

Oral Health for Hoosiers with Disabilities:
Indiana Family Caregiver Survey Report

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**THE INDIANA INSTITUTE ON
DISABILITY AND COMMUNITY**

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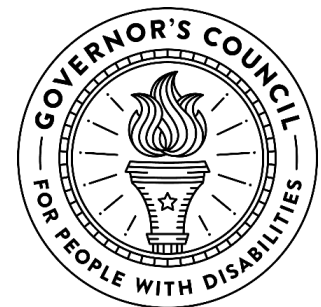


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Executive Summary

This report presents the results from an online survey of family caregivers of individuals with disabilities in Indiana. The survey was conducted by the Center for Health Equity at the Indiana Institute on Disability and Community at Indiana University Bloomington. The survey was a part of a larger oral health project funded by the Indiana Governor's Council for People with Disabilities. The goal of this survey was to determine the oral health needs of people with disabilities in Indiana. This survey has collected comprehensive information on oral health status and care for individuals with disabilities, as well as their experience with access to dental care, via their family caregivers.

The survey was conducted online between July 15, 2020 and August 18, 2020. Five hundred and ninety-nine eligible respondents were included in the analysis. The following are highlights of the survey results:

- The majority of the respondents (family caregivers of individuals with disabilities) were female (50.5%), married (77.9%), non-Hispanic white (51.8%), and parents of the family member with a disability (59.6%). The average age of the family caregivers was 40.6.
- The average age of individuals with disabilities the respondents primarily cared for was 28.5. Most of the people with disabilities were reported to live in their own home or apartment (48.8%) or in parent's or relative's home (35.5%).
- Regarding the type of disability of their family members with disabilities, the respondents reported independent living disability (57.3%) most commonly, followed by cognitive disability (50.8%) and self-care disability (43.9%). The top four conditions of those with disabilities were speech or language impairment (14.0%), learning disability (13.9%), autism spectrum disorder (10.2%), and intellectual disability (8.4%).
- The large majority of the respondents reported having a regular dentist (usual source of dental care [USDC]) without including a hospital emergency room, for the person with a disability (83.8%).
- For the respondents reporting no USDC, the top five common reasons were as follows: 'cannot find a dentist who is competent in working with individuals with disabilities' (17.2%), 'family member's (the person with a disability) fear, apprehension, nervousness, or dislike of going to a dentist' (12.9%), 'concern that the person with a disability will have difficulty controlling his/her behavior' (11.8%), 'cannot afford care' (10.8%), and 'cannot find a dentist who accepts insurance plan' (10.8%).
- A large proportion of the respondents with a regular dentist for the person with a disability reported that the facilities of the usual source of dental care for the family member were not accessible. Only 40.1% reported their dental providers provided accommodations for communication; 46.1% of dental providers had accessible entrances; 45.3% dental equipment; 48% office spaces; and 51.9% parking spaces.

- One in ten respondents reported that they primarily went to hospital emergency room for the dental care of the person with a disability (9.6%).
- More than one-third of the respondents (35.6%) reported that it took more than one hour to take the person with a disability to the dental office. (14.2% for 61 minutes to 90 minutes; 9.6% for 91 minutes to 120 minutes; and 11.8% for more than 2 hours).
- The majority of family caregiver respondents reported that their dental care providers usually or always allowed them to be present during dental care services (74.2%) and helped them to feel like a partner in the dental care of the person with a disability (74%). However, some respondents felt that the dental providers “sometimes” (29.4%) or “never” (9.4%) listened to them carefully.
- Half of respondents reported a delayed dental care for their family member with a disability in the past 12 months (50.1%). The five main reasons were as follows: ‘No accommodation available for communication with dentists or oral health professionals’ (13.3%), COVID-19 pandemic (13.3%), ‘dentist too far away from where I live’ (12.9%), ‘Family member’s (the person with a disability) fear, apprehension, nervousness, or dislike of going to a dentist’ (8.7%), and ‘Dentist’s office/clinic or dental equipment (for example, dental chair) not physically accessible’ (7.2%).
- Two-thirds of the respondents reported that they had taken the person with a disability to the hospital emergency room at least once in the past 12 months because of dental care or dental pain (66.3%).
- More than one-fifth of the respondents reported that their family member with a disability did not have any kind of health insurance during the past 12 months (22.2%). About one-third of the respondents reported that although their family member with a disability was covered by health insurance during the past 12 months, they had gaps in health insurance coverage in that period of time (30.8%).
- Regarding oral health literacy, about 30% of the respondents reported that they were ‘moderately’ confident in filling out medical/dental forms by themselves (28.5%). In addition, 8.2% were “slightly” confident and 6.3% were “not at all” confident in filling out forms.
- Regarding the condition of mouth and teeth of the person with a disability, more than two-thirds of the respondents reported that their family member with a disability had ‘excellent, very good, or good’ condition (68.9%) whereas 31.1% reported ‘fair or poor’ condition.
- A significant proportion of the respondents reported that their family member with a disability had frequent or chronic difficulty in various oral health conditions during the past 12 months: 51.8% for a tooth ache or sensitive teeth; 47.8% for bleeding gums; 44.6% for cavities; and 36.1% for difficulty eating or chewing.

- Of the respondents who have a family member age 13 and over with a disability, about two-thirds of them (63.2%) reported that their family member with a disability had lost their permanent teeth because of tooth decay or gum disease. One in four respondents reported that the person with a disability had lost six or more permanent teeth: ‘all’ (13.1%) and ‘6 or more, but not all’ (12.7%).
- Approximately one-third of family caregiver respondents reported that the person with a disability could ‘sometimes’ perform at-home oral care (e.g., tooth brushing or flossing) on their own (31.1%). About one in seven respondents reported the person with a disability could “never” do it on their own (13.6%).
- The majority of the respondents reported that they needed education or training on providing at-home oral care for the family members with disabilities (54.6%).

Introduction

This report presents the results from an electronic survey of family caregivers of people with disabilities in Indiana. The survey was conducted by the Center for Health Equity of the Indiana Institute on Disability and Community at Indiana University Bloomington. This survey was conducted to identify the current landscape for oral health and dental care for Hoosiers with disabilities. The goal of this survey was to determine the oral health needs of people with disabilities in Indiana through their family caregivers. This survey collected comprehensive information on oral health for individuals with disabilities and their experience in access to dental care.

Survey Instrument

For the development of the survey, the project team conducted a literature review of oral health needs and experiences with dental care services for people with disabilities. We then conducted key informant interviews with both adults with disabilities and family caregivers of individuals with disabilities to get an in-depth understanding of their experiences in accessing dental care services, either for themselves or on behalf of their family member with a disability. The project staff revised the survey draft based on feedback from a small number of family caregivers of Hoosiers with disabilities, as well as staff from disability and family support organizations. Lastly, the project staff conducted a pilot test of the electronic survey with several individuals who were asked to test the survey on different devices (mobile phone, website, etc.). The final survey consisted of 56 questions which were a mix of multiple-choice questions and open-ended questions.

Participant Recruitment

The survey was conducted online using the Qualtrics survey tool between July 15, 2020 and August 18, 2020. Survey participants were recruited through multiple ways, including announcements in organization newsletters, websites, and social media. The following various disability and family support organizations were asked to share the announcement directly with the families they serve and to share in their organizational newsletters, websites, and social media accounts:

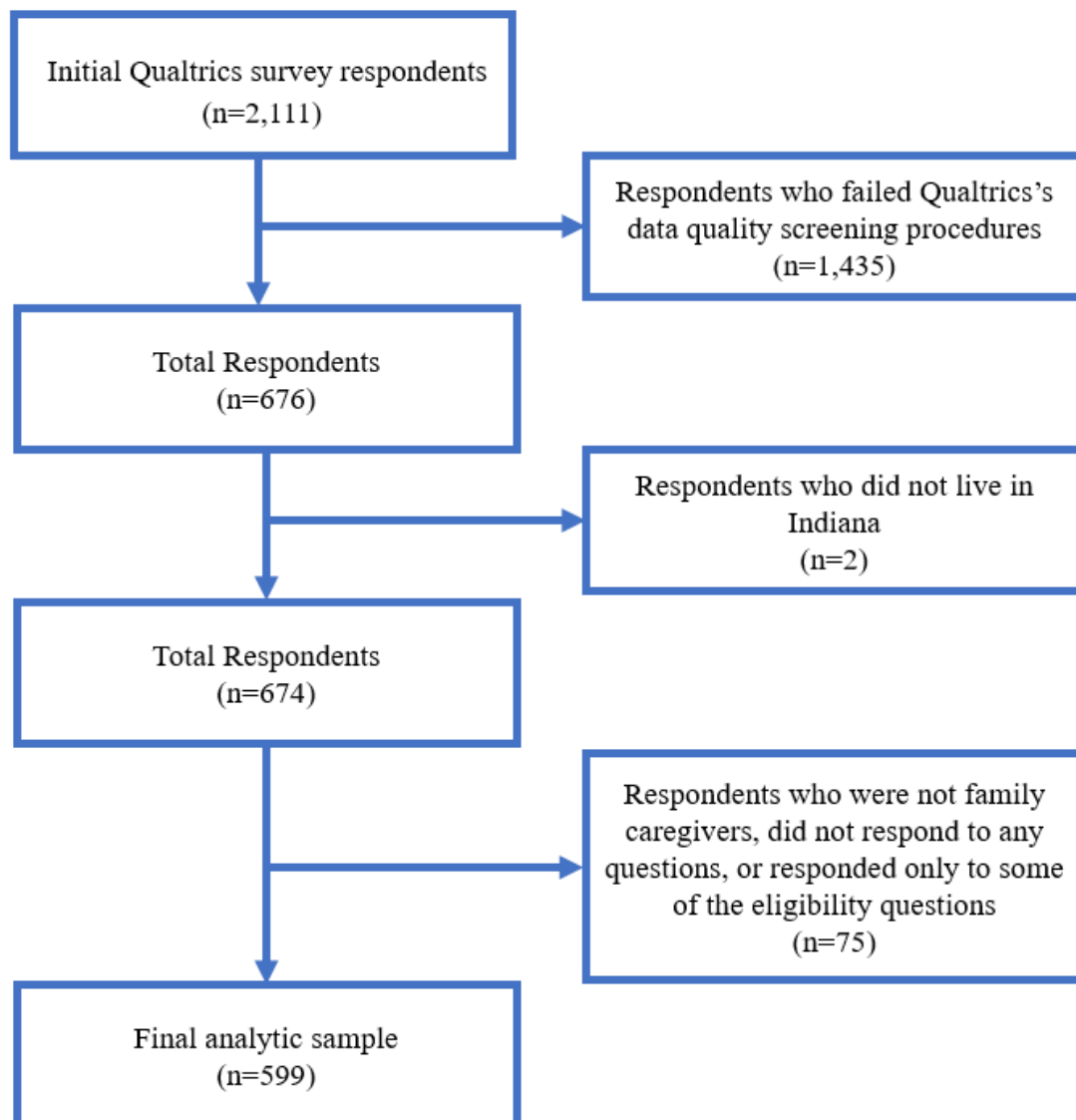
- Arc of Indiana
- Autism Society of Indiana
- Down Syndrome Indiana
- Family Voices Indiana
- IN*SOURCE
- Riley's Children Health
- Special Olympics Indiana
- United Cerebral Palsy of Greater Indiana
- Children's Special Health Care Services with Indiana Department of Health
- Indiana Resource Center for Autism

After the initial round of recruitment, these organizations were approached again in early August to share the announcement a final time. Additionally, the survey was promoted through the website and social media accounts of the Indiana Institute on Disability and Community.

Participants

In order to participate in the survey, participants needed to meet three inclusion criteria at the time of the survey: a) at least 18 years old and over, b) live in Indiana, and c) have a family member with a disability in Indiana for whom they were the primary caregiver. Participation in the survey was voluntary. A total of 2,111 initial responses were collected. Sample validity and data integrity were examined using the data quality screening procedures of Qualtrics including machine response, duplicate responses, and response patterns. Qualtrics has fraud prevention and detection features that are recommended for an online data collection platform (Pozzar et al., 2020). After removing ineligible respondents (e.g., those who did not meet the inclusion criteria; no response to any questions on the survey, etc.), the final sample size was 599. For description of the analytic sample selection process, see Figure 1.

Figure 1. Analytic sample selection process



Data Cleaning Process

Inconsistent responses across the survey questions among the same survey participants were examined during a data cleaning process. When inconsistent responses were identified during the data cleaning process, they were removed or treated as missing. For instance, multiple respondents were found not to be family caregivers, a survey eligibility requirement. They identified as nurses or doctors for the persons with a disability. These respondents were removed in the analytic sample. In another example, some respondents' response in question 39 (age group of the person with a disability) did not match the age they stated in question 5 (age of the person with a disability). Inconsistent responses like these were treated as missing in the analytic sample.

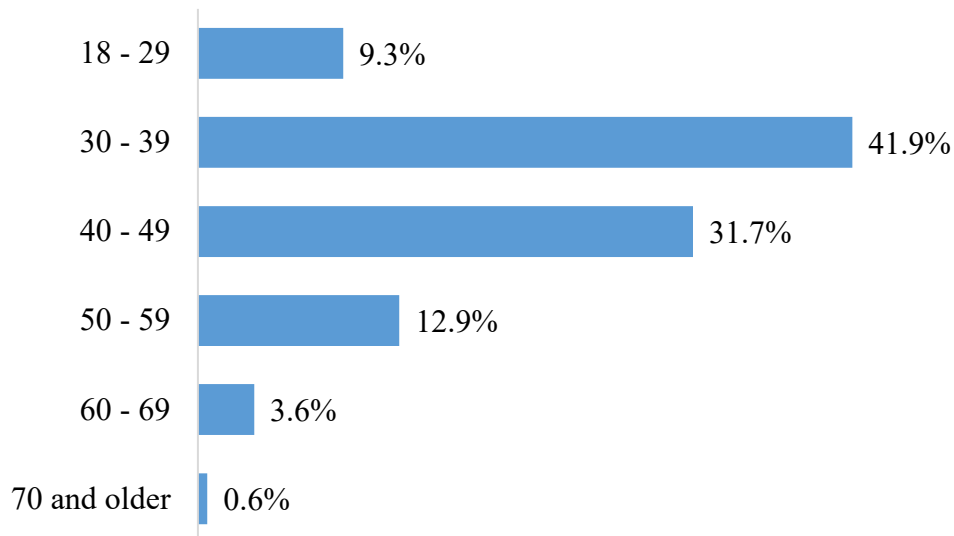
Results of the Survey

The results of the family caregiver survey consisted of five sections: description of family caregivers; description of people with disabilities; disabilities and health conditions; experience with access to dental care; and oral health status and care. The results of the survey are presented for those five sections.

Description of Family Caregivers

- The average age of family caregivers of individuals with disabilities was 40.6, and the median age was 39. They ranged from 21 to 73 years old. See Figure 2.

Figure 2. Age categories of family caregivers



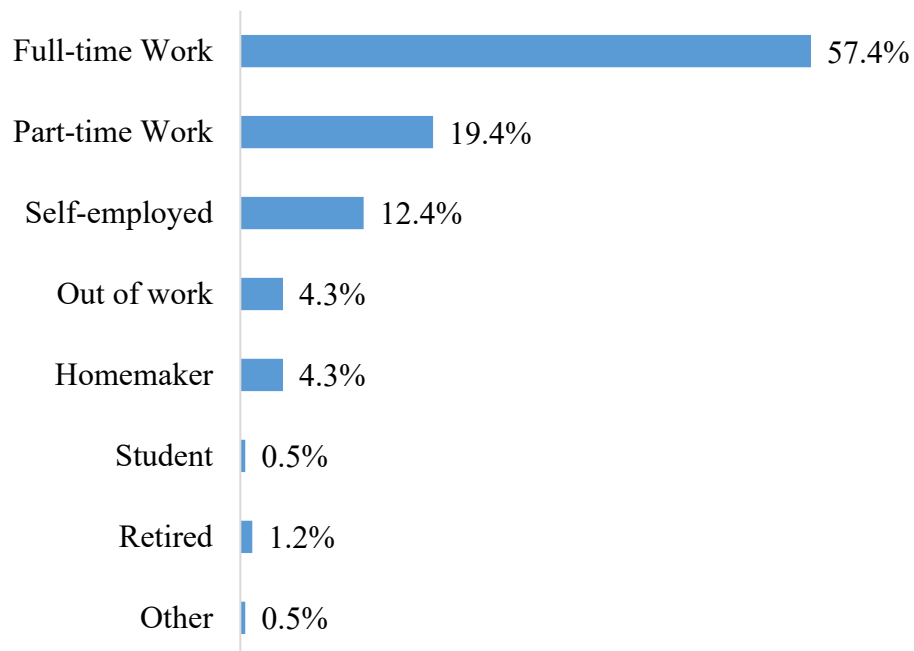
- More than half of the family caregivers identified as non-Hispanic white (51.8%). See Table 1.

