Formal Report submitted to the
LOUISIANA DEPARTMENT OF HEALTH
and Other Relevant Agencies

by the

Louisiana OCDD Task Force on Dental Services for Adults with Developmental Disabilities

December 11, 2020
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Louisiana Dental Task Force for Adults with Intellectual/Developmental Disabilities

The Louisiana Dental Task Force for Adults with intellectual/developmental disabilities (I/DD) was established as a result of a motion passed by the State Advisory Committee for the Louisiana Office for Citizens with Developmental Disabilities. The purpose of this Task Force is:

To address the needs of adults (18 years and older) with I/DD who need anesthesia or IV sedation for a routine dental exam and cleaning because of aversions they have to probing in their mouth or inability to cooperate throughout the dental exam and cleaning process with the intent of preventing serious health issues while providing medical care cost savings in the State and developing recommended strategies to address these barriers. A proposal will be provided for LDH management to consider (OCDD and Medicaid offices as well as to the Deputy Secretary and Undersecretary).

Members of the Task Force are:
Mary Kay Cowen: Chair, LA Dental Task Force; Member, OCDD SAC; Vice Chair, Jefferson Parish Region 10 RAC; Family Member/Advocate
Robert Blue: Tribal Liaison, OCDD Liaison, Behavioral Health, Healthy Blue
Brandon Bueche': LA Medicaid Program Manager, LA Medicaid, LDH
Jacquelyne Cobb: Administrative Assistant to Julie Foster Hagan, OCDD, LD Health
Annette Droddy: Executive Director, Louisiana Dental Association
Kathy Dwyer: Chair, LA OCDD SAC; Chair, Jefferson Parish Region 10 RAC; Family Member/Advocate
Dr. Charlie Foy: President, LA Dental Lifeline Network
Melissa Garcia: Oral Health Coordinator, Oral Health Promotion, Well-Ahead LA, LDH/OPH
Kevin Guillory: LA Medicaid Program Manager, LDH
Steve Kauffman: Disability Rights LA (Former LA Advocacy Center)
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Andrea Perry: LA Medicaid Program Manager, LDH
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Monica Roberts, RDH, MAT: Dental Hygienist Clinical Coordinator, OCDD Resource Center - Dental Unit, LDH
Karen Scallan: Policy Advocate, Special Needs and Parent Support Services; Family Member/Advocate
Susan McIlwain: Executive Director, Crossroads Louisiana (Private Provider)
Bobby Waldo: CPA, Family Advocate

The Dental Task Force conducted monthly meetings beginning July 11, 2019 through October 9, 2020. The meetings included representatives from Louisiana Medicaid Office, OCDD, and Dr. Gremillion, Dean, LSU School of Dentistry. Through these meetings the Dental Task Force discussed the following.

Introduction

Adults with intellectual and developmental disabilities (I/DD) have gone too long without the necessary and needed dental care. Families frequently have to search for someone willing to see their loved one
only to find out that they are not able to provide the services needed. One barrier is because many adults with I/DD have aversions to probing in their mouth. So they are not able to tolerate the physical contact and time needed to examine, clean, and x-ray their teeth. And “unfortunately, interactions with patients who have disabilities may become uncomfortable when the care providers themselves are unfamiliar with their disabilities.” (National Council on Disability, Fall 2017, p.1)

This is a result of dental professionals not being properly trained in treating adults with I/DD, particularly those with aversions and other challenging behaviors. Nor have many dental professionals had meaningful interpersonal interactions with individuals with I/DD. The American Academy of Developmental Medicine also notes that “people with I/DD regularly face an uphill battle in finding clinicians properly trained to treat them because most dentists lack proper training and exposure regarding the health and psychological needs of the I/DD population.” (National Council on Disability, Fall 2017, p.1) “According to a series of studies, 75% of dental students reported little to no preparation in providing care to people with I/DD.” (National Council on Disability, Fall 2017, p.4)

Many pediatric dentists see children with I/DD. But once a child becomes an adult, they are typically referred to a family dentist. And often family dentists have turned away adults with I/DD because of their lack of training, lack of personal interaction, or lack of coverage to state funded programs which leaves families with nowhere to go for services. Others have referred adults with I/DD to specialty programs with long waiting lists. Some of the programs offer only an exam and cleaning and aren’t equipped to provide anesthesia that is needed for the individuals with aversions and challenging behaviors. The few that are equipped to administer anesthesia are costly with the services rarely covered by insurance. There are rare cases where Medicaid may cover the cost if it can be justified that the dental care with anesthesia will be more cost efficient than the resulting health issues if the individual goes untreated.

