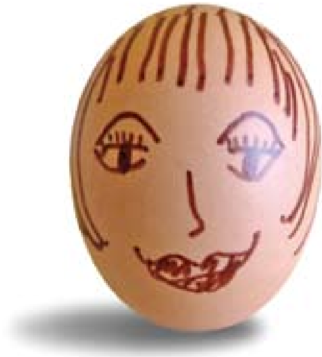
CDA JOURNAL, VOL 37, Nº6



Dental Services for Individuals With Special Health Care Needs Are an Increased Reality for Practitioners in California

H. BARRY WALDMAN, DDS, MPH, PHD; ALLEN WONG, DDS; AND STEVEN P. PERLMAN, DDS, MSCD

ABSTRACT A series of government and voluntary agency reports is used to compare the increasing growth of the numbers of children and adults with disabilities and special health care needs in California and the nation. Demographic data are used to emphasize the extent and impact of these special needs. The finding that dental care is the service most needed but not received by children with special needs is cited with a challenge to the profession.

AUTHORS

H. Barry Waldman, DDS, MPH, PHD, is a distinguished teaching professor, Department of General Dentistry, Stony Brook University, N.Y.

Allen Wong, DDS, is a clinical assistant professor, Arthur A. Dugoni School of Dentistry, San Francisco.

Steven P. Perlman, DDS, MSCD, is global clinical director, Special Olympics, Special Smiles; associate clinical professor, pediatric dentistry, Boston University School of Dental Medicine; and in private pediatric dentistry practice in Lynn, Mass.

In a previous presentation in the *Journal of the California Dental Association*, the authors explored the reality that dental care for individuals with developmental disabilities is expensive, but needed.[1] That paper was followed by an article with the results from the 2000 Census that, nationally, "... more than 2.6 million U.S. children between the ages of 5 and 15 ... 5.8 percent in that population group had one or more disabilities, including almost 300,000 children in California."[2]

In that manuscript, the authors detailed the number of children with disabilities in the various cities, metropolitan areas, and congressional districts in California in an effort to increase awareness of the extent of the problem. The authors challenged dental practitioners to meet the oral health needs of this population but recognized the fact that at the time, "... during their predoctoral education, current dental school graduates (did) not gain the necessary expertise to treat the special needs patients."[2-4] The recent modification of dental school accreditation standards, which requires that, "Graduates must be competent in assessing the treatment needs of patients with special needs" is but one of many steps to provide the needed care.[5]

Note: The Commission on Dental Accreditation defines "patients with special needs" as "those patients whose medical, physical, psychological, or social situations that make it necessary to modify normal dental routines in order to provide

dental treatment for that individual. These individuals include, but are not limited to, people with developmental disabilities, complex medical problems, and significant physical limitations."[5]

The term "assessing" does not mean actual treatment but just an evaluation. The postdoctoral general dentistry programs maintain the same definition for patients with special needs, but go a step further in their competency statement. The postdoctoral general dentistry programs (AEGD/GPR) list: "... assess, diagnose, and plan for the provision of multidisciplinary oral health care for a wide variety of patients including patients with special needs."[6]

TABLE 1

Percent of U.S. Children With Special Health Needs Who Have These Selected Conditions: 2005-06[8]

	Percent
Allergies	53.0%
Asthma	38.8
Attention deficit disorder/Attention deficit hyperactivity disorder	29.8
Depression, anxiety, or other emotional problems	21.1
Migraine or frequent headaches	15.1
Intellectual disability	11.4
Autism/autism spectrum disorder	5.4
Joint problems	4.3
Seizure disorder	3.5
Heart problems	3.5
Blood problems	2.3
Cerebral palsy	1.9
Diabetes	1.6
Down syndrome	1.0
Muscular dystrophy	0.3
Cystic fibrosis	0.3

Increasing Numbers

A series of recent reports from government and voluntary agencies provides revised estimates of the increasing number of individuals with disabilities throughout the country and in California, as well as the continuing difficulty in securing needed services.[7-10] It is now estimated that nationally, there are 10.2 million children (13.9 percent of all noninstitutionalized children); including 964,200 in California (9.9 percent of all children in the state).[8]

In addition, there are about 50 million adults with disabilities in the country, including 4.6 million in California (19.1 percent of the adults in the state).[9]

Nationwide

Children

While the focus of a demographic review of the number of youngsters with special health care needs (SHCN) emphasizes the millions of children with a wide range of needs, it is critical that the impact on the entire family also be considered. The emotional, economic, missed school days (and the need for coverage), and social complexities, the intersibling and interparental conflicts, and the ongoing efforts to secure needed services are but some of the unimaginable day-to-day and year-to-year difficulties faced by households in which a child with SHCN resides.

