

# A Survey of Parents with Children on the Autism Spectrum: Experience with Services and Treatments

Tracy A Becerra, PhD, OTR/L; Maria L Massolo, PhD; Vincent M Yau, PhD; Ashli A Owen-Smith, PhD; Frances L Lynch, PhD; Phillip M Crawford, MS; Kathryn A Pearson; Magdalena E Pomichowski, MPH; Virginia P Quinn, PhD; Cathleen K Yoshida, MA; Lisa A Croen, PhD

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## ABSTRACT

**Introduction:** Autism spectrum disorders (ASD) are lifelong neurodevelopmental disorders, and little is known about how parents address the health and psychosocial consequences of ASD. Few studies have examined use of various treatments and services in a large, diverse sample of children with ASD and their families.

**Objective:** This paper presents methods to create an autism research resource across multiple large health delivery systems and describes services and treatments used by children with ASD and their families.

**Methods:** Four study sites conducted a Web survey of parents of children and adolescents with ASD who were members of Kaiser Permanente. We tabulated data distributions of survey responses and calculated  $\chi^2$  statistics for differences between responders and nonresponders.

**Results:** The children of the 1155 respondents were racially and ethnically diverse (55% white, 6% black, 5% Asian, 9% multiracial, 24% Hispanic) and representative of the total population invited to participate with respect to child sex (83% male), child age (57% < 10 years), and ASD diagnosis (64% autistic disorder). The most frequently used services and treatments were Individualized Education Programs (85%), family physician visits (78%), and occupational and speech therapy (55% and 60%, respectively). Home-based programs frequently included implementation of social skills training (44%) and behavior management (42%). Prescription medication use was high (48%). Caregivers reported disruption of personal and family routines because of problem behaviors.

**Conclusion:** These survey data help to elucidate parents' experiences with health services for their children with ASD and serve as a potential resource for future research.

the higher figure applying to people with co-occurring intellectual disabilities.<sup>4</sup> Considering the prevalence of ASD in the US, the aggregate cost of caring for all affected individuals is approximately \$61 billion per year.<sup>4</sup>

Evidence-based treatment approaches for ASD are lacking. The most commonly available treatments primarily target behaviors and focus on improving daily functioning, communication, and social skills.<sup>5-7</sup> Although early behavioral intervention can improve outcomes for some children with ASD, response to treatment varies widely, and it is not yet known which children benefit from which treatments.<sup>8</sup> Medications prescribed for ASD often have minimal empirical support,<sup>9</sup> and there are no US Food and Drug Administration-approved drugs for treatment of ASD's core symptoms.<sup>10</sup> In light of the dearth of evidence-based ASD treatment options, parents are using numerous alternative approaches to treat ASD's core behavioral symptoms and commonly reported co-occurring medical conditions.<sup>11</sup> However, there is little understanding of how parents address all of the health and psychosocial consequences of ASD.

Several studies have surveyed parents about drugs, diets, and/or therapies used to treat their children with ASD and their satisfaction with those treatments, but result interpretation is limited by use of convenience sampling<sup>12,13</sup> and small sample sizes.<sup>14</sup> To date, few studies have

## INTRODUCTION

Autism spectrum disorders (ASD) are lifelong neurodevelopmental disorders typically detected in early childhood. Although symptoms differ from person to person, people with ASD share core similarities that are defined by impairments in social interaction and communication and restricted stereotyped behaviors.<sup>1</sup> ASD prevalence in the general population has increased dramatically since the mid-20th century from 1 case per 2000 people in

1966<sup>2</sup> to approximately 1 in 68 today.<sup>3</sup> This increase is partially attributable to changes in diagnostic standards over the years, availability of services, and heightened public awareness. However, increased prevalence also may reflect changing environmental and/or genetic factors.

Caring for children with ASD can be demanding and expensive. According to a current economic analysis, the lifetime cost of supporting a person with ASD in the US averages between \$1.4 and \$2.4 million,

Tracy A Becerra, PhD, OTR/L, is a Postdoctoral Research Fellow at the Department of Research & Evaluation for Kaiser Permanente Southern California in Pasadena. E-mail: [tracy.a.becerra@kp.org](mailto:tracy.a.becerra@kp.org). Maria L Massolo, PhD, is a Senior Research Project Manager for the Division of Research in Oakland, CA. E-mail: [maria.l.massolo@kp.org](mailto:maria.l.massolo@kp.org). Vincent M Yau, PhD, is a former Staff Scientist for the Autism Research Program at the Division of Research in Oakland, CA. E-mail: [vincentmyau@gmail.com](mailto:vincentmyau@gmail.com). Ashli A Owen-Smith, PhD, is a Behavioral Scientist and Assistant Professor in Health Management and Policy at Georgia State University in Atlanta. E-mail: [aowensmith@gsu.edu](mailto:aowensmith@gsu.edu).

