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Health of Children 3 to 17 Years of Age With Down Syndrome in the 1997–2005 National Health Interview Survey

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What's Known on This Subject

There have been sizable gains in child survival rates and life expectancy among children with DS. However, studies document or suggest many health problems. Population-based data are needed.

What This Study Adds

This study provides population-based estimates for recent medical and long-term developmental conditions among children with DS. Many conditions are increased in comparison with the general population of US children, seem more pronounced in early childhood, and have measurable health impacts.

ABSTRACT

OBJECTIVE. This study provides population-based estimates of recent medical conditions, concurrent developmental disorders, and health impact and utilization indicators for US children with and without Down syndrome.

METHODS. The sample included children 3 to 17 years of age in the 1997–2005 National Health Interview Survey Child Sample Core and specifically included 146 children with Down syndrome, 604 children with mental retardation but without Down syndrome, and 95 454 children without either condition reported. Developmental and medical conditions, health status, and service use were reported by parents or other knowledgeable caregivers.

RESULTS. After adjustment for demographic factors, children with Down syndrome had higher odds, compared with children without mental retardation, of recent food/digestive allergy, frequent diarrhea/colitis, ≥ 3 ear infections in the previous year, very recent head/chest cold, and developmental disabilities other than mental retardation. They had increased odds that approached significance for recent seizures, very recent stomach/intestinal illness, and asthma. They had substantially higher rates (threefold or higher, compared with children without mental retardation) for nearly all health impact and health and special education service use measures. Of note, $>25\%$ of children with Down syndrome needed help with personal care, regularly took prescription medications, had recently seen a medical specialist, and received physical therapy or related therapy. The comparison group with mental retardation without Down syndrome represented many children with multiple serious disabilities who also had high rates of medical conditions and high levels of health impact and service use.

CONCLUSION. These findings provide empirical, population-based data to inform guidelines for frequent monitoring and support for children with Down syndrome. *Pediatrics* 2009;123:e253–e260

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Key Words

Down syndrome, mental retardation, health status, developmental disabilities, child health services

Abbreviations

DS—Down syndrome
NHIS—National Health Interview Survey
ADHD—attention-deficit/hyperactivity disorder
RSE—relative SE

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ALTHOUGH MORTALITY RATES among persons with Down syndrome (DS) remain increased, relative to the general population, studies in developed countries document sizable gains in child survival^{1–4} and life expectancy, which has been estimated at 50 to 60 years.^{1,5} However, mortality rates vary according to whether a child has a concurrent heart defect, which occurs in $\sim 50\%$ of children born with DS.^{1,2,6–8} Moreover, studies document or suggest many health problems beyond heart defects among children and adults with DS, including other congenital anomalies,^{2,6,9} childhood leukemia,^{1,6–8,10} thyroid disease,^{6,8,10,11} autoimmune diseases, including celiac disease and diabetes mellitus,^{7,8,10,12–14} dermatologic conditions,^{6,8,10,15–17} hematologic disorders other than leukemia,^{8,18,19} seizure disorders,^{7,8,20–22} hearing^{6,8,11,14,15,23} and vision^{6,8,14,15,23} impairments, autism and other behavioral problems,^{8,24–26} orthopedic disorders,^{6,8,15,27} and speech and language disorders.^{8,28} The physiologic and structural impairments in DS also predispose children to increased risks for recurrent episodic illnesses such as otitis media,^{8,29} bronchitis and other respiratory conditions,^{6,8,15,30} and gastrointestinal symptoms.^{13,15}

Although risks for medical and developmental conditions among persons with DS have been described, analyses were often based on clinical case series, without direct comparisons with persons without DS. Studies with non-DS comparison groups were often small, were not population-based, and spanned a large age range and time period. The few comparative population-based studies were also limited in that they were based on registries that captured only the most serious sequelae, that is, those resulting in hospitalization or death.^{2,7,10} There is a lack of population-based data on episodic illnesses that do not generally require hospitalization. Moreover, there has been little study of the impact of concurrent developmental and medical conditions affecting children with DS on their health care and other support needs. Studies describing functional limitations in self-care, communication, and social interactions^{27,31–33} and increased health care utilization^{15,32} among children with DS were often based on small clinical or convenience samples and/or lacked comparison groups. As medical advances offer children with DS the potential for longer lives, additional study of a full range of health impact measures among populations of children with DS is needed.

