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ISSUE BRIEF

Improving the Oral Health of Hoosiers With Disabilities: Current Landscape and Recommendations

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Background

The Center for Health Equity (CHE) at the Indiana Institute on Disability and Community, with support from the Indiana Governor's Council for People with Disabilities, has been conducting the Oral Health for Hoosiers with Disabilities Project since October 2018. The long-term goal of this project is to improve oral and general health and well-being for Hoosiers with disabilities and to advance quality of life for those with disabilities and their caregivers. There was an absence of comprehensive and up-to-date information about the oral health needs of Hoosiers with disabilities. To identify the current landscape for oral health and dental care for Hoosiers with disabilities, CHE conducted the following research activities: a) literature reviews of oral health needs and experience with dental care services for people with disabilities, as well as the capacity and needs of the dental workforce regarding the delivery of dental care to patients with disabilities; b) key informant interviews with adults with disabilities, family caregivers of individuals with disabilities, and dental professionals in Indiana; and c) two online surveys (a survey of family caregivers of Hoosiers with disabilities and a survey of dentists practicing in the state of Indiana).

In this section, the results of our literature reviews are briefly summarized. In the Findings section, we report the outcomes of our key informant interviews and two online surveys.

Literature Review of the Oral Health Needs of People with Disabilities

People with disabilities in the United States have greater oral health and dental care challenges compared to the general population. They are more likely to be from lower socio-economic groups and have more dental diseases and receive fewer dental services than the general population.^{1,2} Individuals with disabilities have significantly higher rates of tooth decay and dental care issues such as tooth extractions, fewer fillings, and tooth loss.³ Additionally, they have less oral health knowledge and access to dental care.⁴

Working-age adults ages 18-64 with disabilities are more likely to experience delayed and forgone needed dental care compared to their counterparts without disabilities.⁵ Such disparities are more substantial for adults with multiple disabilities.⁵ Also, working-age adults with disabilities, except for those who are deaf or hard of hearing, are less likely to have private dental

insurance.⁵ Children with intellectual and developmental disabilities sometimes have trouble accessing dentists because providers are reluctant to provide care for those with more complex needs and behavior issues.⁶ People with disabilities often encounter difficulty accessing and using dental care because of geographical distance,¹ physical barriers (e.g., inaccessible dental equipment and office including parking space and ramps),⁷⁻¹⁰ and communication barriers.⁸ Dental providers may not have ready access to appropriate forms of communication such as American Sign Language interpretation or alternative formats of written documents for people who are blind or have low vision.¹⁰

As facilitators of dental hygiene and dental care access, caregivers play an important role in the dental care and oral health of people with disabilities. But they can encounter challenges. Caregivers may lack knowledge about their child's dental history and about available dental services.¹¹ Caregivers may face financial constraints because some dental providers are unwilling to accept their child's insurance due to reimbursement issues or because treatment is expensive.¹¹ For caregivers supporting an individual with intellectual disabilities, some caregivers have concerns that the person may be aggressive if the caregiver attempted to help clean their teeth.¹² Negative prior experiences can make caregivers reluctant to help with oral care.¹²

Literature Review of the Capacity and Needs of the Oral Health Workforce Regarding Provision of Dental Care to People with Disabilities

Many individuals with disabilities encounter challenges in finding a competent dentist who can meet their oral health needs. Dentists are sometimes unfamiliar with the challenges that people with disabilities experience in obtaining and receiving oral and dental care,¹³ or they do not have adequate training and experience treating this group.⁷ Major barriers reported by dentists and hygienists in seeing patients with disabilities include behavior management of a patient, inadequate training/experience, the severity of a patient's condition, inadequately trained staff, accessibility of their facility, limited treatment time, and inadequate insurance reimbursement.^{6,14-16}

Efforts have been made to ensure that dental professionals address the oral health needs of people with disabilities. In 2004, the Commission on Dental Accreditation (CODA) initiated a requirement that dental students be competent in assessing the treatment needs of people with special health care needs by January 1, 2006 (SHCN).¹⁷ Patients with SHCN include those with developmental disabilities, cognitive impairment, complex medical problems, significant physical limitations, as well as vulnerable older adults.¹⁸ Additionally, in 2018, the American Dental Association (ADA) Principles of Ethics and Code of Professional Conduct was revised to include the provision that "dentists shall not refuse to accept patients into their practice or deny dental service to patients because of the patient's race, creed, color, gender, sexual orientation, gender identity, national origin or disability".¹⁹ Dentists are also required to refer to or consult with other dentists or medical professionals to meet a patient's care needs, if necessary.¹⁹ As of 2020, predoctoral programs are required to train students to assess and manage the treatment of patients with special needs; dental hygiene program students must be competent in providing dental care to special needs patients; and dental assistant students must be familiar with patients with SHCN whose conditions would modify normal dental routines.²⁰

