

National Profile of Children with Down Syndrome: Disease Burden, Access to Care, and Family Impact

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Objective To measure the co-morbidities associated with Down syndrome compared with those in other children with special health care needs (CSHCN). Additionally, to examine reported access to care, family impact, and unmet needs for children with Down syndrome compared with other CSHCN.

Study design An analysis was conducted on the nationally representative 2005 to 2006 National Survey of Children with Special Health Care Needs. Bivariate analyses compared children with Down syndrome with all other CSHCN. Multivariate analyses examined the role of demographic, socioeconomic, and medical factors on measures of care receipt and family impact.

Results An estimated 98 000 CSHCN have Down syndrome nationally. Compared with other CSHCN, children with Down syndrome had a greater number of co-morbid conditions, were more likely to have unmet needs, faced greater family impacts, and were less likely to have access to a medical home. These differences become more pronounced for children without insurance and from low socioeconomic status families.

Conclusions Children with Down syndrome disproportionately face greater disease burden, more negatively pronounced family impacts, and greater unmet needs than other CSHCN. Promoting medical homes at the practice level and use of those services by children with Down syndrome and other CSHCN may help mitigate these family impacts. (*J Pediatr* 2011; ■: ■-■).

See editorial, p ●● and related article, p ●●

Down syndrome, a common chromosomal condition, occurs in an estimated 14.47 per 10 000 live births, or approximately 6000 children every year in the United States.¹ Children with Down syndrome are considered children with special health care needs (CSHCN); CSHCN are defined by the Health Resources and Services Administration (HRSA) as children “who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”² As mortality rates for children with Down syndrome have improved,³ health services must address these children’s increased need for care access, especially because of the concurrent increase in co-morbidities associated with the disorder. In addition, health policies must consider the socioeconomic and familial impact of having a child with Down syndrome, especially for more vulnerable families.

Children in whom Down syndrome is diagnosed have increased risk for a number of co-morbid health conditions.⁴⁻¹² Other co-morbidities, such as depression and attention deficit/hyperactivity disorder, have been described as co-morbid conditions associated with Down syndrome; however, such associations have been derived primarily from clinical samples rather than from large epidemiological studies.¹³

Despite the extensive knowledge of health conditions in children with Down syndrome, the impact of Down syndrome on families and access to health care for persons with Down syndrome remains understudied.^{4,14} In general, studies have consistently shown that CSHCN have unmet health care and family support needs^{15,16} that can be ameliorated by the presence of insurance,¹⁷ higher family incomes,¹⁷ and the receipt of care within a medical home.¹⁸ Despite their importance, medical homes have been found to be less prevalent in CSHCN, especially children with severely rated conditions.¹⁸ Overall, families of CSHCN face increased financial costs and work losses. A 2004 study found that that approximately 25% of families with CSHCN reported needing to stop or reduce work time, >50% of families with CSHCN reported paying \$500 per year or more in out-of-pocket expenses,¹⁷ and 40% of families of CSHCN reported a financial problem when accessing care.¹⁹ However, the presence of insurance and

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AAP	American Academy of Pediatrics
CSHCN	Children with special health care needs
HRSA	Health Resources and Services Administration
ID	Intellectual disability
NS-CSHCN	National Survey of Children with Special Health Care Needs
SHCN	Special health care needs

receipt of coordinated care or care within a medical home has been shown to mitigate these detrimental factors.¹⁹

Such impacts are especially salient for families of children with Down syndrome, because children with Down syndrome have at least 3 times as many outpatient visits and are more frequently hospitalized than other children.²⁰ The medical and social service costs for children with Down syndrome are also significantly higher than for other children.²⁰ These issues are compounded by the frequency and cost of visits caused by the co-morbidities children with Down syndrome often face.²⁰ However, research has also shown that families of children with Down syndrome fare comparably better than families of other CSHCN for family stress and functioning,²¹ what some researchers have called a “Down syndrome advantage.”¹⁴