Such poor access to dental care can lead to many adults with I/DD having fair to poor overall health because of the lack of care. In fact, “adults with disabilities are four times more likely to report their health to be only fair or poor than people without disabilities. More specifically, studies have shown that adults with developmental disabilities are at risk for multiple health problems including poor oral health. Further, in 2002, the U.S. Surgeon General reported that, compared with other populations, ‘adults, adolescents, and children with [intellectual disability (sic)] experience poorer health and more difficulty in finding, getting to, and paying for appropriate health care,’ (National Council on Disability, Fall 2017 p. 2). Other barriers are offices that are not accessible or equipment that may not accommodate an adult with a disability as well as the additional time that may be needed to treat an adult with I/DD. And then there’s the lack of understanding of individuals, particularly adults, with I/DD that can present a challenge in providing effective care.

With these findings, the National Council on Disability recommended the following (National Council on Disability, Fall 2017):

**Recommendation to Federal Policymakers**

1. NCD recommends that Congress further amend the Public Health Service Act to authorize additional grants to public and nonprofit dental care providers to expand resources (including but not limited to proper and accessible equipment) and deliver, in specific, proper dental care to people with I/DD in scarcity areas (geographic areas that are not reasonably accessible to facilities equipped to provide such care), and to bolster loan repayment programs (not excluding
the 9 Student to Service Loan Repayment Program of the National Health Service Corps) for dentists training or already properly trained in the treatment of people with I/DD and are willing to provide that specialized care in the aforementioned scarcity areas.

2. NCD recommends that Congress form an advisory committee to determine and rectify any existing or potential conflicts of laws or programs, or other identifiable impediments, as a means of streamlining efforts for maximum efficiency in achieving these policy goals.

Recommendation to State Policymakers

3. NCD recommends states that have limited their Medicaid coverage of adult dental benefits provide the more extensive coverage options, including a per person annual expenditure cap of at least $1,000.

Recommendation to the Commission on Dental Accreditation

4. NCD recommends a modification to the relevant dental school accreditation requirement. All dental students must have more robust training in the care of I/DD patients. As opposed to simply requiring that dental students be “competent in assessing the treatment needs of patients with special needs,” NCD recommends students be required to “demonstrate clinical practice skills to perform the designated treatment; and to demonstrate a sensitivity to their ancillary needs (including respectful nomenclature, supported decision making, knowledge of living arrangements that might impact compliance, communication avenues, and systems of support).”

Recommendation to the American Dental Association

5. NCD recommends that the American Dental Association review its current Principles of Ethics and Code of Professional Responsibility and make certain modifications to better reflect the rights of people with disabilities. It must modify its standard with respect to Patient Selection whereby it is established that “While dentists, in serving the public, may exercise reasonable discretion in selecting patients for their practices, dentists shall not refuse to accept patients into their practice or deny dental service to patients because of the patient’s race, creed, color, sex, national origin or disability, unless it is medically necessary due to the patient’s disability or medical condition, in which case the dentist shall refer the patient to another care provider with the specialized skill and training required to meet the patient’s needs.”

After the National Council on Disabilities recommendations to the Commission on Dental Accreditation (CODA), the American Dental Association revised its code of conduct in November 2018 “prohibiting dentists from denying care to patients with intellectual, developmental, or physical disabilities. If a dentist did not have the equipment or expertise to meet an individual’s special needs, the revised code of conduct now requires them to refer the patient to an appropriate dentist instead of turning them away.” (Disability Scoop, February 2019).
In August 2019, the Commission on Dental Accreditation (CODA) passed revised accreditation requirements for pre-doctoral dental, orthodontics, dental hygiene, and dental assistant programs requiring dental schools to now train students in managing treatment of patients with I/DD. The revised accreditation now requires:

1. Pre-doctoral program and orthodontics program dental students to be trained to assess and manage the treatment of patients with “special needs [sic].”
2. Dental hygiene program students to be competent in providing care to “special needs [sic]” patient populations.
3. Dental assistant program students to be familiarized with patients with “special needs [sic]” including patients whose medical, physical, psychological, or social conditions make it necessary to modify normal dental routines.

CODA defines “people with ‘special needs (sic)’ as people with developmental disabilities, cognitive impairment, complex medical problems, significant physical limitations, and the vulnerable elderly.” (Appendix A: National Council on Disabilities, August 2019) Changes for the pre-doctoral dental, dental hygiene, and dental assistant programs were effective July 1, 2020, with changes to the orthodontics programs effective January 1st.

Section 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. (Commission on Dental Accreditation, July 1, 2020: Accreditation Standards For Dental Education Programs, 2-25, p. 30)

Issues identified by the Louisiana OCDD SAC Dental Task Force

The Louisiana OCDD SAC Dental Task Force identified the following issue for adults with I/DD needing dental services.

