



Oral Health and Disabilities in Michigan: Barriers and Solutions



Special Thanks

This oral health needs assessment was completed with contributions from the following people. We thank them for their work on this report.

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Introduction



In 2021, the Delta Dental Foundation engaged McMillen Health to discover the needs, barriers, and challenges that adults with disabilities and their caregivers who live in Michigan face in accessing oral health care and maintaining optimal oral health.

Interviews and focus groups were conducted with individuals with disabilities, their caregivers, and dental care providers. Participants were asked a variety of questions ([Appendices A1-A10](#)) to determine their experiences and perspectives when it comes to the oral health of individuals with disabilities. These questions covered the areas of at-home care, professional care, and financial concerns. As shown on pages 17-41, participants relayed a wide variety of stories, from having enjoyable dental health experiences to having traumatic ones.

This oral health needs assessment was conducted for the Delta Dental Foundation of Michigan, Ohio, Indiana, and North Carolina. Project Accessible Oral Health consulted on the development of the research design and assisted in the research activities. McMillen Health conducted the study and developed and designed the report.

Purpose

A note on defining disabilities:

Much research available on disabilities looks at either one specific disability (e.g., Down syndrome, autism) or category of disability (e.g., developmental, physical). McMillen Health engaged participants with no exclusivity to a particular disability or category of disability. However, in the following sections, this report references “intellectual and developmental disabilities (IDD)” and other exclusive terms because of the research resources from which the data was available. When this report says “disability(ies),” it is referencing a broad swath of all disabilities.



According to the Centers for Disease Control and Prevention (CDC), adults in Michigan have a slightly higher rate of disability (28.2%) when compared to the US average (25.65%).ⁱ Specifically, 8.3% of adults have difficulty with independent living (running errands, going to the doctor alone) and 4.7% have disabilities with self-care (dressing, bathing).ⁱⁱ

The 2025 State of Oral Health Plan states that nearly one-third of adults aged 18 years and older did not have a dental visit during the past year.ⁱⁱⁱ Low-income, non-white racial identification and lack of insurance were shown to be determinants of whether dental visits occurred, evidenced by the proportions of those groups who had no dental visit in the last year:

- 55% of adults from households with less than \$20,000 income.
- 35% of Black Michiganders.
- 38% of Michganders with disabilities.
- 55% of uninsured adults.^{iv}

Adults with disabilities are vulnerable to oral health disease while also being less likely to access oral health care due to a combination of barriers. According to the 2025 State of Michigan Oral Health Plan, adults with disabilities were less likely to have visited a dentist or received a teeth cleaning in the past year compared to adults without disabilities. Adults with disabilities were less likely to have dental insurance and less likely to visit a dentist due to the cost of oral health care.

People with disabilities have a much higher rate of prevalence of comorbid medical conditions that affect dental care, such as aspiration pneumonia, seizure disorders, sensory processing disorders, behavioral and mental health needs and increased prescription use. They are also more susceptible to injury and violence that causes oral trauma.

Compared to adults without disabilities, adults with disabilities in Michigan have higher rates of caries (dental decay) and are more likely to have six or more missing teeth.^v



They may have difficulty or the inability to express their needs about pain they may be experiencing. These compounding secondary conditions affect dental treatment and are often unrecognized, misunderstood or dismissed. This creates barriers to effective care and potentially leads to ineffective care or denial of care altogether.

One study found that among 4,732 people with intellectual disabilities, there was 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.^{vi} Misaligned or missing permanent teeth, delayed



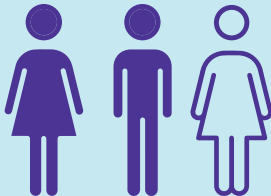
80.3%

of adults with disabilities have periodontitis



25%

of adults with disabilities may require advanced behavioral guidance techniques



2/3

of adults with disabilities are not able to receive oral health care without some form of modified support

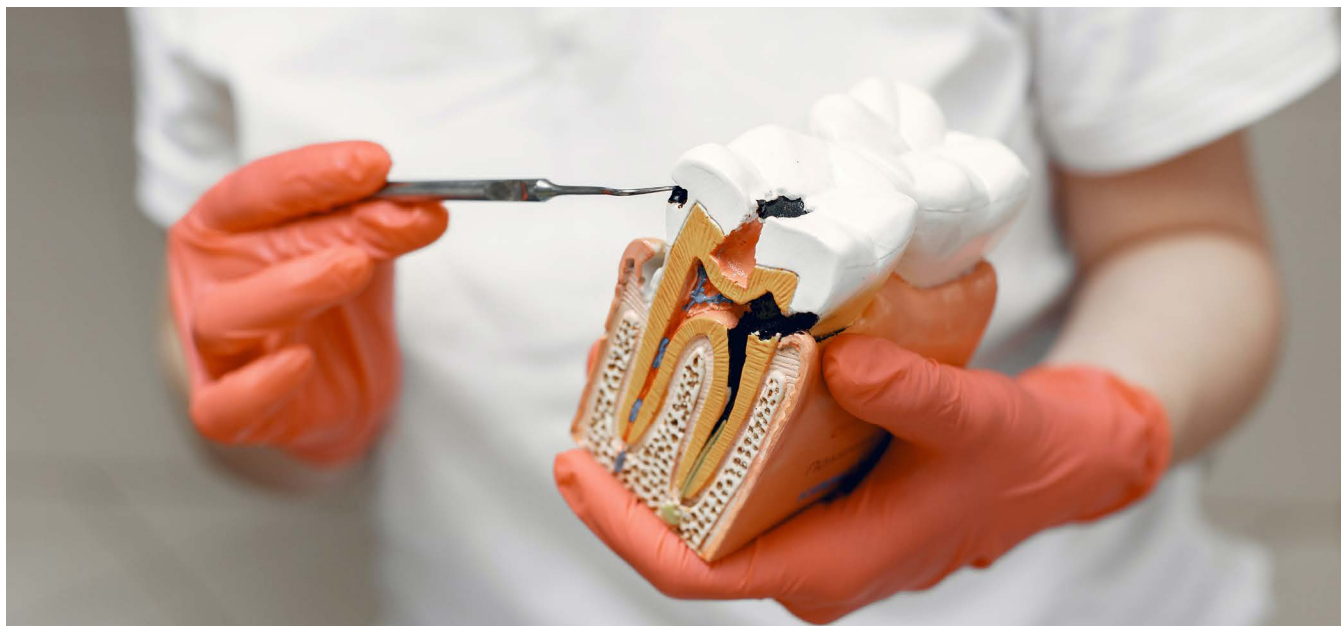
eruption and underdeveloped tooth enamel are more common in this population. In addition, damaging oral habits may be present, such as bruxism (tooth grinding), mouth breathing, tongue thrusting, self-injurious behavior and pica (eating non-food items).^{vii} The majority (80.3%) of adults with disabilities have periodontitis, and 10.9% are edentulous (have no teeth). The extensive health needs of people with disabilities means that 25% may require advanced behavioral guidance techniques, 40% need some form of behavioral assistance and two-thirds are not able to receive oral health care without some form of modified support.

This disparity in oral health for people with disabilities begins 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.^{viii} For children in low-income situations, without insurance or with greater disabilities, the odds of unmet dental needs increase. These patterns create oral health problems that extend into adulthood.

Over 78% of children with disabilities needed dental care in the past twelve months.



Literature Review



Individuals with disabilities often have more serious dental health issues than the general population.^x Research on oral health in this population has traditionally focused on small study groups and much of the research has been on youth.^x This shows an historic bias against studying this topic in adults with disabilities. Many of the research studies have focused on one type of disability at a time, creating an inability to look at a broad scope of the concerns that the adult population of people with disabilities face.

However, more recently, several research studies have been conducted to test oral health educational and technical interventions for people with disabilities. Shin and Saeed^{xi} looked at what makes toothbrushing difficult and how education might make it better. They found the parts of toothbrushing that were most difficult are anything requiring dexterity, and education did not greatly improve this. Education for caregivers has been shown by Binkley et al^{xii} to improve at-home dental care, including the number of times teeth were brushed per day.

Other projects have looked at the perspectives of people with disabilities and their caregivers. For people with disabilities, the most important part of a dental visit is the dental team being informed on concerns that people with disabilities face regarding their oral health.^{xiii} Another study found that lack of meaningful communication was the biggest issue in oral health care.^{xiv}



One aspect of this lack of meaningful conversation with dental care providers can be understood as “diagnostic overshadowing,” a common and potentially dangerous practice of dismissing the complaint, needs or condition of a person with disabilities as something related to their disability diagnosis, rather than looking into other causes and then treating for the complaint itself. Such dismissals lead to missing diagnoses and nontreatment of conditions or misdiagnosis and mistreatment.