Table 1. Racial/ethnic groups of family caregivers

Race/Ethnicity	Percent
Non-Hispanic White	51.8%
Non-Hispanic Black	14.1%
Hispanic/Latino/a/x or Spanish Origin	13.4%
Non-Hispanic Asian	9.1%
Non-Hispanic American Indian or Alaska Native	10.7%
Non-Hispanic Native Hawaiian or Pacific Islander	0.4%
Non-Hispanic Other	0.5%

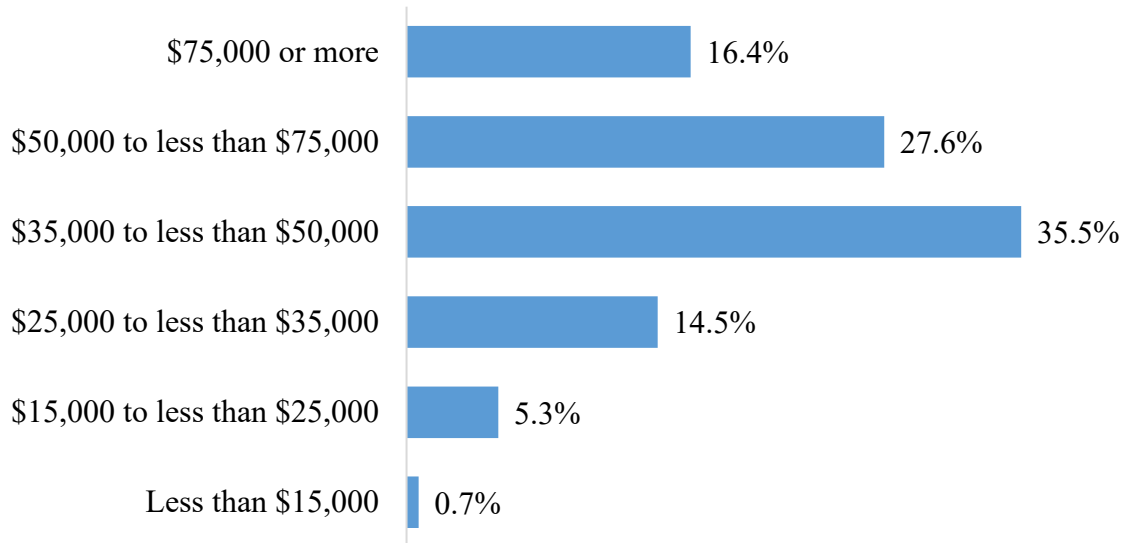
- Most of the caregivers reported being married (77.9%); and slightly more than half were female (50.5%). The majority of respondents reported working full time (57.4%) or part time (19.4%). See Figure 3.

Figure 3. Employment status of family caregivers



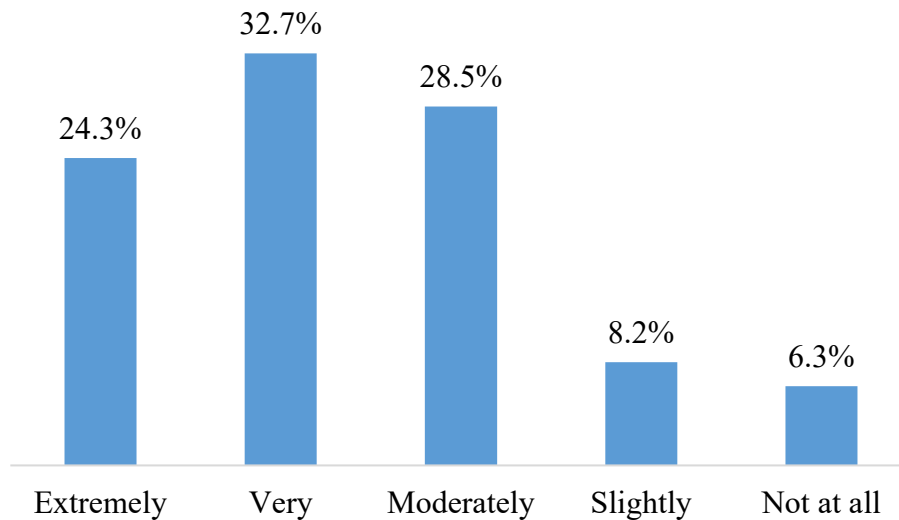
- The majority of the respondents reported having higher education experience (some college or technical school, 37.9%; Bachelor’s degree or higher, 42.3%). Approximately half of the respondents reported earning an annual income of \$50,000 or higher (44%). See Figure 4.

Figure 4. Annual household income of family caregivers



- Regarding oral health literacy, it was measured with one question: ‘How confident are you filling out medical/dental forms by yourself?’ About 30 percent of the respondents reported that they were ‘moderately’ confident in filling out medical/dental forms by themselves (28.5%). In addition, 8.2% were “slightly” confident and 6.3% were “not at all” confident in filling out forms. See Figure 5.

Figure 5. Confidence level of caregivers when filling out dental or medical forms



- Although family caregiver respondents came from 88 counties, they came from the following counties most frequently: Marion (8.7%), Allen (5.6%), Hamilton (4.2%), Lake (3.5%), Monroe (2.6%), and Tippecanoe (2.6%). See Figure 6.

Figure 6. Map of the counties that respondents came from in Indiana

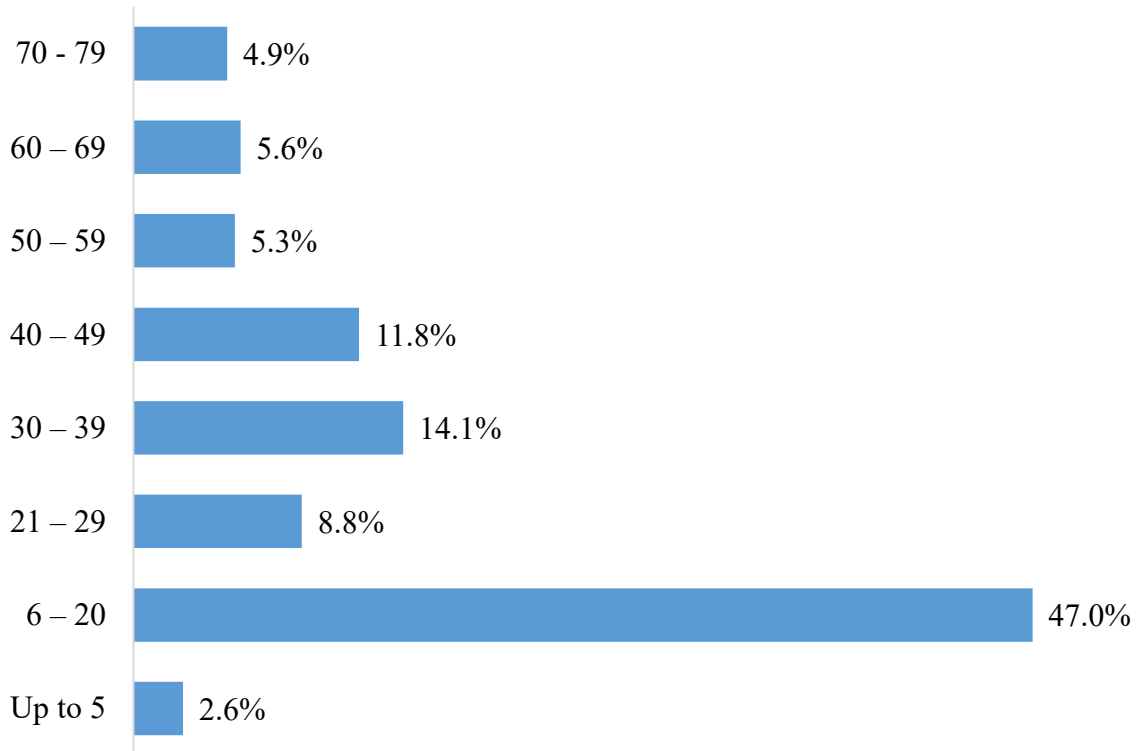


Note: White: 0 respondents; Yellow: 1 – 4 respondents; Blue: 5 – 9 respondents; Orange: 10 – 19 respondents; Green: 20+ respondents.

Description of People with Disabilities

- The average age of people with disabilities was 28.5, and the median age was 21.5. They ranged from 1 to 78 years old. See Figure 7.

Figure 7. Age categories of people with disabilities



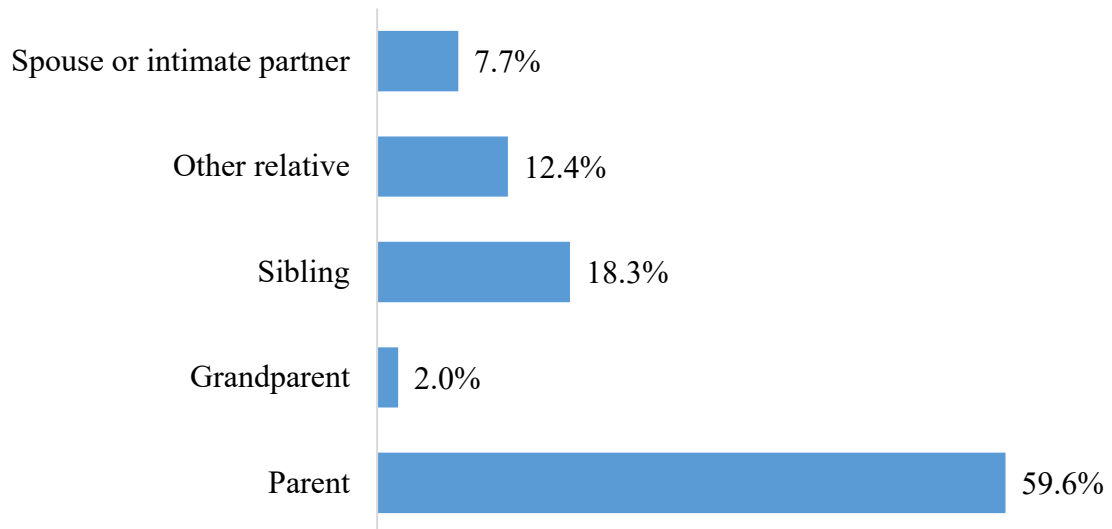
- People with disabilities were primarily identified as male (65.6%) and non-Hispanic white (51.8%). See Table 2.

Table 2. Racial/ethnic groups of people with disabilities

Race/Ethnicity	Percent
Non-Hispanic White	51.8%
Non-Hispanic Black	14.1%
Hispanic/Latino/a/x or Spanish Origin	13.4%
Non-Hispanic Asian	9.1%
Non-Hispanic American Indian or Alaska Native	10.7%
Non-Hispanic Native Hawaiian or Pacific Islander	0.4%
Non-Hispanic Other	0.5%

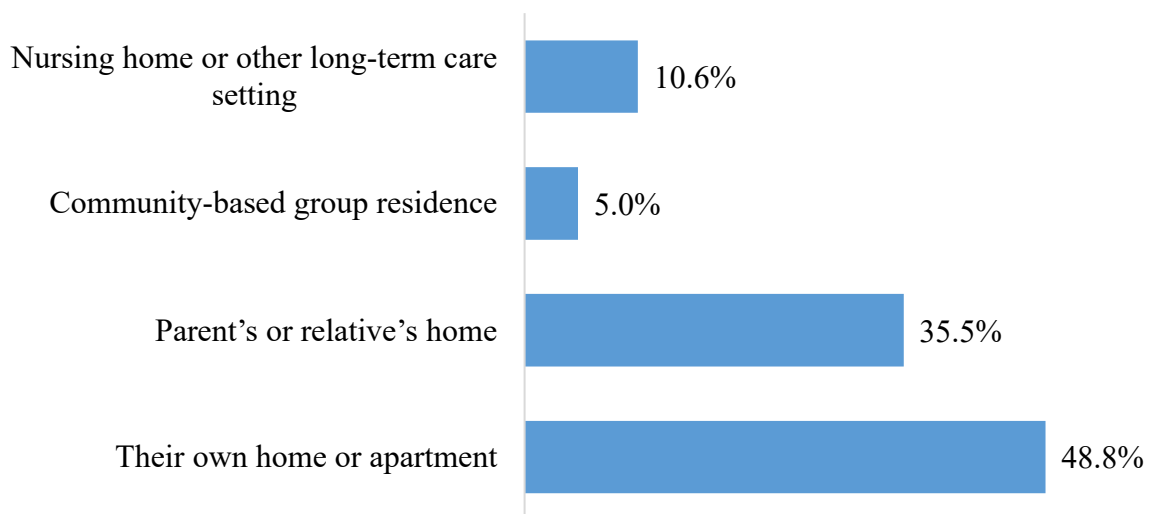
- The majority of people with disabilities were mainly cared for by a parent (59.6%). See Figure 8.

Figure 8. The caregiver’s relationship to the person with a disability



- Half of the respondents reported that their family member with a disability lived in their own home or apartment (48.8%). An additional one-third of persons with a disability were reported to live in their parent’s or relative’s home (35.5%). See Figure 9.

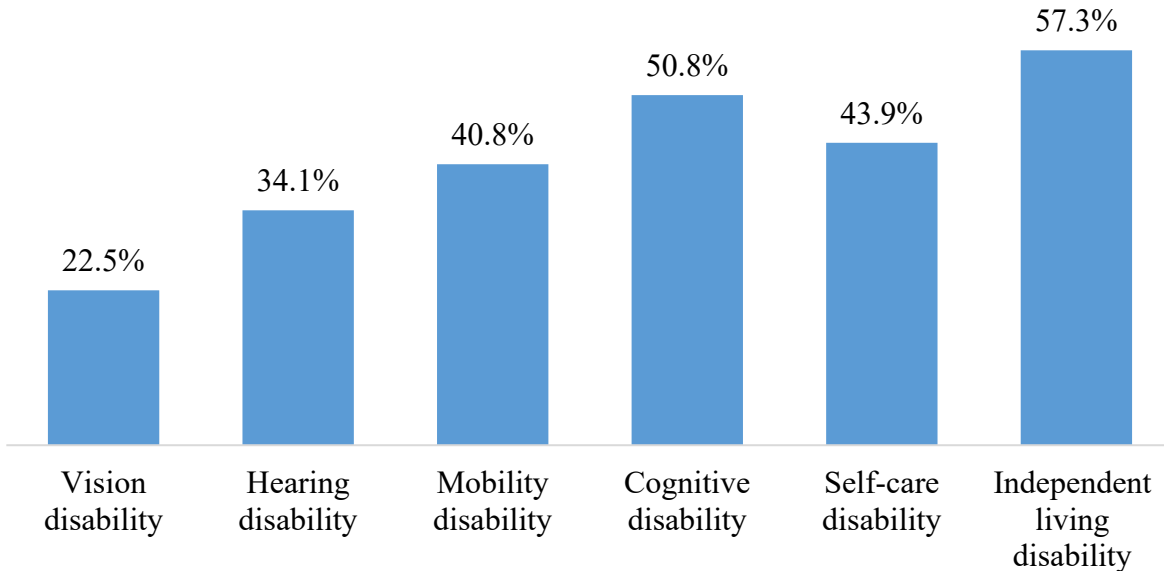
Figure 9. The current living situation for persons with disabilities



Disabilities and Health Conditions

- Regarding the type of disability of the family member with a disability, independent living disability (57.3%) was most commonly reported, followed by cognitive disability (50.8%) and self-care disability (43.9%). See Figure 10.

Figure 10. Family members' types of disability



For the identification of disabilities, the following questions were used:

- Vision Disability: Is the person with a disability blind, or does he/she have serious difficulty seeing, even when wearing glasses?
- Hearing Disability: Is the person with a disability deaf, or does he/she have serious difficulty hearing?
- Mobility Disability: Does the person with a disability have serious difficulty walking or climbing stairs?
- Cognitive Disability: Does the person with a disability have serious difficulty concentrating, remembering, or making decisions because of a physical, mental, or emotional condition?
- Self-Care Disability: Does the person with a disability have difficulty dressing or bathing?
- Independent Living Disability: Because of a physical, mental, or emotional condition, does the person with a disability have difficulty doing errands alone, such as visiting a doctor's office or shopping?

- When asked about conditions the person with a disability had ever been told by a doctor, healthcare provider, teacher, or school official, top four conditions reported are as follows: speech or language impairment (14%), learning disability (13.9%), autism/autism spectrum disorder (10.2%), and intellectual disability (8.4%). See Table 3.

Table 3. Conditions of the family members with disabilities

Condition	Percent
Speech or language impairment	14.0%
Epilepsy or seizures	4.6%
Learning disability	13.9%
Intellectual disability	8.4%
Autism	10.2%
Asperger’s syndrome	3.0%
Cerebral palsy	3.3%
Down syndrome	3.6%
Developmental disabilities – other ⁺	4.2%
Traumatic brain injury	2.5%
Spinal cord injury	2.8%
Muscular dystrophy	2.3%
Attention Deficit Disorder (ADD) or Attention Deficit Hyperactive Disorder (ADHD)	4.8%
Asthma	3.2%
Other respiratory disease [†]	1.4%
Angina or coronary heart disease	1.3%
Depressive disorder [*]	3.1%
Heart attack	1.0%
High blood pressure	2.7%
Congenital heart disease	2.9%
Diabetes (not including pre-diabetes or borderline diabetes)	1.9%
Arthritis	2.0%
Tourette syndrome	1.8%
Blood disorders [※]	1.3%

⁺ Developmental disabilities other than learning disability, intellectual disability, autism, Asperger’s syndrome, cerebral palsy, or down syndrome

[†] Other respiratory disease (e.g., lung cancer, chronic obstructive pulmonary disease [COPD], etc.)

