



## **Medicaid Oral Health Coverage for Adults with Intellectual & Developmental Disabilities – A Fiscal Analysis**

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**National Council on Disability**

March 9, 2022

National Council on Disability (NCD)  
1331 F Street NW, Suite 850  
Washington, DC 20004

***Medicaid Oral Health Coverage for Adults with Intellectual & Developmental Disabilities –  
A Fiscal Analysis***

National Council on Disability, March 9, 2022  
Celebrating 38 years as an independent federal agency

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## National Council on Disability

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An independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families.

### Letter of Transmittal

March 9, 2022

President Joseph R. Biden Jr.  
The White House  
Washington, DC 20500

Dear Mr. President,

People with Intellectual and Developmental Disabilities (I/DD) in the United States suffer significant health disparities compared to their nondisabled counterparts and report unmet medical, prescription and dental needs. With respect to dental needs, Medicaid does not uniformly provide adults with I/DD dental coverage and in 12 states no basic Medicaid dental benefits are provided for adults with I/DD, aside from limited waiver programs available in seven of those states. As a result, people with I/DD in those jurisdictions often forego preventative and routine dental care and seek emergency dental care in hospital emergency rooms at significantly greater costs.

On behalf of the National Council on Disability (NCD), your federal disability policy advisor, I submit this report for your consideration entitled *Medicaid Oral Health Coverage for Adults with Intellectual and Developmental Disabilities – A Fiscal Analysis*. In this report, NCD examines the cost in those jurisdictions of not providing Medicaid dental benefits for adults with I/DD and determines that it is more cost effective and fiscally responsible to provide those benefits than to continue excluding those benefits. Doing so is also consistent with your Administration's commitment to equity for underserved communities, including people with disabilities, and your commitment to fiscal responsibility.

This report was motivated by a central research question: should the Centers for Medicare and Medicaid Services require all state Medicaid agencies to implement Medicaid reimbursement and payment policies that promote access to dental care for adults with I/DD, and would doing so be cost-effective over the long term? The answer is "absolutely yes" to both questions. Because Medicaid adult dental benefits vary widely by state, and because there is a dearth of research on how the Medicaid program should best address oral health disparities for adults with I/DD, this report examined the relationship between states' Medicaid dental benefits and the receipt of basic dental care among adults with I/DD; the relationship between state waiver programs and receipt of dental care; and the estimated cost and potential savings of implementing basic dental Medicaid benefits in states that do not currently offer it. Additionally, this study examined the role of coordination between Developmental Disability agencies and Medicaid agencies for improving access to dental care. Finally, the study identified promising Medicaid-funded state and private strategies for expanding dental care for adults with I/DD.

Key findings include that in the 12 states that do not currently provide dental benefits, the total estimated cost of providing extensive dental benefits to adults with I/DD would be approximately

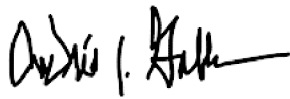
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\$19.6 million annually, with those state government's responsible for approximately \$7.3 million of that cost. NCD estimates that these costs would be more than fully recovered through reductions in emergency department use and hospital admissions and reductions in the cost of treating several chronic diseases the root cause of which are poor oral health. We estimate federal and state governments combined would realize a return on investment (ROI) of approximately \$7.7 million beyond recovering the initial cost, annually, and the share of that ROI for those 12 states would total close to \$3 million, annually.

NCD looks forward to briefing your Administration on the findings and recommendations in this report and stands ready to work with federal agencies, state governments, the disability community, and other stakeholders to facilitate better access to oral healthcare for people with I/DD through Medicaid, and to do so as a means of fiscal responsibility as well.

Respectfully submitted,

A handwritten signature in black ink, appearing to read "Andrés J. Gallegos", with a long horizontal flourish extending to the right.

Andrés J. Gallegos  
Chairman

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(The same letter of transmittal was sent to the President Pro Tempore of the U.S. Senate and the Speaker of the U.S. House of Representatives.)

