



Published in final edited form as:

Spec Care Dentist. 2015 March ; 35(2): 68–77. doi:10.1111/scd.12084.

Preventive dental health care experiences of preschool-age children with special health care needs

Colleen E. Huebner, PhD, MPH [Northwest Center to Reduce Oral Health Disparities, Professor]

Department of Health Services, Box 357230, University of Washington, Seattle, WA USA
98195-7230

Donald L. Chi, DDS, PhD [Northwest Center to Reduce Oral Health Disparities, Associate Professor]

Department of Oral Health Sciences, Box 357475, University of Washington, Seattle, WA USA
98195-7475

Erin Masterson, MPH [Northwest Center to Reduce Oral Health Disparities, Graduate Research Assistant]

Department of Oral Health Sciences, Box 357475, University of Washington, Seattle, WA USA
98195-7475

Peter Milgrom, DDS [Northwest Center to Reduce Oral Health Disparities, Professor]

Department of Oral Health Sciences, Box 357475, University of Washington, Seattle, WA USA
98195-7475

Abstract

Purpose—This study examined the preventive dental health care experiences of young children with special needs and determined the feasibility of conducting clinical dental examinations at a community-based early intervention services center.

Methods—Study methods included 90 parent interviews and dental examinations of their preschool-age children.

Results—Thirteen percent of the children received optimal preventive care, defined as twice daily tooth brushing with fluoridated toothpaste and two preventive dental visits in the prior 12 months; 37 percent experienced care that fell short in both areas. Optimal care was more common among children of parents who reported tooth brushing was not a struggle and those with a personal dentist. Parents' opinion of the study experience was generally positive.

Conclusions—Few children with special needs receive effective preventive care early, when primary prevention could be achieved. Barriers to optimal care could be readily addressed by the dental community in coordination with early intervention providers.

INTRODUCTION

In the years 2009–2011, approximately 15 percent of all children and youth under 18 years of age living in U.S. households met the definition for “special health care needs” (SHCN) because they had or were “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.”¹ The prevalence of young children, under 6 years of age, who met this definition was 9.3 percent in 2009–2011 and corresponds to a population estimate of over 2.3 million children.²

Many children with SHCN require extra effort and time for adequate oral hygiene and require specialized professional dental care because of behaviors and sensitivities that interfere with routine tooth brushing, ability to tolerate dental visits, problems associated with malocclusion or overgrowth of gum tissue related to medications.^{3,4,5,6} Parents of children with special needs may have difficulty establishing a dental home for their children⁷ and the disease burden of dental caries is high.^{8,9}

Most published reports about the oral health of individuals with SHCN focus on older children and adults. There are a limited number of studies on dental caries among children with specific disabilities or medical conditions and even fewer studies on infants or preschool-age children. Published studies often yield conflicting results. For example, the caries rate among individuals with intellectual disabilities has been described as similar to the general population but there is more untreated caries among those with intellectual disabilities.¹⁰ In contrast, a study of low-income children found higher caries prevalence among those with developmental delay (including children with intellectual disabilities and communication problems) than among the children without developmental delays.¹¹ A study of caries prevalence in children with and without asthma found higher caries rates among 3-year-old children with asthma but no difference among children at 6 years of age.¹²

Studies of children within disability groups also yield mixed results. For example, a study of caries in children with asthma compared those who used medication to control asthma with those who did not. The authors report no increased risk of caries in the primary dentition but increased risk of caries in newly-erupted permanent teeth of children who used asthma medication.¹³ Reports of caries rates among children with autism spectrum disorder relative to children with or without other disabilities, are also mixed.^{10,14,15} Seow¹⁶ identified an association between very low birth weight, less than 1500 grams, and enamel defects in the primary dentition associated with systemic conditions that led to insufficient mineralization of the teeth or as a consequence of intubation or mechanical ventilation. Nelson¹⁷ proposed an association between very low birth weight, a correlate of developmental delay,¹⁸ and dental caries via this biological pathway.

When considered together, it is likely the inconsistent findings from observational studies reflect heterogeneity among the children in their underlying conditions, family circumstances, access to dental treatment and to preventive services. A consistent finding from on-going national surveys of parents of children ages birth to 17 years is that a significantly higher proportion of children with disabilities and other special needs are rated

to be in fair or poor oral health (versus good, very good or excellent oral health) than are children without special needs. In addition, as the number of needed special therapies or services increases, children are reported to be in poorer oral health.¹⁹ Type of disability may be relevant too. For instance, proportionately more children with speech or behavior disorders, learning disabilities, physical limitations, developmental delays or autism are described as being in poor or fair dental health compared to children with other conditions including asthma or diabetes.²⁰

Overall, parents report the need for early and continuous dental services is higher among children with special needs and that dental services are costly.²¹ Dental care is the most common unmet health care need among their children.²²

Missing from the existing descriptive information are adequate data about the characteristics and circumstances of very young children with special health needs that could exacerbate or attenuate the risk of dental problems, including barriers to tooth brushing at home and their use of professional preventive dental care. Additionally, it is not known how best to identify these children for large population-based studies of oral health or to provide oral health education to their parents. A possibility explored in this study is to reach parents of special needs children by collaborating with community-based early intervention centers.

There were three aims to this study. The primary aim was to describe the preventive dental health care experiences of young children with special health care needs. The second aim was to assess individual, interpersonal and community influences on their preventive dental health care experiences. Third was to determine if it feasible to conduct clinical dental examinations of young high-risk children at a familiar community site rather than at a specialty medical or dental setting. If it is feasible, this approach could be used to gather prevalence data on the oral health of young children with special needs, including children who have not yet entered the dental care system, provide oral health education to parents, and introduce families to the importance of establishing a dental home.