Since 1997, the National Health Interview Survey (NHIS), an annual US population-based survey, has included a child sample. A parent or other knowledgeable caregiver responds to questions about the child's health and health care, including a specific query about DS. A previous study indicated that maternal report is valid for DS.³⁴ Therefore, the NHIS afforded a unique opportunity to assess the health status of US children with and without DS.

METHODS

Survey Description and Sample Selection

The NHIS is an annual, multistage, probability-sample, household survey of the US civilian noninstitutionalized population.³⁵ Demographic and health information on all members of selected households is collected during an in-person interview with a knowledgeable household member. In addition, 1 child <18 years of age is selected randomly from each family with children. Information pertaining to that child's medical conditions and health status is collected from the adult family member who "knows about the health of all the family members," usually a parent (>90%).

This analysis uses data from the 1997–2005 NHIS Child Sample Core supplemented with selected demographic information collected for the household. The sample for 1997–2005 included 117 520 children, of whom 96 345 were 3 to 17 years of age. Children <3 years of age were excluded from this analysis because many outcomes of interest were not collected for younger children. Data on both DS and mental retardation were available for 96 204 children (99.9%). Sample sizes were similar over the 9 survey years. Response rates for the annual child surveys approached or exceeded 80%.

Ascertainment of DS and Definitions for Comparison Groups

DS was ascertained with the question, "Has a doctor or health professional ever told you that [child's name] had Down's syndrome?" A comparison group of children with other causes of mental retardation was identified on the basis of a negative response to the DS question but an affirmative response to the question, "Has a doctor or health professional ever told you that [child's name] had mental retardation?" Another general-population comparison group consisted of children whose parents answered no to both the DS and mental retardation questions (it should be noted that children with reports of disabilities other than mental retardation were not excluded). The final sample included 146 children with DS, 604 children with mental retardation but without DS, and 95 454 children from the general population without either condition. Although, the currently accepted terminology for mental retardation is "intellectual disability,"³⁶ we use the term mental retardation in the tables and text because this was the specific term used in the NHIS.

Co-occurring Conditions and Health Impact and Service Utilization Outcomes

Interviewers asked parents whether their child had a previous asthma diagnosis and whether the following conditions occurred in the 12 months preceding the interview: asthma attack, hay fever, respiratory allergy, food/digestive allergy, eczema/skin allergy, frequent diarrhea/colitis, frequent severe headaches/migraines, ≥ 3 ear infections, and seizures. Interviewers also asked about very recent occurrences (onset in the 2 weeks preceding the interview) of head or chest colds and stomach or intestinal illnesses with vomiting or diarrhea. The sample sizes for these latter 2 outcomes were slightly reduced because the items were not included in the 1997 survey.

In addition to mental retardation, the survey included questions on other developmental disorders, including attention-deficit/hyperactivity disorder (ADHD), autism, and cerebral palsy (ascertained by using comparable verbiage as for DS and mental retardation), blindness (ascertained with the question, "Is [child's name] blind or unable to see at all?"), hearing impairment (respondent indicated that "deaf or a lot of trouble hearing" best described the child's hearing without a hearing aid), and recent (in the previous 12 months) stuttering or stammering. We combined these conditions into a single "any other developmental condition" outcome and separately assessed the individual disorders with ≥ 3 cases in the DS and comparison groups.

Health impact was assessed with 5 questions addressing the child's functional status (Appendix), which were similar to components of screening questions used to identify children with special health care needs in other national studies.³⁷ Service utilization outcomes included types of health care providers and visit frequency during the previous 12 months and current use of special educational/early intervention services (Appendix).

