

**Pediatric Oral Health Interfaces Background Paper:**  
**Children With Special Health Care Needs; Patient,  
Professional and Systems Issues**

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## Summary

Children with special health care needs (CSHCN) are defined as those who have disabilities that affect daily life activities and influence the delivery of health care, including dental care. CSHCN challenge dentists with physical, medical, social, and communication limitations that require the modification of customary dental practice.

The dental education and care system has had mixed results in caring for CSHCN, and currently, parents of children with special health care needs identify access to dental care as a significant problem. This may be largely due to the fact that dentists are unwilling to care for children whom they have been inadequately prepared to manage.

In addition to a lack of well-trained providers, the health care delivery system for CSHCN has a complicated and inadequate financing mechanism, poorly integrated services, and a lack of quality standards. Goals to improve the dental health care system to address these issues may include:

- Making it easier for consumers to negotiate within the system;
- Making care comprehensive in nature;
- Ensuring family satisfaction with quality;
- Ensuring that the system is sufficiently funded; and
- Providing pediatric care that is easily transitional to adult oral health care.

An ideal oral health care system for families of CSHCN is one that is accessible, affordable, and staffed by educated and prepared providers and staff. These professionals would safely deliver individualized, compassionate, quality care that includes education, prevention, and treatment. This ideal care system would be well integrated with the overall care system in which CSHCN participate. In addition to these broad goals, short-term steps can be taken to push oral health into the vision of health for CSHCN and maximize available health resources.

## Introduction

Children with special health care needs (CSHCN) is the current descriptor used to characterize children who have--or are at increased risk for--a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.<sup>1</sup> The term CSHCN replaces a family tree of terminologies including *handicapped*, *special*, *exceptional*, *disabled*, and *special needs*. Today's terminology represents, in part, an evolution of our understanding of a chronic impairment affecting one or more aspects of daily living, the unique needs of the families of such children, and their need for and use of health care, educational, and other supportive services. Further, the term implies recognition of the limitations of a medical model that attempts to characterize CSHCN according to singular or multiple diagnoses.

Since the early 1960s, when the Kennedy administration focused on handicapping conditions and initiated several federal education, treatment, and preventive programs related to persons with handicaps, policies and practices concerning persons with disabilities have been in flux. Considerable attention has been devoted to this population again in recent years, beginning with the passage of the *Education for All Handicapped Children Act* (Public Law 94-142), the

*Americans with Disabilities Act*, and culminating recently in a 10-year action plan to organize, finance and deliver services to CSHCN by the year 2010.<sup>2</sup>

Dentistry's participation in care of the special-needs population has been spotty at best, with early involvement in programs such as:

1. The Maternal and Child Health University Affiliated Programs which intended to "train the trainers" and develop an ever-growing number of trained dentists who could, in turn, train more dentists, and in particular, pediatric dentists;
2. Genetic prevention and intervention programs that addressed oral and facial aspects of common genetic conditions; and
3. The Robert Wood Johnson grants to dental schools for training of dental students to care for the handicapped.<sup>3</sup>

Pediatric dentistry has had a long involvement with CSHCN, including with some of the programs above, and has cultivated relationships with advocacy groups such as United Cerebral Palsy (UCP). Pediatric dentists have served on multi-disciplinary teams devoted to both developmental disabilities and chronic illnesses such as leukemia and cystic fibrosis.

This paper describes the current state of dental care for CSHCN in the U.S. and provides a background on the evolution of the system available to CSHCN families. It also presents a scorecard for how the current system addresses the six goals of the Healthy People 2010 plan,<sup>2</sup> and addresses major issues and obstacles looming against improvement of the system. Finally, an idealized system of oral health care for CSHCN is presented from the viewpoint of a family with a CSHCN. This includes recommendations for changes in the current system of care, financing, and professional education.

## **Care of CSHCN Yesterday and Today**

Before World War II and immediately thereafter, dental care of CSHCN blended with overall dental care of children because of the universal distribution of dental caries, the indiscriminant distribution of infectious, congenital, and other disorders, and the lack of a specialized dental profession. In the 1950s, dentists interested in special-needs patients formed the Academy of Dentistry for the Handicapped, now the Academy of Dentistry for Persons with Disabilities. In addition the specialty of pediatric dentistry was created in the late 1940's and embraced the care of all children. The 1960s brought further attention to the needs of the handicapped, and pediatric dentistry took on an increasingly active role in providing services along with other medical and rehabilitative disciplines attendant to special-needs patients.

The recognition of the adult handicapped patient's dental needs prompted the Robert Wood Johnson Foundation to fund dental school education programs that focused on the care of handicapped patients in the early 1970s. The program was marginally successful,<sup>4</sup> showing only minor increases in dental school graduates' acceptance of the disabled in their practices. Participating dental schools gradually dismantled programs and few non-participating schools were inspired to begin educational-care programs. Accreditation standards for predoctoral dental training programs required exposure to the disabled patient in the 1980s, but these standards have since been weakened to an option for students to take such courses as an elective,<sup>5</sup> and exposure of dental students to clinical care of the disabled remains limited.<sup>6</sup>

It is therefore not surprising that only a small percentage of the general dental workforce makes CSHCN a portion of their practice.<sup>7</sup> Pediatric dentistry became the default caretaker of dental care for the all special-needs patients (children and adults alike) largely because it addressed the demands of SHCN patients transparently. Pediatric dentists' skills were useful in managing lingering residual problems such as poor communication and uncontrolled movement even as these patients aged.