METHODS

Study design

The design was a cross-sectional study of parents and their preschool-age children with SHCN.

Conceptual Model of Influences on Preventive Dental Health Care Experiences

Patrick's model of social-cultural influences on oral health and oral health disparities²³ guided our selection of variables. The model posits sources of influence at the individual, interpersonal, community and further distal or "macro" levels. The primary individual (child or parent) variables examined in this study were the child's complexity of health care needs, child's age, and the parent's educational level. We considered parent's description that brushing their child's teeth was sometimes a struggle as an interpersonal (child-parent) influence. Parent's report that their child had a personal dentist who knows the child well was considered a community-level characteristic. Parent's report that their child's insurance was adequate to cover the child's dental needs was identified as a potential macro influence,

in keeping with the conceptual model, because the dental benefits and allowed costs of an insurance plan are outside the control of individual parents or children.

Data source and sample

The data were obtained from parents and children who met qualifying criteria for specialized therapies or educational services provided by “Part C” of the Individuals with Disabilities Education Act (IDEA). This federal grant program assists States to implement a system of early intervention services for children who are younger than three years of age who have developmental delays or diagnosed physical or mental conditions that have a high probability of resulting in developmental delay or disability. Dental providers are not typically well-integrated in the early intervention service network.

The study sample was of families associated with one early intervention service center located in Spokane County, a non-fluoridated area in eastern Washington State. The Center provides physical, speech and mental health therapies, special education, nutrition and feeding counseling. Approximately 85 percent of the center's clients meet federal eligibility guidelines for the public insurance programs Medicaid or CHIP (Children's Health Insurance Program), a program for uninsured children in families with modest incomes but too high to qualify for Medicaid.

Eligible study participants were parents and children who were current or former clients, or who were eligible for services at the center but were on the waiting list for admission. To examine children who might be at different stages of caries progression, the sample was planned to include approximately 30 children in each of three age groups: 2 years, 3 years and 4 years of age. All parents were able to communicate in the English language. Children who were unable to receive medical services in a community-based (versus hospital) setting were excluded from the study.

Potential participants were notified of the study through an electronic newsletter of the center sent routinely to current and former clients, by posters displayed in the common areas of the center, or by fliers mailed to parents of age-eligible former clients of the center. The recruitment materials instructed interested parents to telephone the center for further information or to speak directly with the lead member of the center-based research team. Parents with further interest made an appointment for an in-person meeting with one of three center-based nurses trained in the study protocol and trained in the ethical conduct of research. At that time, the nurse completed verbal and written informed consent procedures and obtained the parent's written consent.

Data collection

There were two components to data collection: a parent interview and a dental examination of the child. The interviews were conducted in person by one of three center-based nurses who were trained by the study PI to use a semi-structured interview guide and record parents' responses in writing. The interview began with questions about diagnosed health conditions drawn from the National Survey of Children with Special Health Care Needs²⁴ and items from a validated screening tool used to identify children with special health care needs based on parents' report of functional limitations relative to the child's peers and the

child's needs for special services due to medical, behavioral, or health conditions that have lasted, or are expected to last, at least one year.²⁵ The interviews included questions about family demographics and multiple items about parents' dental hygiene efforts,²⁶ use of preventive dental services²⁴ and children's oral health status.²⁷ Most interviews took from 40 to 50 minutes to complete. The interviewers wrote parents' responses directly on the interview guide and the interviews were audio-recorded. The majority of the interviews were conducted without the child present. At a later date, members of the university-based research team compared the audio recordings to the hand-written record made by the nurses. The written record was edited for completion and clarified in order to code parents' responses to open-ended questions.

Dental exams took place in medical exam rooms at the early intervention center on dates other than those of the interviews. The exams were conducted by one trained and calibrated pediatric dental resident who had experience working with children with special health care needs. The exams were performed using a portable dental chair, headlamp, disposable mirror and probe. Nurses employed by the center were trained to assist the dentist. To assess dental caries, the teeth were first dried with gauze. The presence of non-cavitated smooth surfaces and occlusal lesions were determined by visual exam as described by the Basic Screening Survey of the U.S. Association of State and Territorial Dental Directors²⁸ and decayed, missing, and filled teeth (dmft) as described by the World Health Organization.²⁹ Inter-rater agreement was established between the examiner and an experienced dentist previously trained in the WHO protocol. The reliability sample was 20 preschool-age children who were not study participants. Agreement on the presence or absence of caries experience, per tooth, was greater than 0.85, using Cohen's Kappa agreement statistic.

A brief exit interview conducted by staff nurses at the conclusion of the dental exam asked parents to identify aspects of the study that were difficult or beneficial for them or their child, if they would choose to participate "today" given their actual experience and if they would recommend the study to other parents of children with SHCN. We asked also if slight changes that would increase study demands on the families would have affected their willingness to participate.

Parents received a gift card to a local store as a token of appreciation for completing the interview and a second gift card for the visit that included the dental examination of their child. Results of the dental examination were shared with each parent upon its completion. Parents were offered written referral information for local dentists known to treat children with special needs and to accept low-income children covered by the public insurance program, Medicaid. Additionally, at the end of the examination, parents received a gift of toothbrushes and toothpaste for their family (adults and children) and a children's story book about tooth brushing.