Despite education and training requirements, dental students do not gain necessary experience treating patients with disabilities. Many dentists do not believe that their dental education prepared them to treat patients with disabilities.^{6,21,22} Despite this lack of preparation, dental

students have a strong desire and intention to treat individuals with special needs.²³⁻²⁵ Most dental hygiene programs provide information about patients with special needs, but only 42% of surveyed programs required students to gain clinical experience with patients with SHCN.²⁶ A survey of dental hygiene students and faculty found that the majority had not taken a formal course in disabilities or special education.²⁷

Findings from Key Informant Interviews and Online Surveys

Key Informant Interviews

The Center for Health Equity conducted interviews with people with disabilities, family caregivers, and representatives of the dental workforce (dentists, university-level dental educators, researchers) in Indiana, to examine the oral health needs of Hoosiers with disabilities and the current capacity and needs of the Indiana dental workforce to meet those needs.

Everybody is saying we can't do it for this reason or that reason, and so nobody's doing anything. They think, we'll just send her to somebody else, but then you run out of somebody else's eventually and that's where we're at. We've run out of somebody else's.

From the interviews with people with disabilities and family caregivers, the following themes became apparent: 1) disability status presents obstacles in receiving quality dental care services and maintaining at-home oral health care for people with disabilities; 2) people with disabilities may delay or forgo dental care because of costs; 3) oral home care may be challenging for some people with disabilities because of issues related to disability; 4) family caregivers experience frustrations when not included in planning and treatment decisions; 5) people with disabilities and families have found there is a lack of specialized dental services; and 6) the dental workforce in Indiana generally lacks the training and capacity to provide respectful, person-centered care and services to people with disabilities.²⁸

Medicaid reimbursement is already less than traditional insurance coverage and then these individuals may require additional time and resources making the already lower reimbursement even lower to the dentist.

The interviews with representatives of the dental workforce revealed the following themes: 1) there is limited training on how to work with people with disabilities in educational programs; 2) there is an overreliance on pediatric dentists to provide care for adults with disabilities; 3) there is a need to increase Medicaid reimbursement and dispel misconceptions regarding Medicaid programs and patients; 4) limited insurance coverage prevents people with disabilities from obtaining necessary dental health services; and 5) dentists have difficulty navigating the Medicaid system. Those themes indicate that insurance reforms are needed to improve access to dental care for people with disabilities, and that the provision of care for Hoosiers with disabilities is hindered by the lack of access to hospital-based services.²⁹

I don't think that they get enough training, enough lectures, enough background to really feel comfortable working with patients with disabilities. It's the lack of training, lack of courses, lack of interaction between the students and the faculty and the clinic.

Online Surveys

Survey of Family Caregivers of Hoosiers with Disabilities

The goal of this survey was to determine the oral health needs of people with disabilities in Indiana as perceived by their caregivers. The analytic sample consisted of 599 family caregivers who met the following inclusion criteria at the time of the survey: a) 18 years old and over, b) live in Indiana, and c) have a family member with a disability in Indiana for whom they were the primary caregiver. The following are highlights of the survey results³⁰:

- Regarding the type of disability of their family members with disabilities, the respondents (family caregivers) reported independent living disability (57.3%) most commonly, followed by cognitive disability (50.8%) and self-care disability (43.9%). The top four conditions of those with disabilities were speech or language impairment (14.0%), learning disability (13.9%), autism spectrum disorder (10.2%), and intellectual disability (8.4%).
- The large majority of the respondents reported having a regular dentist (usual source of dental care [USDC]) which does not include a hospital emergency room, for the person with a disability (83.8%).
- For the respondents reporting no USDC, the top five common reasons were as follows:
 - “Cannot find a dentist who is competent in working with individuals with disabilities” (17.2%)
 - “Family member’s (the person with a disability) fear, apprehension, nervousness, or dislike of going to a dentist” (12.9%)
 - “Concern that the person with a disability will have difficulty controlling his/her behavior” (11.8%)
 - “Cannot afford care” (10.8%)
 - “Cannot find a dentist who accepts insurance plan” (10.8%)