Pediatric dentists continue to perform a disproportionately high amount of care for CSHCN, by virtue of their training in disabilities,<sup>8</sup> exposure to these patients in residency, and their tendency to care for the Medicaid population in larger numbers than general dentists.<sup>9</sup> Unfortunately, as a workforce totaling only about 5000, the capacity for providing oral health services to CSHCN is woefully inadequate today. The mainstreaming or de-institutionalization process that occurred in the late 1970s and 1980s in the U.S. (which placed older handicapped patients as well as some teenagers back into community settings) created a rush for dental services, and much of this demand was met by pediatric dentists alone.

No figure on a pediatric dentist-to-CSHCN population ratio is currently available. This may be due to a host of unclear factors on both sides of such an equation, including—on the patient side—the ever-debated definition of special health care needs and varied reimbursement mechanisms—and on the provider side—the diverse types of disabilities served by the dentist, the availability of primary care (versus hospital care), the number of patients seen per provider, and volunteerism. A simple calculation, using patient estimates of Newacheck et al.<sup>1</sup> would consider about 5,000 U.S. pediatric dentists and 1.2 million CSHCN nationwide for a pediatric dentist-to-CSHCN ratio of about 1:250. But the accuracy of this number is also complicated by the fact that like other areas of disability care, pediatric dentistry suffers from a “lag in transition” (i.e., families tend to stay with a pediatric provider who is willing to care for their disabled child for as long as possible due to the difficulty finding adult care or adult care that is sensitive and capable). Given this fact, a ratio of 1:250 may be relatively low--and thus optimistic--considering that about 54 million adults have disabilities.<sup>10</sup>

## **General Dentists Are Unwilling to See CSHCN**

The unwillingness of dentists to see the special-needs population stems from lack of training and thus comfort in their care.<sup>10</sup> This finding has been consistent in numerous studies over the last 3 decades<sup>11-13</sup> and confirms the ineffectiveness of predoctoral dental education in developing a body of dentists who are willing and able to care for CSHCN. These findings were reaffirmed recently in a large-scale study of ADA-member dentists, which found general dentists do not treat special-needs patients, and those who do have been exposed to hands-on training. With the dearth of experience in dental school, and with only about 20 percent of dental graduates seeking general practice residencies where such training is available, lack of care is not surprising.

The choice to train more general dentists to care for the disabled versus training more pediatric dentists is not a simple one. Many of the obstacles are the same for both specialties—lack of faculty, institutional barriers, and competing educational needs. Paradoxically, training more pediatric dentists would create an environment that would foster improved training of dental students by increasing faculty, establishing liaisons with CSHCN clinics and treatment teams, and equipping dental school physical plants to care for these types of patients. The same opportunities would be created in affiliated training centers.

An additional option to train more general dentists to care for CSHCN is to mandate a postgraduate year for all dental graduates as a requisite for licensure. This idea has met mixed reaction from the educational community, which, without federal or state help, would be hard-pressed to create adequate sites for such training to accommodate the thousands of dental graduates produced each year.

## Patient Problems and Challenges

In addition to an unprepared and unwilling workforce, patient and system obstacles present significant challenges to CSHCN’s access to oral health care. These include patient characteristics often defining CSHCN or aspects of the health care delivery system designed for normal patients that confound efficient and effective care of CSHCN. Twenty years ago, Entwistle and Casamassimo<sup>14</sup> speculated that, in addition to professional readiness issues, dental care of CSHCN is stymied because patients with disabilities can present challenges (which they termed problems or risk factors) to dental providers who are largely solo practitioners in a cottage industry setting. **Table 1** lists these problems and provides examples of each as they relate to community dental practice.

**Table 1. Problems Presented by Patients with Special Health Care Needs**

Problem Area	Examples Manifesting Problem Area
Accessibility	<ul style="list-style-type: none"> <li>▪ Offices not physically accessible according to Americans With Disabilities Act</li> <li>▪ Offices not on public transportation routes</li> <li>▪ Office procedures not accommodating to special needs scheduling issues</li> </ul>
Financial	<ul style="list-style-type: none"> <li>▪ Office does not accept Medicaid</li> <li>▪ Office not familiar with alternative funding sources</li> <li>▪ Patient receives public assistance</li> <li>▪ Poor vocational training, lack of employment or underemployment</li> <li>▪ Inadequate health coverage</li> </ul>
Psychosocial	<ul style="list-style-type: none"> <li>▪ Competing health issues</li> <li>▪ Fear of health care</li> <li>▪ Intellectual deficits</li> <li>▪ Social deprivation</li> <li>▪ Low priority for oral health</li> </ul>
Mobility and Stability	<ul style="list-style-type: none"> <li>▪ Uncontrolled movement</li> <li>▪ Muscle weakness</li> <li>▪ Short attention span</li> <li>▪ Hyper kinesis</li> </ul>
Communication	<ul style="list-style-type: none"> <li>▪ Lack of speech</li> </ul>

