



Parental perceptions of unmet dental need and cost barriers to care for developmentally disabled children

Stephen T. Schultz DDS, MS, MPH Jonathan D. Shenkin DDS, MPH Alice M. Horowitz PhD

Stephen T. Schultz is a Dental Public Health Resident, NIDCR/NIH; Jonathan D. Shenkin was a Dental Public Health Resident, National Institute of Health, Bethesda, MD, and now is a resident in pediatric dentistry, University of Iowa. Alice M. Horowitz is a Senior Scientist, NIDCR/NIH. Correspond with Dr. Shenkin at jonathan-shenkin@uiowa.edu.

Abstract

Purpose: The purpose of this investigation was to describe and assess the disparities, if any, in parental perceived cost barriers to oral health care among developmentally disabled children using a national data set.

Methods: Data from the 1997 National Health Interview Survey (NHIS) were analyzed using a SUDAAN statistical package.

Results: After adjusting for age and sex, parental perception of unmet need was significantly associated with developmentally disabled children 2-17 years in lower socioeconomic groups.

Conclusions: Though most children from lower socioeconomic groups are eligible for Medicaid coverage, parents of these children perceive cost barriers to dental care. Children with developmental disabilities face even more perceived barriers to care based on family income. (*Pediatr Dent* 23:321-325, 2001)

Introduction

Access to dental care for children is influenced by socioeconomic status (SES)⁽¹⁾. Recent studies have shown an association between low utilization of dental services for children and enrollment in Medicaid^(2,3). As well, studies have shown that children with disabilities are more likely to have unmet dental need than any other medical need⁽⁴⁾. One of the objectives of Healthy People 2010 (Objective 21-2) is to reduce the amount of untreated tooth decay among children and adolescents, including those with disabilities⁽⁵⁾. Few studies in the United States have investigated the oral health of children with developmental disabilities, their utilization of dental services or access to care⁽⁶⁾. Understanding the oral health of children with disabilities, and barriers to access of care, is of growing interest because of the significant increase in the population of children with special health care needs in the United States.

Since, 1990, the proportion of children considered disabled and enrolled in Medicaid in the United States has changed markedly. One estimate is that there are more than 12 million special needs children, representing 18 percent of the total U.S. child population⁽⁷⁾. This increase is due primarily to children receiving Supplemental Security Income (SSI) which has increased its enrollment from about a quarter million children in 1989 to nearly a million in 2000⁽⁸⁾. SSI provides cash benefit to disabled children, and entitles children in most states to Medicaid coverage⁽⁹⁾. This increase in enrollment is due primarily to: 1) changing eligibility requirements that included mental health disability for children; 2) new regulations that

allowed determination of disability for children with multiple conditions; and 3) an outreach effort to enroll children. The result has been a substantial increase in the number of children that have behavioral related diagnoses, such as attention deficit disorder⁽¹⁰⁾.

A recent report from the U.S. General Accounting Office (GAO) investigated barriers to care for children with disabilities. The report acknowledged that disabled children with low-income are eligible for benefits through SSI, and usually automatically receive Medicaid coverage. The report went on to describe numerous cost-related barriers to care for children with disabilities, as well as SSI families limited knowledge of programs and services available to their children⁽¹¹⁾. The GAO study was corroborated by a survey conducted in Oregon that showed that children receiving SSI were less likely to have received a service due to cost than children receiving Medicaid only. The survey of parents also identified unmet dental care needs as the most common unmet health service among children, and parents of disabled children stated that their children had more unmet dental care than parents of children receiving Medicaid only⁽¹²⁾.

The purpose of this investigation was to describe and assess the disparities, if any, in perceived cost barriers to oral health care among developmentally disabled children using a national data set. This study compared the time since last contact with a physician and the time since last contact with a dentist for children with and without developmental disability. Reported non-receipt of needed oral health care in children with and without developmental disabilities because of cost concerns also were compared.

The types of conditions that fall under the term 'developmental disability' are varied and include cognitive as well as physical disabilities⁽¹³⁾. This study focused on the following developmental disabilities: mental retardation, cerebral palsy, attention deficit disorder, Down syndrome, autism, and other developmental delay. These categories are reported in the 1997 NHIS⁽¹⁴⁾.

