

See discussions, stats, and author profiles for this publication at: <https://www.researchgate.net/publication/6531239>

The Relationship Between Autism and Parenting Stress

Article in PEDIATRICS · March 2007

DOI: 10.1542/peds.2006-2089Q · Source: PubMed

CITATIONS

200

READS

219

5 authors, including:



Catherine E Rice

Emory University

98 PUBLICATIONS 5,311 CITATIONS

SEE PROFILE

Some of the authors of this publication are also working on these related projects:



Study to Explore Early Development [View project](#)



Efficiency of NODA app for diagnosing autism spectrum disorder [View project](#)

PEDIATRICS®

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

The Relationship Between Autism and Parenting Stress

Laura A. Schieve, Stephen J. Blumberg, Catherine Rice, Susanna N. Visser and
Coleen Boyle

Pediatrics 2007;119;S114

DOI: 10.1542/peds.2006-2089Q

The online version of this article, along with updated information and services, is
located on the World Wide Web at:

http://pediatrics.aappublications.org/content/119/Supplement_1/S114.full.html

PEDIATRICS is the official journal of the American Academy of Pediatrics. A monthly publication, it has been published continuously since 1948. PEDIATRICS is owned, published, and trademarked by the American Academy of Pediatrics, 141 Northwest Point Boulevard, Elk Grove Village, Illinois, 60007. Copyright © 2007 by the American Academy of Pediatrics. All rights reserved. Print ISSN: 0031-4005. Online ISSN: 1098-4275.

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™



The Relationship Between Autism and Parenting Stress

Laura A. Schieve, PhD^a, Stephen J. Blumberg, PhD^b, Catherine Rice, PhD^a, Susanna N. Visser, MS^a, Coleen Boyle, PhD^a

^aNational Center on Birth Defects and Developmental Disabilities, ^bNational Center for Health Statistics, Centers for Disease Control and Prevention, Atlanta, Georgia

The authors have indicated they have no financial interests relevant to this article to disclose.

ABSTRACT

OBJECTIVE. We assessed associations between parenting a child with autism and stress indicators.

METHODS. In the 2003 National Survey of Children's Health, parents or other knowledgeable adult respondents for children aged 4 to 17 years reported their recent feelings about their life sacrifices to care for their child, difficulty caring for their child, frustration with their child's actions, and anger toward their child. Responses were compiled in the Aggravation in Parenting Scale. Parents of children reported to have autism ($N = 459$) were compared with parents of: (1) children with special health care needs including emotional, developmental, or behavioral problems other than autism that necessitated treatment (children with other developmental problems [$N = 4545$]); (2) children with special health care needs without developmental problems ($N = 11\,475$); and (3) children without special health care needs ($N = 61\,826$). Weighted estimates are presented.

RESULTS. Parents of children with autism were more likely to score in the high aggravation range (55%) than parents of children with developmental problems other than autism (44%), parents of children with special health care needs without developmental problems (12%), and parents of children without special health care needs (11%). However, within the autism group, the proportion of parents with high aggravation was 66% for those whose child recently needed special services and 28% for those whose child did not. The parents of children with autism and recent special service needs were substantially more likely to have high aggravation than parents of children with recent special service needs in each of the 3 comparison groups. Conversely, parents of children with autism but without recent special service needs were not more likely to have high aggravation than parents of children with other developmental problems.

CONCLUSIONS. Parenting a child with autism with recent special service needs seems to be associated with unique stresses.

www.pediatrics.org/cgi/doi/10.1542/peds.2006-2089Q

doi:10.1542/peds.2006-2089Q

The views in this article are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention.

Key Words

autism, autistic disorder, parenting, parent-child relations, psychological stress

Abbreviations

ASD—autism spectrum disorder

NSCH—National Survey of Children's Health

CSHCN—children with special health care needs

FPL—federal poverty level

SCHIP—State Children's Health Insurance Program

Accepted for publication Sep 15, 2006

Address correspondence to Laura A. Schieve, PhD, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Mailstop E-86, 1600 Clifton Rd, Atlanta, GA 30333. E-mail: lschieve@cdc.gov

PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275); published in the public domain by the American Academy of Pediatrics

AUTISM IS A neurodevelopmental disorder characterized by early onset (before 3 years old) of significant impairment in social interaction and communication and unusual, stereotyped behaviors. Parents of children with developmental disabilities face challenges placing them at risk for high levels of stress and other negative psychological outcomes. Parenting a child with autism may pose additional stressors related to the child's challenges in communicating, difficult behaviors, social isolation, difficulties in self-care, and lack of community understanding. Several studies reported increased psychological distress, including depression, anxiety, and components of stress, such as decreased family cohesion and increased somatic complaints and burnout, among parents of children with autism and related autism spectrum disorders (ASDs) in comparison to parents of typically developing children¹⁻⁴ or parents of nonautistic children with mental retardation or other developmental disabilities.³⁻⁴ In addition, in several studies of parents of children with ASDs, the child's behavior and conduct problems were most strongly related to parent stress, rather than other autism symptoms, severity of developmental delay, or adaptive skills.⁵⁻⁷

Studies to date have been limited by small sample sizes and low statistical power and low response rates with possible selection bias. Generalizability was also limited because samples were typically drawn from clinical settings, schools, or parent organizations.