A specific case study highlights this pattern with a patient suffering undiagnosed late-stage facial cancer leading to premature death. He was continually prescribed antibiotics for worsening facial swelling and pain under the false assumption that his intellectual disability and poor hygiene were to blame.^{xv} By the time he arrived at an emergency care facility and received a thorough exam of his symptoms, the cancer was too advanced to treat. While specific and extreme, such cases are not an anomaly. 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.^{xvi} They review tools to help overcome the phenomena, including techniques to communicate with people who are verbally limited or nonverbal. The authors define these patients as those who communicate with a form of communication other than verbal, or those who have “no recognized formal methods of communication.”^{xvii} Without such a tool, if a person with disabilities who is also nonverbal 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 Shield et al, a dental passport tool that includes information about the individual’s



abilities in communication and mobility is highlighted as an example of an effective, practical approach for surfacing patient needs in a clear way.^{xviii}

Another phenomenon that leads to decreased care for individuals with disabilities is Social Role Valorization (SRV). The term, coined by Wolf Wolfensberger,^{xix} refers to the societal view of people with intellectual and developmental disabilities as burdens and as pitiful. These views contribute to a low sense of incentive to support these individuals' health care. When these individuals are seen as not contributing to society and not worthy of support and care, it creates systemic marginalization. SRV often stems from stigmatization by individuals in society who are responsible for decision-making in regards to people with disabilities, such as medical professionals and legislators.

Modifications, such as the passport tool studied by Shield et al, for people with disabilities offer practical solutions for preventing more common and unnecessarily harsh or dangerous procedures as well as for saving costs.^{xx} In a comparison of the specialized provider Lee Specialty Clinic in Louisville, Kentucky, with national averages for care, we see the results of not offering modifications.^{xxi} Lee Specialty Clinic modifies 67% of its services to people with disabilities and sees only a 1.8% surgical referral rate. This contrasts with the national average rate of modifying only 15% of services, linked to a rate of 25% operating room referral.^{xxii} Modifications mean that more people with disabilities avoid surgery and are more likely to keep their teeth. Notably, controlling for individual costs of the operating room, regardless of who refers the patient, there are significant cost savings. Because the referral rate is so much lower with modifications, the overall operating room costs are \$98,550 for the clinic and \$1,368,750 by the national average—1,388% less overall costs by offering



\$98,550

overall operating room costs are for the clinic



\$1,368,750

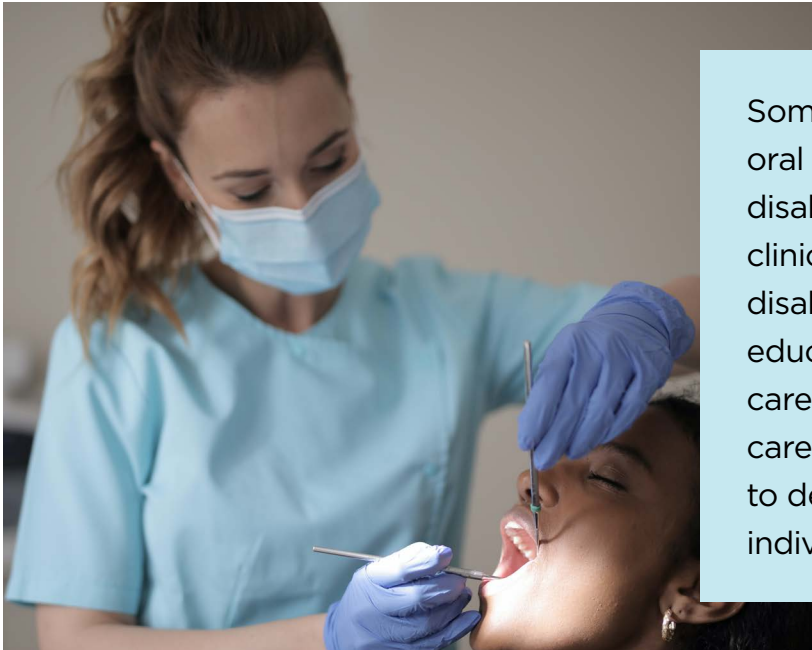
national average operating room costs



1,388% less

overall costs by offering modifications.

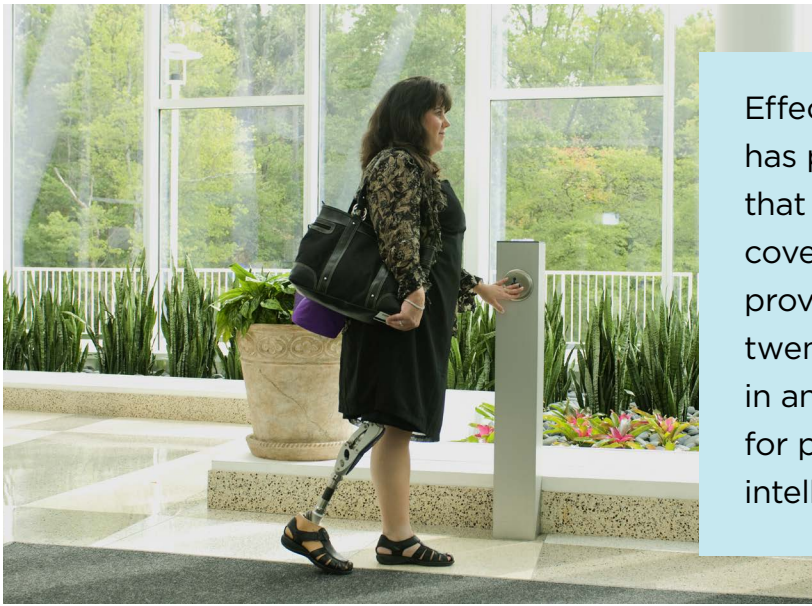
modifications. Costs and outcomes in dental care can be improved for people with disabilities by serving their needs in the dental visit, but this practice is not yet familiar nor understood by many oral health care providers.



Some suggestions for improving oral health care for people with disabilities include specialized dental clinics,^{xxiii} support for people with disabilities who face insensitivity,^{xxiv} education and training for caregivers,^{xxv} social support for caregivers^{xxvi} and improved access to dentists who specialize in care for individuals with disabilities.^{xxvii}

Dental professionals mirrored some of these same challenges, stating that they lack proper training, their staff are not properly equipped to handle behavioral challenges and they are not able to dedicate the extra time needed for their patients with disabilities.^{xxviii}

Throughout the United States, state governments are revising budgets and developing oral health initiatives that will impact the future of dental health for individuals with disabilities. In some states, legislators are proposing cuts in adult dental health benefits under Medicaid as a way to reduce budget costs. 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 dental care for diagnostic, preventive and restorative services, as well as endodontics, periodontics, prosthodontics, oral and maxillofacial surgery, orthodontics and emergency care. The law depends on approval from the Centers for Medicare & Medicaid Services as well as budget appropriation from the legislature. 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 oral health initiatives.

Dentist Survey

In 2019, the ADA revised its Code of Conduct offering guidance prohibiting blanket denial of care to patients with physical, developmental or intellectual disabilities. If a dentist lacks the capability, expertise or equipment to serve a specific special need, the dentist needs to refer the person with disabilities to a qualified dentist as they would with all of their referrals, rather than simply turning individuals away with refusal of care.

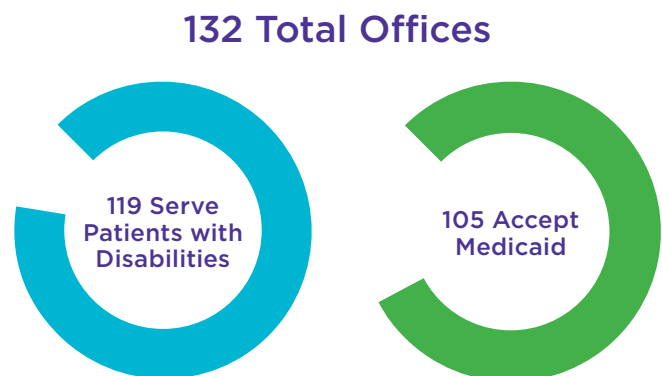
ADA Code of Professional Conduct

Section 4 Principle: Justice (“fairness”). The dentist has a duty to treat people fairly.

While dentists in serving the public, may exercise reasonable discretion in selecting patients for their practices, dentists shall not refuse to accept patients into their practice or deny dental services to patients because of the patient’s race, creed, color, gender, sexual orientation, gender identity, national origin or disability.

In the spring of 2021, McMillen Health conducted a survey of dentist offices throughout the state of Michigan. The surveys were conducted by calling dentist offices and following a script as a “secret shopper” to ask questions about whether the office accepts Medicaid insurance and if they work with patients who have disabilities ([see Appendix A10 for script](#)). The purpose of conducting the surveys as a secret shopper was to ascertain the type of responses that an actual patient or caregiver would receive if they were to call the office themselves. The list of offices to call was obtained from the Michigan Department of Health and Human Services.^{xxix}

In total, information was obtained on 132 dentist offices. Of those 105 (79.5%) accept Medicaid and 119 (90.1%) state they work with patients with disabilities. It should be noted, however, that because the list of offices with whom we spoke were identified by the state as serving low-income populations, the percentage of offices that accept Medicaid and work with patients with disabilities is not necessarily



representative of all offices in the state of Michigan. When the offices were asked if they make accommodations for specific sensitivities and behaviors, 11 said they would need to refer a patient out to another dentist who specializes in this care or refer for sedation to receive oral health care services.

Staff and interns conducted the survey phone calls. The following quotes from their notes show the range of accommodations that dentist offices are willing or unwilling to make.