TABLE 1 Demographic Characteristics of Children 3 to 17 Years of Age With and Without DS in the United States, 1997–2005

	n (%)		
	Children With DS	Children Without DS but With Mental Retardation	Children Without DS or Mental Retardation
Child gender			
Male	83 (58.4)	364 (55.6)	49 170 (51.2)
Female	63 (41.6)	240 (44.4)	46 284 (48.8)
Child age			
3–5 y	31 (19.1)	50 (10.6) ^a	19 203 (19.8)
6–10 y	41 (30.8)	177 (29.1)	30 201 (33.5)
11–17 y	74 (50.1)	377 (60.3)	46 050 (46.7)
Race/ethnicity			
White	111 (79.0)	392 (66.6) ^b	71 616 (77.1)
Black	21 (13.1)	167 (26.0)	16 009 (15.6)
All other	14 (7.9)	45 (7.4)	7829 (7.2)
Maternal education			
Less than high school	35 (19.7)	153 (24.4)	17 137 (16.2) ^a
High school/general equivalency diploma	45 (36.8)	171 (32.1)	25 165 (28.5)
More than high school	51 (43.4)	209 (43.5)	45 067 (55.3)
Household income			
<100% of poverty level	24 (16.5)	155 (32.5) ^b	12 732 (16.3)
100% to <200% of poverty level	30 (26.9)	132 (24.8)	16 780 (21.6)
≥200% of poverty level	63 (56.6)	202 (42.7)	45 623 (62.0)

Unweighted sample size and weighted proportions are presented.

^a $P < .10$, in comparison with children with DS.^b $P < .05$, in comparison with children with DS.

Statistical Analyses

All estimates were weighted to reflect the noninstitutionalized population of children nationally. SEs, statistical tests, and models were adjusted to account for the complex sample design by using Sudaan 9.0 (Research Triangle Institute, Research Triangle Park, NC). We present prevalence estimates for each outcome for children with DS and each comparison group. Because the observed numbers of children with both DS and some health outcomes were small, we calculated relative SEs (RSEs) ($\text{SE/prevalence estimate} \times 100$) and indicate the estimates that have high variability (RSE of $>50\%$). For each outcome, we assessed differences between the DS and comparison groups with χ^2 tests and odds ratios derived from multivariable logistic regression models. In addition to the presence or absence of DS, each model included child gender, age, and race and maternal education. All outcomes were also assessed separately within strata based on child age and gender, to assess the potential for different risks and associations. Age- and gender-specific prevalence ratios were calculated by comparing children with DS with children in the general population. Age-specific comparisons between the DS group and the other mental retardation group were not informative, because the prevalence ratios were very imprecise because of small numbers. Therefore, those data are not presented. We tested for a secular trend in DS prevalence with logistic regression analyses that included survey year as a continuous independent variable. Human subject review was not required for this study.

RESULTS

Between 1997 and 2005, the average annual prevalence of DS among US children 3 to 17 years of age was 14.3 cases per 10 000. No secular trend was evident (data not shown). Children with DS were younger, more often white, and less likely to live in low-income households than were children with other causes of mental retardation (Table 1). They were generally comparable to the general population of US children. However, a slightly smaller proportion of children with DS had mothers who had greater than a high school education (43% vs 55%; $P < .10$).

Children with DS were more than twice as likely as children in the general population group to have recently had a food/digestive allergy, frequent diarrhea/colitis, ≥ 3 ear infections, and seizures (Table 2). These associations remained strong after adjustment; however, because of small numbers, the confidence interval for the seizure association included 1.0. In addition, children with DS were at moderately increased risk for asthma and respiratory allergy and very recent head/chest cold and stomach/intestinal illness; these associations reached or approached statistical significance after adjustment. In contrast, children with DS had risks similar to those of children with other causes of mental retardation for most of the medical conditions examined (Table 2). In fact, children with other causes of mental retardation had higher risks for frequent severe headaches and seizures than did children with DS.

