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Seeking Solutions:
Dental Health and Disabilities in Indiana

Developed and Designed by McMillen Health
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Megan Wilkinson
McMillen Health

Angel Winchester
McMillen Health

Alysia Marshall-Seslar
McMillen Health

Lettie Haver
McMillen Health

Barbie Vartanian
Project Accessible Oral Health

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Think differently about disabilities.

DELTA DENTAL FOUNDATION

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Introduction

In this report, McMillen Health summarizes a 2022 dental health needs assessment of adults with disabilities in Indiana. **McMillen conducted this research to illuminate the needs, barriers, and challenges of adults with disabilities and their caregivers in seeking dental health care.** This assessment also reports on a range of responses to such needs, barriers, and challenges.

For the purposes of this research, McMillen Health performed a literature review as well as interviews, focus groups, and surveys with people with disabilities, their caregivers, and dental care providers. Interviewees and survey takers answered a variety of questions (see Appendix on page A1) to help assess the variety of experiences and perspectives on the subject. Specifically, questions addressed at-home care, professional care, and financial barriers and concerns. Questions for dental providers covered training and professional development. **From the interviews and focus groups, themes emerged, as did a range of personal stories spanning from beneficial, positive experiences to traumatic, harmful ones.** Along with interviews, McMillen Health also conducted a statewide survey of dental offices to learn more about access to dental health care for adults with disabilities. This survey was completed using a "secret shopper" script and provided information on what types of interactions, accommodations, and support adults with disabilities can expect when they contact a dental office in Indiana. A digital dental health directory was developed from this secret shopper survey to allow users to search for dentists by county.

McMillen Health conducted the study, as well as developed and designed the report. Project Accessible Oral Health consulted on the research design and assisted in the research activities.

Purpose

A note on defining disabilities:

There exists in the literature a wide variety of labels for people with disabilities, so our review of the literature reflects that variety. This study was inclusive of all disabilities, including intellectual and developmental disability (IDD), neurodivergent disability (e.g., autism), and physical disabilities (e.g., blindness, cerebral palsy). In this report, we use specific terms when we are referring to a specific disability or category of disability. We use the word "disability" or phrase "adult with disability" as inclusive of all individuals who have atypical abilities.

Adults with disabilities face multiple barriers to health care, increasing their vulnerability to dental health disease. The dental healthcare field does not often research and teach about these barriers and tools that could address them. **The purpose for this project is to clarify these barriers and outline a range of responses that may better serve the dental healthcare needs of Hoosier adults with disabilities.**

In Indiana, the rate of disability in adults (28%) is slightly higher than the US average (25.65%)[i]. Specifically, 14% of Hoosier adults have difficulty with mobility (walking or climbing stairs), 13% with cognition (concentrating, remembering, or making decisions), 8% with independent living (running errands, going to the doctor alone), and 4% have disabilities with self-care (dressing, bathing, etc.).[ii] These difficulties present a variety of barriers to ideal dental health care.

14%
of Hoosier adults have difficulty with mobility

13%
of Hoosier adults have difficulty with cognition

8%
of Hoosier adults have difficulty with independent living

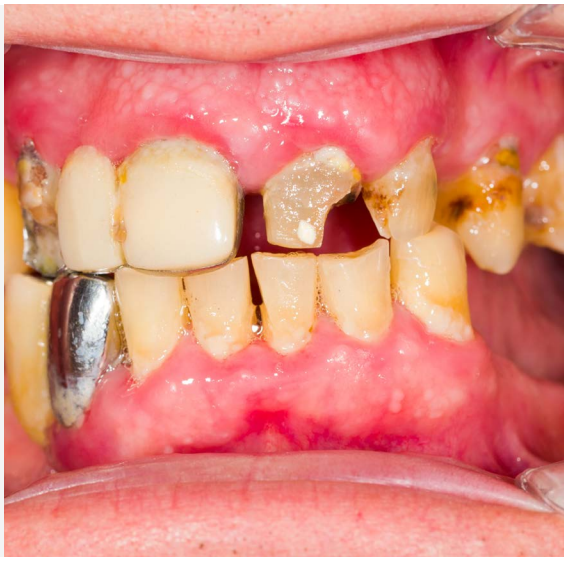
4%
of Hoosier adults have difficulty with self-care

According to the 2020 dental health metrics from the Oral Health Program of the Indiana Department of Health, 35.6% of Hoosier adults aged 18 years and older did not have a dental visit during the past year.[iii] **Individuals with disabilities are even less likely to visit the dentist, making them at a higher risk for dental health problems.** This disparity can be attributed to long-established barriers to accessing health care – poverty, minority status, and rural location – as well as to additional barriers specific to each individual. Additional barriers can include transportation, financial hurdles, scheduling difficulties, and access to dental offices that serve adults with disabilities.

Disparities in dental health for individuals with disabilities begin in childhood. **Children with disabilities are more likely to have caries and less likely to visit the dentist.** Over 78% of children with disabilities needed dental care in the past twelve months.[iv] Socio-economic status, insurance options, and the severity of a child's disabilities will all influence the accessibility and regularity of quality dental care. **Patterns of poor dental care will lead to more dental problems and poor dental hygiene habits that extend into adulthood.**

In 2020, Indiana University's Center for Health Equity conducted a statewide, online survey of 599 caregivers of individuals with disabilities. Half (50.1%) of respondents reported that their family member with a disability experienced delayed dental care in the previous 12 months. Notably, only 13.3% of these delays were attributed to COVID-19-related issues.[v] The survey also showed that about two-thirds (63.2%) of respondents with a family member with a disability, aged 13 and older, lost permanent teeth as a result of tooth decay or gum disease. The report goes on to note that, "One in four respondents reported that the person with a disability had lost six or more permanent teeth: 'all' (13.1%) and '6 or more, but not all' (12.7%)."[vi]

For people with IDD, dental health is the number one unmet health need. Research demonstrates disparities in outcomes and obstacles.



Individuals with IDD:

- May have difficulty or the inability to express their needs about pain or other concerns.
- Have a higher rate of gingivitis and periodontal disease than the general population; they develop caries at the same rate as the general population, but the prevalence of untreated dental caries is higher.[vii]
- Are more likely to have misaligned or missing permanent teeth, delayed eruption, and underdeveloped tooth enamel.

Many have damaging oral habits, such as bruxism (tooth grinding), mouth breathing, tongue thrusting, self-injurious behavior, and pica (eating non-food items).

Individuals with IDD are more likely to have secondary medical conditions that affect their dental care. Conditions such as aspiration pneumonia, seizure disorders, sensory processing disorders, and behavior and mental health needs. These secondary conditions are often unrecognized, misunderstood, or dismissed. **This creates barriers to quality dental care or prevents individuals from receiving dental care altogether.**

Additionally, the majority (80.3%) of adults with IDD have periodontitis (gum disease) and 10.9% are edentulous (have no teeth).[viii]

The extensive health needs of people with disabilities include: [ix]

25% may require advanced behavioral guidance techniques

40% need some form of behavioral assistance

Two-thirds are not able to receive dental health care without modified support

Framework

Social Role Valorization

In examining the motivation of nondisabled individuals to address the needs of adults with disability in dental health care, a theory called **Social Role Valorization (SRV) illuminates the harm of the societal view of people with intellectual and developmental disabilities as burdens and as pitiful.** The foundation of SRV is that the good things in life are afforded to individuals who are deemed worthy – and those deemed unworthy are denied services and care. This view can be directed toward all individuals with disabilities and toward any population perceived to have low social status. The view contributes to a low sense of incentive to provide meaningful support. **Looking at dental health through the SRV lens allows opportunities for training that examines and eliminates this limited belief through practices that reinforce individuals' sense of self and competency.**

Health Equity Framework

The Health Equity Framework is grounded in the realization of health disparities seen in people with disabilities. **This framework recognizes that there are systemic barriers to healthcare for people with disabilities.** Within the framework is the want to see equity in healthcare for people with disabilities. According to the National Council on Disabilities, a guide to improving health equity includes using accessible medical equipment and improving data collection about healthcare for people with disabilities.[x] **This report seeks to add to the data available about adults with disabilities and to bring awareness to the need for equitable access to dental healthcare.**

Literature Review

Individuals with disabilities often have more serious dental health issues than the general population. Still, most research has not focused on the overall state of dental health needs for adults with disabilities. There is also a lack of research on how adults with disabilities and their caregivers access dental health care. The research on individuals with disabilities tends to focus largely on youth, individuals with intellectual or developmental disabilities specifically, or a single type of disability. Some studies also review dental health educational materials and technical interventions for people with disabilities and their caregivers.

Indiana University's Center for Health Equity began its Oral Health for Hoosiers with Disabilities Project in 2019, adding valuable research to the field.[xi] The Center has collected and shared data from online caregiver and dentist surveys as well as interviews with multiple informant groups. Using this data, the Center has developed and shared recommendations for practice and policy changes.

Home Care

An important aspect of understanding the dental health care needs for individuals with disabilities is research on caregivers, including family and professional caregivers.

Education for caregivers has been shown by Binkley et al. to improve at-home dental care for people with IDD, including the number of times teeth were brushed per day.[xii] Shin and Saeed looked at what makes toothbrushing difficult and how education might make it better. They found that the biggest difficulties were dental hygiene steps that required dexterity. Education did not greatly improve this.[xiii] Wilson et al. looked at existing research pointing to gaps in examining the effectiveness of tools for supporting motivation versus investigating tools for improving the technical approach, finding the latter is far more common and the former is needed.[xiv]

This literature review also notes a distinction between the availability of caregiver education for paid staff versus for family caregivers. Wilson et al. further call for research on the effectiveness of caregiver education over time, specifically asking if technical training is more effective when combined with motivational training on the value of caring for the dental health of people with IDD. Lee et al. report that "more than half of the [Family Caregiver of Hoosiers with Disabilities Survey] respondents reported that they needed education or training on providing at-home oral care for family members with disabilities (54.6%)."[xv]

Dental Provider Care

Dental care and dental care barriers for individuals with disabilities can be broken into the following five dimensions:

1. Availability
2. Accessibility
3. Accommodation
4. Acceptability
5. Affordability

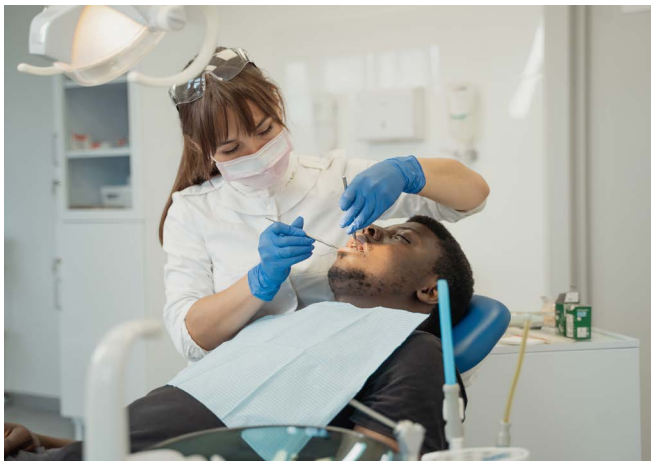
These dimensions help differentiate the various challenges encountered and ensure that solutions address the actual concerns.[xvi] These terms can overlap but defining them separately clarifies the needs for adults with disabilities in dental healthcare.

