

## Experiences in Dental Care Access among Hoosiers with Disabilities: Summary of Key Informant Interviews

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### Project Overview

The Center for Health Equity at the Indiana Institute on Disability and Community at Indiana University Bloomington, with support from the Indiana Governor's Council for People with Disabilities, is conducting research to collect comprehensive data about the oral health needs of people with disabilities as well as the current capacity and needs of dentists in Indiana.

### Interviews with People with Disabilities and Family Caregivers

From July to October 2019, the Center for Health Equity interviewed eight individuals with disabilities and seven family caregivers about their recent experiences in dental care and oral health care needs.

In order to identify potential participants, staff sought the assistance of key disability organizations that serve families (e.g., Family Voices Indiana and Arc of Indiana) and advocate for specific disability groups (e.g., Down Syndrome Indiana, United Cerebral Palsy Association of Central Indiana, and American Council of the Blind Indiana). Other organizations that support people in the community were also approached, for example, Centers for Independent Living. An effort was made to have a good representation based on disability, gender, geographic location, and age. The interview questions covered dental insurance, access to dental care, accommodations at dental facilities, communication about dental procedures and follow-up care, and oral care at home.

The seven family caregivers had children with ages ranging from age 3 to age 27, and their children's disabilities included Down syndrome, Cerebral palsy, Autism, Intellectual Disability, and genetic disorders. The eight adult key informants ranged in ages from 30's to late 60's. Their disabilities included cerebral palsy, spina

### Key Findings

Disability status presents obstacles in receiving quality dental care services and maintaining at-home oral health care for people with disabilities.

- People with disabilities have difficulty in finding a dental care provider.
- People with disabilities may delay getting care because of having additional oral health needs that are costly.
- Oral home care may be challenging because of issues related to disability.

The dental workforce in Indiana lacks the training and capacity to provide respectful, person-centered care and services to people with disabilities.

- Dental providers need regular training on how to interact with people with disabilities, effectively communicate with them, and accommodate their needs.
- Family caregivers experience frustration when not included in planning and treatment decisions.
- People with disabilities and families found there is a lack of specialized dental services such as sedation and hospital-based care.

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bifida, deaf-blindness, deafness, blindness, mobility impairment, and spinal cord injury. Most of the key informants resided in cities, but a few were from more rural counties.

## KEY INFORMANT INTERVIEW THEMES

### **Theme 1: Disability status presents obstacles in receiving quality dental care services and maintaining at-home oral health care for people with disabilities.**

#### **1a. Finding a provider that treats people with disabilities is a major barrier in obtaining dental care services.**

Interviewees recounted how insurance issues are an initial obstacle in receiving dental care. A common problem is finding a provider that accepts their insurance, especially Medicaid, and also treats people with disabilities. Most of those interviewed have private insurance or Medicaid, but in either case, there was a struggle to find a dental care provider. Difficulties in finding a provider are more pronounced for those with Medicaid.

*A woman who is deaf and has a spouse who is also deaf shared that “Many of the dentists in the area would not work with deaf. They’re scared, I think, the communication limitations, and so they kept turning us down. Three or four different dentists did that.”*

*One mother “...called a couple [of dentists], and they had told me they wouldn’t take her...a lot of people won’t take her on, because if something happens, they don’t want responsibility of it.”*

*“It’s hard to find a dentist that will take you with having Medicare and Medicaid. So, I haven’t been able to find one. Or there’s a long waiting list.”*

After developing a positive relationship with a dental provider, some interviewees explained that they had difficulty finding a good dental provider after their previous one retired or died. This led to a delay in receiving dental care for months and even years. For some, this is an impending problem.

*A woman who has seen her dentist for 11 years shared that “He’s semi-retired, he doesn’t work five days a week ... he’s getting close to 80 years old, so I don’t know what I’m going to do.”*

*“Well, I had a really good dentist for a long time. The one that I had as a child...He died. And then I had another dentist who was pretty good. But he got older and...I tried to find another dentist. And I had a lot of trouble finding a dentist.”*

Family caregivers shared feelings of helplessness in finding a provider that meets the needs of their family members with disabilities. Parents want quality dental care for their children with disabilities and believe in the importance of oral health. However, parents reported that they could not find the services their children need; for some, it was preventative care, and for others, specialized services such as restorative and sedation services. At times, they felt frustration and desperation. They have little to no control over these factors.