- A large proportion of the respondents with a USDC for the person with a disability reported that the facilities of USDC for the family member were not accessible. Only 40.1% reported their dental providers provided accommodations for communication; 46.1% of dental providers had accessible entrances; 45.3% dental equipment; 48% office spaces; and 51.9% parking spaces.
- Nearly two-thirds of all respondents reported that they had taken the person with a disability to the hospital emergency room at least once in the past 12 months because of dental care or dental pain (66.3%).
- One in ten respondents reported that they *primarily* went to hospital emergency room for the dental care of the person with a disability (9.6%).
- More than one-third of the respondents (35.6%) reported that it took more than one hour to take the person with a disability to the dental office: 14.2% for 61 minutes to 90 minutes; 9.6% for 91 minutes to 120 minutes; and 11.8% for more than 2 hours.
- Half of the respondents reported a delayed dental care for their family member with a disability in the past 12 months (50.1%). The five main reasons were as follows:
 - “No accommodation available for communication with dentists or oral health professionals” (13.3%)
 - “COVID-19 pandemic” (13.3%)
 - “Dentist too far away from where I live” (12.9%)
 - “Family member’s (the person with a disability) fear, apprehension, nervousness, or dislike of going to a dentist” (8.7%)
 - “Dentist’s office/clinic or dental equipment (for example, dental chair) not physically accessible” (7.2%)
- A significant proportion of the respondents reported that their family member with a disability had frequent or chronic difficulty in various oral health conditions during the past 12 months:
 - “Toothache or sensitive teeth” (51.8%)
 - “Bleeding gums” (47.8%)
 - “Cavities” (44.6%)
 - “Difficulty eating or chewing” (36.1%)
- Approximately one-third of the respondents reported that the person with a disability could “sometimes” perform at-home oral care (e.g., tooth brushing or flossing) on their own (31.1%). About one in seven respondents reported the person with a disability could “never” do it on their own (13.6%).
- More than half of the respondents reported that they needed education or training on providing at-home oral care for family members with disabilities (54.6%).

Survey of Indiana Dentists

The goal of this survey was to determine the current capacity and needs of dentists practicing in Indiana regarding the provision of dental care to patients with disabilities. The analytic sample consisted of 142 dentists who met the following inclusion criteria at the time of the survey: a) 18 years old and over; b) currently hold an active dental license issued by Indiana; and c) currently provide dental care to patients in Indiana. The following are highlights of the survey results³¹:

- Approximately three-fourths of dentists reported general practice as their primary practice (73.2% for general practice vs. 26.6% for specialty practice). The most common specialty services routinely performed by dentists included: pediatric dentistry (16.5%),

prosthodontics (14.7%), oral and maxillofacial surgery (14.4%), periodontics (12.6%), and endodontics (11.7%).

- Only two in five dentists reported that they are currently enrolled as Indiana Medicaid providers (40.9%). Of those dentists enrolled, nearly three-fourths currently accept new Medicaid patients (74.1%).
 - The three most selected reasons for dentists not enrolled as Medicaid providers or not accepting new Medicaid patients are as follows:
 - “Low reimbursement rates” (27%)
 - “Broken appointments (e.g., late cancellations/rescheduling or no-shows)” (17.6%)
 - “Complicated paperwork” (14.8%)
 - Three-fifths of the dentists reported that they planned to maintain their practice as is, in the next five years (59.0%), and that more than a quarter planned to retire (26.9%). Of those dentists planning to retire, 75% of them were enrolled as Medicaid providers.
 - Most of the dentists “somewhat” agreed or “definitely” agreed that they were prepared to treat patients in various underserved population groups. The dentists reported that they felt least prepared for providing dental care to children with developmental disabilities (77.6%, “somewhat” agreed and “definitely” agreed combined), followed by children with sensory disabilities (80.3%), children with physical disabilities (83.2%), and adults with sensory disabilities (84.0%).
 - The dentists reported their experience in special care dentistry through the following educational activities: academic training including didactic or clinical education (16.0%); residency training (15.6%); or continuing education (19.3%). Approximately 40 percent of the dentists reported their involvement in special care dentistry through clinical practice (37.9%).
 - The dentists selected the following three as the most common barriers to their provision of dental care to individuals with disabilities:
 - “Patient behavior” (23.0%)
 - “Severity of disability” (22.6%)
 - “Care is more time consuming” (10.3%)
 - The dentists reported the following topics as most important for dental professionals to know regarding patients with disabilities:
 - “Behavior management” (23.5%)
 - “Effective strategies for communicating with patients” (15.1%)
 - “How to reduce patients’ anxiety” (13.0%)
 - “Effective preparation for treating patients with disabilities in practice” (10.5%)
- These four topics were also selected most frequently as training topics in which the dentists expressed interest if trainings were made available.