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# Contents

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Acknowledgments .....	7
Executive Summary .....	9
Acronym Glossary .....	13
Introduction .....	17
Chapter 1: Research Questions and Methodology .....	21
Research Methods .....	23
<i>Virtual Stakeholder Meeting</i> .....	23
<i>Key Informant Interviews</i> .....	24
<i>Questionnaire of Directors of State Developmental         Disabilities Agencies</i> .....	24
<i>Medicaid Oral Health Policy Database (MOHPD)</i> .....	24
<i>TMSIS Data Analysis</i> .....	25
Chapter 2: Barriers to Oral Health Care for Adults with I/DD .....	27
Chapter 3: The Role of Medicaid in Providing Dental Services for Adults with I/DD .....	31
Chapter 4: Analysis of State Medicaid Dental Coverage, Medicaid Reimbursement Rates, and Receipt of Oral Health Care Among Adults with I/DD .....	35
Chapter 5: Opportunities and Recommendations for Change Within Medicaid .....	47
Opportunities in Medicaid .....	47
Medicaid-funded Initiatives to Expand Access to Services .....	51
Chapter 6: Opportunities Outside of Medicaid .....	55
Areas for Future Research .....	56
Conclusions .....	59

Key Recommendations .....	61
Congress: .....	61
States: .....	61
U.S. Department of Health and Human Services .....	62
Appendices .....	63
Appendix A: Agenda and Attendee List for Virtual Stakeholder Meeting .....	65
Appendix B: Questionnaire to State Directors of Developmental Disabilities Agencies .....	69
Appendix C: Details About the Fifty-State and DC Medicaid Oral Health Policy Database .....	73
Appendix D: <i>ICD-10</i> Diagnosis Codes for Autism Spectrum Disorder, Intellectual Disability and Related Conditions, Cerebral Palsy, and Other Developmental Delays .....	85
Appendix E: Details About T-MSIS Sample .....	87
Appendix F: Developmental Disabilities Agency Leader Questionnaire Responses About Barriers to Oral Health .....	89
Endnotes .....	93



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## Executive Summary

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Adults ages eighteen years and older with intellectual and developmental disabilities (I/DD) experience poorer oral health and significant barriers to obtaining oral health care, relative to adults without I/DD. Poor oral health not only often leads to chronic oral pain and disease, it also increases the likelihood of experiencing poor physical health. Further, poor oral health can lead to poor nutrition, poor sleep, and reduced quality of life.

Most adults with I/DD rely on Medicaid for medical and dental care. State Medicaid programs are not required to provide adults with dental benefits. Currently, twelve states do not provide adult Medicaid beneficiaries with coverage for basic dental care, exacerbating the barriers to oral health care faced by adults with I/DD.

Recent state-level research suggests that providing adults with dental benefits through Medicaid reduces overall Medicaid costs for states. Expanded Medicaid coverage has been linked to reductions in emergency department (ED) visits and hospital admittances for nontraumatic dental condition (NTDC). Further, studies indicate that receipt of basic dental

care reduces the cost of treating other chronic conditions, such as diabetes and heart disease.

Even in states that provide dental benefits in Medicaid, people with I/DD still face barriers to receiving care, in part because of the lack of dental providers who participate in Medicaid who can treat adults with I/DD. Prior research has shown that increasing Medicaid reimbursement rates for physicians increased access to medical care among all adult Medicaid beneficiaries. Prior research has also demonstrated that increasing Medicaid reimbursements for dental providers

increased receipt of dental care among children. However, prior research has not examined whether increased dental

reimbursement rates increased the availability of dental care for adult Medicaid beneficiaries with I/DD.

This report is motivated by a central research question: should the Centers for Medicare and Medicaid Services (CMS) require state Medicaid agencies to implement Medicaid reimbursement and payment policies that promote access to dental care for adults with I/DD, and could that ultimately be a cost-effective option over the long term?