Measures

Our measures of preventive dental health care were based on parents' responses to open-ended questions designed for this study that asked parents if they had begun brushing their children's teeth, the frequency of tooth brushing at home, and the type of toothpaste used (fluoridated, non-fluoridated, or no toothpaste). The question to ascertain children's receipt

of professional preventive care was drawn from the U.S. National Survey of Children's Health 2007. It is: "During the past 12 months, how many times did [Child's name] see a dentist for preventive dental care such as check-ups and dental cleanings?" We used these data to determine the proportion of children who met professional recommendations for tooth brushing (twice daily with fluoridated toothpaste),³⁰ receipt of professional preventive care (a dental examination every six months or more often),^{3,31} neither of these recommendations, or both. "Optimal" preventive dental health care was defined as brushing twice daily with fluoridated toothpaste and the receipt of at least two preventive dental visits in the prior 12 months.

To examine variation in preventive dental health care experiences related to individual characteristics of the study children, we compared two groups of children who were relatively more or less complex in terms of their special needs. For this comparison, we formed two mutually-exclusive groups from parents' responses to the CSHCN screener²⁵ in accord with formula established by Bramlett and colleagues.¹⁹ The groups were of children who needed elevated services or therapies for at least 12 months or more and had functional limitations expected to last 12 months or more (group 1) and children who needed elevated services or therapies for 12 months but were not expected to have long-term functional limitations (group 2). We tested one other child-level influence on preventive dental care experiences: the child's age (coded as less than 36 months, 36–47 months, or 48 months or older) and tested one parent-level influence: the parent's education level (high school graduate or less vs. education beyond high school).

Tooth brushing struggles, our measure of interpersonal influence, reflects parents' responses to the open-ended question "How do you feel about brushing your child's teeth if it is something he/she doesn't want to do?" Examples of their responses are: "I do it less often," "I keep at it" and "I feel bad." For purposes of analysis, we compared parents who indicated "This is never a problem for us," (no struggles) with those who described any negative experience or effort needed to overcome resistant behavior.

Our measure of community influence was based on the parent's answer to the question: "Do you have one or more persons you think of as your child's personal dentist ... who knows your child well and is familiar your child's health history?" There were three response options: "no," "yes, one person" and "yes, more than one person." Both "yes" responses were combined to form a binary variable (no vs. yes, the child has a personal dentist). Adequacy of insurance, a macro-level influence, was based on parent's response to the question: "Does the child's dental insurance offer benefits to cover services that meet his/her needs?" (coded as yes vs. no).

Children's current oral health status was ascertained by parent's rating of the child's overall oral health status on a 5-point scale that ranged from excellent to poor,²⁷ report of current dental concerns based on a 16-item symptom checklist, and by the dentist's clinical examination.

Ethical approval

All study procedures, including the informed consent process, were approved by the Human Subjects Division of the University of Washington.

Data analysis

Data management and analyses were conducted with SAS version 9.3. Descriptive statistics are presented for all independent and dependent variables. Fisher's exact tests, to accommodate small expected cell sizes, were conducted to examine associations between individual, interpersonal and community influences and preventive dental health care experiences.

RESULTS

Characteristics of the parents and children

Characteristics of the parent and child participants are presented in Table 1. Parents' age ranged from 19 to 66 years (the eldest was a grandparent). The majority (67%) was 30 years or older; 91 percent were mothers. The average number of years of parents' formal schooling was 14.39 and the majority (72%) had completed schooling beyond high school. The largest racial/ethnic group was White, non-Hispanic (83%) and this is true of the geographic region in which the families resided. As intended, most children were age 24 to 59 months at the time of the dental exam. Three children were out of the age range due to the scheduling needs of their families; at the time of the exam their ages were 23 months, 60 months and 62 months. A balance among the number of children ages 2, 3 and 4 years old was not achieved. The average age was 35.56 months and the majority (69%) was of current clients less than 3-years old. Twenty-four percent were 3-years old and 7 percent were age 4 years or slightly older. There were more boys (64%) than girls in the study sample.

All children met at least one qualifying criteria on the Special Needs Screener²⁵ indicating special service needs due to conditions that lasted or were expected to last at least 12 months. The most common diagnosed conditions were neurodevelopmental disabilities (80%), specifically developmental delay (80%), or autism (6%) or Down syndrome (10%) and some children were described as having more than one of these conditions. Other conditions that affected at least 15 percent of the sample are presented in Table 1. The types of special therapies and services received by the children are presented in Table 1 also; the most common was therapy for developmental (e.g., speech or physical) delay. Seventy-six percent of all children were described by their parents as having one or more functional limitations expected to last 12 months or more. The four most common limitations were in: communication (affecting 80% of the children), coordination or physical movement (71%), self-care (e.g., feeding or dressing oneself: 60%), and learning (57%). The proportion of children with long-term needs for special therapies or services and long-term functional limitations was 76 percent.

As a group, the children had multiple contacts with early intervention service professionals as well as numerous encounters with medical providers; 21 percent had four or more visits for preventive medical care in the prior 12 months. Forty-two percent of parents reported

ever receiving advice from a non-dental professional about their child's oral health. The most common sources of advice were physicians (reported by 20 parents), speech therapists (8 parents), or medical specialists (5 parents). Other categories of providers noted by one parent each included a mental health specialist and a physical therapist.

Preventive dental health care experiences

At the time of the study, all but two parents reported they had tried to brush their child's teeth at least once in the past. For the group as a whole, seven percent were currently brushing their child's teeth less than once per day on average or not at all, 44 percent brushed once per day and approximately half (49%) reported brushing twice a day or more often (Table 2). Sixty percent of parents said they brushed their child's teeth with fluoridated toothpaste. The others reported using non-fluoridated toothpaste or water. Thirty percent of parents reported brushing their child's teeth at least twice a day and using fluoridated toothpaste. Most parents (81%) who were brushing their child's teeth, described some resistance or "struggles" with brushing.

