

ADDRESSING BARRIERS TO ORAL HEALTH AND HEALTH CARE FOR ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES IN NEW JERSEY, FIVE-YEAR PLAN

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Table of Contents

Background	3
Project Overview.....	4
Challenges to Maintaining Oral Health	5
Barriers to Daily Oral Care	5
Barriers to Accessing Professional Dental Care	6
Barriers at the Point of the Dental Encounter: Families’ Perspectives.....	7
Stakeholder Feedback.....	9
A. Policy Gaps and Opportunities to Improve Oral Health and Healthcare for People with IDD	11
A.1 Statewide Dental Plan.....	11
A.1 Recommendation	11
A.2 New Jersey Medicaid Coverage for People with IDD	11
A.2 Recommendation	13
A.3 Limitations of Medicaid Coverage	13
A.3 Recommendation	14
A.4 Lack of Data on Unmet Dental Needs.....	14
A.4 Recommendation	14
A.5 General Anesthesia: Data Analysis	15
A.5 Recommendation	15
A.6 General Anesthesia: Hospitals’ Role	15
A.6 Recommendation	16
A.7 Community Water Fluoridation.....	16
A.7 Recommendation	17
A.8 Partnering with Allies on Shared Policy Priorities	17
A.8 Recommendation	18
B. Training for Oral, Medical, and Helping Professionals to Care for People With IDD.....	19
B.1 Behavior Guidance to Reduce Need for Sedation	20
B.1 Recommendation.....	20
B.2 Expanding the Evidence Base of Best Practices for Behavioral Guidance	20
B.2 Recommendation.....	21
B.3 Loan Repayment Programs for Dentists who Treat People With IDD	21
B.3a Recommendation.....	22

Addressing Barriers to Oral Health and Health Care for Adults with Intellectual and Developmental Disabilities in New Jersey, Five-Year Plan

B.3b Recommendation 22

B.4 Oral Health Training for Direct Support Professionals (DSPs) 22

 B.4 Recommendation..... 22

B.5 Integrating Oral Health with Primary Medical Care 22

 B.5 Recommendation: 23

B.6 Transition to Adult Dental Care 23

 B.6 Recommendation..... 24

C. Community Awareness of the Importance of Oral Health and Access to Oral Health Services 25

 C.1 Trusted Sources of Information 25

 C.1 Recommendation..... 26

 C.2 Finding Dentists 26

 C.2 Recommendation..... 28

Conclusion..... 28

 Oral Health Task Force 28

 Recommendation..... 28

Report Authors..... 29

Special Thank You 29

Appendices:

- **Appendix A: Attendees at Oral Health Summit, October 16, 2019**
- **Appendix B: Attendees at Managed Care Organization Meeting, January 31, 2020**
- **Appendix C: Instructions and Questions for Small Group Discussions During October Summit**
- **Appendix D: Discussion Questions for January 31 Managed Care Organization Meeting**
- **Appendix E: Recommendations for Administering a Survey of Dental Providers in New Jersey**
- **Appendix F: Descriptions of Organizations Listed in Report**

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Background

In September 2018, the New Jersey Council on Developmental Disabilities (NJCDD) awarded Columbia University College of Dental Medicine and the National Center for Children in Poverty (NCCP) an 18-month grant to identify barriers to oral health and health care for people with intellectual and developmental disabilities (IDD) and to develop a five-year advocacy plan designed to improve oral health and health care for people with IDD in New Jersey. The project focuses on oral health care delivery systems, accessing oral health care, and prevention of oral health issues among adults with IDD.

IDD is defined as a disability that begins during childhood, is lifelong, and substantially limits an individual's functioning in several major life activities (e.g., self-care, learning, mobility, communication, self-direction, economic self-sufficiency, and the ability to live independently). Examples of diagnoses associated with IDD include Down Syndrome, Autism Spectrum Disorders, and some presentations of cerebral palsy.

NJCDD is a federal and state-funded organization in New Jersey, whose members include people with IDD and immediate family members and guardians of people with IDD. NJCDD reviews service systems for people with IDD and advises policymakers on the best ways to modify those systems to better serve the population. NJCDD also provides a platform for individuals, family members, advocates, and public and private agencies to develop coordinated advocacy to advance the rights and opportunities of New Jersey residents with IDD and improve their quality of life.

This project was inspired by NJCDD member concerns about accessing comprehensive oral health care for family members with IDD or for themselves. The research literature supports their concerns with evidence of large disparities in oral health status and healthcare access and utilization for people with IDD. People with IDD are more likely to have poorer oral hygiene, increased prevalence of periodontal disease, higher rates of edentulism (i.e., tooth loss), and increased untreated dental caries (i.e., cavities) than the general population.^{1,2,3} Poor oral health is linked to a number of health conditions, including diabetes, hypertension, and other cardiovascular, endocrine, and respiratory diseases.⁴ Oral health is critical to overall well-being and wellness; poor oral health can negatively affect quality of life. Oral pain can interfere with the functions of daily living, including eating, which, in turn, impacts diet and nutrition, sleeping, and conversing. Oral disease and dysfunction result in low self-esteem, alter speech, and affect social interactions, appearance, and behavior—all of which are vitally important for

¹ Anders, P.L. & Davis, E.L. (2010). Oral health of patients with intellectual disabilities: A systematic review. *Spec Care Dentist* 30(3): 110-117.

² Buda, L.V. (2016). Ensuring maintenance of oral hygiene in persons with special needs. *Dent Clin N Am* 60: 593-604.

³ Morgan, JP, Minihan, PM, Stark PC, Finkelman, MD, Yantsides, KE, Park, A, Nobles, CJ, Tao, W, & Must, A. (2012). The oral health status of 4,732 adults with intellectual and developmental disabilities. *JADA* 143(8): 838-846.

⁴ Rautemaa, R., Lauhio, A., Cullinan, M.P., & G.J. Seymour. (2007). Oral infections and systemic disease—An emerging problem in medicine. *Clinical Microbiology and Infection* 13(11): 1041-1047.

people living with IDD.^{5,6} Since a significant proportion of people living with IDD may not be able to verbalize how disease impacts them, regular access to dental services and delivery of comprehensive oral health services are vital for people with IDD. Efforts to prevent oral diseases in this population would decrease the likelihood of serious dental and oral health sequelae, improve treatment efficiency, reduce the cost of treatment, and would improve the overall quality of life for people with IDD and their families.

Project Overview

Data sources

The data collection and research methods included:

1. focus groups and interviews with 16 caregivers of people with IDD
2. focus groups and conversations with 16 people with IDD
3. a review of the research literature
4. a survey of dentists in New Jersey
5. key informant interviews with 49 policymakers, insurance representatives, advocates, medical professionals, service providers, and researchers who are involved in providing dental care to people with IDD in New Jersey and nationally

As part of the project, the team also created a directory of dentists who serve patients with IDD, which combines responses from the survey of dentists and multiple online dental directories. The directory will be released to NJCDD in 2020.

Project Focus: Adults With IDD

Initial field research for this project suggested that although children with IDD face difficulties accessing adequate dental care, adults with IDD typically face additional challenges in accessing and utilizing dental care.⁷ Unlike other dental specialties, pediatric dentists receive training in treating and managing patients with special needs. Furthermore, children are more likely than adults to be on their parents' private dental insurance, and finally, several organizations in New Jersey already focus on improving access to oral health care for children with IDD. This work sought to learn from and complement these efforts in order to provide a roadmap to improve oral health for adults with IDD.

⁵ Rapalo, D.M., Davis, J.L., Burtner, P., & Bouldin, E.D. (2010). Cost as a barrier to dental care among people with disabilities: A report from the Florida behavioral risk factor surveillance system. *Spec Care Dentist* 30(4): 133-139.

⁶ U.S. Department of Health and Human Services. (2000). *Oral health in America: A report of the Surgeon General*. Rockville, MD: U.S. Department of Health and Human Services, National Institute of Dental and Craniofacial Research, National Institutes of Health.

⁷ Stiefel, D. J. (2002). Dental care considerations for disabled adults. *Spec Care Dentist* 22(3):26S-39S; Chi, D.L. (2015). Medical care transition planning and dental care use for youth with special health care needs during the transition from adolescence to young adulthood: a preliminary explanatory model. *Matern Chil Health J* 18(4):778-788.

We focused on the nearly 25,000 adults who are eligible to receive services through the Division of Developmental Disabilities (DDD) in New Jersey.⁸ To access DDD services, an adult must be a NJ resident, 21 or older, have a documented IDD, and be a U.S. citizen or legal permanent resident. DDD services are provided for people who live in group homes, supportive housing, state-run developmental centers, or with their families.⁹

Adults who receive DDD services must also qualify for Medicaid, thus the project focused on adults with IDD who are eligible for Medicaid. Adults with IDD may also have private insurance, may have family members who pay out of pocket for dental care, or may be dual eligible for Medicare. While Medicaid, as a state-run program in New Jersey, provides dental benefits for adults, federally run Medicare does not currently contain a dental benefit.

Challenges to Maintaining Oral Health

The primary data (interviews with family caregivers, self-advocates, and key informants and the survey of dentists) and review of the research literature suggested multiple factors that impact the oral health of adults with IDD.

Families and people with IDD described both barriers to daily oral care and to accessing professional dental care. While regular professional dental care is important for the prevention and management of dental disease and dysfunction, daily oral care— including tooth brushing, flossing and rinsing—can prevent dental diseases, reduce disease severity, and mitigate many of the quality of life and health declines associated with dental diseases.

Barriers to Daily Oral Care

- **The severity and type of an individual’s disability:** An individual’s functional and health needs can affect their susceptibility to oral disease and their adherence to routine daily oral care (e.g., tooth brushing).¹⁰ Some caregivers reported difficulty ensuring that their family member with IDD brushed adequately because of sensitivity to toothbrushes or other cleaning tools in the mouth.
- **Family support:** An individual’s level of family support can influence the quality of preventative and daily oral care practices at home and the receipt of regular dental visits. Whether an adult with IDD has an involved family caregiver can also influence their ability to communicate oral and dental needs with oral health professionals or advocate for themselves.
- **Place of residence:** People with IDD who live with their families may have poorer access to professional dental cleanings than those who live in group homes or state-run developmental centers. Staff at group homes and state-run developmental centers have

⁸ “About DDD.” Division of Developmental Disabilities, Department of Human Services. Retrieved from <https://www.nj.gov/humanservices/ddd/home/about/>.

⁹ “Where to Apply for Services: Eligibility for Services.” Division of Developmental Disabilities, Department of Human Services. Retrieved from <https://www.nj.gov/humanservices/ddd/services/apply/>.

¹⁰ Daily oral care includes daily routine oral care such as tooth brushing, flossing, denture care and cleaning of the oral soft tissues.

access to dentists able to treat patients with IDD and are required to take individuals to their dental appointments. Family caregivers may have more capacity to support daily oral health care (e.g., tooth brushing) than aides at a group home or center, who may not receive any training on daily oral care.

“When [my brother] first moved into the group home, he started having cavities, and then our family instructed [group home] staff to be more hands-on when he brushes. The staff were very responsive, and he started having fewer cavities.” – New Jersey caregiver of her adult brother with IDD

Barriers to Accessing Professional Dental Care

While the Commission on Dental Accreditation (CODA), which sets the national minimal competency for dental education, indicates that dental students must have worked with and treated a person with special needs, special needs are broadly defined to include not only people with IDD, but also older adults and people with medical comorbidities. As a result, dentists are not specifically trained in treating and managing patients with IDD.

- Lack of expertise in caring for patients with IDD: According to the research literature, many dentists do not treat patients with IDD, particularly adults, because they feel unprepared or inexperienced in treating adults with IDD.^{11,12} Interviews with families conducted for this project confirmed that they had difficulty finding dentists who were trained to treat people with IDD. People who live in less densely populated areas of New Jersey, like southern New Jersey, may have even fewer choices for dentists.
- Lack of providers who accept Medicaid: Most adults with IDD receive dental coverage through Medicaid.¹³ Families reported particular difficulty in finding providers who accept Medicaid *and* are able to provide care for people with IDD. Family members reported paying out of pocket for dental care because the wait time to see a dentist who participates in Medicaid was too long, an appropriate dentist was too far away, or a dentist who could provide high-quality care did not accept Medicaid. In other cases, some people with IDD reported that they were unable to receive some types of dental procedures because they are not covered by Medicaid and they cannot afford to pay for them out of pocket.

“I wish more dentists would accept Medicaid. I got all these offers from area dentists but maybe some of them don’t know how to deal with people with special needs. I think there is some prejudice out there too they don’t want their practice to cater to them.” – New Jersey caregiver with 34-year old son with IDD and physical disabilities.