^{*} Depressive disorder (including depression, major/clinical depression, dysthymia, or minor depression)

[※] Blood disorders (such as Sickle cell disease, thalassemia, or hemophilia)

Experience with Access to Dental Care

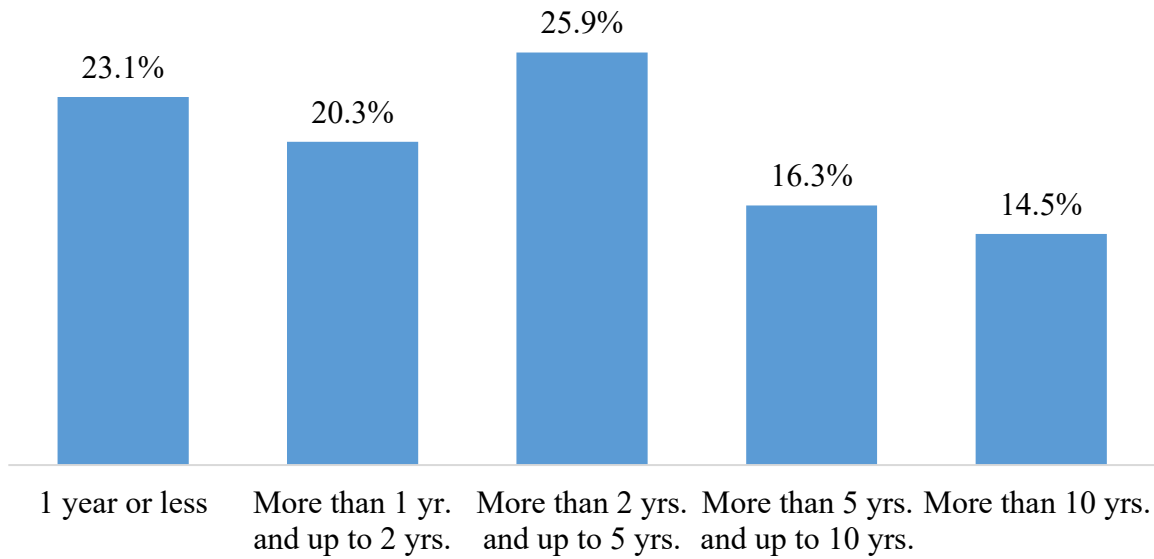
- The majority of respondents (93%) reported that they had a usual source of dental care (USDC)—a dentist they usually go to for the dental care—for their family member with a disability. However, after excluding respondents with a hospital emergency room as a USDC, the percentage of the person with a disability who had a USDC was reduced to 83.8%.
- Regarding reasons for not having a USDC, the top five reasons are as follows: “cannot find a dentist who is competent in working with individuals with disabilities” (17.2%), “family member’s (the person with a disability) fear, apprehension, nervousness, or dislike of going to a dentist” (12.9%), “concern that the person with a disability will have difficulty controlling his/her behavior” (11.8%), and “cannot afford care” (10.8%), or “cannot find a dentist who accepts insurance plan” (10.8%). See Table 4.

Table 4. Main reasons for not having a usual source of dental care for people with disabilities

Reasons for not having a USDC	Percent
Cannot find a dentist who is competent in working with individuals with disabilities	17.2%
Family member’s (the person with a disability) fear, apprehension, nervousness, or dislike of going to a dentist	12.9%
Concern that the person with a disability will have difficulty controlling his/her behavior	11.8%
Cannot afford care	10.8%
Cannot find a dentist who accepts insurance plan	10.8%
No accommodations available for communication with dentist	9.7%
Other	8.6%
The person with a disability seldom or never needs dental care	6.5%
Do not know where to go for dental care	6.5%
Dentist’s office/clinic or dental equipment (for example, dental chair) not physically accessible	5.4%

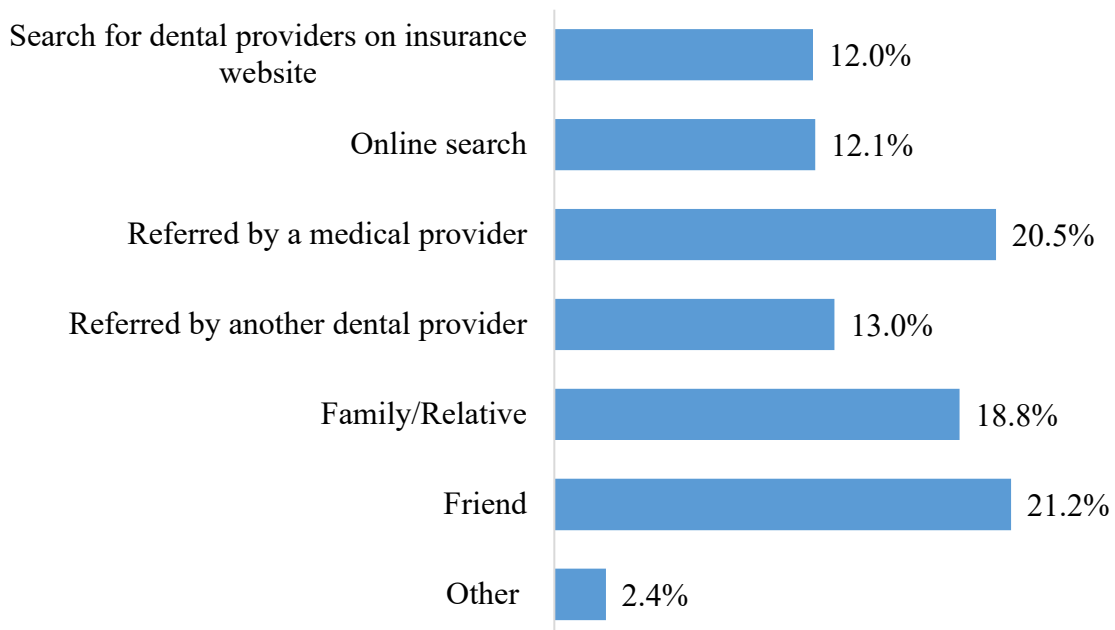
- Approximately one-fourth of the family caregivers reported that people with disabilities have been seeing their dentist for 1 year or less (23.1%). Another one-fifth reported having the dentist for more than 1 year and up to 2 years (20.3%). See Figure 11.

Figure 11. Length of time people with disabilities have been seeing their current dentist



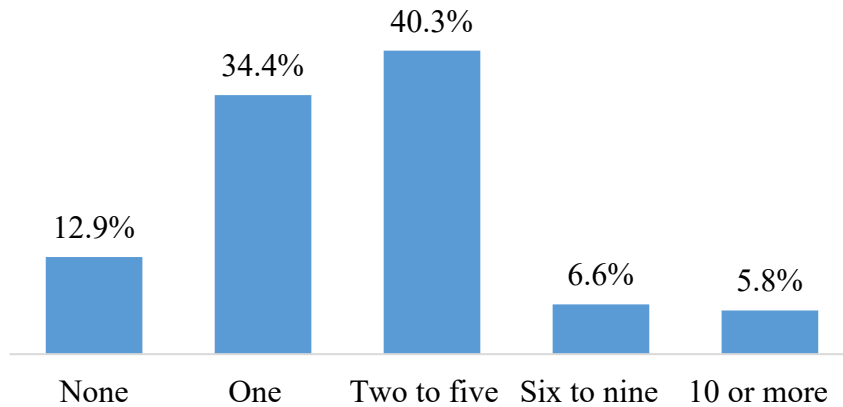
- Family caregivers reported that they found the current dentist for the person with a disability through different means. They were referred to the dentist through a friend (21.2%), medical provider (20.5%), family/relative (18.8%), and another dental provider (13.0%). See Figure 12.

Figure 12. Ways family caregivers found the current dentist for the person with a disability



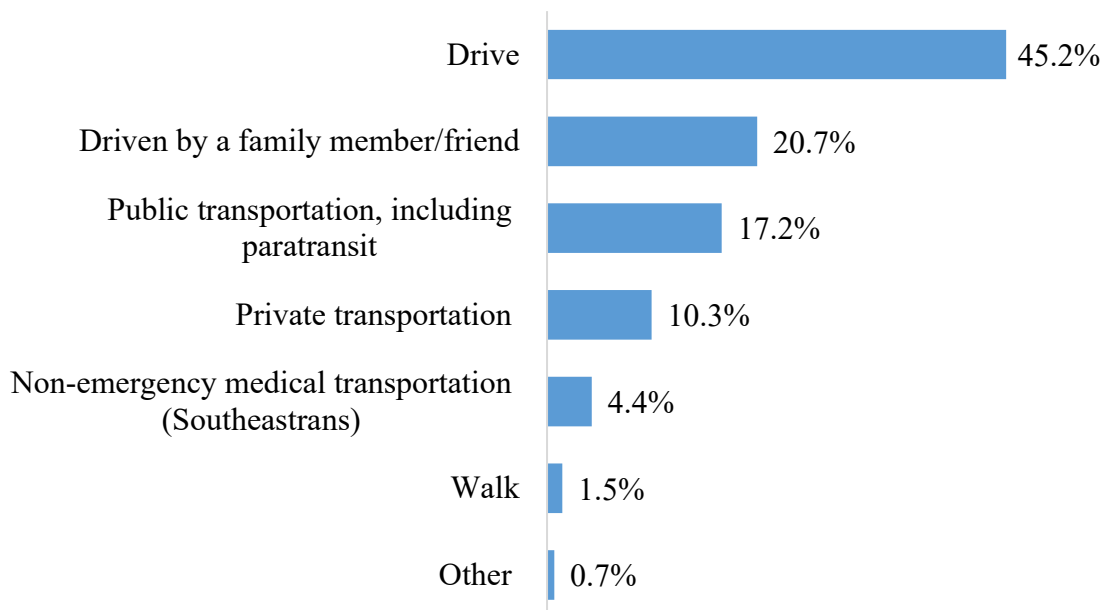
- The majority of family caregivers reported that they had contacted multiple dental offices/facilities before finding the current dentist of the person with a disability (52.7%). See Figure 13.

Figure 13. The number of contacts family caregivers made before finding their current dentist for the person with a disability



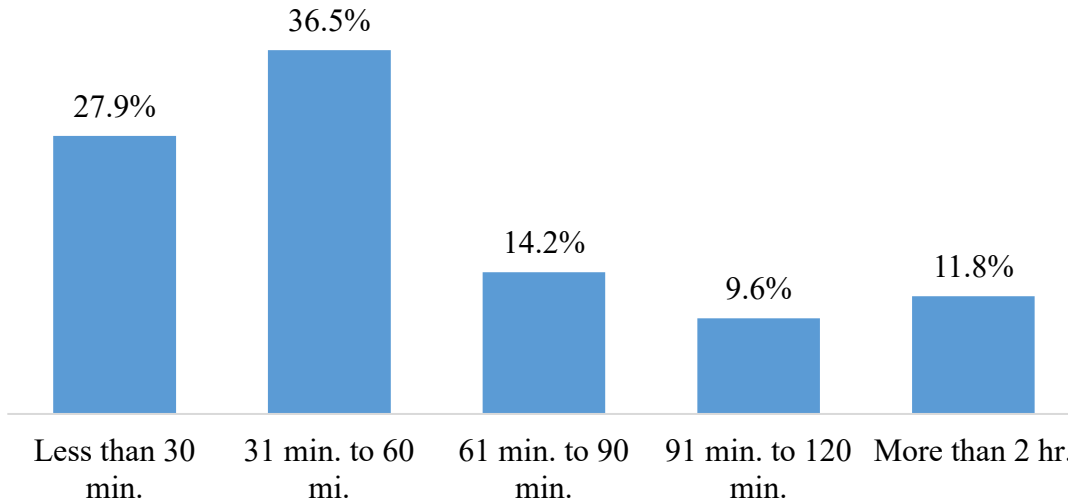
- Approximately one-third of the family caregivers (31.9%) reported that they took the person with a disability to dentist using public transportation including paratransit (17.2%), private transportation (taxi or ride hailing services such as Uber or Lyft (10.3%), and non-emergency medical transportation for traditional Medicaid enrollees (4.4%). See Figure 14.

Figure 14. How family caregivers take the person with a disability to their current dentist



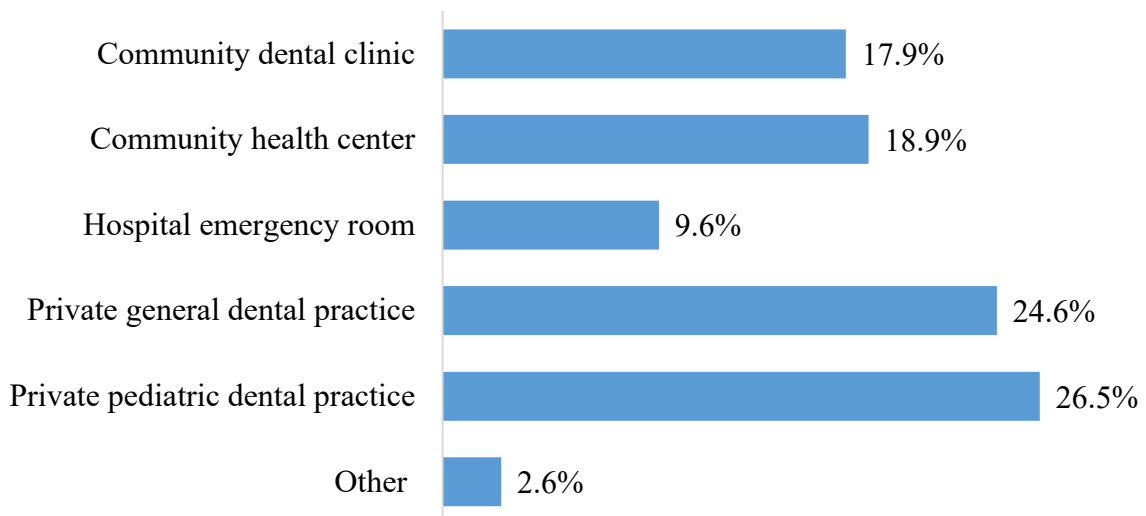
- More than one-third of the respondents (35.6%) reported that it took more than one hour to take the person with a disability to the dental office: 14.2% for 61 minutes to 90 minutes; 9.6% for 91 minutes to 120 minutes; and 11.8% for more than 2 hours. See Figure 15.

Figure 15. Travel time to the dental office for the person with a disability



- People with disabilities primarily went to private pediatric dentist (26.5%) and private general dental office (24.6%) for their dental care. However, one in ten reported having gone to the hospital emergency room (9.6%). See Figure 16.

Figure 16. Types of dental facilities people with disabilities primarily went to for their dental care



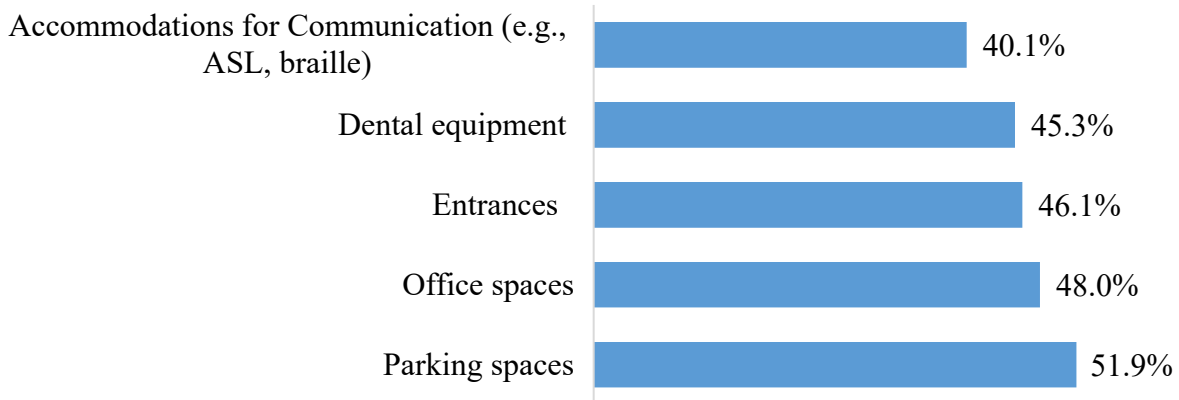
- Two-thirds of the respondents (69.4%) reported that the person with a disability had a dental visit within the past 12 months. Approximately four-fifths of the dental visits were made in Indiana (78.0%).
- Persons with a disability received a variety of dental services during the past 12 months. The four most common dental services they received were as follows: dental cleaning (24.1%), general exams/checkups/consultations (19.7%), x-rays (12.1%), and sealant (6.3%). See Table 5.

Table 5. Dental services that the person with a disability received within the past 12 months

Type	Percent
Dental cleaning	24.1%
General exam, checkup or consultation	19.7%
X-rays	12.1%
Sealant	6.3%
Dental crowns or dental bridge	5.4%
Periodontal scaling or root planing	4.1%
Dentures or removable partial dentures	3.7%
Fillings or inlays	3.4%
Braces or teeth straightening	3.3%
Follow-up visit for periodontal disease management	3.1%
Extraction	3.0%
Abscess or infection treatment	2.8%
Emergency treatment	2.6%
Root canal	2.3%
Treatment for temporomandibular joint disorders	1.8%
Other oral surgery	1.3%
Other	1.0%

- A large proportion of the respondents with a regular dentist for the person with a disability reported that the facilities of the usual source of dental care for the family members with disabilities were not accessible. Only 40.1% reported their dental providers provided accommodations for communication; 46.1% of dental providers had accessible entrances; 45.3% dental equipment; 48% office spaces; and 51.9% parking spaces. See Figure 17.