1. Availability

First, availability considers what, at minimum, is being offered to dental patients in their area. Before addressing other needs, do the services even exist?

Availability also looks at how many people need the service compared to how many people can reasonably use the service. Sometimes these services exist but are in such high demand that they are not a feasible option. If patients are put on waitlists or must schedule an appointment months or years in the future, the services may not be considered available.

For example, if a dental office has a wheelchair-accessible exam room, but also no available appointments for 9 months, the services are not available in a way that is useful to the patient. In this case, the existence of the service is not meeting the needs of the patient population.



A 2022 report from the National Council on Disability highlighted two main challenges relating to availability of dental services for adults with IDD.[xvii] **The first is the availability of dental professionals trained and educated in treating patients with disabilities.**

The second availability challenge identified in the National Council on Disability report is a shortage of operating rooms or dental surgery settings. Some individuals with disabilities need general anesthesia to tolerate dental procedures,

including basic preventive dental care. To use operating rooms, patients must wait for availability in hospitals where surgeries are prioritized over dental procedures. In places where dental surgery clinics exist, there are often long waiting lists. General anesthesia is more dangerous and expensive and requires more coordination by a medical team. Even when this is an option, it is not a readily available one."[xviii]

2. Accessibility

Accessibility considers the barriers individuals with disabilities find when they seek dental health care. This domain focuses on "practically accessing care."[xix] When researching accessibility, we need to look at all aspects of a provider's services and ask, "Can an individual with a specific disability or disabilities obtain dental health care in the existing facility? Are services accessible?"

Accessibility includes the physical design elements of the dental office, as well as the location and travel time to that office. Another consideration for accessibility is the office's location in proximity to public transportation.

Physical design can include designated parking spots or wide entryways with ramps. **Often, compliance with Americans with Disabilities Act (ADA) guidance becomes a standardized bare minimum but is not necessarily appropriate for all individuals.** For example, an office can be wheelchair accessible without the exam room being comfortably maneuverable by a person using a wheelchair.

Questions of accessibility deal with physical design elements such as designated parking spaces, entryways with ramps, gentle slopes or zero entry, and doorways wide enough to accommodate wheelchairs and other assisting devices.

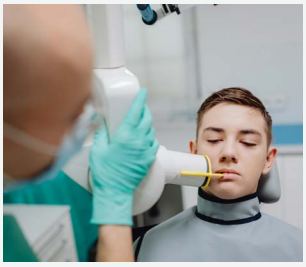
Some research points to the value for dental providers in using audit tools for assessing and tending to accessibility needs.[xx]

Examples of services that help adults with disabilities access dental health care include:

- Range of sedation options
- Wheelchair accessibility
- Receiving dental care while remaining in a wheelchair
- Specialty training for dental professionals
- Flexible scheduling
- Language services

In surveying Indiana caregivers for individuals with disabilities, Lee et al. finds that they report as few as:

46.1%
of dental providers had accessible entrances



45.3%
of dental providers had accessible dental equipment

48%
of dental providers had accessible office spaces

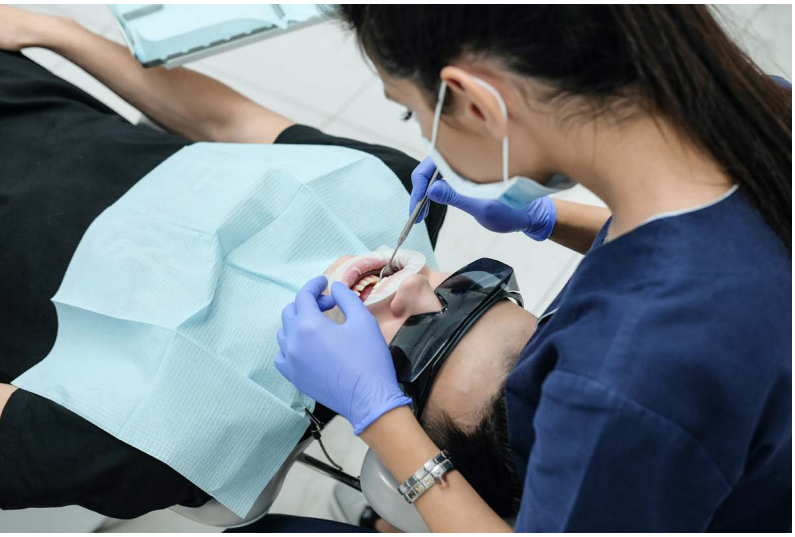
51.9%
of dental providers had accessible parking spaces

7.2% of respondents who reported that their family member with a disability delayed a dental appointment in the last year, stated this was because "dentist's office/clinic or dental equipment (for example, dental chair) not physically accessible."

12.9% reported the same because "dentist too far away from where I live."[xxi]

3. Accommodation

Accommodation considers how a dental office works with an individual with disabilities to counter or remove barriers. This domain also focuses on the relationship between a provider and an individual.[xxii]



Common accommodations for patients with disabilities include quiet exam rooms, dimmed lighting, soothing music, headphones, or fidget toys or comfort items during appointments. Accommodations in scheduling also help patients with disabilities access dental care. This can include flexible scheduling that considers the timing of a patient's medications, meals, restroom concerns, transportation, caregiver availability, or the need to maintain established routines. Scheduling accommodations also include appointments during quieter times during the day, "get to know you" appointments, and flexible re-scheduling policies.

A critical part of the provider-patient relationship is communication. One study showed that the most important factor when people with disabilities visit the dentist is the dental team being informed of the patient's dental health concerns.[xxiii] Another study found that lack of meaningful communication was the biggest issue in dental health care.[xxiv] The research corroborates the need for effective, sensitive, patient-

centered communication. **This communication between dental team and patient needs to be a two-way understanding about dental health needs and plans.** Achieving this requires both the desire and the tools to communicate effectively. Education therefore should address both.

Another communication failure between dental professionals and patients with disabilities is called, **"diagnostic overshadowing."** This is a common and potentially dangerous practice of dismissing new complaints, needs, or conditions as something related to the patient's disability or medical diagnosis. Such dismissals lead to missed diagnoses and nontreatment of conditions, or misdiagnosis and mistreatment.

Research by Clough and Handley reports that the concept and tools for overcoming diagnostic overshadowing are familiar in medical training but relatively new and under-discussed in dentistry.[xxv] They review tools to help overcome the phenomena, including techniques to communicate with people who are verbally limited or nonverbal. Without such a tool, if a person with IDD who is also non-verbal or verbally limited arrives at the dentist hitting their head, for example, the behavior can be overlooked, and pain can be dismissed. In a case study by Sheild et al., a dental passport tool that includes information about the individuals' abilities in communication and mobility is highlighted as an example of an effective, practical approach for surfacing patient needs in a clear, simple way.

In 2019, the Commission on Dental Accreditation (CODA) made a revision to its standards. **Now graduating dental students, dental hygienists, and dental health professionals "must be competent in assessing and managing the treatment of patients with special needs."** Looking at the CODA standards, the intent of this revision is **to ensure that school dental programs are giving students experience in assessing and providing services for individuals with disabilities.** This revision is not retroactive for dental professionals that have already graduated and started practicing. More time will have to pass before we can see the full impact of this new standard.

4. Acceptability

Acceptability is a patient with disabilities' agency to decide if the availability, accessibility, and accommodations meet their needs. **A patient-centered approach that includes the dental professionals and patient's caregivers is the best pathway to acceptable dental services.**

Research in this area is limited; however, there is a global study looking broadly at "barriers in access to healthcare services for women with disabilities (WWD) internationally,"[xxvi] Matin et al. found that women with IDD, "faced barriers in making informed decisions." The study concluded that women with IDD are often rushed and pressured to make healthcare choices without sufficient information. In some cases, providers ignored a woman's healthcare choices. In other cases, a patient's family caregivers made, or attempted to make, healthcare choices for them.

5. Affordability

Affordability looks at how cost is a barrier to dental treatment and care for individuals with disabilities. Cost includes direct costs, indirect costs, and potential costs. Direct cost is the price of treatment while indirect costs include transportation, prescriptions, and loss of earnings during appointments. Potential costs are also a barrier because the unknown price of treatment can prevent an adult with disabilities from seeking dental care. Unfortunately, untreated dental issues only become more costly when left untreated. Extensive and emergency dental procedures have a higher price tag.

According to Lee et al., only two in five Hoosier dentists reported that they are currently enrolled as Indiana Medicaid providers (40.9%). Dentists report that "low reimbursement rates" (27%); "broken appointments (e.g., late cancellations/rescheduling or no-shows)" (17.6%); and "complicated paperwork" (14.8%) account for this.

By addressing these five dimensions, availability, accessibility, accommodation, acceptability, and affordability, adults with disabilities will have far fewer barriers to obtaining regular, quality dental care.

2 in 5
Hoosier dentists are currently enrolled as Indiana Medicaid providers

27%
of dentists report "low reimbursement rates"

17.6%
of dentists report broken appointments

14.8%
of dentists report complicated paperwork

Modification of Services

We can see the difference that modifications can make when looking at a specialized dental provider in Louisville, Kentucky. Lee Specialty Clinic modifies 67% of its services to people with disabilities and sees only a 1.8% surgical referral. In contrast, the national average rate for modifying services is only 15% which is linked to a significantly higher rate (25%) of operating room referrals. Overall operating room costs are $98,550 for Lee Specialty Clinic, while the national average is $1,368,750. That is a 1,388% reduction in overall costs by offering modifications.

