Scientific Article

A Preliminary Analysis of the US Dental Health Care System's Capacity to Treat Children with Special Health Care Needs

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Abstract: Purpose: The purpose of this study was to use existing data to determine capacity of the US dental care system to treat children with special health care needs (CSHCN). Methods: A deductive analysis using recent existing data was used to determine the: possible available appointments for CSHCN in hospitals and educational programs/institutions; and the ratio of CSHCN to potential available and able providers in the United States sorted by 6 American Academy of Pediatric Dentistry (AAPD) districts. **Results:** Using existing data sets, this analysis found 57 dental schools, 61 advanced education in general dentistry programs, 174 general practice residencies, and 87 children's hospital dental clinics in the United States. Nationally, the number of CSHCN was determined to be 10,221,436. The distribution, on average, of CSHCN per care source/provider ranged from 1,327 to 2,357 in the 6 AAPD districts. Children's hospital dental clinics had fewer than 1 clinic appointment or 1 operating room appointment available per CSHCN. The mean number of CSHCN patients per provider, if distributed equally, was 1,792. **Conclusions:** The current US dental care system has extremely limited capacity to care for children with special health care needs. (Pediatr Dent 2011;33:107-12) Received April 9, 2010 / Last Revision January 13, 2011 / Accepted February 16, 2011

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The federal Maternal and Child Health Bureau defines children with special health care needs (CSHCN) 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 service of a type or amount beyond that required by children generally."¹ The most recent estimate is 10.2 million CSHCN younger than 18 years old, which represents 14% of all US children and a modest increase from approximately 13% reported in 2001.²

Although CSHCN make up approximately 14% of the child population, they account for more than 40% of medical expenditures for children overall. ³ Included in CSHCN are those with: epilepsy or other seizure disorders (~4%); cerebral palsy (~2%); autism spectrum disorder (~5%); mental retardation or developmental delay (~11%); and congenital heart disease (~4%). Other conditions, such as hemophilia and muscular dystrophy, are also included, and children may experience multiple conditions.² Children undergoing treatment for cancer or organ transplantation are seemingly not included under the CSHCN umbrella.

Access to dental care is a significant concern for many parents of CSHCN. CSHCN are more likely than other children to have an unmet need for dental care as reported by the National Health Interview Survey (NHIS)⁴ in 1994, which found that approximately 12% of CSHCN had at least 1 of the needed health care services unmet, with dental care being the most deficient at approximately 8%. Under the current system of oral health care delivery, access to dental care is not readily available for all CSHCN.

Many general dentists are reluctant to treat CSHCN due to the complexity of their medical conditions, patient behavior, and inadequate training and experience.⁵ A 2004 study of dental students' experience with patients with mental retardation found that 51% reported they did not get any clinical training to manage these patients.⁶ Predoctoral dental education is not mandated to teach dental students to treat CSHCN,⁷ so newly graduating dentists may not be willing to treat CSHCN patients. General dentists with advanced training also tend to see few CSHCN,⁵ so their treatment falls to pediatric dentists and institutions such as dental schools and hospitals.

Pediatric dentists are trained to care for CSHCN,⁸ but with only about 5,000 practicing in the United States, their ability to serve this population is limited. Hospital-based pediatric dentistry clinical and training programs are a primary source of dental care for CSHCN⁹ as well as care centers for other children with and without dental insurance. These are also limited in number and spread unevenly across the country. Training programs in both general dentistry and pediatric dentistry are a source of care for CSHCN, as are some dental schools. Training institutions, however, report overwhelming numbers of patients and extensive waiting times for appointments.¹⁰

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The capacity of various sources of dental care to treat CSHCN is unknown, as are factors that influence their ability to reach these patients, such as location, financial constraints, primary mission, workforce and expertise. Parents of CSHCN report dental care as their greatest unmet need because⁴: few general dentists see CSHCN⁵; the existing sources of care are saturated¹⁰; and CSHCN must compete with other children for access to these same sources.¹¹ With no studies available to assess the capacity of the dental workforce in caring for CSHCN, we undertook an analysis using available data sources and applying trends identified in existing literature.