The American Academy of Pediatrics (AAP) has developed health care guidelines for patients with Down syndrome⁴; however, application of these guidelines is spotty at best, and the body of literature assessing health outcomes and quality of care has tended to focus on the non-clinical definitions of quality.²² Further, these guidelines largely are based on expert opinion and small clinical studies rather than large population-based data analysis. Here, we use the 2005 to 2006 National Survey of Children with Special Health Care Needs (NS-CSHCN) to profile families of children with Down syndrome. We examine the reported prevalence of Down syndrome, the reported co-morbid conditions of children with Down syndrome, and differences between children with Down syndrome and other CSHCN relative to unmet need and family impacts.

Methods

Our data source is the 2005 to 2006 NS-CSHCN. The NS-CSHCN is a nationally representative random-digit-dial telephone survey supported by the HRSA and conducted by the Centers for Disease Control and Prevention about the health, health care, and impact of special health care needs (SHCN) on families of CSHCN. Households were screened for children <18 years old with SHCN by using a series of questions designed to elicit SHCN status. Interviews were self-reports of parents or guardians (herein “parents”) of one child in each household who qualified as having SHCN.²³ Verbal consent was given by respondents at the time of the interview, and all survey procedures received human subjects’ review approval.²³ The overall response rate was 57.8%.²³ The NS-CSHCN contains information on 40 723 CSHCN, including 395 who were reported as having Down syndrome.

The presence of Down syndrome was determined by parents’ affirmative response when asked: “to the best of your knowledge, does (study child) currently have Down syndrome.” Parents were asked the same question about the presence of asthma, attention deficit/hyperactivity disorder, autism, depression, anxiety, an eating disorder, or other emotional problems, diabetes mellitus, heart problems, blood problems, cystic fibrosis, cerebral palsy, muscular

dystrophy, epilepsy or other seizure disorders, migraines or frequent headaches, arthritis or other joint problems, allergies, and mental retardation/developmental delay. Although the survey question refers to mental retardation, for the remainder of this paper, we will refer to this group of conditions as intellectual disabilities, which is the currently accepted terminology.²⁴ We examine these conditions as co-morbidities.

The medical home measure used in this survey was developed by a HRSA-supported technical expert panel on the basis of the AAP definition.²⁵ Parental report of their child’s health care across 5 domains was used to create the composite measure of medical home; the resulting medical home variable was dichotomous (yes/no). Children were classified as having a medical home when their parents reported that the child had a personal physician or nurse, a usual source of sick and well care, and were receiving family-centered care. Six items were used to determine whether children received family-centered care; these children usually or always had a provider who spent enough time with them, listened well, was sensitive to family values, provided needed information, made families feel like partners in the child’s care, and, when necessary, had an interpreter available. In addition, parents of children with medical homes did not report having problems receiving referrals and received care coordination when necessary. Care coordination was assessed with questions about whether parents received any type of help coordinating care and their levels of satisfaction with physician communication with other doctors or providers. For this analysis, the medical home measure was used in two ways: (1) to predict unmet need and family impact and (2) as an outcome measure of access to health care.

Five measures available in the data set about “family impact” were evaluated: (1) whether the child’s health needs have caused financial problems for the family; (2) whether the family needed additional income to cover child’s medical expenses; (3) whether family members had to reduce or stop working because of the child’s health; (4) whether the family paid \$1000 or more for the child’s medical care in the previous year; and (5) whether the family spent >10 hours providing or coordinating health care for the child per week.

“Unmet need” was defined with 3 different measures: (1) whether the child had any reported unmet need for health care services or equipment during the last year, including preventive and specialist care, prescriptions, and mobility aids; (2) whether the child had unmet need for any of these family support services: respite care, genetic counseling, or mental health or counseling; and (3) whether caregivers report having delayed or foregone any necessary health care for the referent child.

Sociodemographic controls included the child’s age, sex, race, health insurance status, the highest level of educational attainment within the household, the primary language spoken in the household, family structure, and region of residence (Northeast, Midwest, South, or West). Family structure was defined as two-parent (biological/adopted), two-parent (step), single mother, or other family type.