$98,550

overall operating room costs for the clinic

$1,368,750

national average operating room costs

1,388% less

overall costs by offering modifications.

Modifications mean that more people with disabilities avoid surgery and are more likely to keep their teeth. Notably, by controlling for individual costs of the operating room, regardless of who refers the patient, there are significant cost savings. The costs of surgery are lower, and the outcomes are better for adults with disabilities who are properly and regularly served in dental offices. **Unfortunately, many dental healthcare providers still need more education on treating patients with disabilities.** Such education would bolster the motivation to fulfill the five dimensions of care, bringing more equity to dental care.

By offering modifications, dental offices make dental treatment more possible for individuals with disabilities. Modifications include accessible buildings and equipment, accommodations, and specialized services. While modifications promote dental health for patients with disabilities, the absence of modifications is detrimental.

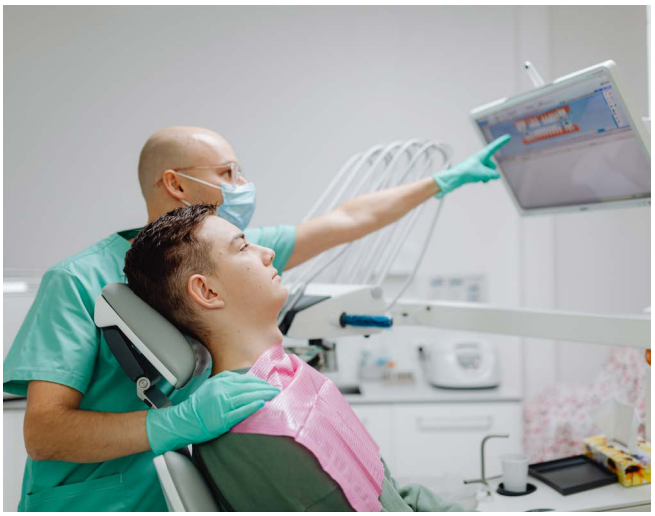
Some suggestions for improving dental health care for people with disabilities include these kinds of specialized dental clinics,[xxvii] support for people with disabilities who face insensitivity,[xxviii] education and training for caregivers,[xxix] social support for caregivers,[xxx] and improved access to dentists who specialize in care for individuals with disabilities.[xxxi] **Dental professionals shared some of these same challenges, stating that they lack proper training, their staff are not properly equipped to handle problem behaviors, and they are not able to dedicate the extra time needed for their patients with disabilities.[xxxii]**

Federally, a movement to address these barriers was reintroduced in November of 2021 with the **Heads Up Act**. **The act calls for the designation of individuals with IDD as a Medically Underserved Population, a designation developed in 1996 that affords groups increased services.**

For example, the designation would mean that more than 25 federal programs could open for care providers of individuals with disabilities, including

- Funding for health centers and public health infrastructure
- Access to loan repayment and training programs
- Incentives for providers such as higher reimbursement rates
- Preference for federal research

Unfortunately, this legislation focuses specifically on people with IDD, excluding the much larger population of people with disabilities.



Another exciting recent development is the report entitled: Medicaid Oral Health Coverage for Adults with Intellectual and Developmental Disabilities – A Fiscal Analysis, recently submitted to President Joe Biden by the National Council on Disability (NCD), the federal disability policy advisor.[xxxiii] The report states:

> In this report, NCD examines the cost in those jurisdictions of not providing Medicaid dental benefits for adults with I/DD and determines that it is more cost effective and fiscally responsible to provide those benefits than to continue excluding those benefits. Doing so is also consistent with your Administration's commitment to equity for underserved communities, including people with disabilities, and your commitment to fiscal responsibility.

This report was motivated by a central research question: should the Centers for Medicare and Medicaid Services require all state Medicaid agencies to implement Medicaid reimbursement and payment policies that promote access to dental care for adults with I/DD, and would doing so be cost effective over the long term? The answer is "absolutely yes" to both questions."

Medicaid Coverage

A significant barrier to dental care for adults with disabilities is insurance coverage. A 2022 report by the National Council on Disability looked at the current impact Medicaid coverage has on adults with IDD.[xxxiv] **Currently, 12 states do not provide Medicaid coverage for basic dental care for adults.** Adults with disabilities, who are already at higher risk for dental issues, are also more likely to depend on Medicaid for insurance coverage. According to the report:

> Adults with I/DD were over three times as likely to receive basic dental care if they lived in a state with extensive or limited Medicaid dental coverage, relative to states with no coverage, and 1.5 times as likely to receive basic dental care, relative to states with emergency-only coverage.

Focusing on the financial impact of Medicaid coverage specifically, the report found that providing coverage for basic dental care would fully pay for itself in savings. What Medicaid does not pay for in basic dental care it eventually does pay for in emergency room visits, hospital stays, and treatments for chronic conditions.

In the 12 states reviewed by the National Council on Disability that do not provide basic dental Medicaid coverage, it would cost $19.6 million to add it. However, the savings would be over $27 million.

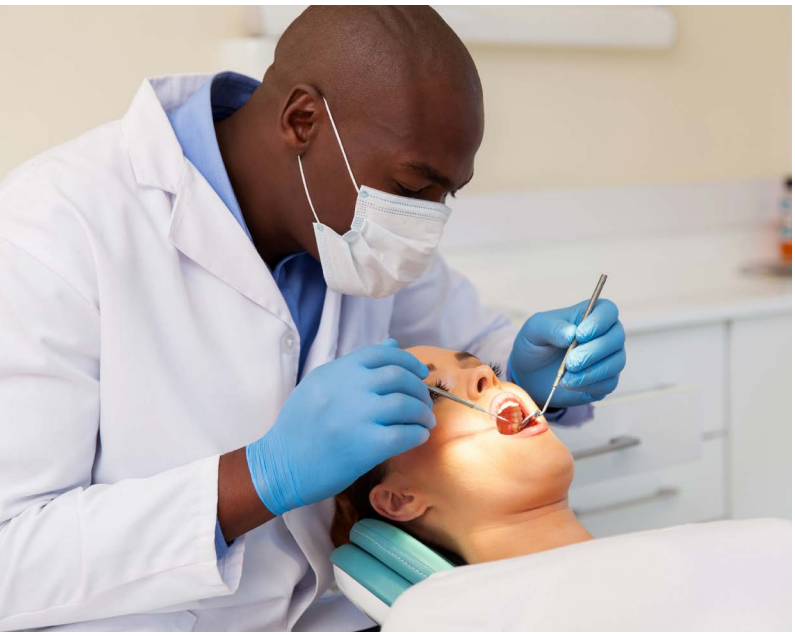
Throughout the United States, state governments are revising budgets and developing dental health initiatives that will impact the future of dental health for individuals with disabilities. There is much work being done in regard to addressing reimbursement rates, which is "in process" and part of grants. In California and Nevada, these proposals were reviewed and denied, ultimately preserving the funding for adult dental benefits. Other states, seeking to expand dental health benefits under Medicaid, were unable to make progress due to the impact of COVID-19. In Hawaii and Maine, plans to expand adult dental health benefits were postponed, with the bills being tabled until future legislative sessions. In New Hampshire, the Governor vetoed a bill to create an adult dental benefit through Medicaid. Despite his veto, the Governor did endorse the creation of a new, affordable model to provide adult dental care covered by Medicaid. The New Hampshire Department of Health and Human Services has continued to move forward with the design and implementation of a Medicaid adult dental benefit.

Effective August 2021, Louisiana has passed legislation to "ensure that comprehensive Medicaid coverage for dental care is provided to each person of age twenty-one or older who is enrolled in any Medicaid waiver program for persons with developmental or intellectual disabilities." The law excludes persons with disabilities who are in intermediate care facilities, though the state is reviewing legislation to study this specific audience's needs and the costs to serve them.

Coverage under the law includes reimbursement for:

- Diagnostic, preventive, and restorative services
- Endodontics
- Periodontics
- Prosthodontics
- Oral and maxillofacial surgery
- Orthodontics
- Emergency care

Significant cost savings are anticipated as people with disabilities pay for and receive preventive care rather than expensive emergency care.



Another promising initiative to provide dental care for individuals with disabilities is taking place in Texas. Beginning in 2019, the state of Texas began researching and developing a pilot project specifically to provide better Medicaid services to individuals with intellectual or developmental disabilities. Research from the early stages of the project have already revealed that a Medicaid dental benefit will reduce emergency room visits. The cost of the dental benefit under Medicaid was entirely offset by the savings on emergency room visit costs, allowing the benefit to essentially pay for itself.

While this initiative was proposed to begin in 2023, organizations have already begun working on the project ahead of schedule. The data collected by these organizations can be used to inform other states on implementing their own dental health initiatives.

Expanding Medicaid coverage of dental care would have a significant positive impact on the health and lives of adults with disabilities. **When examining states where dental care is covered by Medicaid, the report noted that there is still a lack of dentists accepting Medicaid and/or accepting patients with disabilities.** However, additional coverage is not enough to correct the shortage of dental care options for adults with disabilities. Returning to the barriers to dental care for adults with disabilities, we must remember that before a dental service can be affordable, it needs to be available.

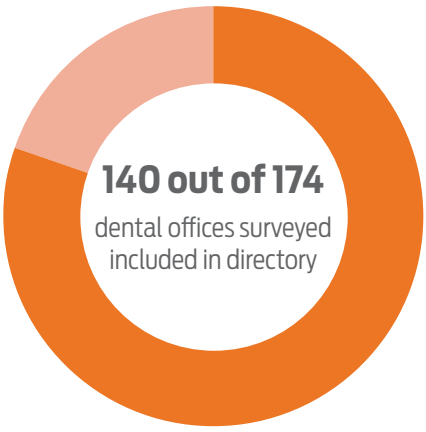
Dental Office Survey

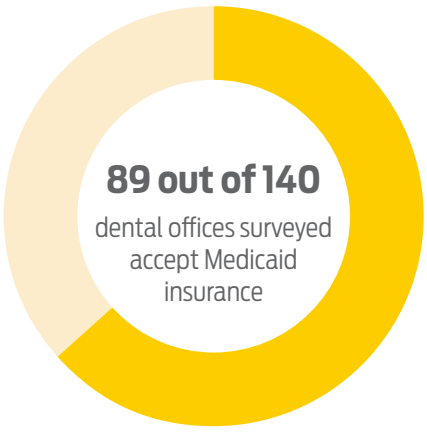
In the spring of 2022, McMillen Health completed a statewide survey of dental offices in Indiana. The survey was completed through a "secret shopper" questionnaire process on the phone with dental offices. This method collected the information and responses an actual patient with a disability or their caregiver would receive. Questions included whether the dental office accepts Medicaid insurance, serves adults with disabilities, and provides accommodations for patients with disabilities.