We examined responses to questions related to stress and aggravation among parents or guardians identified as most knowledgeable about health matters for children in the National Survey of Children's Health (NSCH). We compared responses from parents of children reported to have autism with responses from parents of typically developing children and children with other developmental problems and considered variation across population subgroups.

METHODS

The survey design and sampling methodology for the 2003 NSCH are described separately.^{8,9} We selected children aged 4 to 17 years at interview who were not missing data on autism (0.1%) or special health care needs (1.6%). Our sample included 78 305 children and their corresponding parent (96%) or other adult (4%) identified as the most knowledgeable adult. The interviewer specifically asked to talk to "the parent or guardian who lives in this household who knows the most about the health and health care of" the child selected randomly as the target of the interview. The results thus refer to this specific parent or guardian. For brevity, the respondent is referred to as a parent throughout this report.

Autism was ascertained from the question: "Has a doctor or health professional ever told you that [child's name] has autism?" Children with special health care

needs (CSHCN) were identified by using the CSHCN Screener, which includes questions on 5 health care consequences: need/use prescription medications (except vitamins); need/use more medical, mental health, and education services than most same-aged children; limited/prevented in ability to do things most same-aged children can do; need/get special therapy such as physical, occupational, and speech; have any kind of emotional, developmental, or behavioral problem for which treatment or counseling is needed. A child was classified as having special health care needs if the parent responded affirmatively to any of the 5 health care consequences and 2 follow-up questions: whether the consequence was because of a medical, behavioral, or other health condition; and whether that condition had or was expected to last ≥ 12 months.¹⁰

On the basis of responses to the autism and CSHCN Screener questions, we divided children into 4 mutually exclusive groups by using the following hierarchy: (1) children with autism; (2) CSHCN with other emotional, developmental, or behavioral problems necessitating treatment/counseling (CSHCN with developmental problems); (3) CSHCN but not emotional, developmental or behavioral problems (CSHCN without developmental problems); and (4) children without special health care needs.

We assessed outcomes related to parenting stress and aggravation among parents of children in the 4 groups. For parents of children aged 6 to 17 years, we assessed perception of closeness and ability to share ideas or talk about things that matter with the child. For parents of children aged 4 to 17 years, we assessed reported ability to cope with day-to-day parenting demands and responses on how often in the past month they felt: (1) the child was much harder to care for than most same-aged children; (2) bothered a lot by things the child did; (3) they were giving up more of their life than expected to meet the child's needs; and (4) angry with the child. These latter 4 outcomes were combined into a single measure by using established criteria for the Aggravation in Parenting scale.¹¹ Each of the 4 outcomes was given equal weight in the scale. Scores were in the high-aggravation range if the parent answered usually or always to ≥ 2 outcomes or the parent answered sometimes, usually, or always to ≥ 3 outcomes, with at least 1 response in the usually always range.

Previous studies suggest psychological distress among parents of a child with autism varies by characteristics associated with the child's condition.⁵⁻⁷ Autism includes a spectrum of disorders with a wide severity range. Because diagnosis is solely based on in-depth behavioral observation by a specialized health care professional, populations with less access to services might be subject to underascertainment or delayed diagnosis; this was suggested for Hispanic children in a previous analysis of NSCH.¹² We hypothesized that among parents of a child

with autism, a number of factors might impact or intensify their stress level, including indicators of autism severity and/or current special service needs, factors related to severity (eg, males diagnosed with autism show a wider severity range than females¹³), and factors related to socioeconomic status and culture that might impact resources, access to services, and care-seeking behavior. We examined variation in the composite Aggravation in Parenting outcome by demographic, health

care, and social support indicators (see Table 1) for the autism and 3 comparison groups.

