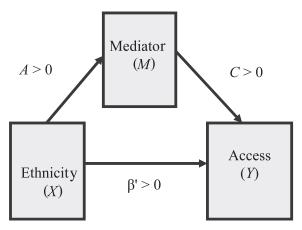


Figure 1. Mediation effects model showing direct and indirect effects and signs of the constituent coefficients.

dependent variable) comparable across the regression equations (MacKinnon & Dwyer, 1993). Second, because logistic regression is highly sensitive to model misspecification, the total effect was calculated as Indirect + Direct, rather than being separately estimated from a model with ethnicity but no mediator, as is the standard approach when the dependent variable is linear; the linear approach does not accurately estimate the total effect (MacKinnon & Dwyer, 1993). Finally, while results from the logistic regressions can be represented as odds ratios, the indirect effects are presented in standardized log-odds form (D. MacKinnon, personal communication, May 31, 2008).

Weighting and variance adjustment. Because the National Survey of Children with Special Health Care Needs is a stratified sample, we used SUDAAN to adjust standard errors and inferential statistic estimates. SUDAAN uses Taylor-series linearization to estimate variance with survey data derived from complex sampling designs such as the national survey (Research Triangle Institute, 2001).

Missing data. Due to missing data on several survey item variables, analyses were conducted on data that were subjected to multiple imputation (Schafer, 1997). A model was developed for generating conditional probability distributions for the missing values from which random draws were made, with this process repeated 15 times and the estimates from the model conducted on each version of the data combined according to rules accounting for the uncertainty of the randomly drawn values (Graham, Olchowski, &

Gilreath, 2007; Rose & Fraser, 2008; Rubin, 1987; Schafer & Graham, 2002). SAS Proc MI was used to conduct the imputation; SUDAAN automatically combined the model results (Research Triangle Institute, 2001).

Indirect Effect Calculations and Hypothesis Testing

From the standardized log-odds of A, β' , and C (labeled, A, β' , and C, respectively), we calculated the indirect effect as AC and the total effect as AC + β' . The indirect effect was then tested for its precision using the Sobel standard deviation (MacKinnon, Krull, & Lockwood, 2000; Sobel, 1982).

Results

The comparison between White and Latino children on health care utilization, quality, and access is reported in Table 2. As is evident from the table, a consistent and robust pattern of ethnic disparities was observed for the three domains of access, utilization, and quality of care. Difficulty using services (24% among Whites and 32% among Latinos), problems getting referrals (28% among Whites and 41% among Latinos), and unmet routine or preventive care needs (3% among Whites and 8% among Latinos) were significant utilization findings at the .05 level. Latino children were more likely to have providers who did not spend enough time with them (21% for Whites, 36% for Latinos; p < .001), providers who were not culturally sensitive (36% for Whites, 46% for Latinos; p < .01), and providers who did not make the parent feel like a partner (15% for Whites, 24% for Latinos; p < .01). Does Not Have a Usual Source of Care (5% among Whites and 10% among Latinos) and Child Has No Insurance (3% among Whites and 10% among Latinos) were significant access findings at the .01 level; Does Not Have a Personal Doctor was also significant (5% White compared with 12% Latino; p < .05). Trends of increased likelihood of having needed care foregone or delayed and having needs unmet by insurance were also found (p < .10).

Mediation Results

Table 3 reports the odds ratios and significance tests for effects A, β' , and C (covariates are not reported but can be requested from the authors), as well as the calculation and test of the indirect

