Health Care Needs of Children With Down Syndrome and Impact of Health System Performance on Children and Their Families

Randall A. Phelps, MD, PhD,* Joseph D. Pinter, MD,* Donald J. Lollar, EdD,*
Joan Guthrie Medlen, MEd, RD, Ld,† Christina D. Bethell, PhD, MPH, MBA‡

ABSTRACT: ***Objective:*** **The functional, financial, and social impact on families of children with Down syndrome (DS) in the United States and the role of the US health care system in ameliorating these impacts have not been well characterized. We sought to describe the demographic characteristics and functional difficulties of these children and to determine whether children with DS, compared with children with "intellectual disability" (ID) generally, and compared with other "children and youth with special health care needs" (CYSHCN), are more or less likely to receive health care that meets quality standards related to care coordination and to have their health care service needs met.** ***Methods:*** **This study analyzed data from the 2005–2006 National Survey of Children with Special Health Care Needs (n = 40,723). Children and youth aged 0 to 17 years with special health care need (CYSHCN) who experience DS (n = 395) and/or IDs (n = 4252) were compared with each other and other CYSHCN on a range of functioning, family impact, and health care quality variables using bivariate and multivariate methods. Data were weighted to represent all CYSHCN in the United States.** ***Results:*** **Compared with CYSHCN without DS, children with DS were significantly less likely to receive comprehensive care within a medical home (29.7% vs 47.3%; $p < .001$). Parents of children with DS were also significantly more likely to cut back or stop work due to their child's health needs (23.5% vs 55.1%; $p < .001$). Although overall system performance was poorer for children with DS compared with those with ID and no DS after adjustment for family income, prevalence on most aspects of quality of care and family impacts evaluated were similar for these 2 groups.** ***Conclusions:*** **In this study, the families of children with DS, and ID generally, are burdened disproportionately when compared with other CYSHCN, reflecting the combination of impairments intrinsic to DS and ID and impacts of suboptimal medical care coordination and social support.**

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Down syndrome (DS) is the most common genetic cause of intellectual disability (ID), with a recent estimate of birth incidence of 1:733.[1,2] More than 400,000 people with DS are currently estimated to be living in the United States.[3] Many children, youth, and adults with DS have multiple medical problems. Even for those who do not, anticipatory guidance and routine screening recommendations add complexity to health care for children and youth with DS.[4–7]

In the current health care climate, overextended primary care providers may have little time to spend with children and families during clinic visits. One might expect that those with the most complex medical problems would have difficulty receiving optimal care. On the other hand, because DS is usually readily recognizable and the diagnosis is usually made before or at birth, children with DS and their families have the advantage of being potentially referred to early intervention and to care coordination services very early on.[4,5] By this logic, one might imagine that families of children with DS would enjoy relatively high rates of optimal care, compared with other children and youth with special health care needs (CYSHCN), given the relatively early diagnosis of DS.[8,9] Studies have assessed the relative health care expenditures of children with DS compared with children without DS and the contribution of specific common comorbid conditions to these costs.[10] These studies suggest positive correlations between parents' mental and physical health with respect to level of health and functioning of their children with DS.[11,12] However, current literature exploring the existence of quality of health

From the *Child Development and Rehabilitation Center, Oregon Health and Science University, Portland, OR; †Healthy Lifestyle Coaching for All Ages and Stages, Portland, OR; ‡Department of Pediatrics, Child and Adolescent Health Measurement Initiative, OHSU School of Medicine, 707 SW Gaines Road, Portland, OR.

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Address for reprints: Randall A. Phelps, MD, PhD, Child Development and Rehabilitation Center, Oregon Health and Science University, 901 East 18th Avenue, Eugene, OR 97403; e-mail: phelpsr@ohsu.edu.

care and care coordination of children with DS compared with other CYSHCN has been lacking.[10–12]

Studies using national survey data have shown that CYSHCN lag behind the general population in their receipt of care within a medical home and impact on the family, such as employment and family stress.[13–16] A recent study, using the 2005–2006 National Survey of Children with Special Health Care Needs (NS-CSHCN), shows that children with DS, compared with other CYSHCN, have a greater number of comorbid health conditions, are more likely to have unmet needs, faced greater family impacts, and are less likely to have access to a medical home.[17] In addition, it is noted that these health care disparities are exaggerated in families with lower income and with other markers of lower socioeconomic status. It is noted that children with ID but without DS experience similar disparities, but data are not shown.