- Some adults (18 years and older) with I/DD, many with severe and profound intellectual disabilities as well as those with behavioral issues, have an aversion to probing in their mouth or are unable to cooperate to allow for proper teeth brushing or general exams, cleaning, and x-rays and therefore require anesthesia or IV sedation in order to receive these services.
- Traditional Medicaid offers an Adult Denture Plan (ADP) for those 21 years old and older that is limited to an exam, diagnostic radiograph, and preapproved dentures and/or partial and denture combination. Any necessary restorations or extractions are not covered. Dental cleansings and outpatient hospital stays requiring anesthesia are not covered. A set of dentures is limited to one set every 5 years for adults who are 18-20 yrs. old, and every 8 years for adults age 21 and older. However, dentures are not an option for individuals diagnosed with severe to
profound I/DD who would not tolerate the construction process, nor be able to wear and maintain them. Additionally, individuals with I/DD should be afforded more comparable preventive and restorative dental remedies that are provided to individuals without I/DD so that they can retain their natural teeth, be free of infectious disease, be able to chew their food properly, maintain proper nutrition, and enjoy their food, as well as have an appealing smile. The Medicaid Managed Care Organization (MCO) plans are limited in services, providers, and restrictive in eligibility or cost prohibitive for individuals with behavioral challenges and complex medical issues.

• There is a severe lack of dental services available for adults who require anesthesia or IV sedation for a general exam, cleaning, or other necessary procedures needed for overall oral and physical health. As of September 2020, there were approximately 3 dentists in the New Orleans area that provide hospital dentistry or anesthesia services for adults with special needs, plus the LSUHSC School of Dentistry that serves approximately 48 patients per year. There is also 1 dentist in Hammond that provides IV sedation, 1 in Monroe, and a clinic in Pineville but the clinic has suspended services due to the COVID-19 pandemic.

NOTE: The facility in Pineville is located at Pinecrest Developmental Center (PDC). Services to qualifying individuals residing in the community were suspended prior to COVID-19. In the later part of 2018 it was reported that the initial reason for suspending services to people with I/DD residing in the community was due to lack of staffing availability to coordinate services and payments. It is understood that LSUSD provided the dentist via a contract and PDC and/or OCDD Resource Center provided administrative staff to support scheduling and payment collection for community-based patients. This clinic formerly functioned as a dental source for residents at PDC and individuals with I/DD in the community and surrounding area. An update of information regarding this clinic’s status for people in the community was requested.

• Reasons for a lack of dental services include:
  o Lack of dental professionals educated and trained to work with adults with I/DD particularly those with behavior issues.
  o A hesitancy of dentists to serve individuals with I/DD because of the costs involved particularly when services including anesthesia aren’t covered by Medicaid or other insurance.
  o Lack of dental clinics and private practitioners with access to anesthesia and the appropriately trained and licensed personnel to administer anesthesia.
  o Dental students may not receive a stipend for providing services in the clinics.
  o University Hospital in New Orleans is the only place that provides dental exams and cleaning with anesthesia. However, currently there is typically a waiting list. The wait has been reported to be anywhere from several months, to a year or even 5-8 years. And they are only able to serve 48 patients per year.

• Families are not able to afford the extraordinary costs involved for a routine dental exam and cleaning which at minimum includes an outpatient surgery center or same-day stay at a hospital and anesthesia. While some costs can be mitigated to around $500 - $800, examples of costs experienced by families were $1,800, $3,000, and even $8,000 depending on the services needed and rendered.

• There is limited dental insurance coverage for dental services particularly for adults with I/DD 18 years and older.
  o For adults with I/DD, legacy Medicaid (through DXC Technology, previously Molina) provides comprehensive care through age 20 but once a beneficiary reaches 21, with
preapproval, only provides one set of dentures/partials eight years for adults 21 and older. However, as previously stated, dentures are problematic for the I/DD population as many are not able to tolerate or properly care for their dentures and may lose them.

- Healthy Louisiana (Medicaid MCO) plans offer value added services up to $500. However, these services are not available to plan participants who are enrolled in specialized behavioral health services through the Healthy Louisiana (Medicaid MCO) plans. Even if a conditional authorization is granted for hospital dentistry or sedation; costs for services with anesthesia at an outpatient surgery center or hospital are well beyond $500.
- Anesthesia and same day stay at a hospital or outpatient surgery center for adults (18 years and older) with I/DD are covered for adults 18-20 years old but are NOT covered by Medicaid for adults 21 yrs. old and older. Nor is outpatient surgery with anesthesia covered by private insurance. Medicaid may allow coverage through an appeal process but ONLY IF you can document significant health issues could arise and costs to address the health issues would exceed the costs for dental care with anesthesia and same day stay at a hospital.

- Few hospitals or outpatient surgery centers are equipped with the necessary dental equipment to perform the dental services needed. Currently in the New Orleans area only Ochsner, University Hospital, and Children’s Hospital offer facilities for use by dentists. And Children’s only serves children up to 18 years of age with some exceptions to 21 years of age. Leaving only 2 facilities available in the entire Greater New Orleans area for adults.
- There is a 6-month wait for an operating room facility.
- Costs to setup dental services at a hospital or same day surgery center may be as much as $25,000 - $50,000 for the necessary equipment.
- Because of poor dental hygiene and lack of dental services with anesthesia or IV sedation, dental care for adults with I/DD is poor or even nonexistent which puts individuals with I/DD at risk for serious health issues such as heart attacks, strokes, infection, etc.