Table I. Sociodemographic characteristics of children with special health care needs by Down syndrome status

	Estimated frequency of CSHCN with Down syndrome*	Percent of CSHCN [†]		Adjusted OR (95% CI): Down syndrome versus other CSHCN [‡]
		Down syndrome	Other CSHCN	
Total	98	1.0	99.0	–
Medical home [§]				
Present	25	29.7	47.3	0.53 [§] (0.37-0.76)
Not present	60	70.4	52.7	reference
Insurance status [§]				
Private only	36	37.1	59.4	0.48 (0.21-1.13)
Public only	33	33.4	28.0	0.80 (0.37-1.75)
Both public and private	20	20.8	7.2	1.84 (0.84-4.03)
Other comprehensive	3	3.3	2.0	1.37 (0.48-3.96)
Uninsured	5	5.4	3.4	reference
Household poverty status				
0%-99% FPL	25	25.9	19.3	1.46 (0.71-2.98)
100%-199% FPL	29	30.2	22.0	1.47 (0.75-2.87)
200%-399% FPL	27	27.5	29.9	1.53 (0.94-2.48)
≥400% FPL	16	16.4	28.8	reference
Highest level of education (household)				
Less than high school	8	7.8	6.8	0.56 (0.27-1.16)
High school graduate	25	25.9	23.1	0.72 (0.45-1.15)
More than high school	65	66.3	70.2	reference
Child's age [¶]		9.0	9.9	0.97 (0.92-1.01)
Child's sex				
Male	47	48.4	59.5	reference
Female	50	51.6	40.5	1.50 [§] (1.07-2.12)
Child's race				
Hispanic	18	19.0	11.7	1.11 (0.50-2.47)
White, non-Hispanic	53	54.0	65.5	reference
Black, non-Hispanic	19	19.3	16.2	1.09 (0.65-1.84)
Other, non-Hispanic**	8	7.7	6.6	1.02 (0.49-2.12)
Primary language in home [§]				
English	85	86.7	95.4	0.39 (0.15-1.01)
Other	13	13.3	4.6	reference
Family structure				
2 parent (biological or adoptive)	51	53.9	55.0	reference
2 parent (step)	10	10.1	10.0	0.78 (0.39-1.55)
Single mother	27	28.4	29.9	0.71 (0.46-1.09)
Other	7	7.7	5.2	1.17 (0.62-2.17)
Region				
Northeast	14	14.8	17.9	reference
Midwest	24	24.1	24.0	1.46 (0.86-2.47)
South	40	41.0	38.6	1.44 (0.85-2.46)
West	20	20.1	19.6	1.19 (0.65-2.15)

FPL, federal poverty level.

*Estimated frequency of CSHCN with DS in population of CSHCN. Frequencies are expressed in thousands.

†Columns total to 100%.

‡The reference category for the logistic regression is other CSHCN.

§P < .001.

¶P < .05.

||P < .01.

**Other, non-Hispanic includes those of mixed race.

Household income as a percentage of the federal poverty level was also included.

Statistical Analyses

Data were analyzed with Stata software version 9 (Stata Corp, College Station, Texas). Analyses were weighted according to the survey's complex sampling procedure to represent the national population of CSHCN. Analyses took into account all imputations of income. With the exception of income, all survey questions reported as "don't know or "refused" were coded as missing data.

Statistical differences for all categorical variables were conducted by using χ^2 analyses, and mean differences were compared by using *t* tests to examine differences in socioeconomic and demographic characteristics and co-

morbid conditions between children with Down syndrome and other children. ORs and 95% CIs are presented for logistic regressions that predict the presence of a medical home, factors of unmet need, and measures of family impact comparing children with Down syndrome with all other CSHCN, controlling for disorder type, number of co-morbid conditions, and socioeconomic and demographic factors.