We sought to describe the demographic characteristics and functional difficulties of these children and to determine whether children with DS, compared with children with ID generally and compared with other CYSHCN, are more or less likely to receive health care that meets quality standards related to care coordination and to have their health care service needs met. Specifically, we sought to determine how children with DS compare with other CYSHCN with respect to national performance measures for CYSHCN measures in the NS-CSHCN, including:

1. Receipt of health care services within a medical home.
2. Parental perception of the quality of communication with the physician.
3. Communication of their child's physician with other physicians and with educators and other professionals.
4. Receipt of needed care coordination.
5. Rates of unmet health care needs.

Finally, we also sought to determine the relative burden on families of children with DS and ID when compared with other CYSHCN.

METHODS

Dataset

This study analyzed public-use data from the 2005–2006 National Survey of Children with Special Health Care Needs (NS-CSHCN)[18] using the NS-CSHCN dataset prepared by The Child and Adolescent Health Measurement Initiative's Data Resource Center on Child and Adolescent Health. NS-CSHCN is led and sponsored by the Maternal and Child Health Bureau (MCHB) and conducted by the National Center for Health Statistics for the Centers for Disease Control and Prevention.[19–21] The Data Resource Center Indicator Dataset for the NS-CSHCN merges NS-CSHCN public use data files and provides numerous constructed variables of relevance for research applications using MCHB-approved coding conventions for the key variables used in this analysis. In each of the 50 states and District of Columbia, telephone interviewers screened at least 3000 households with children to identify CSHCN, using a random-digit-dial approach. In-depth interviews were conducted with the parents of 750 to 850 CSHCN per state in 2001 and again in 2005–2006. For the purposes of the NS-CSHCN, children with special health care needs are defined as "those who have 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" and were identified using the validated CSHCN Screener.[21] Specific health conditions asked about for children meeting the criteria for children and youth with special health care needs (CYSHCN) included asthma (39.0%), attention-deficit hyperactive disorder/attention deficit disorder (29.9%), autism/attention deficit disorder (5.3%), intellectual disability (ID) ("mental retardation" + "developmental delay" = 11.4%), emotional problems (21.1%), diabetes mellitus (1.6%), heart problems (3.3%), blood problems (2.3%), cystic fibrosis (0.3%), cerebral palsy (1.8%), muscular dystrophy (0.3%), epilepsy or other seizure disorder (3.4%), migraine or frequent headaches (15.1%), arthritis or other joint problems (4.2%), allergies (53.1%), and Down syndrome (DS) (1%). A parent or legal guardian who knew about the health and health care of the children in the household served as the respondent for the interview. All children younger than 18 years old were screened for special health care needs, and in households with multiple CSHCN, one was randomly selected to be the target of the interview. The overall response rate for the survey was 61.2%. A total of 40,723 interviews were completed, including 395 families with children with DS and 4252 with ID (which includes those children noted to have either "developmental delay" or "mental retardation" in the survey). Respondents reported on demographic characteristics, the child's functional difficulties, health care needs and health care experiences, and the impact of the condition on family functioning.

Statistical Analysis

Key variables were constructed using the NS-CSHCN, and national prevalence was compared between CYSHCN with and without DS using standardized and publicly documented scoring algorithms.[19] Chi-square test and *t* test of statistical significance were conducted as appropriate. Logistic regression was also performed to assess the magnitude and significance of differences in the odds that children with DS experience each of the CYSHCN system performance measures assessed compared with children with ID and no DS, after controlling for differences in household income between these 2 groups. All data were weighted to represent the US population of children aged 0 to 17 years, and standard errors were adjusted for complex sampling using SPSS Complex Samples, Version 17.0. (SPSS, Inc., Chicago, IL).