¹¹ Bayarsikhan, Z., Cruz, S., Neff, J., & Chi, D. (2015). Transitioning from pediatric care to adult care for adolescents with special health care needs: Dentist perspectives (part 2). *Pediatr Dent*. 37(5):447-451.

¹² Davis, M.J. (2009). Issues in access to oral health care for special care patients. *Dent Clin N Am* 53: 169-181.

¹³ Overview of health insurance for people with intellectual disabilities. Centers for Disease Control and Prevention. Retrieved from <https://ihc.brightspotcdn.com/83/b1/2d8f4c8c40dcadd5113733e7dfd0/health-insurance-people-with-id-2019may20.pdf>.

- Lack of awareness about oral issues among non-dental health providers: Key informants reported that medical doctors are often unaware of the behavioral issues that can manifest in non-verbal patients experiencing oral pain, and medical doctors did not routinely “look in the mouth” of patients with IDD. This sometimes led to overmedication for behavioral issues that could be addressed through reducing oral pain or providing appropriate dental care.

Dentists are not routinely trained to provide services in operating rooms (OR) and receiving OR privileges can be difficult for dentists. However, general anesthesia provided in an OR may be required to provide oral health care to some adults with IDD if they are unable to cooperate with oral health care procedures or if they require airway protection during dental care.

- Long waits for general anesthesia: People with IDD experience particularly long waits if they require general anesthesia for dental care; wait times for dental care under general anesthesia in a hospital OR can be as long as two years. In other cases, caregivers pay thousands of dollars out of pocket for general anesthesia because of difficulties associated with getting insurance to cover general anesthesia services.
- Lack of coverage for sedation dentistry: Some caregivers seek sedation dentistry (a “lighter sleep” than general anesthesia) for their family members with IDD who face behavioral and emotional challenges in receiving dental care;¹⁴ however, family members reported that they typically had to pay out of pocket for this service.

Barriers at the Point of the Dental Encounter: Families’ Perspectives

- Dental Fear and Anxiety: Some caregivers experience difficulties in getting their family member with IDD to the dentist because of behavioral or mobility issues. Some people with IDD fear dentists and dental visits. This fear can be exacerbated by previous bad experiences and/or by heightened sensitivity to dental procedures (e.g., vulnerable positioning, bright lighting, strong scents, unfamiliar or unpleasant sounds, etc.). Some people with IDD reported discomfort seeing dentists who they perceive as treating them disrespectfully or who do not explain issues clearly to them.

“First [I’d like a dentist] who treats [my son] like a person with kindness and compassion. Also, someone who isn’t afraid of him and comes up with innovative ways to examine him. Lastly, they do not judge us for his behavior and realize and understand it isn’t our fault and

¹⁴ For the purposes of this report, we use sedation dentistry to mean sedation that does include unconscious sedation or general anesthesia. General anesthesia faces much stricter regulations and requirements than other forms of sedation, including that only an anesthesiologist can administer general anesthesia, and three trained dental personnel, including the doctor, are required to be in the room, with one constantly documenting and monitoring vital signs. See “Sedation Dentistry and Insurance Reimbursement,” (14 November 2016). Retrieved from <https://www.autismnj.org/article/sedation-dentistry-and-insurance-reimbursement/>

no lectures on autism unless it's directly related to helping his oral hygiene.” – New Jersey caregiver of adult son with IDD

- Long waiting room times: Informants report that long waiting room times to see a dentist at a clinic or hospital exacerbate anxiety about going to the dentist, especially when other patients and their families in the waiting room are not understanding about their needs.

“I would like them to be fast, no waiting too long. The longer they wait the more agitated they get. Just to have everything at hand, and do it quick and fast...it's hard when you have to wait in the waiting room and then you have to wait in the exam room, and it's important to have everything ready.” – New Jersey caregiver of child with Autism Spectrum Disorder

- Lack of physical accessibility or sensory-friendly environments: Many dental clinics do not have wide hallways or elevators or the ability to treat patients in their wheelchairs.¹⁵ Caregivers also reported that the waiting room environments (e.g., bright lights) exacerbate sensory difficulties for some patients with IDD, resulting in behavioral issues.

“What would have been better if the entry point was specifically designed for people with IDD, with low stimulation. We had to sit there and wait for like an hour with all the other people. The biggest barrier is the waiting room and lumping us all together with the general population. It's difficult. I am 100% for inclusion, but when it comes to dental and medical care, it should be designed specifically for their needs. My daughter is nonverbal.” – New Jersey caregiver of adult daughter with severe IDD

- Lack of trained dental office staff: Families reported feeling uncomfortable or anxious in some dentists' offices because the front office staff were not trained and/or comfortable working with patients with IDD.

“It would help if the receptionists really understood autism and realized that when we call with recommendations prior to the examination that they take us seriously and relay the information either to the assistant or the doctor. Prior planning makes the visit go much smoother. We don't usually deal with a hygienist but they should also be compassionate, knowledgeable about autism and not afraid to treat people with it. If their dentist is willing to treat kids like ours than the hygienists should have special training too.” – New Jersey caregiver of 18-year-old son with IDD

¹⁵ Rouleau, T., Harrington, A., Brennan, M., Hammond, F., Hirsch, M., Nussbaum, M., & Bockenek, W. (2011). Receipt of dental care and barriers encountered by persons with disabilities. *Spec Care Dentist* 31(2): 63-67.

Stakeholder Feedback

The research culminated in two stakeholder meetings organized by the project team:

(1) a one-day Oral Health summit in October 2019 that brought together 45 stakeholder and leaders within the oral health community, the broader medical community, the public health sector, and social service agencies (the attendee list is in Appendix A) and (2) a half-day meeting in January 2020 to discuss oral health for adults with IDD with all five of New Jersey's Medicaid Managed Care Organizations (MCOs), which contract with the state Medicaid office to provide dental benefits to adults with Medicaid coverage, including those with IDD. The state agencies that oversee Medicaid and services for adults with IDD also attended (i.e., NJ Division for Developmental Disabilities, the NJ Division of Medical Assistance and Health Services, the NJ Department of Human Services, and NJ's state dental director) (see Appendix B for the attendee list).

The goal of both these meetings was to gather feedback from key stakeholders and experts about prioritizing advocacy activities that would lead to improved oral health and health care for people with IDD. At the October summit, the project team presented their findings about barriers to oral health culled from the focus groups, literature review, survey of dentists, and key informant interviews. The project team identified potential foci for advocacy within state and federal policy, training of the oral health workforce, and community education on oral health (see Appendix C for the list of questions posed to the summit participants). The summit attendees discussed specific issue areas within small groups, then discussed each issue area as a large group, and each attendee voted for the advocacy activities within each issue area that they felt should be prioritized to reduce barriers to oral health for adults with IDD. The project team reviewed and analyzed the notes from the small group breakout sessions and the votes of the stakeholders to inform the advocacy goals presented in this report.

The January meeting focused more narrowly on issues related to Medicaid and access to oral health care. Prior to the January meeting, the project team conducted additional interviews with key informants with expertise on NJ Medicaid dental coverage to inform the questions to be discussed at the meeting. These questions are provided in Appendix D. The project team took notes during the group discussion and reviewed and analyzed these notes to inform the advocacy plan.

The advocacy activities fall into three broad categories, which include:

- (A) Policy Gaps and Opportunities to Improve Oral Health and Health Care for People with IDD. (Policy is broadly defined, going beyond state or federal policy, to include administrative rules and procedures under NJ Medicaid and other government agencies as well as other state professional organizations and associations).
- (B) Training for Oral, Medical, and Helping Professionals to Care for People With IDD
- (C) Community Awareness of the Importance of Oral Health and Access to Oral Health Services

Addressing Barriers to Oral Health and Health Care for Adults with Intellectual and Developmental Disabilities in New Jersey, Five-Year Plan

The remainder of the report briefly describes specific issues within each of these three broad categories. Each issue is followed by a recommendation for advocacy or action to address the issues.

A. Policy Gaps and Opportunities to Improve Oral Health and Healthcare for People with IDD

A.1 Statewide Dental Plan

New Jersey is making strides toward better oral health for all New Jerseyans and people with IDD in particular. In July 2019, the New Jersey Department of Health (DOH) announced the hiring of a state dental director for the first time in over 30 years, Dr. Darwin Hayes. Dr. Hayes will “oversee dental services and programs for New Jersey residents,” and he will work with the DOH to “expand oral health initiatives to address [New Jersey’s] most vulnerable populations.”¹⁶ In his first year, the dental director will develop and oversee an Oral Health Plan for New Jersey. Dr. Hayes has already been engaged with the IDD community. He participated in both the October summit and the January 2020 stakeholder meetings for this project and has met with IDD advocates, such as the Arc of Camden to discuss “increasing availability and accessibility of dental services for people with IDD.”¹⁷

A.1 Recommendation

NJCDD, and other IDD advocacy groups, should continue to engage with Dr. Hayes in order to determine the best method for participating in the development of the statewide plan to ensure the needs of people with IDD are well-represented in the plan.

A.2 New Jersey Medicaid Coverage for People with IDD

New Jersey Medicaid, which is administered through five managed care organizations, offers more comprehensive dental services for adults than most other states. All state Medicaid programs are required to offer dental benefits to children under age 21 who receive Medicaid, but states are not federally mandated to provide Medicaid dental benefits to adults. New Jersey, (along with 16 other states and D.C.) offers what is considered an “extensive” dental benefits package for adults covered by Medicaid. Comparatively, three states offer *no* Medicaid dental services for adults, 11 states only offer *emergency* dental services for adults, and 16 additional states offer *only limited* dental benefits for adults on Medicaid.¹⁸

The Health Policy Institute (HPI) of the American Dental Association states that “numerous studies illustrate a statistically significant positive relationship between Medicaid reimbursement rates and...dentist participation in Medicaid.”¹⁹ However, among the states that

¹⁶ New Jersey Department of Health. (8 Jul 2019). New Jersey Department of Health names new state dental director. Retrieved from <https://www.nj.gov/health/news/2019/approved/20190708a.shtml>.

¹⁷ November 13, 2019 Twitter post by the Arc of Camden, <https://twitter.com/arccamdencounty?lang=en>

¹⁸ Cleveland Hearing and Speech Center. (2019). Medicaid adult dental benefits: An overview. Retrieved from https://www.chcs.org/media/Adult-Oral-Health-Fact-Sheet_091519.pdf.

¹⁹ Gupta, N., Yarbrough, C., Vujicic, M., Blatz, A., & Harrison, B. (April 2017). Medicaid fee-for-service reimbursement rates for child and adult dental care services for all states, 2016. Health Policy Institute, American

provide extensive dental coverage for adults through Medicaid, New Jersey's reimbursement rate is the lowest. According to the most recent data available, New Jersey Medicaid reimbursed dentists at 16.5 percent of the fees that dentists regularly charge for adult dental care (comparatively, the next lowest reimbursement rates for states with managed care programs were Oregon's at 29.4 percent and New York's at 34 percent), and at 21.6 percent of the rates of private insurers (the next two lowest states were Oregon at 33.2 percent and Ohio at 45.7 percent).

According to the New Jersey Medicaid Managed Care Organization (MCO) contract, "[m]embers with developmental disabilities or medical or behavioral health conditions that limit their tolerance for dental services" receive expanded dental coverage. This expanded coverage includes more frequent cleanings and fluoride treatments for adults, coverage for a non-standard specialized toothbrush, and the provision of fixed and removable dental prosthetic devices (e.g., dentures and bridgework) as medically necessary. NJ Medicaid also offers a code and reimburses providers for spending additional time with special needs patients during initial and follow-up dental visits (i.e., allows for an additional 30 minutes per visit in a dental office and up to 60 additional minutes in a hospital dental clinic). This provision could potentially be used to further support the behavioral and treatment needs of people with IDD.²⁰

Given the expanded dental coverage for adults with IDD in New Jersey, the challenge of finding dentists who treat people with IDD and also participate in Medicaid likely reflects factors beyond the *average* low reimbursement rates in New Jersey. One, the project research revealed that many dentists (and families) are unaware of the additional Medicaid dental benefits for people with IDD. Two, dentists and participants in the October 2019 and January 2020 meetings suggested that some dentists who want to treat people with IDD are reluctant to participate in Medicaid because they would have to treat all patients with Medicaid who are covered by the lower reimbursement rates. This suggests that to increase the number of Medicaid providers who treat people with IDD, it will be important to train providers who already participate in Medicaid about treatment of people with IDD. Three, some important services for people with IDD are not covered by Medicaid. In particular, dentists cannot charge for multiple desensitization visits, which are often necessary to allow a person with IDD to become comfortable with a particular dentist or office.^{21 22}

Dental Association. Retrieved from

https://www.ada.org/~media/ADA/Science%20and%20Research/HPI/Files/HPIBrief_0417_1.pdf.