**Recommendations by the Louisiana OCDD SAC Dental Task Force**

The Louisiana OCDD SAC Dental Task Force makes the following recommendations to address the issues identified for adults with I/DD needing dental services.

**Recommendation Specific to the LSU School of Dentistry:**

- Develop a pre-doctoral dental education program to train dental students on how to work with adults with I/DD as required by the Commission on Dental Accreditation (CODA). Effective July 1, 2020, CODA requires all pre-doctoral dental education programs to educate students on managing patients with intellectual and physical disabilities and “ensure graduates are competent to assess and manage the treatment of patients with special needs.” (CODA Summer 2019 Pre-doctoral Dental Education Review Committee Report)
- Develop enhanced course work in collaboration with OCDD, the Human Development Center (HDC) of LSUHSC School of Allied Health Professions, the Arc of Louisiana, a physician experienced with complex health care needs, and a behavioral psychologist with expertise in supporting individuals with intellectual/developmental disabilities and co-occurring behavioral health needs.
Coursework should include:

- Introduction of dental students to patients with I/DD through shadowing professionals who assist with caring for clients with I/DD and offering frequent visits to day habilitation service programs to establish comfort with interacting with individuals with I/DD.
- A parent/family perspective component with family members speaking to classes about the challenges they face in providing daily dental care. This will give a full understanding of whether their prescribed goals for in-home dental care can actually be accomplished given constraints family caregivers face, e.g., behavior, medical, and intellectual constraints. It will also enhance family-centered care so that providers know to include families in their decision-making on attainable goals for better oral care.
- A behavioral component including training in Positive Behavior Intervention techniques.
- Addressing needs of children and adults who need anesthesia for a general exam due to aversions to probing in their mouths.
- Addressing children and adults with complex health needs that may need hospitalization for dental procedures due to complex health issues.
- Addressing children and adults with complex health needs (e.g., medically fragile, immune deficiencies, ventilator dependent) who cannot leave their home.
- A clinical rotation of dental anesthesiology residents as well as hygienists.

Replicate a program similar to Tufts University in Massachusetts (Appendix B) that provides clinical services through four hospitals throughout the state with the clinics simultaneously used as pre-doctoral training sites. Tufts University has offered to help provide guidance. (Appendix D). The University of Washington’s Dental Education in the Care Persons with Disabilities (DECOD) program is another program that could be replicated (Appendix C).

- Develop post-doctoral training for CEUs to build and expand the capacity and competency of the dental workforce in public and private practice. Building capacity in the private practice is particularly important so individuals with I/DD can establish a long-term relationship with a dentist for their specialized dental care needs.

Recommendations Specific to the Louisiana Department of Health:

- Increase the number of hospitals and outpatient surgery centers with appropriate equipment available to dentists.
  - Make dental equipment available in area hospitals and outpatient surgery centers for private practitioners that could be rolled out and used when needed.
  - Extend hospital and outpatient surgery center privileges to dentists and hygienists.
- Include dental services for adults with I/DD including anesthesia in the Medicaid Home and Community-Based Waiver program.
  - Identify legislators to sponsor a bill for funding to include dental services in the Medicaid Home- and Community-Based Services program. Dental coverage should include exam, cleaning, x-rays, anesthesia as well as other dental services (e.g., extractions, crowns, etc.) NOTE: The Medicaid Waiver Program was suggested because
if dental services were offered through the State’s Medicaid Plan for the general population it would be too costly.

- Develop a video on provision of appropriate daily dental care and oral hygiene that can be used by caregivers, and require direct support workers to participate in a training with this video on an annual basis.
- Include dental care on Support Coordinators checklist of services needed for waiver recipients.
- Recognize dentistry as a critical part of medical care in the health care and insurance industry.

Recommendations Requiring Collaboration Across Agencies:

- Explore funding opportunities for the LSUHSC School of Dentistry pre- and post-doctoral special needs dental education program as well as funding for services provided at the LSUHSC School of Dentistry and in the community by private providers.
- Establish state licensing requirements through the Louisiana State Board of Licensing to include education and training in serving individuals with I/DD. (State Board of Dentistry would need to be involved).
- Ask the Louisiana DD Council to adopt an initiative as a LaCAN legislative agenda item for dental services to be included in the Medicaid Home and Community-Based Waiver program. (NOTE: The Louisiana DD Council has adopted Dental Services for the DD population in their Five-Year Plan as part of Objective 2.1 regarding increased access to appropriate and affordable health care. See https://laddc.org/wp-content/uploads/2020/10/2022-2026_Plan_Adopted.20.10.22.pdf.)
- Ask the Louisiana Dental Association’s Council on Governmental Affairs for help with legislative outreach for the pre- and post-doctoral special needs dental education program.