Overall, children with DS were significantly more likely than children in the general population and sig-

TABLE 2 Prevalence of Parent-Reported Medical and Developmental Conditions Among Children 3 to 17 Years of Age With and Without DS

	Children With DS, n (%)	Children Without DS but With Mental Retardation		Children Without DS or Mental Retardation	
		n (%)	aOR for DS vs Other Mental Retardation (95% CI) ^a	n (%)	aOR for DS vs No Mental Retardation (95% CI) ^a
Medical conditions					
Asthma (ever)	29 (19.4)	133 (19.2)	1.1 (0.6–1.8)	12 967 (13.2) ^b	1.5 (0.9–2.5)
Asthma attack (previous 12 mo)	12 (8.7) ^c	63 (9.4)	0.8 (0.4–1.9)	5586 (5.8)	1.3 (0.6–2.8)
Hay fever (previous 12 mo)	19 (12.7)	96 (17.5)	0.7 (0.3–1.4)	10 779 (11.4)	1.1 (0.6–2.0)
Any respiratory allergy (previous 12 mo)	28 (19.9)	139 (22.8)	0.8 (0.5–1.5)	12 210 (12.8) ^b	1.7 (1.0–3.0)
Food/digestive allergy (previous 12 mo)	17 (7.8)	55 (7.1)	1.2 (0.6–2.7)	3301 (3.4) ^d	2.6 (1.4–4.9)
Eczema/skin allergy (previous 12 mo)	20 (9.2)	86 (15.5) ^d	0.5 (0.2–1.2)	7578 (8.2)	1.2 (0.7–2.1)
Frequent diarrhea/colitis (previous 12 mo)	9 (5.2) ^c	41 (6.5)	0.5 (0.2–1.2)	1154 (1.2) ^d	2.8 (1.2–6.5)
Frequent severe headaches/migraines (previous 12 mo)	10 (4.9) ^c	87 (14.1) ^d	0.4 (0.2–0.9)	5898 (6.0)	0.9 (0.5–1.7)
≥3 ear infections (previous 12 mo)	25 (17.2)	84 (16.3)	1.5 (0.8–2.9)	5042 (5.2) ^d	4.6 (2.6–8.0)
Seizures (previous 12 mo)	4 (1.4) ^e	94 (16.3) ^d	0.1 (0.02–0.3)	530 (0.6)	2.9 (0.9–9.4)
Head/chest cold (onset in previous 2 wk) ^f	32 (27.6)	132 (24.0)	1.4 (0.8–2.5)	14 341 (17.5) ^b	2.0 (1.2–3.2)
Stomach/intestinal illness with vomiting or diarrhea (onset in previous 2 wk) ^f	11 (10.6) ^c	65 (11.5)	0.8 (0.3–1.8)	4579 (5.7)	1.8 (0.9–3.9)
Developmental conditions					
Developmental condition other than mental retardation ^g	45 (26.2)	426 (67.6) ^d	0.2 (0.09–0.3)	7514 (8.1) ^d	3.9 (2.5–6.3)
ADHD	19 (10.9)	294 (46.7) ^d	0.1 (0.07–0.3)	5646 (6.1) ^b	1.9 (1.0–3.6)
Hearing impairment	7 (4.6) ^e	21 (3.9)	1.1 (0.4–3.6)	403 (0.4) ^b	11.7 (4.0–33.7)
Stuttering	27 (15.6)	102 (16.2)	1.0 (0.6–1.8)	1393 (1.5) ^d	11.6 (6.9–19.6)

Unweighted sample sizes and weighted proportions are presented. The RSEs for estimates that are not flagged are <30%. aOR indicates adjusted odds ratio; CI, confidence interval.

^a Adjusted odds ratios indicate comparisons of children with DS with children in the given comparison group (other mental retardation or no DS or mental retardation), with adjustment for child gender, age, and race and maternal education.

^b $P < .10$, in comparison with children with DS.

^c The RSE is 30% to 35%.

^d $P < .05$, in comparison with children with DS.

^e The RSE for the prevalence estimate is >50%, which indicates that the variance is large and therefore the point prevalence estimate for this condition should be interpreted with caution.

^f Data for 1998–2005 only.