RESULTS

Demographics

Using the National Survey of Children with Special Health Care Needs (NS-CSHCN) data, estimated US prevalence of children and youth with special health care needs (CYSHCN) with Down syndrome (DS) was 1%. This prevalence roughly translates into a 0.15% prevalence among all children aged 0 to 17 years in the United States and is consistent with population-based DS prevalence estimates of DS using other epidemiologic methods.[22] One demographic characteristic that indicates a disparity between families of children with DS and other CYSHCN is household income. Children with DS were more likely to live in households with incomes that are 100% to 199% of the Federal Poverty Level compared with other CYSHCN (31.2% vs 21.8%; $p < .001$) and less likely to live in households with incomes at or above 400% of Federal Poverty Level (16.3% vs 28.9%; $p < .001$). No other demographic variables showed significant differences between the families or children identified with DS and the group of children and youth with special health care needs.

Functional Limitations and Difficulties

As expected, CYSHCN with DS when compared with other CYSHCN were more likely to have parents who reported that they were limited in their ability to perform day-to-day activities compared with other children of the same age (20.9% vs 82.2%; $p < .001$). CYSHCN with DS are also more likely to experience 4 or more functional difficulties (78.6% vs 27.1%; $p < .001$) (Table 1). Although CYSHCN with DS were more likely to be reported as limited in day-to-day activities compared with CYSHCN with intellectual disability (ID) and no DS (87.4% vs 65.2%; $p < .001$), CYSHCN with DS were not more likely to experience a greater number of functional difficulties (Table 2). This suggests that much of the functional difficulty seen in children with DS may be attributable to the high rate of ID seen in children with DS.

Impact on Families

A significantly larger percentage of CYSHCN with DS live in families whose parents reported having to cut back or stop working compared with CYSHCN without DS (55.1% vs 23.5%; $p < .001$), with no differences observed between CYSHCN with DS and CYSHCN with ID and no DS. CYSHCN with DS also had parents who were more likely to report substantially higher rates of having to provide >11 hours per week of health care to their children; paying >$1000 out of pocket per year in medical expenses; and having financial problems due to their child's health needs. Families of CYSHCN with DS had parents who reported higher rates of unmet need for family support services and respite care, genetic counseling, and/or mental health services (Table 3). Similar rates for measures of family impact hold true in this dataset for families of children with ID and no DS (Table 4).

Health Care Quality

In comparing health care quality, CYSHCN with DS had lower rates on the system performance indicators evaluated here. This was also true for CYSHCN with ID and no DS (Table 5):

1. Compared with other CYSHCN, CYSHCN with DS were less likely to receive comprehensive care within a medical home.
2. CYSHCN with DS had parents who reported lower rates of feeling like a partner in their child's care and being satisfied with health care services received, and of receiving family-centered care, whereby they report the child's doctors and other health care providers listen carefully, spend enough time, give needed information, and honor the families' customs and values.

Table 1. Functional Limitations and Difficulties Experienced by Children With DS and by Other CYSHCN

	Down Syndrome	CYSHCN (Without DS)	*p*
Reported child limited in ability to do things other children same age can do due to an ongoing health condition (%/n)	82.2/300	20.9/8,403	<.001
Children reported to have 4 or more types of difficulties (%/n)	78.6/302	27.1/10,455	<.001
Specific: difficulty with self-care activities such as eating or dressing (%/n)	71.3/227	11.3/3,995	<.001
Specific: coordination or movement difficulties (%/n)	61.6/245	13.7/5,184	<.001
Specific: difficulties using hands (%/n)	66.0/4075	10.4/260	<.001
Specific: difficulty speaking, communicating, or being understood (%/n)	91.7/342	21.9/8,063	<.001
Specific: difficulty learning, understanding, or paying attention (%/n)	93.2/343	40.4/15,764	<.001
Specific: behavior or conduct problems (%/n)	47.4/140	28.1/10,472	<.001
Specific: difficulty making and keeping friends (%/n)	37.2/126	20.2/7,537	<.001
Conditions/problems consistently and often greatly affect their daily activities (%/n)	73.4/272	21.0/8,908	<.001
Missed 11 or more days of school due to illness (%/n)	28.3/73	14.2/4,776	<.001

DS, Down syndrome; CYSHCN, children and youth with special health care needs.