Resources Available

The Louisiana OCDD SAC Dental Task Force recognizes the following resources available to address the issues identified for adults with I/DD needing dental services and implement the recommendations.

- Dr. Henry Gremillion, Dean of the LSUHSC School of Dentistry, had stated prior to his death that:
  - He was very excited to initiate a special needs program in the dental school curriculum and felt they would meet the July 1, 2020 deadline stipulated by the Council on Dental Accreditation (CODA).
- Dr. Robert Laughlin, appointed Interim Dean of the LSUHSC School of Dentistry after Dr. Gremillion’s death, met with Task Force member Dr. Frank Martello on Monday, September 14, 2020, and stated that:
  - He would like to start a senior selective program to treat those with I/DD
  - He will make sure that the 1st through 4th year curriculum meet CODA’s new requirements that were effective July 1, 2020.
  - The two surgical suites in the new Dental School building which includes 8 dental chairs will be used for sedation of children and adults with I/DD.
- OCDD Resource Center offers preventative oral health trainings to consumers, families, and provider agencies as well as sensitivity training. They also offer limited technical supports in
private offices, clinics, and educational settings and connect consumers with community-based clinical dental services.

- Louisiana Dental Association and their Council on Governmental Affairs.
- Louisiana Dental Lifeline Network connects patients with dentists who agree to provide non-emergency services. Applicants must lack adequate income to pay for dental care and have a permanent disability or meet other criteria for services.
- Tufts University in Massachusetts (Appendix B and D)
- Exclth Family Health Center in New Orleans has a mobile dental unit that can go out to a location and provide care for clients. There have been discussions of possibly developing a hospital dentistry component by staffing a dentist with hospital dentistry credentials and establishing an agreement with the New Orleans East Hospital to utilize their operating room to provide dental care.
- Families Helping Families statewide network

Organizations available to help with outreach to legislators or other entities in implementing change:

- Disability Rights Louisiana (Formerly the Advocacy Center)
- Healthy Blue
- LA Dental Association
- Quality Support Coordination
- The Arc of Louisiana
- Families Helping Families
- Special Needs & Parent Support Services of LA
- LA Department of Health
- LA Medicaid
- OCDD
- OCDD State Advisory Council
- Region 10 Regional Advisory Committee
- Tufts University willing to mentor

Additionally, the Louisiana Developmental Disabilities Council added dental care for adults as one of their initiatives in their draft five-year plan.
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APPENDICES

A. “At NCD’s recommendation all U.S. dental schools will train students to manage treatment of people with intellectual, developmental disabilities.”

B. Tufts University Department of Public Health and Community Service, Public Health Research and Oral Medicine, Special Care in Dentistry

C. University of Washington DECOD Program
   Dental Education in the Care Persons with Disabilities

D. Staffing Model and Cost Estimate by Beth Conant, Director, Clinic Finance and Administration Tufts University School of Dental Medicine
APPENDIX A

National Council on Disability (2019). “At NCD’s recommendation all U.S. dental schools will train students to manage treatment of people with intellectual, developmental disabilities.”
At NCD's recommendation, all U.S. dental schools will train students to manage treatment of people with intellectual, developmental disabilities.
"Every dental patient in America deserves the same care, whether or not they have a disability," said NCD Chairman Neil Romano. "NCD applauds this decision that we view as necessary for people with ID/DD to obtain critical access to dental treatment, which is critical to the total health of all people."

CODA held and passed four related votes regarding the predoctoral dental, orthodontics, dental hygiene, and dental assistant programs:

For predoctoral programs and orthodontics programs, dental students must be trained to assess and manage the treatment of patients with "special needs [sic]."

For dental hygiene programs, students must be competent in providing care to "special needs [sic]" patient populations.

For dental assistant programs, students must be familiarized with patients with "special needs [sic]" including patients whose medical, physical, psychological, or social conditions make it necessary to modify normal dental routines.

CODA generally defines people with "special needs [sic]" as people with developmental disabilities, cognitive impairment, complex medical problems, significant physical limitations, and the vulnerable elderly.

Changes for the predoctoral dental, dental hygiene, and dental assistant programs are required to take effect by July 1, 2020, with changes to the orthodontics programs required by Jan. 1.

NCD first made recommendations to CODA following its 2017 issue brief "Neglected for Too Long: Dental Care for Patients with Intellectual and Developmental Disabilities," in which NCD’s findings included:
• Adults with developmental disabilities are at risk for multiple health problems including poor oral health.
• People with I/DD regularly face an uphill battle in finding clinicians properly trained to treat them because most dentists lack the proper training and exposure with respect to the health and psychosocial needs of this population.
• According to one study, more than 50 percent of dental and medical school deans have stated that their graduates are not competent to treat patients with I/DD; as a result, people with I/DD are more likely to have poor oral hygiene, periodontal disease, and untreated dental caries than are members of the general population.
• People with I/DD have been more likely to not have had their teeth cleaned in the past five years, or never to have had their teeth cleaned, than those who are not disabled.
• Due to the lack of proper skills among dentists, dental care is often more difficult to find than any other type of service for people with I/DD.

