An Evaluation of School Involvement and Satisfaction of Parents of Children with Autism Spectrum Disorders

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Abstract

Parental school involvement and satisfaction are unstudied in families raising a child with an autism spectrum disorder (ASD). To fill this gap, the current study utilized a national sample of families (N = 8,978) from the 2007 Parent and Family Involvement in Education survey (U.S. Department of Education, National Center for Education Statistics, 2006–2007). Parents of children with ASDs were found to be more likely than parents of children without the disorder to attend parent–teacher conferences, meet with school guidance counselors, and help with homework. Parents of children with ASD were also more dissatisfied with the level of communication provided by the school. There was a significant positive correlation between parental school involvement and parental school satisfaction. These findings have important implications for how schools interact with families with children with ASD.

Key Words: autism; school; parent involvement; national survey

Within the United States, students with autism spectrum disorders (ASDs) make up one of the largest populations of students receiving special education and related services (U.S. Department of Education, National Center for Education Statistics, 2010). The term ASD is specifically used in reference to a group of developmental disorders including autistic disorder, Asperger syndrome, and pervasive developmental disordersnot otherwise specified (PDD-NOS; American Psychiatric Association, 2000). Children diagnosed with ASDs are distinguished by an exhibition of repetitive or stereotyped behaviors, impairments in social functioning, and deficits in communication. ASDs have gained widespread recognition as the rate of diagnosis for these disorders has increased dramatically in the past decade (Autism and Developmental Disabilities Monitoring Network Surveillance Year 2006 Principal Investigators, Centers for Disease Control and Prevention, 2009).

Coinciding with a notable increase in prevalence over the last few decades, there has also been a growing trend of litigation involving the parents of children with ASDs and education agencies that serve these children (Mandlawitz, 2002; Turnbull, Wilcox, & Stowe, 2002). One of the most critical outcomes of this legal action was the mandate in the 1997 amendments to the Individuals with Disabilities Education Act that parents of children with disabilities be involved in their children's education. Through such legislation, school professionals and families may play an equally active role in shaping the education experiences of children with disabilities. Despite these changes, the relationship between parents of children with autism and education professionals remains relatively unexplored and undervalued. Moreover, little to no attention has been paid to the parents of children with ASD and how involved they are in their children's schools as well as their level of satisfaction with the school.

Among regular education students, parent involvement has been found to help mediate a child's developmental trajectory in schools and is consistently linked to positive academic and social outcomes (Amato & Rivera, 1999; Fan & Chen, 2001; Hill & Taylor, 2004; Topor, Keane, Shelton, & Calkins, 2010). Parents who are involved in their child's education are more likely

to see their child graduate high school while reducing the likelihood of their child receiving disciplinary actions, including suspensions and expulsions (Astone & McLanahan, 1991; Sheldon & Epstein, 2002). Furthermore, parents who are involved and invested in their children's schooling are less likely to have children with behavioral problems (Comer, 1984; Powell, Son, File, & San Juan, 2010; Rogers, Wiener, Marton, & Tannock, 2009). For these reasons, among others, parental involvement is considered to be a best practice for children by the National Research Council (2001).

Despite the presence of a large body of literature dedicated to regular education students, few studies have identified the impact or level of parental involvement within and outside of school for children receiving special education services, particularly those children with developmental disabilities like ASDs. Benson, Karlof, and Siperstein (2008) investigated the role of parental school involvement in a child's education for 95 children with ASD and found that involvement in school and home activities was directly correlated to the number and quality of activities the school provided to parents to encourage involvement. Furthermore, they found that the severity of the child's behaviors influenced the level of parental involvement, with the most impaired children having the lowest level of parental involvement.

Another study of 45 families of children with ASD or related disorders conducted by Spann, Kohler, and Soenksen (2003) further illuminates the need to assess the impact of parental involvement on a child's education. Although the majority of parents, who were recruited from support groups, reported relatively high levels of participation in their child's education, with 51% reporting communicating with their child's school daily and 56% reporting at least moderate involvement with the individualized education program (IEP), the level of involvement, as well as school satisfaction, decreased as the children's age increased. When asked how well the school was addressing their child's needs, 83% of parents whose children were between the ages 15 and 18 reported that the schools were inadequate, as opposed to 36% of parents whose children were from 4 to 5 years of age.

In regard to involvement with homework, the literature dedicated to children with autism also remains largely absent, with few studies exploring this relationship even among children receiving

special education services. The literature suggests that parents are more likely to participate in their child's homework when their child or their child's teacher expresses that the involvement is expected or needed (Balli, Demo, & Wedman, 1998; Hoover-Dempsey & Sandler, 1997). Heller, Spooner, Anderson, and Mims (1988) observed that homework completion for students receiving special education services may be directly related not only to parental attitudes toward homework completion but also to the willingness of parents and teachers to work together. Further confounding the relationship between parents and homework involvement, Bryan and Nelson (1994) observed that parental involvement in homework is the greatest during elementary school while diminishing into junior high school for children with special education needs.