^g Includes ADHD, autism, blindness, cerebral palsy, hearing impairment, and/or stuttering. Only conditions with ≥3 cases in each group (DS, other mental retardation, and no DS/mental retardation) are presented individually.

nificantly less likely than children with other causes of mental retardation to have another developmental condition reported (Table 2). Among individual conditions with sufficient sample sizes, children with DS had higher rates of ADHD, hearing impairment, and stuttering than did children in the general population and lower rates of ADHD than did children with other causes of mental retardation. Although small sample sizes precluded individual assessment of several disabilities for children with DS, it is noteworthy that the group with other causes of mental retardation had relatively high rates for many concurrent disabilities. In addition to the nearly 50% prevalence of ADHD and 4% prevalence of hearing impairment presented in Table 2, 11% of children with mental retardation without DS had a report of autism, 10% had a report of cerebral palsy, and 3% were reported to be blind. Therefore, the comparison group with other causes of mental retardation seems to represent many children with >1 serious disability.

Age-specific prevalence estimates for many medical conditions were greater for the youngest children with DS (3–5 years of age). Individual prevalence rates should be interpreted with caution, because stratum-specific samples were small and therefore RSEs were large.

Nonetheless, a consistent pattern of results according to age was notable for several conditions (Table 3). Relative to young children without mental retardation, young children with DS had three- to fivefold increases in asthma, recent asthma attack, respiratory allergy, food/digestive allergy, and frequent ear infections and a sevenfold increase in recent frequent diarrhea/colitis. Prevalence ratios decreased as child age increased, and rates of some conditions were not elevated among children 11 to 17 years of age with DS; the exceptions were frequent ear infections (sixfold increase) and frequent diarrhea/colitis and food/digestive allergy (twofold increases for both, although the confidence intervals included 1.0). Rates of concurrent developmental conditions among children with DS were similar (24.0%–30.6%) across age groups. Although most conditions were reported more commonly for boys than for girls, gender-specific prevalence ratios comparing boys and girls with DS with their counterparts in the general population (data not shown) were generally similar to the adjusted odds ratios for the total sample presented in Table 2.

Children with DS had substantially higher estimates (threefold or higher) for nearly all health impact and health and special education service use measures, com-

TABLE 3 Associations Between DS and Medical and Developmental Conditions According to Child Age

	Age 3–5 y		Age 6–10 y		Age 11–17 y	
	Proportion of DS Group, %	PR (95% CI)	Proportion of DS Group, %	PR (95% CI)	Proportion of DS Group, %	PR (95% CI)
Medical conditions						
Asthma (ever)	46.0	4.2 (2.6–6.8)	19.2 ^a	1.5 (0.8–3.0)	9.4 ^a	0.6 (0.3–1.2)
Asthma attack (previous 12 mo)	24.9 ^a	4.5 (2.1–9.7)	9.2 ^b	1.6 (0.5–1.8)	2.1 ^b	0.4 (0.1–1.3)
Hay fever (previous 12 mo)	10.6 ^b	1.5 (0.4–5.0)	15.2 ^a	1.5 (0.7–3.2)	11.9 ^a	0.9 (0.4–1.7)
Any respiratory allergy (previous 12 mo)	28.2 ^a	2.7 (1.3–5.9)	28.0	2.2 (1.3–3.8)	11.8 ^a	0.9 (1.4–4.8)
Food/digestive allergy (previous 12 mo)	11.7 ^b	3.4 (1.1–10.1)	6.6 ^b	2.0 (0.7–5.8)	7.1 ^a	2.1 (0.9–4.5)
Eczema/skin allergy (previous 12 mo)	12.6 ^c	1.3 (0.5–3.4)	8.7 ^b	1.0 (0.4–2.9)	8.2 ^a	1.1 (0.5–2.2)
Frequent diarrhea/colitis (previous 12 mo)	10.8 ^b	7.1 (2.1–24.0)	5.6 ^b	5.4 (1.7–17.1)	2.7 ^b	2.4 (0.8–7.3)
≥3 ear infections (previous 12 mo)	30.2 ^a	2.9 (1.5–5.6)	11.5 ^c	2.1 (0.9–5.0)	15.7 ^a	5.7 (2.9–11.4)
Head/chest cold (onset in previous 2 wk) ^d	27.1 ^a	1.1 (0.5–2.3)	37.8	2.2 (1.3–3.9)	22.0	1.5 (0.9–2.5)
Developmental condition other than mental retardation ^e	25.0 ^a	5.8 (2.8–12.0)	30.6	3.7 (2.2–6.3)	24.0	2.5 (1.6–4.0)

Weighted proportions are presented. Age-specific prevalence ratios comparing children with DS and children in the general population comparison group were not further adjusted because of small sample sizes within age groups. The RSEs for estimates that are not flagged are <30%. PR indicates prevalence ratio; CI, confidence interval.