²⁰ Contract between State of New Jersey Department of Human Services, Division of Medical Assistance and Health Services and Medicaid Contractor. Retrieved from <https://www.state.nj.us/humanservices/dmahs/info/resources/care/hmo-contract.pdf>.

²¹ Desensitization is an intervention consisting of gradual exposure to anxiety-/fear-provoking stimuli using relaxation strategies at each step of the process as an incompatible behavior response to the anxiety/fear.

²² Schwartz, S. Basic Techniques for Management of the Infant and Toddler Dental Patient Desensitization. Dentalcare.com Retrieved from <https://www.dentalcare.com/en-us/professional-education/ce-courses/ce54/desensitization>

A.2 Recommendation

Form a coalition that includes NJCDD, other advocates for people with IDD, state health department and Medicaid representatives, and the NJ MCOs to explore options for addressing oral health care issues among people with IDD.

The active participation of the five Medicaid MCOs and the New Jersey Medicaid representatives at the January 2020 meeting reflected their interest and engagement in addressing access to oral health care among people with IDD. Scheduling regular meetings of the coalition would build on the initial progress made at the January 2020 meeting. Based on the project team's experience working on this issue, to ensure meetings are task-focused and productive, resources will be needed to support a person or organization to organize the meetings, set goals for the meeting, prepare agendas, and undertake relevant background research to inform each meeting, such as providing information about approaches other states take to address reimbursement of Medicaid providers who treat people with IDD.

Some possible options for increasing the availability of Medicaid providers who treat people with IDD and improving access to oral health care for people with IDD through the Medicaid system are:

- Offering more flexible reimbursement for desensitization activities and/or time-based reimbursement, rather than procedure-based reimbursement
- Offering enhanced reimbursement to Medicaid providers who complete continuing education about treating people with IDD
- Educating dentists about New Jersey's expanded dental coverage for people with special needs

A.3 Limitations of Medicaid Coverage

"I wish dentists would cover more procedures. If you need extensive work done you should get it. You shouldn't have to settle for something because it's cheaper." — Group home staff member

In the focus groups, people with IDD and families of people with IDD described instances when their dentist recommended dental procedures that were not included in the Medicaid benefit package. Patients who could not afford to pay out of pocket ended up forgoing care altogether, or, like one self-advocate, receiving an alternative treatment that was covered as a stop-gap solution, but not the originally recommended treatment that was not covered. This left patients with persistent oral pain and, in one case, no upper teeth, leading to an inability to eat any hard-to-chew foods, requiring a change of diet, and deeply affecting quality of life. Families and people with IDD did not know why the procedures were denied for payment by Medicaid.

The NJ Medicaid MCOs are required to provide care management services, which, among other functions, assist patients in finding trained dentists who can treat them and help them with resolving issues related to coverage and payment for medically necessary services. However, this service may be underutilized because some families and people with IDD are either

unaware of the service or unsuccessful in engaging with this service. Information about care management may need to be disseminated through more avenues, such as IDD advocacy groups, or potentially provided in formats that are more accessible.

A.3 Recommendation

Increase the IDD communities' knowledge of care management services currently provided by the MCOs. The coalition, described above, should review the current care management materials, formulate solutions to make them as accessible as possible to the IDD community, and identify additional dissemination avenues. For instance, NJCDD and other IDD advocacy groups could support the dissemination of care management information through their networks.

“The receptionist told us that Medicaid will only pay for a cleaning every 6 months, but that’s not true. Every person with Medicaid that gets services from DDD has a special care manager, and they’re in a special division with their Medicaid HMO. Those people are able to get a cleaning every 3 months with a special code. But the receptionist doesn’t know that stuff. I emailed my brother’s care manager at his HMO...and they are taking care of it.” – New Jersey caregiver of an adult brother with IDD (quote summarized for clarity)

A.4 Lack of Data on Unmet Dental Needs

There are currently no representative data for New Jersey about unmet dental needs for adults with IDD; thus the project team was unable to assess how many people were affected.²³ This was a barrier to fully understanding and documenting the scope of this problem in New Jersey specifically. Data on unmet needs are important for convincing legislators to act and for raising the funds to address the issue. Such data can also be used to track progress made through the recommended actions and policy modifications.

A.4 Recommendation

Through the coalition meetings described above, identify currently available data that could be used to track unmet dental needs of people with IDD.

At the January 2020 meeting, participants discussed potentially combining data from DDD with Medicaid claims data to identify the oral health care services provided to adults who receive DDD services and to understand their needs. Progress on this issue requires more in-depth and detailed conversations between DDD, the Medical Assistance and Health Services agency, and the Medicaid MCOs to determine whether and how to best integrate these sources of data. These conversations could be held in the coalition meetings, described previously.

²³ A survey of elderly people and people with physical disabilities in New Jersey indicated that 53 percent had a dental check up in the last year. Among those who lived in a nursing home, 71 percent had a regular check up in the last year. Source: National Association of States United for Aging and Disabilities. (2016). Medicaid oral health coverage for older adults and people with disabilities. Retrieved from <https://www.astdd.org/docs/nasaud-medicare-oral-health-coverage-for-adults-10-2016.pdf>.

A.5 General Anesthesia: Data Analysis

Based on our interviews with caregivers and key informants, people with IDD face long wait times for general anesthesia (as long as two years). While New Jersey state law requires that insurance plans cover general anesthesia for people with serious disabilities,²⁴ several key informants noted that hospitals are increasingly reluctant to provide operating room time for dentistry. In New Jersey, general anesthesia can also be administered in a doctor's office under strict regulations. People who have complex medical needs may require general anesthesia for dental procedures because it protects their airways through intubation, unlike in lower levels of sedation.

Some caregivers seek out sedation dentistry (i.e., "lighter sleep" than general anesthesia and typically without intubation or an airway placed) when their family members with IDD do not have medical complications but are highly sensitive or reactive to dental procedures. These families, however, report difficulty obtaining insurance coverage for sedation dentistry.

Some special needs dental clinics have substantially reduced the need for sedation by using behavior management techniques and procedures. This approach is explored in more detail Section B that focuses on training.

A.5 Recommendation

Some data about hospital wait times for general anesthesia are collected by NJ's Division of Medical Assistance and Health Services, according to participants at the January 2020 meeting. These data should be analyzed, to the extent possible, to shed light on potential factors that lead to long wait times for anesthesia. This data could also be potentially combined with or further illuminated using data managed by the New Jersey Hospital Associations' (NJHA) Big Data Analysis Center. The NJHA Center for Health Analytics, Research, and Transformation (CHART) plans to use big data analytic approaches to identify and address gaps in care.²⁵

A.6 General Anesthesia: Hospitals' Role

"[My daughter] is a happy young woman with vibrant blue eyes and a broad bright smile. Well... a bright smile roughly every 4 1/2 years. It seems at best, with extensive planning, [my daughter] has the opportunity to have her teeth cleaned once every 4 ½ years." – New Jersey caregiver of an adult child with multiple disabilities, including severe cognitive delay, Type 1 diabetes, and reoccurring lung issues.

The caregiver quoted above mentioned several barriers to accessing routine dental care for her daughter, whose disabilities and conditions require dental care under anesthesia. The caregiver

²⁴ Lichtenstien, L. (14 Nov 2016). Sedation dentistry and insurance reimbursement. *Autism New Jersey*. Retrieved from <https://www.autismnj.org/article/sedation-dentistry-and-insurance-reimbursement/>.

²⁵ Kent, J. (2018 Sept 6). NJ Hospital Association Launches Big Data Analytics Center. *Health IT Analytics*. Retrieved from <https://healthitanalytics.com/news/nj-hospital-association-launches-big-data-analytics-center>.

recounted barriers she encountered every time she attempted to schedule dental cleanings for her daughter, including last-minute insurance denials for routine dental cleaning in the operating room, a lack of dentists with operating room privileges, and up to 18 months of waiting for available OR space for dental work. In fact, she said, “[i]t was actually easier to schedule orthopedic surgery than a simple cleaning. There seems to be something fundamentally wrong with that.”

Based on discussions at the January 2020 meeting, Medicaid provides coverage for sedation dentistry and dental care under anesthesia when appropriate, and patients should work with the care managers if those procedures are denied. This issue could be addressed, in part, through improving access to care managers, as described above.

However, based on key informant interviews and the stakeholder meetings, a probable reason wait times for general anesthesia are long is because of the lack of time and space in operating rooms devoted to dental procedures. Furthermore, it is difficult to coordinate medical and dental treatment that could be provided while the patient is under anesthesia. A fuller solution to reduce wait times and coordinate care may lie within the hospitals, rather than within the dental community.

“If you’re going to have dental care provided in a hospital under anesthesia – give parents the option of coordinating care with other medical needs to get as much medical work done as possible e.g. like a pap smear. Especially in a hospital that’s a teaching facility. Parents are so freaking exhausted.” – New Jersey caregiver with adult daughter with severe IDD

A.6 Recommendation

IDD advocates should engage directly with hospitals and hospital associations, such as the NJHA, to raise awareness of this issue and to identify strategies to address this issue.

A.7 Community Water Fluoridation

Key informant interviews and caregiver focus groups suggest that family members and people with IDD sometimes face challenges in the performance of daily oral care in the home. Some people with IDD have difficulty tolerating tooth brushing or are inconsistent about tooth brushing. Sometimes daily oral care is not the highest priority among caregivers, given the many demands on their time.

Gaps in preventive oral care are compounded by inconsistent and poor fluoridation of New Jersey’s water supply. Fluoride prevents tooth decay, reducing both the prevalence and severity

of dental decay, according to multiple rigorous studies.²⁶ The Centers for Disease Control and Prevention (CDC) cites water fluoridation as one of the top 10 major public health advances of the 20th Century, but fewer than 15 percent of New Jersey residents have access to fluoridated water, compared to 66 percent of the U.S. population. New Jersey ranks 49 out of 50 states, ahead of only Hawaii, in the percentage of population reached by community water fluoridation (CWF).²⁷ Water fluoridation is an important preventive mechanism for people unable to tolerate tooth brushing. While access to comprehensive dental care and optimal daily oral care are vital to improving oral health for people living with IDD, access to fluorides and fluoridated water will likely result in less severe dental decay, thus reducing pain and morbidity and resulting in shorter and less difficult dental visits.

In New Jersey, a single water utility provides water to several communities, and all communities served by the water utility must vote to allow CWF.²⁸ Despite the strong evidence of CWF benefits and safety, there are groups in New Jersey that fear the negative health impacts of CWF, as well as government control over drinking water supplies, as reasons preventing CWF.

The New Jersey Dental Association, the New Jersey Association of Health Plans, and the Rutgers School of Dental Medicine have advocated for statewide water fluoridation for many years. These efforts have not resulted in state-mandated CWF, most recently failing to be passed in 2013 and 2018.²⁹

A.7 Recommendation

NJCDD and other advocates for people with IDD should connect with CWF advocates and lend the voice of the IDD community to current advocacy efforts for CWF. Raising awareness of the greater vulnerability among people with IDD to tooth decay and the importance of CWF for this population, in particular, could support CWF efforts. If successful, this effort would benefit all New Jerseyans.

A.8 Partnering with Allies on Shared Policy Priorities

State legislators can address issues through statewide changes in legislation, such as CWF. Other issues that could potentially be addressed through state policy include student loan

²⁶ “Statement on the evidence supporting the safety and effectiveness of community water fluoridation.” (6 Jun 2018). Centers for Disease Control and Prevention. Retrieved from <https://www.cdc.gov/fluoridation/guidelines/cdc-statement-on-community-water-fluoridation.html>.

²⁷ “Percent of population served by CWS that are receiving fluoridated water.” (2014). Topic: Water Fluoridation. Oral Health Data, Centers for Disease Control and Prevention. Retrieved from https://nccd.cdc.gov/oralhealthdata/rdPage.aspx?rdReport=DOH_DATA.ExploreByTopic&isYear=2014&isTopic=WFR&go=GO.

²⁸ Matthau, D. (2019). Most NJ towns don’t have fluoridated water—but these do. *New Jersey 101.5*. Retrieved from <https://nj1015.com/most-nj-towns-dont-have-fluoridated-water-but-these-do/>.

²⁹ Stetler, C. (30 Jan 2019). Why New Jersey should have fluoride in its water. *Rutgers Today*. Retrieved from <https://news.rutgers.edu/qa/why-new-jersey-should-have-fluoride-its-water/20190128#.XYJ8Ly5KlJA>.

repayment for dentists who specialize in treating people with IDD (described in more detail in Section B) and increasing operating room time and space for dentists treating people with IDD, among others.