Results

Of CSHCN in the United States, an estimated 98 000 had Down syndrome in 2005 to 2006 (Table I). The sample of the NS-CSHCN was limited to children who were found to have a SHCN during screening and does not reflect the rate

Table II. Percentage of children with special health care needs with Down syndrome and likelihood of co-morbid conditions by presence of Down syndrome

	Down syndrome*	Other SHCN*	OR (95% CI): Down syndrome versus other SHCN†
Asthma‡	19.8	39.0	0.39 (0.26-0.58)
ADD or ADHD	23.3	29.9	0.71 (0.48-1.06)
Autism or ASD‡	18.4	5.3	4.05 (2.60-6.30)
Intellectual disability‡	89.1	10.6	68.83 (46.55-101.78)
Emotional problems	22.0	21.1	1.06 (0.71-1.57)
Diabetes mellitus	0.5	1.6	0.30 (0.07-1.21)
Heart problems‡	24.3	3.3	9.36 (6.44-13.60)
Blood problems	2.1	2.3	0.89 (0.29-2.75)
Cystic fibrosis	0.8	0.3	2.94 (0.63-13.68)
Cerebral palsy‡	6.6	1.8	3.84 (1.77-8.33)
Muscular dystrophy§	1.4	0.3	4.24 (1.19-15.09)
Epilepsy or other seizure disorder§	7.0	3.4	2.12 (1.08-4.17)
Migraine or frequent headaches¶	7.2	15.1	0.43 (0.24-0.78)
Arthritis or other joint problems¶	9.8	4.2	2.47 (1.34-4.55)
Allergies‡	39.4	53.1	0.57 (0.41-0.80)
Mean number of co-morbid conditions‡	2.7	1.9	1.41 (1.29-1.55)

ADD, attention deficit disorder; ADHS, attention deficit hyperactivity disorder; ASD, Autism spectrum disorder.

*Columns total to 100%.

†The reference category for the logistic regression is Other CSHCN.

‡ $P < .001$.

§ $P < .05$.

¶ $P < .01$.

of Down syndrome in children who do and do not have SHCN.¹ After adjusting for socioeconomic and demographic factors, children with Down syndrome were 47% less likely to have a medical home than other CSHCN. Children with Down syndrome were less likely to be reported as having access to private insurance.

Table II compares reported co-morbid conditions between children with Down syndrome and other CSHCN. Analysis shows that children with Down syndrome were 68.8 times more likely to have intellectual disability (ID) and 9.4 times more likely to have heart problems than other CSHCN. They were also significantly more likely to be reported as diagnosed with autism spectrum disorder, muscular dystrophy, cerebral palsy, arthritis or other joint problems, and epilepsy or another seizure disorder, consistent with earlier research.^{11,26} However, they were less likely to be reported as having asthma, migraines or frequent headaches, and allergies than other CSHCN.

Children with Down syndrome were 40% less likely to have a medical home and more than two times more likely to have unmet needs for care and family support services than other CSHCN (**Table III**; available at www.jpeds.com). Families of children with Down syndrome were significantly more likely to report family impacts than were families of other CSHCN (**Table IV**; available at www.jpeds.com); they were 1.8 times more likely to report financial problems caused by the child's condition and nearly 3 times as likely to report that a family member had to reduce or stop work because of the child's health. However, children with Down syndrome were no more likely to report delaying or foregoing care or that the family needed additional income to cover the child's medical expenses than other CSHCN.

Consistent with the medical home literature,^{18,19} the presence of a medical home mitigated access to care and family

impacts for all children. Medical homes reduced unmet need for family support by 78% and unmet need for health care services by 62%. Family impacts were reduced substantially; having a medical home reduced the likelihood of needing additional income by 58%, the likelihood that the child's health caused financial problems by 56%, and the likelihood that a family member had to reduce or stop work by 53%.