Frances L Lynch, PhD, is a Health Economist and Senior Investigator at the Center for Health Research in Portland, OR. E-mail: [frances.lynych@kpchr.org](mailto:frances.lynych@kpchr.org). Phillip M Crawford, MS, is a Research Associate at the Center for Health Research in Portland, OR. E-mail: [phillip.m.crawford@kpchr.org](mailto:phillip.m.crawford@kpchr.org). Kathryn A Pearson is a former Research Project Manager at the Center for Health Research in Portland, OR. E-mail: [kathryn.a.pearson@gmail.com](mailto:kathryn.a.pearson@gmail.com). Magdalena E Pomichowski, MPH, is a former Research Associate at the Department of Research & Evaluation for Kaiser Permanente Southern California in Pasadena. E-mail: [magdalena.e.pomichowski@kp.org](mailto:magdalena.e.pomichowski@kp.org). Virginia P Quinn, PhD, is a former Research Scientist II in the Department of Research & Evaluation for Kaiser Permanente Southern California in Pasadena. E-mail: [virginia.p.quinn@kp.org](mailto:virginia.p.quinn@kp.org). Cathleen K Yoshida, MA, is a Data Consultant at the Division of Research in Oakland, CA. E-mail: [cathleen.k.yoshida@kp.org](mailto:cathleen.k.yoshida@kp.org). Lisa A Croen, PhD, is a Senior Research Scientist at the Division of Research in Oakland, CA. E-mail: [lisa.a.croen@kp.org](mailto:lisa.a.croen@kp.org).

examined differences in use of various ASD treatments in a large, diverse sample of children and adolescents with ASD across multiple geographic locations.<sup>15,16</sup>

In 2009, the Mental Health Research Network was established with funding from the National Institute of Mental Health to link data from 9 not-for-profit health systems spanning more than 10 million people in 11 states.<sup>17</sup> By leveraging information from Health Plan electronic medical records (EMRs), the research collaboration was designed to address research questions using a large, diverse, and well-characterized population with insurance coverage. A subgroup of Mental Health Research Network researchers developed an autism registry with the goal to create a large, comprehensive, and dynamic interregional database to enable rapid identification and enrollment of patients into large-scale studies investigating treatment interventions and to develop pharmacogenomic and etiologic hypotheses.

To complement data routinely collected in the Health Plan EMR, four participating sites conducted a survey to gather information from parents of children and adolescents with autism about services and treatments received primarily outside of their Health Plan. This article describes the

survey methods and provides an overview of the services and treatments accessed by families of children with ASD.

**METHODS**

**Setting**

Four Kaiser Permanente (KP) Regions participated in this study: KP Northern California (KPNC), KP Southern California, KP Northwest, and KP Georgia. These sites provide services to more than 8 million Health Plan subscribers (KPNC = 3.8 million, KP Southern California = 4.0 million, KP Northwest = 524,000, and KP Georgia = 270,000). KP is a large nonprofit, prepaid, integrated health care delivery system, and most insurance, administrative, and clinical functions are provided within its Health Plan, hospitals, and physician groups. Its integrated structure enables KP to make extensive use of EMRs in supporting clinical practice, administrative functions, and communication with its members. Each site obtained approval for the study from its local institutional review board.

**Eligibility Criteria**

Eligible participants were parents or caregivers of children age 17 years and younger as of April 2012, who were KP members between February and April 2012. Their child's EMR needed to include at least one ASD diagnosis. All 4 sites identified English speakers as eligible to participate. KPNC also contacted eligible Spanish speakers to pilot recruitment feasibility in a non-English-speaking population.

**Recruitment, Enrollment, and Consenting Methods**

A packet containing a recruitment letter and fact sheet explaining the study was mailed to households of eligible children. The recruitment letter, which was mailed in batches over several months, included a link to the Web survey, login instructions (username and password), and a telephone number to call if a participant did not have access to a computer and wanted to complete the survey by telephone. All Web survey respondents completed an online consent form before completing the survey. Participants completing the survey by telephone verbally consented, and all of their responses were recorded using the online

tool. KPNC mailed a Spanish version of the recruitment letter to families for whom the EMR indicated Spanish as the primary language and the need for an interpreter.

**Follow-Up Activities for Nonresponse**

Follow-up activities, which varied across sites according to available project resources, ranged from one additional mailing of the invitation letter to the mailing of multiple letters, e-mail solicitation, and telephone calls to nonrespondents. At one site, for example, a reminder letter stamped "Final Notice" was sent in a bulk mailing to all families who had received the initial invitation letter but had not started the survey within ten weeks. The number of phone calls and messages left on answering machines varied by site. Most participants who started but did not complete the survey received reminders via mailings and telephone calls that encouraged them to finish and offered help to do so. Follow-up with Spanish speakers was handled exclusively via telephone by a bilingual, bicultural research assistant who scheduled and conducted interviews in Spanish and entered the consent and survey responses online in the English instrument.

**Incentives**

Families at 2 sites received \$15 gift cards for completing the survey, and participants at 2 other sites received no immediate incentives. At the end of the study, randomly selected participants at 3 of the 4 sites received a prize (an iPad or \$100 gift cards).

**Web Survey Details**

The Web survey obtained information about services and treatments received by affected children and their families and the parent/caregiver's experience of having a child with ASD. Topics covered by the 231-question survey included the child's ASD diagnosis, parent satisfaction with care provided during the previous year, services and treatments received during the child's lifetime and the prior 3 months, the Caregiver Strain Questionnaire,<sup>18</sup> the Pediatric Quality of Life Inventory,<sup>19</sup> the effect of the child's ASD on parents' employment, demographic information, educational resources of interest to the family, and willingness to participate in future research (Figure 1).