	<ul style="list-style-type: none"> <li>▪ Sensory impairment</li> <li>▪ Intellectual impairment</li> </ul>
Medical	<ul style="list-style-type: none"> <li>▪ Medications</li> <li>▪ Allergies (latex)</li> <li>▪ Congenital deformities</li> </ul>
Preventive Preventive (cont.)	<ul style="list-style-type: none"> <li>▪ Special high sucrose diets</li> <li>▪ Poor motor function</li> <li>▪ Oral motor dysfunction</li> <li>▪ Saliva-altering medications</li> <li>▪ Competing life activities</li> </ul>
Treatment Planning	<ul style="list-style-type: none"> <li>▪ Compromised life activity</li> <li>▪ Limited life span</li> <li>▪ Oral/systemic relationships (cleft palate)</li> </ul>

These challenges serve as obstacles to care for patients because most dental practices are not equipped to manage them within the mainstream of care.<sup>3, 15, 16</sup> Ironically, mainstream dental patients often present constellations of these same problems in proportions beyond that of the minimally involved special needs patient, and dental practices seem to be able to compensate. It is unclear then the extent to which bias, stigma, and professional timidity also contribute to the impact these problems have for CSHCN in dental practice and why, even in the absence of treatment-altering problems, practices will decline to care for SHCN patients. Recent data<sup>7</sup> suggest that patients' behavior and level of disability may be major factors, but it is unclear whether this refers to chair-side or waiting room aspects of each.

## Health System Issues

System obstacles are less clearly defined in the dental literature. Stiefel<sup>10</sup> suggests that (1) the lack of an integrated service delivery system, (2) the need for regional and academic treatment centers, (3) the need for interdisciplinary training, (4) the need for integration of systemic and oral health, and (5) the ignorance of non-dental caregivers are some of the system issues affecting the delivery of care to special needs patients of all ages. Other reports support the need to better educate caregivers,<sup>17</sup> address the lifestyle factors affecting care,<sup>18</sup> and establish the inter-relationship between systemic and oral health in CSHCN.<sup>19</sup>

Stein<sup>20</sup> presents an excellent portrayal of system and patient issues important for the long-term care of CSHCN, which can also be adapted to a discussion of the oral health care delivery system as depicted in **Table 2**. The isolated nature of dental practice removes oral health care somewhat from general health system considerations. Individual dentist preference and patient characteristics still largely determine whether CSHCN are treated. However, in attempts to move the estimated 12 million or 18 percent of U.S. CSHCN<sup>21</sup> into oral health care, health system issues will need to be addressed.

**Table 2: Systems Issues Impacting on Oral Health Care for Children With Special Health Care Needs**

Systems Issues	Examples Manifesting in The Oral Health Care Delivery System
Technology Dependence	<ul style="list-style-type: none"> <li>▪ Confinement to bed or wheelchair</li> <li>▪ Respirator dependency</li> <li>▪ Gastrostomy feeding prompting more frequent care visits</li> </ul>
Caregiver Dependence	<ul style="list-style-type: none"> <li>▪ Blurring of roles in oral health affecting care delivery and home health activity</li> <li>▪ Lack of clarity related to payment, consent, and other issues related to care delivery</li> </ul>
Lack of Definitions Related to Oral Health	<ul style="list-style-type: none"> <li>▪ Reimbursement and medical necessity denials related to care that insures normal development, facilitates habilitation or is rehabilitative in nature</li> <li>▪ Fluctuating and inconsistent locus of responsibility for care related to oral health issues such as oral surgery, dietary modification and physical therapies</li> </ul>
Lack of Appropriate Services	<ul style="list-style-type: none"> <li>▪ Unskilled oral health interventions (e.g., care coordination by non-dentist)</li> <li>▪ Lack of approval for rare but necessary services related to oral health (e.g., general anesthesia coverage for restorative care)</li> <li>▪ Approval for inappropriate services (e.g., payment for lingual frenectomies)</li> </ul>
Financing Care	<ul style="list-style-type: none"> <li>▪ Limited coverage for some special needs</li> <li>▪ Low reimbursement for dental procedures by public programs</li> </ul>
Care Delivery Models	<ul style="list-style-type: none"> <li>▪ Poor institutional dental services</li> <li>▪ Inadequate coordination of oral health with other care needs</li> <li>▪ Lack of oral health expertise</li> <li>▪ Inadequate transition to adult oral health care</li> </ul>
Quality Issues	<ul style="list-style-type: none"> <li>▪ Inadequate quality assurance standards and measures</li> </ul>

The *Technology dependence* of CSHCN creates significant challenges to standard dental practice. Some of these challenges may include

- A professional learning curve to deal with ramifications of devices and aids such as in-dwelling catheters and gastrostomy feeding tubes;<sup>22</sup>
- Accessibility compromise due to physical confinement and permanently attached devices (e.g., respirators on wheelchairs connected to tracheostomies); and
- Unknown medical risks due to devices and the medications attendant to their use, as well as medical/surgical advances that place children at increased risk (e.g., organ transplants.)<sup>23</sup>

Management of these issues is hampered by lack of research and an absence of accepted clinical care guidelines. Caregivers of CSHCN often naively assume that dental providers are apprised of these technologic advances and know how to deal with them appropriately.