Table 3 Mediation Results

	Effect	ct A	Effe	Effect β'	Effe	Effect C	Indirect	Total effect:	Indirect effect as	Sobel
Mediator and dependent variable	OR	A	OR	β′	OR	C	effect: AC	$AC + \beta'$	% of total effect	t-test
Provider does not spend enough										
time with child	1.72	0.196	0.81	-0.075	1.55	0.158	0.03	-0.04		1.82^{+}
Delayed care	1.68	0.184	1.31	0.094	2.01	0.246	0.05	0.14	32.5	2.41*
Difficulty using services	1.90	0.283	1.10	0.044	2.63	0.426	0.12	0.16	73.3	1.99^{+}
Problems with referrals										
Provider does not listen carefully										
Delayed care	1.20	0.063	0.84	-0.063	2.20	0.278	0.02	-0.05		0.74
Difficulty using services	1.14	0.044	1.38	0.110	2.95	0.365	0.02	0.13	12.8	0.52
Problems with referrals	1.23	0.097	1.22	0.091	3.96	0.318	0.03	0.12	25.3	0.57
Provider is not culturally sensitive										
Delayed care	1.55	0.158	0.81	-0.076	1.71	0.192	0.03	-0.05		1.91
Difficulty using services	1.58	0.159	1.28	0.084	2.57	0.325	0.05	0.14	38.1	2.43*
Problems with referrals	1.49	0.175	1.16	0.063	2.79	0.448	0.08	0.14	55.4	1.47
Provider does not make parent										
feel like partner										
Delayed care	1.93	0.226	0.74	-0.103	2.89	0.362	0.08	-0.02		2.67*
Difficulty using services	1.88	0.214	1.24	0.074	3.01	0.372	0.08	0.15	51.9	2.66*
Problems with referrals	1.90	0.283	1.13	0.056	2.61	0.423	0.12	0.18	68.3	1.84*

Note. Effect A is the mediator regressed on ethnicity. Effect β' is the dependent variable regressed on ethnicity. Effect C is the dependent variable regressed on the mediator, controlling for ethnicity, using standardized values. Indirect effect as a percent of total effect is valid only when AC > 0 and $\beta' > 0$.

p < .10. p < .05.

effect. After accounting for the mediator, the association between ethnicity and the dependent variable—the direct effect (β')—was not significant in any of the models. Based on the findings in Table 2, all of the utilization variables were tested in exploratory analysis for the presence of mediation, requiring positive A, β' , and C. Delayed Care did not demonstrate a positive β' , but Difficulty Using Services and Problems with Referrals demonstrated positive coefficients on all three effects. These two variables were therefore tested for mediation effects.

Mediation Calculation, Total Effect, and Test

The log-odds A, β' , and C were standardized (and relabeled A, β' , and C), with AC as the mediation effect and $AC + \beta'$ as the total effect. The findings were mixed, with several models demonstrating significant mediation and several being nonsignificant.

For Provider Does Not Spend Enough Time with Child, the mediation effect was significant for Difficulty Using Services (AC = 0.05, total effect = 0.14, indirect as percent of total = 32.5%; p <.05) and Problems with Referrals (AC = 0.12, total effect = 0.16, indirect as percent of total = 73.3%; p < .10). For Provider Does Not Listen Carefully, mediation was not significant with any of the dependent variables. For Provider Is Not Culturally Sensitive, significant mediation was observed for Difficulty Using Services (AC = 0.05, total effect = 0.14, indirect as percent of total = 38.1; p < .05). For Provider Does Not Make Parent Feel Like a Partner, significant mediation was observed for Difficulty Using Services (AC = 0.08, total effect = 0.15, indirect as percent of total = 51.9%; p <.01), and there was a trend-level effect found for Problems with Referrals (AC = 0.12, total effect = -0.18; p < .10).

Discussion

Our study aims to describe the extent of ethnic disparities in health care access and utilization and then to determine if inadequate health care quality mediated the relationship between ethnicity and health care utilization. To the best of our knowledge, this study is the first investigation that has described ethnic disparities in the health care access and utilization of Latino children with autism and other developmental disabilities,

building on existing evidence of disparate patterns of late diagnosis for Latino children with autism (Mandell et al., 2009; Mandell, Listerud, Levy, & Pinto-Martin, 2002). We note that a significant proportion of White children with autism and other developmental disabilities also had lower-quality health care outcomes, but Latino children consistently had worse outcomes, and they are our focus here.