^a The RSE is 30% to 40%.

^b The RSE for the prevalence estimate is >50%, which indicates that the variance is large and therefore the point prevalence estimate for this condition should be interpreted with caution.

^c The RSE is 40% to 50%.

^d Data for 1998–2005 only.

^e Includes ADHD, autism, blindness, cerebral palsy, hearing impairment, and/or stuttering.

pared with children in the general population (Table 4). Notably, 17% had limited mobility, >25% needed help with personal care and were regularly taking prescrip-

tion medications, and >20% had ≥2 health impact indicators. In addition, more than one third had recently seen a medical specialist and/or a physical therapist or

TABLE 4 Health Impact and Health Services Utilization Indicators Among Children 3 to 17 Years of Age With and Without DS

	Children With DS, n (%)	Children Without DS but With Mental Retardation		Children Without DS or Mental Retardation	
		n (%)	aOR for DS vs Other Mental Retardation (95% CI) ^a	n (%)	aOR for DS vs No Mental Retardation (95% CI) ^a
Health impact					
Limited ability to walk, run, or play	32 (17.2)	175 (28.2) ^b	0.5 (0.3–0.8)	1694 (1.7) ^b	12.1 (7.3–20.0)
Uses special equipment (eg, brace, wheelchair, or hearing aid, excluding ordinary eyeglasses or corrective shoes)	12 (6.2) ^c	103 (18.1) ^b	0.3 (0.1–0.6)	834 (0.8) ^b	8.5 (4.2–17.3)
Needs help with personal care needs (eg, eating, bathing, dressing, or getting around inside home)	42 (26.2)	178 (30.2)	0.7 (0.4–1.1)	284 (0.3) ^b	108.1 (66.5–175.8)
Has taken prescription medication regularly for ≥3 mo	43 (29.2)	310 (53.1) ^b	0.3 (0.2–0.5)	11 574 (12.4) ^b	2.7 (1.6–4.5)
Received care at home from nurse or other health care professional (previous 12 mo)	3 (3.4) ^d	47 (9.8) ^b	0.3 (0.1–1.2)	341 (0.4)	10.0 (2.9–34.3)
≥2 health impact indicators	35 (20.7)	205 (34.0) ^b	0.5 (0.3–0.8)	1391 (1.5) ^b	17.4 (10.7–28.4)
Health care and special education services utilization					
Medical specialist (previous 12 mo)	53 (36.4)	232 (40.0)	0.7 (0.4–1.1)	11 493 (12.6) ^b	3.9 (2.5–6.2)
Mental health professional (previous 12 mo)	25 (17.0)	251 (43.2) ^b	0.3 (0.1–0.4)	5850 (6.3) ^b	3.0 (1.7–5.3)
Physical, speech, respiratory, or occupational therapist or audiologist (previous 12 mo)	61 (43.7)	291 (48.3)	0.7 (0.4–1.1)	4631 (5.2) ^b	14.7 (9.5–22.7)
>9 office visits (previous 12 mo)	24 (16.0)	165 (27.2) ^b	0.4 (0.2–0.8)	5369 (5.7) ^b	3.1 (1.7–5.6)
>1 emergency department visit (previous 12 mo)	11 (8.1) ^c	16.8 (2.0) ^b	0.5 (0.3–1.0)	6014 (6.1)	1.5 (0.8–3.0)
Surgery or medical procedure (previous 12 mo)	15 (10.7)	63 (10.1)	1.0 (0.5–2.0)	4427 (4.8) ^e	2.5 (1.3–4.9)
Current special educational or early intervention services	97 (65.8)	481 (80.1) ^b	0.4 (0.2–0.7)	5540 (6.1) ^b	27.7 (17.9–42.3)

Unweighted sample sizes and weighted proportions are presented. The RSEs for estimates that are not flagged are <30%. aOR indicates adjusted odds ratio; CI, confidence interval.