Figure 17. Respondents’ perceptions about how accessible the dental offices they go to for the person with a disability



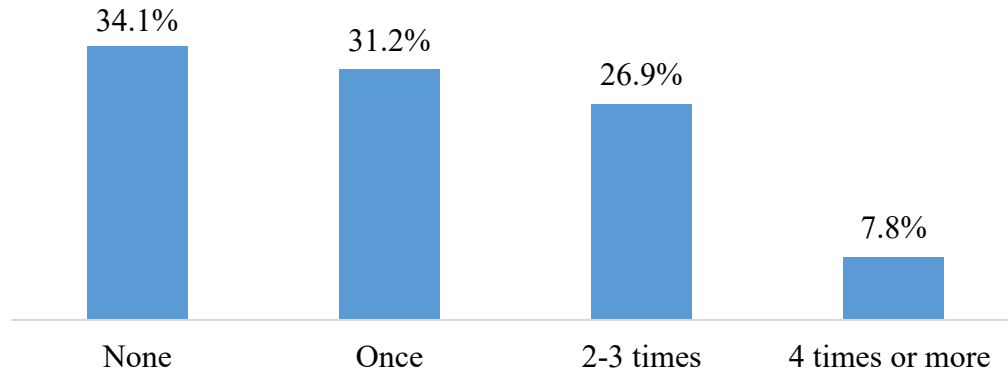
- Half of respondents reported that the family member with a disability had experienced delayed dental care in the past 12 months (50.1%). The top five main reasons are as follows: ‘No accommodation available for communication with dentists or oral health professionals’ (13.3%), COVID-19 pandemic (13.3%), ‘dentist too far away from where I live’ (12.9%), ‘Family member’s (the person with a disability) fear, apprehension, nervousness, or dislike of going to a dentist’ (8.7%), and ‘Dentist’s office/clinic or dental equipment (for example, dental chair) not physically accessible’ (7.2%). Respondents explained that their family member with a disability could not receive treatment during the COVID-19 pandemic because many offices were closed, or appointments were canceled. See Table 6.

Table 6. The main reasons for delayed dental care for people with disabilities

Reason	Percent
No accommodation available for communication with dentists or oral health professionals	13.3%
Coronavirus pandemic (COVID-19)	13.3%
Dentist too far away from where I live	12.9%
Family member’s (the person with a disability) fear, apprehension, nervousness, or dislike of going to a dentist	8.7%
Dentist’s office/clinic or dental equipment (for example, dental chair) not physically accessible	7.2%
Could not find a dentist who accepts insurance plan	6.7%
Could not afford care	6.4%
I could not get time off work	6.0%
No transportation	5.4%
No appointments available	5.2%
Concern that the person with a disability will have difficulty controlling his/her behavior	4.9%
Need for anesthesia	4.6%
Did not know where to go to get care	4.2%
Other	1.0%

- Nearly two-thirds of respondents reported that they had taken the person with a disability to the hospital emergency room at least once in the past 12 months because of dental care or dental pain (66.3%). See Figure 18.

Figure 18. Emergency department visits for dental care issues for individuals with disabilities in the past 12 months



- More than one-fifth of the respondents reported that their family member with a disability did not have any kind of health insurance during the past 12 months (22.2%). About one-third of them reported that although their family member with a disability was covered by health insurance during the past 12 months, they had gaps in health insurance coverage in that period of time (30.8%).

For the persons with disability that were covered, the most common plan was government assistance plans, like Medicaid (28.1%), which is followed by insurance through the caregiver’s current or former employer or union (21.4%), insurance through insurance of the family member with a disability (19%), and insurance purchased directly from an insurance company (17.6%). See Table 7.

Table 7. The types of dental insurance of the person with a disability

Dental Insurance Type	Percent
Government assistance plan (e.g., Medicaid, Medical Assistance)	28.1%
Insurance through caregiver’s current/former employer/union	21.4%
Insurance through his/her (PWD) current/former employer/union	19.0%
Insurance purchased directly from an insurance company	17.6%
Children’s Special Health Care Services (CSHCS) program	8.3%
Indian Health Service	4.4%
TRICARE or other military health care	1.0%
Other	0.2%

- In terms of general satisfaction with dental care for the person with a disability, most respondents were satisfied (very satisfied [42.8%], somewhat satisfied [40.2%]). However, about one fifth of the respondents was either somewhat dissatisfied (9.3%) or very dissatisfied (7.7%).
- Regarding patient- and family-centered dental care, the majority of respondents reported that their dental care providers usually or always allowed them to be present during dental care services (74.2%) and helped them to feel like a partner in the dental care of the person with a disability (74%). However, some respondents felt that the dental providers “sometimes” (29.4%) or “never” (9.4%) listened to them carefully. They also reported that the dental providers sometimes (18.6%) or “never” (9%) listened carefully to the person with a disability. See Table 8.

Table 8. The levels of dental provider communication and interaction with the family caregiver and/or the person with a disability

Patient/Family-Centered Care	“Always” or “Usually”	“Sometimes”	“Never”
Spend enough time with the person with a disability	63.8%	29.5%	6.7%
Listen carefully to you	61.3%	29.4%	9.4%
Listen carefully to the person with a disability	72.4%	18.6%	9.0%
Show sensitivity to your family’s values and customs	62.5%	29.2%	8.3%
Provide specific information you needed concerning the person with a disability	69.5%	23.8%	6.8%
Help you feel like a partner in the dental care of the person with a disability	74.0%	18.3%	7.7%
Make it easy for you to ask questions or raise concerns	63.8%	29.8%	6.4%
Make it easy for the person with a disability to ask questions or raise concerns	63.5%	29.0%	7.4%
Allow you to be present with the person with a disability during dental care services	74.2%	17.7%	8.1%

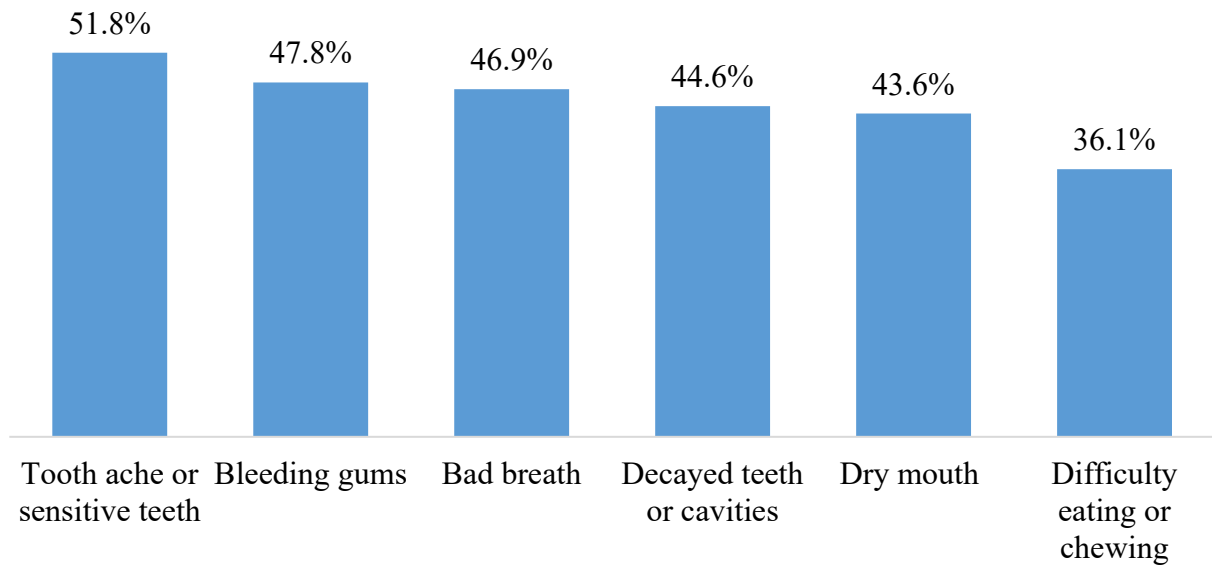
- Family caregiver respondents were asked about their thoughts on what the dental workforce in Indiana could do to improve their services or practice for people with disabilities. The following are the themes identified from their responses:
 - The Indiana’s dental workforce needs more education and training on how to work with people with disabilities
 - *“I think you should have some kind of training to learn how to deal with people with disabilities”*
 - *“I think they should take an annual course on disabilities.”*
 - *“They should be train to understand that some disabilities are not visible.”*
 - *“Education about disabilities. It is very important to have a dental staff that is knowledgeable about the different behaviors that go along with the disability. Patience and understanding can go a long way!”*
 - Dental providers should show more care and patience
 - *“Be more caring, understanding, & sympathetic with people with disabilities”*
 - *“They're friendly enough, but a little more patience would be nice”*
 - *“I think they are very friendly to people with disabilities, it would be better if you have more patience”*
 - *“They need to care for them as they are people who has feelings and be patient with them.”*
 - *“If you don't have a heart to care don't said that you can do it. I love my son and I'm so frustrated when I see people who don't care. He is a person and he need to be treated like a person.”*
 - Dental providers need to learn better, effective communication with individuals with disabilities and their families
 - *“They need to talk to the person they are doing work on/for AND the parent or guardian. They should have access to sign interpreters.”*
 - *“They need to take the time and care to listen to the caregiver and take serious what they are telling them. Because we know the patient best.”*
 - *“They could improve by listening to the parents and finding options that will work for children such as my daughter.”*
 - *“Take time to listen and explain.”*
 - More dental providers need to accept Medicaid
 - *“Accept Medicaid (particularly orthodontists).”*
 - *“Need more dentist to accept Medicaid. Very few in our area do. I think all medical, dentists and eye [doctors] should be required to accept medicaid to allow them to receive the best care possible and keep the families and caregivers together.”*

- *“More dental practice need to accept Medicaid/Medicare in our area. Because my disabled individual has gone to this particular dentist for over 10 years and is autistic and [won’t] go elsewhere after the dentist chose not to accept Medicaid and Medicare I have to pay out of pocket which is hard but I will do what I have to for my child...”*
- Dental providers need to provide more accessible dental practices for people with disabilities
 - *“Ask patients what accommodations they would like to feel more comfortable at the dentist”*
 - *“Allow caregivers to accompany persons with disabilities while receiving services”*
 - *“Improve the equipment which suit with disabilities”*
 - *“Making room for wheelchairs in the examining rooms”*
 - *“A better chair for taking [x-rays]”*
 - *“More handicap accessible (larger spaces).”*
- There needs to be improved means of locating dental providers who see patients with disabilities
 - *“Directory of providers who are experienced or open to working with a variety of disabilities. Maybe even indicate areas of disability that they are comfortable with. I also know families who seek dentists who use sedation, but I do not personally need that for our child.”*
 - *“Publish a list of dentists who regularly treat people with disabilities, broken with specialization -- type of pain relief, ages of patients seen, behavioral adaptations or specialty, etc.”*
 - *“More dentist offices need to have a specialty for our disabled population. It is hard to find ones who are willing to take these patients”*
 - *“Right now my son still sees a pediatric dentist, but at 23 yrs old he is going to need to move on but have no idea where to take him.”*

Oral Health Status and Care

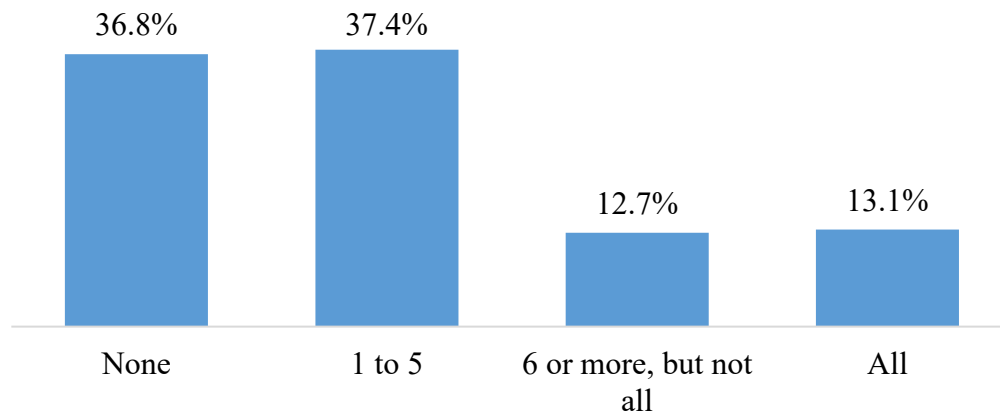
- Approximately three-fourths of the respondents reported that the health status of the family member with a disability was ‘excellent, very good, or good’ (73.5%) whereas 26.5% of the respondents reported that the family member’s health status was ‘fair or poor.’
- Regarding the condition of mouth and teeth of the person with a disability, more than two-thirds of the respondents reported that their family member with a disability had ‘excellent, very good, or good’ condition (68.9%) whereas 31.1% reported ‘fair or poor’ condition.
- A significant proportion of the respondents reported that their family member with a disability had frequent or chronic difficulty in various oral health conditions during the past 12 months. For instance, 47.8% for bleeding gums; 44.6% for decayed teeth or cavities; and 36.1% for difficulty eating or chewing. See Figure 19.

Figure 19. Frequent or chronic oral health conditions in the past 12 months of the person with a disability



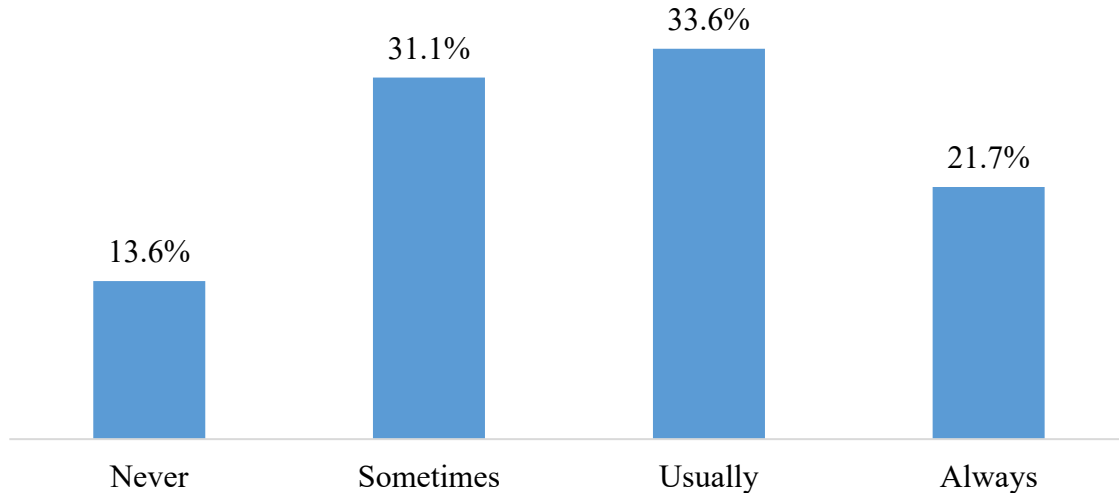
- Of the respondents who have a family member age 13 and over with a disability, approximately two-thirds of them (63.2%) reported that their family member with a disability had lost their permanent teeth because of tooth decay or gum disease. One in four respondents reported that the person with a disability had lost six or more permanent teeth: ‘all’ (13.1%) and ‘6 or more, but not all’ (12.7%). Individuals with disabilities who were less than 13 years old were not included in the analysis given that most children have their permanent teeth (adult teeth) by age of 13 (Journal of American Dental Association, 2006). See Figure 20.

Figure 20. The number of adult (permanent) teeth removed because of tooth decay or gum disease



- More than half of family caregiver respondents reported that the person with a disability could “always” or “usually” performed at-home oral care (e.g., tooth brushing or flossing) on their own (55.3%). However, about 14 percent reported the person with a disability could “never” do it on their own (13.6%). See Figure 21.