Methods

Data Source

The source of data for this study was the 1997 National Health Interview Survey (NHIS). The files from this survey are freely available for downloading from the website of the National Center for Health Statistics (NCHS) and contain no personal

Received January 18, 2001 Revision Accepted June 27, 2001

identifiers. The file used in this study was the sample child file, which contains information on 14,290 children. The variables were used in combinations for descriptive analysis and for logistic regression modeling.

In the 1997 NHIS, two questions were asked pertaining to dental care.

1) During the past 12 months, was there any time when {person} needed any of the following, but didn't get it because you couldn't afford it: ... Dental care (including check-ups)?

2) About how long has it been since {person} last saw or talked to a dentist? Include all types of dentists, such as orthodontists, oral surgeons, and all other dental specialists, and dental hygienists.

A third question was used to compare medical care and dental care use among these children. This question asked: About how long has it been since anyone in the family last saw or talked to a doctor or other health care professional about {person}'s health? Include doctors seen while {he/she} was a patient in a hospital.

The information from these questions was used to examine health disparities in children among those with and without developmental disabilities. Variables for age, race/ethnicity, gender, mother's education, father's education, birth weight, and family socio-economic status were tested for confounding and interaction in these relationships.

Survey Description/Characteristics

The NHIS is a multi-purpose health survey conducted annually by the National Center for Health Statistics of the Centers for Disease Control and Prevention. It is a multistage sample designed to represent the civilian non-institutionalized population of the United States. The first NHIS was conducted in 1957 and has been ongoing continuously since that time.

The questionnaire for the NHIS was redesigned and used for the first time in 1997. For each family in the NHIS, one sample child was selected randomly for inclusion in the study if any child under 18 years was present in the household. The questionnaire for children collected information on health status, health care services, and behavior.

The 1997 NHIS design includes a multistage stratified random sample of the entire United States population. Although the number of primary sampling locations was 358, for confidentiality purposes some of the locations are collapsed on the public user files. Also, both the black and Hispanic populations

were oversampled to allow for more precise estimates of health status indicators in these populations. Personal household interviews were conducted at 39,832 locations yielding 40,632 families and 103,477 individuals. The Sample Child component consisted of 14,290 children under 18 years.

Study Population

The study population for the child component of the 1997 NHIS was all children in the United States from birth through 17 years. Parents of children younger than two were not asked the dental questions; therefore, this project included only children ages 2–17 years for the study population. There were 12,539 children in this age group in the study population, which represented 63,759,070 children in the U.S. population.

Data Analysis

Descriptive analyses and logistic regression analysis were conducted using the SUDAAN statistical package Release 7.00. All analyses were performed using a level of .05 for statistical significance.

Logistic Regression Model

A logistic model was developed to assess this lack of perceived oral health care in children with and without developmental disabilities while adjusting for selected socio-demographic variables. Confounding was defined as a meaningful change of 10% in the odds ratio during modeling. The only variable which showed confounding by the established criteria was the age of the child, which was a negative confounder. Gender of the child, however, was also included in the final model. Interaction in the model was observed with developmental disability and socioeconomic status. To eliminate the interaction effect, separate models were used for different levels of socioeconomic status.

Results

The frequencies of population-reported developmental disabilities were ascertained from the 1997 NHIS. The prevalence in