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*[P]oor oral health can lead to poor nutrition, poor sleep, and reduced quality of life.*

Because Medicaid adult dental benefits vary widely by state, and because there is a dearth of research on how the Medicaid program should best address oral health disparities for adults with I/DD, this study examines multiple state- and federal-level aspects of the Medicaid program. This research examines the relationship between states' Medicaid dental benefits and the receipt of basic dental care among adults with I/DD, the relationship between state waiver programs and receipt of dental care, and the estimated cost and potential savings of implementing basic dental Medicaid benefits in states that do not currently offer it. The role of coordination between developmental disability (DD) agencies and Medicaid agencies for improving access to dental care is examined. Additionally, the study identifies promising Medicaid-funded state and private strategies for expanding dental care for adults with I/DD.

The mixed methods research approach included a comprehensive review of the literature; interviews and conversations with experts, through a stakeholder meeting and key informant interviews; a fifty-state and Washington, DC questionnaire administered to state DD agency leaders; and an analysis of Medicaid claims data provided through the Transformed Medicaid Statistical Information System (TMSIS) by CMS.

Key findings include that in the twelve states that do not currently provide dental benefits, the total

## Report's Areas of Examination

- Relationship between states' Medicaid dental benefits and the receipt of basic dental care among adults with I/DD;
- Relationship between state waiver programs and receipt of dental care;
- Estimated cost and potential savings of implementing basic dental Medicaid benefits in states that do not currently offer it;
- Role of coordination between developmental disability (DD) agencies and Medicaid agencies for improving access to dental care; and
- Promising Medicaid-funded state and private strategies for expanding dental care for adults with I/DD.

estimated cost of providing extensive dental benefits to adults with I/DD would be about \$19.6 million annually, with state governments responsible for approximately \$7.3 million of that cost. NCD estimates that these costs would be more than fully recovered through reductions in ER use and hospital admissions and reductions in the costs of treating several chronic diseases. The recovered costs would total approximately \$27.3 million nationwide

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***[I]n the twelve states that do not currently provide dental benefits, the total estimated cost of providing extensive dental benefits to adults with I/DD would be about \$19.6 million annually, with state governments responsible for approximately \$7.3 million of that cost.***

and \$8.7 million for states. In other words, federal and state governments combined would see savings, or return on investment (ROI), of \$7.7 million, and the share of that ROI that would return to the twelve states would total close to \$3 million. States' ROIs would vary, ranging from \$15,000 in Oklahoma to as high as \$829,000 in Maryland. Table 7 presents the total ROI and the states' shares of the ROI.

Another key finding is that adults with I/DD are significantly more likely to receive basic dental care if they live in states with Medicaid dental benefits for the general adult population, relative to adults with I/DD who live in states without these dental benefits. Additionally, in the twelve states that do not provide basic Medicaid dental benefits to adults, seven have Medicaid waivers that expand dental benefits for adults with I/DD. Adult Medicaid beneficiaries with I/DD in these waiver states were 50 percent more likely to receive basic dental care, as compared to adult Medicaid beneficiaries with I/DD in states without waivers.

Even in states with extensive dental benefits, only one-third of adult Medicaid beneficiaries with I/DD received basic dental care, paid for by Medicaid, in a year. Many barriers to receiving dental care for adults with I/DD remain. Among these barriers is the lack of dental providers who participate in Medicaid. Medicaid reimbursement rates are significantly lower than reimbursement rates provided by private insurers. Although

TMSIS data did not allow us to rigorously assess the impact of raising reimbursement rates on the participation of dental care providers in Medicaid (see chapter 3), prior research indicates that raising Medicaid reimbursement rates increases receipt of medical care among the general adult Medicaid beneficiaries. The report concludes with recommendations at the federal and state

levels and suggestions for more research in key understudied areas. These recommendations include the following:

**Recommendation 1:**

*Require state Medicaid programs to provide*

*adult dental benefits for people with I/DD through federal legislative mandate.* States should have flexibility in implementing dental benefits to ensure they address the needs of their I/DD population. Evaluations of existing state programs should inform the design and the implementation of these benefits.