^a Adjusted odds ratios indicate comparisons of children with DS with children in the given comparison group (other mental retardation or no DS or mental retardation), with adjustment for child gender, age, and race and maternal education.

^b $P < .05$, in comparison with children with DS.

^c The RSE is 30% to 35%.

^d The RSE for the prevalence estimate is >50%, which indicates that the variance is large and therefore the point prevalence estimate for this condition should be interpreted with caution.

^e $P < .10$, in comparison with children with DS.

other ancillary therapist, >10% had >9 recent health care office visits and/or recent surgery/medical procedures, and 66% were currently receiving special education services. For many indicators, age-specific estimates were higher for younger than for older children with DS; within all age groups, however, children with DS had substantially and significantly higher health impact and service utilization rates than did children in the general population (data not shown). In contrast, children with other causes of mental retardation had higher rates for many of these indicators than did children with DS.

DISCUSSION

This study provides population-based prevalence estimates for recent medical and long-term developmental conditions among US children with DS and demonstrates that many conditions are increased, in comparison with the general population of US children, seem more pronounced in early childhood than in late childhood, and have measurable impacts on health care and educational services. The different age effects might be explained in part by congenital heart defects, which affect ~50% of children born with DS.^{1,2,6-8,38} The adverse impact of these defects on other medical conditions might be reduced as birth cohorts age, because of different survival rates among children with heart defects¹⁻⁴ and the use of corrective surgery, which mitigates subsequent adverse effects. Although the NHIS includes questions on congenital and other heart conditions, previous research suggested low sensitivity for parent-reported heart defects,³⁴ and NHIS estimates of heart conditions among children with DS were lower (19% among those 3–5 years of age) than the prevalence expected on the basis of active, population-based, surveillance findings.³⁸ The NHIS prevalence of heart defects decreased with increasing child age (10% among children >5 years of age), which lends some support to the hypothesis of an age-related reduction in health impact.

In this study, children with DS had risks for many episodic medical conditions comparable to those of children with other causes of mental retardation, with lower risks for seizures and headaches. In addition, parents of children with mental retardation but not DS reported higher levels for most health impact and utilization indicators, compared with parents of children with DS. These findings were not completely unexpected. The other mental retardation group encompassed a heterogeneous group of children with various underlying conditions and included many children with serious disabilities in addition to mental retardation.

This study has several strengths. The population-based sample allowed for calculation of estimates among US children with DS and 2 distinct comparison groups. In addition, this study provided a more-comprehensive analysis of the realized health impact and service utilization associated with DS than did previous studies that assessed medical and developmental conditions.

The findings presented here are also subject to potential limitations. DS and other conditions were ascertained through parental report. However, a previous