Parental school satisfaction also remains an understudied area for families of children with disabilities and ASDs, with the limited research available providing contradictory evidence. Spann and colleagues (2003) reported only a 36% level of parent satisfaction with services received by their youngest subset of school-aged children. However, Bitterman, Daley, Misra, Carlson, and Markowitz (2008) uncovered a parent satisfaction level of over 86% for services received from the school district for their ASD child, although parents of children with ASD were significantly less satisfied with various services when compared with families with children with other developmental disabilities. Renty and Roeyers (2006) found parents generally satisfied with services received by their child with ASD, despite complaints regarding diagnostic services, particularly age of diagnosis, which delayed services being sought and obtained.

Perhaps one of the most critical areas where participation is most needed among parents of children with disabilities relates to the development of their child's IEP (Smith, 1990; Turnbull et al., 2002). An IEP is a legal document outlining measurable goals that may include educational and functional targets (i.e., toileting, social skills, etc.; U.S. Department of Education, Office of Special Education Programs, 2006). It also serves as a way to assess and track a child's progress over the year in these goals and allows for parents and teachers to determine whether adjustments need to be made to the plan or curriculum. Hoover-Dempsey and Sandler (1997) found that parents who take an active role in their child's overall education have significantly higher levels of satisfaction with regard to the process of developing the IEP.

To date, the majority of samples drawn to explore parental school involvement and attitudes come from small clinical or convenient samples. Although these samples may benefit from having established diagnoses, they are limited in their representativeness and therefore lack generalizability to other groups of children. The individuals participating in these studies have typically volunteered their time and as a result may lend these studies to sampling and ascertainment biases. Furthermore, previous studies have been restricted to one geographical location, creating homogeneous samples that do not necessarily reflect the heterogeneous nature of children with ASDs and their parents. This is a particular concern when assessing school-based studies, as they typically focus on one particular district or schools within one geographic location. Therefore, there still remains a dramatic gap in substantiated research surrounding the relationship of parent involvement in school-related activities and the development of children with special needs, specifically ASDs.

Utilizing a national, population-based sample, this article fills a crucial gap in the literature by examining the involvement and satisfaction levels of parents of children with ASDs through several domains of family functioning and their intersection with their child's school and education plan. To provide a representative picture of all school experiences, children with ASDs will be compared with the general population as well as children with other disabilities. It is hypothesized that parents of children with ASDs are more likely to be involved in activities relating to their children's academic success, including their homework, a consequence of the children needing more academic support than their typically developing peers. Furthermore, parents of children with ASDs are less likely to be satisfied with their children's IEPs and/or services received when compared with parents of children with other disabilities, a consequence of the children needing more intensive resources than other children with disabilities, which subsequently may not be available at a given school.

Method

The 2007 Parent and Family Involvement in Education Survey (PFI; U.S. Department of

Education, National Center for Education Statistics, 2006-2007) was part of the larger National Household Education Surveys Program, developed by the National Center for Education Statistics. The PFI was conducted from January to May 2007 using a computer-assisted telephone interviews system and was designed to capture the educational experiences of children and their families in schools, with questions regarding communications with teachers and administrators, involvement in the children's schoolwork, and participation in and out of the children's schools. As a nationally representative, multistage, cluster-designed survey, the PFI contains population-based weights that reflect both survey sampling probabilities while allowing for adjustment based on nonresponse and households without telephones.

The PFI consisted of 10,681 households with children in kindergarten through the 12th grade across all 50 states and the District of Columbia (74.1% response rate). The respondent for the PFI was the self-identified adult in the household who was considered the most knowledgeable about the sampled child (73% mothers). The surveys were primarily conducted in English, with a small percentage conducted in Spanish (7%). The data set contains imputed values for all missing values that were calculated using a hot-deck imputation procedure. Further details about the study design, methodology, and data set can be found in Hagedorn, Roth, Carver, Van de Kerckhove, and Smith (2009).

The sample obtained for the current study was restricted to families with a child in public schools (N = 8,978), as children who are either homeschooled or attending a private school are not required by law to be provided an IEP. In the restricted sample, 109 children were identified as having been diagnosed with autism, while 76 children were identified as having been diagnosed with a pervasive developmental disability (PDD); a combined group, after accounting for overlap, included 142 children with an ASD.

Measures

Dependent School Variables

Parental school involvement. Questions pertaining to parental involvement in school included participation in the following events over the past school year: attended a general school meeting, attended a parent–teacher organization or

parent-teacher association meeting, attended a parent-teacher conference, attended a school event, volunteered at the school, participated in fund-raising, served on a committee, or met with the school guidance counselor.

Parental school satisfaction. Parents were asked to rate their level of satisfaction on a Likert scale with the options of *very dissatisfied*, *somewhat dissatisfied*, *somewhat satisfied*, and *very satisfied* regarding the child's school, academic standards, order and discipline, teachers, and any interaction with staff.

Parental perception of school communication. Parents were asked to indicate their level of satisfaction on a Likert scale with the options of very well, just O.K., not very well, and doesn't do it at all for four questions about the school's level of communication in providing progress updates in between report cards, guidance in helping with homework, explanations for placement in a given group or classroom, and information on the parent's expected role at the school.