**Recommendation 2:**

*If a requirement for extensive dental benefits is not legislated at the*

*federal level, states should add dental benefits to adults with I/DD to existing or new 1915(c), 1915(i) waivers, or 1115 demonstrations.* States can refer to waivers in other states that extend dental coverage to adults with I/DD as a starting point or template to design their own programs. States should consider available data about and evaluations of these waiver programs to prioritize the types of dental services and target populations to include in their own waivers. States can use available data as guidance to

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*[A]dults with I/DD are significantly more likely to receive basic dental care if they live in states with Medicaid dental benefits for the general adult population.*

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*Medicaid reimbursement rates are significantly lower than reimbursement rates provided by private insurers.*

maximize access to key, cost-effective dental services while balancing available funding.

**Recommendation 3:** *Other barriers to oral health care must be addressed that could be funded through state Medicaid programs.* Potential approaches include expanding the number of Medicaid providers with expertise in treating adults with I/DD (e.g., linking higher reimbursement rates to education about treatment of adults with I/DD) and addressing transportation barriers. Improved preventive daily oral care provided by caregivers can be supported through state Medicaid programs (e.g., providing oral health training to direct support professionals [DSPs]). Additionally, improving education and support for good oral hygiene for adults with I/DD and coordinating services between DD agencies and Medicaid providers may prevent more serious oral health issues and increase access to oral health care. These issues are addressed in more detail in chapter 6.

**Recommendation 4:** *Improved transparency about managed care organization (MCO) reimbursement rates is needed to identify cost-effective reimbursement rates for Medicaid*

*dental providers who treat adults with I/DD.*

States are increasingly turning to MCOs to provide health care and dental care with Medicaid funding. Most Medicaid beneficiaries receive health care through Medicaid MCOs. However, there is a lack of publicly available data about Medicaid reimbursement rates provided by Medicaid MCOs, which inhibits researchers' and policymakers' ability to assess reimbursement rates that would cost-effectively expand the pool of Medicaid dental providers who treat adults with I/DD.

**Recommendation 5:** *More research is needed to pinpoint clear procedures and policy recommendations that would reduce the need for receipt of dental care in hospital operating rooms and therefore expand access to operating rooms.* Many adults with serious I/DD receive basic dental care under general anesthesia in hospital operating rooms (ORs). Providing basic dental care in the OR is expensive. Further, adults with I/DD typically face long waiting lists to receive such care because of the shortage of available OR space for these procedures. This issue is described in greater detail in chapter 6.

