The UCSF Special Needs Dentistry Summit

A Call to Action for Solving California's Lack of Oral Health Care for People With Special Health Care Needs

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There are millions of Californians who have developmental, mental or physical conditions that make it difficult, if not impossible, to obtain dental and medical treatment under routine circumstances. This population — the special health care needs (SHCN) community — lacks access to even basic oral health care because most dentists, in teaching, group or, individual practice, cannot provide the specialized services these patients require.

On Feb. 12, 2020, UCSF School of Dentistry Dean Michael Reddy convened a diverse group of professionals to address this lack of access to specialized dental care for the SHCN population. Representing a broad cross-section of the medical and oral health care community in Northern California and beyond, the Special Needs Dentistry Summit brought together a select group of individuals capable of identifying the scope and contributing factors of the problem, and to begin outlining a strategy for addressing the issue.

Participants came from myriad sectors: from higher education to government, from clinical care to public policy. All shared a common interest in finding solutions to the chronic problem of poor access to oral health care faced by patients with SHCN.

Background

When it comes to lack of access to oral health care experienced by SHCN patients, Northern California can serve as a proxy for the rest of the state and the nation. Here and elsewhere, there are too few providers who are adequately trained for and/or comfortable in accepting SHCN patients into their practices. Most providers are not financially able to invest in specialized equipment to accommodate patients with severe disabilities, or to absorb the cost of allowing additional appointment time for them. There are fewer still who are equipped or willing to provide services in long-term care or other residential facilities where many of these patients live. Providers who might otherwise be willing to see SHCN patients balk at the extra time and effort required to take a complex medical and social history, acquire necessary consents (when complex legal relationships exist with guardians or caregivers), and determine whether their practice is or is not a good match for the specific needs of each SHCN patient. Those rare practices who do provide care for the SHCN population are so overwhelmed by requests for services that there often is a 2-3 year wait to be seen for treatment.

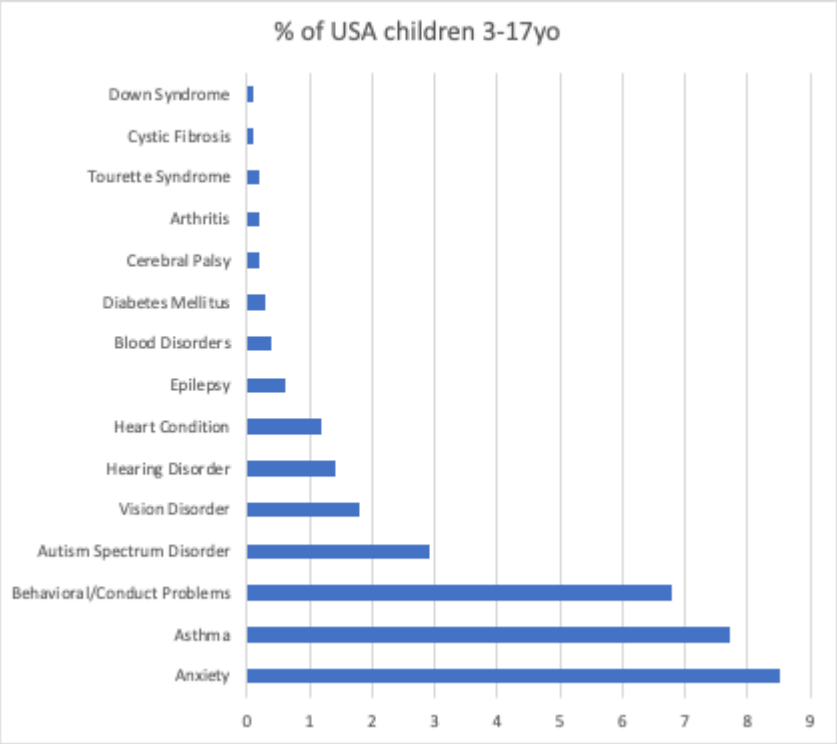
Who is a patient with a special health care need?