This list of dental offices for the survey was created by first collecting information about dental offices in Indiana that accept Medicaid insurance. These were found through the IN.gov website. The next step was to identify which counties were not represented on this list. Further research was conducted to add at least one dental office from each county to the survey. If dental offices stated they accepted Medicaid or if they did not indicate one way or another whether they accepted Medicaid, they were added to the list. Any offices that indicated they did not accept Medicaid were not added, resulting in counties with no dental offices to survey.

In total, 174 offices were surveyed. **Using information from the survey, a digital directory was created of 140 dental offices that accept adult patients with disabilities.** Those dental offices that refer patients with disabilities to other offices and those that only serve children were removed from the list. Of the final 140 dental offices, eighty-nine (63.6%) accept Medicaid insurance.

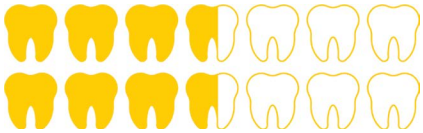
Accommodations included sunglasses, music on a Bluetooth speaker or in headphones, televisions, fidget toys or comfort items in the exam room, having a caregiver in the room, and 'get to know you' visits. Some offices offered to schedule appointments during quieter, less busy times of the day or to reserve a quiet exam room. Other dental offices stated that they specialized in working with patients with "fears about the dentist" and were willing to provide any or as many accommodations as necessary to successfully care for patients.



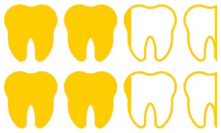


One survey question asked about the office's ability to serve patients with severe disabilities, for example using a wheelchair. These responses provided information about wheelchair accessibility for seventy-two (51%) of the offices included in the directory. The range of responses to this question included not being wheelchair accessible to offering some or most procedures while the patient remains in their wheelchair. For offices that are wheelchair accessible, most require patients to transfer to the exam chair.

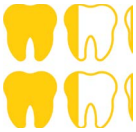
Of the seventy-two dental offices that shared information about wheelchair accessibility, only three (.04%) were not wheelchair accessible. Looking at the remaining sixty-nine offices, four (.06%) would allow the patient to remain in their wheelchair for some or all procedures. Forty-three dental offices specifically stated that patients would need to transfer to an exam chair, but over half of those offices (58%) are not able to assist the patient in transferring.



72 out of 140
dental offices surveyed provided information about wheelchair accessibility



43 out of 72
dental offices surveyed stated patients would need to transfer to exam chair

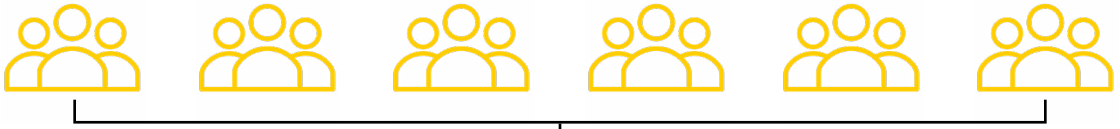


25 out of 43
dental offices surveyed are not able to assist the patient in transferring

 **= 10 dental offices**

Focus Groups, Interviews, and Surveys

Six focus groups were conducted.



Five of these were virtual and one was in person.

Participants in these groups were from around the state and consisted of a variety of participant groups.

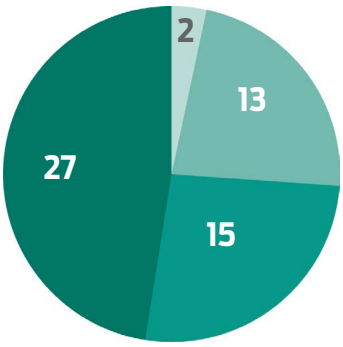
Two were conducted with a total of 13 adults with disabilities.

Two were conducted with a total of 14 dental professionals.

Two were conducted with a total of 8 caregivers, support professionals, and teachers.

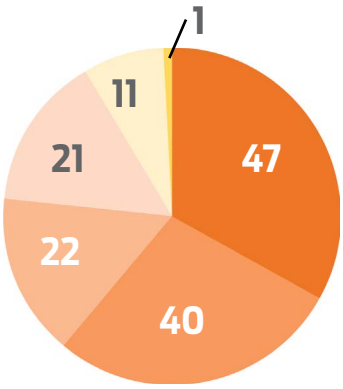
Fifty-two one-on-one interviews were conducted with:

- 27 caregivers, support professionals, and teachers
- 15 dental professionals
- 13 adults with disabilities
- 2 individuals who have a disability but are also support professionals for others

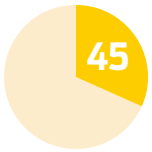


One hundred forty-two individuals responded to our online survey. The respondents included:

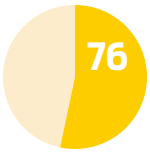
- 47 (33.1%) adults with disabilities
- 40 (28.2%) family members of adults with disabilities
- 22 (15.5%) dental professionals
- 21 (14.8%) staff caregivers
- 11 (7.7%) others – provide other social support services, such as vocational rehabilitation.
- 1 (0.7%) other – both a parent of an adult with disabilities and a dental professional



The results of the survey showed:



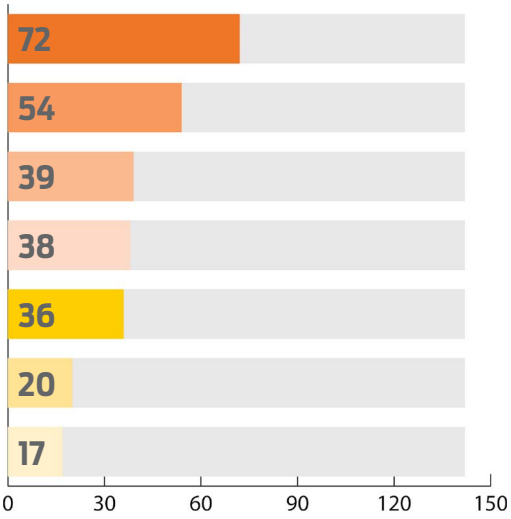
45 (31.6%) said their teeth or the teeth of the person they support had "very healthy" or "mostly healthy" teeth



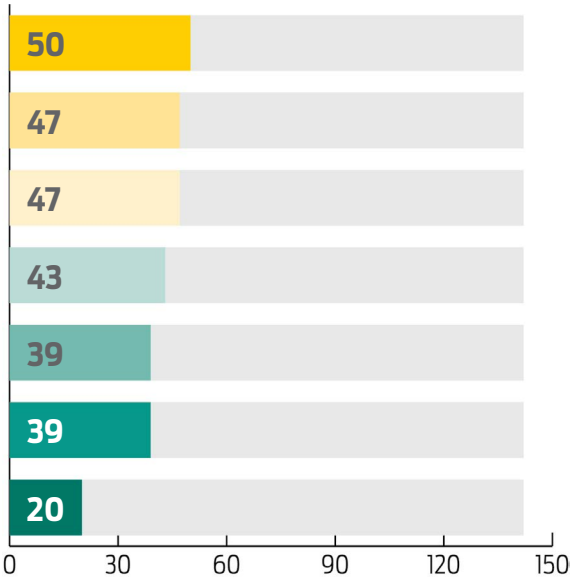
76 (53.5%) said their teeth or the teeth of the person they support had "very unhealthy" or "kind of unhealthy" teeth

We asked the 142 participants, "What are the hardest parts about taking care of your teeth at home?" We asked that people with disabilities answer for themselves, support professionals and caregivers answer what they felt were challenges for the person they support, and dental professionals answer what they felt were challenges for their patients with disabilities.

- I have a hard time remembering to brush and floss my teeth – 72 (50.7%)
- I'm not sure how to brush or floss my teeth very well – 54 (38.0%)
- The toothbrush is hard to hold – 39 (27.5%)
- I don't like to brush my teeth – 38 (26.8%)
- Medicines make my teeth unhealthy – 36 (25.3%)
- I don't think it's hard at all to take care of my teeth at home – 20 (14.1%)
- I can't afford a toothbrush, toothpaste, or floss – 17 (12.0%)



We asked the 142 participants, "What are the hardest parts about going to the dentist?" We asked that people with disabilities answer for themselves, support professionals and caregivers answer what they felt were challenges for the person they support, and dental professionals answer what they felt were challenges for their patients with disabilities.



- I don't drive and it's hard to get a ride to the dentist – 50 (35.2%)
- I don't have insurance and can't afford to pay for most things at the dentist. – 47 (33.1%)
- I am scared to go to the dentist. – 47 (33.1%)
- I can't find a dentist who will take my insurance – 43 (30.3%)
- My physical condition makes it hard to get around at the dentist office. – 39 (27.5%)
- I had a dentist treat me bad in the past, so I don't like to go now. – 39 (27.5%)
- I don't think it's hard at all to go to the dentist. – 20 (14.1%)

Case Study: Dr. Larson*

Dr. Larson is a general dentist, assistant professor of dentistry, and director of hospital and special needs dentistry at a school of dentistry. She cares for medically complex adults and teaches her students how to treat them as well. Many of her patients are adults with IDD.

Her philosophy is that students should gain hands-on experience in treating patients with disabilities.

> As someone who has spent my whole career treating individuals with disabilities, I think it's important not only for students to learn about it in lectures and textbooks, but to be exposed firsthand and to truly be able to apply principles that they're learning in a classroom setting to clinical care. I think it's been proven time and time again that those who aren't comfortable with it probably won't do it.**

Dr. Larson recognizes a general lack of comfort for dentists to provide comprehensive care for patients with disabilities. She believes that training the next generation of dentists to recognize that much of dental care is the same for patients with disabilities as it is for those without. This level of comfort will reduce the need for referring patients out and make for a better experience for the patient.