*Caregiver dependence* of CSHCN may also create dental practice challenges related to compliance, behavior, home care, and competing (and often far more challenging) health issues such as feeding, care of surgical and prosthetic sites, and monitoring. The typical dental professional makes assumptions regarding a healthy child's independence, developmental pathways, and ability to assume personal responsibility. Many dental professionals are unaware of the dependency of CSHCN and thus do not provide useful information to caregivers who are, for the most part, parents with extreme lifestyle burdens as a result of their special needs child. Further, the dental provider often assumes a normal path of development and skill acquisition in children and thus suggests roles for CSHCN that are still assumed by caregivers and complicated by disability. This leads to frustration for both provider and caregiver and alters the effectiveness of interventions. Dependency issues extend into payment responsibility and, during a child's late teenage years, into consent. Again, these issues are not clear-cut in most cases and useful guidelines are unavailable.

Dentistry continues to have problems with the health system's ever-changing and often unclear definition of *medically necessary care*.<sup>24</sup> For CSHCN this is even more cloudy an issue despite attempts by organized dentistry to include both adjunctive medical care to assist in delivery of dental care (e.g., general anesthesia for severely disabled children) and habilitative or rehabilitative treatment necessitated by a condition (e.g., fluoride trays for home-applied fluoride in cases of head and neck irradiation for childhood cancer ) within the definition.<sup>25</sup> In spite of the Surgeon General's report<sup>26</sup> and admonitions by the Institute of Medicine,<sup>27</sup> oral-systemic relationships continue to be poorly defined and as a result, reimbursement for services, ownership of care, and interdisciplinary cooperation all suffer.

The *general lack of expertise of the dental profession* is still another system issue that affects the care of CSHCN. A body of literature to support care of these children is still lacking and many techniques are mired in approaches that date back 50 years--many based on clinical opinion and most untested for safety and efficacy.<sup>28</sup> For example, use of restraint with CSHCN continues to be a mainstay of care, yet the dental literature relates to immediate safety considerations, not efficacy or long-term effects.<sup>29</sup> Should patient challenges and professional bias be eradicated tomorrow, it is unlikely that the dental workforce could respond without additional training and global system-wide modification. Commentary in both the dental and medical literature<sup>20, 30</sup> suggests that the current structure and capability of American health care and the philosophical goals of the "medical<sup>31</sup> and dental<sup>32</sup> home" may not be realistic for CSHCN.

Perhaps the most overwhelming and daunting health system issue is *financing of oral health care*. This topic is covered extensively in a separate *Interfaces* paper on delivery and financing systems, but several special considerations relate specifically to CSHCN. Rather than

suffering from a shortage of sources, payment for oral health care (and in some cases, adjunctive medically necessary care) can be characterized by a variety or “patchwork” of sources--all different in nature with eligibility determined by economic need, type of disability, or some other method. Commercial insurance varies in its applicability to CSHCN because of pre-existing conditions clauses, coverage limits, and limitations in code or procedure descriptors for “orphan” procedures not commonly done in dentistry for the general public. About 89 percent of CSHCN have some source of payment for health care, as determined by the National Health Interview Survey on Disability.<sup>21</sup> The percentage of families without insurance cite expense of coverage as the main reason for not having it.<sup>1</sup> The following facts are relevant to this discussion:

1. Those CSHCN who have private insurance --- which is the majority ---tend to be under-insured.
2. The myriad funding sources confound and tend to discourage dental providers who are not accustomed to managing them.
3. Medicaid and SCHIP-funded CSHCN often face the same discrimination in access as healthy income-eligible children due to low reimbursement of providers. CSHCN are often doubly discriminated against, however, because of their disability.
4. Even privately insured families may be faced with massive competing health care costs (e.g., surgery, frequent hospitalization, and physical therapy) that preclude them from being able to attain equitable treatment by the private practice community and make compliance with dental care difficult.

The availability of *limited care delivery models* presents still another health system problem for care of CSHCN. This issue has only surfaced since persons with disabilities have been incorporated into the mainstream of care with no significant dental care system modification to accommodate large numbers of patients entering community-living environments.<sup>30</sup> As stated previously, the overwhelming capacity of the dental system is in private general dentistry practices, and penetration of CSHCN into this sector remains low. Two conceptual approaches to improving CSHCN access to general dentists each suggest promise, though both are only theoretical at this stage. The first is a multidisciplinary model of care<sup>33</sup> made up of dental and other health professionals sharing care in an organized and efficient manner. This model has been effective in academic health centers focused on specific problems of certain disabilities (e.g., cleft lip and palate). Broader application of this concept to multiple disabilities, however, has not yet occurred. The second conceptual approach is what Stiefel<sup>10</sup> describes as an integrated care delivery model with private offices, schools, regional centers, and academic health centers all coordinated in the care of CSHCN. Such a system is already in place to some degree but is not efficient and has disproportional allocation of care. The linkages between elements of the integrated model are tenuous and responsibilities are not clearly defined.

The current system is best described as a loose construct of independent care models. Examples of what this care may provide in an academic health or regional centers for the disabled include:

1. Familiarity and dedication to this population;
2. Constellations of services which hold promise for truly integrated care;
3. The opportunity to develop efficiencies and cost-sharing;
4. Expertise, and
5. The ability to assist in transition to adult care for older CSHCN.