- American Academy of Pediatric Dentistry (AAPD): a person who has “any physical, developmental, sensory, behavioral, cognitive, or emotional impairment or limiting condition that requires medical management, health care intervention and/or use of specialized services or programs.” (AAPD Guidelines and Reference Manual. 2019; 39:20-27)
- Maternal Child Health Bureau (MCHB): children with special health care needs “who have or are at 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." (Pediatrics, 1998: 102:137-140)

These definitions — which extend to adults as well — include a wide range of developmental or acquired disabilities with varying degrees of severity. A single individual may manifest one or several of the following health-related issues. The majority (78.4%) of children and youth with special health care needs (CYSHCN) manifest at least one or more conditions described in Table1. (childhealthdata.org 2017-18)

TABLE 1: Top 15 Special Health Conditions in Children



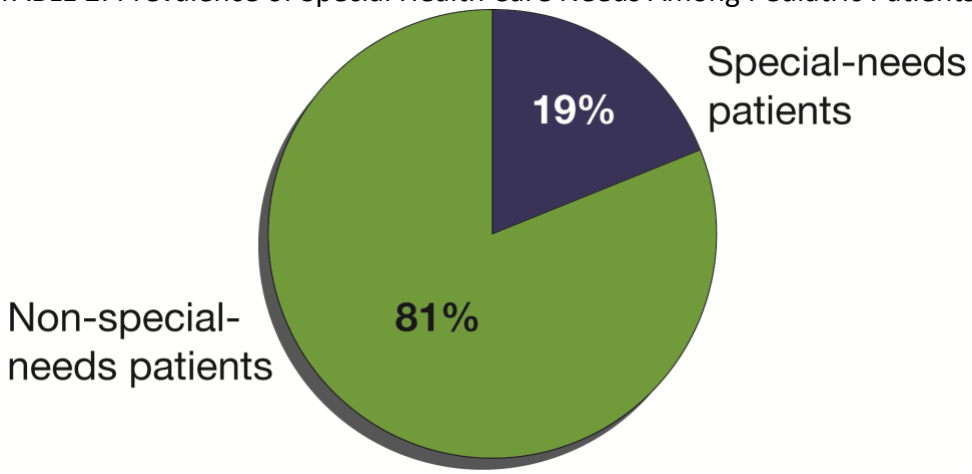
Scope

Estimating the extent of the SHCN patient population in Northern California, or even in just the San Francisco Bay Area, is difficult at best. Census data and other population-based studies have not focused specifically on this group. Even among pediatric patients, there has been little success in tracking data on dental health in the SHCN cohort.

Without data derived from a well-planned and executed needs assessment, we are left to rely on "best estimates" based on the prevalence of developmental disabilities per 1,000 population as tallied by the National Survey of Children's Health (NSCH) Data Resource Center (Table 2). This estimate places the SHCN population at 19% of the total juvenile population (this

proportion is extrapolated to the overall population). This also does not factor in those patients whose special needs derive from physical disabilities.

TABLE 2: Prevalence of Special Health Care Needs Among Pediatric Patients



The 32 counties that comprise Northern California have a population of 14,389,000 (United States Census Bureau, Annual Estimates of the Resident Population: April 1, 2010 to July 1, 2018. U.S. Census Bureau, Population Division. Web. May 2019. http://www.census.gov/). Using the 19% estimation would mean that more than 2.7 million persons in Northern California have SHCN stemming from development disabilities alone. The nine-county San Francisco Bay Area, with a population of 7,235,000, would expect to have a SHCN population of nearly 1.4 million. It is obvious that the potential demand for SHCN-focused care far exceeds the current health care system's ability to provide even basic oral health care services for this population.

Pediatric vs Adult SCHN Care

Regardless of age, persons with SHCN face numerous, and sometimes onerous, obstacles in obtaining basic health care services as compared to the general population (Waldman et al). Access to oral health care services is foremost among the specific unmet health care services for the SHCN population. The problem of access to care is compounded when patients transition from the care of a pediatric dentist to that of a dentist who provides adult services (Waldman et al, Newacheck et al).

In general, pediatric dentists are adequately trained in providing care for children and adolescents who are medically compromised and whose complex health care needs classify them as SHCN. However, there are very few general dentists who have been properly trained to assume the oral health care of this population as adults. As a result, when these adolescent

SHCN patients reach the point of "aging out" of pediatric practices, they have few options for care.

A recent publication on this issue (Chavis and Canares) cites several systemic challenges which must be addressed and overcome if we are to find solutions to the dilemma of care access:

1. Inadequate workforce and number of adequately trained general dentists who are equipped and have the confidence and willingness to treat adult SHCN patients.
2. Lack of recognition of the size and scope of the SHCN population's access to care problem by policy makers, legislators and the general public; and similar lack of understanding of the pain and suffering that this population endures as a result of this shortcoming.
3. Inadequate resources and alternative forms of care delivery to help overcome the increased barriers to care (financial, physical and geographic) that confront SHCN patients and their families or caregivers.