Parental homework involvement. Four questions were asked about the parents' involvement in their child's homework on a daily basis, including whether the child has a place in the house to complete homework, whether the family has rules for homework, whether the parents check their child's homework, and how many days a week the parent helps with homework.

Parental satisfaction with IEP. The final four questions relate to how satisfied parents are with items in their child's IEP on a Likert scale with the options very dissatisfied, somewhat dissatisfied, somewhat satisfied, and very satisfied regarding the school's communication, the quality of the child's teachers or therapists, the school's ability to accommodate their child's needs, and the school's commitment to help their child learn. These questions were limited to children who were receiving special education services.

Child-level Predictors

ASD diagnosis. The primary independent variable was derived from a question pertaining to developmental disabilities: "Has a health professional told you that [child's name] has any of the following disabilities? 1) Pervasive Developmental Disorder or PDD? 2) Autism?"

Other disability. A derived variable was created that indicates whether a parent had been told that his or her child has any disability besides

an ASD, including a specific learning disability, mental retardation, a speech or language delay, a serious emotional disturbance, deafness or another hearing impairment, blindness or another visual impairment not corrected with glasses, an orthopedic impairment, or attention deficit disorder (ADD) or attention deficit/hyperactivity disorder (ADHD). Individuals with other disabilities, but not ASDs, serve as a comparison group for various models.

Demographics. Information regarding the child's age, race, gender, and ethnicity was obtained from explicit questions in the survey. Family-level predictors included income level (divided into four groups: <\$35,000, \$35,000-\$60,000, \$60,001-\$100,000, >\$100,000), household type (two-parent household with two biological or adoptive parents vs. other household types), number of children, level of parent education, immigrant status, and employment status (working 50 or more weeks a year). These variables were also obtained from explicit questions in the survey. School-level predictors pertained to the size of the school, level, urbanity, region of the country, and whether the parents had a choice in picking the public school.

Statistical Analysis

Weighted multiple logistic regression models were performed for each school outcome of interest with ASD as the primary predictor, adjusting for child demographics (gender, age, race, and ethnicity), as well as family (income, number of children, household type, immigrant status of parents, education level of parents, and whether parents maintain regular employment) and school predictors (size, location, level, urbanity, region of country, and whether school was chosen by parents). Two series of logistic regression models were run, with the first comparing parents of children with ASDs with the rest of the population for general school questions and the second comparing parents of children with ASDs with parents of children with other disabilities, with or without an IEP. For questions pertaining to IEP items, a single weighted multiple logistic regression model compared children diagnosed with an ASD with an IEP with children without an ASD diagnosis with an IEP. Within the models, satisfaction measures were divided into satisfied (coded as 0) and dissatisfied (coded as 1), while agreement measures were divided into agree

(coded as 0) and *disagree* (coded as 1). School communication measures were divided into *very well* (coded as 1) and all other outcomes (coded as 0). Measures were dichotomized to increase statistical interpretability and avoid power issues associated with small sample size. All analyses were performed using Stata 10.1 (College Station, Texas).

Secondary analyses explored the relationship between the number of comorbid conditions for children with ASDs and the level of parental involvement and satisfaction using weighted multiple linear regression models. In these models, the outcome was the number of parent school involvement activities, the number of school items with which the parent is satisfied, or the number of IEP items with which the parent is satisfied. Covariates included in the weighted linear regression model matched those included in the weighted multiple logistic regression models. A final analysis calculated the correlation between parental involvement and parental satisfaction for children with ASDs, children with other disabilities, and children from the general population.

Results

Sample Differences

Table 1 includes weighted (generalizable to the U.S. population) descriptive statistics of children with and without an ASD. In the weighted sample, 1.7% of children were identified as having an ASD, with 1.2% being identified as having autism. There were several notable weighted demographic differences between children with and without an ASD. Children with ASDs when compared with children in the general population were more likely to be male (84.1% vs. 51.5%, p <.0001) and have an IEP (70.3% vs. 7.6%, p <.0001). Children with ASDs were also more likely to live in households with lower incomes compared with children from the general population (p = .01). Table 2 compares children with ASD with children from the general population on mental and physical disabilities. Children with ASD were more likely than children from the general population to have learning disabilities (63.2% vs. 9.1%, p < .0001), mental retardation (16.7% vs. 0.7%, p < .0001), ADHD (42.3% vs.)9.5%, p < .0001), speech or language problems (62.1% vs. 8.1%, p < .0001), emotional disturbances (27.4% vs. 3.1%, p < .0001), deafness or

hearing impairments (8.2% vs. 2.1%, p = .005), blindness or visual impairments (5.0% vs. 1.4%, p = .002), and orthopedic impairments (9.2% vs. 2.4%, p < .0001). A total of 86.3% of children with an ASD presented with an additional disability, while 19.3% of children from the general population presented with any disability. On average, children with ASDs had significantly more disabilities (2.0 vs. 0.3, p < .001) than children from the general population.

The type and number of disabilities were further explored within the subgroup of children with ASDs, that is, between autism and PDDs. Children with autism were more likely to present with speech or language problems (71.5% vs. 37.6%, p = .02) compared with children with PDD but were less likely to be diagnosed with ADHD (33.8% vs. 64.3%, p = .04). There were no significant differences in number of disabilities between the two subgroups with ASDs (autism: 2.0 vs. PDD: 2.1; p = .96) or in the percentage of children with at least one additional disability (autism: 88.9% vs. PDD: 86.0%; p = .40).