Topic	Description
1. Diagnosis information	Child's age, sex, caregiver information, ASD diagnosis subtype (ASD, Asperger's syndrome, autistic disorder, and pervasive developmental disorders not otherwise specified), age at first concern, type of developmental concerns, age at first diagnosis, diagnosis determination, if have sibling with ASD, opinion about the cause of ASD.
2. Parent satisfaction with care	Communication with health care providers, care coordination and satisfaction, ability to navigate the health care system, provider sensitivity towards the family's values and customs, provider support for caregiver's capacity in decision making.
3. Services and treatments	Recent or ever use, cost, and perceived effectiveness of health and educational services, programs and treatments provided at home, diets, medicines, vitamins, supplements, herbs, and complementary and alternative medicine (CAM); school setting and supports. <b>Examples:</b> Applied behavioral analysis (ABA), early start Denver model (ESDM), and relationship development intervention (RDI); home activities such as special diets, yoga and special exercises, and visits to the emergency room, family doctor, and medical specialists.
4. Caregiver Strain Questionnaire	Problems caregivers may experience regarding time, disruption of family routines, deprivation, and trouble with neighbors, school, or the law, because of a child's emotional problems. Feelings of isolation, embarrassment, worries about the family's future, guilt, tiredness, and the effect of the child with ASD on the parent's work.
5. Pediatric Quality of Life Inventory (Peds QL™)	Physical, emotional, and social functioning of the child affected by ASD.
6. The effect of child's ASD on parent's work or school	Employment status, job category, pay, impact of child's ASD on ability to work, focus/perform, time off, hours missed, needing to change jobs/schedule or stop working, advance in a job, childcare issues.
7. Demographic information	Caregiver race, ethnicity, highest level of education, marital status, language spoken in the home, household income.
8. Educational resources for family	Topics on ASD requested to help care child; helpful resources, best method to provide information, interest in educational services about ASD.
9. Willingness to participate in future research	Types of research willing to participate, preferred method of participation and contact, preference on incentives, reasons for not wanting to participate in future research.

Figure 1. Nine major survey topics. (A larger version is available online at: [www.thepermanentejournal.org/files/2017/16-009/Figure1.pdf](http://www.thepermanentejournal.org/files/2017/16-009/Figure1.pdf).)

Among the services and treatments received, we also explored complementary and alternative medicine services including chiropractic care, traditional Chinese medicine, equine therapy, and energy therapy such as Reiki, for which descriptive results are available in a separate manuscript.<sup>20</sup> For each service or treatment listed, the caregiver indicated if the intervention was ever used, if it was used during the prior 3 months, the cost incurred, the extent of service use, and its perceived effectiveness. With regard to educational services, the questions focused on setting (regular classroom, regular classroom with support services, or special education classroom).

Two standardized questionnaires were included in the survey: the Caregiver Strain Questionnaire<sup>18</sup> and the Pediatric Quality of Life Inventory.<sup>19</sup> The Caregiver Strain Questionnaire<sup>18</sup> explores problems caregivers may experience regarding time; disruption of family routines; deprivation; and trouble with neighbors, school, or the law because of a child's emotional problems. The questionnaire also addresses feelings of isolation and embarrassment, worries about the family's future, guilt, tiredness, and ASD's effect on the parents' work. The Pediatric Quality of Life Inventory focuses on physical, emotional, and social functioning of children affected by ASD.

### Statistical Methods

Demographic differences between respondents and nonrespondents were tabulated, and  $\chi^2$  tests were used to test for differences that were considered significant when the p value was lower than 0.05. The distributions of Web responses from study participants were also calculated.

## RESULTS

### Web Survey Respondents

English-language invitation letters were mailed to 8943 English-speaking parents, and 166 Spanish-language invitation letters were mailed to Spanish speakers. It was possible for parents to receive multiple letters depending on the number of children eligible in the household. Across all sites, 9109 children with ASD were identified, and 175 (2%) invitation letters were returned because of incorrect addresses. We received 1155 (13%) parent responses to the survey. Survey completion time ranged between 50

and 120 minutes, and most surveys were completed during weekday evening hours. Thirteen English-speaking, predominantly white/non-Hispanic individuals chose to respond by phone instead of online. As we expected, no Spanish speakers responded to the online English-language survey, but unexpectedly we also received no initial telephone responses from this group. We followed-up with a randomly sampled group of approximately 10% of potential respondents (N = 18) by telephone; among this group, 16 (89%) completed the survey by telephone.

Sites with fewer eligible families and more resources (including staff) obtained higher returns in response to intensive follow-up and availability of phone help or in-person consenting (response rates of approximately 23%). By contrast, sites that kept to traditional recruitment strategies such as mailed invitations and limited phone or e-mail follow-up saw lower response rates (7% to 15%).

Survey respondents reflected the population invited to participate with respect to their children's sex ( $p = 0.60$ ), age ( $p = 0.76$ ), ASD diagnosis type ( $p = 0.48$ ),

**Table 1. Demographic characteristics of children with autism spectrum disorders in families invited to complete a survey**