The Financial Impact on Access

From birth through age 16, children with SHCN traditionally have received their oral health care within the pediatric dentistry community. Pediatric dentistry training programs devote significant portions of their didactic curriculum and clinical experience to the treatment of SHCN patients. Although most pediatric dentists in private practice do not accept MediCal Dental (formerly DentiCal) as reimbursement for their services, the majority do see children and adolescents with SHCN whose parents have private insurance.

However, the majority of California's SHCN patient population are beneficiaries of MediCal Dental and depend on this system for their oral health care needs. Most private-practice dentists — pediatric or general — do not accept MediCal Dental patients because of the low reimbursement rates. As a result, the majority of SHCN patients must rely on the Community Health Center/FQHC health network to receive needed dental care.

Most providers within this safety-net system are general practitioners, few of whom have had the training or experience to deal with SHCN patients. These general dentists end up referring SHCN patients to tertiary care medical centers and advanced education training facilities for both routine and emergency services. This approach results in the two- to three-*year* wait times SHCN patients must endure for even an initial appointment.

Despite the wait times, these safety-net programs in Northern California see large numbers of child and adolescent SHCN patients for routine preventive oral health care. Some of these, especially university programs (locally, University of California, San Francisco, and the University of the Pacific), provide comprehensive restorative and surgical services to this population up to approximately 16-17 years of age. This is the age when patients begin to develop dental (periodontal, endodontic, prosthetic) as well as medical (congestive heart

failure, adult cancers, metabolic complications such as type 2 diabetes) problems that are frequently beyond the scope of pediatric practice. It is no coincidence that this also is the point when SHCN patients begin to encounter significant access-to-care problems. Moreover, at age 26 these SHCN patients are no longer covered by their parents' or guardian's private insurance, thus increasing their dependence on publicly subsidized programs, in turn further intensifying the oral health care access problem. By this age, most SHCN patients present with circumstances beyond the capabilities of both pediatric and general dentists.

Steps Toward Solutions

In 2019, New York University College of Dentistry opened its Oral Health Center for People with Disabilities, providing comprehensive care for patients whose disabilities or medical conditions prevent them from receiving care in a conventional dental setting. The center offers physical accommodations such as reclining wheelchair platforms and sedation suites, along with a specialized treatment team composed of multidisciplinary faculty, a nurse practitioner, a nurse, a social worker, three patient-service representatives, a clinic manager, and a patient care coordinator. Its affiliation with NYU's dental school offers student dentists opportunities to glean valuable knowledge and experience in treating SHCN patients.

On the local level, University of the Pacific's Dugoni School of Dentistry has offered a Special Care Clinic headed by Dr. Paul Subar, and a Virtual Dentistry program, developed by Dr. Paul Glassman, bringing dental care to adults and children with significant behavioral/developmental issues in rural or other remote settings through telehealth technology. The UOP Special Care Clinic has a long waiting list and wait times have been made longer by the almost universal reduction in dental care caused by the COVID-19 public health emergency. Limited operating-room time is available to UOP dentists at California Pacific Medical Center; due to limited capacity, wait times for non-urgent treatment under general anesthesia can be 2-3 years.

The Special Needs Dentistry Summit, hosted by UCSF School of Dentistry, sought to move the needle even further. Stakeholders and experts from across the nation were invited; see Appendix 1 for the complete list of attendees.

The morning agenda (see Appendix 2) consisted of invited presentations by key stakeholders and policy makers addressing various aspects of oral health issues for the SHCN population, followed by a panel discussion with five experts who gave an overview of the problem based on their perspectives and experience. In the afternoon, attendees split into four workgroups, each of which was tasked with developing strategic approaches and next steps for development of a local and statewide agenda to solve this access-to-care problem.

Outcome and Recommendations

A wrap-up session concluded the day with strategies for future consideration. Several themes and recommendations emerged repeatedly throughout the event and are listed here as priorities moving forward.

