



June 2005

CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Some children have or are at increased risk for chronic medical, developmental, behavioral, or emotional conditions that require a greater amount and complexity of services than are needed by most other children. This group, referred to as children with special health care needs (SHCNs), represents an important vulnerable and underserved population. Children with SHCNs include those with conditions such as asthma, diabetes, birth defects, developmental disabilities such as autism and cerebral palsy, and mental illness. However, the definition of SHCNs developed by the federal Maternal and Child Health (MCH) Bureau and widely adopted over the past 10 years is not based on specific medical diagnoses.¹ The definition is designed to identify broadly all children with increased service needs, regardless of the specific condition, and to highlight the importance of integrated systems of health care and other support services to meet these needs.

Based on the MCH Bureau definition, an estimated 13%-16% of children nationwide have SHCNs.^{2,3} Children with SHCNs are less likely than other children to receive needed medical and other health-related services.³ In addition, a recent national study found that out-of-pocket health care expenditures are on average two-times higher among families of children with SHCNs compared to other families.⁴

To determine the number and percentage of children (<18 years old) with SHCNs in Los Angeles

TABLE 1

Percent of Children with Special Health Care Needs Los Angeles County, 2002-03

	Percent	95% CI	Estimated #
LA County	15.0%	13.9 - 16.2	398,000
Age Group			
0 to 5 years	10.2%	8.4 - 11.9	84,000
6 to 11 years	15.4%	13.6 - 17.3	150,000
12 to 17 years	19.4%	17.0 - 21.7	164,000
Gender			
Male	17.5%	15.8 - 19.2	236,000
Female	12.5%	10.9 - 14.0	162,000
Race/Ethnicity			
Latino	11.9%	10.6 - 13.2	187,000
White	21.6%	18.7 - 24.4	116,000
African-American	25.4%	20.4 - 30.4	69,000
Asian/Pacific Islander	9.6%	6.8 - 12.4	25,000
Federal Poverty Level*			
0-99% FPL	14.4%	12.3 - 16.5	129,000
100%-199% FPL	12.8%	10.7 - 14.9	100,000
200%-299% FPL	14.1%	11.4 - 16.7	54,000
300% or above FPL	19.7%	17.3 - 22.1	114,000

* Based on 2002 Federal Poverty Level (FPL) thresholds which for a family of four (2 adults, 2 dependents) correspond to annual incomes of \$18,859 (100% FPL), \$37,718 (200% FPL), and \$56,557 (300% FPL).

1. McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics* 1998;102:137-140.
2. Newacheck PW, Kim SE. A national profile of health care utilization and expenditures for children with special health care needs. *Arch Pediatr Adolesc Med* 2005;159:10-17.

3. van Dyck PC, Kogan MD, McPherson MG, Weissman GR, Newacheck PW. Prevalence and characteristics of children with special health care needs. *Arch Pediatr Adolesc Med* 2004;158:884-890

4. Newacheck PW, Inkelas M, Kim SE. Health services use and health care expenditures for children with disabilities. *Pediatrics* 2004;114:79-85.

County and to assess their access to health care services, a set of SHCNs screening questions were included in the 2002-03 Los Angeles County Health Survey.⁵ These questions are based on the MCH Bureau definition, have been tested in research studies to ensure that they accurately identify children with SHCNs, and have been used in national surveys.⁶

Nearly One in Six Children in the County has Special Health Care Needs

The survey results indicated that 15.0% of children (or 398,000 children) in the county had SHCNs. The percentage of children with SHCNs was 10.2% among those less than 5 years of age, 15.4% among those 6-11 years old, and 19.4% among those 12-17 years old (Table 1). The percentage with SHCNs was higher among boys (17.5%) than girls (12.5%). The percentage was also higher among African-Americans (25.4%) and Whites (21.6%) than among Latinos (11.9%), and Asians/Pacific Islanders (9.6%). Among Latinos, the percentage was slightly higher among children from English-speaking households (14.8%) than from Spanish-speaking households (10.4%).⁷

The percentage with SHCNs was higher among children living in households with incomes above 300% of the federal poverty level (FPL) (19.7%) than among children in lower income households (13.7%). However, this relationship varied by race/ethnicity (Figure 1). Among Latino and Asian/Pacific Islander children, the percentage with SHCNs was higher among those from higher income households. However, among African-American children, the percentage was higher among those from lower income

households and, among White children, the percentage did not vary by income.