A.8 Recommendation

IDD advocates should organize an educational seminar for state legislators around the importance of key policy issues that affect oral health for people with IDD, including CWF. In preparing the educational seminar, NJCDD should work with organizations, such as Project Accessible Oral Health, the American Academy of Developmental Medicine and Dentistry (AADMD), the New Jersey Dental Association, the New Jersey Dental Hygiene Association, the New Jersey Oral Health Coalition, and the Association of New Jersey Health Plans, to identify shared legislative priorities.

Representatives of these potential ally organizations attended both stakeholder meetings. Descriptions of ally organizations are provided at the end of this report (see Appendix F).

B. Training for Oral, Medical, and Helping Professionals to Care for People With IDD

Advocates and dental associations have succeeded in recent years to improve training for dental professionals to care for people with IDD. In 2018, the American Dental Association (ADA) revised its Principles of Ethics and Code of Professional Conduct to better reflect the rights of patients with disabilities. The revisions now “explicitly prohibit dental care providers from denying care to patients because of their disability, as was already the case based on a patient’s race, creed, color, sexual orientation or gender identity, or national origin.” Additionally, the Code specifies “that patients with disabilities in need of another dentist's skills, knowledge, equipment, or expertise should not be turned away and should instead be referred to dentists able to provide the necessary care.” These changes are important because the ADA Code governs the behaviors and practices of dentists and typically informs the standard upon which state laws and regulations are based.

In July 2019, the Commission on Dental Accreditation (CODA) changed its standards to require dental schools to train students in the management and treatment of patients with special needs. CODA defines people with “special needs” as people with developmental disabilities, cognitive impairment, complex medical problems, significant physical limitations, and the vulnerable elderly.³⁰ For predoctoral programs, students must be trained to assess and manage the treatment of patients with IDD. For dental hygiene programs, students must be competent in providing care to special needs patient populations. For dental assistant programs, students must be familiarized with patients with special needs, including patients whose medical, physical, psychological, or social conditions make it necessary to modify normal dental routines. Dental schools must put these standards in place by July 1, 2020 for the predoctoral dental, dental hygiene, and dental assisting programs.

New Jersey has been a leader in providing education to dental professionals about treating patients with special needs. In 2017, the National Council on Disabilities (NCD), an independent federal agency, cited Rutgers School of Dental Medicine in New Jersey as a leader in training dentists to treat people with IDD. Rutgers School of Dental Medicine is one of only a handful of dental schools that already go beyond the CODA requirements in training new dentists in the treatment of people with special needs.³¹

Although the dental community has been making strides toward improving the capacity of the future dental workforce to treat patients with IDD, people with IDD often have difficulty finding

³⁰ Commission on Dental Accreditation. (Summer 2018). Proposed dental education standards revisions. Retrieved from https://www.ada.org/~media/CODA/Files/2019%20ADEA/Appendix3_predoc_standard_2-25.pdf?la=en.

³¹ National Council on Disability. (2017). Neglected for too long: Dental care for people with intellectual and developmental disabilities. Retrieved from https://ncd.gov/sites/default/files/NCD_Dental%20Brief%202017_508.pdf.

dentists who are able to treat them because most dentists in the field still lack exposure, training, and comfort around this population’s health and psychosocial needs.³

B.1 Behavior Guidance to Reduce Need for Sedation

“I’d like to be able to take him in, be able to see the dentist, meet the people around, get in the chair, turn on the instrument, and let us see how he takes it. We leave, and come back the next week and do the same thing. You know, just steps to get into the place where maybe he would want to open his mouth. Because if we can’t get him to open his mouth, what I’m dreading is having to put him to sleep just to get into his mouth.” – New Jersey caregiver of a four-year-old with Autism Spectrum Disorder

Key informants noted that some special needs dental clinics have substantially reduced the need for sedation and general anesthesia by using behavioral guidance techniques, such as desensitization, and by providing extensive training for dentists in treating people with IDD. For example, according to recent evidence provided to the project team by Dr. Matt Holder, co-director of the Lee Specialty Clinic in Kentucky, such techniques resulted in an OR referral rate of just 2 percent at the Lee Specialty Clinic, compared to the national average of 25 percent for patients with IDD. This approach, in turn, saved over \$1.2 million in OR costs.

B.1 Recommendation

Raise awareness among insurers/third-party payers of the potential for substantial cost savings made possible by office-based behavioral guidance and desensitization techniques that keep patients out of the hospital for receipt of dental care. Facilitate learning from existing insurer programs, such as Inclusive Dental, administered by AmeriHealth Caritas in the Philadelphia area, that ties enhanced reimbursement to continuing education and training on effective practice for treating people with IDD. Use the coalition meetings, described in Section A, as a platform to raise awareness of these practices in New Jersey.

B.2 Expanding the Evidence Base of Best Practices for Behavioral Guidance

A recent systematic and comprehensive review of the evidence-based dental practices for people with IDD, completed in 2018 by UMass Medical School’s Eunice Kennedy Shriver Center, found there was lack of rigorous evidence about best practices for behavioral interventions that would allow dentists to treat people with IDD in their offices without sedation or pharmacologic management.^{32,33} Developing a rigorous evidence base like this would take many years, as it would require multiple academic studies.

³² Bonardi et al., 2018.

³³ Bonardi, A., Clifford, C.J., & Fleming, C.K. (2018). Oral health care for adults with IDD: A summary of evidence-based and promising practices. Eunice Kennedy Shriver Center CDDER and UMass Medical School. Retrieved from

B.2 Recommendation

Support expanding the evidence base of best practices for behavioral guidance and desensitization techniques. IDD advocacy groups could support this work by providing direct support to researchers who study this topic, by advocating to foundations for more funding for such studies, or by providing support to researchers to write proposals for large government grants for such work.

B.3 Loan Repayment Programs for Dentists who Treat People With IDD

Loan repayment programs could motivate younger dentists to bring their education about treating people with IDD into the workforce.

Federal Initiative: The Healthcare Extension and Accessibility for Developmentally Disabled and Underserved Population (HEADs UP) Act was introduced in April 2019 in the federal House of Representatives. The HEADs UP Act would direct the Health Services and Resources Administration (HRSA) to designate people with IDD as a medically underserved population,³⁴ release federal funds for health services infrastructure to treat people with IDD, provide loan repayment programs for dentists and physicians who treat this population, establish preferences for federal research funding from the National Institutes of Health for people with IDD, and authorize more favorable reimbursement rates for providers who treat people with IDD.³⁵ As of the writing of this report, the HEADS UP Act has not been voted on in Congress.³⁶

Both the American Public Health Association and the AADMD have called on HRSA to designate people with IDD as medically underserved.³⁷ According to key informant interviews, people with IDD meet the HRSA standards for qualifying as medically underserved; however, to date, HRSA has not been able to make that designation.

New Jersey Initiative: Dental (Doctor of Dental Surgery/DDS or Doctor of Dental Medicine/DMD) students have been able to earn up to \$120,000 in student loan repayment through the Primary Care Practitioner Loan Redemption Program of New Jersey (NJLRP). The NJLRP is designed to encourage health care professionals to practice in state-designated underserved areas or federally designated health professional shortage areas (HPSAs). Primary care providers provide primary health care services at an NJLRP-approved placement site for a

https://shriver.umassmed.edu/sites/default/files/UMASS_Document_OralHealthCareforAdultIDD_CDDER_2016_Tagged_0.pdf.

³⁴ Moulton, Fitzpatrick introduce HEADs Up Act. (1 May 2019). Retrieved from <https://moulton.house.gov/news-stories/press-releases/moulton-fitzpatrick-introduce-heads-up-act/>.

³⁵ Ibid.

³⁶ HEADs Up Act. H.R. 2417. 116th Congress (2019-2020). Retrieved from <https://www.congress.gov/bill/116th-congress/house-bill/2417/text>.

³⁷ Integrating oral health for people with disabilities. (7 Nov 2016). WITH Foundation blog. Retrieved from <https://withfoundation.org/integrating-oral-health-for-people-with-disabilities/>.

minimum of two years. This program is subject to state appropriations and available funding, and as of July 1, 2019 there is no funding for new applicants.³⁸

B.3a Recommendation

NJCDD and other IDD advocacy groups should work with organizations like AADMD who support HEADS UP to adapt their advocacy tools for New Jersey.

B.3b Recommendation

NJCDD and other IDD advocacy groups should connect with New Jersey state legislators through the educational seminar, described in Section A, to support HEADS UP or the state-based student loan repayment programs for dentists who treat people with IDD.

B.4 Oral Health Training for Direct Support Professionals (DSPs)

Group homes and licensed settings must arrange transportation to dental and medical appointments and schedule an annual dental exam and annual physical for each resident. Daily oral care, however, can be challenging for residents. According to a key informant who provides oversight of oral care for adults with IDD in group home settings, DSPs do not receive oral health training prior to working in the group home setting; instead, training is provided on the job. However, because of the high turnover of DSPs, regular and continuous training about oral health care is necessary. In the caregiver focus groups, many noted the issue of high turnover rates among DSPs as a factor in the provision of daily oral care, and the recognition of signs and symptoms associated with oral need. For example, DSPs may be unaware that changes in eating patterns, emotional well-being, or other changes may indicate oral pain.

B.4 Recommendation

Work with DDD to integrate oral health training into the curriculum and onboarding of DSPs.

B.5 Integrating Oral Health with Primary Medical Care

Several studies suggest that better integration of oral health care and primary medical care would result in better treatment for people with IDD.^{39,40,41} According to key informant

³⁸ Primary care practitioner loan redemption program of New Jersey (NJLRP). Rutgers University. Retrieved from <https://lrp.rbhs.rutgers.edu/>.

³⁹ Brownlee, B. (2012). White paper: Oral health integration in the patient-centered medical home (PCMH) environment: Case studies from community health centers. Qualis Health. Retrieved from <http://www.dentaquestfoundation.org/sites/default/files/resources/Oral%20Health%20Integration%20in%20the%20Patient-Centered%20Medical%20Home,%202012.pdf>.

interviews, some medical doctors do not pay enough attention to the impact of oral health on general health. Furthermore, some prescription drugs taken by adults with IDD for behavioral issues can result in dry mouth, which can heighten the risk of oral health problems, particularly dental caries.⁴² There is also a tendency among medical professionals to attribute behavioral issues to the developmental disability rather than look for possible underlying oral issues, such as oral pain.⁴³ The Oral Health Program within the New Jersey Chapter of the American Academy of Pediatrics (NJAAP) has begun this work among pediatricians, but, to our knowledge, no organization is working with primary caregivers who treat the adult population.

B.5 Recommendation:

Draw on NJAAP's work to advocate for the training and incorporation of oral health risk assessments among adult primary care providers serving those with IDD. Establish referral systems between primary care providers and dentists serving those with IDD.

B.6 Transition to Adult Dental Care

The medical community has dedicated attention to the importance of the transition from pediatric to adult care for many years. Organizations, such as the New Jersey Transition to Adult Coordinated Care (NJTACC) at the Children's Hospital of Philadelphia and the Arc of New Jersey's Mainstreaming Medical Care program, have delved deeply into how best to support the transition into adult medical care for people with IDD. Additionally, the Boggs Center on Developmental Medicine at Rutgers Robert Wood Johnson Medical School developed the New Jersey Action Blueprint for Transition to Adult Health Care.⁴⁴

The transition from pediatric to adult dental care is equally important in maintaining oral health status. The American Academy of Pediatrics (AAP) recommends that pediatric dentists work with their patients with IDD to establish a dental home as they transition to adulthood.⁴⁵ AAP

⁴⁰ LeRoy, L., Pekruhn C., Mitchell, F., & Polintan, L. (2012). Returning the mouth to the body: Integrating oral health and primary care. Washington, DC: Grantmakers in Health. Issue brief No. 40. Retrieved from https://www.gih.org/files/FileDownloads/Returning_the_Mouth_to_the_Body_no40_September_2012.pdf.

⁴¹ Special needs: Medical Home. (2018). NJ Department of Health. Retrieved from <https://nj.gov/health/fhs/specialneeds/medical-home/> <https://www.astdd.org/bestpractices-bpa-special-needs.pdf>.

⁴² U.S. Department of Health and Human Services.(2000). Oral health in America: A report of the Surgeon General. Rockville, MD: U.S. Department of Health and Human Services, National Institute of Dental and Craniofacial Research, National Institutes of Health.

⁴³ Ibid.

⁴⁴ Spitalnik, D. M., Coffield, C. N., & Ellien, S. (2014). The New Jersey action blueprint for transition to adult health care. New Brunswick, NJ: The Boggs Center on Developmental Disabilities. Retrieved from <https://rwjms.rutgers.edu/boggscenter/products/documents/BoggsCenter-TransitionBlueprintFINAL.pdf>.