validation study reported 90% sensitivity and 100% specificity and positive predictive value for maternally reported DS,³⁴ and the DS prevalence computed here from NHIS data matches expectations based on birth prevalence.³⁹ In addition, this study was primarily limited to recent occurrences of overt medical conditions, which should be reasonably understood and recalled by parents. Although data on the validity of parental reports of developmental conditions are limited, a previous study comparing autism prevalence estimates in the NHIS with parentally reported estimates from an independent, population-based survey of US children conducted during the same time period suggested high reliability and internal convergent validity.⁴⁰ A separate study reported moderate to high sensitivities for parent-reported vision impairment and behavioral disorders but low sensitivity for parent-reported hearing impairment.⁴¹ Although validation studies are generally encouraging, we cannot completely discount the possibility that parents of children with DS might be more vigilant about care-seeking than parents of children in the general population or that, conversely, parents of children with DS might be prone to underreporting some medical conditions if the greater number and frequency of conditions confronting their children render some conditions less relevant. Although we assessed children with other causes of mental retardation separately, we had limited data on the underlying causes of those children's disabilities, and we lacked IQ data to classify any group of children with respect to their level of cognitive functioning. Our sample of 146 children with DS was sufficient for many of the outcomes assessed, because they were fairly prevalent among children with DS. For a few conditions (eg, recent seizures and hearing impairment), however, the point estimates were unstable, as indicated by large RSEs. Similarly, many age-specific estimates had large RSEs. We present these data because the comparisons with children without DS are still valid, findings are interpreted in the context of the corresponding confidence limits, and results provide meaningful data on the population health impact associated with DS. Despite the limited sample size, the patterns of results according to age were distinct and consistent for many conditions. Previous studies that examined similar conditions had smaller samples, were not population-based, included both children and adults, and/or did not include a comparison group of children without DS.^{6-8,10-17,20-27,29,30} Although the NHIS included questions on several chronic health conditions, including cystic fibrosis, diabetes mellitus, and arthritis, there were insufficient children with DS for calculation of prevalence estimates. The NHIS includes only noninstitutionalized persons. Although Census data from 2000 indicated that only 0.2% of children <18 years of age were living under formally authorized, supervised care or in the custody of institutions,⁴² children with DS with the greatest levels of disability might have been excluded from the NHIS. Finally, our estimate of children with DS who were enrolled in special education/early intervention programs (66%) is perhaps lower than expected. This result is not driven by the youngest or oldest children, because we observed

similar proportions (72.5%) for children 6 to 10 years of age. The NHIS does not include questions to assess whether services were being received in self-contained classrooms versus mainstreaming into regular education classrooms or whether some children with DS were attending private schools, were not attending school, or were being home-schooled.

CONCLUSIONS

DS poses a substantial health burden in childhood, although the health impact is somewhat reduced for older children. These findings have implications for clinical practice, because they provide empirical evidence to inform guidelines regarding frequent clinical monitoring and support for children and adolescents with DS.^{43–45} In addition, the findings underscore the importance of population-based planning for service provision for children with DS and their families. Current medical costs are estimated to be 12 to 14 times higher for children with DS than for those without DS.⁴⁶ Additional research on access to care, unmet health and educational needs, and the impact of early intervention services and comprehensive coordinated primary health care on the subsequent health and development of children with DS is needed.

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APPENDIX Questions Used to Assess Health Impact and Health Care Utilization in the NHIS, 1997–2005

Question	NHIS Variable Name
Health impact	
Does [child's name] have any impairment or health problem that limits his or her ability to (crawl), walk, run, or play? Is this an impairment or health problem that is expected to last 12 mo or longer?	IHMOB, IHMOBYR
Does [child's name] have any impairment or health problem that requires him or her to use special equipment (eg, brace, wheelchair, or hearing aid, excluding ordinary eyeglasses or corrective shoes)?	IHSPEQ
Because of a physical, mental, or emotional problem, does [child's name] need the help of other persons with personal care needs (eg, eating, bathing, dressing, or getting around inside the home)?	PLAADL
Does [child's name] now have a problem for which he or she has regularly taken prescription medication for at least 3 mo?	PROBRX
During the past 12 months, did [child's name] receive care at home from a nurse or other health professional?	CHCHYR
Health care and special education services utilization	
During the past 12 mo, have you seen or talked to the following about [child's name] health:	
Medical doctor who specializes in a particular medical disease or problem (other than obstetrician/gynecologist, psychiatrist, or ophthalmologist)?	CHCSYR81
Physical therapist, speech therapist, respiratory therapist, audiologist, or occupational therapist?	CHCSYR5
Mental health professional (eg, psychiatrist, psychologist, psychiatric nurse, or clinical social worker)?	CHCSYR1
During the past 12 mo, how many times has [child's name] seen a doctor or other health care professional about his or her health in a doctor's office, clinic, or some other place (excluding hospital and emergency department visits)?	CHCNOYR2
During the past 12 mo, how many times has [child's name] gone to a hospital emergency department about his or her health?	CHERNOY2
During the past 12 mo, has [child's name] had surgery or other surgical procedures as either an inpatient or an outpatient?	CSRGYR
Does [child's name] receive special educational or early intervention services?	PSPPEDEIS

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