She also has goals for developing continuing education (CE) so that interested dental professionals can get similar experience and develop more of a comfort. This education would likely include case reviews and discussions of equipment and methodologies necessary to use with the patient.

* Names have been changed for confidentiality.

** Quotes have been slightly edited for clarity and brevity.

> I think the big barriers to dental care for individuals with disabilities are a lack of educated, willing practitioners. I think we're changing just some of the stigmas around it. You don't have to necessarily do advanced training to see a patient or two in your community, the dental care is the same. It's the patient management that becomes very important. People generally are living longer, they're living longer with their teeth, and they're living longer with ailments and disabilities.

Dr. Larson hopes for a future in which her university has a clinic dedicated to individuals with medical complexity and IDD that has appropriate equipment, plenty of space, knowledgeable staff, and fully integrated student involvement. This type of clinic would go beyond accreditation requirements and give patients a place for well-rounded treatment.

> I think the future of dentistry is going away from isolating dentistry from medicine, and instead integrating them. I think that our disabled patients and our most medically vulnerable patients are great examples and great teaching tools for our students to realize that.

Training Needs

Throughout the interviews, a need for training was often mentioned by participants. Training or education was talked about for all people involved in dental health care for adults with disabilities – support professionals, family members, the individuals, and dental professionals.

Training for Support Professionals

Support professionals include direct service providers (DSPs) that support people with disabilities in a wide variety of daily living tasks. DSPs are often responsible for working with individuals on many health and social goals. Support professionals also include other professionals who support people with disabilities, such as vocational rehabilitation (VR) specialists, who help the individuals with specific areas of their life.

During interviews, training for support professionals was often seen as necessary because of how involved they are in individuals' life and health. For example, DSPs do not have a required training that teaches the importance of dental health and ways to accommodate for a variety of physical and emotional needs when it comes to daily mouth care. DSPs may only receive training about each specific client and what goals they are working on.

> I worked in a group home that had a lot of non-verbal participants and they couldn't really tell you what they wanted. Sometimes people would just shove a toothbrush in their mouth and expect them to go along with it. So that is where a lot of education needs to be, to teach professionals to be professional and include the participants in their care.
>
> **–Beth, VR specialist and former DSP**

Staff training is a big challenge to at-home care for our clients. The staff need training on the importance of oral health care as well as the techniques to do it. Currently, we talk about dental care at orientation and then we do client-specific training. If we get back a dental report that's not very good, we train again on proper hygiene.

–Phyllis, group home nurse

Training for Family Members

Some participants pointed out that when adults with disabilities enter a supported living environment (a "group home"), they already have dental health issues that require extensive dental work and possibly even removing many or all of their teeth. One of the first things the supporting organization has to do is get the person in for a dental exam and treatment. This can be a traumatic experience, especially if the individual has not been used to going to dental appointments.

Many support professionals and dental professionals felt the root cause of dental issues in adults with disabilities was at least partly due to a lack of education for the family members. Good lifelong dental health can usually be traced back to children who developed good dental hygiene habits early in life. If family members of people with disabilities did not know the importance of dental hygiene or did not have the education to make daily dental hygiene a success, then the individual may have been set up to have poor dental health in their adulthood.

A challenge for my patients with disabilities is that their caregivers are not always informed or educated on oral health care.

–Cindy, dental hygienist

If a patient can't care for themselves alone, I try to explain to the caregiver about what to do and when.

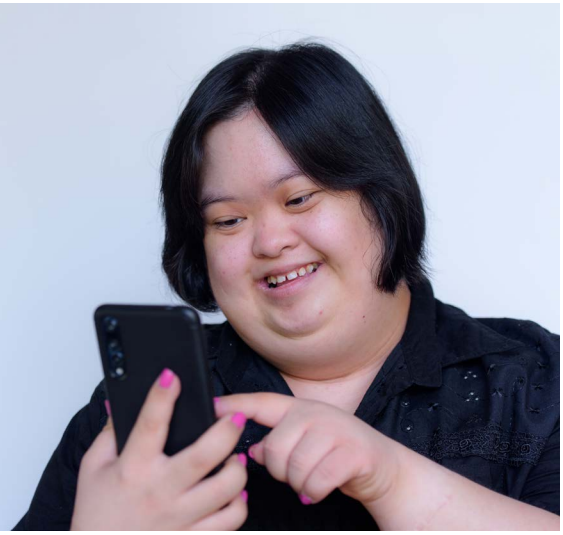
–Riley, dental hygienist

A lot of times our clients come into the home when they are older, and they've been with their families. They have significant dental issues that we have to deal with right away because the families all say they didn't like brushing their teeth. They didn't want to force it. And then we'll have to tackle everything at once. We get them to the dentist, hopefully within that first month, and they do a complete exam. We then work with the family to educate them and say, "Okay, this is where we are. But, going forward, we're going to take it step by step to get them so that they're desensitized to this whole process and get them out of pain."

–Laura, support professional

Training for Individuals

Though many adults with disabilities receive support in their daily tasks, we encountered a wide range of dental hygiene that individuals were able to do on their own. For example, blind individuals may need some assistance in finding the right toothpaste at the store but can do all other dental hygiene tasks on their own. On the other hand, an adult with an intellectual disability may be able to do only small parts of dental hygiene with assistance.



Participants commented that education for individuals with disabilities, especially those with intellectual disabilities, would be helpful. They felt this education should cover things like what to expect at the dental office, why we should brush our teeth, why healthy foods are good for us, and other similar topics. It is important for these educational resources to be easy to understand, yet not childish. One person even suggested short TikTok™-style videos on a variety of dental health topics.

In vocational rehabilitation, hygiene is important because people should have decent hygiene to get a job. I've had one or two clients where dental hygiene was the main issue. They hadn't been taught about that as a child.

–Beth, VR specialist and former DSP

I had insurance until I was 18. Then I got Medicare and Medicaid at 18 from social security because of being blind. But I didn't start going to the dentist until 2020, because I didn't know what my insurance covered.

–Carson, legally blind since birth

For someone who has developmental disabilities, it's important to make sure oral care is on their schedule, making sure they remember to do it, maybe teaching them how to do it properly. A lot of times when I talk to someone about their hygiene, they tell me they forget to do it. I work with them on a checklist for their bathroom, sticky notes, or alarms on their phone. Whatever works for them.

–Emily, VR specialist

You really need to have a good understanding of that person's ability based on their executive functioning and cognitive ability when thinking about oral health. Every student won't be able to sit in a presentation and watch someone showing them how to brush teeth. Maybe someone needs to physically come in with a model and show them and let them practice it. It has to be hands-on for some students depending on their learning style.

–Iris, special education teacher for adults seeking high school diplomas

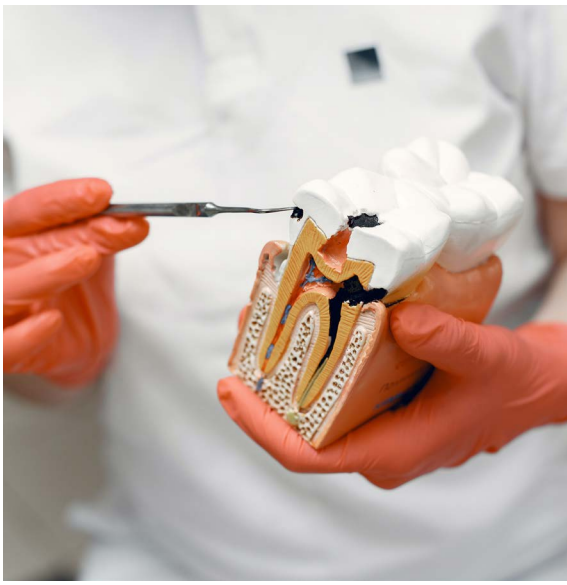
Compliance is a huge issue when I'm working with individuals on their goals of independent toothbrushing. Spending time learning to properly care for their teeth and mouth is not something most of my clients want to do.

–Tara, support professional

I like brushing my teeth. I have a wireless Bluetooth toothbrush. It says to stay in one spot for 30 seconds. I'm all done in two minutes.

–Clay, individual with IDD

Training for Dental Professionals



Unfortunately, we spoke to several participants who had had negative experiences at a dental office, ranging from annoying to traumatic. For example, one direct support professional (DSP) stated that a dental professional would only speak to her in the exam room, even though the patient was there and could understand most of what they were saying.

These participants felt it would benefit people with disabilities if dental professionals were required to go through disability training. We also spoke to dental professionals who had experience working with people with disabilities. Most of what they had learned was from years of learning on-the-job. Many gave advice for new dental professionals, which can be summarized as be patient, follow the patient's lead, and recognize that everyone is different. Participants also stated they would have benefitted from more training on this topic during school.

One example of such training is currently in development. **The American Academy of Developmental Medicine and Dentistry (AADMD) is working to develop a curriculum for undergraduate students, faculty, and residents that covers the lifespan of people with disabilities as it relates to their dental health**. The National Inclusive Curriculum for Health Education (NICHE) will also include video interviews with people with disabilities and their families, as well as educational resources that can be used interactively between professionals and patients.

> I think that education is so important for dentists and hygienists. The education should make sure they know that if someone does have a disability, they should treat them like any other person and make sure they're getting the care they need. Person first language is a big part – I can't tell you how many doctor's appointments I went to with people in group homes where the doctor looked at me instead of the client the whole time.
>
> **–Beth, VR specialist and former DSP**

> It's important for hygienists to understand that everyone is different, even if they have the same disability. It would be nice to include speakers in dental training, such as caregivers that can talk about their experiences.
>
> **–Riley, dental hygienist**

> I really haven't received any training to work with people with disabilities. It has been 25 years of treating those patients. There's a learning curve and everybody is different. It's really a matter of trying to figure out how to read someone and gauge how much you can get done in what amount of time.
>
> **–Dr. Powell, dentist**

> One of the best things dental professionals can learn is to take it slow with patients with disabilities. Build rapport and go with their flow. The more you force anything, the more they will resist.
>
> **–Jenna, dental hygienist**

Sometimes people get awkward or uncomfortable and don't really know how to handle disability, and then sometimes people are overly helpful. So, I tell anyone working with someone with a disability, in any setting, just ask them, "How may I best assist you?" Because, for example, vision loss is such a spectrum that maybe someone could read a document with a magnifier, whereas I couldn't. So, just asking someone, "how may I assist you?", goes a long way in any setting.