By parent report, 21 percent of the children had received zero preventive dental visits in the prior 12 months, 32 percent had received one preventive visit and 47 percent had received two or more preventive dental visits. All but five children were reported to have public or private dental insurance. Three had no dental insurance and two parents did not know the answer to this question. Of the 85 with dental insurance, 86 percent of parents (77) judged it as adequate to meet their child's dental needs. Two parents said their insurance was not adequate and the others did not know or had not yet used their child's dental insurance. Fifty-eight percent of parents said their child had a personal dentist. Twenty-percent of the children had never been to a dentist, for any reason (data not shown).

Thirteen percent of the children were considered to have optimal preventive dental health care in that they met universal recommendations for preventive care: they received twice daily brushing with fluoridated toothpaste and had completed two preventive dental visits in the prior 12 months. Fifty percent met the recommendation for home care or for professional care, but not both. More than one-third (37%) of the children's care met neither of these recommendations (Table 2).

Results of tests of associations between potential sources of influence on preventive dental health care and optimal care are presented in Table 3. In this study, nearly all children (94%) had dental insurance that either met their dental needs or had not been used. Thus, due to lack of variability, insurance status was not included in the analysis. Tests of association showed that none of the individual-level variables (child's complexity of needs, age, or parental education) were associated with optimal care, whereas there were significant associations with the interpersonal and with the community-level variables. Specifically, parents who reported that tooth brushing was never a struggle were more likely to report their child received optimal preventive dental health care (Fisher's exact test; $p = 0.05$). Likewise, parents who reported their child had a personal dentist were more likely to describe optimal preventive dental health care for their children (Fisher's exact test; $p = 0.01$).

Children's oral health status

At the time of the interview, 90 percent of parents reported their child was experiencing one or more problems with their teeth. The most common, each affecting more than one third of the children, were problems associated with teething, sucking and tooth grinding (Table 4). Overall, 12 percent of the children were rated by their parents to be in poor or fair oral health. The dental examination determined that 24 percent of the children had at least one decayed, missing or filled tooth.

Feasibility of conducting oral examinations at the study site

One goal of this study was to determine the feasibility of conducting oral examinations in community settings and determine if parents of young children with special health care needs would be open to doing so. No parent who indicated interest in the study declined the interview however three parents did not return with their child for the dental examination due to family vacation or other scheduling conflicts. They explained the exam would be of little benefit because their child had established dental care in the community.

The dental exams took 15 minutes on average. The exam included a caries assessment and two other assessments (for *Streptococcus mutans* and enamel defects) not reported here. No exam was rescheduled due to behavior of the child that prevented completing the protocol or a parent's request to stop the exam.

Parents' opinions of the study experience for them and their children

We conducted exit interviews with 67 of the 90 parent participants; 23 were missed due to a data collection error on the part of the study team. Of the parents who participated in the interviews, all said they would enroll in the study again and would recommend it to other parents of children with SHCN. Sixty-four (96%) said they would be willing to participate if the study required more than the two contacts asked of them. Sixty-one parents (91%) said they would have agreed to participate if the study asked for an examination of the parents. Of the 62 parents with other children, 60 (97%) said they would have participated if we had asked to conduct a dental examination of their other children.

In response to open-ended questions about the difficulties and benefits associated with study participation, 58 percent of parents described one or more difficulties and 97 percent reported one or more benefits. The number of times each type of difficulty or benefit was reported and illustrative responses given by the parents are presented in Table 5. The sums exceed the number of interviews because each parent could report more than one difficulty or more than one benefit. The most common difficulty, noted by 29 (43%) parents, was it was hard for their child to tolerate the dental examination. Parents described more benefits than difficulties and only two said there was no benefit to them or their child. The most common benefit, reported by 45 (67%) parents, was the information and advice given by the examining dentist. One parent said, "I learned something from your dentist. She gave me very specific information I hadn't previously received from my pediatric dental practice." Another parent said a benefit was "confirmation that I was doing good oral care."

DISCUSSION

The primary aim of this study was to describe the preventive dental health experiences of young children special needs. Study participants were parents and children enrolled in the federal Early Intervention Program for Infants and Toddlers with Disabilities. As is typical of children in early intervention programs, the study children generally had frequent interactions with health professionals for special therapies and medical care due to complex and numerous health or developmental conditions. Their use of preventive dental services was considerably less frequent. Slightly less than half the children (47%) had received two or more preventive dental visits in the 12 months prior to the study and one-fifth (21%) had received none at all. In comparison, 63 percent had two or more medical visits for preventive care in the prior 12 months and only 1 percent had no preventive medical visits in this time frame. The lack of dental services was not for lack of perceived need. Ninety-percent of parents reported their child had at least one dental problem and 24 percent of the children were found to have decayed, missing or filled teeth.

All but two parents reported brushing their child's teeth and approximately half reported achieving the recommendation to brush twice a day or more. Our findings are consistent with studies of parents of typically-developing preschool-age children that find approximately half- to two-thirds of parents report brushing their children's teeth twice a day^{32,33} and that most parents describe difficulties including uncooperative children.²⁶ When tooth brushing and professional preventive dental health services were considered together, we found only 13 percent of the children had the benefit of both, at the recommended frequency, and 37 percent lacked in both areas. Optimal preventive dental health care was low overall, however it was more common among children of parents who reported tooth brushing was not a struggle for them and was more common among children with a personal dentist. These two barriers could be readily addressed by the dental community in coordination with early intervention providers in the form of on-site dental screenings, topical fluoride applications, and parent education and coaching in how to brush a young child's teeth.