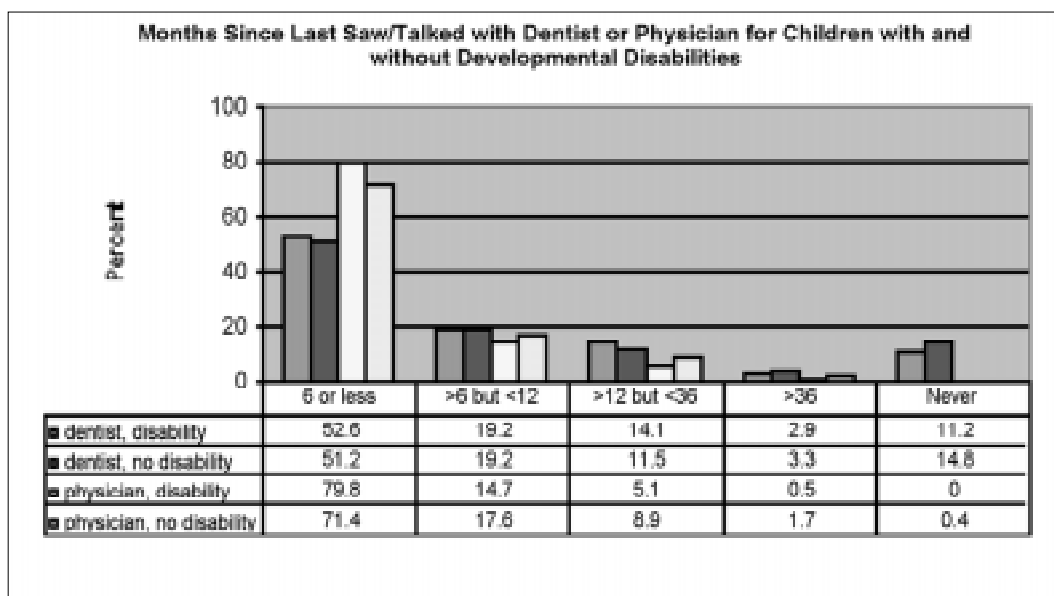


Fig 1.

Percentage of Children With and Without Various Developmental Disabilities Who Have Not Received Oral Health Treatment Because of Cost Considerations

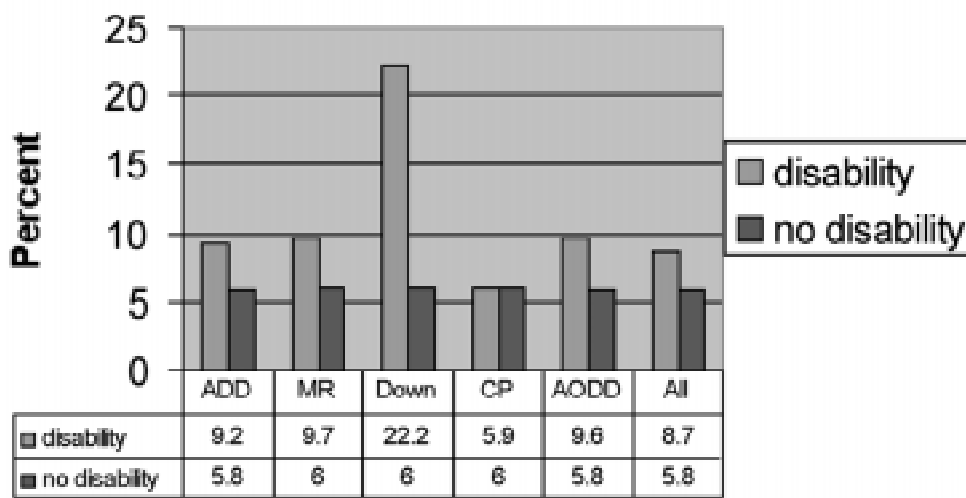


Fig 2. Note: ADD=Attention Deficit Disorder, MR=Mental Retardation, Down=Down syndrome, CP=Cerebral Palsy, AODD=Autism and Other Developmental Delay, and All=All Conditions

children 2-17 years for each of these disabilities is: mental retardation 0.6 percent, cerebral palsy 0.4 percent, attention deficit disorder 5.2 percent, Down syndrome 0.2 percent, autism 0.1 percent, and other developmental delay 3.6 percent. One or more of these disabilities is present in 7.3 percent of the children 2-17 years in the population of the United States.

Figure 1 shows that, children with a developmental disability compared to those without are more likely to have seen a physician or have had someone in the household talk to a physician regarding their health within the past six months (80% vs. 71%, respectively). This relation is not observed with respect to contact with dentists. Children with and without developmental disabilities are equally likely to have seen or talked to a dentist within the past six months (53% vs. 51%, respectively). Also, children with and without developmental disabilities are more likely to have seen a physician than to have seen a dentist. Moreover, children with and without developmental disabilities are more likely never to have had contact with a dentist than to never have had contact with a physician (11% and 15% vs. 0% and 0.4%, respectively).