1. Identify resources and fund a Special Needs Population Survey and Needs Assessment Pilot Project in Contra Costa, Alameda, San Francisco and Sacramento Counties. Advancement is impossible without an accurate understanding and assessment of the oral health needs of the region's SHCN population. Survey methodology will be shared and replicated in other counties throughout California. This survey and needs assessment likely would best be undertaken by the office of the California State Dental Director in collaboration with county health departments with the assistance of the Divisions of Public Health Dentistry at UCSF and UCLA as well as the California Dental Association (CDA). The data derived from this survey and needs assessment is necessary as a baseline against which to measure any changes in access to care in the provision of increased levels of oral health care (e.g. preventive and restorative services) to this population over time.
2. UCSF should continue to lead this initiative and to continue to support the concept by identifying the dedicated resources necessary to support the project. This would, first and foremost, entail the appointment and support of a lead person who would be charged with the formation of an interdisciplinary Advisory Group consisting of local and regional stake holders to facilitate the following agenda and to develop evidence-based policies protocols for serving the SHCN population in Northern California:

    a. Proactively plan and pursue a strategy to introduce/support a legislative agenda designed to provide more state and federal funding for programs dedicated to improving the improved access to oral health care for the SHCN population. (David Chiu AB 2146)

    b. Feasibility and funding plan for a Special Needs Dental Facility similar to the NYU center, which was described by Dr. Ronald Kosinski in his presentation at the February symposium.

    c. Promote the formation of a joint UCSF/UOP/UCLA task force hosted by CDA to brainstorm best practices and to mount a unified statewide approach to supporting the adoption of legislation and policy development described above in #a.

    d. Develop an inter-institutional curriculum and supporting infrastructure (as designated by CODA) which would give all California predoctoral dental students

concentrated exposure to and experience in dealing with the SHCN population. (Utilization of a collaboration with existing UOP faculty and programs would be ideal.) New CODA guidelines specifically address the necessity of including training pre-doctoral dental students in delivering oral health care to the SHCN population under Clinical Sciences Specific Standard Relating to Special Needs:

2-25 Graduates **must** be competent in assessing and managing the treatment of patients with special needs.
Intent:
An appropriate patient pool should be available to provide experiences that may include patients whose medical, physical, psychological, or social situations make it necessary to consider a wide range of assessment and care options. As defined by the school, these individuals may include, but are not limited to, people with developmental disabilities, cognitive impairment, complex medical problems, significant physical limitations, and the vulnerable elderly. Clinical instruction and experience with the patients with special needs should include instruction in proper communication techniques including the use of respectful nomenclature, assessing the treatment needs compatible with the special need, and providing services or referral as appropriate.

e. Expand existing GPR programs at UCSF (possibly in affiliation with Bay Area FQHC programs, similar to what UCSF Pediatric Dentistry has done to expand the number of residency slots) to include significant GPR and predoctoral elective rotation experience in service to the SHCN population.

f. Use Bay Area Dental Special Needs Anesthesia as a Bay Area pilot group for the design and implementation of a Bay Area needs assessment survey and for the recruitment of dental providers pursuing advanced training in SHCN dentistry with opportunities using such incentives as: a) loan repayment b) affiliated faculty appointments c) predoctoral dental student rotations to gain experience in providing preventive and interventional care to SHCN populations.

g. Formation of an Interagency Council between DHCS, DDS and CDPH in order to expand upon the MediCal Dental case management service to facilitate completion of paperwork, gathering consents, and matching patients with an appropriate dental provider.

h. This Interagency Dental Council would partner with CDA to fund a Special Needs Dentistry (SND) professorship at each graduate training program in the state in order to support training and increase access to care for persons with SHCN. This network of SND experts could then advocate for a consistency of standards and educational guidelines for SHCN oral health care to advocate for the provision of

oral health care needs in this population as well as to develop integrate a "Virtual Dental Home "concept to better serve this population.

i. In collaboration with Dr. Paul Glassman, design and develop a robust telehealth system with core faculty providers working in concert and providing indirect supervision of remotely located ancillary (RDH, RDA, EFRDA) personnel who are trained and equipped to deliver preventive and early interventional services to the SHCN population in geographically remote communities and residential facilities.

It is essential to bring public and philanthropic funding into this equation. California Assembly Bill 2146 (currently on hold), sponsored by Assemblyperson David Chiu, is intended to authorize public university dental schools to utilize intergovernmental transfers to support the training and dental care that these schools provide to Medi-Cal beneficiaries. The SHCN community would be obvious beneficiaries of this legislation. But it should not stop here.