Last year, NCD successfully worked with the American Dental Association to revise its Code of Professional Conduct to state that “dentists shall not refuse to accept patients into their practice or deny dental service to patients because of the patient’s...disability.” This code revision was adopted by many states as state law of professional conduct.

First established as an advisory council within the Department of Education in 1978, NCD became an independent federal agency in 1984. In 1986, NCD recommended enactment of an Americans with Disabilities Act (ADA), and drafted the first version of the bill which was introduced in the House and Senate in 1988. Since enactment of the ADA in 1990, NCD has continued to play a leading role in crafting disability policy, and advising the President, Congress and other federal agencies on disability policies, programs, and practices.

SOURCE National Council on Disability
APPENDIX B

Tufts University
Department of Public Health and Community Service
Public Health Research and Oral Medicine
Special Care in Dentistry
Patients being treated Tufts Dental Facilities
Bringing a commitment to socially responsible education, patient care, research, and community engagement, the Department of Public Health and Community Service fosters optimal health and quality of life through population-based oral health disease prevention practices and healthy lifestyle behaviors. Reflecting Tufts University’s mission of community service and citizenship development, the department not only provides comprehensive instruction and conducts research in a wide array of public health topics, it also serves as a role model for future dentists to understand the interplay among individual, caregiver, and health care provider groups through extensive outreach programs bringing prevention education and quality services to patients in need of dental care. Research and population-based programs in the Department include Advanced General Dentistry (GPR/AEGD) postdoctoral training; Community-Based Oral Health Prevention and Engagement; Community Service Learning Externships; Geriatric Dentistry; Global Service Learning; Health Communication, Education and Promotion; and Special Care in Dentistry, Tufts Dental Facilities (TDF).
Public Health Research and Oral Medicine

Special Care in Dentistry

The School of Dental Medicine makes a direct impact on thousands of lives through the various programs facilitated by the Division of Special Care in Dentistry. The division takes a proactive role in providing quality, locally-based clinical services and aggressive preventive education programs to under-served populations. Without the division’s outreach, most of these patients would not otherwise receive dental health care, due to issues such as the difficulties that characterize treatment of disabled individuals and the decreasing number of dentists who accept state-provided health insurance. By bringing specially-trained dentists, hygienists and other dental health care providers directly to patients who need treatment the most, the division has set a national benchmark for serving the special needs population.

Commonwealth of Massachusetts Dental Program for Persons with Special Needs in Partnership with Tufts Dental School

Since 1976, Tufts Dental Facilities (TDF) have provided comprehensive oral health care to developmentally disabled individuals in Massachusetts. The result of a contractual partnership between the Tufts University School of Dental Medicine and the state’s Department of Developmental Services, the nationally recognized program – the largest of its kind – serves more than 7,000 patients at seven clinics throughout the state. The program also maintains arrangements with four hospitals to address the needs of patients who require IV sedation or general anesthesia for treatment. Focused on the dental health needs of individuals with intellectual disabilities, autism, blindness and Down syndrome, Tufts Dental Facilities depend on the support of university, community, government, hospital and private healthcare resources to fill an important health care gap for this population.

Serving Patients with Developmental Disabilities in the Tufts Community Dental Health Program

As part of the larger Community Dental Health Program, Tufts serves approximately 2,500 patients with developmental disabilities in about 191 locations. Most (about 1,900) of those patients are children. Sites include schools, including schools specifically for children with disabilities, adult day activity centers, community organizations, and group residences. Eight dental hygienists travel throughout the state with portable dental equipment, providing oral health education, screening, dental cleaning, dental sealants and fluoride applications to patients. Hygienists also
make referrals to local dentists and offer ongoing case management services, providing a critical continuum of care that extends beyond twice-yearly cleanings. The Community Dental Health Program also gives third-year dental students from Tufts exposure to treatment for patients with disabilities. Students from the Massachusetts College of Pharmacy and Health Sciences’ Forsyth School of Dental Hygiene rotate through the community dental program specifically to gain experience with patients with special needs.

Special Care Rotation

Unlike most dental schools, Tufts offers students a unique opportunity to work with special needs patients in a clinical setting. Before graduating, students are required to spend one week at one of the Tufts Dental Facilities.

General Practice Residency Program

Through the General Practice Residency Program, students spend about 40 percent of their time working with special needs patients – significantly more than they would at a typical hospital or community health center. Like the Special Care Rotation, this experience provides important exposure to both the challenges and rewards of working with the special needs population.
APPENDIX C

University of Washington
Dental Education in the Care of Persons with Disabilities
University of Washington DECOD Program
Dental Education in the Care of Persons with Disabilities

DECOD (Dental Education in Care of Persons with Disabilities) at the University of Washington School of Dentistry was established in 1974 to train dental professionals in providing dental care to persons with disabilities.