The robust evidence that inadequate health care quality mediates the relationship between ethnicity and health care utilization offers support for the Institutes of Medicine finding that the clinical encounter is an important predictor of health care disparities (Smedley et al., 2002). When such behaviors are inadequate, this results in observed ethnic disparities. We first consider the study's limitations before discussing its implications.

Limitations

We cannot infer causality from these crosssectional data. Data from the National Survey of Children with Special Health Care Needs lacked the temporal ordering needed to derive a causal effect in the context of an indirect effects model: three separate time points are required, one for each of the variables (Shadish, Cook, & Campbell, 2002). Alternatively, it is possible that health care access and utilization are associated with ethnicity through a common unmeasured third variable. While we have confidence that the covariates included in the models capture some of these third variable effects, we cannot rule out the effects of unobserved variables. Some of these unobserved variables, including socioeconomic status, have been described in the previous literature (Emerson & Baines, 2010; Krahn et al., 2006; World Health Organization, 2010). Consequently, what we have identified as a mediation effect is a net effect of multiple gross effects that cannot be perfectly disaggregated. The Institutes of Medicine's model of health care access and utilization disparities supports a positive relationship between health care quality and health care utilization (Smedley et al., 2002). We therefore assume that the gross effect of health care quality on service utilization contributes positively to this net effect.

Further, research has not yet established whether any type of indirect effect can be transformed by exponentiation and interpreted accordingly as an odds ratio (D. MacKinnon,

personal communication, May 31, 2008). Consequently, all mediation effects findings are presented in log-odds form.

We also note that the population of Latinos in the United States is a large and heterogeneous group. We were not able to measure level of acculturation, documentation status, or country of origin with this data set. Further research could fruitfully examine how these issues contribute to the health care access and utilization of Latinos living in the United States.

Finally, we note that the extant research (Smedley et al., 2002) overwhelmingly indicates that racial and ethnic disparities in health care access and utilization are jointly produced from the aggregated effects of factors at the individual, clinician, and system level. As such, inadequate health care quality is one facet of this complex problem. Analyzing the full spectrum of factors that contribute to ethnic disparities is beyond the scope of any single study. However, understanding the role of inadequate health care quality is useful because it identifies a potentially malleable mechanism that policy makers can use to address disparities in the health care access of Latino children with autism and other developmental disabilities.

Despite these limitations, the study has important strengths. It employed a nationally representative sample of children with autism and other developmental disabilities. These findings are therefore representative of the entire U.S. population. The fact that families were not part of a clinical population of service recipients is another important strength and reduces selection bias. The employment of a range of critical covariates, all of which have been implicated in inadequate health care access, utilization, and quality, strengthens the likelihood that we are fairly estimating the true mediation effects here.

Implications

The first part of the study was directed at identifying the extent of ethnic disparities in health care access, utilization, and quality for Latino children with autism and other developmental disabilities. Across all indicators, Latino children fared far worse than their White peers. These findings mirror disparate access that has been reported elsewhere for Latino children without disability (Flores, 2010; Flores & Tomany-Korman, 2008).

This evidence is particularly disturbing in light of the public policy attention that racial and ethnic disparities have received. Ending these disparities has been part of Healthy People, the nation's public health blueprint, for years (see U.S. Department of Health and Human Services, 2000). Almost 10 years after the publication of the landmark Institutes of Medicine study cataloging racial and ethnic disparities in health care for the nondisabled population (Smedley et al., 2002), the present findings indicate that adverse outcomes continue to be the norm. And deleterious outcomes for vulnerable children with autism and other developmental disabilities can result in secondary health conditions that are costly and harmful from a public health standpoint as well as to families.

When we examined the direct effect between ethnicity and measures of health care access, utilization, and quality, a robust pattern of deleterious outcomes for Latino children with autism and other developmental disabilities emerged. This pattern of ethnic disparities is troubling, given the decades of evidence about persistent and pernicious patterns of inadequate health care access and utilization that has been found for Latinos without disability in the United States and efforts to remediate such inequities (Smedley et al., 2002).