In 2005-06, 1 in 5 households (21.8 percent) with children had one or more youngsters with SHCN. Children with SHCN are defined as "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."[11]

The reality is that while numerous practitioners currently are treating many of these youngsters (many of whom who have various forms of health insurance coverage), great numbers of other children (and adults) with SHCN are unable to secure needed care because of series of factors (including, the past lack of dental school training) and the misguided perception that all children with SHCN needs are beyond practitioner abilities. But more than half of the children with SHCN have any number of allergies, more than one-third have asthma.

Nevertheless, 30 percent have attention deficit disorder, and more than 1 in 10 have an intellectual disability (**TABLE 1**).

- 16.1 percent of male and 11.6 percent of female children have SHCN.[8]
- The prevalence of SHCN among the child population does not vary significantly by income group; prevalence rate in each income group (from below federal poverty levels to incomes well above the poverty level) are approximately 14 percent.[8]
- The proportion of children with disabilities increases with age, from 8.8 percent of children less than 6 years old, to 16 percent in the 6-11 year group, and 16.8 percent in the 12-17 years. Some of this increase in the early years may be associated with the recognition of the need for special care as chil-

dren enter their first school years.[8]

■ The prevalence of children with SHCN is highest among multiracial children, 18 percent; followed by non-Hispanic whites, 15.5 percent; non-Hispanic blacks, 15 percent; American Indian/Alaska Native, 14.5 percent; and Native Hawaiian/Pacific Islander children, 11.5 percent. The prevalence rate is lowest among Hispanic children, 8.3 percent, and Asian children, 6.3 percent.[8]

Adults

The prevalence rate of the 50 million adults with disabilities increases with age. The median prevalence rate by state increases from 12.3 percent for young adults between 18 and 44 years, to 23.6 percent for the 45-64 age group, and 32.7 percent for the 65+ population.[9] Within two decades, 1 in 5 U.S. residents (about 70 million individuals) will be 65 years and older. One in 4 will be 65 year or older in six states: Florida, Maine, Montana, New Mexico, North Dakota, and Wyoming.[12]

If the current estimate prevails (about one-third of the 65 and older population has one or more disabilities), then there needs to be preparation for almost 24 million seniors with disabilities (plus the current and next generations of youngsters with special needs).[9]

TABLE 2

The Proportion of Children in California and Countywide by Selected Demographic Characteristics, Health Insurance Coverage and Access to Health Services: 2005-06[8]

	California	National
Children with special health care needs	9.9%	13.9%
AGE		
0-5 years	5.6	8.8
6-11	11.7	16.0
12-17	12.4	16.8
GENDER		
Male	11.7	16.1
Female	8.1	11.6
POVERTY LEVEL		
0-99% federal poverty level	6.9	13.9
100-199% federal poverty level	9.8	14.0
200-399 federal poverty level	10.9	13.6
400% federal poverty level-plus	11.4	14.0
HISPANIC ORIGIN AND RACE		
Non-Hispanic white	13.9	15.5
Non-Hispanic black	15.1	15.0
Asian	5.2	6.3
Hispanic	6.2	8.3
Spanish-speaking household	3.7	4.6
English-speaking household	10.1	13.1
HEALTH INSURANCE COVERAGE		
No insurance some time in past year	8.0	8.8
Current insurance is inadequate	35.5	33.1
ACCESS TO CARE		
Has unmet special health care needs	17.1	16.1
Difficult to get needed referral	27.6	21.1
No usual source of care when sick, rely on emergency room	7.4	5.7

California

Although the proportion of children with SHCN in California (9.9 percent) is lower than the national average (13.9 percent), the proportion of adults with disabilities and the national average is the same (19.1 percent).