Because for 94% of children with autism, English was the primary household language and health insurance was available, stratification on these factors was infeasible. We restricted our sample on these 2 criteria before undertaking stratified analyses. In single-factor stratified analyses, we observed considerable variation in proportion of parents with high Aggravation in Parenting score

TABLE 1 Demographic, Health Care, and Parental Social Support Characteristics of Children With Autism and Children Included in the 3 Comparison Groups

	Weighted % (SE) ^a			
	Children With Autism (N = 459)	CSHCN With Other Developmental Problems (N = 4 545) ^b	CSHCN Without Developmental Problems (N = 11 475)	Children Without Special Health Care Needs (N = 61 826)
Demographic characteristics				
Age, y				
4–10	59.4 (3.8)	42.3 (1.3) ^c	47.0 (0.8) ^c	50.2 (0.4) ^c
11–17	40.6	57.7	53.0	49.9
Sex				
Male	79.9 (2.7)	63.0 (1.3) ^c	56.2 (0.8) ^c	49.0 (0.4) ^c
Female	20.1	37.0	43.8	51.0
Race/ethnicity				
Hispanic	9.9 (3.3)	12.7 (0.9)	9.8 (0.6)	18.0 (0.3) ^c
Non-Hispanic white	70.5 (4.5)	65.1 (1.4)	68.5 (0.9)	60.3 (0.4)
Non-Hispanic black	15.6 (4.0)	16.1 (1.2)	14.6 (0.7)	14.4 (0.3)
Non-Hispanic other/multiple race	4.1 (1.1)	6.1 (0.7)	7.1 (0.5)	7.2 (0.2)
Highest education in household				
Less than high school	26.4 (4.0)	39.2 (1.4) ^c	27.9 (0.8)	34.6 (0.4) ^c
High school or more	73.6	60.9	72.1	65.4
Household income relative to poverty				
<200% FPL ^d	39.8 (4.6)	51.5 (1.4) ^c	35.1 (0.9)	39.0 (0.4)
≥200% FPL	60.2	48.5	64.9	61.0
Family structure				
2 parents, biological and/or adopted	57.5 (4.4)	40.5 (1.3) ^c	60.6 (0.8)	61.9 (0.4)
2 parents, stepfamily	9.9 (2.6)	15.7 (1.0)	10.4 (0.5)	10.1 (0.2)
Single mother, no father present	28.8 (4.6)	37.2 (1.4)	25.0 (0.8)	23.1 (0.3)
Other	3.8 (1.0)	6.7 (0.5)	4.0 (0.3)	5.0 (0.2)
Total No. of children in the household				
1	23.1 (2.6)	22.0 (0.8)	23.0 (0.5)	19.1 (0.2)
2	37.3 (3.7)	36.4 (1.2)	39.8 (0.8)	39.3 (0.3)
>3	39.6 (4.5)	41.6 (1.4)	37.2 (0.9)	41.6 (0.4)
Primary language in household				
English	98.4 (0.7)	93.3 (0.7) ^c	95.2 (0.6) ^c	86.7 (0.3) ^c
Other	1.6	6.8	4.8	13.3
Health care characteristics				
Any health insurance coverage?	98.1 (0.6)	93.6 (0.6) ^c	95.1 (0.4) ^c	89.7 (0.2) ^c
If insured, Medicaid/SCHIP?	36.4 (4.1)	47.2 (1.4) ^c	29.0 (0.8)	26.6 (0.4) ^c
Mental health care (last 12 mo)?	49.3 (4.1)	62.7 (1.3) ^c	8.7 (0.5) ^c	3.2 (0.1) ^c
Personal doctor or nurse? ^e	91.1 (2.6)	86.1 (1.0)	91.7 (0.5)	81.4 (0.3) ^c
If personal doctor or nurse, need special services (last 12 mo)? ^f	72.0 (4.0)	55.1 (1.4) ^c	19.2 (0.7) ^c	4.6 (0.2) ^c
Social support				
Someone to turn to for emotional help in parenting?	89.3 (2.1)	83.1 (1.1) ^c	89.6 (0.6)	86.1 (0.3)

^a SE was adjusted to account for complex sample design using statistical software.

^b CSHCN with other developmental problems includes children reported to have an emotional, developmental, or behavioral special health care need but not reported to have autism.

^c $P < .05$ on the basis of χ^2 comparison of percentage distribution in a given comparison group to the percentage distribution among children with autism.

^d FPL was derived from household income level on the basis of US Department of Health and Human Services guidelines.

^e Personal doctor or nurse was defined as a health professional who knows the child well and is familiar with child's health history.

^f The need for special services includes physical therapy, medical equipment, special education, or counseling needed in past 12 months.

for the autism group according to whether or not the child recently needed special services (eg, physical therapy, medical equipment, special education, or counseling). We examined this factor further as a possible marker for current autism severity. No other factor emerged as such an important discriminator of Aggravation in Parenting among parents of children with autism. Because need for special services was only ascertained for children indicated to have a personal doctor or nurse, these in-depth analyses required additional restriction to children with a personal doctor or nurse. The final restricted sample included 87% of children in the original autism sample, 83% of CSHCN with developmental problems, 85% of CSHCN without developmental problems, and 74% of children without special health care needs. In this sample, we stratified results of high Aggravation in Parenting scores by each demographic, health care, and social support factor and need for special services in the past 12 months simultaneously. Although we observed additional variation in patterns of high Aggravation in Parenting scores for the autism and comparison groups by several demographic and health care factors, we did not formally test for the statistical significance of possible effect modifications. We present the stratum-specific estimates to highlight the range in aggravation across subgroups and the complexity of assessing parenting stress associated with autism. Because only general questions on stress and aggravation were included in the NSCH, this analysis is viewed primarily as a descriptive, hypothesis-generating study.