Characteristics	Survey responders (n = 1155)	Survey nonresponders (n = 7607)	$\chi^2$ statistic	p value
<b>Sex, no. (%)</b>				
Female	196 (17.0)	1344 (17.7)	0.27	0.60
Male	954 (82.6)	6262 (82.3)		
Missing <sup>a</sup>	5 (0.4)	1 (0.0)		
<b>Last autism spectrum disorder diagnosis, no. (%)</b>				
Autistic disorder	732 (63.4)	4945 (65.0)	1.47	0.48
Other specified pervasive developmental disorders	352 (30.5)	2279 (30.0)		
Unspecified pervasive developmental disorders	66 (5.7)	381 (5.0)		
Missing <sup>a</sup>	5 (0.4)	2 (0.0)		
<b>Age at recruitment, no. (%)</b>				
0-4	218 (18.9)	1419 (18.7)	1.17	0.76
5-9	432 (37.4)	2808 (36.9)		
10-14	420 (36.4)	2891 (38.0)		
15-17	80 (6.9)	489 (6.4)		
Missing <sup>a</sup>	5 (0.4)	0 (0.0)		
<b>Age at first diagnosis, no. (%)</b>				
0-4	504 (43.6)	3509 (46.1)	7.06	0.07
5-9	462 (40.0)	2775 (36.5)		
10-14	165 (14.3)	1216 (16.0)		
15-17	19 (1.6)	105 (1.4)		
Missing <sup>a</sup>	5 (0.4)	2 (0.0)		
<b>Race-ethnicity, no. (%)</b>				
White non-Hispanic	638 (55.2)	3121 (41.0)	428.44	< 0.01
Black/African American non-Hispanic	67 (5.8)	677 (8.9)		
Native American/Alaskan native non-Hispanic	4 (0.3)	19 (0.2)		
Asian non-Hispanic	61 (5.3)	1004 (13.2)		
Native Hawaiian/Pacific Islander non-Hispanic	2 (0.2)	25 (0.3)		
Multiracial non-Hispanic	102 (8.8)	105 (1.4)		
Hispanic	273 (23.6)	2037 (26.8)		
Missing (all unknown) <sup>a</sup>	8 (0.7)	619 (8.1)		

<sup>a</sup> Not used in p value calculation.

and age at first ASD diagnosis ( $p = 0.07$ ) (Table 1). Most respondents had a boy (82%) younger than age 10 years (57%) with a diagnosis of autistic disorder (65%). Although respondents were more likely than nonrespondents to be non-Hispanic white or non-Hispanic multiracial and less likely to be black or Asian, there was racial and ethnic diversity among the respondents. Additional characteristics of survey respondents are summarized in Table 2. Most respondents spoke English at home (88%), had a college or graduate degree (57%), were married or living with a partner (75%), and had an annual gross household income higher than \$60,000 (56%).

**Services and Treatments**

Respondents used a variety of services and treatments for their child with ASD (Table 3). The most prevalent educational and medical services used were Individualized Education Programs (86%) and family physician visits (78%). There also was high use of occupational therapy (OT) (55%) and speech therapy (ST) (60%) services and special help in the mainstream classroom (58%). The most prevalent educational setting was public school (72%) followed by private school (6%), with most children placed in all-day regular (22%) or special education (20%) classrooms. Children 0 to 4 years of age had significantly higher recent use of family physician visits (45%); physician visits were used less frequently for children ages 5 to 9 years (32%), ages 10 to 14 years (32%), and ages 15 to 17 years (27%) ( $p = 0.02$ ). The youngest children also used OT and ST services most frequently: OT, 46% (ages 0-4), 26% (ages 5-9), 12% (ages 10-14), and 8% (ages 15-17),  $p < 0.01$ ; ST, 53% (ages 0-4), 33% (ages 5-9), 19% (ages 10-14), and 15% (ages 15-17),  $p < 0.01$ . Children ages 5 to 14 years had the most recent use of social skills training (14% vs 4% for children ages 0-4 years,  $p = 0.04$ ) and special help in the mainstream classroom (35% vs 22% for children ages 0-4 years,  $p = 0.03$ ). Finally, the oldest children (ages 15-17 years) used more individual counseling (29%) and group therapy (12%) than younger children (individual counseling: ages 0-4 years [9%], ages 5-9 years [15%], and ages 10-14 years [23%],

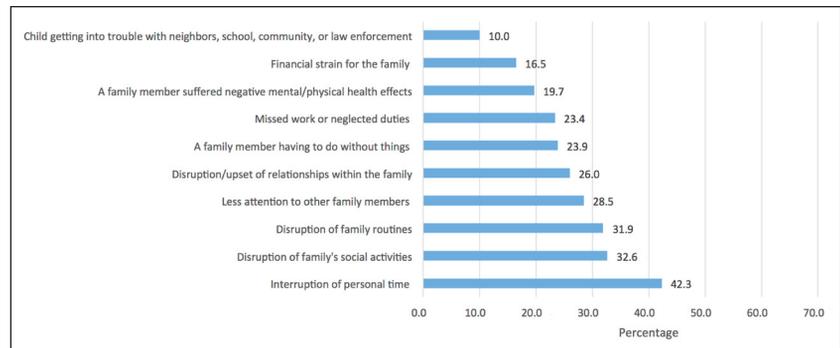


Figure 2. The Caregiver Strain Questionnaire: Problems caregivers reported experiencing as a result of their child's problem behaviors. Percentage of caregivers who reported "quite a bit/very much" in response to the question, "In the past 6 months, how much of a problem was the following?"

$p < 0.01$ ; group therapy: ages 0-4 years [5%], ages 5-9 years [6%], and ages 10-14 years [4%],  $p < 0.01$ ).

In general, most parents perceived support services to be helpful (Table 3), and 50% to 60% of parents said hospital stays,

emergency services, and visits with a nutrition specialist were helpful. About 37% of parents reported trying a special diet, and most parents perceived that most special diets had no effect (Table 3). Casein-free or gluten-free diets were the special diets