Table 2. Functional Limitations and Difficulties Experienced by Children With ID,[a] With or Without DS

	ID Without DS	ID With Down Syndrome	*p*
Reported child limited in ability to do things other children same age can do due to an ongoing health condition (%/n)	65.2/2637	87.4/272	<.001
Children reported to have 4 or more types of difficulties (%/n)	81.0/3151	83.1/272	0.545
Specific: difficulty with self-care activities such as eating or dressing (%/n)	56.2/1990	75.5/210	<.001
Specific: coordination or movement difficulties (%/n)	51.6/2025	65.8/220	.002
Specific: difficulties using hands (%/n)	49.1/2039	72.2/242	<.001
Specific: difficulty speaking, communicating, or being understood (%/n)	76.8/2945	92.8/299	<.001
Specific: difficulty learning, understanding, or paying attention (%/n)	90.7/3489	95.3/304	.081
Specific: behavior or conduct problems (%/n)	51.6/1924	47.5/117	.402
Specific: difficulty making and keeping friends (%/n)	52.5/1879	40.3/116	.016
Conditions/problems consistently and often greatly affect their daily activities (%/n)	69.6/2744	78.3/249	.030
Missed 11 or more days of school due to illness (%/n)	24.1/736	29.7/62	.240

ID, intellectual disability; DS, Down syndrome. [a]"Intellectual disability" as per caregiver response to survey question: "To the best of your knowledge, does child currently have mental retardation or developmental delay?"

3. CYSHCN with DS who require communication between doctors have parents who report higher levels of dissatisfaction with doctor-to-doctor communication and doctor-to-school communication.
4. CYSHCN with DS were more likely to have parents who reported neither receiving care coordination when needed nor receiving any extra care coordination needed.
5. CYSHCN with DS were also more likely to have parents who report some type of unmet needs for specific health services.

In addition to the health care quality indicators, children aged 0 to 11 years with DS, and children with ID generally, are reported to be less likely to have met all 5 core Maternal and Child Health Bureau (MCHB) outcomes for CYSHCN. These outcomes are that (a) families feel like partners and are satisfied with the services they receive; (b) families receive coordinated, ongoing, comprehensive care within a medical home; (c) families have adequate private and/or public insurance to pay for the services they need; (d) CYSHCN have preventive health care visits where they might receive early and continuous screening; and (e) families find community-based services easy to access. CYSHCN with DS who were aged 12 to 17 years, and youths with ID and no DS, are less likely than other CYSHCN to have received services necessary to make appropriate transitions to adult health care, work, and independence. CYSHCN with DS, or with ID and no DS, are also less likely to have received care that has met all 6 core MCHB outcomes for quality, which include the 5 criteria listed above for children, plus the criterion that youth receive the services necessary to make appropriate transitions. The odds that CYSHCN aged 12 to 17 years with DS meet each MCHB core outcome are significantly lower than for CYSHCN with ID and no DS after adjusting for household income (adjusted odds ratio: 0.16; 95% confidence interval 0.045–0.575) (Table 6). The age stratification of 0 to 11 years and 12 to 17 years was used because the MCHB core indicators included in the database create this age stratification, with both age groups sharing the same 5 core indicators, and the 12 to 17 years age group also including a "Transition to Adulthood" core indicator. Income is a moderator of quality in the younger age group but not the older age group. Regardless of income level, core indicators of quality are met at extremely low levels for this age group, making income class distinctions insignificant.

Table 3. Impact on Finances, Work and Support for Families With Children With DS and for Other CYSHCN

	Down Syndrome	CYSHCN (Without DS)	*p*
Family member(s) cut back or stopped working due to child's health needs (%/n)	55.1/209	23.5/8939	<.001
Parents provide 11 or more hours per week coordinating health care (%/n)	30.2/101	9.5/3506	<.001
Financial problems for family due to child's health needs (%/n)	36.4/122	17.9/7323	<.001
Families pay $1000 or more out-of-pocket in medical expenses per y for CSHCN (%/n)	31.7/99	19.9/8825	0.001
Unmet needs for family support services: respite care, genetic counseling, and/or mental health services (%/n)	16.8/53	4.7/1854	<.001

DS, Down syndrome; CYSHCN, children and youth with special health care needs.