–Eve, legally blind individual

I like it when the dentist tells me what I did something right or if I missed something. I like it when they let me know what needs to be fixed.

–Clay, individual with IDD

[Interviewer: Is there anything your dentist could do better?] I'd like to know when my appointments are. Call me ahead of time. They're not really good about it.

–Caitlin, individual with IDD

My greatest hope is that working with children and adults with disabilities will become a mandatory part of dental education and training for all dental staff, if it isn't already.

–Tara support professional

I really want our students to be exposed to it, be hands-on with it, and see that these patients are just like others, but perhaps need more time allocation or consideration of comfort to at least offer the capability of being a dental home for them. We try to stay ahead of the curve and get our students as much experience as possible.

–Dr. Larson, assistant professor of dentistry

Case Study: Gabrielle

Gabrielle is in her early 30s, is a director of a disabilities services organization, and has muscular dystrophy (MD). For her, MD means decreased hand dexterity and grip as well as using a wheelchair most of the time. Dexterity issues and using a wheelchair has led to challenges in her dental care.

She has described her experience with dental offices as "accommodating but not accessible," meaning that she can get into the office and exam room, but she does not feel it is designed with someone like her in mind.

> While my personal dentist is very accommodating, it still is a very tight situation in the office. I have to back my chair into the space and then transfer to the dentist chair. I'm still able to transfer, so I choose to do that. Then they do the cleaning, but I honestly don't know how they would accommodate me if I wanted to stay in my wheelchair. In general, the services have been accommodating, but by no means is the facility accessible.

Gabrielle has encountered inaccessibility in every area of a dental office. From a reception desk that is too high, to X-ray equipment that is unable to accommodate her staying seated. She must back into the exam room and often runs into a cabinet. She can transfer herself to the exam chair, so she does, but laying in the chair for the time it takes to complete an exam and cleaning can be quite uncomfortable for her condition.

Gabrielle has mentioned to the dental staff that, as her MD progresses, she may eventually need to stay in her wheelchair instead of transferring to the exam chair. Staff has said, "We will figure it out." However, Gabrielle feels a more proactive approach would be beneficial.

> I don't think it should necessarily be on a case-by-case basis. Hopefully, they would have some process implemented across the board. I do live in a smaller community, so there is probably a smaller number of people who have physical disabilities using a wheelchair than in other communities. So, I guess it's not an immediate concern.

Gabrielle works in her community with people with disabilities and their families. Through her work, she encounters a variety of concerns over dental care. For example, she spoke to a mother who took her young child to the dentist and was charged a $250 fee for the challenging behavior of her child. The fee was not discussed ahead of time and the mother was quite angry. Gabrielle is concerned that this type of treatment from dental professionals will lead to families who are not able or not willing to go to the dentist regularly.

> Not prioritizing dental health is probably some lack of education but then it's about taking their kid one time and it was a horrible experience or they hear a story about someone else's experience. So, they think, "We're not going to do that again, until it's a necessity." Many of our parents would rather avoid a situation. if it's not dire, then why make a super uncomfortable situation for their kid or the doctor or whatever it may be.

Gabrielle would like to see all doctors and dentists, in general, receive more training around sensory and behavioral needs of their patients with disabilities. She has seen some improvements over time in the accessibility of offices and in the way patients with disabilities are treated, but there is still room for improvement in this area.

Access Needs

As mentioned in the Literature Review section, accessibility is an important factor for people with disabilities receiving the dental care they need. Accessibility includes finding a dentist willing to work with adults with disabilities, the physical design of an office, and having a dental office that is geographically accessible.

Finding a Dentist

For people with disabilities and those who support them, finding a dentist to suit their needs is a major hurdle. **Many participants spoke about the challenges of finding a dental office that accepts Medicaid insurance and is willing to work with people with disabilities.** Beyond simply being willing, it is especially rare to find a dental team who is enthusiastic about their patients with disabilities and has the familiarity to make a dental visit a positive experience for the adult with disabilities.

In addition to more comprehensive training for dental professionals, as mentioned above, another solution for this barrier would be for more dental offices to accept Medicaid. **If more dentists accepted Medicaid, then all the patients with Medicaid would not overwhelm a few offices in a given community.** One reason for not accepting Medicaid that we heard about from participants is low Medicaid reimbursement. Dental offices cannot justify the cost of dental work and the time it takes to bill Medicaid for the low amount of reimbursement. **Higher Medicaid reimbursement would encourage more dental offices to accept Medicaid insurance.**

> I work in several rural counties and finding a dentist that is decently close is almost impossible. Nobody takes Medicaid. There's always Riley, but that's a long drive. Many of these people have no cars. I have one kid who kept missing school for dental problems. His parents received a letter because of all his missed days, but they just couldn't find a dentist who would take Medicaid.
>
> **–Barb, mother of adult with autism and VR specialist**

I think the biggest challenge with going to the dentist is that are limited providers who will even take Medicaid. Then, a lot of our consumers require some sedation to do just a yearly exam because they are so afraid of the dentist and there are no providers around here that will do these things.

–Brooke, group home director

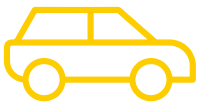
Getting to the Dentist

When looking for a dentist, many people must look outside of their immediate area. This could be because they live in a small, rural community with few choices. It could also be because they need a dentist who is able to sedate and who has access to hospital facilities to do so. Whatever the reason, there are many adults with disabilities and those who support them who must try to figure out a way to travel a great distance. These same people may either not have reliable transportation or are not able to take the time away from their families and jobs to spend the day going to the dentist.

Potential solutions to this barrier are to bring the dentists to the people or to provide transportation for people to get to the dentists.

One of the biggest challenges for my patients with disabilities is getting access to care. They are usually on fixed incomes and have to have transportation arranged for their visits.

–Kay, dental hygienist



The biggest challenge always, for vision loss, is transportation. I always either have to get a ride or Uber; there's not an easy way to get to the dentist. So then, making appointments can be a little difficult because it has to fit the schedule of someone in my life. Or I have to Uber and after the appointment wait for another Uber.

–Eve, legally blind individual

In all my 27 years working with this population, it is the rural areas where people have the most issues because they don't have access to dental care. They either don't have transportation or there just isn't any dentist. Because what dentist is going to want to get out of dental school and go live in the poorest county? For all kinds of healthcare things, they have the blood drive bus, red cross or whatever that travel. If they had a dental service like that, maybe something like that would work.

–Emily, VR specialist

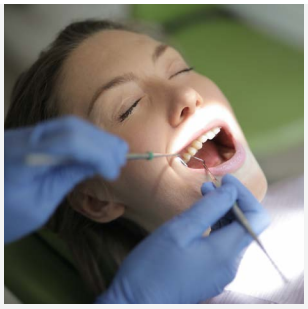
Accessing the Office

The physical design of a dental office is important for people with disabilities. Participants with a range of physical needs commented on the positive and negative accessibility they had come across. This includes:

An office front door that was complicated to find for a blind person

Waiting areas that were difficult to maneuver in a wheelchair

Exam rooms that did not have enough room for the person attending the appointment with the patient



Lights, music, and other sounds that make the experience overwhelming for people with sensory processing disorders

Solutions for these accessibility issues would be for offices to go beyond the requirements in the ADA.[xxxv] For example, an office that can fit a wheelchair could be more accessible if the furniture was built for a person at a seated height or if the dentist exam chair did not require the person to transfer themselves from their wheelchair. More on these needs can be found below in the Disability-Specific Needs section.

> One of the biggest challenges I have with serving patients with disabilities is when the patient is in a wheelchair. I am a fairly small person and have struggled helping with transfers.
>
> **–Cindy, dental hygienist**

> It can be intimidating to have to navigate a new dentist office on your own and ask for assistance. At one office I've been to, one part is upstairs, and the other part is downstairs, so I have to get assistance and it can feel overwhelming at times.
>
> **–Eve, legally blind individual**

> I carry my cane and people still feel like they want to just go and grab you, and they don't know how to guide you. Some dental offices have equipment sticking out from the walls. I've bumped my face on them. So, I'm bumping into equipment, tripping over equipment, and people really just don't know how to guide people that are visually impaired. It's just best to ask that person, how can I assist you? Don't just go up and grab them and start trying to lead them somewhere.
>
> **–Kendra, visually impaired individual**

> We have buildings from the 1930s and we have buildings from the 2000 era. Although the building itself is accessible, we are definitely working towards a more inclusive environment for our patients. We currently work in what we consider a more standard environment where the operatories are basically aimed for more ambulatory patients. But we are currently renovating a space in our oral surgery clinic to have a movable chair, to have a wider doorway, just kind of more forward thinking for the patients that we do see here at the school.
>
> **–Dr. Larson, assistant professor of dentistry**

Case Study: Barb

Barb is an employment specialist who works with high school students and adults with disabilities, has a 19-year-old son with severe autism, and has a grandson with Angelman syndrome and Down syndrome. She recognizes how dental health interacts with all these pieces of her life.

In her work, good dental hygiene is necessary for her clients because poor hygiene can lead to difficulties in gaining employment. Many of her clients have poor dental health because they or their families either do not have insurance or do not have access to dental care in their area. Barb works in a very rural part of the state where it is often necessary to drive to a nearby county for dental or medical healthcare.

> I see a lot of bad teeth. I had one client who had one nub of a tooth in the front. He lived in a small town and couldn't get to a dentist who would do the oral surgery because they were at least 25 miles away. That would be fine for you or me because we have cars, but he rode a bicycle. He couldn't be hired because it looked like he had, for lack of a better term, meth mouth. I have a lot of folks who have bad breath and a lot of missing teeth or very decayed teeth. That's very hard when you're trying to find someone a job.

Barb's 19-year-old son inherited her "bad teeth." This, added to his sensitivities around toothbrushing and going to the dentist, have made dental health a lifelong struggle for him. When he was quite young, he had a traumatic experience going to the dentist. After that, it was necessary for him to be under anesthesia for any dental care. He also has a limited diet because of his preference for high-carb foods and aversion to a wide variety of foods.

