

### **Highlights**

- Though it does prohibit other forms of discrimination, the American Dental Association's Principles of Ethics and Code of Professional Conduct does not currently prohibit a practitioner from refusing to accept a patient based on their disability, generally.
- The American Academy of Developmental Medicine 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.
- Requirements of the Commission on Dental Accreditation do not require that dental school graduates be proficient in treating patients with I/DD, they only require graduates be competent in "assessing" treatment needs.
- Absent more generous Medicaid coverage, solutions must be sought to help encourage dental care providers to serve this underserved population despite the financial predicaments of those providers.

# Neglected for Too Long: Dental Care for People with Intellectual and Developmental Disabilities

#### Fall 2017

This policy brief is designed to provide insight concerning the lack of dental care many people with intellectual and developmental disabilities (I/DD)\* continue to experience due to a shortage of properly trained dental care providers and, consequently, a lack of dental care providers willing to provide that care.

The brief will provide recommendations regarding how to begin to rectify the problem, including modifying dental school accreditation and professional ethics requirements. It will also recommend that Congress amend the Public Health Service Act,<sup>1</sup> thereby providing more public funding and student loan debt forgiveness to improve dental care.

### Introduction

Unfortunately, interactions with patients who have disabilities may become uncomfortable when the care providers themselves are unfamiliar with their disabilities. This may lead to a lack of care and, accordingly, a lack of preventive care. 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."

There are multiple factors to consider as to why people with I/DD face challenges in finding proper care, including, among others, guardianship complications and compensation. Often times providers are concerned about the length of time it might take to treat just one patient with I/DD. As noted in NCD's 2005 publication The Right to Health: Fundamental Concepts and The American Disability Experience, dental care is a frequently forgotten area within the overall health care equation; and dental offices are often inaccessible and their equipment may not accommodate many disabilities. As was also noted, even when the physical environment has been adapted, a lack of understanding of disability issues among health professionals can minimize the effectiveness of the services provided, thus

<sup>\*</sup> NCD recognizes that not all people with I/DD require particular accommodations when receiving dental care

## Discuss with NCD

NCD is available to provide you with advice and assistance pertaining to these and other issues of importance to people with disabilities and welcomes any inquiries from you. NCD would be happy to provide information and analysis in person or via email to Members of Congress and staff. Please contact NCD's Legislative Affairs Specialist, Phoebe Ball, at pball@ncd.gov, or by phone at (202) 272-0104.

creating another roadblock for those claiming their health care rights. Insufficient dental school training in this space is part and parcel of these phenomena.

While laws such as the Rehabilitation Act<sup>7</sup> and, more broadly, the Americans with Disabilities Act<sup>8</sup> are useful tools for claiming one's right to accessible health care, including dental care, the cost to litigate such cases is not inexpensive. It is prudent to look for solutions to a problem before the need for litigation arises. To begin with, **NCD recommends 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. Finding financial incentives through government programs for care providers to train for and treat people with I/DD is also worth considering.

The lack of proper training among dental students is among the most rooted problems. These future care providers are not adequately exposed to the I/DD population during their education to begin with. While there are some dental programs across the United States that do train their students in the care of patients with I/DD, a sample of which are examined here as potential models for the creation of other such programs, **NCD recommends all dental students have more robust training in the care of I/DD patients.** As such, a modification by the Commission on Dental Accreditation is also worth examining.

### **Principles of Ethics and Code of Professional Conduct**

The American Dental Association's *Principles of Ethics and Code of Professional Conduct* does not prohibit a practitioner from refusing to accept a patient based on their disability, generally. It does, however, prohibit other forms of discrimination at Section 4.A., as provided, where it states 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 or national origin." <sup>10</sup> This point is relevant because the established principles of ethics in a given profession is typically the guide a professional is taught to use in determining how to conduct themselves as they push forward in their career. Those principles of ethical obligations (as might be adopted by each respective state's law), also subjects practitioners to a legal liability concerning the proper execution of their professional conduct. Interestingly, the American Dental Association's principles do, though, mention one disability at Section 4.A.1. with respect to patients with bloodborne pathogens, as an advisory opinion, wherein it states that:

A dentist has the general obligation to provide care to those in need. A decision not to provide treatment to an individual because the individual is infected with Human Immunodeficiency Virus [(HIV)], Hepatitis B Virus, Hepatitis C Virus or another bloodborne pathogen, based solely on that fact, is unethical. Decisions with regard to the type of dental treatment provided or referrals made or suggested should be made on the same basis as they are made with other patients. As is the case with all patients, the individual dentist should determine if he or she has the need of another's skills, knowledge, equipment or experience . . ."<sup>11</sup>