DECOD provides approximately 3,500 dental visits per year to persons with disabilities. It is a major resource for Washington citizens who have developmental or acquired disabilities. Approximately 70 percent have developmental disabilities (examples: intellectual disability, cerebral palsy, autism), the remaining 30 percent have acquired disabilities (e.g. traumatic brain injury, multiple sclerosis, stroke, ALS). The majority of patients are enrolled in Apple Health Washington state insurance.

DECOD Goals

Clinical Services – DECOD provides dental care that is not otherwise available in the community for patients with developmental and acquired disabilities. Clinical services include diagnostic, emergency, and comprehensive dental and oral health care services. The goal is to improve oral health and contribute to the well-being and oral function of clinic patients.

Education – DECOD seeks to broaden the pool of dental providers by providing hands-on training and exposure to patients with developmental and acquired disabilities. The goal is that more clinicians will see patients with disabilities in their practices to strengthen and expand patient care capacity across the state of Washington and nationally.

Quality – DECOD is a teaching institution committed to improving quality of care for patients with disabilities.

Qualifying Disabilities
- Developmental disabilities
- Cerebral Palsy
- Intellectual Disability
- Autism
- Down syndrome
- Others
- Acquired disabilities – the following acquired disabilities are qualifying at this time
  - Traumatic Brain Injury
  - Stroke
  - MS
  - ALS
  - Muscular Dystrophy

Clinical Instruction
The DECOD Program at the University of Washington is a special program of the School of Dentistry that prepares dental professionals to meet the special oral health needs of persons with disabilities.
The DECOD Clinic works hard to provide dental Providers training in treatment of Patients with Special needs through all phases in their Dental careers.

For Students
We provide training to dental students, dental hygiene students and dental assisting students. Our dental hygiene and Dental assisting students come to our clinic to receive training through our partnerships with hygiene and assisting programs throughout the state of Washington. All University of Washington dental students rotate through the DECOD clinic in the 3rd year of dental school as part of the Oral Medicine Clerkship program. All 4th year dental students spend 1 week in DECOD to expand and solidify the skills acquired in the clerkship.

We offer a DECOD elective to 4th year students interested in further training in special care dentistry in which the student see patients in the DECOD one clinical session per week for one quarter to learn better assess and treat patients with disabilities.

The DECOD student fellowship is offered to dental students during the 4th year. The Student Fellowship is designed for dental students who have completed the DECOD elective and express an exceptional interest in special care dentistry. The student fellowship will include didactic and supervised clinical care for persons with disabilities.

For Residents
The University of Washington Department General Practice Residency (GPR) Program in partnership the DECOD program is excited to host one PGY2 position in special care dentistry. This Partnership began 2015. GPR PGY2 special car dentistry residents must have completed an accredited AEGD of GPR PGY1. Residents will not only complete a second year of General Practice Residency but they will also complete a Leadership Education in Neurodevelopmental and Related Disabilities (LEND) fellowship. Prospective residents should aspire to become leaders in special care dentistry and advocate for patients with special needs. Such leadership may take the form of teaching, research, clinical practice, administration or policy making.

Residency. For more information one the PGY2 position and application process please visit the GPR page.

For Fellows. DECOD offers a one month fellowship for practicing dentists, dental hygienists and dental assistants. This fellowship is designed for those already in the dental workforce who are interested in expanding their skill and knowledge regarding the dental care of patients with disabilities. Chairside training and supervised delivery of care is emphasized. 100 hours of continuing education credit and a certificate is offered upon completion of the DECOD fellowship.

Fellowships
DECOD offers a one month fellowship for practicing dentist dental hygienists and dental assistants. The fellowship requires 20 clinical days of clinical training at The University of Washington and 5 days of special care didactic training.

DECOD Clinical training will cover
- Adaptations to care for patients with disabilities.
- Risk assessment and treatment planning for patients with special health care needs.
- Treatment of medically complex patients.
- Communication strategies for patients with special health care needs.
- Working with caregivers to maintain oral health for persons with disabilities.
- Treatment of patients with dental anxiety through desensitization and or oral sedation.
Other areas of clinical which may be covered include geriatric care for patients in long term facilities. The geriatric portion of the fellowship is provided at the fellows’ request and dependent on clinic availability.

**How to apply**

All applicants must have a Current US license or be licensed in Canada or Puerto Rico. Applicants are allowed to complete one DECOD fellowship per calendar year.