Children with ASD Versus General-Population Children

Parents of children with ASDs were more likely to have attended a parent-teacher conference (OR =3.01, 95% CI [1.15, 7.90], p = .03) and to have met with the school guidance counselor (OR =3.63, 95% CI [1.98, 6.67], p < .001) when compared with parents of general-population children. These parents were also more likely to be involved in their child's homework, both checking their child's homework (OR = 3.75, 95%CI [1.19, 11.85], p = .02) and helping their child with homework one or more days a week (OR =5.90, 95% CI [2.09, 16.65], p = .001). Finally, these parents were less likely to be satisfied with the level of communication from the school about their child's placement (OR = 0.32, 95% CI [0.14, 0.75], p = .008) when compared with parents of general-population children.

Children with ASD Versus Children with Other Disabilities

The second series of adjusted weighted multiple logistic regression models compared children with ASD with children with other disabilities. Parents of children with ASDs were more likely to have attended a parent–teacher conference (OR = 2.79, 95% CI [1.03, 7.56], p = .04) and to have met

Table 1 Weighted Child, Family, and School Demographics of Children with and Without Autism Spectrum Disorders (ASDs)

	Overall	With ASD		Weighted test	
Characteristics	(n = 45,517,480)	(n = 7/55,590)	(n = 44,761,890)	statistic ^a	p value
Child characteristics					
Male	52.1%	84.1%	51.5%	43.67	< .0001
Age (mean)	11.6	12.0	11.6	0.65	.52
Race				1.43	.24
White	68.2%	68.4%	68.2%		
African American	17.8%	24.2%	17.7%		
Other	14.0%	7.4%	14.1%		
Hispanic	20.1%	18.3%	20.1%	0.16	.69
Has IEP	8.6%	70.3%	7.6%	328.67	< .0001
Family characteristics					
Household income				4.02	.01
<\$35,000	34.0%	50.6%	33.7%		
\$35,000-\$60,000	21.5%	17.0%	21.6%		
\$60,001-\$100,000	24.2%	17.6%	24.3%		
>\$100,000	20.3%	14.8%	20.3%		
Number of children in house				1.34	.26
1	22.9%	32.2%	22.7%		
2	55.0%	51.2%	55.1%		
3 or more	22.1%	16.6%	22.2%		
2-parent household (biological					
or adoptive)	70.8%	63.2%	70.9%	1.78	.18
At least one immigrant parent	28.6%	19.3%	28.7%	2.87	.09
At least one college-educated					
parent	76.1%	81.3%	76.0%	1.25	.26
At least one regularly					
employed parent	99.0%	99.8%	99.0%	2.14	.14
School characteristics					
Enrollment over 1,000 students	s 29.7%	22.4%	29.8%	2.43	.12
Urbanity				2.73	.05
City	21.6%	15.9%	21.7%		
Suburb	11.4%	16.0%	11.4%		
Town	36.5%	26.4%	36.6%		
Rural	30.5%	41.7%	30.3%		
Geographic location				0.39	.74
Northeast	17.6%	15.0%	17.6%		
South	36.0%	36.3%	36.0%		
Midwest	22.0%	27.1%	21.9%		
West	24.4%	21.6%	24.5%		
School level				0.14	.86
Elementary	44.0%	42.3%	44.1%	0.11	.00

(Table 1 continued)

Table 1 Continued

Characteristics	Overall $(n = 45,517,480)$	With ASD $(n = 755,590)$	Without ASD $(n = 44,761,890)$	\mathcal{C}	p value
Middle school/junior high Senior high school	23.5% 32.5%	22.1% 35.6%	23.5% 32.4%		

Note. IEP = individualized education program.

with the school's guidance counselor (OR = 2.26, 95% CI [1.22, 4.19], p = .01) compared with parents of children with other disabilities. Parents of children with ASDs were less likely to be satisfied with the level of school communication regarding the child's placement (OR = 0.35, 95% CI [0.15, 0.80], p = .01) and role in the school (OR = 0.26, 95% CI [0.10, 0.68], p = .005) compared with parents of children with other disabilities. No significant differences were found between parents of children with ASD and parents of children with other disabilities regarding IEP plans after adjustment.

Comorbid Disabilities

The number of comorbid disabilities appeared to decrease the level of parental involvement for children with an ASD ($\beta = -0.39$, p = .01) in the weighted multiple linear regression model (see Table 3), with notable significant predictors in school type, with children in elementary school having the highest level of parental involvement compared with middle ($\beta = -2.49$, p < .001) and high school ($\beta = -5.38$, p < .001). Other

significant predictors included size of school, with parents being more involved in larger schools than smaller schools ($\beta = 1.59$, p < .001), and families with two or more children in the household were less involved than families with only one child ($\beta = -2.30$, p < .001).