## Acronym Glossary

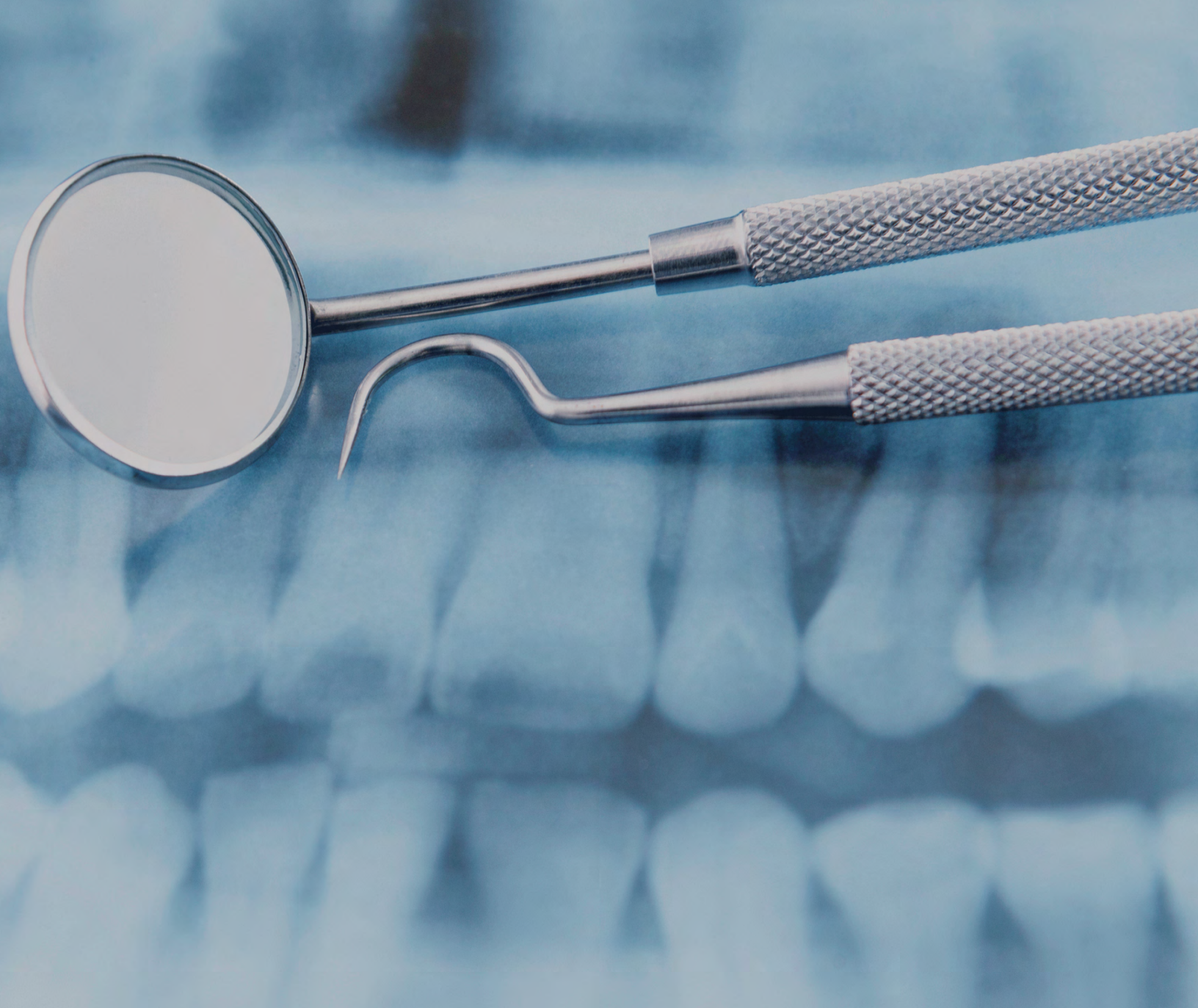
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ABLE	Achieving a Better Life Experience
ACA	Affordable Care Act, short for the Patient Protection and Affordable Care Act signed into law in 2010
ADA	Americans with Disabilities Act <i>or</i> American Dental Association, depending on context
AHRQ	Agency for Healthcare Research and Quality
CDT	Code on Dental Procedures and Nomenclature
CHIP	Children's Health Insurance Program
CLASS	Community Living Assistance Services and Supports
CMS	Centers for Medicare and Medicaid Services
CODA	Commission on Dental Accreditation
COPD	Chronic Obstructive Pulmonary Disease
DD	Developmental Disability/Disabilities
DDD	Division of Developmental Disabilities
DSP	Direct Support Professional
ED	Emergency Department
EPSDT	Early and Periodic Screening, Diagnostic, and Treatment
FFS	Fee for Service
FMAP	Federal Medical Assistance Percentage
HCBS	Home- and Community-Based Services
HEADs UP	Healthcare Extension and Accessibility for Developmentally Disabled and Underserved Populations
HPI	Health Policy Institute
<i>ICD</i>	<i>International Statistical Classification of Diseases and Related Health Problems</i>
IDD <i>or</i> I/DD	Intellectual/Developmental Disabilities
IQ	Intellectual Quotient
KII	Key Informant Interview
MC	Managed Care
MCO	Managed Care Organization
MEPS	Medical Expenditure Panel Survey
MOA	Memorandum of Agreement
MOHPD	Medicaid Oral Health Policy Database
MOU	Memorandum of Understanding

MSDA	Medicaid, Medicare, and Children’s Health Insurance Program (CHIP) Services Dental Association
NADP	National Association of Dental Plans
NASHP	National Academy for State Health Policy
NCD	National Council on Disability
NHIS	National Health Interview Survey
NIDCR	National Institute of Dental and Craniofacial Research
NJCDD	New Jersey Council on Developmental Disabilities
NTDC	Nontraumatic Dental Condition
OR	Operating Room
ROI	Return on Investment
SDF	Silver Diamine Fluoride
SMUP	Special Medically Underserved Population
T-MSIS	Transformed Medicaid Statistical Information System
WIC	Women, Infants, and Children program







The Surgeon General's Report on *Oral Health in America*, released twenty years ago, highlighted the poor oral health outcomes and barriers to obtaining adequate oral health care experienced by people with disabilities. This oral health disparity for people with disabilities remains true today.