**Table 2. Survey respondent demographic information**

Characteristics	Entire cohort (n = 1155)	Spanish-speaking (n = 16)
<b>Language spoken at home, no. (%)</b>		
English	1013 (87.7)	7 (43.8)
Spanish	21 (1.8)	8 (50.0)
Russian	2 (0.2)	0 (0.0)
Other	3 (0.3)	1 (6.3)
Missing/prefer not to answer	116 (10.0)	0 (0.0)
<b>Highest level of education, no. (%)</b>		
High school or less	89 (7.7)	9 (56.3)
Some college	308 (26.7)	1 (6.3)
College degree	390 (33.8)	6 (37.5)
Graduate degree	269 (23.3)	0 (0.0)
Missing/prefer not to answer	99 (8.6)	0 (0.0)
<b>Marital status, no. (%)</b>		
Married/living with partner	866 (75.0)	15 (93.8)
Single	45 (3.9)	0 (0.0)
Separated/divorced	135 (11.7)	1 (6.3)
Widowed	12 (1.0)	0 (0.0)
Missing/prefer not to answer	97 (8.4)	0 (0.0)
<b>Annual household income, no. (%)</b>		
Less than \$10,000	13 (1.1)	1 (6.3)
\$10,000 to \$19,999	22 (1.9)	0 (0.0)
\$20,000 to \$39,999	114 (9.9)	3 (18.8)
\$40,000 to \$59,999	164 (14.2)	6 (37.5)
\$60,000 to \$79,999	191 (16.5)	0 (0.0)
\$80,000 to \$99,999	132 (11.4)	1 (6.3)
\$100,000 to \$149,999	214 (18.5)	0 (0.0)
\$150,000 or more	110 (9.5)	0 (0.0)
Missing/prefer not to answer	195 (16.9)	5 (31.3)

used most frequently (28%); however, about 50% of respondents who reported using these diets perceived they had no effect (48%). A sugar-free diet was perceived as among the most helpful diets (71%) by the few who tried it (11%). Among

the programs used by family members at home, social skills training (44%) and behavior management (42%) were most often implemented. Prescription medication use was high in this population (48% ever use; Table 4). Stimulants were most

frequently used (31%), and 20% reported ever using antipsychotics. Specifically, methylphenidate (23%), the medication used most often, was perceived as helpful by only 38% of parents. The percentage of parents perceiving harmful effects from

**Table 3. Use of services and programs and their perceived effectiveness (N = 1155)**

Services and programs	Ever use	Perceived harmful <sup>a</sup>	Perceived helpful <sup>a</sup>	Perceived no effect <sup>a</sup>
<b>Services with a medical or other professional provider, no. (%)</b>				
Applied behavioral analysis	424 (36.7)	8 (1.9)	385 (90.8)	17 (4.0)
Early Start Denver Model	64 (5.5)	0 (0.0)	50 (78.1)	9 (14.1)
Floortime/developmental, individual, relationship-based	201 (17.4)	0 (0.0)	179 (89.1)	18 (9.0)
Relationship Development Intervention	76 (6.6)	0 (0.0)	59 (77.6)	13 (17.1)
Treatment and Education of Autistic and Communication-Related Handicapped Children (TEACCH)	99 (8.6)	0 (0.0)	80 (80.8)	8 (8.1)
Picture Exchange Communication System	320 (27.7)	4 (1.3)	281 (87.8)	30 (9.4)
Visits for social skills training	356 (30.8)	5 (1.4)	297 (83.4)	37 (10.4)
Other special autism spectrum disorder service	219 (19.0)	1 (0.5)	179 (81.7)	22 (10.0)
Hospital or other program requiring overnight stay	56 (4.8)	6 (10.7)	29 (51.8)	23 (41.1)
Emergency Department/urgent care	394 (34.1)	25 (6.3)	201 (51.0)	134 (34.0)
Autism spectrum disorders-related medical evaluation	646 (55.9)	10 (1.5)	513 (79.4)	92 (14.2)
Family physician visits (ie, pediatrician, nurse practitioner)	890 (77.1)	20 (2.2)	647 (72.7)	202 (22.7)
Medical specialist visits (ie, neurologist, gastroenterologist)	491 (42.5)	12 (2.4)	359 (73.1)	95 (19.3)
Occupational therapy visits	636 (55.1)	2 (0.3)	551 (86.6)	66 (10.4)
Physical therapy visits	291 (25.2)	4 (1.4)	229 (78.7)	46 (15.8)
Speech therapy visits	695 (60.2)	5 (0.7)	616 (88.6)	58 (8.3)
Visits with a nutritionist/dietitian/feeding specialist	228 (19.7)	6 (2.6)	136 (59.6)	74 (32.5)
Individual counseling/therapy	518 (44.8)	9 (1.7)	384 (74.1)	99 (19.1)
Group therapy	293 (25.4)	12 (4.1)	209 (71.3)	55 (18.8)
Family counseling/therapy	293 (25.4)	3 (1.0)	219 (74.7)	58 (19.8)
Case management	352 (30.5)	6 (1.7)	266 (75.6)	66 (18.8)
Family support group	219 (19.0)	5 (2.3)	174 (79.5)	35 (16.0)
Other service	143 (12.4)	1 (0.7)	119 (83.2)	21 (14.7)
<b>School/education services, no. (%)</b>				
Special help in the mainstream classroom	665 (57.6)	47 (7.1)	556 (83.6)	42 (6.3)
Individualized Education Program/504 plan meetings	989 (85.6)	25 (2.5)	914 (92.4)	34 (3.4)
Individual counseling by school counselor, psychologist, or therapist	569 (49.3)	12 (2.1)	449 (78.9)	73 (12.8)
Group counseling or therapy at school	357 (30.9)	9 (2.5)	282 (79.0)	41 (11.5)
Other services/meetings at school related to autism spectrum disorders	479 (41.5)	10 (2.1)	416 (86.8)	32 (6.7)
<b>Special diets, no. (%)</b>				
Casein-free or gluten-free diet	326 (28.2)	8 (2.5)	127 (39.0)	156 (47.9)
The Feingold diet	36 (3.1)	0 (0.0)	15 (41.7)	18 (50.0)
Additive-free diet	116 (10.0)	0 (0.0)	64 (55.2)	39 (33.6)
Sugar-free diet	125 (10.8)	0 (0.0)	89 (71.2)	33 (26.4)
Another diet	75 (6.5)	1 (1.3)	55 (73.3)	14 (18.7)
<b>Programs family members use independently at home, no. (%)</b>				
The Denver Model	82 (7.1)	0 (0.0)	63 (76.8)	9 (11.0)
Behavior management program	483 (41.8)	8 (1.7)	439 (90.9)	27 (5.6)
Applied behavioral analysis	378 (32.7)	5 (1.3)	348 (92.1)	19 (5.0)
Floortime	276 (23.9)	4 (1.4)	240 (87.0)	23 (8.3)
Picture Exchange Communication System	293 (25.4)	5 (1.7)	254 (86.7)	30 (10.2)
Social skills training	513 (44.4)	5 (1.0)	469 (91.4)	32 (6.2)