Figure 2 depicts the percentage of children who had not received needed oral health care because of perceived financial constraints according to category of developmental disability. Children with Down syndrome have the highest level of non-receipt of oral health care because of cost considerations (22%), followed by children with mental retardation (10%), autism and other developmental delays (10%), and attention deficit disorder (9%). Children with cerebral palsy, however, follow a different pattern: in children with and without cerebral palsy, perceived cost considerations apparently play a similar role in their non-receipt of oral health care (6% vs. 6%, respectively).

Figure 3 shows the disparity in receiving oral health care because of cost among children with and without developmental disabilities. For all categories except the upper middle class

income group (at least 2 but less than 5 times the poverty index), developmentally disabled children are less likely to have received needed oral health care. The greatest disparity is seen among children from families in the poorest income group, where children with developmental disabilities are more than twice as likely not to have received needed oral health care compared to children without developmental disabilities (15% versus 7%). The weighted number of children represented in Figure 3 with a disability in

ascending order of poverty ratio is: 58,791; 77,873; 193,899; 42,111; and 26,829. The weighted number of children represented in figure 3 without a disability in ascending order of poverty ratio is: 247,220; 569,494; 119,172; 930,425; and 48,888.

The results of the logistic regression analysis for the association of parental perception of unmet need and developmental disabilities are summarized in Table 1. Logistic models were developed for different levels of income to poverty ratios. These levels were chosen based on breaks in the data produced by graphing parental perception of unmet need for children with developmental disability versus income to poverty ratios. The odds ratio for children with family incomes greater than two times the poverty ratio did not reach statistical significance. The odds ratios for the subpopulations of families with less than two times the poverty threshold and less than 1.25 times the poverty threshold were significant (1.61 and 2.02, respectively). These data suggest that the poorest families are more than twice as likely to have reported that their developmentally disabled children did not receive needed oral health care for reasons of cost compared to normal children of the poorest families while controlling for age, gender, and income level.

Discussion

There are more than 12 million special needs children in this country, representing 18 percent of the total U.S. child population⁽⁷⁾. They have chronic physical, developmental, behavioral, or emotional conditions, such as autism, attention deficit disorder, cerebral palsy, mental retardation, and others. Title V programs of individual states provide medical care for special children⁽¹⁵⁾, but these programs provide oral health care in only nine states while 19 others provide limited oral health care under special circumstances. Though Medicaid and the

Percent of children whose parents perceive an unmet dental need due to cost by presence of a developmental disability in the child according to family economic status

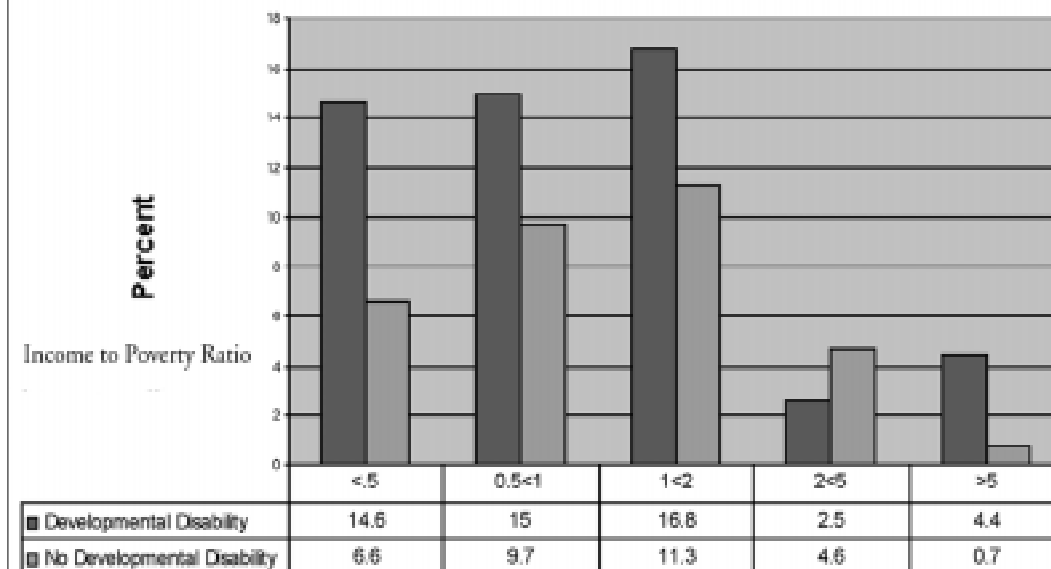


Fig 3. Note: Percent differences for those with and without developmental disabilities for all categories of income to poverty ratio are significant at the $p < .001$ level.