## Introduction

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The Surgeon General's Report on *Oral Health in America*, released twenty years ago, highlighted the poor oral health outcomes and barriers to obtaining adequate oral health care experienced by people with disabilities.<sup>1,2</sup> This oral health disparity for people with disabilities remains true today. People with intellectual and developmental disabilities (I/DD) are particularly vulnerable to poor oral health outcomes.<sup>3</sup> According to numerous studies, they have poorer oral hygiene, increased prevalence of periodontal disease, higher rates of edentulism (tooth loss), and increased numbers of untreated dental caries (cavities) than the general population.<sup>4-6</sup>

One in four adults (approximately 63 million adults)<sup>7</sup> in the United States has a disability,

and approximately 7.3 million Americans have an I/DD.<sup>8,9</sup> In this report, the term *I/DD* is used to encompass both intellectual and developmental disorders that typically manifest before the age of eighteen years and “uniquely affect the trajectory of the individual’s physical, intellectual, and/or emotional development.”<sup>10</sup> An intellectual disability is often identified by an intellectual quotient (IQ) score of below seventy to seventy-five.<sup>11</sup> Conditions considered I/DDs include autism spectrum disorders, Down syndrome, fetal alcohol syndrome, and some forms of cerebral palsy, among others. While people with I/DD display a wide range of behaviors and functional abilities, I/DD is typically characterized by delays or limitations in development, intellectual learning skills, and adaptive behavior when compared to the general population.

Oral health is critical to overall physical and emotional well-being. Poor oral health is linked to multiple health conditions, including diabetes, hypertension, and other cardiovascular, endocrine, and respiratory diseases.<sup>12</sup> 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 and altered speech and affect social interactions, appearance, and behavior—all

### Poor Oral Health Outcomes of Adults with I/DD

- Poorer oral hygiene;
- Increased prevalence of periodontal disease;
- Higher rates of edentulism (tooth loss); and
- Increased numbers of untreated dental caries (cavities) than the general population.

of which are vitally important for people with I/DD.<sup>13,14</sup> Because a significant proportion of people with I/DD may not be able to verbalize how disease impacts them, and untreated oral health problems may lead to or be an indicator for serious health issues, regular access to dental services and delivery of comprehensive oral health services are vital.

Adults with I/DD, however, face substantial barriers to obtaining the oral health care services they need.<sup>15</sup> People with disabilities have a greater likelihood than those without disabilities of being uninsured or

delaying or forgoing necessary health care.<sup>16</sup>

Adults with I/DD are less likely to have private dental insurance and are more likely to delay or forgo dental care.<sup>17</sup> People with I/DD face greater barriers finding dentists to provide treatment,

such as fillings, gum therapy, and extractions when necessary, than people with other types of disabilities.<sup>18</sup> Many dentists do not treat

patients with I/DD, especially adults, because they feel unprepared to treat them.<sup>19,20</sup> Further, patients with I/DD may have to travel long distances to find a qualified dental provider; a lack of transportation is a common reason people with I/DD have trouble finding a physician, despite Medicaid providing nonemergency medical transportation services.<sup>21,22</sup>

*The Role of Medicaid.* In assessing oral health care and financing, for those with I/DD, it is crucial to examine Medicaid, the program

under which the majority of those with I/DD are enrolled and receive medical care—and, depending on the state—dental care. Nearly 60 percent of people with I/DD in the United States rely on Medicaid for health care coverage, including dental care.<sup>23</sup> And while the Affordable Care Act and Medicaid expansions have reduced barriers to health care for the general population

of adults, adults with disabilities face ongoing disparities in access to health care.<sup>24</sup>

Currently, Medicaid expends billions of dollars on dental services. In 2019, the United States spent

roughly \$143 billion on dental care every year, which represents approximately 4 percent of overall health care spending. About 11 percent of all dental expenditures were paid by the Centers for Medicare and Medicaid Services