The purposes of this study were to: determine the capacity of the US dental care system to treat CSHCN; and create a national portrait of care available from known sources, using data from national sources and a recent survey of children's hospitals.¹¹

Methods

This study used available national data, making assumptions on care based on existing literature to construct a conceptual model of capacity for dental care for CSHCN. Children's hospital data for this study was drawn from dental clinic administrator and hospital administrator surveys by Ciesla et al. in this same issue.¹¹ Data came from hospitals and institutes affiliated with the National Association of Children's Hospitals and Related Institutions (NACHRI), a nonprofit membership organization promoting the well-being of children and families through clinical care, research, training, and advocacy.

Additional data used in this analysis were obtained from online databases, literature-based reports, and websites, including the: National Survey of Children with Special Health Care Needs²; American Dental Association (ADA)¹²; American Dental Education Association (ADEA)¹³; American Academy of Pediatric Dentistry (AAPD)¹⁴; National Center for Health Statistics¹⁵; US Organ Procurement and Transplantation Network; and Scientific Registry of Transplant Recipients.¹⁶

Model development

Assumptions. The model makes several initial assumptions, which may or may not reflect the actual situation in all instances. The first assumption or convention is that this model looks at primary care dentists and not specialists. We were interested in identifying dentists who could provide the breadth of services characterized by the dental home¹⁷ concept, which would exclude most dental specialty practices other than pediatric dentistry.

A second assumption is that capacity-related data is time sensitive. Our sources reflect the status of care availability at a point in time when published or accessed for this report. This convention was deemed necessary to allow stability in data sets and reflects the reality of securing information from large databases, which is subject to change over time periods. Hence, fluctuations in program and provider numbers certainly may alter the profiles created in this analysis, which should be considered when this report is used. A third assumption is to treat each entity known to care for CSHCN as a single unit. For example, a private practice pediatric dentist was considered a unit of capacity, equal to a clinic or dental school. It was determined early on that true capacity would be almost impossible to determine. For example, even among pediatric dental practices, the number of special needs children treated or potentially treated varies greatly based on a host of factors, and no data source was found that would allow precise allocation of capacity for most sources of CSHCN care. The capacity convention used for most care providers in this analysis is liberal and, in all likelihood, the capacity is far less than hypothesized.

A fourth assumption was to use the accepted CSHCN definition and, thus, the number of CSHCN from a large US database rather than create an artificial subclassification that may or may not fit into the categorization of capacity used by schools or other databases. That number was 10,221,436.² Use of a national, widely accepted definition would allow broader application of this analysis in policy matters.

Data were stratified into the 6 AAPD districts as a way to portray data and findings, because manual allocation of pediatric dentists to another schema would have taken far more time. The availability of CSHCN, dental schools, pediatric dentistry residency training programs (hospital and university-based), advanced general dentistry training, and children's hospitals by state from most databases we used made the district allocation seem the most time-economic and useful for this report. The last assumption, which might seem like a gross deficiency at first, was the decision to exclude the community of general dentists from our analysis, since they, as a group, do not see measurable numbers of CSHCN. Confidence was felt in that decision because of the weight of existing literature and the failure of predoctoral education to mandate training in the care of CSHCN.

Data components and sources. The number of CSHCN was obtained from The National Survey of Children with Special Health Care Needs (2006) and listed by state. At the time of this analysis, there were 57 dental schools, 176 general practice residency (GPR) programs, 69 pediatric dental residency programs, and 61 advanced education in general dentistry (AEGD) programs in the United States.

This information was gleaned from the ADA and ADEA websites^{12,13} and was considered current as of November 2009. The number of children's hospital dental clinics, their annual patient visits, and general anesthesia capacity were obtained from a survey by Ciesla et al.¹¹ of NACHRI-affiliated children's hospitals. The number of pediatric dentists was obtained from the AAPD's 2009 CEO report and was considered current as of March 2009. The distribution of states in the AAPD districts was available from that organization and remains current.

Statistical analysis and data manipulation. The available data were aggregated or subdivided as needed using simple arithmetic calculations. In the results to follow, the actual arithmetic functions are described related to each table or figure. Existing data from the previous surveys were crosstabulated with data obtained from online databases. This data were analyzed using SPSS 13 software (SPSS Inc, Chicago, Ill). Descriptive statistics and frequency analyses were performed. The chi-square test and cross-tabulations were used for correlations, and a significance level was set a priori P<.05.