All estimates were weighted to reflect the noninstitutionalized population of children nationally. We assessed differences between the autism and comparison groups with χ^2 tests adjusted to account for the complex sample design by using SUDAAN software.¹⁴ We did not adjust for multiple comparisons; we present *P* values as an indication of stability of the estimates.

Human subjects review was not required for this study.

RESULTS

Children with autism were more likely than children in each comparison group to be 4 to 10 years old, male, live in a household in which English was the primary language, have health insurance, and have recently needed special services (Table 1). Children with autism were more likely than CSHCN with developmental problems other than autism to live in a household with: 2 parents, ≥ 1 parent or other adult who completed high school, and income $\geq 200\%$ of the federal poverty level (FPL). In addition, their parents were more likely to have someone to turn to for emotional help in parenting. Children with autism were less likely than CSHCN with other developmental problems to be enrolled in Medicaid/State Children's Health Insurance Program (SCHIP) and to have recently received mental health care.

Parents with a child ≥ 6 years old with autism were less likely than their counterparts in each comparison group to feel they were able to share ideas with their child; however, they were more likely than parents of CSHCN with developmental problems other than autism and equally likely as the 2 comparison groups of children without developmental problems to report feeling very close with their child (Table 2). Parents of children ≥ 4 years old with autism were more likely than parents of CSHCN with other developmental problems to report coping very well with parenting demands, but were also more likely to report difficulty in 1 area of the Aggravation in Parenting scale: feeling their child was harder to care for than most same-aged children; they were less likely to report difficulties in 2 areas: being bothered by things their child does and feeling angry with their child. Parents of children with autism were more likely than parents of CSHCN without developmental problems and parents of children without special health care needs to report difficulty in 3 areas of the scale: feeling their child was harder to care for than most same-aged children, being bothered by things their child does, and giving up more of their life than expected to meet their child's needs. On the composite Aggravation in Parenting scale, parents of children with autism were more likely to score in the high-aggravation range (55%) than parents of CSHCN with other developmental problems (44%), parents of CSHCN without developmental problems (12%), and parents of children without special health care needs (11%).

For parents of children without special health care needs, high parental aggravation declined from 11% to 7% when the sample was restricted on the basis of primary language, health insurance coverage, and having a personal doctor or nurse; there was little change in estimates of parental aggravation for the other groups (Table 3). Stratification on the factors included in Table 1 revealed slight-to-moderate variation in the proportion, with high aggravation among parents of children in the autism and comparison groups (data not shown). Within the autism group, the greatest heterogeneity was with need for special services in the past 12 months: 66% of parents whose child needed special services had high aggravation versus 28% of those whose child did not need special services, a 2.4-fold differential. In the 3 comparison groups, a high Aggravation in Parenting score was only slightly associated (risk ratios: 1.2–1.5) with special service needs.

The disparity in Aggravation in Parenting scores among the parents of children with autism persisted after stratification by both need for special services and other factors (Table 3). More than 55% of parents of children with autism who recently needed special services were classified as having high aggravation (range: 56%–93% across 25 demographic, health care, and social support subgroups examined). Less than 50% of

TABLE 2 Self-reported Feelings Related to Coping, Stress, and Aggravation Among the Parents or Other Persons Identified as Most Knowledgeable About Health Matters for the Children