<sup>a</sup> Harmful/helpful/no effect percentages are based on responses from caregivers who responded to "ever use" regarding the service. Percentages do not add to 100% because one other possible response, "Don't know," is not presented.

prescription medications ranged between 13% and 32%, however. Prescription medication use significantly increased with age (0-4, 10%; 5-9, 25%; 10-14, 47%; and 15-17, 51%,  $p < 0.01$ ).

Results from the Caregiver Strain Questionnaire<sup>18</sup> show that parents experience disruption of personal time (42%), family social activities (33%), and family routines (32%) as a result of their child's problem

behaviors (Figure 2). Parents identified most often with feelings of worry about their child's future (67%) but felt they related well with their child (63%, Figure 3). Notably, they often felt tired or strained (41%) and believed their child's problem behavior took a toll on the family (40%). Less often, they identified with feelings of resentment (4%) or anger toward their child (8%).

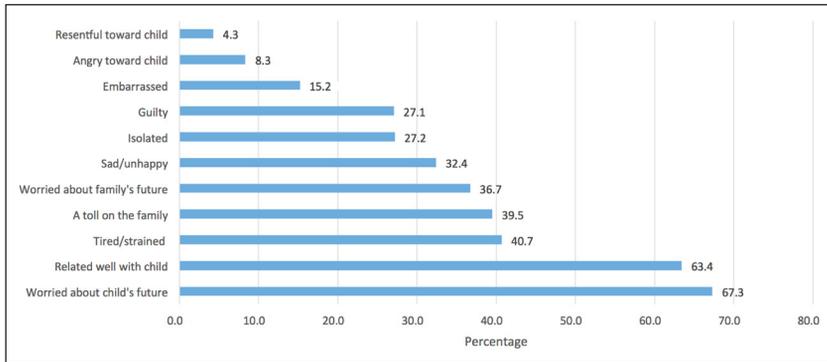


Figure 3. The Caregiver Strain Questionnaire: Feelings caregivers reported as a result of their child's problem behaviors. Percentage of caregivers who felt strongly ("quite a bit/very much") regarding their child's emotional/behavioral problems.

**Future Participation**

Nearly 90% of respondents indicated a willingness to participate in future research studies. Lack of time was the main reason others were not interested (2%). Interest was highest regarding studies on behavioral treatments (70%), the transition to adulthood (70%), and causes of autism (63%). Parents were less interested in participating in studies about medication treatments (34%) and complementary and alternative medicine (42%). Overall, the preferred contact method for future research was via e-mail (70%), and most respondents preferred to participate via the Internet (83%). However, among Spanish-speaking respondents, only 25% preferred to be contacted via e-mail; 75% preferred telephone contact, and 56% preferred to receive mail. Among this group, 69% preferred to participate in research in person, 63% preferred the telephone, and only 25% preferred the Internet. Regarding participation incentives, respondents were most interested in gift cards (78%) or cash (63%) (Table 5).

**DISCUSSION**

Surveys targeting parents are useful to supplement and complement information routinely captured in the EMR. Because parents are the primary decision makers regarding choice of treatments, diets, and other therapies for their children,<sup>21</sup> the data obtained from this Web-based survey, which was administered to a large, ethnically diverse, insured population of families affected by autism, provides valuable information about how families cope with and address issues associated with having a child with ASD.

The extensive nature of our survey (completion times ranged between 50 and 120 minutes) may explain why the overall response rate (13%) was lower than the rate achieved with other Web surveys. A large meta-analysis of more than 39 studies<sup>22</sup> ranging in size from 110 to 12,677 participants that directly compared Web surveys to paper-based surveys found that Web survey response rates vary between 7% and 88% (average of 34%). The study topics included in the meta-analysis included creation of national pediatric musculoskeletal trauma outcomes registries and studies of patient experiences with physicians and alcohol and drug use.