⁴⁵ The reference manual of pediatric dentistry (2019-2020). Retrieved from <https://www.aapd.org/research/oral-health-policies--recommendations/management-of-dental-patients-with-special-health-care-needs/>.

offers an online resource for health care professionals to learn about and discuss the transition to adult medical care that could potentially be used as a model for the dental community.⁴⁶

B.6 Recommendation

Draw on the work of the Arc, Boggs Center, and NJTACC in the medical field and the AAP among pediatricians to design and establish an intra-professional referral system between pediatric dentists and general dentists to facilitate the transition for people with IDD from their pediatric to adult dental homes.

⁴⁶ AAP Transition ECHO: Support transition from pediatric to adult care. American Academy of Pediatrics. Retrieved from <https://www.aap.org/en-us/professional-resources/practice-transformation/echo/Pages/Transition.aspx>.

C. Community Awareness of the Importance of Oral Health and Access to Oral Health Services

A vital component of improving oral health among adults with IDD in New Jersey is raising awareness within the IDD community of both the inter-relationships between and the importance of oral health for quality of life, wellness and physical health, as well as effective daily oral health practices. National and state level organizations that focus on serving the IDD population have developed oral health education materials, webinars, and programs. For example, the Arc of New Jersey recently hosted a webinar about oral health for children with special needs,⁴⁷ DDD offers guidance about oral health care for people with IDD,⁴⁸ the New Jersey Autism Center of Excellence (NJACE) has developed training materials about oral health needs of children with special needs,⁴⁹ and the Special Smiles program run by the Special Olympics organization works to expand access to oral health education along with direct dental care.

C.1 Trusted Sources of Information

The creation and dissemination of educational materials is not always coordinated across organizations to ensure that they reach the largest audience and that organizations are not duplicating efforts. According to caregiver interviews, families were sometimes unable to access information at the time they need it regarding specific oral health issues they are facing.

The caregivers in our study overwhelmingly prefer to find out about resources for their loved ones from someone they know and trust, such as their pediatrician, their own dentist, other family members of individuals with IDD, or IDD-serving organizations. They report attending workshops, webinars, and trainings, and searching the Internet for resources.

The following organizational resources were specifically mentioned by caregivers and people with IDD in the interviews conducted for this project: support groups, the Center for Lifelong Learning, the Matheny Medical and Education Center, Mom2Mom at Rutgers Behavioral Health Center, Autism New Jersey, the LEND program, parent-teacher associations, the Boggs Center on Developmental Disabilities, the Arc, developmental pediatricians, and other health professionals. Government sources of information include PerformCare, the Department of Children and Families (DCF), NJ FamilyCare, the Division of Developmental Disabilities (DDD), and family regional councils at the New Jersey Council on Developmental Disabilities (NJCDD). More information about these organizations is included in Appendix F.

⁴⁷ *Webinar: Oral health for children in special health care needs.* (19 Aug 2019). The Arc. Retrieved from https://www.arcnj.org/news_events/calendar.html/event/2019/08/19/webinar-oral-health-for-children-with-special-health-care-needs/259065.

⁴⁸ *A guide to good oral care for persons with developmental disabilities.* (2004). Office of Quality Improvement, Division of Developmental Disabilities. Retrieved from <https://www.state.nj.us/humanservices/ddd/documents/ddd%20web%20current/publications/Oral%20Care%20Bulletin.pdf>.

⁴⁹ *Service Providers.* New Jersey Autism Center of Excellence. Retrieved from <https://njace.us/resources/service-providers/#1540412658057-c0635043-4a6d>.

Interviewed participants also suggested the following avenues for promoting resources on oral health: County Boards of Social Services, insurance providers (especially Medicaid MCOs), support coordinators through DDD, case managers at DCF's Child Protection and Permanency agency, care management organizations (CMOs), Child Study Teams (a school-based group that help families with a 504 Plan or Individualized Education Plan for their children), and school nurses.

C.1 Recommendation

Create a "One Stop Shop" website for people with IDD and their families to provide one location for relevant oral health information.

The One Stop Shop website would contain information for families, such as, but not limited to, educational materials about the importance of oral health for people with IDD and daily, in-home oral health care techniques and tools; organizations that provide training to people with IDD and family caregivers about oral health, such as the Special Olympics of NJ and The Arc chapters; directory of dental providers who are trained to treat people with IDD (described in more detail below); information about utilizing the MCOs' care management programs for dental services; updates about free dental clinics like the Special Smiles program organized by the Special Olympics of NJ, and information about advocacy related to important oral health policy issues, such as CWF or the HEADs UP Act, described in section A of this report.

To ensure that the website is used by the IDD community, the website should be disseminated through the trusted sources listed above. In addition, the Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families should be aware of and included as a dissemination point.

To create such a website would require resources for an organization or person to compile available materials and, where there are gaps in currently available materials, to develop such resources. It would also require a designated organization to host and maintain the website, and ongoing resources to keep such a website updated.

C.2 Finding Dentists

"[W]hat the parents really need is a directory of dentists that can do work at different levels, either under full sedation, in office, with low levels of sedations and by insurance and what's the best way for the insurance to work for what you need." – New Jersey caregiver

In the interviews conducted for this project, caregivers and individuals living at home reported the most difficulty in finding dentists who have the skills to care for their needs, accept their insurance, and are located nearby. According to the interviews, people who live in group or supervised homes were usually taken to see a dentist or were regularly visited by dentists at the group home. To the project team's knowledge, no representative data is available on dental visits by place of residence to confirm the interview data.

Some caregivers reported that information for dentists they found online was not up to date and did not include detail about whether dentists could treat people with IDD and the level of

severity of the condition they were trained to treat. Many also expressed frustration that provider directories on their insurance websites did not include comprehensive, up-to-date information about the types of insurances accepted by these providers. For example, the dental directory for one insurer typically lists only the insurances relevant to that insurer, but not other insurances accepted by that dental provider.

“It was really frustrating [trying to find a dentist] because it was really time-consuming. You don’t have a lot of time when you’re dealing with [my son with a disability] and dealing with kids. If you do find someone, if he’s not taking Medicaid it doesn’t matter because he does the job. I could go to someone who takes Medicaid, but he might not be good for him.” – New Jersey caregiver with 18 year old son who is nonverbal.

Based on the interview data, people in the IDD community currently learn about dentists who treat people with special needs from a range of sources including: New Jersey Family Care HMO directories, the Dial-a-Smile New Jersey Dental Clinic Directory (issued by the Division of Community Health Services), their family dentist or physician, peers in the IDD community, Autism NJ (which has a directory of dentists online), and other online research.

As part of this project, the project team created a comprehensive directory of dentists who treat people with IDD. The project team reviewed all of the current online directories of dentists in New Jersey. The online directories provided by insurers and by New Jersey state agencies do not contain information about whether dentists treat people specifically with IDD or the level of IDD; instead, they provide information about whether dentists treat people with special needs, which is broadly defined.

To fill this gap, the project team emailed a survey to pediatric and general dentists with public email addresses in New Jersey. Even though the project team emailed over 4,000 pediatric and general dentists multiple times, and the New Jersey Dental Association provided support for the survey by including a link to it in their outreach to members and inviting the project team to speak at their annual conference about the project, the response rates were very low, with just over 100 responses. As a result, we do not recommend creating a directory through an optional survey in the future (see Appendix E that includes recommendations for conducting future surveys of dentists).

To develop a comprehensive and up-to-date directory, it must be created through a mechanism that dentists are required to respond to, such as the surveys insurers currently use to create their directories. Such surveys should be as short as possible, minimize open-ended responses (and instead opt for multiple/drop-down choices), and if necessary, only allow open-ended responses to be entered in standardized formats. Most importantly, dentists must be asked more detailed questions about whether they treat *adults* with IDD, specifically, and what level of IDD they are prepared to treat.

Following the October 2019 summit where the need for such a directory was raised, the Division of Medical Assistance and Health Services, working with the Oral Health Program of the NJ Chapter of the American Academy of Pediatrics, began to create a survey that would be disseminated to Medicaid MCOs to collect information specifically about dentists’ experience

treating people with IDD. NJCDD and the project team have been involved in the conversations to develop this survey.

C.2 Recommendation

NJCDD and other IDD advocacy groups should continue to work with the Division of Medical Assistance and Health to develop and disseminate a survey for Medicaid providers and compile these data into an easy-to-use format for people with IDD and families with IDD.

In the longer term, IDD advocacy organizations should work with private insurers to determine if they could include more detailed questions about treatment of people with IDD in their provider surveys. Another option for collecting this type of information might be during the credentialing process for dentists.

Conclusion

Oral Health Task Force

The research revealed that there are currently some oral health resources for people with IDD in New Jersey. However, organizations do not always coordinate their efforts to address oral health issues for adults with IDD. The research also revealed that there are resources available within the Medicaid program that are not being fully utilized because of lack of awareness within the IDD and dental communities, such as the Medicaid MCO care management programs and additional reimbursements for dentists who treat people with IDD.

The October 2019 summit and January 2020 meeting demonstrated that there is enthusiasm and energy among key stakeholders for addressing disparities in oral health among people with IDD. There are several national and state organizations, consulted throughout this project, that have been working to improve oral health for people with IDD. It will be important to create a structure with designated leadership to coordinate advocacy efforts with these organizations and to build on the work that has already begun. Organizations that can serve as allies and potential partners to NJCDD in improving the oral health and healthcare of adults in New Jersey include, but are not limited to: Project Accessible Oral Health, Special Smiles Special Olympics, the Boggs Center, the Oral Health Program in the American Academy of Pediatrics, American Academy of Developmental Medicine and Dentistry, The Arc of NJ, and the Ombudsman Paul Aronsohn (see Appendix F for more detailed descriptions of these organizations and other organizations described in this report).

Based on the project team's experience on this project, we recommend that one person or organization be responsible for organizing and arranging the task force' meetings, taking and disseminating minutes from the meetings, and undertaking background research between meetings. Resources to support this work would be needed.

Recommendation

Create an Oral Health Task Force to oversee the work described in this advocacy plan.

Report Authors

The principal investigators were Heather Koball, PhD, Co-Director of [The National Center for Children in Poverty](#) and Kavita Ahluwalia, DDS, MPH, Associate Professor at [Columbia University College of Dental Medicine](#). Other project team members included Suma Setty, MPH, Senior Research Associate at The National Center for Children in Poverty and Chelsea Fosse, DMD, MPH, Dental Public Health Resident at NYC Health + Hospitals.

Special Thank You

A Community Advisory Board, composed of self-advocates (individuals with IDD), family caregivers, policymakers, and community-based organizations provided guidance throughout the project. Members of the Community Advisory Board are listed below:

Name	Title and Affiliation
Paul Aronsohn	NJ Ombudsman for Individuals with IDD and Their Families
Caroline Coffield	Director of Preservice Training, The Boggs Center on Developmental Disabilities
Barbara Coppens	Advocate Assistant, Disability Rights NJ
Juliana David	Program Director, NJ Chapter, American Academy of Pediatrics
Akriti Gupta	Pediatric Dental Resident, Brookdale University Hospital and Medical Center
Susan Mancuso	Vice President of Nursing, Clinical Services & Medicaid Long Term Care Services (ICF), Spectrum for Living, Group Home
Daniel Pearson	Outreach and Communications Coordinator, NJ Self-Advocacy Project, The Arc of NJ
Stephanie A. Pratico	Caregiver & Program Manager, NJ Transition to Adult Coordinated Care
Ashley Ritchey	Director, NJ Self-Advocacy Project, The Arc of NJ
Neng Wang	Caregiver and NJCDD Regional Council Member

Consultants to the project included Dr. Glenn Rosivack and Dr. Evan Spivack of Rutgers School of Dental Medicine and the Delta Dental of New Jersey Special Care Treatment Center and Dr. Lyubov Slashcheva of the American Academy of Developmental Medicine and Dentistry (AADMD) and Apple Tree Dental in Minnesota.