Income levels:

- <0.5 means ratio of income to poverty threshold is less than .5
- 0.5 <1 means ratio of income to poverty threshold is at least .5 and less than 1
- 1 <2 means ratio of income to poverty threshold is at least 1 and less than 2
- 2 <5 means ratio of income to poverty threshold is at least 2 and less than 5
- >5 means ratio of income to poverty threshold is at least 5

Children's Health Insurance Program eliminate direct costs for dental care, they have not eliminated parental perception that their child has unmet dental need due to cost considerations.

This study focused on one group of special needs children, those with developmental disabilities. Parents reported that developmentally disabled children are as likely to have seen a dentist recently as children without developmental disabilities (Figure 1). However, parents reported that those disabled children from families in lower income categories are significantly less likely to have received needed oral health care because of cost-related reasons (Table 1). Furthermore, this lack of receipt

Table 1: Association of Lack of Needed Oral Health Care Because of Cost and Developmental Disability in Children

	Odds Ratio	95% Confidence Limits
Income > 2.00 times the Poverty Threshold	1.01	0.64–1.58
Income < 2.00 times the Poverty Threshold	1.61*	1.10–2.34
Income < 1.25 times the Poverty Threshold	2.02*	1.23–3.34

Controlling for age, gender, and income level.
 Data Source: National Center for Health Statistics (1997)
 *Significant at the $P < .05$ level.

of oral health care is greater for families with the lowest incomes, such as those that would be eligible for SSI benefits. This disparity in parental report of unmet dental need is possibly the result of the indirect costs of dental treatment for these children, and correlates with previous findings that dental care is the most common unmet health need among special needs children⁽⁴⁾. Since Medicaid coverage would provide dental care to these children at no cost, other barriers to access indirectly related to cost may be due to inability to get time off from employment, lack of child care services for other children, or difficulty accessing public transportation for the

handicapped, among other possible barriers. Many of these factors have previously been identified as barriers to accessing care for disabled children⁽¹¹⁾. Further study would need to occur to determine actual indirect cost barriers to dental care other than the actual cost of care, to alleviate them as a cost burden.

With respect to reimbursement for services provided to the special needs population, there has been little effort by Medicaid officials to provide sufficient reimbursement to providers⁽¹⁶⁾. Even with improvements to Medicaid reimbursement, some analyses show that there is only marginal improvement in access to services among the general Medicaid population, which could suggest an even more marginal improvement for the special needs population⁽¹⁷⁾.

In addition, and perhaps most importantly, the oral health literacy of the parents/guardians of special needs children likely needs to be improved through health education efforts⁽¹⁾. Special attention must be placed on improving the oral health literacy specifically for children who are from lower income families. Whether the caretakers' perception that they face cost barriers for dental care is real, cannot be determined in this study. What is known is that nearly half of U.S. adults have limited or low functional literacy skills⁽¹⁸⁾. These limited skills are higher among low economic groups, and is common among low income families with disabled children⁽¹¹⁾. It also is known that adults with limited literacy skills struggle with directions for medications, do not understand appointment slips, cannot understand many informed consent documents and do not have the skills to navigate health care systems to access

care⁽¹⁹⁻²²⁾. The task of navigating numerous institutions to obtain health care, especially oral health care, may be especially challenging for people with limited literacy skills. This situation may be heightened if oral health is not valued and if an individual does not know that most oral diseases can be prevented and how to prevent them. Additional research needs to be conducted to determine the impact of oral health literacy on the receipt of oral health care.

Conclusions

1. Children with developmental disabilities are as likely to see a dentist in the past year as children without developmental disabilities.
2. Children with developmental disabilities from the lowest SES level are twice as likely to have parental perceived cost barriers to dental care than children without a developmental disability in the same SES category.
3. Children with Down syndrome are more likely than children with other disabilities to have parental perceived cost barriers to dental care than other developmentally disabled children.