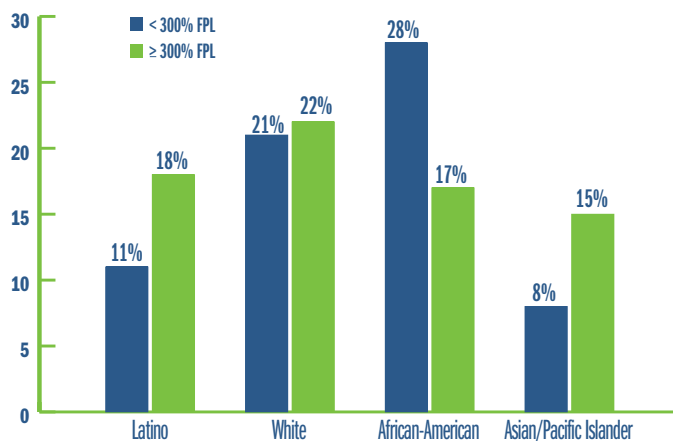
The largest number of children with SHCNs was in the San Fernando Service Planning Area (SPA) (81,000 children). However, the highest percentage of children with SHCNs was in the West SPA (23.4%) and Antelope Valley SPA (22.6%) (Table 2). The lowest percentage was in the Metro SPA (10.2%).

TABLE 2 Percent of Children with Special Health Care Needs by Service Planning Area, 2002-03

	Percent	95% CI	Estimated #
LA County	15.0%	13.9 - 16.2	398,000
Service Planning Area			
Antelope Valley	22.6%	16.6 - 28.7	23,000
San Fernando	15.4%	12.9 - 17.9	81,000
San Gabriel	13.6%	11.1 - 16.1	64,000
Metro	10.2%	7.3 - 13.1	28,000
West	23.4%	17.4 - 29.4	25,000
South	14.6%	11.2 - 18.0	50,000
East	15.0%	12.0 - 18.0	59,000
South Bay	15.7%	12.4 - 19.0	67,000

Although the survey was not designed to collect information on all of the specific conditions that may have contributed to a child's SHCNs, 37% of children with SHCNs had been diagnosed with asthma and 19% with attention deficit hyperactivity disorder. Thirty-five percent were reported by their parents to have an emotional, developmental, or behavioral problem for which the child was receiving treatment or counseling. Twenty-two percent were reported by their parents to be getting or to need "special therapy, such as physical, occupational, or speech therapy."

FIGURE 1 Percent of Children with Special Health Care Needs by Race/Ethnicity and Federal Poverty Level, 2002-03



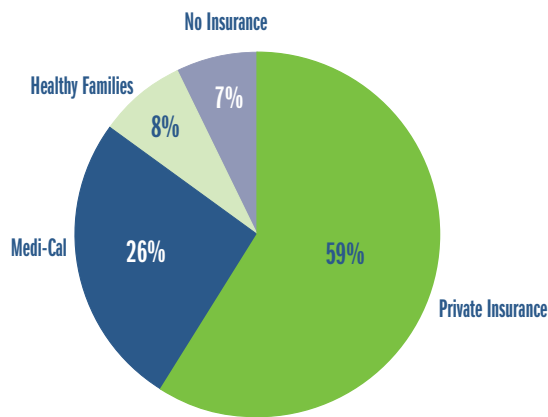
+ Based on 2002 Federal Poverty Level (FPL) thresholds which for a family of four (2 adults, 2 dependents) correspond to annual incomes of \$18,859 (100% FPL), \$37,718 (200% FPL), and \$56,557 (300% FPL).