Our investigation yields a more comprehensive picture of ethnic health care utilization disparities and suggests that the sequence of effects is likely important. As noted previously, the Institutes of Medicine has identified likely factors contributing to ethnic and health disparities occurring at the levels of the individual patient, the health care system, and the clinical encounter between patient and health care service provider. These findings suggest that a possible malleable factor with significant potential to reduce ethnic disparities in utilization is the behavior of the health care provider. Admittedly, the phenomenon of ethnic health care disparities is complex. However, the models included controls for a range of important factors that have been found to be confounders in previous research: child age, Spanish language of parent, parental education, income, health insurance status, severity of the child's condition. Controlling for these covariates, the effect sizes of the mediation were significant and large. The relative importance of the mediation effects is represented by the proportion of the total effect, with

proportions as low as 19% and as high as 61% among the significant mediation findings. We note that mediation effects are often small in health services research, and these results are sizable.

These findings indicate that the ethnic disparities in health care utilization—which ultimately lead to adverse health consequences for Latino children with autism and other developmental disabilities—may well be reduced by improving care at the level of the clinical encounter. Policy makers may be well advised to consider incentives that compel health care providers, particularly those that receive Medicaid reimbursement, to meet benchmarks for patient satisfaction and improve the quality of care they provide.

However, these findings are descriptive and require further corroboration; it would be most useful if they could be replicated with a longitudinal study design. If future research replicates these findings, they provide strong support for aggressive efforts to strengthen the familycentered care that health care providers offer their Latino patients with autism and other developmental disabilities. Three potential policy mechanisms could be employed to reach these targets. First, efforts to promote family-centered, responsive care should be strengthened in clinical training programs and continuing education of health care providers. While numerous initiatives are under way to promote the cultural competence of health care providers (Betancourt, Green, Carrillo, & Park, 2005; Office of Minority Health, n.d.), the present study indicates that more work and a greater investment of resources are needed along these lines.

A second promising policy initiative would be to tie health care provider compensation more directly to quality. These findings support current provisions in the Patient Protection and Affordable Care Act of 2010 to improve health care quality for people with disabilities. This study offers preliminary evidence that such a focus on quality may well be an effective strategy to reduce ethnic disparities in health care utilization for Latino children with autism and other developmental disabilities.

And finally, the present study supports existing calls to expand the pool of available physicians and nurses from the Latino community (DeChavez, Cobo, Schlom, Chatterjee, & Jiang, 2004). The existing evidence suggests that Latinos report better-quality care from physicians

who are culturally competent (Fernandez et al., 2004).

Conclusion

This study found evidence of significant disparities in the health care access and utilization of Latino and White children with autism and other developmental disabilities. Furthermore, the relationship between ethnicity and health care utilization is mediated by the quality of care that is provided. Further investigation is needed to fully understand the mechanisms associated with disparities in health care access and utilization. However, if the evidence generated by this study is replicated, improving the quality of the clinical encounter offers promise as an intervention that will improve health care access and utilization for Latino children with autism and other developmental disabilities.

References

Betancourt, J. R., Green, A. R., Carrillo, J. E., & Park, E. R. (2005). Cultural competence and health care disparities: Key perspectives and trends. *Health Affairs*, 24, 499–505.

Bethell, C.D., Read, D., Stein, R. E. K., Blumberg, S. J., Wells, N., & Newacheck, P. W. (2002). Identifying children with special health care needs: Development and evaluation of a short screening instrument. *Ambulatory Pediatrics*, 2, 38–48.