They indicated they will make a 100% effort before they refer out. Their accommodations have included: dimming lights, playing music and any other calming techniques. They are wheelchair accessible and serve nonverbal patients. For nonverbal patients, someone needs to be with them to communicate on their behalf.

Appointments for patients with disabilities require a three-hour visit. They will dim the lights, can play music, we can bring things that calm the patient and they offer nitrous oxide to soothe.

They stated they don't have a separate room for those with sensory issues but recommend sunglasses for light sensitivity. They do have a larger area that will accommodate those using a wheelchair.

As long as the patient is cooperative and lets them do the cleaning or perform procedures, they will see a patient with disabilities. If not, they will have to refer them out to a different office that accommodates their needs.

They cannot dim the lights but will let patients bring in their own music.

They will only treat a patient if they feel they can do so without distractions.

The majority of the time patients with disabilities get referred out.

Focus Groups and Interviews

Three focus groups were conducted virtually, with participants from around the state. Two of the focus groups consisted of a mix of adults with disabilities (5) and caregivers of adults with disabilities (11). The third focus group had two dental professionals, one adult with disability, and one advocate for people with disabilities. This individual commonly advocates for himself and others with disabilities. He was recruited by another advocate in the state, who also recruited the dental professionals to be a part of this focus group.

Twenty-two one-on-one interviews were conducted with eight adults with disabilities, three dental professionals, and eleven caregivers of adults with disabilities.

How Many?



37

participants

(some participated in both a focus group and an interview)



20

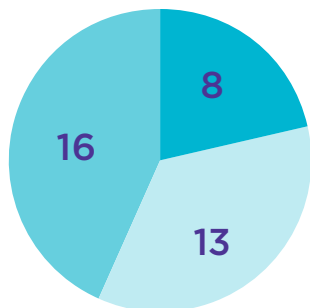
participants in
three focus groups



22

interviews

Adults with Disabilities, Caregivers, Case Workers, Dentists, Other

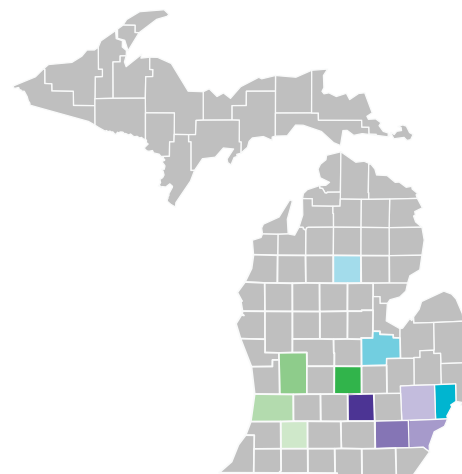


8 people with a disability

13 professionals, including caregivers and dental providers

16 non-professionals, including family members and guardians

Counties



- Allegan: 3
- Clinton: 1
- Ingham: 1
- Kalamazoo: 1
- Kent: 6
- Macomb: 1
- Oakland: 9
- Roscommon: 1
- Saginaw: 1
- Washtenaw: 1
- Wayne: 7
- No address: 5

Case Study: Evelyn and Christopher¹

Evelyn's adult son, Christopher, has an acquired health impairment, and is commonly referred to as a meningitis long-hauler. Christopher has extreme anxiety when it comes to his medical care. Evelyn had been taking Christopher to a dentist who accepted their private insurance. After three visits, the dentist referred them to a pediatric dentist who could better assess the condition of his mouth. Evelyn feels that her son's behaviors are seen as learned or willful misbehaving as opposed to an impairment.

Evelyn had been told the pediatric dentist could sedate Christopher. However, when they attended the appointment, the dental professionals first tried to restrain him. Evelyn referred to this experience as a "disaster":



As a parent, you feel disempowered to step in and tell the medical professional, "Hey, I'm really uncomfortable with what's going on here" because then you look like you're interfering in some practice management that you don't know anything about.

At this point, Evelyn sought out another dentist and had a detailed conversation with them ahead of time about her son's needs and even requested a hygienist that was best suited to care for his needs. Christopher was ready to go on his appointment day, but the scheduled hygienist was not present and no one at the office was aware of Christopher's special health care needs. The hygienist who was available was not patient with Christopher's need for extra attention and time.

Christopher has now been discharged from three dental practices. Evelyn is struggling to feel encouraged to find another dental provider. Because of Christopher's anxiety about medical care being compounded with the poor dental experiences so far, he is more reluctant than ever to see a new dentist.

¹All participant names have been changed for their privacy.

Evelyn has the ability to pay for an extra visit, to help establish a relationship between Christopher and the dentist, so she was all the more frustrated that she did not get this opportunity with any of the dentists they have seen so far.

Evelyn advocates for her son and other individuals with disabilities because she sees oral health for this population as a social justice issue. She acknowledges that she and Christopher, for all the issues they've faced, have had a better experience than others because of having private insurance. Those with Medicaid struggle even further to find a dentist with whom they can even make an appointment. According to Evelyn, "The personal impact is huge, but also the social impact. It's a social justice issue and needs to be seen that way."



Barriers²

Financial Concerns

Financial concerns were the most referenced issue that participants face in their dental health. For example, many participants stated that Medicaid did not cover the services needed, leaving a balance of often thousands of dollars that need to be covered. Some of the participants we spoke to were able to pay for these expenses out of pocket, but many could not.



“My son receives Medicaid, it covers nothing on dental, absolutely nothing in the state of Michigan. No cleaning, no checkups, no dental care at all is covered by Medicaid in Michigan. I don’t know what it is in other states, but in Michigan, there is no dental care at all covered by Medicaid.”

—Pam, parent of an adult with a disability

“He has been sedated a couple of different times, but it was always hard to find a dentist who took the Medicaid insurance for sedation. And so last time he was sedated in a hospital, whatever Medicaid paid for, it was still like \$3,000 out-of-pocket.”

—Jenny, case manager

“We were looking at a \$10,000 expense, even though I had dental insurance. He was not on Medicaid at the time, but I had dental insurance. ... As your only kid, you’re going to do whatever you can. Our insurance covered about \$1,500 and we had to come up with \$7,000 to save his teeth.”

—Maggie, parent of an adult with a disability

“I needed deep cleaning and the deep cleaning that I needed ... they don’t pay for it. I had to skip it because I don’t have that kind of money.”

—Amy, individual with a disability

“I called the office and the receptionist said that they don’t take Medicaid. They told me it was \$135 for a cleaning session. So what I’m planning to do is pay out of pocket for the cleaning. If they find any cavities, I’ll just look for a dentist elsewhere.”

—Hannah, individual with a disability

“Yeah, they don’t cover it. So, I have to [pay] out at one time, \$3,000.”

—Trevor, individual with a disability and peer counselor

²Participant quotes have been lightly edited for brevity and clarity.



Another common theme among participants was the struggle with dentists not accepting Medicaid. Many people have to travel great distances to go to a dentist who accepts Medicaid. With this population, transportation is already a barrier, so traveling outside of their own city can seem like an insurmountable hurdle for many.

“Maybe there is some coverage, but there’s no dentist that accepts Medicaid dental care, because it covers probably a tiny, tiny percentage of the actual cost.”

—Pam, parent of an adult with a disability

“Finding a dentist that accepts Medicaid is extraordinarily difficult because they hardly make anything on those visits.”

—Susan, case manager

“The issues that I’ve seen the most have been for people who are on Medicaid and finding locations that accept Medicaid.”

—Jenny, case manager

In other cases, the only dental providers in the area who accept Medicaid are community health centers with dental clinics. Some clinics have a months-long wait to get an appointment. Others are walk-in only, meaning a person may have to arrive early, wait for hours and is not guaranteed to be seen.

“There’s no dentist taking Medicaid-only people, and we have two newish clinics in the area, but it still seems like forever. We’re always begging and looking for dental support.”

—Maggie, parent of an adult with a disability

“A huge barrier is if there are clinic locations that offer discounted or free services and accept Medicaid, people would struggle with how to get there.”

—Jenny, case manager

“I have bad teeth, and I always had problems going to my dentist, my old dentist. It would be like three to four months until I could get into a place because I have Medicaid.”

—Amy, individual with a disability

The last topic to address within financial concerns is the reduction in community resources for people who struggle to afford dental care. Participants mentioned that in years past, there was a dental fund that allowed people to apply for an amount to cover their dental expenses for the year. A few of the participants mentioned that this was helpful but that it no longer exists.

“We did have one doctor that we worked with here in Kent County for several years, because we were able to tap into the Delta Dental treatment fund that was through the State of Michigan.³ We were able to tap into that, and that was super helpful for years. Then I think it was [former Governor] Snyder that got rid of that one, so we haven’t had any outside assistance.”

—Maggie, parent of an adult with a disability

“The Dental Fund was pretty easy. You just had to submit the request with the estimate of how much the care of the oral needs would cost. And then usually it would go through and then I wouldn’t have any problems. But then the program went away, and since then I’ve had really no luck with getting the needs for my individuals pertaining to their oral care.”

—Odette, case manager

Transportation

Transportation is another concern for many of the participants. For those with more independence and who live in a city large enough to have public transportation, that is an option for them. However, for a majority of people with disabilities, they depend on being driven to their appointment. This leads to transportation being a compounding barrier in accessing dental care.



