Overall Wellness Starts with a Healthy Smile

NC START West
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Background

Research has shown that good oral care is an essential part of good overall health, yet it is an often overlooked aspect of daily hygiene for individuals with intellectual and developmental disabilities (IDD). People with IDD have a higher rate of medical problems and a high rate of unmet medical needs, including poor dental health. There is a higher prevalence of untreated caries, periodontal disease, malocclusion, oral malformations, trauma and injury to the mouth in this population. Individual vulnerabilities that impact dental care include limited ability to understand the importance of good oral care, dislike of daily dental hygiene practices, communication difficulties that prevent accurate self-reports of pain and discomfort, and fear of dental procedures. This becomes a greater challenge for people with sensory integration difficulties and/or comorbid mental health challenges.

Oral/dental pain often goes unrecognized by caregivers and untreated dental problems lead to pain and discomfort, a negative impact on quality of life, and other medical issues. Poor oral health has been linked to cardiovascular and respiratory diseases, diabetes, and gastrointestinal problems. Pain and discomfort can lower the threshold for behavioral and emotional dysregulation, which can then be misattributed to psychiatric and neurodevelopmental disorders. In one analysis of health problems in a psychiatric inpatient sample of people with comorbid IDD and mental health challenges, dental problems were reported in 15% of the individuals.

Systems barriers to good dental care include the need for sedation, cost, locating dentists who are comfortable working with people with complex vulnerabilities, who accept Medicaid funding, are accepting new patients, and accessibility issues related to the geographic location. The time expenditure to adequately support someone with IDD and co-occurring behavioral health challenges is also a factor in gaining access to a dentist as a new patient.

Anecdotally, we have observed a number of individuals whose behavioral health challenges have subsided following the completion of needed dental procedures. These observations primarily involved individuals living with families. Daily oral/dental hygiene practices and regular dentistry can be particularly challenging for families, who often lack training and additional support for ensuring regular oral care as well as limited accessibility to dental providers. In a series of surveys conducted in Israel it was found that better dental condition was generally found for individuals residing in residential care centers as compared to those living in home-based settings. We hypothesized that individuals living in group home settings are likely to have better dental care than those in family type settings because of the challenges associated with behavioral and sensory vulnerabilities, necessitating additional support.

Method

A brief survey was created to identify dental needs and barriers for people with IDD and co-occurring mental health challenges. Using this tool, START Coordinators interviewed primary caregivers in group home and family settings. Results were tabulated and a qualitative analysis was conducted to observe for trends related to individual vulnerabilities and system variables that impact good oral/dental health.

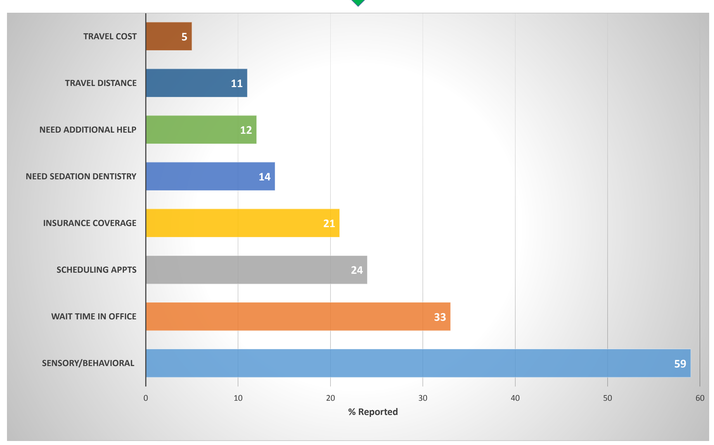
START Information and Reporting System (SIRS) data was used to obtain demographic information. At the time of this survey, NC START West actively supported 146 individuals. Surveys were obtained for 107 individuals, 73% of the active caseload. Of those surveyed, 98% have Medicaid as the payment source for dental needs, which limits what dental services are provided. 78% live in family type settings, the majority in their family homes with parents as respondents (n=53). Other family settings include Alternative Family Living (n=29) and Therapeutic Foster Care (n=1).