	Weighted % (SE) ^a			
	Parents of Children With Autism (N = 459)	Parents of CSHCN With Other Developmental Problems (N = 4545) ^b	Parents of CSHCN Without Developmental Problems (N = 11 475)	Parents of Children Without Special Health Care Needs (N = 61 826)
Parent-reported feelings for sampled children 6 to 17 y old				
Closeness with sample child				
Somewhat/not very/not close at all	12.3 (3.1)	27.5 (1.2) ^c	13.4 (0.6)	13.4 (0.3)
Very close	87.7	72.5	86.6	86.6
Share ideas/talk about things that matter with sample child				
Somewhat/not very/not well at all	53.2 (4.5)	43.5 (1.4) ^c	24.3 ^c (0.7)	22.9 (0.3) ^c
Very well	46.8	56.5	75.6	77.1
Parent-reported feelings for sampled children 4 to 17 y old				
Coping daily demands parenting				
Somewhat/not very/not well at all	50.0 (4.1)	61.4 (1.3) ^c	47.5 (0.8)	42.7 (0.4)
Very well	50.0	38.6	52.5	57.3
Aggravation in Parenting scale items				
In the past month how often did parent feel				
Child was much harder to care for than most children the same age				
Usually-always	54.3 (4.0)	29.2 (1.2) ^c	5.4 (0.4) ^c	4.3 (0.2) ^c
Never-sometimes	45.7	70.8	94.6	95.7
Child does things that bothered parent a lot				
Usually-always	16.9 (2.5)	25.6 (1.3) ^c	5.1 (0.4) ^c	3.5 (0.1) ^c
Never-sometimes	83.2	74.4	94.9	96.5
Parent giving up more life to meet child's needs than expected				
Usually-always	39.8 (4.1)	32.3 (1.3)	12.1 (0.6) ^c	13.3 (0.3) ^c
Never-sometimes	60.2	67.7	87.9	86.7
Angry with child				
Usually-always	4.4 (1.2)	13.4 (1.0) ^c	3.3 (0.4)	2.3 (0.1)
Never-sometimes	95.6	86.6	96.7	97.7
Composite Aggravation in Parenting scale score in highly aggravated range	54.8 (4.2)	44.3 (1.4) ^c	11.6 (0.6) ^c	10.9 (0.3) ^c

^a SE was adjusted to account for complex sample design using statistical software.

^b CSHCN with other developmental problems includes children reported to have an emotional, developmental, or behavioral special health care need but not reported to have autism.

^c $P < .05$ on the basis of χ^2 comparison of percentage distribution for parents represented in a given comparison group to the percentage distribution for parents of children with autism.

parents of children with autism who did not need special services were classified as having high aggravation (range: 18%–45% across 16 subgroups examined). Among those reporting recent special service needs, parents of children with autism within all subgroups examined were more likely to have high Aggravation in Parenting scores than parents of children in all comparison groups. Nearly all differences reached statistical significance. Conversely, among those not reporting special service needs, there were no significant differences in high aggravation between parents of children with autism and parents of CSHCN with other developmental problems.

Although we lacked data to examine specific behavior problems found in association with autism, we further assessed parents of children with autism who responded

affirmatively to a general question on whether the child had difficulties with emotions, concentration, or behavior (89%). These parents were asked to rate the level of family burden these difficulties posed. Level of burden was predictive of high aggravation, but again, the effect varied by special service needs. Among parents whose children needed special services, the Aggravation in Parenting score was high for 93% of those reporting family burden was great, 63% of those reporting family burden was medium, and 51% of those reporting family burden was little-none. Among parents whose children did not need special services, the Aggravation in Parenting score was high for 56%, 33%, and 20% of those reporting family burden was great, medium, and little-none, respectively.

TABLE 3 Restricted and Stratified Analyses of Having a Score in the Highly Aggravated Range on the Composite Aggravation in Parenting Scale Among the Parents or Other Persons Identified as Most Knowledgeable About Health Matters for the Children