Figure 21. How often the person with a disability needed assistance in at-home oral care



- The majority of family caregiver respondents reported that they needed education or training on providing at-home oral care for the family members with disabilities (54.6%).
- Respondents were asked about what they would like to know more about at-home oral care for the person with disability. The following are the common themes that were noted in their responses:
 - Assistance in managing sensory issues of people with disabilities
 - *“Tools/techniques for cleaning with sensory issues. Help with consistently performing oral care independently.”*
 - *“How to clean teeth with oral sensory issues/person will not let you near mouth”*
 - How to improve oral health practices a home
 - *“How to look at disabled person's gums.”*
 - *“I'd like to know something about preventing tooth bleeding”*
 - *“Home care to prevent bad breath”*
 - *“Oral aversion and ways to safely brush teeth without upsetting her.”*
 - *“Best practices for dental care w tube-fed person, cleaning techniques when person is unable to spit”*

- Regarding concerns or issues related to dental care access for the person with a disability during the COVID-19 pandemic, most respondents did not report any issues. For the respondents who did report issues, below are the themes identified.
 - Inconvenience of getting appointments or following-up with cancelled appointments
 - *“Getting an appointment when office was closed.”*
 - *“Many clinics are not open”*
 - *“Access restrictions during the outbreak delayed visits to the dentist”*
 - Some people with disabilities have concerns about wearing face masks
 - *“Many dental offices require visitors to wear masks, but I’m wondering if they are aware that there are individuals with health issues or disabilities who can’t wear masks”*
 - *“We had difficulty accessing the office because my daughter was afraid of the medical masks. She had experienced medical trauma due to frequent surgeries. We almost weren’t able to have her teeth cleaned due to this.”*
 - Caregivers fear that people with disabilities are at high risk for COVID-19
 - *“It was nerve wracking going into dental office not knowing what to ask in terms of sanitizing procedures.”*
 - *“Since we need access to a hospital with [intubation] and anesthesia, I chose to risk waiting another year rather than to risk exposure.”*
 - *“Because my sweetie with a disability has a compromised immune system, we decided to skip one of her for yearly appointments, back in April. She just returned to the dentist at the beginning of August, because I felt more comfortable Doing so in that stage of COVID-19. However, we quite possibly will have to skip her next appointment because of Covid. I will not expose her to a deadly virus if at all possible. I have increased the quality and quantity of her dental care at home.”*
- Respondents were asked to provide comments/concerns regarding oral health needs of Hoosiers with disabilities and related experience in dental care. The following themes were identified:
 - The financial burden is high due to costs and insurance restrictions
 - *“Medicaid needs to be accepted more places than just these high profit, huge dental factories. You never see the same person twice and all they care about is money.”*
 - *“We pay extra for the dentist since they do not bill for Medicaid”*
 - *“We were denied by three different hospitals. I think alot of it had to do with her having Medicaid as her insurance.”*
 - *“Very few orthodontists have Medicaid experience and are willing to work with eligible patients.”*

- There are not enough options for dental providers that treat people with disabilities
 - *“Just very limited choices of providers and options for treatment.”*
 - *“Our greatest concern is finding an adult or general practice dentist who my daughter is comfortable with and who will accommodate her needs.”*
 - *“My child gets very anxious when there is a change in health provider. Dental insurance programs need to have flexibility in out of network providers for neuroatypical patients.”*
 - *“Calling offices from a list or searching on my own is time consuming”*
 - *“Had to drive 60 to 90 miles to a dentist who would see him. Also gets referred to other providers a lot and referral turns into a deadend. We have been trying for over two years now to get a tooth extracted.”*

- Depending on their need, families are unable to find sedation or alternatives to sedation
 - *“My daughter has autism. If she were to go to a dentist she would need to be fully sedated. She would not cooperate. Unless there was a program that would work with her on a weekly basis and was free [because] we do not have the money for multiple visits.”*
 - *“I called several places and they told me he needs to be sedated and he can't so I'm still looking. I ask a lot of people from my Support group and they said that every were it's the same that you need to keep looking until someone wants to take hear you and be patient with your son”*
 - *“People who are disabled and have great fear of the whole procedure should be enabled to utilize a swaddling mechanism to provide comfort and safety during dental work. It should not be necessary to give a disabled person drugs and or have them undergo general anesthesia just to have their teeth cleaned and checked and work done. I realize that by law this is not acceptable; I am saying the law needs to be changed, then.”*

- Families have experienced a lack of accommodations or disability culturally competent care
 - *“Providers consistently want to talk to the caregiver instead of to the patient - presume competence. Don't expect people with sensory issues to just "deal with it" for the duration of the appointment - provide accommodations/be flexible in your care.”*
 - *“Specialist (prosthodontics) Was terrible with special needs. To the point we abandoned trying to get help. He told her that he would make her pretty - which immediately implied she was not with 10 deformed teeth.”*
 - *“I have gotten the impression that they don't think my daughter with Down syndrome should have access to orthodontic care”*
 - *“A lot of providers don't allow parents back with the child during the appointment. They condescend and treat us like we're unintelligent.”*

Limitations

Several limitations should be considered in interpreting the findings of this report. First, our findings are based on self-report about oral health status and dental visits. It is possible that recall error occurs when the respondents do not remember them accurately. People tend to report less physician visits and report more emergency room visits (Ritter et al., 2001). It should be noted, however, that self-report has been widely used in research on health, health behaviors, and health services use. Research shows a good concordance between self-reports and administrative data (Brüne et al., 2021; Jiang et al., 2015). Given the potential discrepancy between self-reports and administrative data, more objective data (e.g., claims data) should be also used in examining the oral health status and dental care access of Hoosiers with disabilities in the future. Second, we did not recruit the participants using a probability sampling technique. The survey participants needed to meet the following inclusion criteria at the time of the survey: 18 years old and over; lived in Indiana; and primarily cared for a family member with a disability in Indiana. The inclusion criteria posed a great challenge in developing a representative sampling frame for the survey. To address it, the project staff collaborated with a variety of disability organizations and disability service organizations statewide on the promotion and dissemination of the online survey. The staff also promoted the survey via social media. It is possible, however, that selection bias occurred given that our sample was not randomly selected. For instance, percentages of the respondents with racial and ethnic background were much higher in the analytic sample than those of the state population. However, such overrepresentation could help capture perspectives from racial and ethnic minority groups with disabilities who experience greater disparities in dental care and oral health (Horner-Johnson et al., 2015). Third, the survey participants were family caregivers of individuals with disabilities. The research staff targeted family caregivers of those with disabilities whom they primarily cared for in the survey. The family caregivers may better understand some of the survey questions and answer them accurately (e.g., dental visits made within the past 12 months, dental care services received during the last dental visit, health insurance) than individuals with disabilities, especially those with cognitive limitations. However, family caregivers may not know the oral health status of individuals with disabilities accurately. Given these limitations, it should be noted that the findings of the survey reflect perspectives of family caregivers of individuals with disabilities, not those of people with disabilities.

The aforementioned limitations warrant careful interpretation of our findings. Nonetheless, our findings collected through a statewide survey provide valuable information about the current landscape for oral health and dental care for Hoosiers with disabilities. This is the first comprehensive data collection about oral health care and status for individuals with disabilities in Indiana, as well as their experience with dental care access. The findings can inform our efforts to address the oral health needs of people with disabilities in the state of Indiana and related needs of their family caregivers.

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Appendix

Results of the Oral Health Project - Family Caregiver Survey

Core Questions: Eligibility

1. Do you live in Indiana?

Type	Frequency	Percent
Yes	599	100.0%

2. Do you have a family member with a disability in Indiana whom you primarily care for?

Type	Frequency	Percent
Yes	599	100.0%

3. What is **your** age?

Type	Frequency	Percent
18 - 29	47	9.3%
30 - 39	211	41.9%
40 - 49	160	31.7%
50 - 59	65	12.9%
60 - 69	18	3.6%
70 and older	3	0.6%
Total	504	100.0%
Missing	95	
<i>Mean: 40.6</i> <i>Standard Deviation: 9.4</i> <i>Minimum: 21</i> <i>Maximum: 73</i> <i>Median: 39</i>		

4. In which county does **the family member with a disability** primarily live?

Type	Frequency	Percent
Adams	11	1.9%
Allen	32	5.6%
Bartholomew	4	0.7%
Benton	15	2.6%
Blackford	6	1.0%
Boone	13	2.3%
Brown	4	0.7%
Carroll	4	0.7%
Cass	5	0.9%

Clark	6	1.0%
Clay	6	1.0%
Clinton	4	0.7%
Crawford	2	0.3%
Daviess	6	1.0%
Dearborn	10	1.7%
Decatur	12	2.1%
DeKalb	10	1.7%
Delaware	11	1.9%
Dubois	1	0.2%
Elkhart	11	1.9%
Fayette	2	0.3%
Floyd	5	0.9%
Fountain	1	0.2%
Franklin	5	0.9%
Fulton	2	0.3%
Gibson	5	0.9%
Grant	3	0.5%
Greene	5	0.9%
Hamilton	24	4.2%
Hancock	7	1.2%
Harrison	3	0.5%
Hendricks	16	2.8%
Henry	10	1.7%
Howard	6	1.0%
Huntington	1	0.2%
Jackson	6	1.0%
Jasper	2	0.3%
Jay	3	0.5%
Jefferson	2	0.3%
Jennings	3	0.5%
Johnson	13	2.3%
Knox	7	1.2%
Kosciusko	7	1.2%
LaGrange	3	0.5%
Lake	20	3.5%
LaPorte	5	0.9%
Lawrence	3	0.5%
Madison	10	1.7%
Marion	50	8.7%
Marshall	1	0.2%
Martin	1	0.2%
Miami	8	1.4%
Monroe	15	2.6%
Montgomery	3	0.5%

Morgan	3	0.5%
Newton	3	0.5%
Noble	5	0.9%
Orange	5	0.9%
Owen	1	0.2%
Parke	5	0.9%
Perry	5	0.9%
Porter	5	0.9%
Posey	3	0.5%
Pulaski	3	0.5%
Putnam	1	0.2%
Randolph	2	0.3%
Ripley	3	0.5%
Rush	5	0.9%
Shelby	3	0.5%
Spencer	4	0.7%
St. Joseph	8	1.4%
Starke	1	0.2%
Steuben	3	0.5%
Sullivan	5	0.9%
Switzerland	4	0.7%
Tippecanoe	15	2.6%
Tipton	2	0.3%
Union	2	0.3%
Vanderburgh	6	1.0%
Vermillion	1	0.2%
Vigo	6	1.0%
Wabash	1	0.2%
Warren	1	0.2%
Warrick	2	0.3%
Washington	5	0.9%
Wayne	14	2.4%
Wells	7	1.2%
Whitley	4	0.7%
Total	599	100.0%
Missing	26	

5. What is the age of **the family member with a disability** you are caring for?

Type	Frequency	Percent
Up to 5	12	2.6%
6 – 20	220	47.0%
21 – 29	41	8.8%
30 – 39	66	14.1%
40 – 49	55	11.8%
50 – 59	25	5.3%
60 – 69	26	5.6%
70 - 79	23	4.9%
Total	468	100.0%
Missing	131	
<i>Mean: 28.5</i> <i>Standard Deviation: 19.6</i> <i>Minimum: 1</i> <i>Maximum: 78</i> <i>Median: 21.5</i>		

Experience with Access to Dental Care

6. Is there a dentist you usually go to for the dental care of the person with a disability?

Type	Frequency	Percent
Yes	557	93.0%
No	42	7.0%
Total	599	100.0%

7. What are the **main** reasons you do NOT have a dentist you usually go to for the dental care of the person with a disability? [Choose up to **THREE** answers]

Type	Frequency	Percent
The person with a disability seldom or never needs dental care	6	6.5%
Cannot afford care	10	10.8%
Cannot find a dentist who accepts insurance plan	10	10.8%
Do not know where to go for dental care	6	6.5%
No accommodations available for communication with dentist	9	9.7%
Dentist's office/clinic or dental equipment (for example, dental chair) not physically accessible	5	5.4%
Cannot find a dentist who is competent in working with individuals with disabilities	16	17.2%
Family member's (the person with a disability) fear, apprehension, nervousness, or dislike of going to a dentist	12	12.9%
Concern that the person with a disability will have difficulty controlling his/her behavior	11	11.8%

Other [specified below]	8	8.6%
Total	93	100.0%
Missing	55	
<i>Other:</i>		
<ul style="list-style-type: none"> • Recommended dentist have long waiting list since COVID-19 • Finding a good fit, person is also large so comfort is of concern. • Just haven't done it since we moved to Indiana • They don't want to put an effort to attend my son and they just want me to go to sedate him • When you get a good dentist they move on to make money with paid customers • Too young • Requires sedation and with her medical diagnosis, no one wants to help • Hard to find a place we like. A lot of the places her medicaid covers are these huge dental groups and you can't ever get the same dentist twice. Very quantity over quality model. Also, Indiana seems to have a lot of dental practices that over treat. 		

8. How long have you been going to this dentist for the dental care of the person with a disability?

Type	Frequency	Percent
1 year or less	128	23.1%
More than 1 year and up to 2 years	112	20.3%
More than 2 years and up to 5 years	143	25.9%
More than 5 years and up to 10 years	90	16.3%
More than 10 years	80	14.5%
Total	553	100.0%
Missing	4	

9. How did you find the current dentist of the person with a disability?

Type	Frequency	Percent
Friend	117	21.2%
Family/Relative	104	18.8%
Referred by another <u>dental</u> provider	72	13.0%
Referred by a <u>medical</u> provider	113	20.5%
Online search	67	12.1%
Search of network providers on dental insurance company website	66	12.0%
Other [specified below]	13	2.4%
Total	552	100.0%
Missing	5	

Other:

- Called dental offices and was recommended to them
- Only one who takes Special Needs patients in my area
- Parent Facebook group
- Behavior Consultant
- Current family dentist
- First steps therapist referred us
- new office opened near our home
- Family dentist
- My kids and I go there also

10. How many different dental offices/facilities did you contact before finding the current dentist of the person with a disability?

Type	Frequency	Percent
None	71	12.9%
One	189	34.4%
Two to five	221	40.3%
Six to nine	36	6.6%
10 or more	32	5.8%
Total	549	100.0%
Missing	8	

11. How do you usually bring the person with a disability to the current dentist?

Type	Frequency	Percent
Drive	249	45.2%
Driven by a family member/friend	114	20.7%
Public transportation, including paratransit (bus, train, or other)	95	17.2%
Private transportation (taxi or ride hailing services such as Uber and Lyft)	57	10.3%
Non-emergency medical transportation (Southeastrans) for traditional Medicaid members	24	4.4%
Walk	8	1.5%
Other [specified below]	4	0.7%
Total	551	100.0%
Missing	6	
<u>Other:</u> <ul style="list-style-type: none">• He drives• Ask for ride		

12. How long does it usually take to get to this dentist from the place where the person with a disability lives?

Type	Frequency	Percent
Less than 30 minutes	154	27.9%
31 minutes to 60 minutes (1 hour)	201	36.5%
61 minutes to 90 minutes	78	14.2%
91 minutes to 120 minutes (2 hours)	53	9.6%
More than 2 hours	65	11.8%
Total	551	100.0%
Missing	6	

13. What type of facility do you primarily go to for the dental care of the person with a disability?

Type	Frequency	Percent
Private <u>general</u> dental practice	144	24.6%
Private <u>pediatric</u> dental practice	155	26.5%
Community health center	111	18.9%
Community dental clinic	105	17.9%
Hospital emergency room	56	9.6%
Other [specified below]	15	2.6%
Total	586	100.0%
Missing	13	

Other:

- all dental work is done at a hospital in a an or setting or at riley in an or setting depending on what the dentist has available
- He hasn't being to a dentist since was 18yr old
- Haven't found one yet.
- Riley Dental it's in the out patient center at Riley Children's Hospital.
- Riley denist
- Pediatric dental inside hospital
- Inside Riley Hospital downtown
- She has never been to a dentist
- Hospital planned "surgical procedure" because must be done while under general anesthesia. My son is tube fed and the recommendation is to not go every year..
- none

14. Is the facility physically accessible regarding the following?

Parking Spaces		
Type	Frequency	Percent
Yes	338	57.9%
No	160	27.4%
Don't Know	86	14.7%
Total	584	100.0%
Missing	15	

Entrances		
Type	Frequency	Percent
Yes	302	51.7%
No	193	33.0%
Don't Know	89	15.2%
Total	584	100.0%
Missing	15	

Office Spaces		
Type	Frequency	Percent
Yes	310	53.2%
No	173	29.7%
Don't Know	100	17.2%
Total	583	100.0%
Missing	16	

Dental Equipment		
Type	Frequency	Percent
Yes	298	51.1%
No	171	29.3%
Don't Know	114	19.6%
Total	583	100.0%
Missing	16	

15. Does the facility provide the person who has a disability with accommodations for communication with a dentist or other oral health professionals, if needed?

[Note: Accommodations for communication can include American Sign Language (ASL) interpreters, communication devices, large print, Braille, etc.]

Type	Frequency	Percent
Yes	267	45.8%
No	185	31.7%
Accommodations not needed	131	22.5%
Total	583	100.0%
Missing	16	

16. Did you visit a dentist or a dental clinic for any reason, for the dental care of the person with a disability, within the past 12 months? Include visits to dentists and dental specialists, such as orthodontists and oral surgeons, as well as dental hygienists.

Type	Frequency	Percent
Yes	410	69.4%
No	181	30.6%
Total	591	100.0%
Missing	8	

17. Was the facility for the last dental visit for the person with a disability located in Indiana?

Type	Frequency	Percent
Yes	320	78.0%
No	90	22.0%
Total	410	100.0%
Missing	8	

18. What services did the person with a disability receive during his/her last dental visit **within the past 12 months?** (Check **ALL** that apply.)