Blumberg, S. J., Olson, L., Frankel, M., Osborn, L., Becker, C. J., Srinath, K. P., & Giambo, P. (2003). Design and operation of the National Survey of Children with Special Health Care Needs, 2001. *Vital Health Statistics 1, 41*. Available at http://www.cdc.gov/nchs/data/series/sr_01/sr01_041.pdf

Blumberg, S. J., Welch, E. M., Chowdhury, S. R., Upchurch, H. L., Parker, E. K., Skalland, B. J. (2008). Design and operation of the National Survey of Children with Special Health Care Needs, 2005–2006. *Vital Health Statistics* 1, 45, 1–188.

DeChavez, P. M., Cobo, A., Schlom, A., Chatterjee, S., & Jiang, F. (2004). Defense of social justice: Latino physicians as a means to reduce disparities. *Harvard Journal of Hispanic Policy*, 16, 111–114.

Emerson, E., & Baines, S. (2010). Health inequalities and people with learning disabilities in the

- *UK:* 2010 (IHAL 2010-03). Available at http://www.improvinghealthandlives.org.uk/uploads/doc/vid_7479_IHaL2010-3HealthInequa lity2010.pdf
- Fernandez, A. F., Schillinger, D., Grumbach, K., Rosenthal, A., Stewart, A. L., Wang, F., Pérez-Stable, E. J. (2004). Physician language ability and cultural competence: An exploratory study of communication with Spanish-speaking patients. *Journal of General & Internal Medicine*, 19, 167–174.
- Flores, G. (2010). Technical report: Racial and ethnic disparities in the health and health care of children. *Pediatrics*, 125, e979–e1020.
- Flores, G., & Tomany-Korman, S. C. (2008). Racial and ethnic disparities in medical and dental health, access to care, and use of services in US children. *Pediatrics*, 121, e286–e298.
- Fry, R. (2008). Latino settlement in the new century (Report of the Pew Hispanic Center). Available at http://www.pewhispanic.org/files/reports/96.pdf
- Graham, J. W., Olchowski, A. E., & Gilreath, T. D. (2007). How many imputations are really needed? Some practical clarifications of multiple imputation theory. *Prevention Science*, 8, 206–213.
- Gurney, J. G., McPheeters, M. L., & Davis, M. M. (2006). Parental report of health conditions and health care use among children with and without autism. *Archives of Pediatric & Adolescent Medicine*, 160, 825–830.
- Javier, J., Huffman, L., Mendoza, F., & Wise, P. (2010). Children with special health care needs: How immigrant staus is related to health care access, health care ulilization, and health status. *Maternal & Child Health Journal*, 14, 567–579.
- Kogan, M., Strickland, B., Blumberg, S., Singh, G., Perrin, J., & van Dyck, P. (2008). A national profile of health care experiences and family impact of autism spectrum disorder among children in the United States, 2005–2006. *Pediatrics*, 122(6), e1149–e1158.
- Krahn, G. L., Hammond, L., & Turner, A. (2006). A cascade of disparities: Health and health care access for people with intellectual disabilities. *Mental Retardation & Developmental Disabilities Research Reviews*, 12, 70-82.
- Krauss, M. W., Gulley, S., Sciegaj, M., & Wells, N. (2003). Access to specialty medical care for children with mental retardation, autism and