*“It’s just finding one that will take care of her. The adult dentist don’t want to do it because she’s pediatric size. The pediatric dentists don’t want to do it because she’s 27. Everybody is saying we can’t do it for this reason or that reason, and so nobody’s doing anything. They think, we’ll just send her to somebody else, but then you run out of somebody else’s eventually and that’s where we’re at. We’ve run out of somebody else’s.”*

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*“I would do anything for [the dentist] at least to save his front teeth...I want [my son] to look somewhat normal...but with his two broken upper front teeth, when he bites me, that's making the bite worse. Because those teeth being jagged are tearing my skin up...I don't want him to gum food...it's taken us 20 years to get him to hold a fork. And if he doesn't have teeth to help him get the food off that fork, then we're going to be at square one again.”*

Once an individual begins receiving services from a provider, transportation to and from appointments can become an issue. Some individuals with disabilities reported that they rely on caregivers, paratransit, or transportation through Medicaid to take them to appointments. For some, their dentist's office location is in an area that makes traveling an inconvenience (e.g., distance).

*“It didn't take me that long to get to my dentist that passed away, because he lived in the same town, so I could get there within 10, 15 minutes. But since he's passed, I have to go longer distances to a dentist, like 30 to 40 minutes away to a dentist appointment.”*

*“I don't drive. And in order for me to get an appointment, I have to schedule it around for one of the times that's available, that will be able to take me. Like here in northwest Indiana, that's one of the largest problems for those – for us that have a form of disability is the transportation, because it's limited...even if you're a part of paratransit, certain areas, they will not take you to.”*

### **1b. Hoosiers with disabilities delay or forgo dental care because of costs.**

Dental care costs can be prohibitive even for those with insurance. Many individuals with disabilities who cannot work or are underemployed are limited in their options. The additional resources needed to treat people with disabilities place financial burdens that they and/or their caregivers cannot always avoid.

Even with Medicaid coverage for her son, one mother “took out a home equity loan” to pay “\$30,000 of his [my son's] bill ... and that was four years ago, four-and-a-half, and we– he has not seen a dentist since.”

An uninsured individual shared that he has “to be very careful about the cost of the dental care. So as a result, I'm really not getting proper dental care ... I'm losing my teeth, and at this point I only have one half of one tooth left. I have to wait until it falls out before I can afford dentures, unfortunately.”

### **1c. Maintaining at-home oral hygiene can be a challenge for people with disabilities and family caregivers.**

In addition to difficulties in finding dental providers and receiving routine care, some individuals with disabilities and family caregivers face barriers in practicing oral hygiene at home. Several caregivers reported that providing regular dental care at home for their family members with disabilities can be difficult depending on the type and severity of disability, and that they did not receive specific guidance from their dental providers.

One woman with a disability said that “flossing is very difficult” and every time she goes to the dentist, they tell her she should “floss better or whatnot. But they don't really have the knowledge about different flossers that would make it easier.”

A mother with a daughter with Down syndrome – “The challenge on my end is just my daughter's compliance level...my daughter is just going to have absolutely no part of me brushing her teeth. And if I continue to try, I'm literally going to get my finger bitten off. You know, I would do my best.”

The same mother also has a son with autism – *“I mean, he's about six-five and I'm six-two, and now that he's bigger than me, he's really letting me know that it's all on him to comply with home care. I mean I remind him and, you know, that I have – so yeah, he's not great...He will not floss because it's too uncomfortable. And again, I can't really force that issue now that he's bigger than I am.”*

### **Theme 2: The dental workforce in Indiana generally lacks the training and resource capacity to provide respectful, person-centered care and services to people with disabilities.**

#### **2a. Dental providers need training in disability sensitivity and awareness to provide efficient and respectful care and services to people with disabilities.**

Dental providers are not always exposed to or have not interacted enough with people with disabilities to understand what their needs are. The dental workforce including the office staff does not always have the necessary training and education to provide appropriate dental care services to people with disabilities.

One mother shared this experience with adult daughter *“it was a fiasco. I was disgusted by her [the hygienist] to be really honest with you...She says, ‘What am I supposed to do with that?’ Pointing at my child, you know, first of all, my child isn't a that, and I understand that, you know, she's complicated, but you know, you do what you can...So, now we are without.”*

*“It's kind of not blind-friendly, meaning that people really don't know how to assist a blind individual.”*

Interviewees were keenly aware that the dental providers they were going to did not have the training needed to meet their dental care needs.

*“You know, I think all dental offices should get some training on working with people with disabilities, with the different types of disabilities.”*

*“...for dentists themselves to be education on how to work – dentists and hygienists how to work with people with disabilities and different disabilities. Have a little education on that so when they do walk into the office it's not as scary.”*

#### **2b. There is room for improvement in accommodations for and effective communication with individuals with disabilities and their family caregivers.**

There was no uniform experience in how interviewees felt that providers, staff, and the physical space of dental offices met their needs. Some key informants' experiences suggest, however, that the dental workforce can better accommodate the needs of patients with disabilities and their caregivers and communicate with them more effectively.