As the number of comorbid disabilities increased, the level of dissatisfaction also increased parent of children with an ASD ($\beta = 0.28$, p = .02) in the multiple linear regression model, with notable significant predictors in school type, with children in middle school having the highest level of parental dissatisfaction compared with elementary school ($\beta = 1.33$, p = .03). The number of disabilities in the population without ASD did not reflect the same trend as in the population with ASD and in fact was associated with an increase in parental involvement (β = 0.13, p = .01). Finally, for children with ASD with an IEP, the number of comorbid conditions and the level of parental satisfaction were directly related; as the number of comorbid conditions of a child with ASD increased, so, too, did the level of parental dissatisfaction ($\beta = 0.29$, p = .014). A

Table 2
Presence of Disabilities in the Weighted Sample

Diagnosis	% without ASD $(n = 44,761,890)$	% with ASD (n = 755,590)	Weighted χ^2	p value
Learning disability	9.1	63.2	203.45	< .0001
Mental retardation	0.7	16.7	242.21	< .0001
Attention deficit/hyperactivity disorder	9.5	42.3	65.72	< .0001
Emotional disturbance	3.1	27.4	73.37	< .0001
Speech or language problems	8.1	62.1	188.84	< .0001
Deafness or hearing impairments	2.1	8.2	12.02	.005
Blindness or visual impairments	1.4	5.0	9.79	.002
Orthopedic impairments	2.4	9.2	16.32	< .0001
Any disability ^a	19.2	86.3	201.76	< .0001

^aAny disability is in addition to autism spectrum disorder (ASD) for the group with ASD.

^aWeighted χ^2 or *t*-test.

nonsignificant trend was noted for children without ASDs but with other disabilities ($\beta = 0.05$, p = .58).

Relationship Between Parental Involvement and Satisfaction

A final analysis calculated correlations between parental involvement and parental satisfaction for various subgroups of children. Parental involvement was positively correlated with parental satisfaction for the entire sample ($\rho = 0.10$, p < .001). The correlation was significant for children from the general population ($\rho = 0.09$, p < .001) and those with non-ASD disabilities ($\rho = 0.14$, p = .003) but not for children with ASDs ($\rho = 0.08$, p = .58).

Discussion

Regarding their children's education, parents of children with ASDs differ from parents of the general population in some important ways. For instance, parents of children with ASDs are more likely to attend parent-teacher conferences, meet with the school guidance counselor, and help their children with their homework. Furthermore, they are less likely to be satisfied with the level of communication from the school regarding their child's placement in a given classroom or group.

These findings are likely to be influenced by the high level of physical and mental disabilities encountered by the population of children with ASDs when compared with the general population. Children with ASDs had dramatically higher rates of learning disabilities, intellectual disabilities, emotional disturbances, ADHD, and speech and language problems when compared with the general population. In this population-based study, approximately 86% of children with ASD presented with at least one comorbid disability, consistent with the literature dedicated to comorbid conditions in children with ASD (Simonoff et al., 2008).

The literature on psychiatric comorbidities in children with ASD also mirrors the study findings of high rates of emotional and behavioral disturbances and mental retardation (Matson & Shoemaker, 2009). Emotional and behavioral disorders are relatively common among children with ASDs, with approximately 43% of children diagnosed with ASD also meeting diagnostic criteria for ADHD (Hofvander et al., 2009), over

a third meeting diagnostic criteria for obsessive compulsive disorder (OCD), and over a tenth meeting diagnostic criteria for oppositional defiant disorder (ODD; Leyfer et al., 2006). Children with ASDs are also more likely to exhibit internalizing symptoms than the general population of children (Kim, Szatmari, Bryson, Streiner, & Wilson, 2000), with depression being more highly associated with children with the least impairing types of ASDs, namely, Asperger syndrome (Ghaziuddin, Ghaziuddin, & Greden, 2002). Parents of children with ASD with comorbid behavioral problems report higher levels of stress than parents of children with ASD alone (Lecavalier, Leone, & Wiltz, 2006), which has the potential to impact a parent's level of school involvement given the increased caregiver burdens.

The results of this study also found children with ASDs to have higher rates of orthopedic problems, as well as hearing and vision problems, when compared with the general population. Previous literature does dictate that children with ASDs are more likely to have co-occurring physical health problems than their typically developing peers. Fragile X syndrome, epilepsy, tuberous sclerosis, cerebral palsy, and obesity have been found to be more common in children with ASD than in the general population (Curtin, Anderson, Must, & Bandini, 2010; Tidmarsh & Volkmar, 2003). However, there is currently little literature dedicated to hearing, vision, and orthopedic problems in children with ASDs compared with children of the general population. A study by Montes and Halterman (2006) found orthopedic problems to be more common in children with ASDs but no differences for hearing or vision problems, which they attribute potentially to their small sample size.