Results

National distribution of available resources. The care resources deemed suitable for caring for CSHCN were plotted

on to the AAPD districts and are depicted in Figures 1 through 4. These include: dental schools and AEGD and GPR programs (Figure 1); children's hospital clinics and residencies (Figure 2); and active pediatric dentists (Figure 3). In Figure 4, we combine all available care resources, as described in the methods, and place them in aggregate in the United States. As might be expected, in Figure 4 resources are concentrated in populated and metropolitan areas, with several tiers of resources; in other words, children's hospitals, dental schools, and advanced general dental training programs often present in a single locale. Of note is the paucity of complete resources in the north central plains states and several far western states.

Children's hospitals are more likely to be found in the South or Midwest (AAPD districts III and IV) than other locations. The greatest number of children's hospitals is found in district III (48 hospitals) and district IV (49 hospitals). As a state, Texas has the most children's hospitals (17) and accounts for approximately 8% of NACHRI children's hospitals. California and Florida have 15 hospitals each, New York has 13 hospitals, and Ohio has 12. District I had 3 states without a hospital-based dental clinic; districts II, III, and V had 1 state without a dental clinic; district IV had 3 states devoid of hospital-based dental facilities; and district VI had 6 states lacking a comprehensive care hospital-based clinic. Even though district VI is under-represented regionally, California has many hospital-based dental clinics; therefore, the overall capacity of district VI is in line with the capacity of other districts.

Capacity calculations

Children's hospital dental clinics. The report by Ciesla et al.¹¹ gives in detail the nature and characteristics of dental programs affiliated with the nation's children's hospitals; we used some of that data to calculate capacity in our analysis. That survey asked dental managers to provide total annual operating room cases and dental clinic appointments for the last complete year in their institutions, and these were aggregated to give a district total. The appointments and visits represent the absolute maximum number of care opportunities that could be available for CSHCN patients. Table 1 depicts the availability of routine and operating room appointments in dental clinics in children's hospitals in the United States.

Most hospital-based dental clinics reported that fewer than 50% of their patients are CSHCN,¹¹ but the number of care opportunities is still extremely low. Seven states combine to have 49% (43/87) of the total number of hospital-based dental clinics. Although the distribution of hospital-based dental clinics did not vary significantly (P>.20) by AAPD district, district VI, encompassing California and Washington, has the greatest unmet need. The typical children's hospital dental clinic had a very limited capacity for either routine dental appointments or



Figure 1. Number of dental schools, advanced education in general dentistry and general practice residency programs by American Academy of Pediatric Dentistry districts.



Figure 2. Number and distribution of children's hospitals, hospital-based dental clinics, and pediatric dental residencies by American Academy of Pediatric Dentistry districts.



Figure 3. Number and distribution of active pediatric dentists by American Academy of Pediatric Dentistry districts.



Figure 4. Distribution of resources by AAPD district. Representation of children's hospitals with a dental clinic (blue dot), pediatric dental residency program (orange dot), and dental school (green dot). The red dots represent children's hospitals without dental services.

operating room appointments for the CSHCN attributed to their site—not even having 1 appointment per CSHCN available.

All sources

Table 2 combines all sources of dental care capacity to provide a national perspective on the opportunity for care for CSHCN. The first column simply lists the children's hospitals, but is not used in the calculation. As stated in the methods, each column represents "units" considered for the purposes of this report, the same in terms of capacity. The columns for each district are added across to find the provider unit totals, which are then divided into the total CSHCN for that district, yielding a ratio of CSHCN per provider. Readers should remember that each of these providers serve predominantly healthy children, so the availability of appointments for CSHCN is very likely well below the quotient identified in the right-hand column.