Access to Health Care

Nearly all children with SHCNs were reported by their parents to have health insurance (93.1%) and a regular source of health care (95.0%). Fifty-nine percent of children with SHCNs were covered by

- Bethell CD, Read D, Stein RK, Blumberg SJ, Wells N, Newacheck PW. Identifying children with special health care needs: development and evaluation of a short screening instrument. *Ambul Pediatr* 2002;2:38-48.
- Bethell CD, Read D, Neff J, et al. Comparison of the children with special health care needs screener to the questionnaire for identifying children with chronic conditions—revised. *Ambul Pediatr* 2002;1:49-57.
- Households were classified as English-speaking or Spanish-speaking based on the language the parent chose to complete the interview.

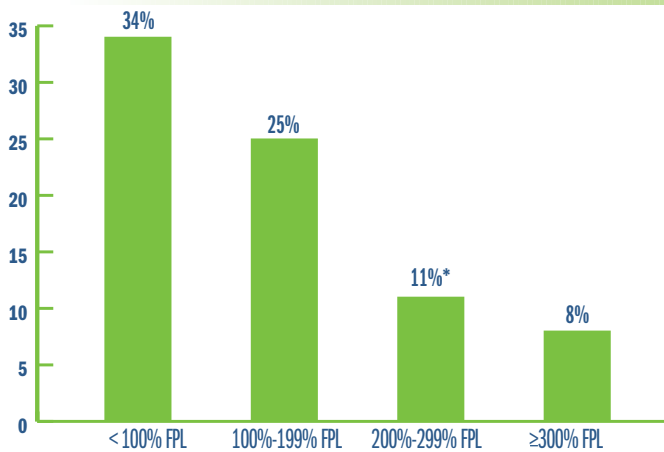
FIGURE 2 Insurance Types for Children with Special Health Care Needs, as Reported by Parents, 2002-03



private insurance, 26.3% by Medi-Cal, and 7.8% by the Healthy Families program (Figure 2).

Despite the high percentage with insurance coverage and a regular source of care, 21.1% of parents of children with SHCNs reported difficulty getting medical care for their child when they needed it. The percentage that had difficulty getting needed medical care was inversely related to household income (Figure 3). Among families living in poverty, 34.0% had difficulty getting needed medical care for their child with SHCNs compared to only 8.0% among families with incomes at 300% or more of the FPL. The percentage that reported difficulty getting needed medical care was also higher among Latino children (27.2%) than children in other racial/ethnic groups (Table 3). This difference was primarily attributable to a much higher percentage reporting difficulty getting

FIGURE 3 Percent of Children with Special Health Care Needs That Had Difficulty Getting Needed Medical Care by Federal Poverty Level, 2002-03



* Based on 2002 Federal Poverty Level (FPL) thresholds which for a family of four (2 adults, 2 dependents) correspond to annual incomes of \$18,859 (100% FPL), \$37,718 (200% FPL), and \$56,557 (300% FPL).

* Estimate should be viewed with caution because of the small sample size.

TABLE 3 Percent of Children with Special Health Care Needs That Had Difficulty Getting Needed Medical Care Los Angeles County, 2002-03

	Percent	95% CI	Estimated #
LA County	21.1%	17.5 - 24.6	83,000
Age Group			
0 to 5 years	19.9%	12.7 - 27.1	17,000
6 to 11 years	24.0%	18.3 - 29.7	36,000
12 to 17 years	19.0%	13.3 - 24.7	31,000
Gender			
Male	18.5%	14.4 - 22.6	43,000
Female	24.8%	18.5 - 31.0	40,000
Race/Ethnicity			
Latino	27.2%	21.6 - 32.7	51,000
White	13.7%	8.0 - 19.3	16,000
African-American	17.0%	8.8 - 25.2	12,000
Asian/Pacific Islander	20.8%*	7.8 - 33.8	5,000
Language of Interview (among Latinos)			
Spanish	37.5%	29.2 - 45.8	40,000
English	13.4%	7.7 - 19.1	11,000
Insurance Type			
Private	10.6%	7.5 - 13.8	25,000
Medi-Cal	30.4%	22.3 - 38.5	32,000
Healthy Families	27.8%*	13.3 - 42.3	9,000
No Insurance	70.9%	55.5 - 86.3	18,000

* Estimate should be viewed with caution because of the small sample size.

needed medical care among Latino children from Spanish-speaking households (37.5%) compared to English-speaking households (13.4%).