Type	Frequency	Percent
General exam, checkup or consultation	139	19.7%
X-rays	85	12.1%
Dental cleaning	170	24.1%
Sealant (thin layer of plastic coating painted onto teeth to prevent tooth decay)	44	6.3%
Fillings or inlays	24	3.4%
Dental crowns (cap that covers tooth), or dental bridge (device that bridges the gap created by one or more missing teeth)	38	5.4%
Dentures (false teeth which can replace missing teeth and that you can take out and clean daily) or removable partial dentures	26	3.7%
Root canal (removal of the nerve from inside the root of a permanent tooth)	16	2.3%
Periodontal scaling or root planing (deep tooth cleaning and removal of hard and soft deposits from teeth above and below gums)	29	4.1%
Follow-up visit for periodontal (gum) disease management	22	3.1%
Extraction (tooth pulled)	21	3.0%
Abscess or infection treatment	20	2.8%
Other oral surgery (mouth surgery)	9	1.3%
Braces or teeth straightening	23	3.3%
Treatment for temporomandibular joint disorders (pain in jaw joint and jaw muscles)	13	1.8%

Emergency treatment (for example, broken tooth, pain, etc.)	18	2.6%
Other [specified below]	7	1.0%
Total	704	100.0%
Missing	16	
<i>Other:</i>		
<ul style="list-style-type: none"> • "happy visit" for desensitization • expander • They don't want to do anything because he is autistic 2 place I visit and they said they can do it when I ask before I go and they take my money • I wish there was a great place to take her and then be able to do what it takes to provide services for her needs. They aren't equipped to care for special needs. They don't care that they are in pain. They mix up records. You have to wait forever to get anything done. • spacers • Her teeth got counted. Plans made for sedation work but hospital refused to allow dentist to work • She had all 4 wisdom teeth removed 		

19. In general, how satisfied are you with the dental care the person with a disability received **during the past 12 months**? Would you say...?

Type	Frequency	Percent
Very satisfied	133	42.8%
Somewhat satisfied	125	40.2%
Somewhat dissatisfied	29	9.3%
Very dissatisfied	24	7.7%
Total	311	100.0%
Missing	17	

20. **During the past 12 months**, how often did the dentist or other oral health professionals of the person with a disability...

Spend enough time with the person with a disability?		
Type	Frequency	Percent
Always	95	30.4%
Usually	104	33.3%
Sometimes	92	29.5%
Never	21	6.7%
Total	312	100.0%
Missing	16	

Listen carefully to you?		
Type	Frequency	Percent
Always	111	35.8%
Usually	79	25.5%
Sometimes	91	29.4%
Never	29	9.4%
Total	310	100.0%
Missing	18	

Listen carefully to the person with a disability?		
Type	Frequency	Percent
Always	103	33.0%
Usually	123	39.4%
Sometimes	58	18.6%
Never	28	9.0%
Total	312	100.0%
Missing	16	

Show sensitivity to your family's values and customs?		
Type	Frequency	Percent
Always	99	31.7%
Usually	96	30.8%
Sometimes	91	29.2%
Never	26	8.3%
Total	312	100.0%
Missing	16	

Provide specific information you needed concerning the person with a disability?		
Type	Frequency	Percent
Always	103	33.1%
Usually	113	36.3%
Sometimes	74	23.8%
Never	21	6.8%
Total	311	100.0%
Missing	17	

Help you feel like a partner in the dental care of the person with a disability?		
Type	Frequency	Percent
Always	103	33.0%
Usually	128	41.0%
Sometimes	57	18.3%
Never	24	7.7%
Total	312	100.0%
Missing	16	

Make it easy for you to ask questions or raise concerns?		
Type	Frequency	Percent
Always	103	33.0%
Usually	96	30.8%
Sometimes	93	29.8%
Never	20	6.4%
Total	312	100.0%
Missing	16	

Make it easy for the person with a disability to ask questions or raise concerns?		
Type	Frequency	Percent
Always	94	30.3%
Usually	103	33.2%
Sometimes	90	29.0%
Never	23	7.4%
Total	310	100.0%
Missing	18	

Allow you to be present with the person with a disability during dental care services?		
Type	Frequency	Percent
Always	111	35.8%
Usually	119	38.4%
Sometimes	55	17.7%
Never	25	8.1%
Total	310	100.0%
Missing	18	

21. During the past 12 months, was the person with a disability **delayed in** getting dental care, tests, or treatments you or a dentist believed to be necessary?

Type	Frequency	Percent
Yes	293	50.1%
No	292	49.9%
Total	585	100.0%
Missing	14	

22. What were the **main** reasons the person with a disability was **delayed in** getting dental care, tests, or treatments you or a dentist believed to be necessary? [Choose up to **THREE** answers.]

Type	Frequency	Percent
Could not afford care	43	6.4%
Could not find a dentist who accepts insurance plan	45	6.7%
Dentist's office/clinic or dental equipment (for example, dental chair) not physically accessible	48	7.2%
Dentist too far away from where I live	86	12.9%
No transportation	36	5.4%
No appointments available	35	5.2%
No accommodation available for communication with dentists or oral health professionals	89	13.3%
I could not get time off work	40	6.0%
Did not know where to go to get care	28	4.2%
Family member's (the person with a disability) fear, apprehension, nervousness, or dislike of going to a dentist	58	8.7%
Concern that the person with a disability will have difficulty controlling his/her behavior	33	4.9%
Need for anesthesia	31	4.6%
Coronavirus pandemic (COVID-19) [specified below]	89	13.3%
Other [specified below]	7	1.0%
Total	668	100.0%
Missing	26	
<i>Delayed in dental services because of COVID-19:</i>		
<ul style="list-style-type: none"> • limited places to perform oral surgery were available. • Inconvenient to go out • Travel restrictions • offices not open • All appointments were cancelled for a period of time, including our scheduled appointment • I am afraid that you will get covid-19 • appointments cancelled • Disabled person was ill and other family member died of Covid-19 • Cleaning and exam delayed; only urgent dental needs addressed. 		

- We avoided public places in April when due for an appointment.
- Services were suspended due to the outbreak.
- The COVID-19 outbreak has led to a temporary shutdown.
- Dental offices closed during shutdown.
- I was not wanting to chance the hospital exposure during COVID-19 because of the intubation and anesthesia
- Social alienation
- Closed because of Covid, emergency only. Said they would call to reschedule but have not done so yet.
- Office closed
- Office shut down

Other:

- Inflexible scheduling options
- had to keep applying for approval from insurance and medicaid
- They said they were going to schedule her out with orthopedic specialist and we have yet to hear from them. I wish there was a good place to take her that does everything
- Need an oral surgeon and cannot find one close
- Was seriously injured in an accident and needed to fully recover before having more surgical procedures
- Hospital refused based on disability
- Oral surgeon completely unable to understand how her disabilities played a role in her wisdom teeth removal. We had an issue because she couldn't eat/drink and have IV sedation. I told them she'd get nauseous if she didn't eat with her morning meds for epilepsy)and he thought he could just do it awake. Ended up rescheduling for later time the next week. And getting her into her neuro prior. Surgeon did not let me come back with her even though I requested to be with her until IV sedation. When I addressed concerns with her epilepsy, surgeon responded it wouldn't bother him if she had a seizure. I mean, come on. He was terrible with disabilities. Just the worst.

23. **During the past 12 months**, how many times has the person with a disability gone to a **HOSPITAL EMERGENCY ROOM** because of any kind of dental care or dental pain?

Type	Frequency	Percent
None	193	33.7%
Once	180	31.4%
2-3 times	153	26.7%
4 times or more	47	8.2%
Total	573	100.0%
Missing	26	

24. **During the past 12 months**, was the person with a disability EVER covered by ANY kind of health insurance or health coverage plan?

Type	Frequency	Percent
Yes, they were covered all 12 months	274	47.1%
Yes, but they had a gap in coverage	179	30.8%
No	129	22.2%
Total	582	100.0%
Missing	17	

25. **During the past 12 months**, was the person with a disability covered by any of the following types of health insurance or health coverage plan? (Check **ALL** that apply.)

Type	Frequency	Percent
Insurance through <u>caregiver's</u> current or former employer or union	135	21.4%
Insurance through <u>his/her</u> (the person with a disability) current or former employer or union	120	19.0%
Insurance purchased directly from an insurance company	111	17.6%
Medicaid, Medical Assistance, or any kind of government assistance plan for those with low incomes or a disability	177	28.1%
Children's Special Health Care Services (CSHCS) program	52	8.3%
TRICARE or other military health care	6	1.0%
Indian Health Service	28	4.4%
Other [specified below]	1	0.2%
Total	630	100.0%
Missing	27	
<i>Other:</i>		
<ul style="list-style-type: none"> • unsure 		

26. How confident are you filling out medical/dental forms by yourself?

Type	Frequency	Percent
Extremely	139	24.3%
Very	187	32.7%
Moderately	163	28.5%
Slightly	47	8.2%
Not at all	36	6.3%
Total	572	100.0%
Missing	27	

27. How do you think the dental workforce in Indiana (e.g., dentists, dental hygienists, dental assistants, or office staff) could improve their services or practice for people with disabilities?

- Provide better comprehensive coverage. Getting more qualified doctors in the area.
- Not sure
- Our dentist has a special hour, 11-12, set aside for just a few patient with I/DD.
- Very good. It's just a little far away. I hope more dental institutions can be set up.
- They should be more understanding about mental health problems on teenagers. They should be train to understand that some disabilities are not visible.
- The cost of dental diagnosis for the disabled is high and the places are few, hope to add some welfare policies and professional medical team to help them
- Provide general health information, including information on care measures for newborns with disabilities and children with disabilities, and visit the nearest dental hospital to begin oral care and rehabilitation as early as possible
- training for autism and sensory supports
- take time to listen and explain, the first dentist we went to didn't listen and didnt explian and just started working and it made my son scared, our current dentist listens and will explain and is aware of his fears and will do what they can to help and they understand he has issues and will accomidate as much as they can
- Should help the disabled
- Help the disabled with dental care
- Special beds that allow proper restraint. Office hours dedicated to special needs. Understanding that pain is extremely unmanageable for cognitive disabilities and more help is needed to maintenance that pain.
- My sons Dentist, is wonderful , with the Disabled community. Other, could learn from him, the patience, and understanding.
- I've had nothing but superb service from our dental care provider.
- Dental staff establishes relationships with patients and communicates the importance of good dental care in a timely manner. Very good and professional
- I think it would be great
- Better understanding and training regarding sensory issues
- none
- Friendly talk to the disabled
- Help the disabled and teach them how to take care of their teeth
- Should be more concerned about the disabled
- Should be more concerned about the disabled
- B: yes.A number of disabled people interactive communication, physical and mental happiness.
- Help the disabled and teach them how to take care of their teeth
- There should be more free services for the disabled
- Help the disabled and teach them how to take care of their teeth
- Be more consistent...
- There should be more free services for the disabled

- Include PWD in discussions/plans! Understanding of sensory sensitivities and accommodations for them. More education/support for dental care at home.
- I think their technology needs to be improved.
- Faster anesthetics should be used
- Very responsible
- Work conscientiously and responsibly, love work, obey the overall arrangement, good image
- Provide some communication equipment for people with disabilities
- Generally speaking, the service was very considerate
- Will basically meet my requirements
- I think dental staff should visit clients regularly to get data
- I think we should call a client frequently to ask about the situation, so as to improve our treatment plan
- Doctors can't have any discrimination
- I think they are great and they are treated equally.
- Their service attitude was very good and they were very responsible to us
- Disabled persons are a disadvantaged group in society, and serving the disabled wholeheartedly is our purpose
- You can compare the best doctors or hospitals
- It would be better if you could come to the door
- People who need to know body language
- People who know sign language or spoken language are needed
- The service is excellent
- The dentist's behavior is too rude. It should be gentle
- It's too violent in dental care
- The charge should be reduced
- Some people look at it differently
- Some equipment for people with disabilities is needed
- no problem
- Change the concept of racial discrimination
- Strengthen the education of doctors
- There is a need for dental staff dedicated to the disabled
- It's good enough now
- It's already perfect
- Build a barrier free access
- Build more dental clinics
- I think there are fewer insurance reimbursements
- The service attitude was very good
- Their treatment cycle is too long
- we should call a client frequently to ask about the situation, so as to improve our treatment plan
- Poor service attitude
- Very good
- the oral health of the disabled is very noteworthy

- For special groups of people can visit the hospital regularly
- Basically, the service was of a very high standard
- The dentist's office is too far away
- The dental clinic charges too much
- More training. Listening to families. Costs are clear up front. Not requiring children to be papoose and not charging for that requirement. Sunglasses, headphones, conscious sedation available.
- The dentist's behavior is too rude. It should be gentle
- More help and services for children with disabilities
- So-so
- yes
- Allow caregivers to accompany persons with disabilities while receiving services (i.e., wherever procedure will allow), while where appropriate PPE.
- I think they are very friendly to people with disabilities, it would be better if you have more patience
- The doctor is very professional and the service is also very good
- How to sufficiently clean and examine while being accommodating and respectful of disabilities
- A better chair for taking x raus
- very good
- perfect
- Improve the equipment which suit with disabilities
- More hours available. Improve accessibility.
- Be professional and service-oriented
- Help the disabled and teach them how to take care of their teeth
- There should be more free services for the disabled
- Should be more concerned about the disabled
- Increase professional knowledge
- Help the disabled and teach them how to take care of their teeth
- Should help the disabled do more dental care
- Should be more concerned about the disabled
- I think they will improve their working attitude
- professional
- Should help the disabled do more dental care
- There should be more free services for the disabled
- Should be more concerned about the disabled
- Help the disabled and teach them how to take care of their teeth
- Be aware that you might need to take a little more time as that person may have high anxiety. Also there are often sensory issues which can cause outbursts at times.
- Directory of providers who are experienced or open to working with a variety of disabilities. Maybe even indicate areas of disability that they are comfortable with. I also know families who seek dentists who use sedation, but I do not personally need that for our child.
- Performing routine work assisting patients' homes.

- no opinion
- Change your attitude and be more patient.
- No bad.
- Provide professional services to those in need
- Improve service quality and hardware facilities
- Improve service quality and hardware facilities
- Help the disabled and teach them how to take care of their teeth
- Publish a list of dentists who regularly treat people with disabilities, broken with specialization -- type of pain relief, ages of patients seen, behavioral adaptations or specialty, etc. Make this available to the Autism, Down syndrome and other disability organizations
- Accept Medicaid (particularly orthodontists), speak directly to person w disability while also speaking w caregiver.
- Should be more concerned about the disabled
- There should be more free services for the disabled
- Should help the disabled do more dental care
- I think they should take an annual course on disabilities.
- Fishers Pediatric Dentistry is the kindest and caring for kids with special needs
- Need more pediatric dentists available. The family dentist practice does not have a pediatric dentist. Was able to choose from a larger list of out of network providers covered under Aetna DMO, but then once they had the only in network pediatric dentist in Indiana who is a 40 minute drive away from us, our out of network authorization was cancelled. We decided it was more important for our child with autism to remain with his current dentist, so we pay out of pocket for his dental care.
- We go to Dr Flecks office inClarksville. They are always great with my son. Always willing to help
- n/a
- Need more dentist to accept Medicaid. Very few in our area do. I think all medical, dentists and eye drs should be required to accept medicaid to allow them to receive the best care possible and keep the families and caregivers together. When I raised my kids it was a family affair you all went to the same eye Dr, dentist and Dr unless you were told a specialist was needed
- More dentist offices need to have a specialty for our disabled population. It is hard to find ones who are willing to take these patients
- I think you should have some kind of training to learn how to deal with people with disabilities
- They need to care for them as they are people who has feelings and be patient with them.
If you don't have a heart to care don't said that you can do it. I love my son and I'm so frustrated when I see people who don't care. He is a person and he need to be treated like a person.
- They need to talk to the person they are doing work on/for AND the parent or guardian. They should have access to sign interpreters.
- They need taught how to work with the parents and especially the patients. They need training on how to work with special needs. They need to have everything in order to

properly care for their needs. They need to take the time and care to listen to the caregiver And take serious what they are telling them. Because we know the patient best. They can't get mad because they are told to shit up and get in a kids face and refuse to take care of the child. They need patience above all.