Medications	Ever use	Perceived harmful <sup>b</sup>	Perceived helpful <sup>b</sup>	Perceived no effect <sup>b</sup>
<b>Total medication use<sup>c</sup></b>	<b>551 (47.7)</b>			
<b>Stimulants</b>	<b>363 (31.4)</b>			
Methylphenidate	265 (22.9)	36 (13.6)	100 (37.7)	14 (5.3)
Amphetamine	184 (17.1)	56 (30.4)	97 (52.7)	26 (14.1)
Atomoxetine	96 (8.9)	30 (31.3)	36 (37.5)	26 (27.1)
<b>Antidepressants</b>	<b>236 (20.4)</b>			
Fluoxetine	155 (14.4)	26 (16.8)	98 (63.2)	23 (14.8)
Sertraline	78 (7.2)	17 (21.8)	44 (56.4)	13 (16.7)
Bupropion	58 (5.4)	14 (24.1)	19 (32.8)	16 (27.6)
<b>Antipsychotics</b>	<b>228 (19.7)</b>			
Risperidone	167 (15.5)	35 (21.0)	106 (63.5)	19 (11.4)
Aripiprazole	105 (9.8)	29 (27.6)	55 (52.4)	12 (11.4)
<b>Anticonvulsants</b>	<b>83 (7.2)</b>			
<b>Antianxiety</b>	<b>24 (2.1)</b>			
<b>Other medication</b>	<b>236 (20.4)</b>			

<sup>a</sup> Only prevalent medications are specifically represented. Drug groups (ie, stimulants, etc) represent all medication responses. Numbers may not add up to 100% because of overlap in medication use. Data are presented as no. (%).  
<sup>b</sup> Harmful/helpful/no effect percentages are based on responses from caregivers who responded to "ever use" regarding the medication. Percentages do not add to 100% because one other possible response, "Don't know," is not presented.  
<sup>c</sup> Medications not specifically presented: Amitriptyline (antidepressant), buspirone (antianxiety), carbamazepine (anticonvulsant), clomipramine (antidepressant), clozapine (antipsychotic), dexamethylphenidate (stimulant), dextroamphetamine (stimulant), fluconazole (other medication), gabapentin (anticonvulsant), haloperidol (antipsychotic), imipramine (antidepressant), ketoconazole (other medication), lamotrigine (anticonvulsant), lisdexamfetamine (stimulant), lithium carbonate (antipsychotic), lithium citrate (antipsychotic), olanzapine (antipsychotic), paroxetine (antidepressant), pemoline (other medication), pimozone (other medication), pregabalin (anticonvulsant), prochlorperazine (antipsychotic), promethazine (antihistamine), quetiapine (antipsychotic), thioridazine (antipsychotic), topiramate (anticonvulsant), valproic acid (anticonvulsant), venlafaxine (antidepressant).

Kalb and colleagues<sup>23</sup> administered 3 Web surveys to families living with autism in the Interactive Autism Network, a US-based research database comprising an online community. The authors reported response rates of 15.8% for a survey on access to health care, 25% for a vaccination history survey, and 27% for a weight and height survey.<sup>23</sup> Although the response rate in our survey was lower than the Kalb et al rates, there are important differences in the samples. Kalb and colleagues surveyed families that had already agreed to participate in research and had completed a baseline survey. In the current study, all families of children with ASD were invited to participate, many of whom had not previously agreed to participate in research. In the Kalb et al follow-up surveys,<sup>23</sup> survey lengths and incentive types were not reported. A major

similarity between our findings and those reported by Kalb and colleagues was the lower response rates among individuals with nonwhite race/ethnicity.

Despite this survey's length and complexity, many parents wrote notes in the free text area in which they supported the project and highlighted the relevance of the data collected. Others suggested additional topics of study, provided more information about their children, or recommended trainings and resources for providers.

Recruitment follow-up activities are important factors affecting response rates. Sites that had the resources and personnel to send reminder mailings or call or e-mail participants had much higher response rates than sites that conducted limited recruitment follow-up activities. It is clear from our experience that the more

labor-intensive and resource-intensive the follow-up, the higher the participation and completion rates. After repeated offers for help with survey completion, some participants finally revealed that navigating the survey back and forth to change answers was difficult. Had we trusted that all participants were going to call us in response to our offer of help in the invitation letter, we would have received more partial responses. However, receiving the offer via mail, e-mail, and phone moved respondents to action. A cost-effective follow-up activity that increased response involved bulk mailing of "final notice" letters to those who had not completed the survey several months after receiving the initial invitation letter.

Considering that filling out forms about health issues is uncommon in many countries in which health literacy rates may be low or where people expect to talk about their concerns with a clinician, we contacted a subsample (10%) of Spanish-speaking individuals via telephone and offered assistance in completing the survey as an interview. The response rate among this group was 89%, but extra time was necessary (2 hours instead of approximately 45-90 min for the online survey). This high response rate confirmed what we had experienced in other studies and what is reported in the literature: The preferred method of communication for Spanish-speaking families, both for recruitment and data collection, is direct contact.<sup>24-27</sup> The presence of a Spanish-speaking research assistant who provided personalized attention and support to participants also contributed to the success of the recruitment strategy. Although telephone interviews are a more resource-intensive mode of data collection, and may be cost prohibitive in studies with large populations, they may be necessary to reach Hispanic people and other populations that typically have lower computer and health literacy.<sup>28</sup> As medicine moves toward a more personalized approach to health, so should medical research. Employing methods that are culturally relevant will lead to higher participation rates across diverse populations and more representative and generalizable results.