Having any type of health insurance improved access to care and reduced family impacts. Having any type of health insurance nearly doubled the likelihood of receiving care in a medical home and reduced the likelihood of unmet needs for health care by as much as 73%. Similar reductions are evident for the likelihood of having unmet needs for family support services and delaying/foregoing care. Having health insurance reduced the likelihood of a family paying at least \$1000 for the child's medical care in the past year by as much as 86% and reduced the likelihood of needing additional income to cover the child's medical expenses by as much as 78%. However, families with a combination of public and private insurance were 1.5 times more likely to spend >10 hours coordinating the child's care than uninsured families.

Discussion

Children with Down syndrome had higher rates of many significantly burdensome concurrent health conditions. Because of the prevalence and severity of these conditions, health services must be responsive to the complex needs of children with Down syndrome. Findings further suggest that these effects can potentially be mitigated by the presence of a medical home and health insurance.

Our findings also contradict the idea of a "Down syndrome advantage," a circumstance in which families of children with Down syndrome experience less stress and fewer

problems with family functioning than families of children with other disabilities.^{14,21} In this study, we found that families of children with Down syndrome faced substantially more, rather than fewer, work and financial impacts. Although these differences may be caused by the comparison of children with Down syndrome with all other CSHCN and not specifically to CSHCN with ID, we found that CSHCN with Down syndrome were not significantly different than CSHCN with ID in work and family impacts or unmet needs for family support services (results not shown). However, parents of children with Down syndrome were significantly more likely to report unmet needs for health care than families of children with ID and other CSHCN.

Use of a medical home provides children with the proper medical care and family supports that have been delineated by the AAP as especially important to promoting health and social functioning for children with Down syndrome through adulthood.⁴ Promoting the use of medical homes is one way that health policy and health service providers can respond to the complex needs of CSHCN. However, children with Down syndrome may be less likely to use medical homes because of the negative compounding effects of other factors that are prevalent in children with Down syndrome; specifically, children with more co-morbid conditions and children without insurance.¹⁸ However, the apparently excessive “medical homelessness” in children with Down syndrome may reflect a limitation of family survey data as a means of addressing the medical home variable. Many children with Down syndrome have relatively few complex health-related needs, and often the complex needs that they experience are concentrated in a period of months, not continuous for many years. Families who regard their children with Down syndrome as “well” may respond negatively to some of the indicator questions about medical homes because they have not used or needed services like care coordination. Alternatively, children with Down syndrome may require more referrals than other CSHCN and so may be more likely to report problems obtaining them. Thus, the medical home measure used in the survey may not be totally reflective of the concept in practice; however, it is important as a survey construct for systematic measurement in population-based studies.

Evidence has also suggested that the provision of a medical home requires more intensive care coordination within medical practices and therefore creates elevated costs for treating CSHCN.²⁷ Support for the medical home model in general and for care coordination in particular exists in most models of national health care reform, including the Patient Protection and Affordable Care Act, which became law in March 2010.²⁸ New initiatives by both public and private health insurers are testing models of enhanced payments to practices that meet new care coordination and other medical home standards.²⁹ These initiatives should improve the access of all CSHCN to a medical home and care coordination services. Because of these and other findings about the ability of medical homes to ameliorate health disparities,^{18,19,30} policies should be developed that focus on promoting the use of medical homes, at both the patient level and at the practice level.

These findings represent cross-sectional parental report data. Although parental report of the presence of a condition is not ideal because of reliance on recall and because reports of co-morbid conditions are not confirmed with clinical diagnosis, past research has shown that these reports are valid.³¹ Because of the cross-sectional nature of the data, there is no way to determine the timing of family impacts, unmet needs, and medical homes. Longitudinal data would be better suited to disentangle the causal ordering of these concepts to most effectively ameliorate unmet needs and family impacts and understand the presence and use of medical homes for CSHCN. Future research, relying on physician reports of condition, a health system or quality improvement definition of medical home, and longitudinal data collection at individual level, should attempt to clarify the timing and nature of these interrelationships. Studies such as the National Children’s Study may be useful in this respect; however, the National Children’s Study does not over-sample CSHCN or children with Down syndrome.³² Results must also be interpreted in light of the sample size and selection effects, including participation biases. Although the survey is population-based, the analysis is based on responses from parents of 395 children reported to have Down syndrome. Further, there is no way to know whether the responses of parents who participated are representative of parents who did not. Finally, these findings compare differences in a nationally representative sample of CSHCN, not a nationally representative sample of all children. Generalizations about differences between children with Down syndrome and other children are limited to the CSHCN population.³³