	Weighted % (SE) ^a			
	Parents of Children With Autism	Parents of CSHCN With Other Developmental Problems ^b	Parents of CSHCN Without Developmental Problems	Parents of Children Without Special Health Care Needs
Unadjusted, full sample	54.8 (4.2)	44.3 (1.4) ^c	11.6 (0.6) ^c	10.9 (0.3) ^c
Restricted to primary language in household English and some health insurance coverage	54.7 (4.3)	43.7 (1.4) ^c	10.5 (0.6) ^c	8.1 (0.2) ^c
Restricted to primary language in household English and some health insurance coverage and personal doctor or nurse ^d	55.4 (4.4)	42.7 (1.5) ^c	10.5 (0.6) ^c	7.4 (0.2) ^c
Restricted and stratified				
Need special services = yes and ^e				
Age, y				
4–10	67.3 (5.8)	42.1 (2.8) ^c	16.0 (2.5) ^c	8.5 (1.3) ^c
11–17	65.1 (6.6)	50.0 (2.4) ^c	12.7 (1.7) ^c	11.8 (1.5) ^c
Sex				
Male	66.0 (5.2)	46.5 (2.4) ^c	12.2 (1.5) ^c	11.0 (1.7) ^c
Female	67.5 (7.6)	46.3 (2.9) ^c	16.6 (2.6) ^c	10.2 (1.3) ^c
Race/ethnicity				
Hispanic	56.3 (21.1)	45.1 (6.6)	9.6 (3.6) ^c	11.1 (3.7) ^c
Non-Hispanic white	61.2 (4.6)	44.8 (2.1) ^c	13.8 (1.5) ^c	9.6 (1.1) ^c
Non-Hispanic black	92.7 (4.3)	50.2 (5.9) ^c	19.3 (6.8) ^c	16.5 (5.3) ^c
Non-Hispanic other/multiple race	67.1 (15.0)	56.1 (6.7)	14.9 (5.2) ^c	10.8 (3.4) ^c
Highest education in household				
Less than high school	59.7 (10.9)	46.4 (3.6)	20.2 (4.6) ^c	17.7 (3.3) ^c
High school or more	67.8 (4.7)	46.4 (2.2) ^c	12.5 (1.3) ^c	8.1 (0.8) ^c
Household income relative to poverty				
<200% FPL ^f	73.6 (8.0)	45.3 (3.1) ^c	20.9 (3.7) ^c	14.7 (2.3) ^c
≥200% FPL	65.8 (4.8)	47.5 (2.4) ^c	11.7 (1.4) ^c	8.2 (1.1) ^c
Family structure				
2 parents, biological or adopted	61.0 (5.3)	45.6 (2.8) ^c	16.0 (2.2) ^c	7.5 (1.0) ^c
2 parents, stepfamily	65.0 (12.7)	45.8 (5.2)	10.7 (3.1) ^c	11.9 (3.1) ^c
Single mother, no father present	78.0 (8.7)	48.0 (3.4) ^c	13.8 (2.4) ^c	16.4 (2.8) ^c
Other	92.3 (5.0)	42.3 (5.6) ^c	4.7 (2.2) ^c	—
Total No. of children in the household				
1	72.2 (5.7)	43.7 (2.5) ^c	10.9 (1.3) ^c	13.2 (1.8) ^c
2	55.8 (6.6)	44.5 (2.9)	14.6 (2.2) ^c	10.9 (1.5) ^c
≥3	74.9 (7.4)	49.9 (3.5) ^c	16.3 (3.3) ^c	8.7 (2.2) ^c
Medicaid/SCHIP				
Yes	78.8 (5.4)	49.0 (2.8) ^c	21.2 (3.6) ^c	17.4 (3.2) ^c
No	57.5 (5.6)	44.5 (2.5) ^c	11.2 (1.3) ^c	8.5 (1.0) ^c
Mental health care (last 12 mo)				
Yes	70.9 (5.4)	47.3 (2.1)	22.8 (4.5) ^c	19.6 (2.8) ^c
No	59.7 (6.9)	43.4 (4.2) ^c	12.1 (1.4) ^c	7.5 (1.0) ^c
Someone to turn to for emotional help in parenting				
Yes	64.9 (4.7)	43.6 (2.0)	12.9 (1.5) ^c	10.1 (1.0) ^c
No	80.9 (7.8)	68.1 (4.6) ^c	27.1 (5.9) ^c	18.1 (7.4) ^c
Need special services = no and				
Age, y				
4–10	17.6 (7.0)	34.4 (3.9)	8.2 (0.9)	6.1 (0.3)
11–17	45.0 (8.6)	40.1 (2.9)	10.9 (0.9) ^c	8.3 (0.3) ^c
Sex				
Male	24.2 (6.7)	34.5 (2.5)	8.9 (0.8) ^c	6.9 (0.3) ^c
Female	44.2 (15.4)	43.6 (4.5)	10.5 (1.0) ^c	7.5 (0.3) ^c
Race/ethnicity				
Hispanic	—	40.8 (10.5)	16.7 (4.4)	10.8 (1.2)
Non-Hispanic white	34.7 (7.8)	37.6 (2.5)	7.6 (0.5) ^c	5.5 (0.2) ^c
Non-Hispanic black	—	39.2 (7.5)	15.2 (2.5)	13.1 (0.8)
Non-Hispanic other/multiple race	—	25.1 (6.7)	13.1 (3.9)	7.8 (1.0)