Parents of children with more disabilities were less likely to be involved in their children's school, a finding that supports previous research (Benson et al., 2008). It is possible that this relationship is an artifact of the level of satisfaction with the school among parents of children with ASD, as parents of children with more disabilities were found to be less satisfied with their children's school. The correlation between parental satisfaction and parental involvement was positive and significant in the overall sample, along with parents of children with non-ASD disabilities. It was not found to be significant for parents of children with ASDs, which may be a

Table 3 Weighted Linear Regression for Parents of Children with Autism Spectrum Disorders

Parental school involvement Parental c	Parental school involvement	lvement	Parental dissatisfaction with school	with school	Parental dissatisfaction with IEP	n with IEP
Predictor	Weighted β 95% CI	p value	Weighted β 95% CI	p value	Weighted β 95% CI	p value
Number of disabilities	-0.39 [-0.69, -0.09]	.01	0.28 [0.04, 0.52]	.02	0.29 [0.06, 0.52]	.01
Male	0.68 [-0.32, 1.67]	.18	-0.42 [-1.10, 0.25]	.22	-0.55 [-1.14 , 0.05]	.07
Age	0.41 [0.14, 0.68]	.003	$-0.14\ [-0.34,\ 0.06]$.16	-0.17 [-0.33, -0.02]	.03
Race						
African American	0.27 [-1.02, 1.57]	89.	-0.79 [-1.86, 0.29]	.15	-1.42 [-2.37, -0.47]	.004
Other	-0.02 [-1.71, 1.66]	86.	0.23 [-1.26, 1.73]	.76	-0.86[-2.37, 0.64]	.26
White (reference)	I	Referent	I	Referent	I	
Hispanic	-0.37 [-1.92 , 1.19]	.64	-0.31 [-1.59, 0.96]	.63	-0.13 [-1.25, 0.99]	.82
Income						
>\$100,000	0.78[-0.44, 2.01]	.21	-0.45 [-1.74, 0.83]	.49	-0.62[-1.65, 0.41]	.23
\$60,001-\$100,000	0.34 [-0.89, 1.57]	.59	-0.41 [-1.51, 0.70]	74.	-0.39 [-1.43, 0.66]	.46
\$35,000-\$60,000	0.59 [-0.50, 1.69]	.29	0.16 [-1.07, 1.40]	62.	0.02 [-1.07, 1.10]	86.
<\$35,000 (reference)	I	Referent	ı	Referent	ı	
Number of children in household						
3 or more	-2.30[-3.57, -1.03]	.001	0.34 [-0.86, 1.54]	.57	-0.68 [-1.84, 0.48]	.38
2	-0.37 [-1.30, 0.55]	.42	0.64 [0.02, 1.26]	.04	0.29 [-0.37, 0.94]	.24
1 (reference)	I	Referent	I	Referent	I	
2-parent household (biological or						
adoptive)	1.19 [-0.37, 2.74]	.13	-0.31 [-1.47, 0.85]	09.	0.25 [-1.02, 1.52]	69.
At least one immigrant parent	-0.49 [-1.69, 0.71]	.42	-0.07 [-0.99, 0.85]	88.	0.17 [-0.74, 1.08]	.71
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parent	1.42 [0.35, 2.50]	.01	0.25 [-0.69, 1.18]	09.	0.30 [-0.39, 0.99]	.39
Enrollment over 1,000 students	1.59 [0.61, 2.58]	.002	-0.32 [-0.92, 0.29]	.30	-1.43 [-2.39, -0.47]	.004
Chosen school	-0.58 [-1.38, 0.25]	.17	-0.46 [-1.01, 0.09]	.10	-0.72 [-1.34, -0.10]	.02

(Table 3 continued)

table 3 Continued

	Parental school involvement	lvement	Parental dissatisfaction with school	with school	Parental dissatisfaction with IEP	on with IEP
Predictor	Weighted β 95% CI	p value	Weighted β 95% CI	p value	Weighted β 95% CI	p value
Urbanity						
City	-0.05[-1.22, 1.11]	.93	0.28 [-0.69, 1.26]	.57	1.18 [0.29, 2.07]	.01
Suburb	0.34 [-0.88, 1.56]	.58	0.22 [-0.81, 1.24]	89:	1.49 [0.51, 2.48]	.004
Town	1.40 [0.31, 2.48]	.01	-0.31 [-1.26 , 0.65]	.52	0.19 [-0.70, 1.08]	.67
Rural (reference)	I	Referent	I	Referent	I	Referent
Geographic location						
South	0.13 [-0.83, 1.08]	62.	-0.09 [-1.20, 1.02]	88.	-0.49 [-1.66, 0.69]	.41
Midwest	0.59 [-0.63, 1.80]	.34	-0.47 [-1.59 , 0.65]	.40	-0.86 [-2.06, 0.35]	.16
West	0.24 [-1.05, 1.53]	.71	-0.62[-1.85, 0.62]	.32	-0.37 [-1.86 , 1.13]	.63
Northeast (reference)	I	Referent	I	Referent	I	Referent
School level						
Senior high school	-5.38 [-7.71, -3.05]	< .001	0.97 [-0.70, 2.63]	.25	1.80 [0.53, 3.07]	900.
Middle school/junior high	-2.49[-3.81, -1.16]	< .001	1.33 [0.12, 2.54]	.03	1.07 [0.03, 2.12]	.04
Elementary (reference)	I	Referent	I	Referent		
Intercept	-0.24 [-4.05 , 3.57]	96.	1.90 [-0.54, 4.35]	.13	1.63 [-0.86, 4.13]	.20

Note. IEP = individualized education program.

consequence of small sample size or perhaps an indication that the school is unable to provide enough services to satisfy the parent, regardless of the parent's own level of involvement. For example, many schools do not offer specialized applied behavioral analysis or other behavioral services that many parents have come to see as standard treatment or intervention methods for their children. In addition, because children with autism also often have multiple service needs (Barrett et al., 2011; Bryson & Smith, 1998; Kohler, 1999; Spann et al., 2003), some form of case management or service coordination may be in order but is not often provided by schools.