Previous research suggests the needs of children for intensive medical services and therapies can overshadow receipt of routine dental services³⁴ and home oral hygiene. This was not true in this study. Children with more complex needs were no more, or less, likely to have received optimal preventive dental health care. In short, few children did. Our interview data did not suggest oral health was a lower-priority health concern. Parents were forthcoming in describing many dental concerns and had a positive opinion of the study procedures.

Admittedly our sample was of parents interested enough to volunteer for the study, however the use of a familiar site for the interview and dental exam was also an advantage to gaining their participation. At least one parent noted this made the exam easier on her child. All parents said they would participate again, even if more was demanded of them. Although we set out to enroll equal numbers of two-, three- and four-year-old children, two-thirds (62 of 90) of the sample were less than 36 months of age and were current clients of the center. This may indicate that parents of current clients found it especially convenient to participate in the interview and exam at the center, a location they visited already several times per week. Based on this experience, we recommend dental outreach efforts focus on early

intervention centers as a place to reach parents of the youngest of these high-risk children in order to establish a dental home for continuous care as the children grow older.

Community matters. Twenty-one percent of children with a personal dentist had optimal preventive dental care as defined, minimally, in this study. This was true of only three percent of children without a personal dentist. Early establishment of a “dental home” in infancy is recommended for all children³⁵ and could be especially beneficial to young children with special needs. Results of this study yield specific suggestions for multiple components of the dental home, including topics for oral health education, advice for risk reduction, instruction in tooth brushing, anticipatory guidance about typical developmental concerns (e.g., infant teething) and discussion of dental concerns specific to a child's medical conditions or developmental disabilities.

The positive response to the study suggests local dentists would be well received by early intervention specialists and parents. The shared knowledge of an early interventionist-parent-dentist team would be ideal to guide risk assessment and planning for early childhood caries prevention and management. We found it was feasible to conduct dental exams at the early intervention center. Parents appreciated the convenience and the expertise of the study dentist who had training, experience and a stated interest in treating young children with special needs..

There are several limitations of this study that could be addressed in future research. First, the study sample was limited to parents of children who sought out early intervention services for their children and thus is not representative of all children with special needs. Second, the sample was too small to test for differences in the oral health care experiences of children who differed in their developmental conditions. A larger study and a different recruitment method (e.g., a national survey using random-digit dialing) is one way to obtain this additional information. A third limitation was the choice of interview question to ascertain use of preventive dental care. The interview question we selected, from the National Survey of Children's Health, is imprecise in that it does not differentiate diagnostic procedures from preventive services. The advantage of using questions from existing national surveys is the availability of comparable data. Indeed our finding that nearly 80 percent of the study children had received at least one preventive dental visit in the prior 12 months, is higher than estimates for the general U.S. population of children less than six years of age.^{36,37}

This study identified two new directions for research. One, based on our finding that 42 percent of parents reported receiving dental advice from non-dental professionals, is to learn more about the accuracy of this information. Inter-professional training could be developed to assist non-dental professionals in their recommendations to parents regarding when to establish dental care for their child, the value of a dental home, and to minimize potential conflicting messages (e.g., about the use of fluoridated toothpaste). A second area for further research is to examine further parents' perception of the importance of preventive dental care relative to their child's medical care needs. In this study, most parents identified one or more dental concerns about their child, yet relatively few acted on this by seeking professional dental services.

CONCLUSIONS

In 1999–2004, the prevalence of caries experience among all U.S. preschool children, ages 3 to 5 years, was approximately 33 percent and had increased over the previous decade.³⁸ These data are used to monitor progress toward the Healthy People goals for the nation. The absence of data specific to the oral health of children with SHCN puts them at a disadvantage for gaining national attention and, in turn, at a disadvantage to garner resources to protect them from unnecessary dental disease. The value of early and preventive dental services for this vulnerable group is inarguable. With increasing age, behaviors associated with emotional disturbance or autism for instance, are likely to become more difficult to manage in the dental office and medications to treat other conditions such as seizures will take an increasing toll on periodontal health. The study reported here found parents of young children with special needs are concerned about oral health yet most do not meet minimal guidelines for preventive dental care for their children. Early intervention service centers that serve children from birth to three years provide an excellent opportunity to monitor the oral health of large numbers of children with special needs, provide resources and referral information to parents for effective caries prevention, and assist parents to establish a dental home for their young children.

Acknowledgements

This research was supported by Award Numbers U54DE019346 and K08DE020856 from the National Institute of Dental & Craniofacial Research, National Institutes of Health, Bethesda, MD USA. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institute of Dental & Craniofacial Research or the National Institutes of Health. The authors thank the nursing staff of the Spokane Guilds' School and Neuromuscular Center, the caregivers and children who participated in this study, and Anne Reeves.