### Related NCD Work

The Current State of Health Care for People with Disabilities (2009)

https://go.usa.gov/xnC9K

The insertion of this "advisory opinion" would appear to be in response to *Bragdon v. Abbott*, 524 U.S. 624 (1998) wherein the U.S. Supreme Court held that an individual's positive HIV status is a "disability" under the Americans with Disabilities Act. 12 The Court further stated that an HIV positive individual's dentist, providing services as a public accommodation, would be in violation of that Act unless it be shown that the provider was faced with a risk to the health or safety of others. Reasonably then, and more broadly, **NCD recommends** section 4.A. of these principles be modified to reflect that other disabilities covered under the Act should also be protected. The relevant section should state 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. [Emphasis added].

This suggested language is inclusive while also recognizing that not every practitioner, at present, will be properly trained in providing specialized care if needed.

### **Dental Training**

The American Academy of Developmental Medicine and Dentistry (AADMD) Consensus Statement on Health Disparities for Persons with Neurodevelopmental Disorders and Intellectual Disabilities notes that people with I/DD regularly face an uphill battle in finding clinicians properly trained to treat them. <sup>13</sup> This is because most physicians and dentists lack the proper training and exposure with respect to the health and psychosocial needs of this population. <sup>14</sup> 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. <sup>15</sup> 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. <sup>16</sup> Additionally, 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. <sup>17</sup>

It has been reported that 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. 18 Again, society's ability to provide proper dental care to people with I/DD rests on whether dentists are properly trained to provide such services at the outset, and said training has been all too scarce. A series of studies of dental and dental hygiene educational programs through the 1990s and early 21st century found that more than 50 percent of dental students reported no clinical training in the care of patients with such specific care requirements, and 75 percent reported little to no preparation in providing care to these patients. 19 Only

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10 percent of general dentists responding in a study indicated that they treated children with cerebral palsy, intellectual disability, or medically compromising conditions often or very often.<sup>20</sup> Further, a national study of dental hygiene programs reported similar findings for treatment of people with disabilities in that 48 percent of 170 programs offered 10 hours or less of didactic training (including 14 percent with 5 hours or less); and 57 percent of programs reported no clinical experience.<sup>21</sup>

### **Dental School Curricula Requirements**

New language for dental and dental hygiene education programs were adopted by the Commission on Dental Accreditation (CODA) in 2004.<sup>22</sup> However, there is still only one accreditation requirement for dental schools with respect to treating patients characterized as requiring specialized dental care, which states, in only quite general terms, that:

Graduates must be competent in assessing the treatment needs 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. The assessment should emphasize the importance of non-dental considerations. These individuals 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 patients with special needs should include instruction in proper communication techniques and assessing the treatment needs compatible with the special need.<sup>23</sup>

This standard clearly does not require that graduates be proficient in the techniques necessary to provide treatment, merely that they "be competent in assessing the treatment needs" of patients with disabilities. Gaining expertise in these areas requires added education and training beyond what is standard dental school curricula. There are, however, some dental schools that go beyond what is required in order to train dentists that are truly knowledgeable and practiced in providing quality specialized dental care to patients, including patients with I/DD.

### Sample of Programs that Train Dental Students in Providing Care for Patients with I/DD

Though they are few and far between, the dental school programs throughout the United States that have built clinics in this space have shown themselves to be leaders in providing education and experience in the treatment of people with I/DD, including programs at Tufts, West Virginia University, the University of Pittsburgh, the State University of New York (SUNY) at Stony Brook, and Rutgers University (among others). As previously noted, the Commission on Dental Accreditation has set a standard that dental school graduates "must be competent in assessing the treatment needs of patients with special needs." <sup>24</sup>

While it is certainly vital that dentists can "assess" patients' treatment needs, it is also imperative that dental programs attempt to prepare students for the actual treatment of patients with I/DD. Through its discourse with the American Academy of Developmental Medicine and Dentistry in examining this issue, NCD was pointed to two dental programs that serve as good specific examples of schools that go beyond the "assessment" requirement in the training of their students: Rutgers and SUNY-Stony Brook.