> When he was young, he started not liking toothpaste. Then he started not liking the toothbrush bristles. By the time he was 10, he did not like to brush his teeth. Even to this day, he'll brush them maybe once a day and it's just a quick brush, sometimes with no toothpaste. He will not floss.

> He used to eat everything, and then about five or six, he started not liking things. He went through a spell where all he would eat was macaroni and cheese. We're talking about a kid who ate everything when he was a baby. Then slowly as he's gotten older, it has declined to pastas, pizza, and cheese rollups. I see that a lot with the adults I work with who have autism. They have a high-carb diet too.

Barb's 22-year-old grandson, on the other hand, has relatively healthy teeth and is able to eat a varied, healthy diet. However, he must also be under anesthesia to go to the dentist. Because of his condition, he can have seizures if in a high-stress or sensory overload situation. Barb's son and daughter-in-law have struggled to find a dentist who will take a patient on Medicaid and who needs anesthesia for dental care. Her grandson is unable to brush his own teeth and is dependent on his parents and older brother for 24/7 assistance.

> They have to find someone who takes Medicaid, can put him under, and who can deal with a child as developmentally disabled as my grandson. They just can't find someone. He didn't inherit my bad teeth, so his teeth aren't as bad, but he doesn't see a dentist regularly at all.

Disability-Specific Needs

Physical Limitations

Physical limitations include being blind, deaf, or a wheelchair user but is not limited to these. Participants also spoke about their dexterity issues and how their dental professionals did not always know how to take this into consideration when educating them on at-home dental care. Participants – adults with disabilities and caregivers alike – spoke about the ways in which their physical needs were or were not considered.

Physical limitations also made at-home dental hygiene habits more difficult. Many people had found ways to work around these limitations. For example, blind individuals reported putting toothpaste directly into their mouth instead of onto the toothbrush, so they could feel how much and where they were applying it.

> I try to floss when I can. It's hard for me because of my motor skills. I use handheld flossers.
>
> **–Caitlin, individual with IDD**

> Growing up, I learned to put the toothpaste on my finger first and then either onto the brush or into my mouth, because if I try to put it on the toothbrush, more than likely, it's falling off. But I have another limitation that I could think of. I don't know if I got everything clean. I feel like people who can see, could look into the mirror and do like a self-inspection like, "Oh yeah, we're looking good." I kind of just go over everything twice and then hope for the best.
>
> **–Carson, legally blind individual**

> I once saw another blind person talk about this and they prefer to use toothpaste with a cap that attaches. If we use a cap that comes off and we knock it off the counter, we lose that cap. It's a small thing but creating things that stay attached makes things easier.
>
> **–Eve, legally blind individual**

I recently started using an electric toothbrush. I brush my teeth with two hands and so I try to ensure I'm getting a cleaner brush by using the electric toothbrush. I think I've had a lot more success with that. But it'd be nice if there was some sort of better grip. A lot of electric toothbrushes are straight, narrow, and smooth.

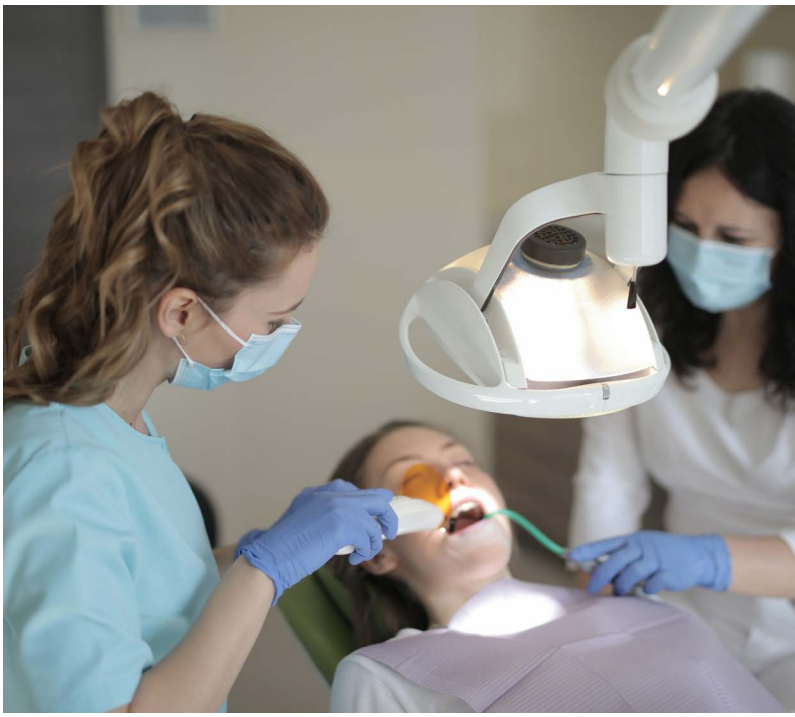
–Gabrielle, individual with muscular dystrophy

Sensory Issues

Many participants either had sensory sensitivities or were caregivers of adults who did. Not all dental offices have the ability to turn down the lights, turn off music, or turn on music depending on the patients' preference.

In our dental office survey, we found that many offices were on a shared speaker system, or the lights shone on several offices, so there was no way for them to make changes. However, the more accommodating offices offered sunglasses to dim the lights and were very willing to allow the patient to bring headphones and listen to music as needed.

For at-home dental hygiene habits, sensory issues came up in connection with aversions to toothpaste and certain types of toothbrushes. Many dental professionals will recommend electric toothbrushes, but some with sensory issues do not like the vibration and sound that these make.



We're always working on dental desensitization because sometimes just having the toothbrush in their mouth is a challenge. Dentists will recommend electric toothbrushes and things that make noise or vibrates. A lot of our consumers do not like that. We will ask the dentist what else they can recommend, but they aren't always able to come up with other solutions.

–Brooke, group home director

I don't like brushing my teeth. I don't like it up against my gums. It's a little better with the soft-bristled toothbrush my mom got me.

–Anna, individual with IDD

(Anna's DSP clarified that she has sensory issues when brushing her teeth)

Those who may be on the autism spectrum or those who may just have sensory deficits, we want to be able to control lighting. We're in a temporary space where we can kind of secure privacy and quiet but it's not ideal. We have a proposed clinic redesign that would have all of those measures for every operatory space that we could see these patients in.

–Dr. Larson, associate professor of dentistry

Anxiety and Trauma

All people, not only those with disabilities, can have anxiety and trauma – especially around going to the dentist. In fact, it is a common story trope that people dislike going to the dentist. However, this anxiety can be particularly burdensome on people with disabilities and their caregivers. If an adult with an intellectual disability has anxiety about new places or has had dental-related trauma, for example, they are likely to become agitated in the dental office. With all the dental equipment around, a physical response to that agitation can quickly become dangerous and costly.

Dental professionals cannot be expected to cure patients' anxiety. However, there are ways they can help the person with disabilities and their caregiver(s) as they work through their behavior support goals. **Dental offices should be willing to offer "get to know you" visits to allow new patients to acclimate to the new spaces and faces.** Another feature of an accommodating dental office is that they are tolerant and understanding with their patients with disabilities if the appointment is not a success.

Whether the patient has an outburst or simply refuses to allow the professionals near their mouth, more leniencies would avoid the person getting fired as a patient.

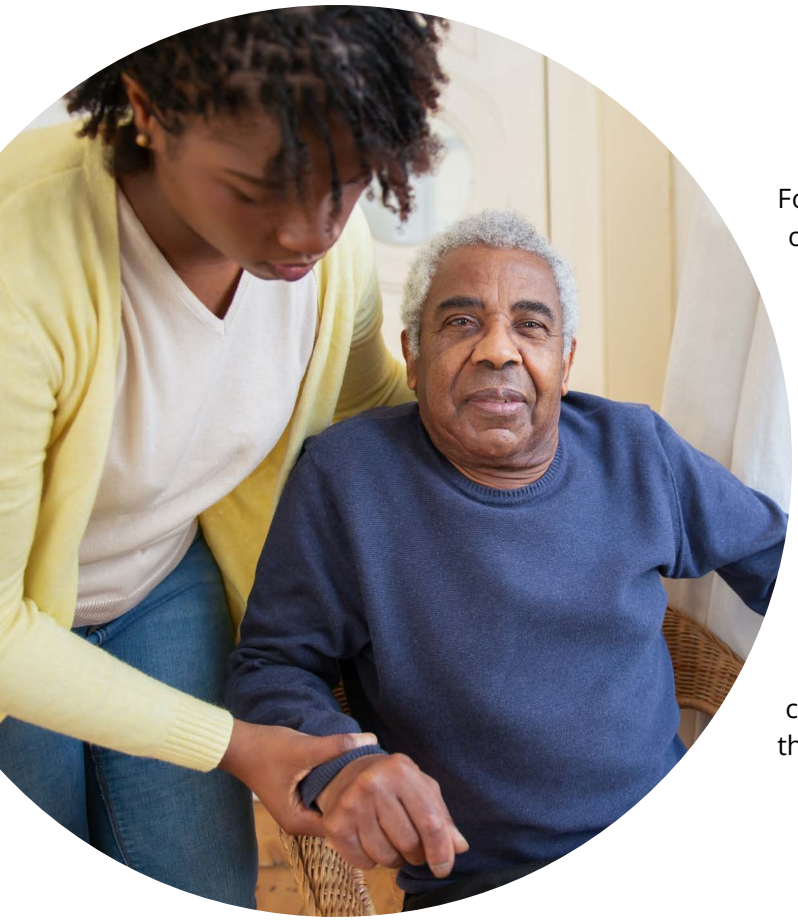
Sticking with a patient through their anxieties and challenging behaviors is more likely to see success in the long run and they may eventually be able to complete a dental appointment.