“For some people it’s that barrier of not having a driver’s license, not having a vehicle, and how are they supposed to get to not just dental appointments, but doctor’s appointments too.”

—Pam, parent of an adult with a disability

³The authors could not confirm the existence of the funds of which this participant spoke.

“Transportation can sometimes be a barrier. So, I know depending on where the person lives and if they’re able to utilize public transportation, sometimes they just don’t know where they need to go on the bus to get there.”

—Kate, case manager



In some cases, the lack of local dentists who accept Medicaid cause a need to travel great distances across the state to access dental care.

“Transportation-wise, because my person lives in Sparta, and then to get all the way to Ann Arbor [about 145 miles away], his parents were going to have to step in and do that.”

—Odette, case manager

“Transportation always seems to be of difficulty for them. Some of them come kind of far. Some of them don’t have the transportation, or public transportation is difficult, or paying for that.”

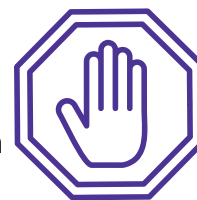
—Dotty, dental hygiene clinical lecturer

“Now he lives in a residential setting, and for a while, a mobile dentist was coming once a year and you could make an appointment. ... making sure his teeth are clean, it’s not easy to say the least.”

—Cathy, parent of an adult with a disability

Access

Access is a major barrier for individuals with disabilities. Sometimes, this comes in the form of physical access challenges, but very often, simply being able to find a dentist and make an appointment are the problems. In the first quote below, Julia mentions that the state does not keep a list of providers who accept Medicaid. Please note, the state does keep a list; however, the list may be too long, too overwhelming, and too difficult to access from a smartphone.^{xxx}



“All of the folks we work with tend to look for Medicaid dentists. And as you probably know, the state does not keep a list. So, you either have to call around and ask or most folks just go to the My Community Dental Clinic.”

—Julia, case manager

“A lot of my individuals, I feel like either they have a dentist, or they have no idea who they can see. I think that just with the Medicaid providers in terms of dentists, is a little bit limited....But I think it’s just finding the provider that will accept [Medicaid] is kind of the biggest struggle that I face with helping my people out and find that resource.”

—Kate, case manager

In other cases, once a dentist office or clinic is found, many report that the wait to be seen is frustrating. Also, any missed appointments can lead to a patient being discharged by the office, further limiting the pool of dentists from which a person can choose. These struggles can cause a person to put off getting any dental care until it is an emergency.

“I find that with those clinics, they’re busy. Sometimes it can take a while to get scheduled. And then we came across the issue where if someone missed an appointment or two, they got discharged from services. So, they could no longer go to the dental clinic if they missed an appointment or two. And in an area where they’re the only people that take Medicaid, that’s a huge problem.”

—Julia, case manager

“Emergency dental, like if you wake up with a toothache. We have people going to the ER because they don’t have a dentist.”

—Maggie, parent of an adult with a disability

Motor and Cognitive Limitations

For many people with disabilities, dexterity limitations make it difficult for them to perform daily oral hygiene tasks. These difficulties can lead to a lack of oral care, or a caregiver may have to perform this task for them. This can hold a person back from independence that they may otherwise be working towards. Motor and cognitive limitations can also be a major struggle when it comes to getting proper oral care in a professional exam setting. Many dental professionals are not able to do a full cleaning, exam, X-rays and more for a person who is not able to sit still or who reacts poorly to having others near their mouth.



“The piece that’s the hardest for him is he has dexterity issues. This is an issue with dental care. He is a little older now and he has a hard time holding a toothbrush. We’ve tried electric, which terrified him. So that was not going to happen anymore. He has a hard time grasping it [the toothbrush]”

—Susan, case manager

“He also wakes up really ugly from the anesthesia, so that’s not the best solution. Unfortunately, you have to work within the system, and it is what we had to do because it wasn’t safe for them to try to do that in a chair. A lot of people who are more cognitively impaired really need that hospital support and a team, not just a dentist and a hygienist.”

—Maggie, parent of an adult with a disability

“I’m sure he’s not getting his teeth flossed, because he would bite the person who was putting her fingers in his mouth. So, we do need to reschedule that appointment with the dentist for the major sedation, X-ray, and the deep cleaning.”

—Cathy, parent of an adult with a disability

“I use a special flosser and of course with my disability, I just got a new electric toothbrush. When I’m out traveling, because of the size of my mouth and my hands, I have to use a children’s toothbrush. Adult toothbrushes are just too big and too hard for me to use, if I want to do a good job.”

—Lana, individual with a disability

Anxiety

About half of all people have some anxiety and fear about going to the dentist.^{xxxii} Participants indicated this is especially true for people with disabilities. Symptoms such as light and sound sensitivity are particular problems for many of the people with whom we spoke. Dentist offices are, by necessity, bright, loud places.



“The barriers may be if they’re struggling with sensory issues. I’ve known individuals that just don’t enjoy brushing their teeth. It might sometimes have to do with a sensory issue if they don’t like the sensation, the flavor, or even just the general feeling.”

—Jenny, case manager

“I think some people are afraid and they get a lot of anxiety so just the fear of going in. Some of my people take a[n as needed] medication before they go to the dentist just to relax.”

—Kate, case manager

“I went there and then my anxiety was spiked up because the medicine wasn’t working. I was explaining it to them like, ‘Hey, the medicine’s not working.’ They didn’t care.”

—Briana, individual with a disability



Anxiety about making appointments and showing up to the dentist office are also anxiety-inducing for many. The anticipation of going to an unfamiliar place and receiving dental services that may be painful can cause people with disabilities and anxiety to put off their dental care.

“I’ve known people who have put off getting fillings or other dental work just because they know that it will be painful. They’re anxious. They can’t get the sedation either. They’d have to pay for sedation out of pocket. So there’s lots of financial barriers.”

—Jenny, case manager

“I think the only hard part for [my son] is the waiting around in the waiting room. When you’re going to have an appointment, you don’t have an appointment at noon, and you see somebody by 10 minutes after. The additional waiting time, I think it’s very difficult for someone with a disability.”

—Cathy, parent of an adult with a disability

“[Long wait times] can be a big challenge for a person or a child that suffers with anxiety. Because they’re sitting there and they’re waiting and they’re waiting. They’re getting uncomfortable and they’re not liking the people that are coming in. You can have some rude people coming into the dentist’s office.”

—Edith, individual with a disability and peer counselor

“However, due to my autism and my neurotype, having that change and then also the anxiety of having to find another dentist and having to call people I don’t know on the phone is very nerve wracking to me. So that’s the reason why I have delayed [seeing the dentist] until now.”

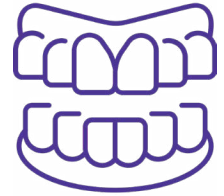
—Hannah, individual with a disability

“I have to have my caregiver go with me. I get scared because the dentist I’ve had, they didn’t know me well. They didn’t care about my disability. They just went ahead and pulled my tooth and didn’t even let me know they were going to pull it.”

—Briana, individual with a disability

Physical Challenges

Participants spoke of the physical challenges they face in their dental care. Some have dentures that are difficult to make feel comfortable, others have smaller than average mouths and need special attention to have a less painful experience.



“I have dentures, but they don’t fit me right. Then I go back to the dentist and complain about it but then they don’t fix the problem.”

—Amy, individual with a disability

“Fortunately, my son has all of his teeth, and we discussed many times, if he should wear an appliance to prevent the teeth grinding. But he was really choking on the appliance. All the dentists that we ever talked to about that, they were nervous he would choke on the appliance.”

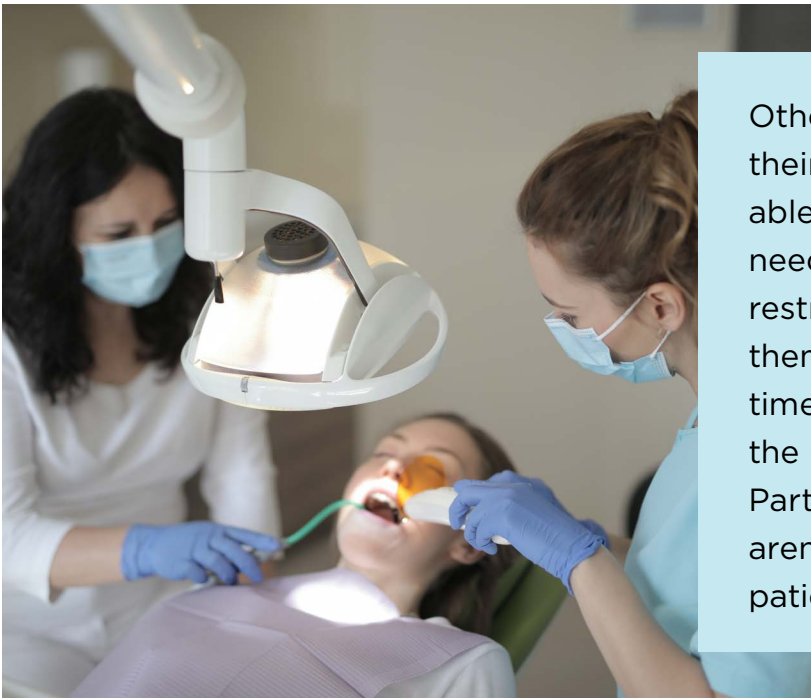
—Cathy, parent of an adult with a disability

“I try to explain to them that they’re going to have to use a kids’ film to do the X-rays of my mouth. They say, ‘Oh no, I think we can do it with the adult.’ They go get the adult size and bring it in. They try to put it in my mouth and then say, ‘Oh, I see what you’re talking about.’ I have a lot of scar tissue in my mouth that blocks the adult film from getting in there and settling down so that I can bite on it. They’ll say, ‘Oh okay, I should have listened to you.’ And I’ll say, ‘Yes, you should have.’ And because I feel like I tried to explain it to them, they didn’t listen to me, so they found out and then brought pain upon me.”