APPENDIX A: ATTENDEES AT ORAL HEALTH SUMMIT OCTOBER 16, 2019

Meeting Attendees at New Jersey Summit to Address Oral Health for People with Intellectual and Developmental Disabilities

Elizabeth M. Boggs Center on Developmental Disabilities

335 George St., New Brunswick, NJ 08901

Facilitated by Columbia University College of Dental Medicine and the National Center for
Children in Poverty

Sponsored by New Jersey Council on Developmental Disabilities

New Jersey Council on Developmental Disabilities (NJCDD)	
Paul Blaustein	Chair, NJCDD
Elizabeth Dalzell	Head of Wellness Committee, NJCDD
Dennie Todd	Disabilities Specialist, NJCDD
Mercedes Witowsky	Executive Director, NJCDD
Project team members	
Dr. Kavita Ahluwalia	Associate Professor of Dental Medicine at CUIMC Director, Postdoctoral Program in Dental Public Health, Columbia University College of Dental Medicine
Dr. Heather Koball	Co-Director, The National Center for Children in Poverty
Suma Setty	Senior Research Associate/Project Director, The National Center for Children in Poverty
Dr. Chelsea Fosse (<i>could not attend</i>)	Special Care and FQHC Dentist and Dental Public Health Resident
Tracy Acheampong	Graduate student intern, Columbia University
Roger Chu	Dental student intern, Columbia University
Project consultants	
Dr. Lyubov Slashcheva (<i>joined remotely</i>)	Dentist, Apple Tree Dental Research Collaborator, Mayo Clinic Secretary, American Academy of Developmental Medicine and Dentistry
Community Advisory Group	
Paul Aronsohn	NJ Ombudsman for Individuals with IDD and their Families
Caroline Coffield	Director of Preservice Training, The Boggs Center on Developmental Disabilities
Barbara Coppens	Advocate Assistant, Disability Rights NJ
Juliana David	Program Director, NJ Chapter, American Academy of Pediatrics
Susan Mancuso, RN, MSN	Vice President of Nursing, Clinical Services & Medicaid Long Term Care Services (ICF), Spectrum for Living, Group Home

**APPENDIX A: ATTENDEES AT ORAL HEALTH SUMMIT
OCTOBER 16, 2019**

Daniel Pearson	Outreach and Communications Coordinator, NJ Self-Advocacy Project, The Arc of NJ
Stephanie A. Pratico	Caregiver & Program Manager, NJ Transition to Adult Coordinated Care
Ashley Ritchey, MSW, LSW	Director, NJ Self-Advocacy Project, The Arc of NJ
Neng Wang	Caregiver and NJCDD Regional Council Member
Key Stakeholders and Collaborators	
Dr. Hosam Alraqiq	Assistant Professor of Dental Medicine, Columbia University Irving Medical Center, College of Dental Medicine
Steven Cook	Executive Director, The Arc of Mercer County
Suzanne Cronin	AmeriHealth Caritas Family of Companies, Keystone First Market
William DePonte	Senior Director of Program Development, Special Olympics NJ
Veronica L. Diaforli	Senior Vice President, Programs, Family Resource Network
Dr. Cecile A. Feldman, DMD, MBA	Dean, Rutgers School of Dental Medicine
Dr. Darwin K. Hayes, DDS, MHA, FAGD	NJ State Dental Director, NJ Department of Health
Angie Hernandez	Intern, The Boggs Center on Developmental Disabilities
Jennifer Langer Jacobs	State Medicaid Director, NJ Department of Human Services
Steve Kess	Vice President, Global Professional Relations, Henry Schein, Inc.
Jaclyn Klepadlo, RDH	President, NJ Dental Hygienists' Association
Dr. Ronald Kosinski	Clinical Director, Oral Health Center for People with Disabilities, Director of Pediatric Sedation and Anesthesia, NYU College of Dentistry
Dr. Thomas Lind, MD, FAAP	Medical Director, NJ Division of Medical Assistance & Health Services
Louise McCarthy	Development Specialist, The Arc Gloucester
Kaylee McGuire	Policy Analyst, NJ Assembly Majority Office, Human Services and Regulated Professions
Yvonne Mikalopas, RDH	Dental Hygienist, Office of Oral Health, Division of Community Health Services, NJ Department of Health
Beverly Roberts	Director, Mainstreaming Medical Care, The Arc of NJ
James Schulz	Director of Governmental and Public Affairs, NJ Dental

**APPENDIX A: ATTENDEES AT ORAL HEALTH SUMMIT
OCTOBER 16, 2019**

	Association
Jonathan Seifried	Assistant Commissioner, Division of Developmental Disabilities, NJ Department of Human Services
Deepa Srinivasavaradan	Southern Regional Coordinator, Family-to-Family Health Information Center, SPAN Parent Advocacy Network
Dr. Bonnie T. Stanley, DDS	Chief, Bureau of Dental Services, NJ Division of Medical Assistance and Health Services Dental Director, NJ FamilyCare Dental Program
Lynn Tobin, RDH, MA	Department of Dental Hygiene, Middlesex County College
Barbie Vartanian	Executive Director, Project Accessible Oral Health, Viscardi Center
Dr. Elisa Velazquez	President, NJ Academy for Pediatric Dentistry
Dr. Sidney Whitman	Chairman, NJ Oral Health Coalition Chairman of the Medicaid Providers Advisory Committee, American Dental Association Director of Pediatric Dentistry, Newark Beth Israel Medical Center

APPENDIX B: ATTENDEES AT MANAGED CARE ORGANIZATION MEETING, JANUARY 31, 2020

Jan 31, 2020 Meeting Attendees Addressing Oral Health for People with Intellectual and Developmental Disabilities (IDD)

The Mary G. Roebling Building, 20 West State Street, Room 218, Trenton, NJ
Facilitated by Columbia University College of Dental Medicine and the
National Center for Children in Poverty
Sponsored by New Jersey Council on Developmental Disabilities (NJCDD)

New Jersey Council on Developmental Disabilities (NJCDD)	
Paul Blaustein	Chair, NJCDD
Dennie Todd	Disabilities Specialist, NJCDD
Mercedes Witowsky	Executive Director, NJCDD
Project team members	
Kavita Ahluwalia, DDS, MPH <i>(could not attend)</i>	Associate Professor of Dental Medicine at CUIMC Director, Postdoctoral Program in Dental Public Health, Columbia University College of Dental Medicine
Chelsea Fosse, DMD, MPH	Dentist, Dental Public Health Resident, NYC Health + Hospitals
Heather Koball, PhD	Co-Director, The National Center for Children in Poverty
Suma Setty, MPH	Senior Research Associate/Project Director, The National Center for Children in Poverty
Insurance Representatives	
Suzanne Cronin	AmeriHealth Caritas Family of Companies, Keystone First Market
Fred DiOrio, DMD	Dental Director, Government Programs, Horizon BCBSNJ
Alison Dorsey, MPH	Senior Director, Government Affairs, WellCare Health Plans, Inc.
Phil Evans	Corporate Dental Initiative Manager, AmeriHealth Caritas Family of Companies, Keystone First Market
Peter F. Fuentes, DMD	National Clinical Director of Oversight, Liberty Dental Plan
Patrick Gillespie	Regional Vice President, State Affairs, Anthem, Inc.
Glenn MacFarlane	Chief Executive Officer, Aetna Better Health of New Jersey
Joseph Manger	Director of Regulatory Affairs, Horizon BCBSNJ
Katrina Mickey, RN, LMSW, CCM	Manager, Health Care Management Services
Pam Persichilli	Vice President of Medical Management, Aetna Better Health of New Jersey
Lon Rosen, DDS	Dental Director, Amerigroup

APPENDIX B: ATTENDEES AT MANAGED CARE ORGANIZATION MEETING, JANUARY 31, 2020

Leo Russ, DDS	Chief Dental Officer, UnitedHealthcare Community Plan of NJ
Maribell Vega, DDS	Senior Director of Dental Services, WellCare Health Plans, Inc.
Noralisa Santiago	Manager, Care Management, WellCare Health Plans, Inc.
State Government Representatives	
Paul Aronsohn	NJ Ombudsman for Individuals with IDD and their Families
Carol A. Grant	Deputy Director, Division of Medical Assistance and Health Services, NJ Department of Human Services
Darwin K. Hayes, DDS, MHA, FAGD	NJ State Dental Director, NJ Department of Health
Donna L. Kurc, DMD, MHA	Regional Dental Consultant, Division of Medical Assistance and Health Services
Yvonne Mikalopas, RDH	State Dental Hygienist, Oral Health Services, Division of Community Health Services, NJ Department of Health
Jennifer Langer Jacobs	State Medicaid Director, NJ Department of Human Services
Thomas Lind, MD, FAAP	Medical Director, State of New Jersey Division of Medical Assistance & Health Services
Jonathan Seifried	Assistant Commissioner of the Division of Developmental Disabilities, NJ Department of Human Services
Bonnie T. Stanley, DDS	Dental Director, NJ FamilyCare Dental Program
Key Stakeholders	
Sarah Lynn Geiger	Vice President, NJAHP
Beverly Roberts	Director, Mainstreaming Medical Care, The Arc of NJ
Ward Sanders	President, New Jersey Association of Health Plans (NJAHP)
Barbie Vartanian	Executive Director, Project Accessible Oral Health, Viscardi Center

APPENDIX C: QUESTIONS AND INSTRUCTIONS FOR SMALL GROUP DISCUSSIONS DURING OCTOBER SUMMIT

Discussion questions for policy small group

Challenges faced by dentists who participate in Medicaid

- *How do we expand dentists' participation in Medicaid and in the Medicaid Special Needs Plan in particular?*
- *How do we address barriers to dentists' participation in Medicaid and the Medicaid Special Needs Plan?*

Limitations of Medicaid coverage

- *How do we best assess the extent of unmet dental care needs among adults with IDD in New Jersey? Would these data be important for advocacy efforts?*
- *How do we improve awareness among families and people with IDD about the parameters of current Medicaid-covered dental care and possibility of appeals for Medicaid coverage?*
- *Who would be the best, most effective actors to convey this information to affected families and individuals?*

Sedation and General Anesthesia

- *How can we reduce wait times and financial barriers for patients whose dental needs require treatment under general anesthesia?*
- *Could we safely expand coverage for sedation dentistry, such that families do not have to pay out of pocket for this service?*

Community Water Fluoridation

- *What would be the pros and cons of focusing on fluoridation in an advocacy plan for people with IDD?*
- *How should advocacy groups focused on improving oral health care and those focused on improving services for people with IDD organize around the issue of expanding CWF in New Jersey?*

APPENDIX C: QUESTIONS AND INSTRUCTIONS FOR SMALL GROUP DISCUSSIONS DURING OCTOBER SUMMIT

Discussion questions for training small group

Dentists

- ***Rutgers School of Dental Medicine already exceeds the CODA requirements for training dentists in treating people with IDD. How do we optimize this training and translate it into the dental work force beyond dental school, particularly for dentists in practice?***

Other oral health providers

- ***How will schools for dental hygienists and dental assistants in New Jersey respond to the changes in CODA requirements?***
- ***What supports or information would be helpful to these schools as they respond?***

Behavior Management to Reduce Need for Sedation

- ***Can we reduce the need for sedation/general anesthesia through behavior management training for dentists?***
- ***How can we provide appropriate training for dentists?***
- ***Would building the evidence base of best practices for behavioral management help toward this goal? If so, how would we best build that evidence base?***

Loan Repayment Programs for Dentists who Treat People with IDD

- ***Would advocacy for the HEADS UP Act be an important area of focus?***
- ***Should the HEADS UP Act not pass, could we work with the state of NJ to designate people with IDD as a medically underserved population and provide a loan repayment program through the state?***
- ***Is advocacy for funding the NJLRP an important area of focus? Is there a possibility for creating additional incentives within the NJLRP for providers to treat patients with special needs? Are there other incentives for dental providers to serve individuals with IDD that New Jersey should consider?***

Oral Health Training for Direct Service Providers (DSPs)

- ***What types of oral health training should be required for DSPs?***
- ***What are the best methods for training DSPs about oral health care and oral health needs?***

Integrating Oral Health with Primary Medical Care

- ***How could oral health be better integrated into the medical care of people with IDD, promoting inter-professionalism between the disciplines? What effective models or pilot programs currently do this? How could these models be scaled up to serve more adults with IDD in New Jersey?***
- ***Are there opportunities to strengthen or create advocacy on this issue in New Jersey?***

Evidence Base and Data Collection

APPENDIX C: QUESTIONS AND INSTRUCTIONS FOR SMALL GROUP DISCUSSIONS DURING OCTOBER SUMMIT

- *What is the best method to build evidence of best practices for treating people with IDD?*
- *What specific areas of dental treatment or oral health should this research focus on? Who should undertake this research?*
- *What are potential available funding sources for this research (e.g., Center for Disease Control, DentaQuest Foundation, Robert Wood Johnson Foundation, WITH Foundation, Golisano Foundation)?*

APPENDIX C: QUESTIONS AND INSTRUCTIONS FOR SMALL GROUP DISCUSSIONS DURING OCTOBER SUMMIT

Discussion questions for community health small group

Education

- ***What are the current gaps in education about daily oral health practices? How can we best fill these gaps?***
- ***How do we raise awareness in the IDD community about the importance of oral health for overall health? What organizations would be best positioned to reach the IDD community and what resources would they need to pursue an awareness campaign?***