Acknowledgements

The authors thank Drs. Dushanka Kleinman and Robert Selwitz for their review of an earlier draft of this manuscript.

References

1. U.S. Department of Health and Human Services. Oral Health in America: A Report of the Surgeon General. Rockville, MD: US Department of Health and Human Services, National Institute of Dental and Craniofacial Research, National Institutes of Health, 2000.
2. U.S. General Accounting Office [GAO/HEHS-00-72]. Dental disease is a chronic problem among low-income populations. Washington, D.C.: April 2000.
3. U.S. General Accounting Office [GAO/HEHS-00-149]. Factors contributing to low use of dental services by low-income populations. Washington, DC: September 2000.
4. Newacheck PW, McManus M, Fox HB, Hung YY, and Halfon N. Access to Health Care for Children with Special Health Care Needs. *Pediatric*;105:760-766, 2000.
5. US Department of Health and Human Services. Healthy People 2010. 2nd ed. With Understanding and Improving Health and Objectives for Improving Health. 2 vols. Washington, DC: US Government Printing Office, November 2000.
6. Shenkin J, Davis MJ, Corbin SB. The Oral Health of Special Needs Children: Dentistry's Challenge to Provide Care. *ASDC Journal of Dentistry for Children* [In press].

7. Newacheck PW, Strickland B, Shonkoff JP, Perrin JM, McPherson M, McManus M, Lauver C, Fox H, and Arango P. An epidemiologic profile of children with special health care needs. *Pediatrics*;102 (1 Pt 1):117-23, 1998.
8. Social Security Administration. Children receiving SSI. Baltimore, MD: June 2000.
9. Social Security Administration. State Assistance Programs for SSI Recipients. Baltimore, MD: January 1999.
10. Perrin JM, Kulthau K, McLaughlin TJ, Ettner SL, Gortmaker SL. Changing Patterns of Conditions Among Children Receiving Supplemental Security Income Disability Benefits. *Arch Pediatr Adolesc Med*;153:80-84, 1999.
11. U.S. General Accounting Office [GAO/HEHS-99-99]. SSI Children: Multiple factors affect families' costs for disability-related services. Washington, DC: June 1999.
12. Mitchell, JB, Khatuisky G and Swigonski ML. Impact of the Oregon Health Plan on Children with Special Health Care Needs. *Pediatrics*;107:736-743, 2001.
13. Doostan D and Wilkes M. Treating the Developmentally Disabled. *West J Med*; 171(2):92-6, 1999.
14. National Center for Health Statistics (1999). Data File Documentation, National Health Interview Survey, 1997 (machine readable data file and documentation). National Center for Health Statistics, Hyattsville, Maryland.
15. Reiss JG and Dearholt D, editors. Directory of State Title V CSHCN Programs - Eligibility Criteria and Scope of Services - 1998 Edition. The Institute for Child Health Policy.
16. Brodeur, P. To Improve Health and Health Care 2001: The Robert Wood Johnson Foundation Anthology/ Stephen Isaacs and James Knickman, eds. Chapter 9-Improving Dental Care. RWJ Foundation, Princeton, NJ: 2000.
17. Mayer, ML, Stearns SC, Norton EC, Rozier RG. The Effects of Medicaid Expansions and Reimbursement Increases on Dentists' Participation. *Inquiry* 37:33-44; 2000.
18. Kirsch, I, Jungeblut A, Jenkins L, et al. Adult literacy in America: A first look at the findings of the National Adult Literacy Survey. Washington, DC National Center for Education Statistics, U.S. Department of Education, 1993.
19. Weiss, BD, Blanchard JS, McGee DL. et al. Illiteracy among Medicaid recipients and its relationship to health care costs. *J Health Care for the Poor and Underserved*;5:99-111, 1994.
20. Davis TC, Meldrum H, Tippy PKP. et al. How poor literacy leads to poor health care. *Patient Care*: 87:94-108, 1996.
21. Baker, DW, Parker, RM, Williams, MV. et al. The relationship of patient reading ability to self-reported health and use of health services. *Am J Public Health* 87:1027-1030, 1997.
22. Gazmararian JA, Baker DW, Williams MV et al. Health literacy among Medicare enrollees in a managed care organization. *JAMA* 281:545-551, 1999.