Such centers are few in number, however and their small capacity and geographic isolation limit their effectiveness within a national system; and while the private-practice dental care system has

tremendous capacity to be a “locus of care” within in a community-based CSHCN system, it remains resistant

Finally, *quality of care and its measurement* remain major health system challenges as they relate specifically to the care of CSHCN. Philosophically, normalized care means application of general quality measures to CSHCN, but even the medical community has expressed concern that disease-based categorizations do not adequately address quality of care issues for all patients.<sup>34</sup> As an example, guidelines do not exist addressing specific oral health care issues for CSHCN and research into questions of care delivery is minimal. To some degree, the nature of dental practice as a large and poorly interconnected group of solo practices precludes development of quality measures. So little research is being done in institutional settings on dentistry for CSHCN that it is unlikely for advances to occur in this area.

### The Ideal Care System --- and the Obstacles to Attaining It Today

The national blueprint for organizing, financing and delivery of health services for CSHCN has been established by the Maternal and Child Health Bureau’s (MCHB) goals for the year 2010.<sup>35</sup> This blueprint includes six core goals and steps to achieve them that are relevant to oral health care. This section of the paper addresses these six core goals, problems related to their achievement, and policy changes required to meet these goals as they relate to oral health. **Table 3** provides a summary of the goals, problems, and policy issues.

**Table 3. Core Goals, Problems in Achieving Them, and Policy Changes**

<b>(Adapted) Core Goal From Express/Healthy People 2010</b>	<b>Problems Existing Today Impeding Achievement</b>	<b>Policy Issues Affecting Likelihood of Achievement</b>
Families of CSHCN will partner in decision making at all levels and be satisfied with (oral health) services received	<ol style="list-style-type: none"> <li>1. Solo dental practice</li> <li>2. Inadequate quality assurance</li> <li>3. Inadequate financing methods</li> </ol>	<ol style="list-style-type: none"> <li>1. Establish quality measures for care delivery</li> <li>2. Establish parity with private insurance</li> </ol>
All CSHCN will receive coordinated, ongoing comprehensive care within a (dental) home	<ol style="list-style-type: none"> <li>1. Inadequate education of dentists</li> <li>2. Inadequate funding methods</li> </ol>	<ol style="list-style-type: none"> <li>1. Increase training of pediatric dentists</li> <li>2. Increase general practice residencies</li> <li>3. Institutionalization of dental school SHCN clinics/ curricula</li> </ol>

All families of CSHCN will have adequate private and/or public (dental insurance) to pay for the services they need	<ul style="list-style-type: none"> <li>• Complicated system of funding</li> <li>• Inadequate reimbursement for dental services</li> <li>• Lack of accepted definition of medical necessity</li> </ul>	<ul style="list-style-type: none"> <li>• Change Medicaid/SCHIP to make CSHCN competitive with the privately insured child</li> <li>• Universal coverage for CSHCN for dentistry</li> <li>• Implement a meaningful medical necessity definition within all payment mechanisms</li> </ul>
All children will be screened early and continuously for (oral problems related to) SHCN	<ul style="list-style-type: none"> <li>• Three-year dental visit policy</li> <li>• Inadequate education of non-dental providers</li> </ul>	<ul style="list-style-type: none"> <li>• Institute the age one year dental visit</li> <li>• Modify education of non-dental professionals to include oral health</li> </ul>
Community (oral health) services will be organized so that families can use them easily	<ul style="list-style-type: none"> <li>• Lack of integration</li> <li>• Inadequate dental resources in community, regional and academic health centers</li> </ul>	<ul style="list-style-type: none"> <li>• Fund development and operation of SHCN academic treatment programs for general and pediatric dentists</li> </ul>
All SHCN youths will make transitions to aspects of adult life, including adult (oral health care)	<ul style="list-style-type: none"> <li>• Inadequate work force</li> <li>• Inadequate education of general dentists in care of CSHCN</li> </ul>	<ul style="list-style-type: none"> <li>• Fund dental school-based treatment and educational programs for general dentists</li> </ul>

*Patient satisfaction and involvement with care decisions* are new concepts for a dental profession that enjoys a demand-over-supply advantage over the public. Declining numbers of dentists per capita<sup>37</sup> will no doubt continue dentistry’s position of “calling the shots.” Families of CSHCN often cannot find dentists who will care for their children and when they do, they may be more likely to take advice and treatment recommendations without question for fear of losing those services. Good data are not available on satisfaction of CSHCN families, but a recent study of Medicaid families suggests that they still find dental care a negative experience<sup>38</sup> even when access is achieved.\*

Measurement of quality care is relatively new to dentistry, and within the vast private practice system of cottage care, it is haphazard at best. Center-based care, particularly in hospitals, offers the greatest likelihood of quality and satisfaction measurement, but

\* In the course of writing this paper, the author was informed of a lawsuit against a pediatric dentist who treated CSHCN during specific hours to take advantage of staffing and low office busyness, which allowed him to devote attention to the additional needs of his CSHCN patients. He was sued under the Americans with Disabilities Act by the family of a child with special health care needs and forced by the courts to offer appointments anytime during the day for CSHCN in spite of risks and complications this might pose for the practice.<sup>39</sup>

implementation of quality and satisfaction measures in dental practice is impractical at this time. Without financial incentives for dentists to care for CSHCN, criticism (defined as how private practice consumers and other outside sources view quality improvement), however constructive, would likely serve as a deterrent to access for this population. The greatest likelihood of success would come as a result of an attractive financing system that rewarded dentists for care of CSHCN and compelled them to retain provider status in that plan. This could make them more likely to accept and take on quality improvement measures within their practices.