REFERENCES

1. McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck P, Perrin J, Shonkoff J, Strickland B. A new definition of children with special health care needs. *Pediatrics*. 1998; 102(1): 137–40. [PubMed: 9714637]
2. Child and Adolescent Health Measurement Initiative. Data Resource Center for Child and Adolescent Health. National Survey of Children with Special Health Care Needs NS-CSHCN 2009/10. Available from: <http://www.childhealthdata.org/browse/survey> Data query on 02/12/2013
3. Norwood KW, Slayton RL, Council on Children with Disabilities and Section on Oral Health. Oral health care for children with disabilities. *Pediatrics*. 2013; 131:614–619. [PubMed: 23439896]
4. Isman, B.; Newton, RN. [Accessed 01/31/2014] Oral Conditions in Children with Special Needs: A Guide for Health Care Providers. California Connections Project (MCJ#06R005), Maternal and Child Health Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services. Reprinted by the National Institute of Dental and Craniofacial Research, July, 2008. Online information available at: <http://www.nidcr.nih.gov/OralHealth/OralHealthInformation/ChildrensOralHealth/OralConditionsChildrenSpecialNeeds.htm>
5. Glassman P, Miller CE. Effect of preventive dentistry training program for caregivers in community facilities on caregiver and client behavior and client oral hygiene. *N Y State Dent J*. 2006; 72:38–46. [PubMed: 16711592]
6. Tesini DA, Fenton SJ. Oral health needs of persons with developmental disabilities. *Dental Clin N Amer*. 1994; 38:483–98.
7. Kenny MK, Mann M, – hard to establish a dental home - Assessing Systems of Care for US Children with Epilepsy/Seizure Disorder. *Epilepsy Res Treat*. 2013; 2013:825824. doi: 10.1155/2013/825824. Epub 2013 Oct 21. [PubMed: 24228175]

8. Anders PL, Davis EL. Oral health of patients with intellectual disabilities: a systematic review. *Spec Care Dent*. 2010; 30:110–117.
9. Morgan JP, Miniham PM, Stark PC, Finkelman MD, Yantsides KE, Park A, Nobles CJ, Tao W, Must A. The oral health status of 4,732 adults with intellectual and developmental disabilities. *J Am Dent Assoc*. 2012; 143:838–46. [PubMed: 22855898]
10. U.S. Department of Health and Human Services. National Institutes of Health. National Institute of Dental and Craniofacial Research. Practical oral care for people with disabilities. National Oral Health Information Clearing House; Bethesda: MD: 2004. publication no. 04-5194
11. Chi DL, Rossitch KC, Beeles EM. Developmental delays and dental caries in low-income preschoolers in the USA: a pilot cross-sectional study and preliminary explanatory model. *BMC Oral Health*. Oct.2013 12(13):53. [PubMed: 24119240]
12. Stensson M, Wendt L, Koch G, Oldaeus G, Birkhed D. Oral health in preschool children with asthma. *Int J of Paediatr Dent*. 2008; 18:243–50. [PubMed: 18489575]
13. Wogelius P, Poulsen S, Sorensen HT. Use of asthma-drugs and risk of dental caries among 5–7 year old Danish children: A cohort study. *Community Dent Health*. 2004; 21:207–11. [PubMed: 15470830]
14. DeMattei R, Cuvo A, Maurizio S. Oral assessment of children with an Autism Spectrum Disorder. *J Dent Hyg*. 2007; 81:1–11.
15. Loo CY, Graham RM, Hughes CV. The caries experience and behavior of dental patients with autism spectrum disorder. *J Am Dent Assoc*. 2008; 139:1518–24. [PubMed: 18978390]
16. Seow WK, Humphrys C, Tudehope DI. Increased prevalence of developmental dental defects in low-birth-weight children: A controlled study. *Pediatr Dent*. 1987; 9:221–5. [PubMed: 3507638]
17. Nelson S, Albert JM, Geng C, Curtan S, Lang K, Miadich S, Heima M, Malik A, Ferretti G, Eggertsson H, Slayton RL, Milgrom P. Increased enamel hypoplasia and very low birthweight infants. *J Dent Res*. 2013; 92:788–94. doi: 10.1177/0022034513497751. Epub 2013 Jul 15. [PubMed: 23857641]
18. Schendel DE, Stockbauer JW, Hoffman HJ, Herman AA, Berg CJ, Schramm WF. Relation between very low birth weight and developmental delay among preschool children without disabilities. *Am J Epidemiol*. Nov 1; 1997 146(9):740–9. [PubMed: 9366622]
19. Bramlett MD, Read D, Bethell C, Blumberg SJ. Differentiating subgroups of children with special health care needs by health status and complexity of health care needs. *Matern Child Health J*. 2009; 13:151–63. [PubMed: 18386168]
20. Kenney MK, Kogan M, Crall JJ. Parental perceptions of dental/oral health among children with and without special health care needs. *Ambul Pediatr*. 2008; 8:312–20. [PubMed: 18922505]
21. 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. [PubMed: 15630052]
22. U.S. Department of Health and Human Services. Health Resources and Services Administration, Maternal and Child Health Bureau. The National Survey of Children with Special Health Care Needs Chartbook 2005–2006. U.S. Department of Health and Human Services; Rockville, Maryland: 2007.
23. Patrick DL, Lee RSY, Nucci M, Grembowski D, Jolles CZ, Milgrom P. Reducing Oral Health Disparities: A Focus on Social and Cultural Determinants. *BMC Oral Health*. 2006; 6(Suppl 1):S4. [PubMed: 16934121]
24. Child and Adolescent Health Measurement Initiative. [Accessed 1/31/2014] Data Resource Center for Child and Adolescent Health. National Survey of Children with Special Health Care Needs NS-CSHCN 2005/06. Guide to Topics and Questions Asked. Online information available from: http://www.childhealthdata.org/docs/cshcn/guide_to_topic_quesets_asked_20052006_nscshcn_508-pdf.pdf
25. Bethell CD, Read D, Stein REK, Blumberg SJ, Wells N, Newacheck PW. Identifying children with special health care needs: development and evaluation of a short screening instrument. *Ambul Pediatr*. 2002; 2:38–47. [PubMed: 11888437]
26. Huebner CE, Riedy CA. Behavioral determinants of parent's twice daily toothbrushing of very young children. *Pediatr Dent*. 2010; 32:48–55. NIHMSID #227947. [PubMed: 20298653]