—Edith, individual with a disability and peer counselor

“I know some dentists don’t have the adequate room for people with wheelchairs. Also, sometimes I have to bring a pillow for my back because of my scoliosis, I don’t sit completely straight on the chair, so I don’t have that support I need.”

—Lana, individual with a disability



Other participants commented on their dental staff's lack of being able to work with their patients' needs. Some dentists try to restrain patients without informing them or the caregivers ahead of time or educating them about the use of protective stabilization. Participants also feel that dentists aren't comfortable working with patients with disabilities.

"We finally found a dentist that saw kids with disabilities... But they required that she be in a straitjacket. She needed the work done. But the notion that you would just go in, tie her down, and the brute force of it, it just wasn't acceptable. So it took us a while. Eventually, we did find a dentist that would see her for practice. Getting used to it, understanding how it works, spending more time."

—Bob, parent of a teen with a disability

"I think that in general dentistry we don't do enough in terms of training around the subset of pediatrics that are children with disabilities or children with anxiety or mental health issues or any other behavioral health issues. You don't know as a patient or a patient advocate what their experience really means."

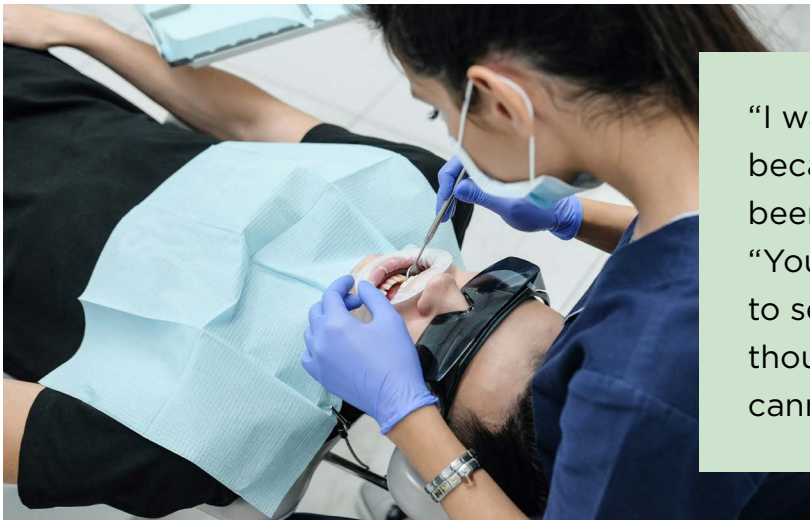
—Evelyn, parent of an adult with a disability

Case Study: Linda and Troy

Linda has faced frustration with the dental care that her son, Troy, has received throughout the last ten years. Troy has autism and needs high supports. He was also diagnosed with epilepsy in 2018. At the age of 12, Linda took Troy to a pediatric dentist who could not sedate him. They tried to restrain him, but he was too strong to be safely restrained. Linda had to begin looking for another dentist who could sedate a pediatric patient. She had to look outside of the town where they live.

Linda thought she had found the perfect dentist. He sedated Troy at the hospital and was able to complete the cleaning, exam and X-rays. The dentist was not comfortable with sedating Troy very often, so they came up with a plan to do cleanings, X-rays and any other necessary dental work every two years. Linda was happy with this arrangement.

Other medical issues prevented Troy from going to the dentist two years later, but he went for dental work the following year. Two years after that, the dentist consulted with Linda and Troy and said there was no need for dental work at that time. Three years later, the dentist again did not see any dental issues that showed a need for sedation and treatment.



“I was kind of taken aback because I thought by then, it’d been like five years,” Linda said. “You really needed a cleaning and to see what was going on. Even though your teeth look clean, they cannot be healthy underneath.”

In April 2020, during the early days of the COVID-19 pandemic, Troy cracked a tooth. Linda had trouble finding an office to see him. However, one dentist was willing to see Troy. The cracked tooth was cracked all the way to the root. The dentist also found six other cavities needing fillings and two teeth with so much decay that they needed to be pulled. This was distressing to Linda, as she had been assured by the previous dentist that Troy did not need any dental care for several years.



Linda has now received education from a dentist about how to better care for Troy's teeth at home. Some recommendations are to stay away from sugary foods, use an electric toothbrush and to concentrate on the outside of Troy's teeth if he will not allow brushing for the full two minutes. Troy's occupational therapist has tried to increase his ability to brush his teeth, but he has low muscle tone in his hands. For now, Linda has had to continue brushing his teeth for him.

The dentist found six other cavities needing filled and two teeth with so much decay that they needed to be pulled.



Solutions

Financial

From the participants' perspectives, a primary solution that would solve many challenges is better Medicaid coverage. Many feel that Medicaid should reimburse better so fewer procedures would need to come out of the patient's pocket. This would especially be important among the disability population, where there are already disparities in dental health. Dental professionals also expressed a desire for better Medicaid reimbursement so they could better serve their patients with disabilities.



“If there were more dentist offices that did what we needed and take Medicaid. There are a lot of loopholes. More dentists who provide sedation and accept our individuals’ insurance [would make the process easier].”

—Odette, case manager

“Well, part of it would be getting a better insurance coverage that dentists would accept that payment for people on Medicaid.”

—Pam, parent of an adult with a disability

“Yes, we do accept insurance, and we also accept Medicaid which many of our special populations have. ... It would certainly be nice if Medicaid reimbursed a little better, obviously, and paid for more procedures than they do right now.”

—Dotty, dental hygiene clinical lecturer

Participants also feel it would be helpful to have better access to information about dentists who accept Medicaid. Having a database of these dentists would make the process of finding a dentist easier, removing one of the barriers from people with disabilities and their caregivers.

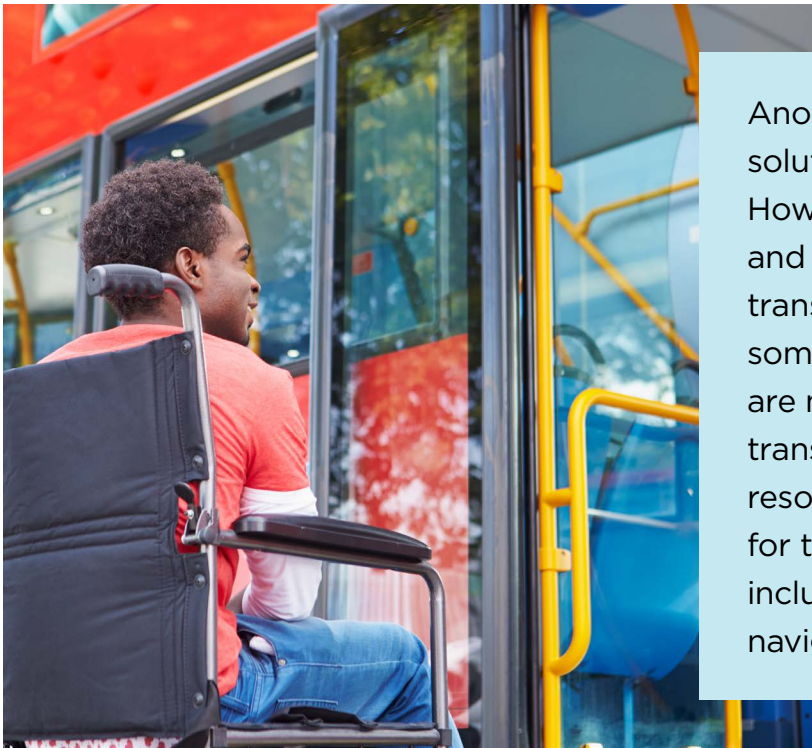
“I think it would be 100% wonderful if we just had a list of providers who serve the IDD population, who accept Medicaid and are accepting new clients.”

—Kate, case manager

Transportation

One theme that came up with several participants was about how to make transportation to and from a dentist more convenient. For many, having a dentist closer to home would be ideal. If more dentists accepted Medicaid, then finding one close by would be much easier.





Another helpful transportation solution is public transportation. However, many smaller cities and towns do not have public transportation options. Additionally, some individuals with disabilities are not able to manage public transportation. Other community resources should be made available for transportation to dental visits, including services to help people navigate public transportation.

“Just having a provider that works best with the IDD population, accepts their insurance, is centrally located in my city, and on a bus line.”

—Kate, case manager

“[Residential] homes are providing transportation for dentist visits. And then on my caseload specifically, I have a lot of people that can utilize the public transportation system. If not, then natural support, I think, would fill in that role or through my organization, we have Uber Health. So we could set up an Uber for them if they didn’t have anyone or any way to get there.”