Secondly, clear guidelines for the care of CSHCN, which could serve as the basis for quality care measurement, do not currently exist. The argument that general pediatric guidelines apply to CSHCN is flawed since some services unique to this population are not described or coded, and some “normal” procedures need to be modified for CSHCN. Until the above reimbursement issues and treatment guidelines are established, the goal of families partnering in care decisions and patient satisfaction will be difficult to achieve.

Finally, any extension of oral health care of the CSHCN to non-dental providers creates still more issues for quality of care and consumer protection. Without the infrastructure of guidelines for care and basic oral health skill training of other health professionals, quality issues are difficult to address.

*Providing CSHCN a “dental home”* also remains a lofty goal given the reluctance of general dentists to see these children. *It is clear that the current CSHCN population cannot be accommodated by existing willing dental providers*, and it would take years to train the thousands of dentists required to meet this goal. Without an educational infrastructure and financing mechanism to entice more providers, oral health care of very young children will continue to be the default responsibility of primary care medical providers and, in fewer cases, pediatric dentists. The effectiveness of this model,<sup>40</sup> however, remains to be demonstrated and it does not address the needs of older CSHCN who have few options for a dental home at this time.

The potential roles of various providers currently serving special needs children within the CSHCN system are presented in **Table 4**. These are identified within a context of existing training and skills, readily available and realistic enhancement of training and skills, and current medical-dental relationships in the care of CSHCN. In these roles, the dentist or pediatric dentist maintains the primary care role, and there is little evidence to support the benefits or effectiveness of delegation of treatment to other health professionals at this time. Certain adjunctive services, many of which are considered vital to quality of life of CSHCN, can be assumed by auxiliary personnel. A logical set of functions could be delegated to physicians and allied therapists. The physician, for example, could oversee medications, while an occupational therapist could be responsible for oral hygiene apparatus modification.

**Table 4: Potential Roles of Providers in the CSHCN Care System**

<b>Provider Type</b>	<b>Role in Oral Health Care</b>	<b>Essential Skills and Background</b>
Dentist	Primary dental services	Pediatric Dentistry or General Dental PGY1 Hospital Year
Hygienist	Preventive services, Health Education, Health Promotion, and Case management	Dental hygiene certificate, Practicum experience in care of CSHCN; CME with

CSHCN

Dental Assistant	Adjunctive auxiliary services, Oral health instruction	Practicum or OTJ training with CSHCN; CME with CSHCN
Primary Care Physician	Primary preventive care until age 3 years	CME on oral health of CSHCN
Specialty Physician	Supportive and co-therapeutic oral health-related care	CME on oral health of CSHCN
Allied Therapist	Specialty-related oral health services (e.g., OT)	CME on oral health needs of CSHCN; Multidisciplinary experience with oral health
Parent/Caregiver	Personal oral hygiene and habilitative services for CSHCN	Instruction in care by primary dental provider; demonstrated skills in procedures

At this time the SHCN system directs oral health issues to the dentist. In a recent paper by Davidson et al,<sup>41</sup> the authors suggest that the primary care physician's role in oral health for CSHCN is limited to referral as it is even for medical sub-specialty care. Therefore, creation of a new constellation of roles may be, at best, a distant possibility.

This leads to consideration of *adequate payment mechanisms* for oral health care. Medicaid, SCHIP, SSI and private insurance cover all but 10 percent of CSHCN,<sup>1</sup> but the history of public funding in providing access to oral health services is abysmal with approximately one-fifth to one-quarter of Medicaid covered children having a dental visit in any given year.<sup>42</sup> The following modifications to current payer systems would need to be adopted in order to achieve significantly improved access for CSHCN:

1. Increased reimbursement within Medicaid and SCHIP to a level that makes CSHCN competitive with non-CSHCN in the dental marketplace (There is growing evidence that increased Medicaid fees improve access and engage more providers.<sup>43</sup>);
2. Supplemental reimbursement increments to dentists tied to severity and functional limitations of CSHCN which impact care;
3. Easy reimbursement for procedures unique to CSHCN;
4. Implementation of a realistic and useful definition of medical necessity that would permit easy reimbursement and access to such services as surgical procedures or sedation, more frequent fluoride treatments and repeated scaling of calculus; and
5. Universal single payer coverage without means testing for CSHCN who do not have private insurance.

In summary, the financing of care must be competitive and simplistic, while address the specific needs of CSHCN.