Children

On a daily basis, 1 in 4 children with SHCN are affected usually, always or a great deal; 38 percent are moderately affected by their special health care needs some of the time. More than one-third of children living in poverty, compared to 16 percent of children in families with incomes of 400 percent of poverty or more, are affected usually, always, or a great deal by their condition. Missing school days, functioning difficulties, and physical and emotional difficulties in dealing with their peers are part of the daily life of youngsters with SHCN.[8]

Compared to national prevalence rates, the proportion of children with SHCN living in California is lower in all age groups, for both male and female children, at all income levels, and among all racial and Hispanic groups (except non-Hispanic blacks, where the percentages are essentially the same.[8] The proportion of children with SHCN is

TABLE 3

Percent of Children With Special Health Care Needs With Reported Health Services Needed but Not Received: 2005-06[8]

	Percent
Preventive dental care	6.3%
Mental health care	3.7
Physical, occupational, or speech therapy	3.1
Specialty care	2.8
Other dental care	2.6
Routine preventive care	1.9
Prescription drugs	1.6
Eyeglasses/vision care	1.4

lowest for Asian and Hispanic children at the national level and in California.

It should be noted that among Hispanics, the proportion of children with SHCN in Spanish-speaking households is one-third the rate in households that are English speaking (TABLE 2). The prevalence among English-speaking Hispanics more closely resembles that of the population as a whole. "These finds are consistent with other studies of the prevalence of health conditions among Hispanic children."[8]

Adults

Almost 1 in 10 U.S. adults with disabilities reside in California. Among adult residents, 17.7 percent of men and 20.3 percent of women have a disability.[9] The proportion of adults with disabilities in the state varies by race/ethnicity. The proportion of adults in California with a disability includes:

- 16.5 percent of Hispanics
- 21.1 percent of non-Hispanic whites
- 25.7 percent of non-Hispanic blacks

In addition, as with national data, the proportion of adults with disabilities in the state increases with age. The proportion of adults with a disability includes:

- 12.4 percent in the 18-44 year population
- 23 percent in 45-64 year age group
- 32.8 percent in the 65-plus year population

Compared to residents without a disability, a greater proportion of California adults with disabilities smoke, 23 percent versus 16 percent; are obese, 32 percent versus 20 percent; and are physically inactive, 20 percent versus 11 percent. One-third of adults with a disability report that their health is very good or excellent. Another third report their health is fair or poor. By contrast, almost two-thirds of adults without disabilities report that their health is very good or excellent.[9]

Health Insurance

The availability of health insurance coverage is the all too frequent sine qua nondeterminant of the accessibility to, and use of, health services. One of the more common first queries at the time of admission to hospitals and entrée to private practices, is the "usual" and for many, the dreaded question, "What type of health insurance do you have?"

In California, 8 percent of children with SHCN (compared to 8.8 percent nationally) had no health insurance at some time in the past years.[8] The inadequacy of current insurance was reported for 35.5 percent of California children with SHCN, compared to 33.1 percent nationally (TABLE 2).

The related limited access to care is reflected in the reports that in California:

- 17 percent of children with SHCN have unmet service needs.[8]
- More than 1 in 4 (27.6 percent) of children with SHCN have a difficult time securing needed referrals for care.[8]
- 7.4 percent of children with SHCN have no usual source of care when sick and rely on emergency rooms for needed care.[8]

Among California Adults With Disabilities

- Ages 18-44 years: 22 percent (371,000 residents) lack health insurance. One-third (564,000 residents) lack a continuous source for health services.
- Ages 45-64 years: 12 percent (208,000 residents) lack health insurance; 11 percent (194,000 residents) lack a continuous source for health care.
- Ages 65-plus years: Most residents are covered by the Medicare program; however, 5 percent (60,000 residents) lack a continuous source for health care.

Type of Health Insurance

The Robert Wood Johnson Foundation 2008 study on children with SHCN and health insurance coverage provides special insight into the relationship between private and public insurance, primarily Medicaid and the State Children's Insurance Program, SCHIP, and the securing of needed services. The report "demonstrates the strength ... (of these public programs) as a safety net for kids."[10]

However, among the children with SHCN in California, 613,000 (64 percent) have private insurance, 321,000 (33 percent) have public coverage, and 30,400 (3 percent) are uninsured; compared, respectively to national levels of (60 percent, 36 percent, and 4 percent). Most significant is the finding related to the relationship between the types of insurance coverage and "delayed or foregone (care)."[10]

In California, among children with SHCN who have:

■ Private insurance: 7 percent have delayed or have foregone care; 5 percent do not have a personal physician.