- other special health care needs. *Mental Retardation*, 41, 329–339.
- Liptak, G. S., Benzoni, L. B., Mruzek, D. W., Nolan, K. W., Thingvoll, M. A., Wade, C. M., & Fryer, G. E. (2008). Disparities in diagnosis and access to health services for children with autism: Data from the National Survey of Childen's Health. *Journal of Developmental Pediatrics*, 29, 152–160.
- Liu, K., Zerubavel, N., & Bearman, P. (2010). Social demographic change and autism. *Demography*, 47(2), 327–343.
- MacKinnon, D. P., & Dwyer J. H. (1993). Estimating mediated effects in prevention studies. *Evaluation Review*, 17, 144–158.
- MacKinnon, D. P., Krull, J. L., & Lockwood, C. M. (2000). Equivalence of the mediation, confounding and suppression effect. *Prevention Science*, *1*, 173–181.
- MacKinnon, D. P., Lockwood, C. M., Hoffman, J. M., West, S. G., & Sheets, V. (2002). A comparison of methods to test mediation and other intervening variable effects. *Psychological Methods*, 7, 83–104.
- Mandell, D., Listerud, J., Levy, S., & Pinto-Martin, J. (2002). Race differences in the age at diagnosis among Medicaid-eligible children with autism. *Journal of the American Academy of Child & Adolescent Psychiatry*, 41, 1447–1453.
- Mandell, D. S., Wiggins, L. D., Carpenter, L. A., Daniels, J., DiGuiseppi, C., Durkin, M. S., ... Kirby, R. S. (2009). Racial/ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health*, 99(3), 493–498.
- Newacheck, P. W., Rising, J. P., & Kim, S. E. (2006). Children at risk for special health care needs. *Pediatrics*, 118, 334–342.
- Office of Minority Health. (n.d.). *Initiatives*. Available at http://www.minorityhealth.hhs. gov/templates/browse.aspx?lvl=3&lvlid=17
- Research Triangle Institute. (2001). SUDAAN user's manual, release 8.0. Research Triangle Park, NC: Author.
- Rose, R. A., & Fraser, M. W. (2008). A simplified framework for using multiple imputation in social work research. *Social Work Research*, 32, 172–178.
- Rubin, D. B. (1987). Multiple imputation for nonresponse in surveys. New York, NY: Wiley.
- Schafer, J. L. (1997). Analysis of incomplete multivariate data. Boca Raton, FL: Chapman Hall/CRC.

- Schafer, J. L., & Graham, J. W. (2002). Missing data: Our view of the state of the art. *Psychological Methods*, 7, 147–177.
- Shadish, W. R., Cook, T. D., & Campbell, D. T. (2002). Experimental and quasi-experimental designs for generalized causal inference. New York, NY: Houghton Mifflin.
- Smedley, B. D., Stith, A. Y., & Nelson, A. R. (Eds.). (2002). *Unequal treatment: Confronting racial and ethnic disparities in health care*. Washington, DC: National Academy Press.
- Sobel, M. E. (1982). Asymptotic confidence intervals for indirect effects in structural equation models. In S. Leinhardt (Ed.), *Sociological methodology 1982* (pp. 290–312). Washington, DC: American Sociological Association.
- Strickland, B., Singh, G., Kogan, M., Mann, M., van Dyck, P., & Newacheck, P. (2009). Access to the medical home: New findings from the 2005–06 National Survey of Children with Special Health Care Needs. *Pediatrics*, 123, e996–1004.
- U.S. Department of Health and Human Services. (2000). *Healthy people 2010 final review*. Available at http://www.cdc.gov/nchs/healthy_people/hp2010/hp2010_final_review.htm
- Weinick, R. M., & Krauss, N. A. (2000). Racial/ethnic differences in children's access to care. *American Journal of Public Health*, 90, 1771–1774.
- World Health Organization. (2010). Better health, better lives: Children and young people with intellectual disabilities and their families. Bucharest, Romania. Available at http://www.euro.who.int/__data/assets/pdf_file/0003/126570/e94430.pdf

- Yu, S. M., Huang, J., Schwalberg, R. H., & Nyman, R. M. (2006). Parental English proficiency and children's health access. *American Journal of Public Health*, 96, 1449– 1455.
- Yu, S. M., & Singh, G. K. (2009). Household language use and health care access, unmet need and family impact among CSHCN. *Pediatrics*, 124, S414–S419.

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Authors:

Susan Parish (e-mail: slp@Brandeis.edu), Lurie Institute for Disability Policy, Heller School for Social Policy and Management, Brandeis University, 415 South Street, MS 035, Waltham, MA 02454, USA; Sandra Magaña, University of Wisconsin-Madison; Roderick Rose, University of North Carolina at Chapel Hill; Maria Timberlake, Brandeis University; Jamie G. Swaine, University of North Carolina at Chapel Hill.