Similarly, private giving makes a tremendous difference. The financial commitment behind a project like NYU's Oral Health Center would be in the millions, even tens of millions of dollars.

We believe that now is the time to correct this deficiency and to develop and implement a strategy to correct this oversight. We believe that we have a moral and ethical obligation to find a solution to this problem and that, under the leadership of UCSF and the entire California oral health community, we can make this happen.

Appendix 1 : Summit Attendees

Brian Bast, DMD, MD	UCSF, School of Dentistry
Lisa Berens, DDS	UCSF, School of Dentistry
David Chiu	California State Assembly
Ellen Darius, RDHA	Alameda County Public Health Department
Juno Duenas	Support for Families of Children with Disabilities
Paul Glassman, DDS	California Northstate University
Sienna Go, MD, CMD	Fairview Developmental Center
Maria Jocson, MD, MPH, FAAP	California Department of Health Care Services
Jayanth Kumar, DDS, MPH	California Department of Public Health
Ronald Kosinski, DMD	NYU College of Dentistry, Clinical Director Oral Health Center for People with Disabilities
Ingrid Lin, MD	Golden Gate Regional Center
Pip Marks	Family Voices of California
Gayle Mathe	California Dental Association
Dharia McGrew, PhD	California Dental Association
Ben Meisel, MD	California Children's Services - San Francisco
Alicia Montell, DDS	San Francisco Dept. of Public Health
Bryan Nokelby DDS	Department of Health Care Services
Temitope Omolehinwa, BDS, DScD	Penn Dental Medicine
Prasanthi Patel	San Francisco Dept of Public Health
Debra Payne	Sacramento County Public Health
Karen Raju	UCSF, School of Dentistry
Michael Reddy, DMD	UCSF, School of Dentistry
David Rothman, DDS	David L. Rothman DDS P.C.
Roy Schutzengel, MD, MBA	California Department of Health Care Services, Integrated Systems of Care Division
Caroline Shiboski, DDS, MPH, PhD	UCSF, School of Dentistry
Eunice Stephens, MPH, MHA	UCSF, School of Dentistry
Ray Stewart, DMD, MS	UCSF, School of Dentistry
Paul Subar, DDS	UOP Dugoni School of Dentistry
Maria Thompson, DDS	UCSF, School of Dentistry

Appendix 2: Summit Agenda

Agenda

Time	Agenda Topic	Presenter
7:30 – 8:00	Check-In and Breakfast	
8:00 – 8:20	Opening Remarks	**Dr. Mike Reddy**, Dean, UCSF School of Dentistry **Mr. David Chiu**, Assemblymember, District 17
8:20 – 9:20	Current State of Dental Special Needs	**Dr. Jay Kumar**, State Dental Director, California Department of Public Health, Center for Chronic Disease Prevention and Health Promotion **Dr. Bryan Nokelby**, Dental Program Consultant, California Department of Health Care Services, Medi-Cal Dental Services Division **Dr. Sienna Go**, Medical Director, Fairview Developmental Center
9:20 – 9:50	Patient Perspectives	**Ms. Norma Rodriguez** **Ms. Frankie Larocca**
9:50 – 10:05	Coffee Break	
10:05 – 10:50	NYU Case	**Dr. Ronald Kosinski**, Clinical Director of Oral Health Center for People with Disabilities, NYU College of Dentistry
10:50 – 11:50	Panel Discussion	**Dr. Paul Glassman**, Associate Dean for Research and Community Engagement, California Northstate University, College of Dental Medicine **Ms. Gayle Mathe**, Director, California Dental Association, Community Health Policy and Programs **Dr. Ben Meisel**, Medical Director, San Francisco Department of Public Health, California Children's Services **Dr. Ronald Kosinski** (see above) **Dr. Ray Stewart**, Division Chair, UCSF School of Dentistry, Pediatric Dentistry **Dr. Paul Subar**, Chair, University of the Pacific, Arthur A. Dugoni School of Dentistry, Department of Diagnostic Sciences,
11:50– 12:30	Lunch	
12:30 – 2:30	Solutioning/ Workgroups	**Ms. Kate Walker**
2:30 – 2:45	Coffee Break	
2:45 – 4:30	Next Steps	**Ms. Kate Walker**
4:30 – 5:00	Wrap Up	**Dr. Jay Kumar (see above)** **Dr. Mike Reddy (see above)**