- Accept them as patients.
- na
- Should help the disabled do more dental care
- services without a dentist's comprehensive oral examination
- Oral health care in traditional dental practice settings
- Increase Access to General and Specialty Dental Services.
- a disproportionate number of ... dentists, dental hygienists, dental assistants, and dental laboratory technicians.
- LESS members of the health care workforce (specifically including dentists).
- a requirement that public health dental hygienists work under the direction of a supervising
- across programs that may foster access and contribute to improving the quality of oral
- To address scope of practice and supervision requirements
- Should help the disabled do more dental care
- Should help the disabled do more dental care
- online services
- Help the disabled and teach them how to take care of their teeth
- There should be more free services for the disabled
- Should help the disabled do more dental care
- clinics and pediatricians are more improved
- There should be more free services for the disabled
- There should be more free services for the disabled
- Main issue for oral surgeon office to evaluate TMJ was that the assessments rely so much on the patient response. Difficult for non verbal patients on autism spectrum.
- More acceptance of Indiana insurances, more pediatric offices that provide a range of care instead of just general services. Pediatric oral surgeon was recommended, list of recommendations was provided but they don't accept insurance and therefore needs have waited.
- N/a
- They need to stop overbooking. We usually have to wait at least an hour before he's seen. There have been times when they forgot we were there and we waited over 2 hours. That is a long time for a child with a disability.
- Education about disabilities. It is very important to have a dental staff that is knowledgeable about the different behaviors that go along with the disability. Patience and understanding can go a long way! Taking an adult who is mentally like having a small child and acting like a small child and not the adult that their body portrays can be very hard on caregiver and client. Every time we go to the dentist , we hope it won't be a freak out moment.
- Great
- They all did a great job and I thank them for it.
- Making room for wheelchairs in the examining rooms

- They need to hire more medical professionals to meet the huge demand for medical care.
- They need to improve appointment efficiency.
- They did their job well, they were professional, they were fantastic!
- They're very patient with my kids.
- Show us how to care for teeth when the person has sensory issues of the mouth and cannot clean teeth effectively. Also, we left a previous practice because they would not let me (parent) accompany my young child during a procedure that caused my child a great deal of fear and anxiety.
- Yes. Right now my son still sees a pediatric dentist, but at 23 yrs old he is going to need to move on but have no idea where to take him.
- Some dental assistants should be more gentle.
- They were very professional and I trusted them.
- nice
- More that accept medicaid/medicare. More that are adaptable to special needs: patient, understanding hygienists, dentist.
- Caring for them is not pitiful! Caring about others is better than everything. When you are with them, don't always emphasize what is good. In fact, some things are very difficult for them to do. You can think from the side and better safeguard their interests
- They're great. We don't need special treatment because it makes us miserable
- The service attitude is very sincere, I like it very much
- Have more rental providers accepting Medicaid. And paying the provider better
- I am very satisfied with the service
- Lower charges
- Very patient
- They are very professional
- Can be more patient
- Ask if accommodations are needed?
- My daughter has autism. If she were to go to a dentist she would need to be fully sedated. She would not cooperate. Unless there was a program that would work with her on a weekly basis and was free bc we do not have the money for multiple visits.
- The practice that treats us is brilliant.
- More dental practice need to accept Medicaid/Medicare in our area. Because my disabled individual has gone to this particular dentist for over 10 years and is autistic and wont go elsewhere after the dentist chose not to accept Medicaid and Medicare I have to pay out of pocket which is hard but I will do what I have to for my child thank goodness they have good oral hygiene but I blame it on "good ol Obama care" it's over \$120.00 out of pocket every 6 mos. Hopefully no dental work is ever needed.
- Provide private office care. It is difficult to get from the parking structure to the Outpatient medical area in the large outpatient care center pushing a wheelchair.
- Dentists who provide care to disabled adults should be permitted to utilize comforting "papoose boards" with Velcro to swaddle the patient if the patient is fearful and/or becomes agitated during treatment. Anxiety drugs should not be a disabled adult's only option in these cases.

- Ask patients what accommodations they would like to feel more comfortable at the dentist.
- Take more time to explain a dental procedure.
- More dental clinics can be built
- The service is very professional.
- none
- acclaim
- esteem
- none
- With all due diligence
- Relatively backward equipment
- Our dental practice worked with our behavior therapist on a desensitization protocol to help overcome anxiety and terminate the need for sedation dentistry.
- celebration
- rave
- celebration
- They need to be patient.
- They've done a good job
- NA
- Sex patient
- More patience
- There is no
- NO
- NO
- I think their service is very professional and conscientious.
- There are uniform service standards
- No good advice
- They've done a good job
- Having more options of outpatient care. I am the "communication device" for my child.
- no
- NO
- NO
- No advice
- No advice
- no
- There's nothing
- Update equipment and train technology regularly
- accept medicaid. More handicap accessible (larger spaces).
- Care more
- Improve the convenience of service
- Change the attitude of medical staff.
- our dentist office has done a great job communicating..
- My son has had a good experience!
- Friendly

- More patience and more counseling
- Friendly
- Be more caring, understanding, & sympathetic with people with disabilities
- They're friendly enough, but a little more patience would be nice
- It's very good. It doesn't need to be improved.
- Hospitals need to be better equipped to allow dentist to use OR for sedation dental care. My daughter was refused her dental work by the hospital because they aren't equipped for any ER that might arise with her
- They need to actually care, first off. They should NEVER deny to let the parent be with them. They should not think concerns like seizures are about them performing the surgery. They need to provide extra help/instructions/safe guards and not act like it's no big deal.
- I don't know why they actually provide excellent service.
- We plan on switching because of our experience. It was very traumatic for my daughter and myself. She has severe oral aversion, but they were rough and forced their way into her mouth anyway. They could improve by listening to the parents and finding options that will work for children such as my daughter. She was so upset she set off her heart monitor and oxygen dipped. This was at a children's hospital.
- Listen to parent more
- No improvement needed
- I wish they would be in more networks
- The sedation dentists don't normally accept Medicaid. We have friends who only have Medicaid for their Autistic son so they take him to the hospital to have his teeth cleaned and it's traumatic for him. I'm sure it costs more than what it costs us. We have private insurance and Medicaid. We end up paying about \$400 out of pocket.
- CSHCS is not widely known to dentists
- They are really good with my son and I think they should let it be known in their advertising that they work with individuals with disabilities
- unsure...
- More understanding and training about disability

Oral Health Status and Care

28. In general, how would you describe the health of the person with a disability?

Type	Frequency	Percent
Excellent	78	13.8%
Very good	163	28.7%
Good	176	31.0%
Fair	85	15.0%
Poor	65	11.5%
Total	567	100.0%
Missing	32	

29. How would you describe the condition of mouth and teeth of the person with a disability?

Type	Frequency	Percent
Excellent	75	13.3%
Very good	141	24.9%
Good	174	30.7%
Fair	120	21.2%
Poor	56	9.9%
Total	566	100.0%
Missing	33	

30. During the past 12 months, has the person with a disability had **FREQUENT** or **CHRONIC** difficulty with any of the following? [Please choose one answer per each difficulty.]

A tooth ache or sensitive teeth		
Type	Frequency	Percent
Yes	291	51.8%
No	271	48.2%
Total	562	100.0%
Missing	33	

Bleeding gums		
Type	Frequency	Percent
Yes	267	47.8%
No	292	52.2%
Total	559	100.0%
Missing	40	

Decayed teeth or cavities		
Type	Frequency	Percent
Yes	250	44.6%
No	311	55.4%
Total	561	100.0%
Missing	38	

Difficulty eating or chewing		
Type	Frequency	Percent
Yes	203	36.1%
No	359	63.9%
Total	562	100.0%
Missing	37	

Bad breath		
Type	Frequency	Percent
Yes	263	46.9%
No	298	53.1%
Total	561	100.0%
Missing	38	

Dry mouth		
Type	Frequency	Percent
Yes	242	43.6%
No	313	56.4%
Total	555	100.0%
Missing	44	

31. How many of the adult (permanent) teeth of the person with a disability have been removed because of tooth decay or gum disease? Include teeth lost to infection, but do not include teeth lost for other reasons, such as injury or orthodontics. (Note: If wisdom teeth are removed because of tooth decay or gum disease, they should be included in the count for lost teeth.)

Type	Frequency	Percent
N/A (the person with a disability is younger than 13 years old.)	55	10.4%
None	174	33.0%
1 to 5	177	33.5%
6 or more, but not all	60	11.4%
All	62	11.7%
Total	528	100.0%
Missing	71	

32. To what extent is the person with a disability able to perform home oral health care (e.g., tooth brushing or flossing) on their own?

Type	Frequency	Percent
Always	123	21.7%
Usually	190	33.6%
Sometimes	176	31.1%
Never	77	13.6%
Total	566	100.0%
Missing	33	

33. Do you need education or training on providing home oral health care for the person with a disability?

Type	Frequency	Percent
Yes	314	54.6%
No	261	45.4%
Total	575	100.0%
Missing	24	

34. What would you like to know more about home oral health care for the person with a disability?

- yes
- yes
- Yes
- How to teach self care
- yea
- Tools/techniques for cleaning with sensory issues. Help with consistently performing oral care independently.
- How to prevent some dental diseases.
- When is oral health best
- I want to know more about it
- yes
- I would like to know more about family oral health care for the disabled
- Yes
- noce
- Yes
- Not really
- I know enough
- I don't want to
- I don't want to
- no problem
- I don't want to
- no
- yes
- yes
- YES
- no
- Regular brushing
- yes
- yes
- no
- Yes i want to know more

- yes
- How can I improve my family members' physical and mental health
- Yes
- YES
- Yes
- none
- Need to be
- Don't need
- Don't need
- best practices for dental care w tube-fed person, cleaning techniques when person is unable to spit
- He has sensory issues, He will only use unflavored toothpaste. I use to order thru Amazon and it came from England can no longer get it. He also need fluoride toothpaste. Going to try ordering the nano toothbrush to see if he like the feel of those better.
- na
- How do disabled people brush their teeth?
- Search Results
Web results
Developmental Disabilities and Oral Health Information
- routine treatment of dental hygiene
- dental health check, dental care, etc
- How to clean teeth with oral sensory issues/person will not let you near mouth
- Yes
- Family oral health care: maintain good oral health habits (fluoride toothpaste, parents help brush teeth) nutrition balance, eat reasonable sweets, regular oral examination, kindergarten oral health care
- How to keep teeth healthy
- A bit detailed
- YES
- I know basic care
- I know a little
- Yes
- How to look at disabled person's gums.
- Protect your teeth
- NA
- general
- I don't know much about
- NO
- NO
- NO
- yes
- yes
- yes
- yes

- NO
- YES
- yes
- yes
- NO
- NO
- yes
- yes
- yes
- yes
- deep understanding
- Persons with disabilities lack the capacity for self-oral health care and require medical and nursing care from oral health professionals, family members and other social service personnel.
- I'd like to know something about preventing tooth bleeding
- Home care to prevent bad breath
- Diet and oral health care
- Yes
- Oral aversion and ways to safely brush teeth without upsetting her.
- Schedule and reminders / help with manipulating oral care tools

35. If you've had any concerns or issues related to dental care access for the person with a disability during the coronavirus pandemic (COVID-19), please provide any comments.

- None. Annual spot is set for later this year. Will see how it goes.
- We cancelled appts not necessary
- It's not convenient to go out.
- It is more difficult to find dental facilities for the disabled during the outbreak.
- mouth pain
- none
- I will help them solve the problem
- N/a
- None
- During the COVID-19 epidemic (COVID-19), I couldn't find my favorite dentist
- Yes, because doesn't clean his teeth that much I always have remain him every day or every other day
- Many dental offices require visitors to wear masks, but I'm wondering if they are aware that there are individuals with health issues or disabilities who can't wear masks
- The dentist didn't go to work normally
- Try not to go out and take precautions.
- Haven't been able to go/schedule.
- went to dentist during COVID-19, hygienist did not do cleaning although they usually start cleanings at age 5.

- None at this time.
- nothing
- Few clinics open
- The doctor still wears a mask when treating my teeth. He is very responsible
- no
- nothing
- It may take longer to see a doctor
- If I have a problem with my teeth, I can't see a doctor in time
- It is best not to go out for dental care during covid-19
- I think it's best to clean up the dentist's home care during covid-19
- Fear of racial discrimination
- no
- No worries
- Worried that doctors would not dare to treat
- It's going to cost more money to treat
- No comments
- No special comments
- I don't know
- During covid-19, you can't go to places where people gather. You should avoid going to clinics
- Covid-19 is hard to get out of the house, so the dentist should be there
- It's very inconvenient to travel
- It's hard to find a doctor for gum problems
- nothing
- nothing
- Strengthen the education of people's concept
- Don't walk around during covid-19
- Many clinics are not open
- It took a long time
- No comments
- During covid-19, large-scale gathering is not allowed to avoid infection with virus
- Wear more masks and ventilate during covid-19
- I am a little worried that they will get infected when they go to the clinic
- Often do not see a doctor
- nothing
- Can't make an appointment to the doctor
- During covid-19, most doctors were in telemedicine.
- none
- You can't go out to the dental clinic
- When is oral health best
- Few clinics open
- It is best not to go out for dental care during covid-19no
- Covid-19 is hard to get out of the house, so the dentist should be there
- no

- It is best not to go out for dental care during covid-19
- Very worried, not convenient to see a doctor
- no
- Affected by COVID-19, it is difficult to go out to see a doctor
- nothing
- Whether people with disabilities are at greater risk of being infected
- During the epidemic, the number of people in hospitals was large, and they were afraid of being infected
- The cause of the epidemic could not seek medical treatment in time
- I don't want my children to go out
- Failure to seek medical attention in time
- none
- We haven't had any problems.
- Dental care during a pandemic is difficult.
- none
- Need to be
- Please provide special shuttle service
- Provide a more beautiful environment and make people feel happy
- Delay in orthodontic followup during closure resulted in less than ideal outcomes. It was nerve wracking going into dental office not knowing what to ask in terms of sanitizing procedures.
- He hasn't had a follow-up since February, before the pandemic lockdowns, so we will see how he adjusts to his next one in August.
- We have been doing fine.
- I try to be efficient in dental care to avoid going out with the disabled person for consultation.
- 1 appointment was postponed.
- na
- hospital / clinic is not a safe place
- I am very worried and afraid go to the clinic /or hospital
- None
- N/A
- Our dental plan got pushed back due to Covid, still have to reschedule appointment
- No
- Appointments always seem to be difficult, during the COVID-19 pandemic.
- no
- During the epidemic period, it is easy to be infected, contact as little as possible, and do a good job of protection
- It's really hard to get face-to-face care
- We cannot go to the clinic for health care during COVID-19, and my own home care is still ineffective
- If there was a problem I am not sure we could find a dentist
- Pay attention to oral care at home during the epidemic
- No concerns

- I will actively help them
- I'd rather not say it
- It must take preventive measures
- My daughter has autism. If she were to go to a dentist she would need to be fully sedated. She would not cooperate. Unless there was a program that would work with her on a weekly basis and was free bc we do not have the money for multiple visits.
- We had difficulty accessing the office because my daughter was afraid of the medical masks. She had experienced medical trauma due to frequent surgeries. We almost weren't able to have her teeth cleaned due to this. The dentist talked to her with just the face shield and slowly had her warm up to the masks
- Because my sweetie with a disability has a compromised immune system, we decided to skip one of her for yearly appointments, back in April. She just returned to the dentist at the beginning of August, because I felt more comfortable Doing so in that stage of COVID-19. However, we quite possibly will have to skip her next appointment because of Covid. I will not expose her to a deadly virus if at all possible. I have increased the quality and quantity of her dental care at home.
- Concerns about getting an appointment.
- None
- The doctor's service attitude is not good
- Dental care services were delayed during the epidemic.
- Unable to live with adequate health services during a pandemic.
- NO
- NO
- As a result of the coronavirus epidemic, some basic dental care services cannot be performed normally.
- Access restrictions during the outbreak delayed visits to the dentist
- Shops close and no one sells
- NO
- NO
- NO
- How to protect?
- You can get COVID-19 on your way to quality
- none
- Articles about teeth can be published for reference
- I can't think of anything
- no
- Don't comment
- Don't comment
- Dental health services were delayed during the epidemic.
- There is no
- no
- Since we need access to a hospital with entubation and anesthesia, I chose to risk waiting another year rather than to risk exposure.
- NO

- NO
- NO
- no
- Online medical consultations are available
- no
- no problem
- The hospital is understaffed
- The oral health problems of people with disabilities are multifaceted. Chewing and swallowing difficulties can make three meals a day a major challenge.
- In contrast, oral preventive care for the disabled is relatively easy to achieve, while their dental treatment is much more difficult.
- none
- Conduct online consultation
- Set up online community dental consultation
- None
- Not able to wear masks
- Gargle with salt water and eat fewer sweets
- NO
- The C19 safeguards are making life a living hell for the disability community. So many insane things going on from masks, to blocked entrances, forced hand sanitizer, to arbitrary rules that have no basis in science or disease mitigation and barriers to services and quality medical care everywhere. I am significantly more concerned about the ramifications of the mitigation efforts than the disease itself, including for my daughter.
- To avoid contagion during the coronavirus (covid-19) pandemic, the person with a disability does not leave home.
- Getting an appointment when office was closed.

36. Please provide any comments or concerns about oral health needs of individuals with disabilities in Indiana and your related experience in their dental care.