Coordination

- ***What is the best way to coordinate and disseminate available oral health training materials and training platforms to the DD community?***
- ***How do we maximize the reach of these educational efforts while reducing any duplicative efforts?***
- ***How can we promote these resources to the IDD community (e.g., individuals with IDD, caregivers, organizations who serve individuals with IDD and their families) and what resources are available to do so?***

Finding Dentists

- ***What would be the best place to coordinate and disseminate the information that is currently available about dentists who serve people with IDD and accept Medicaid?***

Federally Qualified Health Centers

- ***How could the FQHCs best utilize the \$1.6 in additional funding to improve oral health care for people with IDD?***

APPENDIX C: QUESTIONS AND INSTRUCTIONS FOR SMALL GROUP DISCUSSIONS DURING OCTOBER SUMMIT

Instructions for small group discussions

- Select a discussion leader who will ensure the discussion proceeds in a timely fashion and that all group members' voices are heard.
- Select 1-3 people to present the small group discussion in the report-back session (after lunch)
- Select a note-taker (or two) to summarize the group's main points on each discussion question to assist with report back
- Use the background and discussion questions in your topic area presented in the brief (see page numbers under "*Breakout groups*" below) to guide your discussion.
 - Focus on highest priority issues; groups do not have to discuss every issue in their section of the brief.
 - You can introduce additional topics if you feel issues have been missed in the brief.
 - The discussion groups should
 - Prioritize advocacy goals and strategies
 - Identify concrete action steps toward those goals
 - Identify which organizations should work toward those goals

Suggested use of time during discussion (total 70 minutes)

- 10 minutes
 - Review section of brief.
 - Prioritize and think about the discussion questions.
 - Write reflections down on notepads.
- 35 - 40 minutes
 - Discuss highest priority topics and discussion questions.
 - You will likely not have time to discuss all of the discussion questions; prioritize which issues your group would like to discuss.
- 20 - 25 minutes
 - Decide on highest priority advocacy goals and action steps toward those goals for the report back to the larger group
 - Identify which organizations (e.g., government agencies, organizations – be as specific as possible) should take these action steps or collaborate around the steps.

Breakout groups:

- Policy Gaps and Opportunities to Improve Oral Health and Healthcare for People with IDD (pages 6-9 in brief)
- Training for Oral, Medical and Helping Professionals to Care for People with IDD (pages 10-14 in brief)
- Community Awareness of the Importance of Oral Health and Access to Oral Health Services (pages 15-16 in brief)

NOTE: You do not have to stick to your assigned group. If you think your expertise fits another group's topic better, please let the project team know you would like to switch groups.

APPENDIX D: DISCUSSION QUESTIONS FOR JANUARY 31 MANAGED CARE ORGANIZATION MEETING

Addressing Oral Health for People with Intellectual and Developmental Disabilities (IDD)

Friday, January 31, 2020 | 9:00 AM - 1:00 PM

The Mary G. Roebling Building, 20 West State Street, Room 218, Trenton, NJ

Facilitated by Columbia University College of Dental Medicine and the
National Center for Children in Poverty

Sponsored by New Jersey Council on Developmental Disabilities

Credentialing

- What is the status and timeline in New Jersey for the universal dentist application for credentialing dentists who seek to participate in a carrier's provider network (as per legislation approved 1/31/19)?
- How do you anticipate universal credentialing will impact the speed or ease of the credentialing process?
- What factors do you think might influence universal credentialing's roll out?

Directory of dental providers for patients with special needs

- What is the process for alerting MCOs when patients are also registered with NJ's Division of Developmental Disabilities? Based on your currently available data systems, would you be able to track the providers who see people who are registered with DDD? Would you be able to see the volume of patients registered with DDD that a provider sees?
- Do you think standardized measures of providers' experience or training for treating special needs populations could be collected during one of the regular data collection points: (1) the credentialing process, (2) license renewal process, (3) provider participation monitoring (as requirements to survey 100% of the provider network every 2 years) and could be included in a directory?
- Are there other opportunities to collect data about which providers see patients with IDD or other special needs that we haven't listed?
- What are the "Special Needs Surveys" (as mentioned in Horizon's provider manual) – and how could data from those inform the development of the directory?
- What resources do care managers use to refer people to providers who treat people with special needs?

APPENDIX D: DISCUSSION QUESTIONS FOR JANUARY 31 MANAGED CARE ORGANIZATION MEETING

Expanding the provider network

- Are there dental services you provide for special needs members beyond those required by the NJ MCO Contract?
- How do plans educate their provider network about the extra services and time covered for special needs patients? In other words, how do providers understand for which services they will be reimbursed? What about their front office staff who typically handle billing?
 - Are providers aware they can use the behavioral management code multiple times for a single visit for a single patient?
- Our research revealed a hypothesis among dental providers/educators that a key barrier to dentists treating special needs patients was a belief that current reimbursement rates would not cover the cost of care. Yet, we also understand the NJ Medicaid MCOs provide additional reimbursement for behavioral management and extra cleanings and services. What do you think is the key barrier here: the reimbursement amount, lack of knowledge among dentists about reimbursement, or other reasons? How would you recommend we best address this issue in order to expand the availability of providers who take Medicaid and treat people with IDD?
 - Do you sense that providers and office staff are familiar and up-to-date with the policies in the manual?
 - How do you communicate updates in provider policies to your network dentists?
- List of relevant services:
 - Behavior management (D9920): What do you qualify as behavior management? What documentation is required?
 - Case management (D9997), NEW in 2020: “dental case management – patients with special health care needs”
 - Prophylaxis (D1120) frequency: Are 3 month intervals reimbursed? Is pre-authorization required? What is the pre-auth process/requirements?
 - Nutrition counseling (D1310)
 - Oral hygiene instruction (D1330)

APPENDIX D: DISCUSSION QUESTIONS FOR JANUARY 31 MANAGED CARE ORGANIZATION MEETING

Care Managers

- Could you tell us more about how the DDD-funded care coordination agencies interact with care managers from the Medicaid MCOs? What's the intersection between the Individualized Service Plans developed by care coordination agencies and the Plans of Care developed by the MCOs? Do these relationships work well? If not, what are the key barriers to that relationship that are potentially changeable?
- How are patients educated about the reasons for a denied dental procedure?
- How are patients and their families educated about the benefits covered under a plan as a special needs patient?

Data availability

- What utilization data could be provided in aggregate by the MCOs or the state Medicaid office for the DDD population?
- What changes in data collection would need to be made to zero in on utilization among the DDD population? How can we link DDD and MCO data?
- Do providers input the diagnoses of the special needs patient from patients' charts when inputting the billing codes for the services rendered? If not, would doing so help with data collection on this population?
 - Useful information would be: the number of dental visits annually by DDD clients, their diagnoses, their treatments, any other dental outcomes.
- Can predictive modeling software used in care management to analyze future health risks be reported in a way that would be useful to understand baseline status of members with special needs? Are measures from predictive modeling shared with the state?
 - Predictive modeling – mentioned in Aetna's provider handbook – identifies and stratifies members who should be targeted for our care management programs. This modeling "sorts, analyzes, and interprets historical claims, pharmacy, clinical and demographic data to identify gaps in care and to make predictions about future health risks for each member" (Aetna provider manual page 78). They produce monthly target reports of the members most likely to benefit from care management services.
- What useful information and data could the providers' special needs surveys, initial health screen tools, and comprehensive health assessments provide?
- What information could be shared from the utilization management and quality improvement measures (mentioned by UHC in their 2018 provider manual)?

APPENDIX D: DISCUSSION QUESTIONS FOR JANUARY 31 MANAGED CARE ORGANIZATION MEETING

Dentistry with Anesthesia

- Our research suggests that some facilities have waiting lists for anesthesia that are over a year, while other facilities do not have waiting lists. Are there data available that indicate the average wait times and the variation across facilities in wait times for anesthesia for patients with IDD across NJ?
- If facilities vary greatly in wait times, what would be the best way to match the need for services with facilities that are able to accommodate those needs?
- Research suggests that behavioral management is cost effective by reducing the need for anesthesia. How could the Medicaid MCOs participate in advocating for greater use of behavioral management by providers?
- Would the MCOs consider reimbursing the providers for hiring social workers, community dental health coordinators, or someone with experience working with patients with behavioral issues for in office visits?

APPENDIX E: RECOMMENDATIONS FOR ADMINISTERING A SURVEY OF DENTAL PROVIDERS

Recommendations for administering a survey of dental providers in New Jersey

Administration

1. Minimize the need for open-ended responses
2. Offer multiple choice/drop down choices as much as possible
3. Ensure that text entered into the system are in standardized formats. For example, telephone numbers should have only 10 digits, no extra numbers. Ideally, addresses should auto-populate so that the addresses are standardized and aligned with post office addresses (to ensure that there are no mistakes).

Questions to include

1. Dentist name, Practice/Clinic/Program names, addresses of practices, and phone numbers
 - a. Name – Link to DCA NJ license database, so that as they are typing, possible names and license numbers pops up and they must select the one that belongs to them.
 - b. Addresses - Should auto-populate so that the addresses are standardized and aligned with post office addresses (to ensure that there are no mistakes)
 - c. Telephone – Allow only numbers to be entered for this field, and only 10 digits to minimize typos
2. Specialty(ies) (multiple choice/drop-down)
3. Whether the dentist has hospital privileges and which hospitals (multiple choice/drop-down, only bring up an open-ended response box if the hospital is not listed).
 - a. *Note: This was very important to many caregivers whose children required anesthesia for dental care.*
4. What types of special needs are treated and for which age groups (multiple choice/drop-down, include IDD as one of them)
5. Severity of IDD treated with definition and for which age groups, if IDD is selected as one of the special needs treated (multiple choice/drop-down, mild, moderate, severe, profound)
6. Age ranges of special needs patients for which they provide care (multiple choice/drop-down)
7. Gender identity of provider (multiple choice/drop-down)
 - a. *Note: Not sure if this is essential, but dentist's gender was mentioned by a few caregivers in our focus groups/interviews as an important dentist characteristic.*

APPENDIX E: RECOMMENDATIONS FOR ADMINISTERING A SURVEY OF DENTAL PROVIDERS

Questions to include (continued)

8. For each of the practice locations:
 - a. Accessibility features (multiple choice/drop-down, like whether an elevator is available, ASL, handrails, wide hallways, etc., see NJCDD survey for example)
 - b. Type of practice (multiple choice/drop-down, like group home visits, mobile clinic, solo practice, community health center, etc.)
 - c. Whether one can treat in a wheelchair (yes/no)
 - d. Non-English languages spoken (multiple choice/drop-down)
 - e. Payment types/arrangements (multiple choice/drop-down)
 - f. Insurance types accepted (multiple choice/drop-down)
 - g. Counties served (multiple choice/drop-down)
 - h. Behavior management techniques offered with examples (multiple choice/drop-down)
 - i. Open days and hours (multiple choice/drop-down)
 - j. Email (only allow entry in proper format)

APPENDIX F: DESCRIPTIONS OF ORGANIZATIONS LISTED IN REPORT

Name of Organization	Description	Website
Governmental Entities		
Division of Developmental Disabilities, Department of Human Services, State of NJ	The Division of Developmental Disabilities provides public funding for services that assist New Jersey adults with intellectual and developmental disabilities, age 21 and older, to live as independently as possible. Services are available in the community and in five state-run developmental centers.	https://nj.gov/humanservices/ddd/home/
Division of Medical Assistance and Health Services, Department of Human Services, State of NJ	The Division of Medical Assistance and Health Services (DMAHS) administers Medicaid's state-and federally-funded NJ FamilyCare programs for certain groups of low- to moderate- income adults and children. Through these programs, DMAHS serves approximately 1.7 million, or nearly 20%, of New Jersey's residents. Most NJ FamilyCare beneficiaries are enrolled in managed care. With managed care, a health plan coordinates an individual's health care needs.	https://www.state.nj.us/humanservices/dmahs/home/
New Jersey Council on Developmental Disabilities	NJCDD's mission is to engage in advocacy, capacity building and systemic change activities and to ensure that individuals with IDD in NJ and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, integration and inclusion in all facets of life through culturally competent programs. They run statewide family support planning councils for education and long-term support for families of individuals with IDD, run the People First New Jersey chapters who help individuals with IDD speak for themselves and make sure they are heard, and operate the Youth Leadership Training Program to teach young people with IDD a variety of skills to help them become better self-advocates.	https://njcdd.org/
New Jersey Department of Health	The Department's priority is improving population health by strengthening New Jersey's health system. The Department's five branches, Public Health Services, Health Systems, Integrated Health, Office of Population Health and the Office of Policy and Strategic Planning work collaboratively toward that goal. Population health focuses on keeping healthy New Jerseyans well, preventing those at risk from getting sick, and keeping those with chronic conditions from getting sicker. Population health promotes prevention, wellness and equity in all environments, resulting in a healthy New Jersey.	https://www.nj.gov/health/