Despite these limitations, this study addresses a current gap in the literature on children and families with Down syndrome because it provides information on a nationally representative sample of CSHCN that is not otherwise accessible. Policy makers and health care providers should work to find collaborative solutions that address these disparities and support a usual payment source and medical homes for these patients. ■

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Table III. Logistic regression analyses (adjusted ORs and 95% CIs) of access to care by Down syndrome status and other factors

	Medical home	Any unmet need for health care services	Any unmet need for family support services	Child had delayed or foregone health care
Presence of Down syndrome				
CSHCN with Down syndrome	0.60* (0.41-0.88)	2.76 [†] (1.83-4.16)	2.09* (1.23-3.55)	1.01 (0.58-1.74)
Other CSHCN	reference	reference	reference	reference
Number of co-morbid conditions	0.80 [†] (0.78-0.83)	1.31 [†] (1.26-1.36)	1.60 [†] (1.52-1.68)	1.20 [†] (1.14-1.27)
Medical home				
Present	–	0.38 [†] (0.34-0.43)	0.22 [†] (0.17-0.28)	0.41 [†] (0.35-0.48)
Not present	–	reference	reference	reference
Insurance status				
Private insurance	1.93 [†] (1.57-2.39)	0.27 [†] (0.22-0.34)	0.38 [†] (0.26-0.54)	0.14 [†] (0.11-0.18)
Public insurance	1.98 [†] (1.59-2.47)	0.31 [†] (0.25-0.38)	0.67 [‡] (0.46-0.99)	0.14 [†] (0.11-0.18)
Both public and private insurance	1.61 [†] (1.26-2.06)	0.28 [†] (0.22-0.37)	0.81 (0.54-1.21)	0.14 [†] (0.10-0.19)
Other comprehensive insurance	2.21 [†] (1.57-3.10)	0.37 [†] (0.25-0.56)	0.39* (0.20-0.75)	0.28 [†] (0.15-0.52)
Uninsured	reference	reference	reference	reference
Household poverty status				
0-99% FPL	0.65 [†] (0.55-0.76)	2.83 [†] (2.24-3.57)	0.98 (0.68-1.42)	3.19 [†] (2.34-4.36)
100%-199%FPL	0.74 [†] (0.65-0.84)	2.72 [†] (2.24-3.30)	1.30 (0.94-1.79)	2.76 [†] (2.13-3.58)
200%-399%FPL	0.90 [‡] (0.82-0.99)	1.66 [†] (1.41-1.96)	1.12 (0.85-1.48)	1.97 [†] (1.53-2.53)
≥400% FPL	reference	reference	reference	reference
Highest level of education				
Less than high school	0.83 [‡] (0.69-1.00)	0.75 [‡] (0.59-0.95)	0.69 (0.46-1.03)	0.93 (0.69-1.25)
High school graduate	1.02 (0.92-1.13)	0.82* (0.72-0.94)	0.68* (0.53-0.87)	0.94 (0.78-1.12)
More than high school	reference	reference	reference	reference
Age	0.99 (0.98-1.00)	1.02 [†] (1.01-1.04)	0.98 (0.96-1.01)	1.03 [†] (1.01-1.05)
Sex				
Male	reference	reference	reference	reference
Female	1.03 (0.95-1.10)	0.96 (0.86-1.07)	0.78* (0.65-0.94)	0.96 (0.83-1.11)
Race				
Hispanic	0.63 [†] (0.54-0.73)	1.23 (0.99-1.52)	0.95 (0.68-1.33)	1.08 (0.83-1.39)
White, non-Hispanic	reference	reference	reference	reference
Black, non-Hispanic	0.71 [†] (0.63-0.80)	0.84 [‡] (0.71-0.99)	0.71 [‡] (0.54-0.95)	0.69 [†] (0.55-0.87)
Other non-Hispanic [§]	0.76 [†] (0.65-0.89)	1.29 [‡] (1.06-1.56)	1.05 (0.79-1.41)	1.18 (0.93-1.49)
Primary language in home				
English	1.99 [†] (1.51-2.61)	1.63* (1.19-2.23)	1.25 (0.68-2.31)	1.24 (0.80-1.91)
Non-English	reference	reference	reference	reference
Family structure				
2 parent (biological/adoptive)	reference	reference	reference	reference
2 parent (step)	0.82* (0.72-0.93)	0.99 (0.83-1.18)	1.14 (0.85-1.51)	0.93 (0.74-1.17)
Single mom	0.80 [†] (0.73-0.87)	1.20* (1.05-1.37)	1.63 [†] (1.31-2.04)	1.11 (0.93-1.33)
Other	0.68 [†] (0.58-0.80)	0.88 (0.69-1.11)	1.92* (1.28-2.87)	0.88 (0.64-1.21)
Geographic region				
Northeast	reference	reference	reference	reference
Midwest	1.25 [†] (1.13-1.39)	1.00 (0.86-1.18)	0.96 (0.73-1.26)	1.26 [†] (1.02-1.56)
South	1.18 [†] (1.07-1.30)	1.05 (0.90-1.22)	0.96 (0.74-1.25)	1.04 (0.85-1.27)
West	1.04 (0.91-1.19)	1.42 [†] (1.17-1.71)	1.32 (0.98-1.78)	1.66 [†] (1.30-2.11)