*Early screening and repeated screening for oral health problems* related to SHCN is an achievable goal, but is also complicated by workforce inadequacies. The American Academy of

Pediatrics recommends that primary care physicians assume responsibility for the oral health care of children under 3 years of age,<sup>44</sup> yet physician knowledge and skill level in oral health remains uncertain. Further, few would doubt that preventive services such as dental sealants, not typically recommended for primary teeth, would be good preventive practice for CSHCN, but primary care physicians are not able to perform this (or other) minor interventional primary and secondary oral health preventive procedures. Further, the pediatric community admits its lack of dental knowledge and CSHCN create a far more sophisticated overlay of oral health issues. This begs the question of whether the age-1 dental visit, as recommended by the American Academy of Pediatric Dentistry<sup>45</sup> should become a standard of care for CSHCN. If this were to be the case, or if a “dental home” by age-1 policy were to be widely accepted, workforce limitations would still be a major barrier to effectiveness. A simple and potentially effective solution might be to modify the AAP policy to mandate referral of CSHCN by age-1 based on special health care needs being a risk factor for oral health problems.

*Organizing oral health services* so that families can use them efficiently will be a long-term challenge for the oral health care system. Inadequate numbers of trained providers is only one facet of the problem. As stated previously and outlined in Table 1, competing health care issues present psychosocial challenges to families and caretakers of CSHCN and the reality of transportation and time needed to access all needed services is often extraordinary. Adding oral health as an isolated care element (and one that often requires return to medical or other health services as a result—e.g., in the case of assessment for general anesthesia) creates further burden on already stressed families.

Pediatric dentists present the best opportunity for a “dental home” that can coordinate oral health care of CSHCN since:

1. They are the only specialty whose definition and training specifically addresses CSHCN,<sup>8</sup>
2. They are best able to provide the range of services needed by CSHCN within a single location, and
3. Pediatric dentists, after oral and maxillofacial surgeons, compose the specialty most likely to have hospital appointments and professional relationship with pediatricians and other medical sub-specialist and allied health providers.

Recent data suggest that the pediatric dentist is the only real option for the primary oral health care for CSHCN.<sup>6,7</sup> These data deliver a twofold reasoning for why general dentists cannot currently be counted on to service CSHCN. The study found that while dental schools almost all teach general dental students about the disabled, few offer hands on experience. Further, general dentists rarely see either very young children (pre-school) or the disabled upon entry into practice.

A significant and dramatic increase in the number of pediatric dentists would be needed to create even a rudimentary system that would place CSHCN with knowledgeable providers within a network to make care more efficient. Given the unlikelihood of such a scenario, an alternative would be to create pediatric dentistry capacity at regional and academic centers on a national basis. This would require both an increase in the number of pediatric dentists being trained and a dental health infrastructure within the centers. This center-approach offers availability of related services on a one-stop basis, opportunities for cost sharing to compensate for inadequate reimbursements for certain services, integration of dental and non-dental treatments, and eventual transition to adult services.

Public Policy is needed to initiate a national program to create a pediatric dental presence at the regional and academic center level. A combined educational, care delivery, and research model would provide immediate access to care while at the same time training an expanding workforce and creating the opportunity to study care of CSHCN. This program would require massive federal commitment and a reorientation of the medical and dental educational communities.

It would also require reorientation of education of dentists and pediatric dental specialists as “super-specialists” with advanced training in medicine and broadened hospital skills. While programs like this do not currently exist, they would be far easier to implement than shifting the education of physicians to meaningful primary care dentistry, particularly for CSHCN.\*

Finally, *the goal of easy transition of CSHCN to adult care* may be unattainable due to the inadequate workforce of general dentists and the problems attendant with special health care needs. In medicine, transition of children with chronic illnesses such as cystic fibrosis, severe asthma, and spina bifida from pediatricians to internists is often fraught with problems, and these are mirrored in the transition of CSHCN from pediatric dentist to general dentist. These problems include:

1. Adult-oriented general practices that have little interest in or ability to manage parental/family issues;
2. Consent issues as CSHCN become their own guardians,
3. Acquisition of “adult” medical and dental disorders (e.g., periodontal disease becomes a major issue for the older disabled patient<sup>46</sup> whereas it is absent in the child population and overlying medical conditions such as obesity, end-stage cardiovascular disease, and diabetes in Down syndrome)<sup>47</sup>; and
4. Transition from family caregiver to institutional caregiver (e.g., nursing home or other institutional care) of which there are few.

In summary, the goals set for 2010 are lofty, and without system-wide change and massive reforms in education, care delivery patterns, and financing, they cannot be fully achieved. The remedy must be a comprehensive, well-funded, national program to address the education of professionals, increase the numbers of pediatric dentists, and create a network of center-based care that private pediatric dentists can feed into for information, referral, and special services.

## What Do Families Want and Need?

The recent Surgeon General’s Conference on Mental Retardation presented the perspective of children with mental retardation and their families. Here, patients and families were given the opportunity to state how they wish to be treated by health care professionals.<sup>48</sup> This message, derived from the wishes and interests of families and patients with SHCN can be extrapolated to all CSHCN in constructing the ideal oral health care system. **Table 5** describes the elements of a workable health care system conceived by parents and caregivers of CSHCN.

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\* A cautionary note must be made about proposals, theorizing, and policy shifts that attempt to shift a balance of clinical practice --- either to more medicine by dentists or more dentistry by physicians. Such changes not only require a massive shift in professional attitudes and educational infrastructure, but also significant change in practice patterns, reimbursement, licensure, and public attitudes. To solve access problems for CSHCN, the best approach may be to increase supply of pediatric dental providers first, enhance skills of general dentists next, and assess the outcomes.