TABLE 3 Continued

	Weighted % (SE) ^a			
	Parents of Children With Autism	Parents of CSHCN With Other Developmental Problems ^b	Parents of CSHCN Without Developmental Problems	Parents of Children Without Special Health Care Needs
Highest education in household				
Less than high school	19.6 (9.1)	42.3 (4.3)	13.1 (1.5)	10.5 (0.6)
High school or more	34.0 (7.3)	35.0 (2.7)	8.4 (0.7) ^c	6.1 (0.2) ^c
Household income relative to poverty				
<200% FPL	—	40.5 (4.1)	13.9 (1.6)	10.5 (0.6)
≥200% FPL	33.8 (7.5)	33.7 (2.7)	7.8 (0.6) ^c	6.0 (0.2) ^c
Family structure				
2 parents, biological or adopted	39.1 (8.2)	32.3 (3.0)	7.3 (0.7) ^c	5.2 (0.2) ^c
2 parents, stepfamily	—	39.6 (5.7)	11.3 (2.2)	7.7 (0.7)
Single mother, no father present	—	40.1 (4.2)	13.4 (1.7)	12.0 (0.7)
Other	—	49.1 (6.9)	18.7 (5.4)	9.7 (1.2)
Total No. of children in the household				
1	43.6 (10.3)	33.1 (2.7)	10.2 (0.8) ^c	8.2 (0.4) ^c
2	35.7 (9.4)	40.6 (3.0)	8.5 (0.8) ^c	6.9 (0.3) ^c
≥3	—	37.8 (4.7)	10.6 (1.4)	7.1 (0.4)
Medicaid/SCHIP				
Yes	33.2 (10.3)	42.1 (4.3)	15.0 (1.8) ^c	11.3 (0.6) ^c
No	26.2 (7.6)	34.6 (2.5)	7.9 (0.6)	6.1 (0.2) ^c
Mental health care (last 12 mo)				
Yes	27.1 (11.5)	44.6 (3.4)	20.7 (3.7) ^c	17.1 (2.1)
No	28.2 (7.7)	29.3 (2.9)	8.9 (0.6)	7.0 (0.2)
Someone to turn to for emotional help in parenting				
Yes	27.2 (6.8)	36.6 (2.5)	8.2 (0.6)	6.4 (0.2)
No	—	47.6 (8.1)	26.9 (3.7)	18.7 (1.3)

— indicates data are not presented if observed number with score in highly aggravated range was ≤5 or the relative SE was >50%.

^a SEs were adjusted to account for complex sample design by using statistical software.

^b CSHCN with other developmental problems includes children reported to have an emotional, developmental, or behavioral special health care need but not reported to have autism.

^c Weighted % (SE): $P < .05$ on the basis of χ^2 comparison of the percentage of parents represented in a given comparison group who scored in the highly aggravated range on the Aggravation in Parenting scale with the percentage of parents of children with autism who scored in the highly aggravated range.

^d Personal doctor or nurse was defined as a health professional who knows the child well and is familiar with the child's health history.

^e Need for special services includes physical therapy, medical equipment, special education, or counseling needed in past 12 months.

^f FPL was derived from household income level on the basis of US Department of Health and Human Services guidelines.

DISCUSSION

Children with autism face many developmental and physical challenges, often necessitating numerous therapies from several different disciplines. Shifting treatment from expert-driven or provider-based models which are child-centered to models emphasizing a collaborative team approach, in which families are integral members, is gaining attention.¹⁵ Such family-centered models consider family concerns and quality of life in developing treatment plans.

The findings reported here support and inform the need to consider family effects in planning for services of children with autism. We found that overall, the most knowledgeable parents and other adult caregivers of children diagnosed with autism reported high levels on several indicators of stress and aggravation. Their level of Aggravation in Parenting was markedly higher than that observed for parents of children without special health care needs or CSHCN without developmental problems. Parents of children with autism were also more likely to have high levels on the composite Aggravation in Parenting scale than parents of CSHCN with nonautism

developmental problems; however, the association was not homogeneous. For children with an identified personal doctor or nurse, those parents whose child with autism recently needed special service were particularly likely to rate high on the Aggravation in Parenting scale across other demographic, health care, and social support subgroups. However, for parents whose child had autism but did not need special services (representing 28% of children with autism), the level of aggravation was much lower overall and not increased in comparison to parents of CSHCN with nonautism developmental problems.

We cannot discern whether need for special services as reported by parents of children with autism was related to (1) severity of autism behavior difficulties, and/or cognitive functioning, (2) stability (or lack of) of the child's current functioning, (3) the parent's perception of severity and stability, or (4) or some combination of these. Nonetheless, the results underscore the need to consider variability among the families of children with autism.

These data are subject to several limitations. Parent-

reported autism depends on access to appropriate health or educational services for diagnosis and communication about the diagnosis to the parent. The survey queried about "autism" only; thus, children diagnosed with less severe ASDs, such as Asperger disorder or pervasive developmental disorder—not otherwise specified, may be underreported. We assessed parents' self-reported feelings toward the sample child but lacked data to assess how those feelings translated into specific interactions with the child or impacted family functioning in other ways. Because these data are cross-sectional, the temporality of associations between having CSHCN with developmental problems and parent self-report of recent parenting difficulties cannot be definitively established. In addition, the most salient predictor of high Aggravation in Parenting scores, recent special service needs, was only ascertained for children with a personal doctor or nurse necessitating restriction to these children for in-depth analyses; however, the vast majority of children were retained in the restricted sample. Finally, these results pertain to self-identified most knowledgeable parent or guardian. Because each child is assumed to have only 1 such parent, the findings may not be generalizable to all parents or caregivers living with a child with autism.

This study also had many strengths. NSCH is a nationally representative sample of US children. The large sample allowed for more detailed analyses than previous studies, with simultaneous stratification on multiple factors. We compared parents of children with autism to several distinct comparison groups, thus providing a complete frame of reference for our findings.