> About 15 years ago, I had a bad dentist visit. The dentist did not care if I was comfortable or not. The local anesthetic did not work as well as it should. Maybe I could have communicated that better, but I was a timid little kid. They extracted multiple teeth and were excessively rough and violent with their tools. It was extremely painful and uncaring. I didn't go back until this year.
>
> **–Clay, individual with a disability**

> I don't like going to the dentist when they need to use needles. I told my mom that I wanted her to come back to the room and hold my hand because I don't like when the dentist drills.
>
> **–Dana, individual with IDD**

> I have worked with adults with autism and adults with Down syndrome on dental hygiene. With a few clients, we practiced going to the dentist to help alleviate anxiety over dental visits, and also help them to know what they needed to do during a dental appointment.
>
> **–Tara, support professional**

Conclusion



For this needs assessment project, we spoke to a variety of participants, including adults with disabilities, their caregivers, teachers, support professionals, and dental professionals. What we found is that people from all sides wish to have more positive dental care opportunities and better dental health for adults with disabilities. However, conducting dental health hygiene habits and going to dental appointments comes with several barriers. Some of these barriers are systemic issues, such as Medicaid reimbursement, while other barriers are due to a lack of education.

The solutions to these barriers will not come easily but can be addressed. To summarize, the three top solutions that would help address these barriers are:

Increased Medicaid reimbursement rates. This would encourage more dental offices to accept Medicaid insurance. This will give more options to people who are on Medicaid insurance. These options are especially important for people with disabilities, who need dental professionals who understand their needs and are willing to serve them.

Training for individuals with disabilities, their family, their support professionals, and dental professionals. Most of the participants understood the importance of healthy teeth, but if all these groups received training on how to make that happen for people with disabilities, we could hope to see better success in dental healthcare.

More accessible dental healthcare. Physical spaces and attitudes towards disabilities should both be more accessible. Making people with disabilities and their caregivers feel welcome and comfortable will encourage more willingness to keep up with regular dental healthcare.

Appendix

Focus group questions

Individuals with disabilities

- Ice breaker
- Can you tell me about a dentist visit that didn't go very well? What do you think would have made it better?
- Can you tell me about a dentist visit that went well? What was it about that time that made it great?
- In general, do you feel:
  - the dentist/hygienist/assistant explains things in a way you can understand?
  - the office makes a good attempt to make you feel welcome? (such as being wheelchair accessible, talking with respect, having someone read materials to you if needed, etc.)
  - the dentist pays attention to your issues? (such as pain or other problems)
- Let's go through the steps of a dentist appointment and I would like you to tell me what would make it perfect for you. Your answers can be about anything you can think of to make the experience better, such as better technology or something you want the dentist office to do better. If someone else does any of these for you, that's okay – you don't have to answer all of them.
  - Making an appointment
  - Scheduling a pre-visit to go in and meet the dentist and team
  - Getting a reminder call/text/email
  - Arriving to the office
  - Checking in
  - Waiting to be called back
  - Cleaning (primarily with a hygienist)
  - Exam (primarily with a dentist)
  - Other procedures (fillings, getting a tooth pulled, etc.)
  - Checking out (paying) – also ask about insurance coverage (Medicaid/private? Does it cover necessary procedures?)
  - Scheduling next appointment
- What is your dental care routine like at home? (such as brushing and flossing)
  - How much, if any, assistance do you need?
  - Do you do it regularly? How many times a day/week?
  - What are things that make it difficult?
  - What would make it easier? (such as someone to help, a re-designed toothbrush, etc.)

Caregivers:

- Ice breaker
- Can you tell me about a dentist visit with your loved one that didn't go very well? What do you think would have made it better?
- Can you tell me about a dentist visit that went well? What was it about that time that made it great?

- In general, do you feel
  - the dentist/hygienist/assistant explains things in a way you and your loved one can understand?
  - the office makes a good attempt to make you feel welcome? (such as being wheelchair accessible, talking with respect, etc.)
  - the dentist pays attention to your loved one's issues? (such as pain or other problems)
- Let's go through the steps of a dentist appointment and I would like you to tell me what would make it perfect for you and your loved one. Your answers can be about anything you can think of to make the experience better, such as better technology or something you want the dentist office to do better.
  - Making an appointment
  - Scheduling a pre-visit to go in and meet the dentist and team
  - Getting a reminder call/text/email
  - Arriving to the office
  - Checking in
  - Waiting to be called back
  - Cleaning (primarily with a hygienist)
  - Exam (primarily with a dentist)
  - Other procedures (fillings, getting a tooth pulled, etc.)
  - Checking out (paying) – also ask about insurance coverage (Medicaid/private? Does it cover necessary procedures?)
  - Scheduling next appointment
- What is dental care routine like at home with your loved one? (such as brushing and flossing)
  - How much, if any, assistance do they you need?
  - Does it happen regularly? How many times a day/week?
  - What are things that make it difficult?
  - What would make it easier? (such as someone else to help, a re-designed toothbrush, etc.)

Professionals – dentists, hygienists

- Ice breaker
- Do you provide care for individuals with IDD?
- What percentage of your patients would you say have a disability that you know of? (estimate is fine)
- What age range of patients do you care for?
- What training have you had in caring for people with IDD?
  - In dental school? After?
  - Do you think the training was adequate to address your concerns?
  - What could have made it better?
- How comfortable are you currently with treating patients with IDD?
  - What would make you feel more comfortable? Such as more education, support for making accommodations, etc.
- What barriers do you face in caring for individuals with IDD?
  - What would you like to see that would solve that barrier?
- Do you collaborate with patients' other health professionals or case managers? Such as pediatricians, therapists, etc.
  - What do you think are the pros and cons of collaborating?

  - What could make it a more common practice among dental care providers? Or, what would make it a smoother process for you?
- From your perspective, what are the main needs regarding oral health care for children and adults with IDD in your state?
- To what extent are these needs being met by existing resources?

Interview questions

Individuals with disabilities

- How often do you brush your teeth?
  - Are you able to brush your own teeth?
  - Is there anything that you think would make it easier?
- Do you have pain in your mouth? Is it all the time or just sometimes?
- Are you responsible to make your own dental and healthcare decisions?
- Do you have dental insurance? Private or Medicaid?
  - Does your insurance cover all the dental care you need?
  - Have you ever had a time your insurance didn't cover what you needed?
  - How did you pay for anything that didn't get covered?
- How often do you go to the dentist? What is it like when you go to the dentist?
  - Do you like to go to the dentist?
  - Are the people at the dentist office nice to you? Do they answer your questions?
  - Does the dentist or other people in the office take time to teach you about caring for your mouth?
  - Do you think the dentist spends enough time with you?
  - What do you wish they would talk to you about when you are there?
  - Do they make any special accommodations for you? For example, is the office wheelchair accessible? Will they adjust the lights for you? Is the office too loud?
  - Do you like to have any comfort items with you? Does the dentist let you bring that with you to the appointment?
  - Does someone go with you to the dentist, such as a parent or other caregiver? What is it like to have someone go with you?
  - What do you think could be done to make a dental visit better?
  - How do you get to the dentist? If you have to use a paid transportation, how do you pay?
- Is there anything I haven't asked about that you think I should know about going to the dentist?

Caregivers

- Does [person with IDD] live with you or outside your home?
  - Are they verbal or nonverbal?
- Can you describe their daily oral health care routine (any brushing, flossing, etc.)?
  - Do you help them with any part of that routine?
  - What part of the routine is the most difficult for you or them to do? Why?
  - What barriers do you face in providing daily oral health care (toothbrushing, etc)?
  - Where do you turn when you need help in finding resources for dental care or daily oral health care

(if internet is chosen ask what sites)

- Are there times when they don't get any daily oral health care? Can you describe those times?
- Does [person with IDD] have dental insurance coverage? Is it Medicaid or a private insurance?
  - Have they covered all the dental health care that [person with IDD] needed?
  - If not, what was a procedure that they didn't cover? How did you handle that expense?
- When was the last time [person with IDD] went to the dentist?
  - (if a long time) What has kept them from going to the dentist?
  - (if more recent) How often do they go to the dentist? Does [person with IDD] have a dentist they see on a regular basis, about every six months?
  - What barriers have you faced in accessing dental care? (insurance, payment, finding a provider, etc)
  - How difficult or easy is it to get an appointment? Has this been different during the pandemic?
- What has your experience been like taking them to a dentist?
  - Can you tell me about a particular visit?
  - In your opinion, what makes a dentist or dentist office a good choice for [person with IDD]?
    - What would make a dentist or dentist office a poor choice for [person with IDD]?
  - Is there any assistive technology you would need at a dental visit to make it better? (such as a wheelchair accessible dental chair or a tablet to help with communication)
  - Have you ever been told not to do something because your child has a disability? Or have you ever felt your dentist recommended too much intervention (e.g. an unnecessary tooth pull) because your child has a disability?
  - Do you feel your dentist is proficient in providing oral care for [person with IDD]? What could they do better? Do you feel heard when you are trying to explain your child's diagnosis and/or their oral concerns?
  - If you have a regular dentist: does your dentist offer sedation?
    - Have you ever needed to use that option for [person with IDD]? What was your experience like with that?
    - Have you ever felt the dentist recommended sedation when it wasn't really necessary?
    - What was your experience like with getting the sedation covered by insurance?
- How much dental education have you had? What do you wish you knew more about?
  - What is [person with IDD]'s oral health literacy like right now?
  - Would you like to see that improve?
  - What resources do you think would help?
- What are your needs right now around oral health? (find a dentist, insurance, etc)
- What successes have you had with oral health?
- What are your hopes for their oral health overall?

Professionals

- What types of accommodations does your office provide?
  - Are there other accommodations you would like to add to your office?
  - What do you think it would take to make that a reality?
- Do you set aside any specific times on the schedule to accommodate people with IDD?
  - How much time per day/week do you set aside?
  - What do you do if that time is not used up by patients with IDD?

  - What do you do if that time is not enough for the appointment requests you receive from patients with IDD?
- Tell me about the training you have received to care for patients with IDD.
  - In what ways did it or did it not prepare you for the realities of caring for these patients?
  - What do you think should be included in trainings like this?
  - Should it be optional or required training? Why?
  - What would incentivize dental professionals to take additional training?
- What type of insurance does your practice accept? Do you take Medicaid?
  - If not, why not? Such as, the reimbursement is not enough.
  - What would help you make the change to accepting it? What type of reimbursement would make sense? (e.g. more time allowed for a visit, reimbursement for behavior management)
- Has COVID-19 changed the patient mix that you see currently?
  - Why do you think that is?
  - What would you need to get back to normal?
- Does your agency have a budget for oral health-related services and activities for people with IDD outside of Medicaid benefits?
  - If yes, please describe these services and activities and funding sources.

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