Conclusion

The findings of our project research provide valuable information about the oral health needs of Hoosiers with disabilities, as well as the capacity and needs of the Indiana dental workforce in providing dental care to those with disabilities. The results of the key informant interviews and online surveys reinforce the findings of previous research indicating that people with disabilities face significant difficulties in obtaining dental care services and maintaining oral health at home; and that the dental workforce lacks the training and capacity to provide quality dental care to people with disabilities.

Oral health is integral to one's general health and well-being. Access to appropriate dental care and good oral hygiene are critical for achieving optimal health for Hoosiers with disabilities. Changes in multiple areas are necessary for Hoosiers with disabilities to obtain equitable oral health outcomes and receive person-centered, quality dental care. Below are our recommendations to improve the oral and dental care experiences of this group.

Recommendations

On the basis of the findings of comprehensive literature reviews, key informant interviews and online surveys, we make the following policy and practice recommendations:

Policy Recommendations

- 1) **Increase the number of Medicaid providers and reimbursement rates in Indiana.** Roughly 60% of adults with intellectual and developmental disabilities (IDD) have Medicaid coverage.⁸ However, many states face a shortage of dental providers willing to enroll in their Medicaid programs.³² In 2019, about 12.9% of Hoosiers were identified as having a cognitive disability.³³ Low reimbursement rates are frequently cited as the main reason for not accepting patients insured by Medicaid.^{29,31,6,34}
- 2) **Increase education, including experiential education opportunities working with underserved populations, during dental and dental hygiene school.** Research has shown that dental providers who received hands-on experience have a greater likelihood of treating patients with disabilities, greater satisfaction working with people with disabilities, and the perception of fewer barriers to providing care to this population.^{23,35}
- 3) **Expand the definition of medically underserved populations (MUP) for student loan forgiveness and repayment programs.**^{8,36,37} The majority of health professional doctorate program graduates have student loan debt. The average educational debt for dental school graduates in 2019 was \$292,169,³⁸ and the debt-to-income ratio has increased over the past decade.³⁹ Reducing education debt by encouraging the provision of care to individuals with special needs should be the number one priority of public health, dentistry, and medicine.⁴⁰ The MUP designation also provides for special research grants, and Medicaid reimbursements can be enhanced under specific programs.⁴¹ In 2006, the Health Resources and Services Administration (HRSA) Advisory Committee on Training in Primary Care Medicine and Dentistry recommended that the definition of MUP be expanded to include people with intellectual disabilities.⁴² However, the federal government has yet to designate people with disabilities as a MUP.
- 4) **Increase integration of oral health and primary health care.** The delivery of preventive oral health services (POHS) in medical settings allows for dental services in communities without a sufficient dental workforce.⁴³ The majority of patients, dentists, physicians, and Medicaid dental administrators believe that oral health and overall health are connected, and that collaborative care can improve patient outcomes.⁴⁴ Dentists are also interested in expanding dental care to non-traditional dental care locations such as community health centers, primary care offices, or community centers.⁴⁴ State Medicaid policies that allow for POHS in medical offices have been shown to be an effective strategy to increase access to dental care and thus improve oral health for this high-needs population, specifically young children with IDD.⁴³ Medical providers can monitor

children’s oral health, provide referrals, and facilitate dental visits for the highest-risk children until they have a dental home.⁴⁵ The Centers for Disease Control and Prevention is currently developing a national framework to integrate medical and dental care to support populations with unmet oral health needs.⁴⁶