Among children with SHCNs who were uninsured, 70.9% had difficulty getting needed care, compared to 29.8% among those covered by Medi-Cal or Healthy Families, and 10.6% among those covered by private insurance. Among those with private insurance, the percentage that had difficulty getting needed services was three times higher among those living below 200% of the FPL (18.5%) than among those living at or above 200% FPL (6.6%).

Parents of children with SHCNs were more likely than other parents to report language barriers (29.3% vs. 14.2%) and transportation barriers (13.4% vs. 6.0%) in trying to get their child needed services.

Discussion

The survey results indicate that approximately 400,000 children, 15% of all children, in Los Angeles County had special health care needs. The survey found marked disparities in the percentage of children with SHCNs across different racial/ethnic groups and geographic areas. The highest rates were reported among African-American children and children in the West and Antelope Valley SPAs. Among Latino and Asian/Pacific Islander children, the rates were higher among those living in more affluent households, suggesting that lower income children in these populations may be at increased risk of having unrecognized needs. A low rate was also reported in the Metro SPA, a region with a high concentration of low income Latino children. These findings highlight the need for focused efforts to increase detection of children with unrecognized SHCNs and, among those identified, referral for appropriate services.

The survey also found that although most children with SHCNs had health insurance and a regular source of care, approximately one in five had difficulty getting needed services. Difficulty accessing needed services was especially pronounced among children without health insurance, those living in poverty and near poverty, and Latino children from Spanish-speaking households.

What Can Be Done?

Children with SHCNs encompass an extremely diverse group with many types of chronic health and developmental conditions and a broad range of service needs. To address these needs, the American Academy of Pediatrics (AAP) recommends that all children with SHCNs have a “medical home,” including a designated pediatrician or other primary health care provider who can work effectively with parents to ensure that the child’s medical, developmental, and psychosocial needs are met. An effective medical home requires well-integrated, community-based systems of care, including strong linkages between health care providers, schools, social service agencies, developmental service centers (e.g., Regional Centers), mental health providers, child care providers, and family resource centers. The high percentage of Spanish-speaking Latinos who reported difficulty accessing needed services highlights the critical need for linguistically and culturally competent systems of care.

Efforts are also needed to increase early detection of children with SHCNs. For example, timely

Medical Homes for Children with Special Health Care Needs

Who are children with special health care needs?

Those 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 (MCH Bureau, 1998).

Definition of Medical Home

A medical home is an approach to providing routine health care that includes:

- provision of preventive care;
- assurance of ambulatory and inpatient care for acute illness 24 hours daily;
- provision of care over an extended period of time;
- identification of the need for subspecialty consultation and referrals;
- interaction with school and community agencies;
- maintenance of a central record and database with all pertinent medical information; and
- coordination of care.

Source: The Los Angeles Medical Home Project for Children with Special Health Care Needs. <http://www.medicalhomela.org>

Adapted from “Integrated Services Branch for Children with Special Health Care Needs,” Maternal Child Health Bureau Division of Services for Children with Special Health Care Needs, September 1998.

diagnoses of chronic health conditions, such as asthma, are important so that appropriate medical treatment can be provided and other interventions implemented to reduce morbidity and maximize health and developmental outcomes. Early detection of developmental disabilities is especially important because early intervention services have been shown to improve long-term outcomes for some types of disabilities.⁸ Unfortunately, research studies indicate that many children with developmental disabilities are not identified until they reach school-age, beyond the period when intervention can have its greatest benefits.⁹

To improve early detection of developmental

8. Guralnick M, Bennett F (Eds). *The Effectiveness of Early Intervention for At-Risk and Handicapped Children*. 1987, New York, NY:Academic Press.

9. Glascoe FP. Early detection of developmental and behavioral problems. *Pediatr Rev* 2000;21:272-280.

on the web



conditions, several high-quality developmental screening tools are available, including the 10 question PEDS (Parents' Evaluation of Developmental Status), the Ages and Stages Questionnaires, and the Child Developmental Inventories.¹⁰ These tools are easy to administer, require little time (generally less than 10 minutes), and can be used in childcare and pre-school settings as well as physician offices. Efforts are needed to promote the use of these screening tools among pediatricians and other health care providers. Both public and private health care plans should be encouraged to require the use of these tools and to provide reimbursement for their use.