Discussion

This analysis was a first attempt to gauge the capacity of the dental health care system to care for CSHCN and was prompted because of consistent reporting by dentists that they do not treat these children and by parents of CSHCN who report dental care as the most common unmet need for their children. The results of this analysis, if reasonably accurate, confirm the lack of capacity to care for these children. The numbers of CSHCN were based on the CSHCN.org definition/criteria of inclusion; however many more special needs children exist. This year alone, 1,353 pediatric solid organ transplants have been performed.¹⁶

Each year, approximately 12,400 children younger than 20 years old are diagnosed with cancer.¹⁸ Most would agree that these patients are more medically complex and need routine dental care. More disconcerting is that, if the number of CSHCN is multiplied by 2 to account for an exam appointment every 6 months, over 20 million appointments are needed for these children. If restorative care is needed, the capacity shrinks even further. This analysis raises the question whether the system can even handle the care required. It is estimated that there are approximately 144,000 US active general dentists.¹⁹

According to a recent study, only approximately 30% of general dentists report seeing CSHCN often or very often, which would, optimistically, make about 14,400 general dentists actively treating these patients. If added to the various care units listed in Table 2, this would still result in a distribution of approximately 500 CSHCN per unit-provider. This number would constitute an extremely large part of a general practice and not even include adults with special needs. Further, according to the ADA Membership survey,²⁰ the average total number of dentist and dental hygienist visits available per year is approximately 3,832. Assuming excellent oral health among these children necessitating only 2 visits per year, or roughly 1000 visits, the general dental practice is left with only about 1,800 visits.

Unfortunately, it cannot be assumed that private practicing general dentists are willing or trained to see medically complex patients. These patients are usually more difficult to treat from a behavioral and medical standpoint and take more time and resources to treat safely. General dentists may not be credentialed for hospital care and be limited to those CSHCN they can see safely in a private office.

The ADA membership survey also indicated that the average number of combined restorative and hygiene appointments per practicing pediatric dentist was 6,206. If that number is multiplied by the number of practicing pediatric dentists (5,122), there would be a total of 31,787,132 appointments available for CSHCN if the practitioners are

Table 1.OVERVIEW OF THE APPOINTMENT AVAILABILITY FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS (CSHCN) AT U.S. CHILDREN'S HOSPITALS BY AMERICAN ACADEMY OF PEDIATRIC DENTISTRY DISTRICTS*							
District	Total OR cases	Total appointment	Total CSCHN	OR/ Patient	Appt/ Patient		
Ι	3,044	57,800	1,104,390	>.003	.05		
II	2,224	100,623	985,341	>.002	.10		
III	2,246	59,365	2,446,183	<.001	.02		
IV	6,675	171,076	2,123,980	>.003	.08		
V	3,328	48,862	1,769,707	<.002	.03		
VI	1,295	7,398	1,791,835	<.001	.004		
Total	18,812	445,124	10,221436	<.002	.04		

* Data for CSHCN gathered from National Survey of Children with Special Health Care Needs 2005/2006; data includes all CSHCN patients with all diagnoses—not just tertiary care patients.

District	No. of children's hospitals	No. of hospital-based clinics	No. of dental schools	No. of pedodontic residencies	No. of pediatric dentists	No. of CSHCH	No. of CSHCN/per care source*
I	28	15	8	21	760	1,104,390	1,373
II	27	14	6	9	577	985,341	1,626
III	48	14	13	12	1,126	2,446,183	2,100
IV	49	16	13	12	811	2,123,980	2,493
V	36	15	7	6	824	1,769,707	2,077
VI	32	13	10	9	1,193	1,791,835	1,463
Total	220	87	57	69	5,291	10,221,436	1,857

* Computed as the sum of the hospital clinics + dental schools + residencies + practicing pediatric dentists divided by the number of CSHCN.

willing to utilize all appointments for CSHCN. This isn't feasible. Using conservative estimates, if pediatric dentists allotted 10% of their total appointments for CSHCN patients, it would afford only 31% of the CSHCN population access to 1 dental appointment.

Of equally serious concern is the fact that, among our potential care providers, many are in some training capacity, either in dental schools or advanced postdoctoral training. Ciesla et al.¹¹ found that pediatric dentistry residents provide approximately 60% of the staffing within children's hospital-based clinics and the greater the population of CSHCN patients, the greater the staffing by pediatric dentistry residents (P>.02). This analysis points out the precarious nature of caring for CSHCN, particularly those with serious illnesses, who are dependent on the resident workforce in this country.