FPL, federal poverty level.

* $P < .01$.† $P < .001$.‡ $P < .05$.

§Other, non-Hispanic includes CSHCN of mixed race.

Table IV. Logistic regression analyses (adjusted ORs and 95% CIs) of family impacts by Down syndrome status and other factors

	Child's health needs caused financial problems for family	Family needed additional income to cover child's medical expenses	Family members had to reduce or stop working because of child's health	Family paid \$1000 or more for child's medical care in previous year	Family spent > 10 hours providing or coordinating care for child
Presence of Down syndrome					
CSHCN with Down syndrome	1.80* (1.16-2.80)	1.39 (0.90-2.16)	2.96† (1.96-4.49)	1.98* (1.28-3.07)	2.14* (1.33-3.47)
Other CSHCN	reference	reference	reference	reference	reference
Number of co-morbid conditions	1.48† (1.42-1.54)	1.42† (1.37-1.48)	1.57† (1.51-1.63)	1.32† (1.27-1.37)	1.57† (1.50-1.65)
Medical home					
Present	0.44† (0.40-0.49)	0.42† (0.38-0.47)	0.47† (0.43-0.52)	0.58† (0.53-0.63)	0.61† (0.52-0.71)
Not present	reference	reference	reference	reference	reference
Insurance status					
Private insurance	0.42† (0.33-0.52)	0.33† (0.26-0.40)	0.60† (0.48-0.75)	0.58† (0.47-0.71)	0.61* (0.44-0.84)
Public insurance	0.33† (0.26-0.41)	0.22† (0.18-0.28)	0.92 (0.74-1.15)	0.14† (0.11-0.18)	1.11 (0.82-1.52)
Both public and private insurance	0.45† (0.35-0.59)	0.35† (0.27-0.45)	1.13 (0.88-1.47)	0.37† (0.28-0.48)	1.52‡ (1.08-2.14)
Other comprehensive insurance	0.64 (0.40-1.03)	0.50† (0.32-0.76)	0.71 (0.49-1.02)	0.97 (0.69-1.36)	0.85 (0.53-1.36)
Uninsured	reference	reference	reference	reference	reference
Household poverty status					
0-99% FPL	2.46† (1.99-3.05)	2.46† (1.97-3.06)	1.13 (0.94-1.36)	0.35† (0.27-0.45)	1.95† (1.45-2.62)
100%-199%FPL	3.23† (2.73-3.81)	3.31† (2.77-3.97)	1.21‡ (1.04-1.41)	0.64† (0.55-0.74)	1.67† (1.27-2.21)
200%-399%FPL	2.2† (2.00-2.63)	2.17† (1.86-2.53)	1.04 (0.92-1.17)	0.83‡ (0.74-0.92)	1.26‡ (1.02-1.56)
≥400% FPL	reference	reference	reference	reference	reference