An important limitation of the survey is that it did not collect information on the quality of services received by children with SHCNs in the county. Unfortunately, we lack easy ways of defining and measuring quality care for children, especially for children with SHCNs. Given that children with SHCNs account for approximately 40% of all health care expenditures for children,² the development of valid and reliable quality indicators should be one of the highest priorities and must be accompanied locally by the development of robust and integrated information systems to track these indicators. For children with SHCNs, quality indicators should address the broad range of services required by this population as well as the degree to which these services are integrated into coordinated systems of care and include well-defined referral networks.

Centers for Disease Control and Prevention (CDC) in collaboration with a coalition of national partners, has launched a public awareness campaign called, "Learn the Signs. Act Early." It is designed to educate parents about early childhood development, including potential early warning signs of autism and other developmental disabilities. The campaign also encourages parents to ask healthcare professionals about activities and steps that can be taken to foster their child's development.

www.cdc.gov/actearly

Child Health and Disability Prevention (CHDP) Program for L.A. County is a preventive health program under Children's Medical Services (CMS), serving children and youth. CHDP's main purpose is to make sure that children from low and moderate income families and children with Medi-Cal have access to complete preventive exams often at no cost. Exams may include a medical and developmental history, medical and dental screening assessments, vision and hearing screening, and immunizations.

www.lapublichealth.org/cms/chdp/

Regional Centers are nonprofit private corporations that contract with the Department of Developmental Services to provide or coordinate services and supports for individuals with developmental disabilities. They have offices throughout California to provide a local resource to help find and access the many services available to individuals and their families.

www.dds.ca.gov/rc/RCinfo.cfm

California Children's Services (CCS) is a statewide program that arranges, directs, and pays for medical care, equipment, and rehabilitation, when these services are authorized by the program. Services can be authorized for children and young adults <21 years of age who have eligible medical conditions and whose families are unable to pay for all or part of their care.

www.dhs.ca.gov/pcfh/cms/ccs

UCLA Center for Healthier Children, Families & Communities is a multi-disciplinary collaboration between the UCLA School of Medicine and the UCLA School of Public Health dedicated to improving society's ability to provide children with the best opportunities for health and well-being, and the chance to assume productive roles within families and communities.

www.healthychild.ucla.edu

Parents' Evaluation of Developmental Status (PEDS) is both an evidence-based surveillance tool and a screening test. Using ten short questions for parents, PEDS helps professionals identify children at risk for school problems and those with undetected developmental and behavioral disabilities.

www.pedstest.com

Ambulatory Pediatric Association fosters the health of children, adolescents, and families by promoting generalism in academic pediatrics and academics in general pediatrics by understanding the whole child in the context of family and community. Their mission is accomplished through patient care, academics (teaching and research), and advocacy. Information and guidance on child social development are provided.

www.ambpeds.org/socialdevelopment.cfm

10. American Academy of Pediatrics. Committee on Children With Disabilities. Developmental surveillance and screening of infants and young children. *Pediatrics* 2001;108:192-196.



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CHILDREN WITH SPECIAL HEALTH CARE NEEDS

The Los Angeles County Health Survey is a periodic, population-based telephone survey that collects information on sociodemographic characteristics, health status, health behaviors, and access to health services among adults and children in the county. The most recent survey, conducted between October 2002 and April 2003, collected information on a random sample of 8,167 adults and 5,995 children. Interviews were offered in English, Spanish, Cantonese, Mandarin, Korean, and Vietnamese. The 2002-03 survey was supported by First 5 LA, the California Department of Services (through grants to the Maternal, Child and Adolescent Health Program, the Tobacco Control and Prevention Program, and the Alcohol and Drug Program Administration) and the Public Health Response and Bioterrorism Preparedness federal grant. The survey was conducted for the Los Angeles County Department of Health Services by Field Research Corporation.

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**For additional information about the
L.A. Survey: www.lapublichealth.org/ha**