Parents of children with disabilities who are not satisfied with their children's school are less likely to be involved in their children's education, whereas parents who are satisfied are more likely to be involved (Laws & Millward, 2001). It is possible that as the number of disabilities mounts for a child, the inability of school services to satisfy the needs of the child subsequently increases, which could lead to higher rates of dissatisfaction among parents regarding their child's IEP. This hypothesis may also explain the increased rate at which parents of children with ASDs help with homework found in the study compared with parents of children from the general population.

Despite, the overall level of parental involvement decreasing with an increase in the number of disabilities, parents of children with ASD were more likely to attend parent-teacher conferences and meet with the school guidance counselor when compared with parents of children with other disabilities. They also were unsatisfied with the level of communication from the school regarding their child's placement and role in the school. Unsatisfactory levels of communication between teachers and parents appear to be a common complaint from parents of children with special education needs and may translate into the level of parental involvement in homework (Jayanthi, Sawyer, Nelson, Bursuck, & Epstein, 1995).

Limitations

While the Parent and Family Involvement in Education survey provides one of the best glimpses into the school experiences of families raising children with an ASD across the nation, the survey methodology suffers from several limitations. A primary concern is the use of parental reports without external validation of medical or psychiatric diagnoses. Moreover, recall biases may exist, with parents of older children being less accurate when reporting on events regarding diagnoses than parents of younger children. It is possible to alleviate some of these concerns regarding the validity of the diagnosis, given the comparable prevalence of ASDs in the sample to that reported by the 2007 National Survey of Children's Health and the Autism Developmental Disabilities Monitoring Network (Autism Developmental Disabilities Monitoring Network Surveillance Year 2006 Principal Investigators, Centers for Disease Control and Prevention, 2009; Kogan et al., 2009).

A second limitation lies in the cross-sectional nature of the survey, which only provides one time point regarding the relationship between parental school involvement and satisfaction and raising a child with an ASD. It is not possible to make causal inferences between developmental disabilities, or any disability for that matter, and the level of parental involvement, as the temporal ordering of events cannot be determined. In other words, it is not possible to know if low parental involvement in a child's school preceded that child receiving an ASD diagnosis or if it occurred afterward. Similarly, a parent may have had low levels of satisfaction with a given school before the child was diagnosed.

A final limitation concerns the presence of unmeasured confounders that have the potential to bias the relationship between raising a child with an ASD and a parent's level of involvement and satisfaction. Although the study was restricted to public schools in the hopes of minimizing heterogeneity between school characteristics, it is likely that characteristics of size, location, level, urbanity, and region of the country are not sufficient in accounting for all differences between schools. In particular, it is quite possible that the financial health of the child's school and district could account for some of the variability in the parent's level of involvement and satisfaction with the school. Additional school variables might include levels and types of services offered by the school such as applied behavior analysis and service coordination. Unfortunately, this information, as well as whether a school has specific services or resources available for children with ASDs, was not available. Furthermore, a family's experience with a given school is shaped

by many factors that are not addressed in the survey. Parents' level of involvement based solely on events they chose to attend or not should be viewed carefully, as parental involvement goes beyond a physical presence in the school. Moreover, while five questions regarding parental satisfaction with a child's school have the potential to provide an accurate proxy, it is still a limited number of questions to capture a large construct in school satisfaction.

The current study has several strengths to help offset some of the limitations. Most important, the size and the national representativeness of the survey provide the largest picture to date of the schooling experiences of families of children with ASD. Moreover, the use of population-based weights provides a large enough sample of families of children with ASD to allow for sub-investigations based on number of disabilities. Although the questions contained in the survey itself may not tap into all school characteristics, they do provide substantial information about the child's school, including the school type, school size, geographic location, and whether the parent chose the child's school. These variables, combined with those of the child, parent, and family, provide a comprehensive, but not exhaustive, picture of factors that have the potential to influence the parent's level of both involvement and satisfaction with the school, and the results subsequently have the potential to inform policy.

Implications

A number of potential policy implications seem relevant to the findings of this research. First, as we know that parent engagement is related to student learning outcomes (Redding, Langdon, Meyer, & Sheley, 2004), the relationship between parent satisfaction and student success needs to be incorporated into the overall parent engagement plans and efforts of schools. These plans should take into account the complexity of parent needs when they have children with complex and multifaceted diagnoses like autism. Schools will need some ongoing training and technical assistance in this area, to understand how best to articulate what parent engagement might mean for these parents and students and how to know if better engagement leads to better student outcomes. In addition, this information regarding parent engagement, student characteristics, and student success can and should be a part of the school improvement plan required of every public school as part of the No Child Left Behind Act. As parents are a mandatory and critical part of that plan and team, having parents of students with ASD who are actively engaged in the implementation and evaluation of the school improvement plan will enhance the likelihood of the school improving outcomes.