Table 4. Impact on Finances, Work and Support for Families With Children With ID[a] With or Without Down Syndrome

	ID Without DS	ID With Down Syndrome	*p*
Family member(s) cut back or stopped working due to child's health needs (%/n)	54.3/2062	56.8/182	.037
Parents provide 11 or more hours per week coordinating health care (%/n)	28.7/1140	32.5/91	.327
Financial problems for family due to child's health needs (%/n)	34.2/1419	38.8/106	.386
Families pay $1000 or more out-of-pocket in medical expenses per y for CSHCN (%/n)	23.8/1037	32.5/87	.600
Unmet needs for family support services: respite care, genetic counseling, and/or mental health services (%/n)	16.2/641	18.2/48	.570

ID, intellectual disability. [a]"Intellectual disability" as per caregiver response to survey question: "To the best of your knowledge, does child currently have mental retardation or developmental delay?"

DISCUSSION

These results indicate the complexity of the health and functioning of children and youth with Down syndrome (DS), as reported by their parents. The relatively lower income among these families, in the presence of data suggesting that more families are working less and spending more than even other families with children with other special health care needs, is certainly a reasonable contribution to this disparity.

The functional difficulties reported for children and youth with special health care needs (CYSHCN) with DS also suggest an extensive set of problems in living in the world. Four times the percentage of children with DS is reported to be limited in their daily activities than other CYSHCN. The breadth of the functional problems—from self-care through making and keeping friends—suggests a complex array of needs that will often require coordinated care across disciplines and therapeutic interventions.

Measures of health services for CYSHCN with DS were significantly worse than for other CYSHCN, as reflected by less family-centered care, poorer medical communication, inferior care coordination, and less success in meeting benchmarks of health care quality as set by the Maternal and Child Health Bureau (MCHB). CYSHCN with DS were more likely to live in families experiencing a higher impact on the family when compared with other CYSHCN, includ-

Table 5. Health Care Quality, With Respect to MCHB Core Indicators of Quality, Received by Families of Children With DS, Compared With Families With (CYSHCN), and to Families With Children With ID[a] Without DS

	Down Syndrome	CYSHCN (Without DS)	*p* (DS/CYSHCN)	ID (Without DS)	*p* (DS/ID)
Medical home: receive coordinated, ongoing, comprehensive care within a medical home (%/n)	29.7/116	47.3/18,855	<.001	29.8/1106	.971
Families feel like a partner in care and are satisfied with the services they receive (%/n)	41.4/182	57.6/22,979	<.001	42.6/1615	.779
Received family-centered care (%/n)	55.5/210	65.9/25,692	0.012	53.7/1990	.690
Less than very satisfied with needed communication between doctors (%/n)	44.6/142	36.1/16,834	0.037	45.9/1715	.774
Less than very satisfied with needed communication between doctors and school/community programs (%/n)	56.9/103	47.7/5,268	0.125	53.7/1202	.608
Did not receive care coordination help (for those receiving 2+ types of services) (%/n)	56.2/190	31.5/12,363	<.001	54.8/2119	.100
Did not receive extra help with care coordination, when needed (%/n)	46.1/101	32.4/5,435	0.004	43.6/1163	.639
Reported at least one unmet need for 15 specific health care services or equipment (%/n)	38.1/356	15.8/6,090	<.001	29.3/1185	.033
Received the services necessary to make appropriate transitions to adult health care, work and independence (children age 12–17 y only) (%/n)	13.7/21	41.5/7,454	<.001	20.1/299	.277
All 5 MCHB core outcomes achieved (ages 0–11 y) (%/n)	10.7/26	20.5/4,405	0.007	11.1/248	.578
All 6 MCHB core outcomes achieved (ages 12–17 y) (%/n)	0.6/4	13.8/2,317	<.001	3.5/53	.340

MCHB, Maternal and Child Health Bureau; DS, Down syndrome; CYSHCN, children and youth with special health care needs; ID, intellectual disability. [a]"Intellectual disability" as per caregiver response to survey question: "To the best of your knowledge, does child currently have mental retardation or developmental delay?"