The characteristics mirror those supported by professionally generated descriptions of the medical and dental home.<sup>31, 32</sup>

**Table 5. Desirable Characteristics of a CSHCN Family-Centered Oral Health System**

Desirable Characteristic of an Oral Health Care System for CSHCN	Examples Manifesting System Characteristic
Accessible	<ul style="list-style-type: none"> <li>• Dental care is available in a site that is physically accessible</li> <li>• Appointments are available at convenient times</li> <li>• Dental care is available at sites used for other health services</li> </ul>
Competent	<ul style="list-style-type: none"> <li>• Providers are knowledgeable about oral health needs of CSHCN</li> <li>• Providers are knowledgeable about other health needs of CSHCN</li> <li>• Providers are knowledgeable about social, educational, and lifestyle issues of CSHCN</li> </ul>
Affordable	<ul style="list-style-type: none"> <li>• Payment mechanisms afford equal access to care</li> <li>• Payment mechanisms cover direct dental and adjunctive (medically necessary) services</li> <li>• Payment mechanisms are understandable and manageable for both family and provider</li> </ul>
Safe	<ul style="list-style-type: none"> <li>• Care methods with proven efficacy and safety</li> <li>• Trained staff and office readiness for medical emergencies</li> </ul>
Individualized	<ul style="list-style-type: none"> <li>• Treatment plans individualized to account for severity, functional issues, and mixed disorders</li> </ul>

Compassionate	<ul style="list-style-type: none"> <li>• Provider treats patient with appropriate respect and dignity</li> <li>• Facilities designed to make treatment dignified and comfortable</li> <li>• Ethical, normalized care is available</li> </ul>
Quality	<ul style="list-style-type: none"> <li>• Practice utilizes accepted quality measures</li> <li>• Practice adheres to necessary and desirable accrediting and oversight systems</li> </ul>
Educational	<ul style="list-style-type: none"> <li>• Patient education and promotion is a part of practice</li> <li>• Provider and staff can provide developmentally appropriate habilitative and rehabilitative counseling related to oral health</li> </ul>
Integrated	<ul style="list-style-type: none"> <li>• Provider has relationship and referral with patient's other care sources</li> <li>• Care planning and implementation involves other care providers as needed</li> </ul>

Families want a system that is both physically and philosophically accessible. They want their dentist to be knowledgeable about their child's diagnos(es) and his or her functional and oral health problems. Families do not want to be told to achieve ends (good oral hygiene) but rather want guidance on how to identify and achieve those ends for their specific circumstances. Care must be affordable and special treatments must not be priced out of their range of access. Families want providers to offer care that optimizes the development and function of their child, contributes to mainstreaming, and is realistic within the current and future capabilities of the child.

Most parents of normal children do not give safety in the dental office a second thought, perhaps as a result of thorough infection control. However, CSHCN present postural, medical, and treatment issues that have safety implications and parents expect dentists to be able to manage them appropriately. In case of an immediate emergency or delayed morbidity, families also expect the dentist to be able to manage the problem.

Most families desperately desire a care provider who shares their own dedication to their child. In the area of behavior management, for example, parents of CSHCN have very definite opinions on how the dentist should manage their child.<sup>49</sup> These parents also want treatment to be individualized based on needs, risks, and goals that are child-specific. For example, they may choose restorative options that are not comprehensive, but address only aesthetic or functional

considerations and would expect this care to be rendered with the same quality afforded to the general public.

The family also wants to be educated about the unique needs of their child related to oral health. They want dentists who can deliver anticipatory guidance that is useful to them as parents of CSHCN. Finally, parents desire a dental provider with links to the child's other providers. Ideally, this would create coordinated care that is not duplicative or contradictory and would minimize travel, medical expense, and pain and suffering for their child.

## Conclusion and Next Steps

CSHCN present unique challenges to the oral health care system. This paper has attempted to describe the state of care today, offer goals for an improved system of care, and present an ideal model for parents of CSHCN. Today, CSHCN have poor access to oral health services and those services available are limited, of unsure quality, and isolated in a system of care that is not integrated or adequately financed. These problems parallel those of other disadvantaged who suffer oral health disparities<sup>50</sup> and prove that we have a long way to go before meeting the goals set for 2010 or creating an ideal oral health care system envisioned by parents of CSHCN.

Unfortunately there are also few opportunities for immediate or temporary 'stop-gap' measures to address some of these problems. State Medicaid budgets are under great pressure due to a stumbling economy; significant workforce increase would take years to accomplish, and even educational policy shifting is years in the making. Some short-term improvements, however, may include the following:

1. Alteration of accrediting standards of the Commission on Dental Accreditation to require *meaningful* predoctoral education in the area of care of the disabled;
2. Continuation or expansion of Title VII programs which have already increased the number of pediatric dentist training positions significantly in the last five years;
3. Amending dental practice acts to facilitate function of dental hygienists in care facilities to at least provide preventive services to CSHCN;
4. Making dental case management an allowable Medicaid expense nationally;
5. Modifying national pediatric health supervision guidelines to place CSHCN in dental offices by the time they reach one year of age; and
6. Mandating oral health as a consideration in guidelines for all CSHCN, irrespective of the nature of the disability or need.

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