Treatment and service use results complement findings of health care use in the

**Table 5. Survey respondents' opinions regarding future research**

	Entire cohort (N = 1155), n (%)	Spanish-speaking (N = 16), n (%)
<b>Type of research studies willing to participate in</b>		
Behavioral treatments	805 (69.7)	13 (81.3)
Medication treatments	398 (34.5)	4 (25.0)
Stress reduction/coping strategies (parent/caregiver)	620 (53.7)	8 (50.0)
Complementary and alternative medicine treatments	482 (41.7)	8 (50.0)
Causes of autism	730 (63.2)	15 (93.8)
Genetic studies	697 (60.3)	13 (81.3)
Environmental risk factors	606 (52.5)	13 (81.3)
Transition to adulthood	813 (70.4)	16 (100.0)
Not interested in participating in any research studies	35 (3.0)	0 (0.0)
<b>How would you prefer to participate in future studies?</b>		
In person	486 (42.1)	11 (68.8)
Over the telephone	359 (31.1)	10 (62.5)
Over the Internet	953 (82.5)	4 (25.0)
Using TV/DVD	198 (17.1)	3 (18.8)
<b>How would you like us to contact you about participating in future studies?</b>		
Mail	704 (61.0)	9 (56.3)
Telephone	226 (19.6)	12 (75.0)
E-mail	809 (70.0)	4 (25.0)
Through kp.org	236 (20.4)	2 (12.5)
Please do not contact	1 (0.1)	0 (0.0)
<b>Special offers attracting the most interest</b>		
Free transportation	99 (8.6)	6 (37.5)
Free child care	190 (16.5)	5 (31.3)
Cash	728 (63.0)	12 (75.0)
Gift card	898 (77.7)	12 (75.0)
Free medicine/treatment	344 (29.8)	7 (43.8)
Free assessment/evaluation	443 (38.4)	5 (31.3)
Other	50 (4.3)	0 (0.0)

same KP sites using EMR data.<sup>29</sup> Cummings and colleagues<sup>29</sup> found high rates of visits to the pediatrician (82% to 93%), OT (5% to 16%), and ST (3% to 14%) compared to age- and gender- matched controls without ASD. Pediatricians typically see children for at least 11 well-child visits by their third birthdays and are a good source of continuous care, support, and education for families with children with ASD.<sup>30</sup> Specialized therapies such as OT and ST target core symptoms in self-regulation, cognition, and social-communication skills. Similarly, social skills training, a common treatment method for adolescents, can be effective for those with high-functioning autism in natural, everyday educational settings.<sup>31</sup>

In addition to routine and specialty ASD care, prescription medications may help to stabilize or to manage problem behavior. The data in the present survey on prescription medication use are consistent with results of another study that used EMR data that indicated that stimulants, specifically methylphenidate, are the most commonly prescribed drugs for children with ASD because they target hyperactivity, impulsivity, disinhibition, and inattention.<sup>32</sup> A novel finding from our survey suggests that parents perceive this medication as helpful less often. The antipsychotics risperidone and aripiprazole are the only 2 medications approved by the US Food & Drug Administration for the treatment of ASD, and these drugs are intended to target problem behavior (irritability) rather than ASD core symptoms.<sup>9,10</sup> However, among those reporting use of these drugs, 21% to 26% perceived them as harmful, and an additional 11% perceived them to have no effect.

This survey also made it possible to assess parents' perceptions of the negative impact of their child's problem behaviors. The impact on daily activities was frequent, with 42% of parents reporting interruption of their personal time. However, it is the parents' responses to the Caregiver Strain Questionnaire that reflects how they cope. Respondents often reported feeling tired or strained and that their child's problem behavior took a toll on the family. However, most parents believed they related well with their child while also worrying about their future. Health

professionals can support parents who must manage the health and psychosocial consequences of having a child with ASD by understanding prevalent family commitments and providing resources to help them cope with their child's challenges.

This study offered several advantages over other studies that have surveyed families affected by autism. First, this survey was conducted within the membership of a large health care delivery system employing a comprehensive and standardized EMR. This provided the opportunity to compare and to validate selected survey responses to information stored in the EMR (such as basic demographic information) and to augment EMR data with patient information not routinely recorded in the EMR such as satisfaction with care and out-of-plan health care use. In addition, the data collected in this initial survey will serve as the baseline for longitudinal follow-up studies conducted within this population. Second, this large study gathered information on more than 1000 children from different racial/ethnic and socioeconomic backgrounds across four geographically distinct study sites, increasing the generalizability of the survey results. Typically, large sample sizes are difficult to obtain when studying a condition of low prevalence such as autism. By leveraging information across millions of families obtaining health care through KP, it was possible to identify a sizable population willing to contribute to meaningful research.

Several study limitations must be mentioned. First, the entire study population was insured, potentially reducing the generalizability of the study findings, although some of the study's children were covered under the Medicaid program. Because the survey was Web-based, results largely represented computer-literate families with access to the Internet. Although this is an important caveat, recent studies indicate that the vast majority of households have access to the Internet.<sup>33</sup> Families also had to have a certain degree of health literacy to answer questions about external services and treatments that their children were receiving. These limitations may explain in part the lower response rates among ethnic minorities.<sup>28</sup> Response rates were lower among black and Asian subgroups,

potentially affecting the generalizability of our findings. Interestingly, response rates were higher among caregivers reporting multiple races/ethnicities. Although most respondents were non-Hispanic and white, many minority populations were represented (45%). Additionally, follow-up activities were not uniform across all study sites because of budgetary constraints, staffing, and other issues.

## CONCLUSION

These are important new data on the underresearched topics of parents' decision-making processes regarding ASD treatment. This Web survey also helps to identify future areas of research relevant to families caring for children with ASD and will help to develop more effective ways to provide better services. Findings about complementary and alternative medicine use in this population have been previously published,<sup>20</sup> and additional analyses will be the subject for future publications. ❖

## Disclosure Statement

*The author(s) have no conflicts of interest to disclose.*

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## Never Too Late

It is never too late to expand the mind of a person on the autism spectrum.

— Temple Grandin, PhD, b 1947, American professor of animal science, consultant to the livestock industry on animal behavior, and autism spokesperson