27. National Institute of Health. [Accessed 01/31/2014] National Center for Dental and Craniofacial Research and Centers for Disease Control. Dental, Oral, and Craniofacial Data Resource Center. Oral health questions included in national surveys. Online information available from: <http://drc.hhs.gov>
28. Association of State and Territorial Dental Directors. Basic Screening Survey for Children. Revised 2003
29. World Health Organization. Oral Health Surveys: Basic Methods. 4th edition. 1997.
30. American Academy of Pediatric Dentistry. [Accessed 04/04/2014] Policy on Early Childhood Caries (ECC): Unique Challenges and Treatment Options, revision 2011. Online information available from: http://www.aapd.org/media/Policies_Guidelines/P_ECCUniqueChallenges.pdf
31. American Academy of Pediatric Dentistry. [Accessed 04/04/2014] Guideline on Periodicity of Examination, Preventive Dental Services, Anticipatory Guidance/Counseling, and Oral Treatment for Infants, Children, and Adolescents, revision 2013. Online information available from: http://www.aapd.org/media/Policies_Guidelines/G_Periodicity.pdf
32. Pine CM, Adair PM, Nicoll AD, Burnside G, Petersen PE, Beighton D, Gillett A, Anderson R, Anwar S, Brailsford S, Broukal Z, Chestnutt IG, Declerck D, Ping FX, Ferro R, Freeman R, Gugushe T, Harris R, Lin B, Lo EC, Maupome G, Moola MH, Naidoo S, Ramos-Gomez F, Samaranayake LP, Shahid S, Skeie MS, Splieth C, Sutton BK, Soo TC, Whelton H. International comparisons of health inequalities in childhood dental caries. *Community Dent Health*. 2004; 21:121–30. [PubMed: 15072481]
33. Vargas CM, Monajemy N, Khurana P, Tinanoff N. Oral health status of preschool children attending Head Start in Maryland, 2000. *Pediatr Dent*. 2002; 24:257–263. 2002. [PubMed: 12064502]
34. Nelson LP, Getzin A, Graham D, Zhou J, Wagle EM, McQuiston J, McLaughlin S, Govind A, Sadof M, Huntington NL. Unmet dental needs and barriers to care for children with significant special health care needs. *Pediatr Dent*. 2011; 33:29–36. [PubMed: 21406145]
35. American Academy of Pediatric Dentistry. [Accessed 04/04/2014] Guideline on Infant Oral Health Care, revision 2012. Online information available from: http://www.aapd.org/media/Policies_Guidelines/G_infantOralHealthCare.pdf
36. Huebner CE, Bell JF, Reed S. Receipt of preventive dental care among U.S. children and youth: A population-based study of the 2005-2008 Medical Expenditure Panel Surveys. *Matern Child Health*. 2013; 17(9):1582–1590. DOI 10.1007/s10995-012-1168-7.
37. Bell JF, Huebner CE, Reed S. Oral Health Need and Access to Dental Services: Evidence from the National Survey of Children's Health, 2007. *Matern Child Health*. 2012; 16:S27–S34. DOI 10.1007/s10995-012-0992-0.
38. U.S. Department of Human and Health Services. [Accessed 01/31/2014] Healthy People 2020 – Improving the Health of Americans. Oral Health of Children and Adolescents, OH-1.1. Online information available from: <http://healthypeople.gov/2020/topicsobjectives2020/objectiveslist.aspx?topicId=32>

Table 1

Characteristics of the Study Parents and Children (n = 90)

	Mean (SD) or % (count)
Parents	
Age (yrs)	33.80 (9.45)
Education (yrs)	14.39 (2.46)
Gender (female)	91 (82)
Race/Ethnicity	
White, not Hispanic	83 (75)
African American	7 (6)
Native American or Alaska Native	7 (6)
Hispanic, White	3 (3)
Children	
Age (months)	35.56 (10.70)
Gender (male)	64 (58)
Developmental and Health Conditions	
Neurodevelopmental disability (developmental delay, autism or Down Syndrome)	80 (72)
Gastroesophageal Reflux Disease (GERD: current or past)	60 (54)
Allergies (including food allergies)	31 (28)
Emotional problems	19 (17)
Heart problems	16 (14)
Asthma	16 (14)
Special Therapies or Services Needed for 12 Mos or More	
Therapies (e.g., speech or physical therapy)	92 (83)
Medical care, mental health or educational services	88 (79)
Medication	37 (33)
Treatment or counseling for emotional or developmental problems	30 (27)
One or More Functional Limitation Compared with Peers, Expected to Last 12 Mos or More	76 (68)
Types of Functional Limitations Compared with Peers	
Speaking, communicating or being understood	80 (72)
Coordination or physical movement	71 (64)
Self-care	60 (54)
Learning, understanding or paying attention	57 (51)
Difficulty using his/her hands	41 (37)

	Mean (SD) or % (count)
Behavior problems	30 (27)
Feeling anxious or depressed	18 (16)
Preventive Medical Visits (past 12 mos)	
None	1 (1)
1	36 (32)
2	27 (24)
3	15 (14)
4+	21 (19)
A Non-Dental Professional Discussed Oral Health	
No, never	58 (52)
Yes, at least once	42 (38)