Highest level of education					
Less than high school	0.67† (0.53-0.85)	0.80 (0.62-1.02)	0.95 (0.77-1.18)	0.38† (0.27-0.54)	1.43* (1.10-1.86)
High school graduate	0.77† (0.67-.088)	0.84‡ (0.74-0.97)	0.87‡ (0.77-0.99)	0.75† (0.65-0.86)	1.14 (0.97-1.35)
More than high school	reference	reference	reference	reference	reference
Age	0.99 (0.98-1.00)	0.99 (0.98-1.00)	0.94† (0.93-0.95)	1.01 (1.00-1.02)	0.90† (0.89-0.92)
Sex					
Male	reference	reference	reference	reference	reference
Female	0.97 (0.88-1.07)	0.99 (0.89-1.10)	1.04 (0.95-1.14)	1.14* (1.04-1.24)	1.05 (0.92-1.20)
Race					
Hispanic	0.80‡ (0.66-0.96)	0.90 (0.74-1.10)	1.08 (0.90-1.28)	0.78* (0.65-0.94)	1.25 (0.93-1.69)
White, non-Hispanic	reference	reference	reference	reference	reference
Black, non-Hispanic	0.69† (0.58-0.82)	0.95 (0.81-1.13)	0.86 (0.74-1.00)	0.45‡ (0.37-0.54)	0.98 (0.81-1.19)
Other, non-Hispanic [§]	1.08 (0.90-1.30)	1.23† (1.01-1.49)	0.90 (0.75-1.07)	0.85 (0.71-1.03)	0.92 (0.73-1.15)
Primary language in home					
English	0.83 (0.63-1.09)	1.03 (0.76-1.40)	0.60† (0.47-0.77)	0.85 (0.62-1.16)	1.36 (0.92-2.02)
Non-English	reference	reference	reference	reference	reference
Family structure					
2 parent (biological/adoptive)	reference	reference	reference	reference	reference
2 parent (step)	0.83‡ (0.70-0.99)	0.86 (0.72-1.04)	1.13 (0.95-1.33)	0.85‡ (0.72-1.00)	0.79‡ (0.62-1.00)
Single mom	1.10 (0.98-1.25)	1.12 (0.99-1.27)	0.98 (0.87-1.10)	0.93 (0.83-1.05)	0.85 (0.72-1.00)
Other	0.89 (0.71-1.11)	0.86 (0.69-1.07)	0.74* (0.60-0.91)	1.05 (0.86-1.28)	1.08 (0.80-1.46)
Geographic region					
Northeast	reference	reference	reference	reference	reference
Midwest	1.03 (0.89-1.19)	1.02 (0.87-1.19)	0.94 (0.83-1.07)	1.16‡ (1.03-1.32)	0.97 (0.80-1.19)
South	1.04 (0.91-1.20)	1.11 (0.96-1.29)	0.92 (0.81-1.04)	1.26† (1.11-1.42)	0.94 (0.78-1.14)
West	0.98 (0.83-1.17)	1.16 (0.96-1.40)	0.89 (0.76-1.04)	1.03 (0.88-1.21)	0.98 (0.77-1.24)

FPL, federal poverty level.

* $P < .01$.† $P < .001$.‡ $P < .05$.

§Other, non-Hispanic includes CSHCN of mixed race.