Table 6. Logistic Regression, Showing Impact of Family Income, and Contribution of DS, on Meeting MCHB Benchmarks of Quality Healthcare for Children With ID[a]

Logistic Regression	Odds Ratio
Met all 5 core outcomes, age 0–11 y: children with ID	
Income	
0–99% FPL	1.041 (0.559–1.937)
100–199% FPL	1.088 (0.630–1.878)
200–399% FPL	1.025 (0.610–1.723)
DS	0.760 (0.373–1.547)
Met all 6 core outcomes, age 12–17 y subpopulation: children with ID	
Income	
0–99% FPL	1.665 (0.360–7.691)
100–199% FPL	1.969 (0.374–10.365)
200–399% FPL	2.073 (0.458–9.372)
DS	0.161 (0.045–0.575)

MCHB, Maternal and Child Health Bureau; ID, intellectual disability; FPL, Federal Poverty Level; DS, Down syndrome. [a]"Intellectual disability" as per caregiver response to survey question: "To the best of your knowledge, does child currently have mental retardation or developmental delay?"

ing detrimental effects on work, finances, and formal social supports. Poorer quality of care combined with greater service needs and functional difficulties makes children with DS ideal populations for assessing the degree to which the health care system is functioning as an integrated, comprehensive, family-centered system of care, which is a goal for all CYSHCN as outlined in Title V legislation and the federal MCHB systems of care model. By these standards, we are not doing well for this group of children and youth and their families.

Generally speaking, the DS and ID groups are quite comparable in terms of function, family impact, and quality of care. There is a mild trend toward greater severity of impact of DS when compared with ID. Given the limitations of methodology, we can only conjecture as to the reason for these differences, but the causes for these differences may include higher rates of medical comorbidity in DS and/or greater variance in the ID population. In this context, it should be noted that the database does not include scores on tests of cognition; rather, the survey asks for parents to identify whether or not their child has "developmental delay or mental retardation." It is a fair assumption that most children with DS would have moderate cognitive impairment. In comparison, the ID group would likely include a larger number of children with milder cognitive impairment. The rate of comorbid medical conditions may also be expected to be lower in the ID group.

Disabilities are a product of the interaction between impairments, which are intrinsic to an individual and that individual's context or environment.[23] According to guidelines for the assessment and care of children and youth with developmental disability published by the American Association on Intellectual and Developmental Disabilities, the purpose of assessing limitations is to guide the development of appropriate supports for the individual in question. It is expected that the provision of individualized supports will significantly improve functioning.[24] Implicit in these guidelines is the understanding that although cognitive and adaptive impairments are not reversible, intellectual disability (ID) and associated functional difficulties can be ameliorated by environmental modifications, therapeutic interventions, and family supports. The data presented here show that children with DS have more functional limitations and difficulties than other CYSHCN. However, because children with DS also are more likely to have suboptimal health services, care coordination, and social support compared with other CYSHCN, it is not appropriate to conclude that the functional limitations associated with DS in these data cannot be further ameliorated. Quite the contrary, it is logical that by increasing the level of services and supports for children with DS to a higher standard, impact on families may be expected to be reduced and function expected to be increased.

The data from this study suggest that CYSHCN with DS, as well as CYSHCN with ID, and their families receive a lower quality of care than other CYSHCN. Health professionals must be more aware of these complexities as they assess, treat, and refer this population. There already exists a network of comprehensive DS clinics, and of interdisciplinary child development clinics, for the diagnosis and treatment of children with developmental disability. To address the problems described, we suggest that this network needs to be expanded and that more effort should be placed on using these centers to improve the training of pediatricians, internists, and family medicine specialists regarding the health care needs of children and adults with DS.

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