Demographic Info	Participants N = 107
Children & Transitional Youth (8-20)	55 (51%)
Adults (21-78)	52 (48%)
Males	63 (59%)
Females	44 (41%)
Medicaid	105 (98%)
Living in family type setting	83 (78%)
Group living setting	24 (22%)
Persons with ASD	50 (47%)
Persons with 1 MH condition	20 (19%)
Persons with 2 or more MH conditions	87 (81%)

Survey Questions

- Does the person you support have a dentist? If yes, how far do you travel for appointments?
- When was this person's last dental appointment?
- How often does this person visit the dentist?
- Does this person use a PRN medication to help stay calm during dental appointments?
- Is sedation necessary?
- Are there existing dental concerns? If yes, what are those concerns?
- What makes a dental visit challenging? (check all that apply)

What makes a dental visit challenging?



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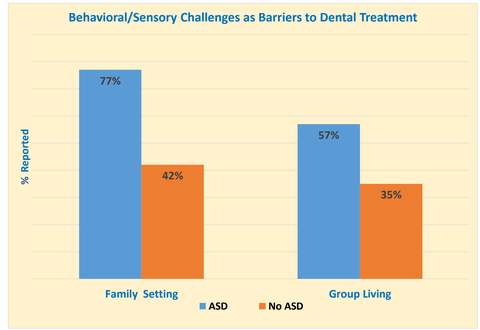
Findings

Most respondents cited multiple reasons that contribute to challenges obtaining dental care. The most frequent issue that makes dental visits difficult is the presence of behavioral or sensory challenges, as reported by 59% of the respondents. Survey results indicate that 35% of all respondents have identified dental issues. Of this group, 66% have behavioral or sensory challenges related to dental visits.

Of note is the higher frequency of behavioral/ sensory challenges reported by caregivers in family settings as compared to staff in group living settings. This finding is most apparent for persons with ASD.



Systems barriers to receiving good dental prevention and treatment were identified as long wait times in office (33%), difficulty scheduling appointments (24%), difficulty finding dentists who accept Medicaid/limited coverage for procedures (21%), difficulty finding dental practices that offer sedation (14%), the need for additional help while at the office or in the parking lot (12%), travel time to the dentist (11%), and the cost of travel to appointments (5%). 23% of the respondents reported no challenges (16 families and 8 group living).

It was reported that 47% of the surveyed group had visited the dentist in the previous 6 months, however, 21% currently do not have a dentist. 29% receive a PRN medication to help them remain calm during dental appointments. Gastroesophageal reflux (GERD) is a recognized cause of dental decay. No difference was found in the frequency of GERD between groups of individuals with reported dental issues as compared to those with none identified.

Summary

The data gathered from this survey will be used to advocate for access to timely and appropriate dental care, in an effort to address both individual vulnerabilities and systems barriers and to enhance wellbeing. Specialized training for dental professionals is needed to increase capacity for good dental health for persons with IDD and/or mental health conditions. The availability of dental clinics accepting Medicaid and offering sedation is a need across our region.

Strategies to address dental anxiety, and training for caregivers in effective ways to provide preventative oral hygiene are high priorities. It is recommended that families and teams pursue occupational therapy and applied behavioral therapy to evaluate and address sensory needs and teach desensitization techniques. START Therapeutic Coaching can support families in providing oral sensitivity tools, social stories and visual strategies to promote preventative dental care. START can also help teams find helpful tools and protocols on a variety of online sites.

NCDHHS developed a dental health training program that was made available in December 2021. The *Oral Health Training Program for Adults with Intellectual and Developmental Disabilities (I/DD)* program targets care providers of adults living in Intermediate Care Facilities and group homes in an attempt to make a positive impact in supporting their dental health. It would be beneficial for NCDHHS to make this program available to families and family-type residential caregivers, with modifications to include strategies for children.

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