—Odette, case manager

“[Is there anything that would make it easier for you to go to the dentist?] Have somebody accompany me.”

—Trevor, adult with a disability

“Maybe a caregiver could go with them and help them to understand what is going on and why this is important to them. I think it would be a big asset to the community of people with disabilities who are not comfortable. Some people are not comfortable doing anything outside of their homes, if they have a disability, because I do know some people like that, and I have motivated a lot of people to get out of their home.”

—Edith, adult with a disability and peer counselor

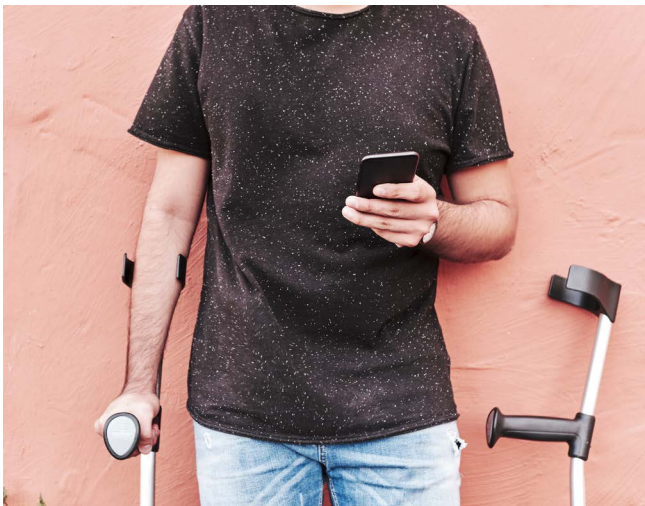
Many areas of Michigan are quite remote, where there is little access to any amenities, including dental care. A solution for this would be a mobile dental unit that specializes in dental care for adults with disabilities. In some areas, there is a mobile unit that travels to elementary schools. However, there is nothing similar for adults.

“I think it would be fantastic if there would be ... a couple of the elementary schools here in Holland, they have a mobile unit called Miles of Smiles or something like that. It comes to the schools and does dental care for kids whose families are low income.”

—Pam, parent of an adult with a disability

Education and Caregiver Assistance

The role of a caregiver is extremely important in the life and well-being of an individual with disabilities. Supporting and educating caregivers will have a large impact on the health of this population. Many of the participants felt it would be helpful for them to have education on oral health care. Individuals with disabilities, their family members and case workers all agreed that more education on this topic would be helpful.



“Creating videos is ... it’s a helpful option because it’s something that can be used whenever the person is comfortable with watching it. Then they could watch it more than once, which would also be nice.”

—Jenny, case worker

“And definitely training for direct care staff on several things, on the necessity for good oral care and dental care.”

—Cathy, parent of an adult with a disability

“I would say all of the above [a book, video, and class], simply because there’s a lot of people who are not able to read. And then there’s a lot of people who are visually impaired, and there’s some people who, no matter what you put in front of them, they’re not able to understand it.”

—Edith, individual with a disability and peer counselor

“I don’t think there’s exact training on oral health. I could be wrong. Throughout the five years I’ve been in adult foster care homes, I haven’t ... I don’t think there’s any exact care on how to care for the oral health of the individuals that live in the home. That’d probably be something that’d be beneficial to them.”

—Odette, case worker

“And then, some ongoing time with a hygienist talking about what is the best way to brush your teeth. I know they used to have these big toothbrushes and teeth and doing more of some of that one-on-one showing, demonstrating type stuff to make sure that things are being done appropriately. Because a lot of times, instead of hearing instructions, people with developmental disabilities learn better by seeing, by watching someone do it or watching a demonstration like that. And they need reinforcement, so it’s not like you can do it once and assume that they’ve got it.”

—Pam, parent of an adult with a disability

Some participants have used trial and error to find what works for them, their family members, or their clients. They provided several tips that have been helpful in their own experiences as they have navigated dental care challenges. These suggestions are a few of the options that can be included in educational resources for other caregivers.

“For her, routine is important. So, the bedtime routine is just... that’s when the most serious dental care part happens. But the thing is that you have to have the mindset. We’re going to put what seems like an unreasonable amount of work and effort into the front end, and then that’s going to pay off for the next 70 years.”

—Bob, parent of a teen with a disability

“Right after you get dressed in the morning, you’re brushing for two minutes, you set a timer, and then you move on to an activity you enjoy. They understand that there’s a consistency there, and then they get to do something that they like to do afterwards. I would suggest to a caregiver to do your best. Putting it in their mouth, even if, at first, it’s for a second. Giving them praise every time that they put the toothbrush in their mouth. Then reinforcing that behavior to hopefully make them more comfortable with just having that oral stimulation and going from there with increasing the time.”

—Jenny, case manager

“We had electric toothbrushes everywhere, so we’d put them up by his ears. We would just flood him, basically, to get him used to loud noises. Then I started flossing his teeth at home so that he was getting used to someone putting their hands into his mouth, because that’s disgusting and it’s hard to explain. Structure is the biggest thing now, day and night. ‘Did you brush your teeth and did you take your meds?’”

—Maggie, parent of an adult with a disability

“My son doesn’t necessarily want to have anything going in his mouth, so he’s chewing the toothbrush. So, it would require some significant training, I think, on what’s the best approach to take, and that would probably have to be like individually determined.”

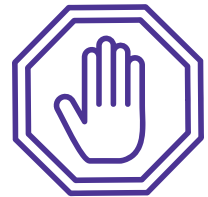
—Cathy, parent of an adult with a disability

“And I think that the other thing that is helpful is the dentist has actually talked with my daughter about the long term. And for many of us, we can’t associate the long-term effects of what’s going to happen if I don’t brush my teeth today. But the dentist and the hygienist still continually talk with her about the long-term effects and the loss of teeth later in life.”

—Paula, parent of an adult with a disability

Access

Parents greatly appreciate any flexibility in scheduling that a dentist office can provide. As one parent pointed out, it is difficult to know if any given day will be a good or bad day to attempt to get the individual to an appointment. They would like options for weekend appointments when the office will be slow, and some leniency when they need to cancel or reschedule at the last minute.



“Eventually, I found this doctor. He works on the weekend. And he’s willing to come in the first thing in the morning for my son. So, I follow Sunday appointment at 8:30 or 9:00 in the morning. Scheduling an appointment is never a problem. Once I’m done with this visit, straight away to make sure I get the spot, I scheduled for six months later, assuming there’s no extra work needed. Scheduling an appointment is not a problem.”

—Ting, parent of an adult with a disability

“Dental appointments get set six months in advance and they always want to catch you on your way out of the dental visit. So, I’ve got a kid that’s already hanging off the ceiling, and then they want me to try to schedule my dental visit six months out. It would be really helpful if I’m on a call list and they just called me two weeks before and said, ‘Guess what? We have an appointment two weeks from now. Would you like to come in?’”

—Evelyn, parent of an adult with a disability

“The only problem that I have is with the appointments. I think they could be a little bit more lenient, because when you have a child with a disability, every day might be a different day. You don’t know how their behavior is. So, if they were a little bit more open to understanding. I know this appointment was made six months out, but right now we’re having a bad day. So, if you can be a little bit lenient. If I have to call at the last minute and say, ‘Hey, right now, I can’t make it to the appointment’ that doesn’t count against me.”

—Fiona, parent of a teen with a disability

Other participants had ideas for making the dentist office experience easier and more accessible. One would like a separate office or entrance that would make patients with disabilities more comfortable. A dental hygiene clinical lecturer pointed out some of the features their school has, which would make a better experience if these features were included in more offices.

“If they have a special office, where people with disabilities can go in. And I’m not saying separated from other people but have an office where maybe some people who are not comfortable, they can go in through another door or something, that can help them to be more comfortable in going into the dentist office.”

—Edith, individual with a disability and peer counselor

“We have a wheelchair transfer. We have a bariatric for those over a certain weight chair. We have... where the parking is, the access is all on the same level. And then we have an elevator that takes them right up to the clinic.”

—Dotty, dental hygiene clinical lecturer

Improving the Dentist Office Experience

Most participants felt that dentists could serve individuals with disabilities better if they had been trained in school to care for these patients’ special health care needs. They commonly stated that dental school curriculum should include exposure to caring for patients with disabilities. In particular, many wanted dental staff to talk to the patient directly and explain things in a way they can understand.



“There should be more training around people’s medical history, oral health as your whole health, as opposed to just this person in this moment. And in terms of the training, I think there’s an implicit bias kind of training that could be beneficial for dental providers and office staff around individuals with disabilities.”

—Evelyn, parent of an adult with a disability

“It’d be wonderful if dentists were to have a class on special needs people.”

—Joanna, parent of an adult with a disability

“Their staff should be trained to work with disabled people, to be more understanding. Not just for dentists that take Medicaid, for dentists in general.”

—Hannah, individual with a disability

“Part of our CODA, our dental hygiene standards is that all the students need to meet, to have experience, and be competent in working with those with special needs.”