**Application**

- 1-2 letters of recommendation
- A personal statement describing your interest in the fellowship and how you hope to apply the fellowship skills learned.
- There is a $1000.00 fee is associated with our DECOD fellowship
APPENDIX D

Staffing Model and Cost Estimate by Beth Conant, Director, Clinic Finance and Administration Tufts University School of Dental Medicine
### Staffing Model and Cost Estimate by Beth Conant, Director, Clinic Finance and Administration Tufts University School of Dental Medicine

<table>
<thead>
<tr>
<th>Department</th>
<th>LSU Model</th>
</tr>
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<tbody>
<tr>
<td>Tufts University School of Dental Medicine</td>
<td></td>
</tr>
<tr>
<td>Finance Budget Projection</td>
<td>Full Time Fringe 1</td>
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<tr>
<td>SUMMARY</td>
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<td>Clinical And Other Educational</td>
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<td>4304</td>
<td>Deductions From Revenue</td>
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<tr>
<td>Total Revenue</td>
<td>22,100</td>
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</tbody>
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| Account | EXPENSES - Compensation Cost | 5003 | Faculty (10) | 10,000 | 10,000 | 10,000 | 10,000 | 10,000 | 10,000 | 10,000 | 10,000 | 10,000 | 120,000 |
| 5004 | Patient Registration (1,0) | 4,000 | 4,000 | 4,000 | 4,000 | 4,000 | 4,000 | 4,000 | 4,000 | 4,000 | 4,000 | 48,000 |
| 5004 | Patient Registration (1.5) | 4,000 | 4,000 | 4,000 | 4,000 | 4,000 | 4,000 | 4,000 | 4,000 | 4,000 | 4,000 | 48,000 |
| 5004 | Hygienist (1.0) | 5,417 | 5,417 | 5,417 | 5,417 | 5,417 | 5,417 | 5,417 | 5,417 | 5,417 | 5,417 | 65,000 |
| 5004 | Hygienist (1.5) | 5,417 | 5,417 | 5,417 | 5,417 | 5,417 | 5,417 | 5,417 | 5,417 | 5,417 | 5,417 | 65,000 |
| 5004 | Dental Assistant (1.0) | 3,120 | 3,120 | 3,120 | 3,120 | 3,120 | 3,120 | 3,120 | 3,120 | 3,120 | 3,120 | 37,440 |
| 5004 | Dental Assistant (1.5) | 3,120 | 3,120 | 3,120 | 3,120 | 3,120 | 3,120 | 3,120 | 3,120 | 3,120 | 3,120 | 37,440 |
| 5051 | Full Time Benefits | 10,434 | 10,434 | 10,434 | 10,434 | 10,434 | 10,434 | 10,434 | 10,434 | 10,434 | 10,434 | 125,212 |
| 5055 | Part-Time Benefits | - | - | - | - | - | - | - | - | - | - | - |
| Total Benefits | 10,434 | 10,434 | 10,434 | 10,434 | 10,434 | 10,434 | 10,434 | 10,434 | 10,434 | 10,434 | 10,434 | 125,212 |
| Total Compensation w/ Fringe | 45,500 | 45,500 | 45,500 | 45,500 | 45,500 | 45,500 | 45,500 | 45,500 | 45,500 | 45,500 | 45,500 | 540,032 |

| Account | EXPENSES - Non-Compensation Cost | Jul | Aug | Sep | Oct | Nov | Dec | Jan | Feb | Mar | Apr | May | Jun | Year End Total |
| 5100 | Purchased Services | - | - | - | - | - | - | - | - | - | - | - | - | - |
| 5200 | Student Aid | - | - | - | - | - | - | - | - | - | - | - | - | - |
| 5300 | Travel | - | - | - | - | - | - | - | - | - | - | - | - | - |
| 5400 | Materials & Supplies | 5,000 | 2,000 | 3,500 | 6,100 | 2,000 | 23,500 | 4,200 | 2,200 | 5,200 | 6,000 | 4,400 | 4,000 | 68,100 |
| 5500 | Administrative Costs | 2,700 | 400 | 1,000 | 300 | 500 | 2,000 | 3,200 | 5,000 | 2,000 | 2,900 | 2,000 | 4,000 | 25,400 |
| 6000 | Allocations (DPs) | - | - | - | - | - | - | - | - | - | - | - | - | - |
| Total Non Compensation | 7,700 | 2,400 | 4,500 | 6,400 | 2,500 | 25,500 | 7,400 | 7,200 | 8,300 | 6,400 | 8,000 | 93,500 |
Questions:

- With about 30,000 to 33,000 of the DD population having Statements of Approval, how many adults actually need dental care?
- How long will it take to put together courses teaching dental students to work with behaviorally challenged adults? (6 months to a year or more?)
- How can we affect a change in the medical and health insurance field to recognize dentistry as a critical part of medical care?
- Would there be a way to come up with a voucher program with a dental fee schedule for individuals who are not covered under any programs or insurance?
- What other forms of funding can be provided (providers offering better discounts, non-profits, foundations, etc.)?
- How can a mobile unit similar to the one used by Excelth (but smaller) be made available for individuals who cannot be transported to a clinic?
- How do we provide continuous care during the transitioning from child to adult care?