CONCLUSIONS

Our data suggest that parents or primary caregivers of children with autism may face unique stresses and may benefit from family-centered treatment. Future studies are needed to confirm and expand on these findings, with a focus on the many specific stresses that may adversely impact the array of families with a child with autism.

REFERENCES

- Higgins DJ, Bailey SR, Pearce JC. Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder. *Autism*. 2005;9:125–137
- Sivberg B. Coping strategies and parental attitudes, a comparison of parents with children with autistic spectrum disorders and parents with non-autistic children. *Int J Circumpolar Health*. 2006;61(suppl 2):36–50
- Weiss MJ. Hardiness and social support as predictors of stress in mothers of typical children, children with autism, and children with mental retardation. *Autism*. 2002;6:115–130
- Yirmiya N, Shaked M. Psychiatric disorders in parents of children with autism: a meta-analysis. *J Child Psychol Psychiatry*. 2005;46:69–83
- Lecavalier L, Leone S, Wiltz LJ. The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *J Intellect Disabil Res*. 2006;50:172–183
- Hastings RP, Kovshoff H, Ward NJ, Espinosa FD, Brown T, Remington B. Systems analysis of stress and positive perceptions in mothers and fathers of pre-school children with autism. *J Autism Dev Disord*. 2005;35:635–644
- Bromley J, Hare DJ, Davison K, Emerson E. Mothers supporting children with autistic spectrum disorders: social support, mental health status and satisfaction with services. *Autism*. 2004;8:409–423
- Kogan MD, Newacheck PW. Introduction to the volume on articles from the National Survey of Children's Health. *Pediatrics*. 2007;119(suppl 1):S1–S3
- Blumberg SJ, Olson L, Frankel M, Osborn L, Srinath KP, Giambro P. Design and operation of the National Survey of Children's Health, 2003. *Vital Health Stat 1*. 2005;(43):1–124
- Bethell CD, Read D, Stein RE, Blumberg SJ, Wells N, Newacheck PW. Identifying children with special health care needs: development and evaluation of a short screening instrument. *Ambul Pediatr*. 2002;2:38–48
- Macomber JE, Moore KA. 1997 NSAF benchmarking measures of child and family well-being. Report No. 6, NSAF methodology reports. Urban Institute. Available at: www.urban.org/url.cfm?ID=410137. Accessed November 28, 2006
- Centers for Disease Control and Prevention. Parental report of diagnosed autism in children aged 4–7 years: United States, 2003–2004. *MMWR Morb Mortal Wkly Rep*. 2006;55:481–486
- Yeargin-Allsopp M, Rice C, Karapurkar T, Doernberg N, Boyle C, Murphy C. Prevalence of autism in a US metropolitan area. *JAMA*. 2003;289:49–55
- Research Triangle Institute. *SUDAAN Language Manual*. Release 9.0. Research Triangle Park, NC: Research Triangle Institute; 2004
- Becker-Cottrill B, McFarland J, Anderson V. A model of positive behavioral support for individuals with autism and their families: the family focus process. *Focus Autism Other Dev Disabil*. 2003;18:113–123

The Relationship Between Autism and Parenting Stress

Laura A. Schieve, Stephen J. Blumberg, Catherine Rice, Susanna N. Visser and
Coleen Boyle

Pediatrics 2007;119;S114

DOI: 10.1542/peds.2006-2089Q

Updated Information & Services	including high resolution figures, can be found at: http://pediatrics.aappublications.org/content/119/Supplement_1/S114.full.html
References	This article cites 12 articles, 3 of which can be accessed free at: http://pediatrics.aappublications.org/content/119/Supplement_1/S114.full.html#ref-list-1
Citations	This article has been cited by 5 HighWire-hosted articles: http://pediatrics.aappublications.org/content/119/Supplement_1/S114.full.html#related-urls
Subspecialty Collections	This article, along with others on similar topics, appears in the following collection(s): Office Practice http://pediatrics.aappublications.org/cgi/collection/office_practice
Permissions & Licensing	Information about reproducing this article in parts (figures, tables) or in its entirety can be found online at: http://pediatrics.aappublications.org/site/misc/Permissions.xhtml
Reprints	Information about ordering reprints can be found online: http://pediatrics.aappublications.org/site/misc/reprints.xhtml

PEDIATRICS is the official journal of the American Academy of Pediatrics. A monthly publication, it has been published continuously since 1948. PEDIATRICS is owned, published, and trademarked by the American Academy of Pediatrics, 141 Northwest Point Boulevard, Elk Grove Village, Illinois, 60007. Copyright © 2007 by the American Academy of Pediatrics. All rights reserved. Print ISSN: 0031-4005. Online ISSN: 1098-4275.

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™