■ Public insurance: 11.5 percent have delayed or have foregone care; 10 percent do not have a personal physician.[10]

Needed Services

The 2001 and 2005-06 National Survey of Children with Special Health Care Needs both reported that "The services most commonly reported as needed but not received was dental care ..." In the 2005-06 study, 6.3 percent of children with SHCN were reported to need preventive dental care, but did not receive it. The service with the next highest percent that was needed but not received the mental health care, 3.7 percent. In addition, 2.6 percent of children with SHCN needed but did not receive "other dental care" (**TABLE 3**).

So What Do All These Numbers and Proportions Mean?

The reality is that whether it is in California or the rest of the nation, there is an increasing number of youngsters and adults with disabilities and special health care needs who are surviving and increasingly are dependent upon community health providers for services — including dental practitioners. The repeated finding that dental care ranks highest as "the needed but not provided service" is a reflection of the often-cited inadequate educational preparation of practitioners to provide needed care, the financial constraints of the Medicaid program and its Byzantine administrative functioning, and the actual difficulties in providing the needed care.[13,14]

The change in dental and dental hygiene school accreditation requirements to prepare the next generations of practitioners to provide services is a step in the right direction. However, unless there is a dramatic increase in the number of practitioners actually providing needed services, the growing unmet dental needs of the children with SHCN will become an increasing problem as these youngsters reach their middle and older years, a time of soaring numbers of elderly with disabilities and escalating costs for all phases of health services.

Yes, thousands of dentists are providing needed care to the many individuals with special needs. But in the interim period until the arrival of the newly trained men and women, how does one explain to the 10.2 million children with special health care needs in the country (including 964,200 in California) and about 50 million adults with disabilities in the country, (including 4.6 million in California), that dental care ranks highest as "the needed but not provided service"? ■■■■

REFERENCES

1. Waldman HB, Perlman SP, Dental care for individuals with developmental disabilities is expensive, but needed. *J Calif Dent Assoc* 30(6):427-32, 2002.
2. Waldman HB, Perlman SP, Almost 300,000 children (age 5 to 15) with disabilities in California. *J Calif Dent Assoc* 32(9):651-5, 2004.
3. Fenton SJ, People with disabilities need more than lip service (editorial). *Spec Care Dent* 19:198-9, 1999.
4. Waldman HB, Perlman SP, Preparing to meet the dental needs of individuals with disabilities. *J Dent Educ* 66:82-4, 2002.
5. Commission on Dental Accreditation, Accreditation standards for dental education programs, Chicago. *Am Dent Assoc* July 30, 2004.
6. American Dental Association, Standards for dental education programs. Web site: http://www.ada.org/prof/ed/accred/standards. Accessed Feb. 23, 2009.
7. Maternal and Child Health Bureau, The national survey of children with special health care needs: Chartbook, Rockville, Md., 2001, Department of Health and Human Services, 2004.
8. Maternal and Child Health Bureau, The national survey of children with special health care needs: 2005-2006. Rockville, Md., Department of Health and Human Services, 2007.
9. Centers for Disease Control and Prevention, Disability and health state chartbook, 2006: Profiles of health for adults with disabilities. Atlanta, Ga. Centers for Disease and Control and Prevention, 2006.
10. Robert Wood Johnson Foundation, A needed lifeline: Chronically ill children and public health insurance coverage, 2008. Web site: http://www.rwjf.org/pr/product.jsp?id=33671 Accessed Feb. 24, 2009.
11. McPherson M, Arango P, et al, A new definition of children with special health care needs. *Pediatrics* 102(1):137-40, 1998.
12. Census Bureau. Interim population projects, 2005. Web site: http://www.census.gov/population/www/projections/projectionsagesex.html. Accessed April 15, 2009.
13. Waldman HB, Fenton SJ, et al, Preparing dental graduates to provide care to individuals with special needs. *J Dent Educ* 69(2):249-54, 2005.
14. White PH, Access to health care: Health insurance considerations for young adults with special health care needs/disabilities. *Pediatrics* 110(6):1328-35, 2002.

TO REQUEST A PRINTED COPY OF THIS ARTICLE, PLEASE CONTACT H. Barry Waldman, DDS, MPH, PhD, Department of General Dentistry, School of Dental Medicine, Stony Brook University, Stony Brook, N.Y. 11794-8706.