APPENDIX F: DESCRIPTIONS OF ORGANIZATIONS LISTED IN REPORT

<p>Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families</p>	<p>Governor Phil Murphy appointed Paul Aronsohn in 2018 to head the newly created Office of the Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families. The office aims to be a source of information, coordinate with the State Council on Developmental Disabilities, assist with navigating the process for obtaining services from DDD and Division of Children's System of Care, and serve as a general resource for individuals with IDD and their families.</p>	<p>https://www.nj.gov/governor/news/news/562018/approved/20180419c_ombudsman.shtml</p>
<p>Insurance Entities</p>		
<p>AmeriHealth Caritas, Inclusive Dental Program</p>	<p>AmeriHealth Caritas Pennsylvania is a Medicaid managed care health plan serving the Lehigh/Capital and Northwest regions of Pennsylvania. AmeriHealth Caritas launched Inclusive Dental, a program designed to address a growing concern around oral health care barriers for individuals with disabilities. The Inclusive Dental Program raises awareness around the oral health care barriers of people with disabilities, develops resources and trainings designed to support current providers and future dentists through partnerships with local professional schools, and advocates for better policies to address the oral health needs of individuals affected by disabilities and their families. AmeriHealth Caritas is a mission-driven organization, part of the Independence Health Group in partnership with Blue Cross Blue Shield of Michigan.</p>	<p>https://www.amerhealthcaritaspacom/index.aspx</p>
<p>Medicaid Managed Care Organizations</p>	<p>Five Managed Care Organizations participate in New Jersey's NJ FamilyCare program, the state's Medicaid program: Aetna Better Health, Amerigroup New Jersey, Inc., Horizon NJ Health, UnitedHealthcare Community Plan, and WellCare. Under managed care, clients enroll in a health plan which manages their healthcare and offers special services in addition to the benefits to which Medicaid clients are entitled.</p>	<p>https://www.state.nj.us/humanservices/dmahs/info/resources/care/</p>
<p>New Jersey Association of Health Plans</p>	<p>The New Jersey Association of Health Plans (NJ AHP) is a non-profit corporation created to serve its member health plans with a mission of fostering understanding in the value that health plans contribute to New Jersey's health care system. They educate policy makers, regulators, and opinion leaders on the implications of specific policy proposals, promote collaborative efforts among health plans, providers, purchasers, brokers and consumers to expand access to high-quality, affordable, and accessible health care, and act as a resource for interested parties on New Jersey's health care system, among other activities.</p>	<p>http://njahp.org/</p>

APPENDIX F: DESCRIPTIONS OF ORGANIZATIONS LISTED IN REPORT

New Jersey FamilyCare	NJ FamilyCare is New Jersey's publicly funded health insurance program and includes CHIP, Medicaid, and Medicaid expansion populations. That means qualified NJ residents of any age may be eligible for free or low cost health insurance that covers doctor visits, prescriptions, vision, dental care, mental health and substance use services and even hospitalization.	http://www.njfamilycare.org/Default.aspx
PerformCare, the Department of Children and Families (DCF)	PerformCare New Jersey is a mission-based behavioral health managed care organization and the Contracted System Administrator (CSA) for the State of New Jersey's Department of Children and Families, Children's System of Care (CSOC). PerformCare is the single point of access to a wide array of behavioral health, intellectual and developmental disability services as well as substance use treatment for youth and families throughout New Jersey.	http://www.performcarenj.org/index.aspx
National Organizations		
American Academy of Developmental Medicine and Dentistry (AADMD)	AADMD is a non-profit membership organization of interdisciplinary health professionals - including primary physicians, medical specialists, dentists, optometrists, nurses, and other clinicians - committed to improving the quality of healthcare for people with intellectual and developmental disabilities (IDD) through membership, education, and advocacy. They provide a national forum for healthcare professionals who provide clinical care to people with IDD, assist in reforming the current system of healthcare to better serve people with IDD, assist with preparing clinicians to care for patients with IDD, provide curriculum to IDD training programs, increase the body and quality of patient-centered research, disseminate specialized information to families, and establish alliances between advocacy and health care organizations to achieve better healthcare.	https://www.aadmd.org/
Project Accessible Oral Health, The Viscardi Center	Project Accessible Oral Health is a global public-private partnership and the first to nationally assemble and connect a consortium of dental and medical professionals, corporations, organizations, policymakers, educators, people with disabilities, caregivers, and other stakeholders in pursuit of equal access to culturally competent oral healthcare. The Project's mission is to act as a collective catalyst for change that will not only improve access to oral healthcare, but also ultimately improve the overall health of the disability community.	https://www.viscardicenter.org/pao/h/
New Jersey Professional Associations		

APPENDIX F: DESCRIPTIONS OF ORGANIZATIONS LISTED IN REPORT

<p>New Jersey Oral Health Coalition, American Academy of Pediatrics, New Jersey Chapter</p>	<p>The New Jersey Oral Health Coalition works in partnership with the NJ Department of Health, DentaQuest Foundation, Horizon Foundation for NJ, and other public and private organizations to foster greater medical-dental collaboration for advancing prevention strategies, develop adequate financing structures, and increase the number of qualified dental providers skilled to meet the oral healthcare needs of children in NJ. They launched a new website to support the Oral Health Wellness Campaign with information and resources for caregivers, families, community members, and providers (http://www.healthyteethnj.com/).</p>	<p>https://njaap.org/programs/oral-health/</p>
<p>New Jersey Dental Association, American Dental Association</p>	<p>With the majority of dentists in the State of New Jersey belonging to NJDA, it is one of the largest state dental associations in America. NJDA's mission is to serve and support its members and foster the advancement of quality, ethical oral healthcare for the public. It supports public dental health initiatives, such as Give Kids a Smile, and other programs that provide free treatment to various populations.</p>	<p>https://www.njda.org/</p>
<p>New Jersey Dental Hygienists' Association</p>	<p>The New Jersey Dental Hygienists' Association (NJDHA) is the organization representing the professional interests of dental hygienists in New Jersey. NJDHA is a constituent of the American Dental Hygienists' Association (ADHA).</p>	<p>https://www.njdha.org/</p>
<p>New Jersey IDD-Serving Organizations</p>		
<p>Autism New Jersey</p>	<p>Autism New Jersey is a nonprofit agency committed to ensuring safe and fulfilling lives for individuals with autism, their families, and the professionals who support them. Through awareness, credible information, education, and public policy initiatives, Autism New Jersey leads the way to lifelong individualized services provided with skill and compassion. Autism New Jersey also maintains a database of health care professionals who have been submitted by families affected by autism. Their database of dentists was a source for the directory created as part of this project.</p>	<p>https://www.autismnj.org/</p>
<p>The Boggs Center on Developmental Medicine, Robert Wood Johnson Medical School, Rutgers, The State University of New Jersey</p>	<p>The Boggs Center is New Jersey's federally designated University Center for Excellence in Developmental Disabilities (UCEDD) and is part of Rutgers Robert Wood Johnson Medical School, Department of Pediatrics. The Boggs Center provides community and student training and technical assistance, conducts research, and disseminates information and educational materials.</p>	<p>https://rwjms.rutgers.edu/boggscenter/about/overview.html</p>

APPENDIX F: DESCRIPTIONS OF ORGANIZATIONS LISTED IN REPORT

<p>LEND program, The Boggs Center</p>	<p>NJLEND is The Boggs Center's Leadership Education in Neurodevelopmental and Related Disabilities program, and is part of a national network of LEND programs. NJLEND prepares graduate-level health and allied health fellows to provide high-quality, interdisciplinary, family-centered, culturally competent care addressing the complex needs of children with autism, related disabilities and other maternal and child health populations. All NJLEND fellows are paired with a Faculty Mentor from their discipline who works with the fellow to integrate NJLEND requirements with the requirements of the student's academic program, as well as to guide and reflect on their individual leadership development throughout the LEND year.</p>	<p>https://rwjms.rutgers.edu/boggscenter/student/LEND.html</p>
<p>Center for Lifelong Learning</p>	<p>The Center for Lifelong Learning is a school part of the Educational Services Commission of New Jersey public schools located in Parlin, NJ for students ages 3-21 with autism and multiple disabilities. Staff utilize research based programs to support CLL students in developing skills of independence in communication, vocational, life skills, daily living skills, social skills, and academics. With a current enrollment of over 200 students, the Center for Lifelong Learning has a preschool disabled class, six classes for students with multiple disabilities and seventeen classes for students with autism.</p>	<p>https://www.escnj.us/Domain/145</p>
<p>Mainstreaming Medical Care Program, The Arc of New Jersey,</p>	<p>The Arc of New Jersey is the state's largest organization advocating for and serving child and adults with IDD and their families. The Arc's Mainstreaming Medical Care Program promotes quality health care for people with developmental disabilities throughout NJ. They provide information and engage in advocacy on NJ's Medicaid Managed Care Organizations for individuals with IDD, organize an annual health care conference that focuses on current information on the medical, dental, and behavioral health care for people with IDD, and produce fact sheets on a variety of topics, among other activities</p>	<p>https://www.arcnj.org/programs/mainstreaming-medical-care/mmc.html</p>

APPENDIX F: DESCRIPTIONS OF ORGANIZATIONS LISTED IN REPORT

<p>Matheny Medical and Education Center</p>	<p>Matheny is a special hospital for children and adults with medically complex developmental disabilities, a special education school providing academics, combined with functional life skills, for students aged 3-21, and a comprehensive outpatient center meeting the health care needs of people with all types of disabilities in the community. Matheny also trains healthcare professionals, therapists and educators in how to work effectively with persons who have developmental disabilities. Matheny runs several group homes, and provides services to people with disabilities from communities throughout New Jersey and offers contract services and consulting to public school districts to help them better manage the challenges of education special needs students.</p>	<p>http://www.matheny.org/about/</p>
<p>Mom2Mom, Rutgers Behavioral Health Center</p>	<p>Mom2Mom is a 24/7 peer-support helpline for mothers of children with special needs in NJ directed by Rutgers University Behavioral Health Care and funded by the New Jersey Department of Children and Families. They provide peer support, clinical assessment, provide access to a database of specially trained service providers for referrals, and support groups.</p>	<p>http://www.mom2mom.us.com/</p>
<p>New Jersey Autism Center of Excellence</p>	<p>The New Jersey Autism Center of Excellence (NJACE) is a statewide innovative, comprehensive and collaborative network to promote quality research, professional training and build public awareness aimed to improve the lives of individuals with Autism Spectrum Disorder (ASD) across the lifespan.</p>	<p>https://njace.us/</p>
<p>New Jersey Transition to Adult Coordinated Care Program, Children’s Hospital of Philadelphia</p>	<p>Children’s Hospital of Philadelphia (CHOP) created The New Jersey Transition to Adult Coordinated Care program (NJTACC), an interdisciplinary specialty care team, to help families and patients through a comprehensive approach achieve a successful transition into adulthood. This program is meant to address the unique challenges faced by teens and young adults with IDD as they transition from pediatric to adult services and medical care. They provide care coordination, home and community planning, occupational therapy evaluation and rehabilitative therapy, and psychiatry telemedicine. Their clinic is located in Plainsboro, NJ.</p>	<p>https://www.chop.edu/centers-programs/new-jersey-transition-adult-coordinated-care-program</p>

APPENDIX F: DESCRIPTIONS OF ORGANIZATIONS LISTED IN REPORT

<p style="text-align: center;">Rutgers School of Dental Medicine</p>	<p>The Rutgers School of Dental Medicine's mission is to improve oral health and quality of life through the education of oral health professionals and scientists, the conduct of research, the promotion of health, and the delivery of oral health care to communities throughout the state and beyond. They operate the Delta Dental of New Jersey Special Care Center, one of the few facilities in the state that exclusively treat patients with special needs, including patients with Down Syndrome, cerebral palsy, and autism.</p>	<p style="text-align: center;">http://sdm.rutgers.edu/</p>
<p style="text-align: center;">Special Olympics New Jersey</p>	<p>Special Olympics New Jersey is not-for-profit 501(c) 3 organization whose mission is to provide sports training and athletic competition to children and adults with intellectual disabilities, completely free of charge. They also operate the Special Smiles program, which provides Special Olympics athletes comprehensive oral health care information, free dental screenings, and instructions on proper brushing and flossing techniques. Special Olympics athletes also receive important supplies like toothpaste, toothbrushes and fluoride varnish.</p>	<p style="text-align: center;">https://www.sonj.org/</p>