- 5) **Provide “virtual dental homes” for adults with disabilities who cannot easily access the nearest dental provider.** A virtual dental home is a type of telehealth service that provides ongoing, year-round access to preventive oral health services in community settings (e.g., schools, group homes, and adult daycare) and delivers evidence-based preventive care aimed at sustainable oral health.⁴⁷ Dental hygienists and assistants collect dental information, conduct exams, and collaborate with dentists to create treatment plans. This type of intervention is less expensive and allows for greater access to dental care for children, seniors, and people with disabilities because it provides dental care in community settings.⁴⁸

Practice Recommendations

- 1) **Dental providers need to provide patient-centered quality care to patients with disabilities.** Patient-centered care means that a person and their social well-being is at the center of the decision-making process, with an understanding of the significant roles played by individual behavior, context, and lifestyle.⁴⁹ For patient-centered care to be successful for people with disabilities, dental providers need more training to be clinically competent to provide quality care to this population. This also includes enhancing their disability cultural competence about how to work with people with disabilities. Additionally, dental services need to be accessible to people with disabilities in regard to access to the dentist’s office, office setup, dental equipment, and communication with patients. Dental providers should provide behavioral, social, and physical support to help patients with SHCN receive services.⁵⁰
- 2) **For the provision of quality dental care to people with disabilities, the dental workforce needs to consider communication styles, accommodations, and accessible care, in addition to clinical competence.**
 - a. Good communication is essential to good clinical practice and reduces patient anxiety.⁵¹ Examples of accommodations include the following: allow for extra time for an individual to respond; minimize background noise; use pre-prepared written responses; not shout or use jargon; know when and when not to use gestures; and provide sign-language interpreters.^{51,52} It is also important to speak to the patient with a disability directly.
 - b. Provide accommodation based on individual need.
 - i. For individuals with vision disability, dental providers should utilize the individual’s other senses to facilitate a positive experience (e.g., descriptive explanation of every step of examinations [audio cues]).⁵³ Dental providers should work with these individuals to accomplish oral hygiene tasks independently and communicate ways to adapt their routines.⁵⁴
 - ii. For patients with mobility limitations, patients or caregivers should be asked about their preferred method for transfer to the dental chair and

receive help transferring if needed. Transfer steps should be practiced by the dental team before a transfer is attempted, and, during transfer, a patient's anxiety can be addressed by announcing each step beforehand.⁵³

- iii. For individuals who are deaf or hard of hearing, communication is crucial. Determine the patient's preference for communication.⁵² Accommodations include removing unnecessary background noise and music, using visual clues, using clear face masks/shields to allow for lip reading, and providing sign language interpreters.⁵³
 - iv. For children with SHCN, such as those with autism spectrum disorder, dental providers can provide educational and behavior guidance techniques before and during appointments.⁵⁵ Techniques include the use of picture cards, instructional video clips, and virtual reality.⁵⁵ This may help patients feel less overwhelmed by the multiple forms of stimuli and become comfortable with providers. Allow for flexibility when scheduling appointments and minimize wait times.^{53,56} Pre-visits can aid in desensitization, and use of social stories and pictures can also reduce anxiety.^{53,56,57}
- c. To provide accessible dental care for patients with disabilities, the dental workforce needs training on the concepts of access under disability civil rights laws, such as the Americans with Disabilities Act and Section 504 of the Rehabilitation Act, including effective communication, barrier removal, and modifications to practices and procedures to accommodate patients with disabilities.⁵⁸

- 3) **Proper oral health education for people with disabilities and their caregivers is integral to meeting the long-term oral health needs of people with disabilities.** Both caregivers and individuals with disabilities report that they need better education about maintaining oral health and how to access dental services.^{30,28,59} For example, mothers of children with Down syndrome reported being unaware of their children's dental problems and the benefits of a dental visit.¹¹ Dental care providers can assist them by providing oral health education that is practical and customizable to individuals' and their caregivers' needs.⁶⁰
- 4) **For people with disabilities to achieve optimal oral health, paid and family caregivers are encouraged to provide appropriate support to individuals with disabilities to regularly engage in oral hygiene at home.** The individuals with disabilities should be encouraged to develop independent skills as well as being assisted when necessary. Creating a daily oral care routine can help facilitate oral care for people with intellectual disabilities.¹² Scheduling oral care at set times can make it easier to remember when to do it, and doing oral care in a relaxing environment can be helpful.¹² Caregivers should provide verbal reminders and be models for people with disabilities on how to properly clean teeth.¹²

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