- Concerned for patient to be referred to specialist (oral surgeon) who doesn't know of patient's disabilities. Ie orthodontist OR wisdom teeth removed.
- The cost is high. I hope some benefits can be added.
- They should be more aware about mental disability on teenagers.
- Sorry, I have no idea.
- inability to communicate
- none
- Do more oral care
- N/A
- None.
- Madison County dental staff communicates the importance of good dental care in a timely manner, very good and very professional
- I would like him to learn about brush his teeth more

- none
- Communicate and interact with them.
- Providers consistently want to talk to the caregiver instead of to the patient - presume competence. Don't expect people with sensory issues to just "deal with it" for the duration of the appointment - provide accommodations/be flexible in your care.
- None at this time.
- The anesthesia took a long time
- It is suggested that they can enter the community regularly
- The service was very comprehensive, the attitude was very good
- Thank you doctor
- Can dental diseases be treated by remote video
- How long do you need dental care
- If there is no health care, will there be a big problem
- I think the oral health of the disabled is very noteworthy
- I think that doctors should be considerate of patients and can take the initiative to provide door-to-door service
- Doctors cannot treat all patients
- no
- Brush your teeth frequently
- Worried that doctors would not dare to treat
- In daily life, too much attention is easy to forget
- Faster treatment is needed
- More advanced treatment is needed
- no
- I think we should help the disabled more and provide more services
- I don't think there are enough dental clinics. We should build more
- Try to avoid being late for unnecessary food in daily life
- Gum health should be checked regularly
- No comments
- No comments
- Hope never to get sick
- I hope there is a barrier free access
- There are a lot of people who don't care about gum health
- Multiple continuous treatment is required
- Let the dentists serve more
- There are few dental clinics
- I think there are fewer insurance reimbursements
- Oral health is related to diet
- There are a lot of old hospital equipment
- Dental hospitals charge too much
- Build more dental clinics in Indiana
- none
- There are too few dental clinics. It's too far from home
- The charge can be reduced a little bit

- It would be better if you could come to the door
- I don't think there are enough dental clinics. We should b
- no
- A lot of providers don't allow parents back with the child during the appointment. They condescend and treat us like we're unintelligent. One charged me \$600 for my son's cleaning.
- no
- During covid-19, you can't go to places where people gather. You should avoid going to clinics
- I hope to pay more attention to children's dental health
- I feel very satisfied
- It takes a lot of time due to backward medical equipment
- I hope the government will pay more attention to this aspect
- Clean mouth in time
- Maintain oral hygiene
- Indiana has done too little
- Keep your mouth clean
- I have no concerns, I think the current oral health system is adequate.
- oral hygiene procedures can be carried out.
- none
- Need to be
- Improve service quality and optimize hardware facilities
- No opinion
- The first dentist we saw put my daughter in a straight jacket and strapped her to the chair -- asked me to help hold her down. All children with disabilities should have their permanent teeth sealed as they emerge and the state should help pay for this if needed to prevent future dental costs. The ADA has blocked this legislation in the past and it is outrageous and self serving. We need our own lobbyist to push the legislation that any child receiving government funding should have mandatory sealants on permanent teeth as they emerge -- just as vaccines are mandatory. Oral health is just as important as physical health and the two are directly tied to a higher quality of life.
- Very few orthodontists have Medicaid experience and are willing to work with eligible patients. We feel fortunate to have access to an excellent one who serves many members of our diverse community and whose financial policies put services within reach of many. Our pediatric dentist is also well known as disability-friendly, and her hospital privileges are very helpful. In North Indy we are spoiled for choice and access; families in other parts of the state sometimes have much less choice.
- I realize that I am very fortunate to be able to afford out of pocket dental cleanings. I hope we never have a dental emergency or need cavities filled until he is old enough to be seen by our family dentist. My child gets very anxious when there is a change in health provider. Dental insurance programs need to have flexibility in out of network providers for neuroatypical patients.
- I believe more visits should be provided by Medicaid for preventative care.
- It's hard to brush my son teeth due to all his sensory issues but we take our time

- We have changed dental clinic because sometimes the space in the office is small and it is somewhat uncomfortable with the wheelchair and the instruments of the dentist, you must also wait a lot and that increases your stress levels.
- I went to 1 place they told they can handle my autistic son, he is very nice, he was ok with everything but
 1. They don't have especial equipment (as they promise)
 2. Don't have gas (as they promise)
 3. The doctor never touch him always the assistant. I feel like my son has a infectious disease not autism.
 4. He just said that one of the things they put in his mouth for xrays was disgusting and she said he had behavior problems and he needs to go to a special place

I called several places and they told me he needs to be sedated and he can't so I'm still looking. I ask a lot of people from my Support group and they said that every were it's the same that you need to keep looking until someone wants to take hear you and be patient with your son
- They ALWAYS have masks on even before covid and my child relies on lip reading and has made the office aware of this and they still wear mask.
- Had to drive 60 to 90 miles to a dentist who would see him. Also gets referred to other providers a lot and referral turns into a deadend. We have been trying for over two years now to get a tooth extracted.
- na
- N/A
- the service area is improved
- This is an important topic as dental care is often overlooked by non disabled persons, let alone those with disabilities.
- Calling offices from a list or searching on my own is time consuming. A parent database of providers for various insurances would be helpful.
- It is very difficult to get someone with Medicaid, as their primary insurance, in to a hospital to get dental work done that they need to get anesthesia because the work cannot get done while awake . For example, we had wisdom teeth pulled, cavities filled, teeth cleaned, x rays, and sealants that all had to be done and we had a very hard time getting any hospital to take our daughter to get the work done. We were denied by three different hospitals. I think alot of it had to do with her having Medicaid as her insurance. I would've liked for her to be able to do the work at Riley but because she is an adult they denied doing the work. I felt like they would of been able to be better with dealing with her disability and behavior. We ended up at IU Med Center, which we had a great dentist, who performed the work. I don't think staff was as well equipped to work with the disability and the behavior that goes along with it.
- Community dental clinics are well suited to the needs of seniors
- The parking lot for the community dental office is too far away.
- Excellent and professional dental practice too far from our home.
- Would live to see a “directory” of “friendly” dentist who serve Disabled clients.
- Dentists need more specialized training to deal with different conditions.
- Private dental office bills are a bit high.
- Regular care

- We pay extra for the dentist since they do not bill for medicaid. It is better for our son due to proximity to home, smaller office (less stimulation), very kind hygienist.
- Implement a dental care program to keep your teeth healthy
- It is more useful than anything to cultivate children's good habit of protecting teeth from childhood
- Every time the cost of care is a bit high, it is best to reduce it relatively
- Would rarely brush teeth on her own. I have to put toothpaste on the toothbrush for her daily and check daily that she brushed (by checking the toothbrush)!! Also needs reminded to repeat brushing if not done well. Flossing is repeated reminders.
- Advance Family dentist was great but they no longer accept Medicaid insurance .. we need more trained providers
- Difficulty in chewing and swallowing can make three meals a day a major problem in life. As a result, disability may also lead to malnutrition, tooth decay, periodontal disease or other dental diseases that cause tooth loss, thereby affecting normal chewing and language functions.
- It's better to be gentle
- I'm afraid they won't be treated in time.
- No
- Dental care must be paid attention to every day
- My daughter has autism. If she were to go to a dentist she would need to be fully sedated. She would not cooperate. Unless there was a program that would work with her on a weekly basis and was free bc we do not have the money for multiple visits.
- Let patients stay with their original dentist and not have to change providers due to changes in Obamacare it's hard to tell someone with autism that they cant go see their regular dentist because guardian has to pay out of pocket and cant afford it :(
- Where do disabled adults, over the age of 25, go for dental cleanings and care?
- Our greatest concern is finding an adult or general practice dentist who my daughter is comfortable with and who will accommodate her needs.
- People who are disabled and have great fear of the whole procedure should be enabled to utilize a swaddling mechanism to provide comfort and safety during dental work. It should not be necessary to give a disabled person drugs and or have them undergo general anesthesia just to have their teeth cleaned and checked and work done. I realize that by law this is not acceptable; I am saying the law needs to be changed, then.
- Concerns about needing extra dental care.
- None
- Train more dentists
- none
- none
- No opinion
- No opinion
- none
- You can't buy toothpaste
- No comments
- No comments
- No comments

- Learn more about the patient's actual needs.
- Maintain good oral hygiene
- none
- no
- There is no
- There is no
- NO
- NO
- NA
- Regular care is essential
- There is no
- Keep your teeth clean
- Just very limited choices of providers and options for treatment.
- NO
- NO
- NO
- What can't I think of
- no
- no
- no
- There are too few community health centres
- difficult to find a good provider who accepts medicaid and difficult to coordinate sedated cleaning with other sedated procedures.
- Disability can also lead to malnutrition, dental caries, periodontal disease or other dental diseases resulting in tooth loss, affecting normal chewing and speech function.
- Some severely disabled people are unable to repair their missing teeth due to their lack of self-control.
- under medicare - I believe my son has to go once a year for a physical. Dental cleaning MUST be done as preventative twice a year too.
- none
- It's important to keep your teeth clean
- Dental hygiene is important
- Regular dissemination of knowledge on oral health
- He grinds his teeth & need them restored because of it
- Popularize dental knowledge and maintain oral hygiene
- Worry about dentists can not communicate with the disabled, patience, not careful and other factors
- Medicaid needs to be accepted more places than just these high profit, huge dental factories. You never see the same person twice and all they care about is money. The ace we went put a freaking facemask on her after she had her wisdom teeth out. Unbelievable. She was shaking like crazy, and the oral surgeon goes "oh, she's just cold".
- there are personnel trained to care for people with disabilities, you only have to research and consult to find the dental care staff that meets the needs of the person with disabilities

- The general care has been great. Peds Dent has several special needs patients and works well with them. Specialist (prosthodontics) Was terrible with special needs. To the point we abandoned trying to get help. He told her that he would make her pretty - which immediately implied she was not with 10 deformed teeth.
- I have gotten the impression that they don't think my daughter with Down syndrome should have access to orthodontic care
- Dr. David Painter in Fort Wayne and Auburn is wonderful!!! Not only does he clean my son's teeth (he has spastic Cerebral Palsy), he has done 1 root canal and 8 crowns for me with sedation.
- Too fee orthodontists in Medicaid and CSHCS network

Disabilities and Health Conditions

37. Is the person with a disability deaf, or does he/she have serious difficulty hearing?

Type	Frequency	Percent
Yes	190	34.1%
No	367	65.9%
Total	557	100.0%
Missing	42	

38. Is the person with a disability blind, or does he/she have serious difficulty seeing, even when wearing glasses?

Type	Frequency	Percent
Yes	125	22.5%
No	431	77.5%
Total	556	100.0%
Missing	43	

39. What is the age of the person with a disability you are caring for?

Type	Frequency	Percent
0 – 4 (Less than 5)	5	1.0%
5 – 14	148	28.3%
15 and older	370	70.7%
Total	523	100.0%
Missing	76	

40. Because of a physical, mental, or emotional condition, does the person with a disability have difficulty doing errands alone, such as visiting a doctor's office or shopping?

Type	Frequency	Percent
Yes	176	57.3%
No	131	42.7%
Total	307	100.0%
Missing	92	

41. Does the person with a disability have serious difficulty concentrating, remembering, or making decisions because of a physical, mental, or emotional condition?

Type	Frequency	Percent
Yes	279	50.8%
No	270	49.2%
Total	549	100.0%
Missing	39	

42. Does the person with a disability have serious difficulty walking or climbing stairs?

Type	Frequency	Percent
Yes	223	40.8%
No	323	59.2%
Total	546	100.0%
Missing	42	

43. Does the person with a disability have difficulty dressing or bathing?

Type	Frequency	Percent
Yes	240	43.9%
No	307	56.1%
Total	547	100.0%
Missing	41	

44. Has a doctor, health care provider, teacher, or school official ever told you that the person with a disability has any of the following conditions? (Check **ALL** that apply.)

Type	Frequency	Percent
Speech or language impairment	137	14.0%
Epilepsy or seizures	45	4.6%
Learning disability	136	13.9%
Intellectual disability (formerly known as mental retardation)	82	8.4%
Autism or Autism Spectrum Disorder (ASD)	100	10.2%
Asperger's syndrome	29	3.0%
Cerebral palsy	32	3.3%

Down syndrome	35	3.6%
Developmental disabilities other than learning disability, intellectual disability, autism, Asperger's syndrome, cerebral palsy, or down syndrome	41	4.2%
Traumatic brain injury	25	2.5%
Spinal cord injury	27	2.8%
Muscular dystrophy	23	2.3%
Attention Deficit Disorder (ADD) or Attention Deficit Hyperactive Disorder (ADHD)	47	4.8%
Asthma	31	3.2%
Other respiratory disease (e.g., lung cancer, chronic obstructive pulmonary disease [COPD], etc.)	14	1.4%
Angina or coronary heart disease	13	1.3%
Depressive disorder (including depression, major/clinical depression, dysthymia, or minor depression)	30	3.1%
Heart attack (myocardial infarction)	10	1.0%
High blood pressure (hypertension)	26	2.7%
Congenital heart disease	28	2.9%
Diabetes [not including pre-diabetes or borderline diabetes]	19	1.9%
Arthritis	20	2.0%
Tourette syndrome	18	1.8%
Blood disorders (such as Sickle cell disease, thalassemia, or hemophilia)	13	1.3%
Total	981	100.0%
Missing	58	

Demographic Information: Individuals with a Disability

45. What is your relationship to the person with a disability you are caring for?

Type	Frequency	Percent
Parent	264	59.6%
Grandparent	9	2.0%
Sibling	81	18.3%
Other relative	55	12.4%
Spouse or intimate partner	34	7.7%
Other [specified below]	0	0%
Total	443	100.0%
Missing	156	

46. In what type of setting does **the person with a disability** live?

Type	Frequency	Percent
Their own home or apartment	271	48.8%
Parent's or relative's home	197	35.5%
Community-based group residence (group home, community-based intermediate care facilities, or agency-operated apartment-type setting)	28	5.0%
Nursing home or other long-term care setting	59	10.6%
Other	0	0%
Total	555	100.0%
Missing	44	

47. Is the person with a disability of Hispanic, Latino/a/x, or Spanish origin?

Type	Frequency	Percent
Yes	76	13.8%
No	475	86.2%
Total	551	100.0%
Missing	48	

48. Which one or more of the following would you say is the race of the person with a disability? (Check **ALL** that apply.)

Type	Frequency	Percent
White	327	57.0%
Black or African American	97	16.9%
Asian	63	11.0%
American Indian or Alaska Native	79	13.8%
Native Hawaiian or Pacific Islander	3	0.5%
Other [specified below]	5	0.9%
Total	574	100.0%
Missing	41	
<i>Other:</i>		
<ul style="list-style-type: none"> • Mix • Caribbean • Amerasian • Black/Caucasian 		

Type	Frequency	Percent
Non-Hispanic White	295	51.8%
Non-Hispanic Black	80	14.1%
Non-Hispanic Asian	52	9.1%
Non-Hispanic American Indian or Alaska Native	61	10.7%

Non-Hispanic Native Hawaiian or Pacific Islander	2	0.4%
Non-Hispanic Other	3	0.5%
Hispanic/Latino/a/x or Spanish Origin	76	13.4%
Total	569	100.0%

49. What gender does the person with a disability identify as?

Type	Frequency	Percent
Male	366	65.6%
Female	192	34.4%
Other	0	0%
Total	558	100.0%
Missing	41	

Demographic Information: Family Caregiver

50. Are you of Hispanic, Latino/a/x, or Spanish origin?

Type	Frequency	Percent
Yes	71	12.7%
No	486	87.3%
Total	557	100.0%
Missing	42	

51. Which one or more of the following would you say is your race? (Check **ALL** that apply.)

Type	Frequency	Percent
White	333	58.8%
Black or African American	87	15.4%
Asian	62	11.0%
American Indian or Alaska Native	81	14.3%
Native Hawaiian or Pacific Islander	1	0.2%
Other [specified below]	2	0.4%
Total	566	100.0%
Missing	43	
<i>Other:</i>		
<ul style="list-style-type: none"> • Mix • Caribbean 		

Type	Frequency	Percent
Non-Hispanic White	295	51.8%
Non-Hispanic Black	80	14.1%
Non-Hispanic Asian	52	9.1%
Non-Hispanic American Indian or Alaska Native	61	10.7%
Non-Hispanic Native Hawaiian or Pacific Islander	2	0.4%
Non-Hispanic Other	3	0.5%
Hispanic/Latino/a/x or Spanish Origin	76	13.4%
Total	569	100.0%

52. What is the highest grade or level of school you have completed?

Type	Frequency	Percent
Some high school or less (No high school diploma)	29	5.2%
High school graduate or GED completed	81	14.6%
Some college or technical school	211	37.9%
Bachelor's degree or higher	235	42.3%
Total	556	100.0%
Missing	43	

53. What gender do you identify as...?

Type	Frequency	Percent
Male	275	49.5%
Female	281	50.5%
Other	0	0%
Total	556	100.0%
Missing	43	

54. What is your marital status?

Type	Frequency	Percent
Married	433	77.9%
Not married, but living with a partner	2	0.4%
Never married	16	2.9%
Divorced	4	0.7%
Separated	16	2.9%
Widowed	85	15.3%
Total	556	100.0%
Missing	43	

55. Which of the following is your best estimate of the total combined income of your household in 2019, including income from all sources such as wages, salaries, Social Security or retirement benefits, and so forth?

Type	Frequency	Percent
Less than \$15,000	4	0.7%
\$15,000 to less than \$25,000	29	5.3%
\$25,000 to less than \$35,000	80	14.5%
\$35,000 to less than \$50,000	195	35.5%
\$50,000 to less than \$75,000	152	27.6%
\$75,000 or more	90	16.4%
Total	550	100.0%
Missing	49	

56. Which of the following best describes your current employment status?

Type	Frequency	Percent
Employed full-time for wages	325	58.5%
Employed part-time for wages	104	18.7%
Self-employed	64	11.5%
Out of work	25	4.5%
A homemaker	25	4.5%
A student	3	0.5%
Retired	7	1.3%
Other [specified below]	3	0.5%
Total	556	100.0%
Missing	43	
<i>Other:</i>		
<ul style="list-style-type: none"> • Currently not working to care for my daughter during C19. No other reasonable options exist. • I'm not working • Supplemental worker, full time mom and full-time student 		