—Dotty, dental hygiene clinical professor

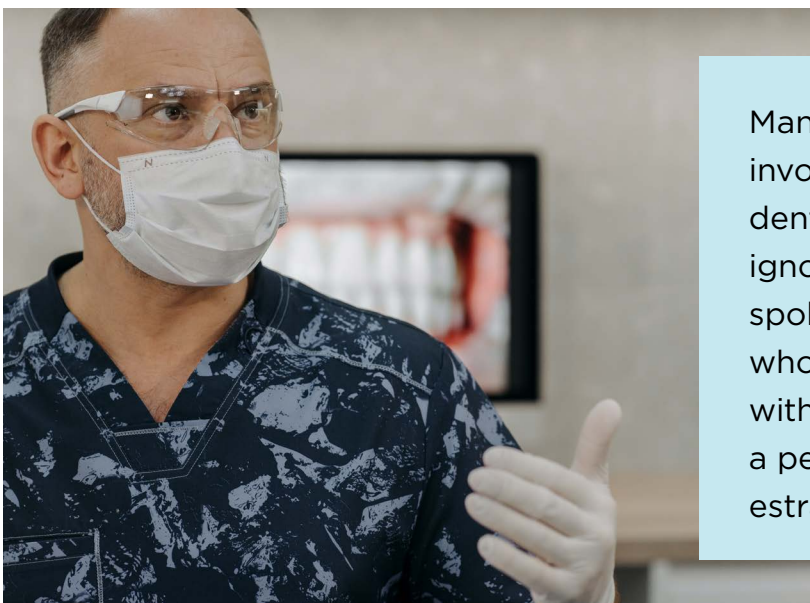
“A very friendly, nice receptionist to greet my son firsthand would be ideal. Then, the dentist experience would be somebody who explains to him what they’re doing before they do it and giving him the respect, I guess, of what any one of us would want.”

—Joanna, parent of an adult with a disability

Participants felt strongly that dental staff should talk directly to the patient with disabilities. Many had experiences that involved the dentist or other dental staff talking past or ignoring the patient and instead spoke directly to the caregiver who came to the appointment with the patient. This can make a person with disabilities feel estranged and even infantilized. A better approach would be to talk directly to the patient and—only if the patient is not able to answer clearly—look to the caregiver for clarification.

“Talk to the person, even if the caregiver’s going to be doing the answering, you want to look at the person when you speak”

—Cathy, parent of an adult with a disability



Many had experiences that involved the dentist or other dental staff talking past or ignoring the patient and instead spoke directly to the caregiver who came to the appointment with the patient. This can make a person with disabilities feel estranged and even infantilized.

“When a dentist takes the time to acknowledge that and treat someone humanely as they would anybody else, that’s quite a plus.”

—Melanie, case worker

“I would want a dentist to give us the respect of the explanation [of what they’re doing]. Calm, and caring, and understanding of people with special needs.”

—Joanna, parent of an adult with a disability

“Last time my daughter was at the dentist, she came out smiling, she was giggling, she was laughing, she was talking about how the dentist talked to her and he explained everything that he was doing before he did it. And he told her to tap him to let him know if she has any pressure or if she’s feeling anything. And whenever she tapped him and let him know, he would stop.”

—Celine, parent of an adult with a disability

“I’m fortunate enough that my dentist’s office knows that I have special needs myself. And they’re nice enough to keep me with the same two or three hygienists so that they know me well enough to know the precautions they have to take.”

—Rebecca, individual with a disability and caregiver

Some participants also offered tips and tricks that have made their experience at the dentist office more enjoyable. These are things that all dentist offices can do for their patients with disabilities to make their visit easier. When individuals with disabilities have a more enjoyable experience going to the dentist, they are less likely to have as much anxiety the next time they have an appointment.



“For a long time, I was always bothered with the bright light to see my mouth clearly. So, I would always close my eyes, but now I ask for sunglasses. The last couple of times I also asked to put on the lead jacket because I like pressure therapy.”

—Hannah, individual with a disability

“They always drape my son for about five minutes before they start anything, and they just laugh and talk and then there’s also a TV. Those kinds of distractions are super.”

—Maggie, parent of an adult with a disability

“When they offered the radio, and they took the time... It’s that kindness and the gentleness and the patience. They can sense that the person’s anxious and they take the time to calm them. Sometimes they change the subject, ‘Oh, what TV show do you like?’ It makes an enormous difference. And when I would find a dentist like that, that’s who we would keep going back to.”

—Melanie, case worker

“When my daughter goes in for a dental cleaning, one of the dental techs will sit next to her and hold her hand. She likes it when people comb her and give her soft touches, and so they do that. The dental technician can be cleaning her [teeth] and somebody else is helping keep her calm and talking to her. They just do an amazing job of befriending her and being her support. I really appreciate that.”

—Paula, parent of an adult with a disability

“This one dentist had TVs in the ceiling of the chair. So, when you went back, you could see the TV. It was cool.”

—Natalie, parent of an adult with a disability

“I like that they understand, and they just take things slow. And this is the funny thing, because of my anxiety and stuff, they put pictures of my favorite actor up on the computer so I just can stay calm during it. So just little stuff that they can do is always a plus.”

—Lana, individual with a disability and peer counselor

“My dentist office has a TV right there. So I think that’s always helpful because it’s kind of a distraction. Some of my individuals that might be overstimulated by the noise going around, headphones might be a good idea. I also think allowing a staff person, or a loved one, or whoever, to go back with them to help with their nerves would be beneficial as well. Or if they have like a favorite toy or stuffed animal, anything to make them feel comfortable in the chair.”

—Odette, case worker



“I know when I go to my dentist, they have like a menu to offer a blanket, coffee, or music. For a person with a disability, it might be good to have something to ask, ‘What would you make your child more comfortable?’ And offer to dim the light or have a quieter place without tons of people.”

—Maya, case worker

“That’s where my son has his most anxiety is going into the exam room... So, we found a dentist that has the air filtration system where he takes out all the smells, so we don’t have that medical smell. The lights are dimmer, he’s the only one in the room with him. So, you don’t have hygienists, assistant, everyone rushing in on him.”

—Lisa, parent of an adult with a disability

“I took him every six months because that is the annual checkup that he entitled under his private insurance. But if I get to do it every three months initially while my son cannot do anything but sit in the waiting room, that will help maybe speed up the whole process of getting him comfortable.”

—Ting, parent of an adult with a disability

A few participants had thoughts on how to make appointment reminders more beneficial to them. Many of them pointed out that they need multiple reminders. With these reminders, they are more likely to make it to the appointment. Keeping appointments is important not only for the care a patient will receive, but also because if a patient misses too many appointments, they can be dropped as a patient. With so few dentists who take Medicaid and who work with patients with disabilities, it is important for patients to keep in good standing at an office with whom they are established.

“I like all reminders. So, text would probably be my first choice. Then phone call second choice and my third choice would be an email, and just one [email].”

—Natalie, parent of an adult with disabilities

“I would say a text first, email, and then a phone call. I need all three.”

—Hannah, individual with a disability

“I like that my dentist will call me the day or two days before, and they would leave me a voice message reminding me that I have an appointment.”

—Edith, individual with a disability and peer counselor

“I work with adults who live on their own with special needs. And for really all the individuals that I work with, they prefer a card. Very few of them have cell phones and aren’t texting, they’re not emailing, and they don’t have computers. And they love to get a card that has a picture...And they tape it up and they can look at it and they know. I have individuals who do not read, but they can see the picture of the dentist and that’s helpful for those specific people.”

—Melanie, case worker

Another aspect of dental appointments about which participants had much to say is booking appointments. For those who make their own appointments, some would prefer to do it online so they can go at their own pace and not have to speak to a person who might make them nervous. For others, having a back-up appointment would be ideal for them in case they are not able to make it to the first one. Others commented that reducing the time it takes to be seen would make a more perfect dental appointment.

“I would like to book an appointment online so I don’t have to talk to the receptionist at all. This would be for not just me but for many other people. Also, sometimes dentists they’re open 8:00 to 4:00 or something like that. But if you’re not able to call during that time to make an appointment, online booking is always accessible.”

—Hannah, individual with a disability

“My idea of a perfect appointment would be to have two time slots. Maybe have a second day that you set up a time that is for just in case. Because as a parent, things happen. Things come up and you might not be able to make it to that appointment. And where you could just already have a backup appointment. I know sometimes my kids get a little anxious and things run over. And then you know you only have that certain amount of time, that 10 to 15 minutes. And if you don’t make it to your appointment, then you’re booted out, so you have to reschedule.”

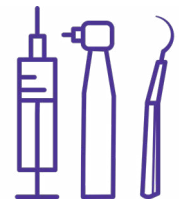
—Celine, parent of an adult with a disability

“I was just going to say the perfect appointment would be when you have an appointment, you arrive, and you check in and within three to five minutes of being in that waiting room you’re called back into the chair. That’s a perfect appointment.”

—Paula, parent of an adult with a disability

Equipment

Caring for one’s oral health at home can be a challenge, but some participants had some good ideas to solve challenges. For issues with dexterity or sensitivity, electric toothbrushes are a big hit. For individuals who do not like to have their teeth brushed, changing the toothpaste flavor can help. When a person has a smaller than average mouth, a child’s size toothbrush helps them to reach everywhere they need to for a healthy, clean mouth.



“I found that using an electric toothbrush helps a lot more because I’m very sensitive with toothbrushes.”