Some interviewees believed that improvements can be made to the physical access of buildings and exam rooms:

*“And even the dentists that I go to now, her office is accessible. But if there's inclement weather, because of the steepness of her ramp to get into her office, I would have to cancel my appointment.”*

*“...it's pretty small office, and, you know, by the time they get the equipment in the rooms ... getting around the ends of it and stuff are, you know, kind of a sludge”*

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Some would also like to have more accommodations during treatment such as having:

*“...a chair that lowers down more ... [the dental chair] it’s hard to get up in.”*

A wheelchair user would like more dentists to *“let people who use wheelchairs stay in their chairs instead of having to transfer out. That would be a lot easier for people... having to worry about transferring to the dental chair if you don't have to that's one last thing to worry about.”*

In comparison, one individual shared that *“the exam rooms were very, very large and very accommodating and the staff was very accommodating as well.”*

Some interviewees reported that their dental providers successfully communicated the oral health status and dental procedures to them or their family members.

*“...the dental hygienist—she explained everything before she even looked on the inside of my mouth, before she even did all the testing on the teeth and began the cleaning of the teeth. She described everything, I'm telling you, from what she was going to do, how she was going to do it...She explained it all. She even [asked] ...'Did you want to get your whole mouth done, or would you rather do one part and come back? Because it will probably be a little painful to do both parts,' and it was my choice to say, 'Okay, we're just going to do the top.' And that's what we did.”*

*“We've always understood everything pretty well. And my daughter [with a disability] seems to understand everything too.”*

However, there were incidents where dental providers should be more sensitive to the needs of their patients with disabilities and their caregivers regarding effective communication and respective care, which suggests the necessity of regular education for the dental staff.

During cleanings one mother noted that her daughter’s previous hygienist explained things well but a new hygienist *“didn’t say a word while she was doing it.”*

One blind informant said that *“Well, it would be nice if they did not send those reminder cards because of the fact that I may not be able to scan it...”*

*“If they could just train their staff to understand when they get a call from the relay service, don't just hang up, then everything breaks down, you know, contact people in the office who might have experience with that, and teach the new people that this is a relay call, and it's communicating with the deaf...I don't want to have to train somebody every time I go.”*

### **2c. A person-centered approach to care is important to family caregivers.**

Some caregivers expressed frustration that their providers did not listen to their concerns. As family caregivers, they feel that they know their family members best.

*“I think the biggest thing is just parents know their children best and to listen to what the parents say.”*

*“Well, number one is that the practitioner has to learn to listen to this person's parents. That's the biggest thing, is that they don't listen to the parents. Parents are ones that have grown up with this child. They know what will set them off, or what makes them comfortable.”*



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Dental providers should be open to learn from individuals with disabilities or their caregivers, and involve them in the dental care planning.

### **2d. Individuals and family caregivers lack access to sedation or hospital-based services.**

Some interviewees stated that they or their children need sedation for treatment because of their disability. It helps to calm them and symptoms related to their disability. However, some dental providers do not have the resources or hospital privileges to provide some sedative options.

*“...I've had my dental, my wisdom teeth pulled. And for that, I wanted to be sedated, but they wouldn't sedate me because I had cerebral palsy...So, that was challenging because my whole entire body was spasming out during the whole process.”*

*“I just know it's been really frustrating because the dentist that my husband and I go to here in town, you know, I put the word out with him trying to see if there's anyone else that does the sedation-type dentistry that we need, because I am a person that feels like dental care is very important. But yet, the accessibility for people with special needs is few and far between in the State of Indiana...”*

One family is currently without a dentist because their provider no longer provides care in the hospital. Her children were patients at Riley Hospital for Children for a number of years but were referred to another clinic.

*“My son had his teeth cleaned two separate times. My daughter never did get her teeth cleaned. You can't even get into her mouth so he [a dentist] never even really got a good look at her teeth. We went there two different times, and he just kept saying, 'She just needs to get to know me.' Well, then when we were there in March of this year, he said, 'Yeah,' he said, 'I'll go ahead and set it up' [a hospital appointment].”* When she called to follow-up, she was told that the *“office policy changed and we no longer do that.”*

### **2e. People with disabilities and caregivers expressed gratefulness in finding a well-trained provider.**

Some interviewees reported that they have been able to form positive relationships with dental providers who displayed a willingness and initiative to treat people with disabilities. They feel lucky to have care under a dentist who is comfortable and competent in treating people with disabilities. This highlights the great challenge Hoosiers with disabilities and their family caregivers encounter in finding competent dental providers in Indiana.

*“He [a dentist] does a really good job. When I first met him, I pretty much told her disability and what's wrong, and I don't know. He just already kind of knew how to care for her, and I thought that was really good ... I will say they're calm, and they're patient with her”*

*“[Some people] aren't lucky enough to live in a town with a – you know, with a dentist that, you know, has adequate training to address, you know, this population...I had no idea when [our daughter] was born and we learned that she had Down syndrome that there are other kids with Down syndrome who were born without permanent teeth. I mean, our dentist knew that. He knew that that is – that can be a co-occurring condition with Down syndrome...I mean—And so just the fact that we have a doctor [dentist] that does and gets that, I think it's huge and I also think it's rare.”*