Within the Rutgers program,<sup>25</sup> training of predoctoral students includes both didactic and clinical components. Rutgers' Special Care Treatment Center (SCTC) facility contains nine fully equipped dental operatories, one of which is dedicated to dental hygiene and two of which are specially configured to accommodate large wheelchairs and stretchers. The operatories, unlike standard dental school student treatment bays, are all enclosed to permit privacy and are equipped with individual x-ray and nitrous oxide delivery units.

Lectures to the predoctoral students by SCTC faculty regarding care for patients with I/DD are provided in several courses spread throughout the four-year curriculum, including among others: 1) pediatric dentistry: two lecture hours focusing on medical and dental issues in the most commonly encountered I/DD populations; 2) clinical communications: two lecture hours addressing specialized communication challenges and techniques for people with I/DD; 3) third-year problem-based learning seminar: three small-group seminar hours covering case-based assessment of people with I/DD primarily, including medical history, consultations and diagnostics, triage and treatment planning essentials; and 4) a fourth-year elective in specialized care dentistry: 20 lecture hours of advanced topics in specialized care, focusing on interdisciplinary issues. SCTC faculty also provide didactic education to pediatric dentistry and prosthodontic postgraduate programs as well as dental assisting and dental hygiene programs, and a lecture series for oral medicine and general practice residency residents and fellows. SCTC faculty have also provided continuing dental education for community dentists through the school's program.

All fourth-year dental students at Rutgers are required to complete a one-week rotation through the SCTC. During this week, they serve as direct care providers to patients with I/DD primarily, as well as the complex geriatric population. The students provide any needed diagnostic, preventative, restorative or surgical services under the supervision of SCTC faculty. There is a strong focus on reinforcing the individuality of people with disabilities, identifying opportunities for interdisciplinary care, developing communication skills, integrating medical and dental knowledge as well as principles of basic sciences in treatment planning and care, and introducing specialized techniques optimized for people with disabilities, if needed. By the completion of the week-long rotation, students demonstrate competency in patient assessment by taking and passing a patient-based competency exercise.

Similarly, in the SUNY-Stony Brook School of Dental Medicine, a program was created to prepare students for the treatment of patients with disabilities whereby those students receive the didactic portion beginning in their second year as an integrated component of the Children's Dentistry curriculum. The course includes

# Supported Decision Making

Supported decision-making (SDM) is an alternative to guardianship that allows an individual with a disability to work with a support network of people they have chosen to help them make decisions including regarding medical care. Dentists and other medical practitioners who are required to obtain informed consent should be aware of this and other alternatives to guardianship so that they can accommodate the individual.

Supported decision-making is discussed in depth in NCD's report on guardianship, which will be posted to NCD's website in 2018.

a seven-hour series addressing the needs of patients with varied disabilities, including risk of disease identification, appropriate scope of care, informed consent, management of behavioral issues, and conventional versus alternative treatment approaches. In their third-year, students are presented with medical, developmental, and social topics specific to care of patients with disabilities. As the students progress during that year, they provide treatment to patients with increasingly complex needs and management challenges. Finally, in their senior year, all students participate in a 13-week comprehensive care clinic that is specific to adults with disabilities. A postgraduate program is also available and includes a 12-month fellowship.<sup>26</sup>

Clearly, the more experience and practice dental students receive with I/DD patients the more comfortable they will be to provide services to that population upon entering private practice. In consideration of this, NCD recommends a modification to the relevant dental school accreditation requirement.

As opposed to simply requiring that students be "competent in assessing the treatment needs of patients with special needs," NCD recommends students also "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)."

Per Dr. Evan Spivack, Professor of Pediatric Dentistry at the SCTC, the thinking behind the mere "assessment" requirement of the CODA standard is that not every school has an equitable amount of resources to build such a specific clinic. These programs also require hiring qualified professors who are content with the salary a university can provide in comparison to how much compensation is available in private practice. The creation of such a clinic has often come by way of educators with a personal dedication to the cause of proper treatment for those in the I/DD community.

Dr. Steven Perlman, Clinical Professor of Pediatric Dentistry at the Boston University School of Dental Medicine, added that patients with I/DD often have no choice but to travel several hours away to clinics such as those found at Rutgers and SUNY-Stony Brook because of the difficulty in finding private practitioners who are properly trained, willing, and able to provide the care they need. Perlman, who provided care for the late Rosemary Kennedy, at the request of her sister, the late Eunice Kennedy Shriver, has noted that many patients with I/DD may need some form of sedation or general anesthesia to complete the medically necessary dental care. In speaking with other practitioners, it was also noted that in the rare instance that the treatment provider *did* have the proper training, this process clearly requires more time than other patients are likely to need, thus private practitioners, many of whom have student loan debt they must pay, obviously find it more financially feasible to treat three patients in the time it would take to care for one patient with I/DD (a patient also unlikely to have private insurance).