Finally, because it is possible that parent satisfaction might be improved with the development of services that could both boost student outcomes and reduce parent stress, schools should seek partnerships with other providers to increase their capacity to either offer or link parents to services such as applied behavior analysis, other therapies, and some form of case management or service coordination. Engaging community partners in building these services not only will expand the school's capacity to improve both parent engagement and satisfaction but will also address student outcomes.

Future research studies should continue to employ population-based surveys but should provide information at multiple time points to effectively determine the impact of raising a child with ASD on a parent's experience with that child's school. A longitudinal survey will also provide information about any changes to a child's diagnosis, as well as educational needs, and will be instructive as to the time points in a child's schooling when parent and school communication is most necessary or has the greatest impact.

Conclusion

Currently, children with ASDs are four times as likely to require educational and school-based services when compared with children without the disorder (Mandell, Walrath, Manteuffel, Sgro, & Pinto-Martin, 2005). Parents of children with ASDs, therefore, are prime individuals to target in the hopes of improving parental involvement in the school. However, important first steps will require improving the level of parental satisfaction seen within the schools. Given that parents of children with ASDs are more likely to attend parent-teacher conferences and meet with the school guidance counselor, these school interactions may serve as ideal platforms for improving communication between the school and family and enhancing the quality and level of parental involvement.

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Cette étude examine l'accès, l'utilisation et la qualité des services de soins de santé pour les enfants latinos autistes ou ayant un trouble du développement. Nous avons analysé les données du sondage national américain des enfants ayant des besoins de santé spéciaux (N= 4414 enfants autistes ou ayant d'autres troubles du développement). En comparaison aux enfants caucasiens, les enfants latinos autistes ou ayant d'autres troubles du développement, avaient moins accès aux services de santé et la qualité et l'utilisation des services étaient moins bonnes. Nous avons ensuite testé les modèles médiateurs pour déterminer si la qualité des soins de santé a un effet médiateur sur la relation entre l'ethnie et les disparités dans l'utilisation des soins de santé. Trois des quatre indicateurs de qualité (les dispensateurs de services ne passent pas assez de temps avec l'enfant, les dispensateurs ne sont pas sensibles à la culture, et les dispensateurs ne font pas sentir les parents comme des partenaires) étaient des médiateurs importants. Ces analyses suggèrent que les interventions visant à améliorer la sensibilité culturelle des dispensateurs de services et leur comportement durant les rencontres cliniques pourraient réduire les disparités dans l'utilisation des soins de services des enfants latinos autistes ou ayant un autre trouble du développement.

Une évaluation de l'implication scolaire et de la satisfaction des parents d'enfants atteints d'un trouble du spectre autistique

Benjamin Zablotsky, Katelyn Boswell et Christopher Smith

L'implication des parents dans la vie scolaire et leur satisfaction ne sont pas étudiées chez les familles qui élèvent un enfant avec un trouble du spectre autistique (TSA). Pour combler cette lacune, les auteurs de la présente étude ont utilisé un échantillon national de familles (N=8978) provenant d'un sondage effectué en 2007 et intitulé *Parent and Family Involvement in Education Survey* (sondage sur l'implication des parents et des familles dans l'éducation). Les parents d'enfants atteints d'un TSA étaient plus susceptibles que les parents d'enfants sans le trouble d'assister à des rencontres parents-enseignants, de rencontrer les

conseillers en orientation scolaire et d'aider avec les devoirs. Les parents d'enfants atteints d'un TSA étaient également plus insatisfaits quant au niveau de communication fourni par l'école. Il y avait une corrélation positive significative entre l'implication scolaire des parents et leur satisfaction vis-à-vis l'école. Ces résultats ont des implications importantes sur la façon d'interagir des écoles auprès des familles avec des enfants atteints d'un TSA.

L'environnement familial et les troubles du comportement chez les enfants, adolescents et adultes avec un syndrome du X fragile

Jan Greenberg, Marsha Seltzer, Jason Baker, Leann Smith, Steven Warren, Nancy Brady et Jinkuk Hong

Nous avons examiné comment l'environnement familial est associé avec les aspects du phénotype du syndrome du X fragile durant l'enfance, l'adolescence et l'âge adulte. Les mères d'enfant (N = 48), d'adolescent (N = 85) et d'adulte (N =34) avec un syndrome du X fragile ont participé à une recherche multisite. Pour les enfants et adultes présentant un syndrome du X fragile, un environnement chaleureux et positif ainsi que l'absence de critique sont associés à moins de troubles du comportement. Bien qu'un niveau plus élevé de critiques était associé à un taux plus élevé de troubles du comportement, il n'y avait pas de lien significatif entre des environnements chaleureux et positifs et les troubles du comportement durant l'adolescence. L'établissement de programmes psychoéducatifs pour les familles, visant à réduire les critiques des parents, pourrait être bénéfique autant pour les personnes ayant un syndrome du X fragile que pour leur famille.

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