A little more than 35% of responding children's hospitals indicated that private practitioners from the community provide emergency services and consultations to the hospitals in the absence of a dental service. While parents of CSHCN may admittedly prefer to have their children treated at a hospital-based dental clinic, one has to worry where these patients will get care if this clinic or residency program closes. Corroborating the paucity of resources, these same respondents indicated that patients may be referred to private practice, a dental school, or another hospital.

It seems obvious that an immediate source of relief to this over-burdened system would be the training and graduation of more pediatric dentists, especially in areas that are the most underserved. Currently, there are approximately 870 postdoctoral pediatric dentistry residency training positions. Estimates suggest that the number of active pediatric dentists would need to be tripled to begin to approximate the CSHCN demand. Even if the number of residency positions were increased to 1,000, it could take close to 10 years for pediatric dentists alone to meet the dental needs of this patient group. Both the ADA and AAPD have demonstrated their commitment to improving access to care by increasing the number of dental schools and pediatric residency training programs. In fact, since the data was originally collected for this study, 9 new pediatric residency programs and 4 new GPR programs have been created and 1 new dental school has opened.

Recently, many states have pursued increased credentialing/expanded duties for midlevel providers in underserved areas. While CSHCN are underserved, the policy implications of the system's limited capacity should be evident. It is unlikely that flooding the system with mid-level providers would ameliorate the problem, as most of these envisioned providers will have little training in the medical issues affecting these children and few, if any, would be able to practice in settings where these children receive medical care, according to existing statutes and privileging. If mid-level providers were trained and effective at treating healthy children, then perhaps this would free needed appointments for CSHCN.

Casamassimo²¹ has proposed a tiered system of care for CSHCN, beginning with the general dentist and then moving to pediatric dentists or regional treatment centers. Clearly, from our analysis, the pediatric dentistry workforce would be quickly overwhelmed, even if these providers were willing to see these patients. Tertiary care centers such as children's hospitals would be called upon to treat far more CSHCN than is proposed in this analysis' equal distribution. Any plan for health care reform would need to infuse the system with capacity if CSHCN are to have access equivalent to other children.

Another issue affecting access to dental care for CSHCN patients in this analysis is proximity to a dentist, dental clinic, or hospital. For those patients living in states without a dental school or comprehensive care dental clinic at the hospital, the average travel time to get dental care may exceed 4 hours. If a CSHCN patient lived in Bismarck, North Dakota, and went to Minneapolis for care, the distance is 427 miles—or more than 6 hours in a car. It isn't reasonable to expect families with CSHCN to be located close to all needed resources. States lacking in services still have large numbers of CSHCN, and while the national average is approximately 14% for CSHCN, it is approximately 14% (27,853 children) in Montana, 11% (43,306 children) in Idaho, and 12% (16,541 children) in North Dakota.

As a preliminary view of capacity, this analysis has several limitations, not the least of which is a lack of detail on individual unit capacity to see these patients. For example, a pediatric dentistry residency program may be housed at a children's hospital solely or may be housed at multiple sites. Furthermore, we were unable to attribute detail on the nature of special needs, which clearly would impact the ability of certain providers, such as dental schools, to care for these patients in a predoctoral clinic. The role of finances could not be assessed either, with many CSHCN having payment problems due to other competing costs. Finally, as aforementioned, we have no real measure of the contribution that the general dental community makes to capacity to care for CSHCN. In one study, dentists who accepted Medicaid practiced in rural areas, were older, and were more likely to see CSHCN,5 but the extent of this capacity component could not be determined. Other than estimates of general dentists¹⁹ and pediatric dentists in a regional distribution,²² no studies we could locate addressed capacity for CSHCN. This analysis is the first known attempt to determine the availability of care for CSHCN from the standpoint of sheer numbers of children per capable providers.

Conclusions

Based on this analysis, using a subset of dental providers who were deemed capable of caring for children with special health care needs (CSHCN), the following conclusions can be made:

- 1. The average patient load per provider is approximately 2,000 CSHCN.
- 2. Children's hospitals cannot provide even 1 dental appointment or operating room visit per CSHCN.
- 3. The distribution of treatment capacity resources varies from district to district, with the fewest resources in the western United States.

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