### Medicaid

Approximately 60 percent of people in the United States with I/DD rely on Medicaid for their health insurance coverage;<sup>27</sup> and Medicaid's reimbursement doesn't always suffice. While comprehensive dental coverage is mandatory for children enrolled in Medicaid, dental benefits for adults eligible for Medicaid varies depending on the state.<sup>28</sup> States determine the scope of the dental services covered. While some states provide extensive coverage with more generous expenditure caps annually, others provide limited coverage with shorter caps, and some states only provide coverage for emergency relief alone.<sup>29</sup> Obviously, there is an ongoing debate concerning the proper allocation of public funds with respect to health care, and more specifically dental care, both nationally and within each respective state; however, the effect proper dental care has on preventing larger health concerns and costs cannot be underestimated.30 NCD recommends states that have limited their Medicaid coverage of adult dental benefit identify and implement mechanisms to pay for and provide more extensive coverage, including a per-person annual expenditure cap of at least \$1,000. Ultimately, absent more generous Medicaid coverage funding, solutions must be sought to not only produce better trained dental care providers in this space, but also to help encourage health care providers to serve the underserved despite their financial predicaments.

### **Underserved Population**

Many federal programs designed to improve access to health care services are offered through designations made by the Health Resources and Services Administration (HRSA), in accordance with the Public Health Service Act as amended.<sup>31</sup> As noted above, some people with I/DD experience significant health disparities, poorer health, and a lack of access to care. Also, as previously noted, not enough providers and specialists are trained or make themselves available to provide proper dental care to people of the I/DD population, thus creating a situation of medical underservice whereby patients must travel exceptionally long distances to find the clinics that do provide specialized care.

Currently, government programs that may help resolve these issues require population groupings based upon geography, which is problematic for people with I/DD. Historically, many people with I/DD were institutionalized and received what medical and dental care they may have received in the facility in which they resided, far removed from the rest of society and, for many decades, outside of meaningful oversight in terms of their care. The conditions at institutions such as Willowbrook, the largest facility of its kind and the most notorious for having been described by Robert Kennedy as a "snakepit," were extremely poor, with one former resident blaming her 19 years at Willowbrook for her mouth full of cavities.<sup>32</sup> (Because of this history and because institutionalization runs counter to the goals of the Americans with Disabilities Act, NCD has a longstanding position in favor of deinstitutionalization.)

Following the exposure of the deplorable conditions of many state-run institutions in the 1970s and following, the trend toward deinstitutionalization swept across the country and people with I/DD have no longer necessarily lived in congregate settings in the same geographic location, thus ineligible to access

many government programs that may otherwise help address their ongoing inadequate dental care.<sup>33</sup> Because deinstitutionalization was a significant civil rights achievement that advanced the equality of opportunity for people with disabilities to be full participants in society with respect to housing, employment, and community living, it should not result in a different step backward in equality of opportunity with respect to finding and availing oneself of accessible and appropriate dental care.<sup>34</sup>

As a means of helping to rectify the lack of proper dental care for people with I/DD, NCD recommends that Congress further amend the Public Health Services 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 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 care in the aforementioned scarcity areas. 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 the policy goals outlined above.

### **Conclusion**

Post-deinstitutionalization, many people of the I/DD population have become more reliant on local practitioners for their dental care and specialized clinics are often quite a distance away from many who could make use of them. It is imperative that members of the dental profession recognize their professional responsibility and dental students be provided with improved training in this area accordingly. It is also essential that Congress strengthen programs that provide dental practitioners additional incentives to provide that care once they enter practice.

Limited access to proper dental care is a significant problem for many people with I/DD. NCD's recommendations are intended to rectify this problem and secure professional dental care for people with I/DD in the same manner as others and in compliance with the Americans with Disabilities Act and the Rehabilitation Act.

### Recommendations

### 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

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 perperson 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."* 

### **Endnotes**

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- 5. Ibid., 425.

- 6. National Council on Disability. 2009. "The Current State of Health Care for People with Disabilities." 89.
- 7. 29 U.S.C. § 794.
- 8. 42 U.S.C. § 12101.
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- 20. Ibid.
- 21. Ibid.
- 22. Ibid., 251.
- Commission on Dental Accreditation. Accreditation Standards for Dental Education Programs. § 2-24.
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