—Hannah, individual with a disability

“I think certainly a delicious tasting toothpaste that anybody would like to have in their mouth would be a good thing. I also order for my son the motorized [toothbrush] one that vibrates, because I feel like it’s going to clean his teeth better than just a manual toothbrush. And I think he’s a little less inclined to bite on it, and I do replace it every two months.”

—Cathy, parent of an adult with a disability

“I use a certain toothpaste, because my teeth are very sensitive, and the dentist told me it was because of me having been fed the lye when I was a baby, and it still affects me as an adult. He also noticed that in the very back of my mouth that I was not getting in there to clean my teeth very well. So, he suggested that I use a kid’s toothbrush instead of an adult toothbrush.”

—Edith, individual with a disability and peer counselor

“We’re trying to get some various adaptations for dental aids that people use, the larger handled toothbrush, various things like that, so that when we do our oral hygiene instruction, we can actually show them what could be done for a particular patient.”

—Dotty, dental hygiene clinical professor

Case Study: Ting and Wei

Ting's son, Wei, was born premature at just over one pound. Due to his small size, contracting meningitis, and other issues, Wei spent six months in the Neonatal Intensive Care Unit. Later, at the age of three, he was also diagnosed with autism. Wei has behaviors that may make a dental visit challenging and has been known to injure himself. Because of having had experience with anesthesia due to prior medical issues, Ting did not want to have Wei sedated for dental care unless it was a last resort.

If Wei has a fear or anxiety about going somewhere, his self-injurious behaviors will increase, and he may even hit his head on objects. Ting is a big believer in being proactive to make sure her son's dental health is the best it can be. She limits his sugar intake and regularly brushes his teeth to keep from needing to go to the dentist often.



To me, I'm very big about proactive. I find that if I am proactive, maybe my son is predictable. We dealt with our special needs for a long time. You know what will work, what will not work. I try to eliminate all the negative scenarios or possibilities that can happen [and try] to get a positive experience. It's not guaranteed. But I find from my point of view, the only thing I can do to help myself, always about helping myself, is to eliminate anything that I can potentially see that is a problem and be as prepared as possible to avoid any meltdown, or I break down.

Acclimating Wei to the dentist was a long, gradual process, but it has paid off. Ting takes Wei to the dentist office every six months, but at first, never even made it in the door. Her goal in the beginning was to just have him recognize the building. After a visit or two, she had him go into the waiting room and had staff introduce themselves. After several visits, Wei had still not made it to an exam chair. Eventually, he was able to sit in the exam room. However, as soon as his behaviors began, the appointment was over, and they left without Wei even opening his mouth for the dental staff. Ting stayed patient. Finally, after about four years, Wei sat in the waiting room, opened his mouth, and allowed the dentist to look into his mouth. Wei is now, at 20 years old, able to sit in an exam chair and allow a minor cleaning for a few seconds at a time. Ting still has to start preparing Wei about a month before the dentist appointment, talking to him every day about the dentist and telling him it will be okay.



For Ting, an extremely important part of dental care for her son is the dentist and the office staff to be extremely patient with him. She does not mind if they need to charge for the visit, even without any work being done. She appreciates their willingness to do things like come out to the parking lot just to say hello to Wei and make him feel welcome. Another vital consideration is that medical and dental professionals listen to her about her son's needs. Wei was in the hospital under anesthesia for a procedure unrelated to dental care and they did not follow her request to be called into the recovery room before he woke up. This resulted in a traumatic experience for Wei and almost \$10,000 in fees for additional sedation.

Conclusion



Major barriers to oral health for people with disabilities include financial concerns, transportation, access, anxiety and physical challenges. The financial burden of dental treatment was the greatest barrier. Medicaid, and even private dental insurance, often does not cover the total expense of dental treatments.

Where once there were community resources to help people pay for dental care, there is no longer funding for many of these programs. There are fewer dentists accepting Medicaid, which not only creates a financial barrier but also a transportation barrier. This is especially a hardship for people living in rural areas or in cities that do not have public transportation. At dental offices that accept Medicaid, there are typically long waits before an appointment is available. Then, if an appointment is missed for any reason, the patient can be discharged by the office.

For people with disabilities, motor and cognitive limitations can impede daily dental hygiene practices. These individuals are then dependent on caregivers to perform these tasks. Motor and cognitive limitations can also impact the ability of dental professionals to complete dental procedures. Anxiety and fear about dental visits are common. The additional distress caused by lights and sounds, anxiety about making appointments and the anticipation of long waits and painful procedures can discourage a person from going to the dentist regularly. Finally, dental offices may lack the appropriate dental equipment or practices for individuals with disabilities, including wheelchair accommodation or inappropriate use of restraints during procedures.

In response to these barriers, there are solutions to promoting oral health and increasing access to dental care for individuals with disabilities that came up

throughout the study. Expanding public transportation in cities would allow better access to dental services. More dentists accepting Medicaid could also reduce the need to travel long distances for dental care. Individuals with disabilities could also benefit from more flexible dental office policies regarding scheduling and missed appointments. Better accommodations such as building accessibility, intentionally designed waiting areas and more accommodating equipment would encourage patients to regularly return for dental care.

Learning requirements for dental health practitioners, especially those that are experience-based, would also be of great benefit to improving quality and availability of care for people with disabilities. To that end, as of October 2019, the Commission on Dental Accreditation (CODA), updated accreditation requirements, as recommended by the National Council on Disability. Today, students hoping to practice dental care must receive now-mandatory training in serving people with disabilities as follows:

For predoctoral programs and orthodontic programs, dental students must be trained to access and manage the treatment of patients with “special needs. For dental hygiene programs, students must be competent in providing care to “special needs patient populations.” For dental assistant programs, students must be familiarized with patients with “special needs” including patients whose medical, physical, psychological, or social conditions make it necessary to modify normal dental routines.

Further still, currently operating dentists require necessary training and support in providing useful care to people with disabilities. In an effort to impact this need—and to improve private dental insurance coverage—the Delta Dental of Michigan, Ohio, and Indiana, with the encouragement of the Delta Dental Foundation, began offering enhanced benefits, tools and training in January 2021 for member employers that opt in to these benefits. The enhanced benefits include additional dental visits or consultations prior to an appointment to accommodate various special health care needs, including preparing a patient for what to expect in an actual visit; up to four cleanings a year; the use of silver diamine fluoride for cavities when dental instruments are not tolerated; and treatment modifications for patients with sensory issues, behavioral challenges, severe anxiety or other barriers to treatment.



Individuals with disabilities often rely on caregivers to create and even perform daily dental hygiene routines. An increase in education on the importance of oral health would lead to better health outcomes overall for individuals with disabilities.

In line with these solutions, this report recommends the following three solutions as the most impactful in improving oral health for individuals with disabilities in Michigan.

1. Dental professionals need better training in providing services to patients with special needs. Increased education about caring for patients with disabilities would lead to higher quality dental services for individuals with disabilities. Exposure to and practice with these patients in dental school and professional training programs would help the dental professionals to feel more confident in their abilities to serve these patients.
2. Expanding Medicaid reimbursements for dentists would encourage more dental offices to accept Medicaid. As there is currently low incentive to accept Medicaid reimbursement, individuals with Medicaid struggle to find care. This is compounded for individuals with Medicaid and disabilities. Greater access would lead to better dental health among this population.
3. Increasing education on oral health for individuals with disabilities and the people who care for them would encourage better and more consistent dental care at home. Individuals with disabilities often rely on caregivers to create and even perform daily dental hygiene routines. An increase in education on the importance of oral health would lead to better health outcomes overall for individuals with disabilities.

Appendix

Focus Group Questions for 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.)

Interview Questions for 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?

Focus Group Questions for 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.)

Interview Questions for 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?

Focus Group Questions for Dental Professionals

- 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 for Dental 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.

Dentist Office Survey Script

Hi, I saw on your website you take patients of xyz age. Is that right?

I'm trying to find a dentist for my son/brother that has autism. Do you accept patients with special needs?

[no] Oh okay, thank you. My other child doesn't have special needs. Do you take Medicaid if I needed to get him in for an appointment? (Or you can say that you yourself have Medicaid and might need an appointment.)

[no] Okay, thanks for your time.

[yes] Okay, great. I'm making a few other calls, but I'll call back if I need to make an appointment.

[yes] Okay great, so your office can make accommodations for him? Like, sometimes he needs the lights dimmed if he gets overwhelmed. ... Great. And do you take Medicaid?

[no] Okay, thank you anyways. Oh, and by the way, I have a friend in a Facebook group with a child/adult child who uses a wheelchair and is non-verbal. They're also looking for a dentist. Would you take a patient with more severe special needs? (Can be a little vaguer, since this is for a "friend." May need to say something like "I'm not totally sure what type of disability they have, what would be something you take or don't take?")

[yes] Okay, great. I'm making a few other calls, but I'll call back when I'm ready to make an appointment. Oh, and by the way, I have a friend in a Facebook group with a child/adult child who uses a wheelchair and is non-verbal. They're also looking for a dentist. Would you take a patient with more severe special needs? (Can be a little vaguer, since this is for a "friend." May need to say something like "I'm not totally sure what type of disability they have, what would be something you take or don't take?")

Thank you so much for your time!



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