Table 2

Preventive Dental Health Care Experiences

	% (count)
Preventive Dental Health Care	
Tooth brushing frequency	
Parent brushes child's teeth < 1/day	7 (6)
Parent brushes child's teeth 1/day	44 (40)
Parent brushes child's teeth 2/day	49 (44)
Child's teeth are brushed with fluoridated toothpaste	60 (54) ^I
Tooth brushing can be a struggle	81 (71) ^I
Preventive dental visits (past 12 months)	
None	21 (19)
1	32 (29)
2 or more	47 (42)
Access or Barriers to Professional Preventive Services	
Child has insurance adequate to meet dental needs	86 (77)
Child has a personal dentist	58 (52)
Meets Recommendations for Preventive Behaviors	
No: brushes < 2/day and received < 2 preventive dental visits in past 12 months	37 (33)
Brushes 2/day with fluoridated toothpaste but received < 2 preventive visits in past 12 months	17 (15)
Not brushing 2/day with fluoridated toothpaste but received 2 preventive dental visits in past 12 months	33 (30)
Optimal: brushes 2/day with fluoridated toothpaste and received 2 preventive dental visits in past 12 months	13 (12)

^ITwo parents who had not yet begun brushing were excluded from this computation.

Table 3

Bivariate Associations between Individual, Interpersonal and Community Influences and Optimal Preventive Dental Health Behaviors

Influences on Preventive Dental Behaviors	Optimal Behaviors	Less than Optimal	P value ¹
Individual	%(count)	%(count)	
Child's Complexity of Needs			1.00
Elevated services and functional limitations	14 (3)	86 (19)	
Elevated services, no functional limitations	13 (9)	87 (59)	
Child's Age			0.31
< 36 months	13 (8)	87 (54)	
36–47 months	9 (2)	91 (20)	
48 months	33 (2)	67 (4)	
Parent's Level of Education			0.50
High school graduate or less than high school	8 (2)	92 (23)	
Education beyond high school	15 (10)	85 (55)	
Interpersonal²			0.05
Parent reports tooth brushing can be a struggle	10 (7)	90 (64)	
Parent reports tooth brushing is not a struggle	29 (5)	71 (12)	
Community			0.01
Child has no personal dentist	3 (1)	97 (37)	
Child has a personal dentist(s)	21(11)	79 (41)	

¹ Comparisons are based on Fisher's exact tests because the sample sizes are small and there are expected values in the table less than 10.

² Two parents who had not yet begun brushing were excluded from this computation.

Table 4

Parent and Dentist Report of Child's Oral Health Status

Child's Current Oral Health Status	% (count)
Parent-report of dental problems (yes)	90 (81)
Teething	39 (35)
Sucking	37 (33)
Grinding (day or night)	38 (34)
Poor hygiene	17 (15)
Build-up or tartar	16 (14)
Stains	14 (13)
Soft teeth (e.g., soft enamel)	11 (10)
Cavities	10 (9)
Pain	9 (8)
Trauma	7 (6)
Had teeth pulled	4 (4)
Broken teeth	8 (7)
Other	12 (11)
Parent-report of oral health status as fair or poor	12 (11)
Dental caries by professional examination (yes, any decayed, missing or filled teeth)	24 (21)

Table 5

Parents' Opinions of the Study Experience for Them and Their Children

Opinion about Participating in the Study (yes)	%(count) ¹
Would enroll if asked today	100 (67)
Would recommend the study to others	100 (67)
Would participate if it required more than 2 contacts	96 (64)
Would participate if it required dental exam of parent	91 (61)
Would participate if it required dental exams of other children	97 ² (60)
Difficult Aspects of Participating for Parent or Child (yes) ³	
None: <i>It was easy.</i>	42 (28)
Aspects of the exam were hard for child to tolerate: <i>The whole thing! He is so afraid of the dentist. Flossing.</i>	43 (29)
External constraints (e.g., transportation or time): <i>Finding child care. Remembering my appointment.</i>	10 (7)
Unfamiliar with the study dentist: <i>My child not knowing the examiner.</i>	5 (3)
Emotionally difficult to see child in distress: <i>Listening to him cry during the exam, having to hold him down.</i>	2 (1)
Dental problems were identified: <i>Finding out he has more cavities.</i>	2 (1)
Other: <i>We are working on oral-motor issues</i>	2 (1)
Benefits of Participating for Parent or Child (yes)	
None	3 (2)
Exam gave dental status, useful info and advice: <i>Information about tooth crowding. She (dentist) gave me very specific information I hadn't previously received. Knowing he has healthy teeth. Dentist gave me pointers about troublesome areas on my child's teeth.</i>	67 (45)
Free dental supplies: <i>Cool light-up toothbrush!</i>	15 (10)
Gift card: <i>Appreciate the gift cards. Gift cards to help buy diapers.</i>	15 (10)
The dentist's manner was appreciated: <i>Your dentist took more time than our regular dentist.</i>	10 (7)
Dentist gave advice about home care: <i>Brushing techniques.</i>	9 (6)
Dentist gave referral to area dental care: <i>Getting referral to dentist.</i>	6 (4)
Dentist gave advice about future dental needs: <i>Information about her teeth and what to expect in the future.</i>	6 (4)
It was good for child to "practice" a dental visit: <i>Good trial experience before her first "real" dental experience. My child is ready to go to the dentist now, he did amazing!</i>	6 (4)
Other: <i>Got to visit friends (at the Center study site)</i>	8 (5)

¹ 67 of 90 (74%) of the parents completed exit interviews.

² Five parents had no other children.

³ Parents could describe more than one difficulty or benefit associated with study participation.