(CMS) programs, with 9.6 percent of dental expenditures attributed to Medicaid spending.<sup>25</sup>

However, not all states provide Medicaid

coverage for routine or preventive dental services for adults with I/DD. While states are required to provide dental benefits to children enrolled in their Medicaid state plans, adult dental benefits in Medicaid are optional.<sup>26,27</sup> Currently, twelve states provide emergency-only or no dental coverage at all for adults in their Medicaid programs. Some states that do not provide dental coverage for the general adult population in their Medicaid state plan have Medicaid 1915 home- and community-based

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*Oral disease and dysfunction result in low self-esteem and altered speech and affect social interactions, appearance, and behavior—all of which are vitally important for people with I/DD.*

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*Nearly 60 percent of people with I/DD in the United States rely on Medicaid for health care coverage, including dental care.*



and/or 1115 demonstration waivers that provide dental care to people with I/DD, but these are typically small programs that do not cover the states' entire adult population with I/DD.<sup>28</sup>

*Medicaid Reimbursement.* Understanding the structure of Medicaid reimbursement for providers is important to this study's focus on cost-effective dental care for adults with I/DD. Dentists participating in Medicaid may be reimbursed by a fee-for-service (FFS) method or by Medicaid managed care organizations (MCOs). In the FFS model, dentists receive payment directly from state Medicaid agencies for each service they provide to patients. The maximum fee for each service is set by the state Medicaid program, and it is provided in a fee schedule that is publicly available.

When services are delivered through Medicaid MCOs under contract with the state Medicaid program, dentists are reimbursed in a different manner. In a managed care system, the state Medicaid program contracts with several MCOs to provide dental care to Medicaid beneficiaries. Each MCO is typically paid a capitated rate per enrolled member per month by the state Medicaid program. The MCO then negotiates a reimbursement rate with dentists who are contracted to provide care to the MCO plan participants. MCOs are not required to publicly disclose these negotiated reimbursement rates.<sup>29</sup> Reimbursements may vary by provider, type of patients, location within a state, and plan.

Some states deliver some Medicaid services through FFS and other services through MCOs. Furthermore, some state-MCO contracts are for a certain region of the state or a certain population.

Therefore, depending on the patients seen and their different coverages, dentists may bill the Medicaid MCO at the contracted rate for some patients and the state Medicaid program at the FFS rate for other patients.<sup>30</sup>

Managed care is used extensively to deliver Medicaid services nationwide; about 70 percent of all Medicaid beneficiaries currently receive health care through comprehensive managed care.<sup>31,32</sup> People with disabilities are less likely to be enrolled in managed care than people without disabilities; however, states are increasingly including enrollees with complex needs in managed care.<sup>33</sup>

There is lack of data about the reimbursement rates provided by Medicaid MCOs, which has an impact on the available

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*Currently, twelve states provide emergency-only or no dental coverage at all for adults in their Medicaid programs.*

research about reimbursement rates for dental care.<sup>34</sup> In states that provide preventive dental services, FFS rates are substantially lower

than reimbursement rates provided by private insurance companies.<sup>35</sup>

Likely in part because of low reimbursement rates, 43 percent of general dentists participate in Medicaid or CHIP, further constraining the availability of dental services for people with I/DD who rely on Medicaid.<sup>36,37</sup> About 73 percent of pediatric dentists, 56 percent of oral surgeons, and 53 percent of public health dentists participate in Medicaid or CHIP. A lower proportion of specialty dentists, like those in orthodontics (40 percent), endodontics (28 percent), and periodontics (25 percent) participate in Medicaid or CHIP. Additionally, younger dentists are more likely to participate in Medicaid than older dentists.

## Participation Rates Medicaid or CHIP

- 43 percent of general dentists
- 73 percent of pediatric dentists
- 56 percent of oral surgeons
- 53 percent of public health dentists
- 40 percent of orthodontists
- 28 percent of endodontists
- 25 percent of periodontists
- Younger dentists more likely to participate than older ones

### *Potential Cost Savings Through Provision of Preventive Dental Care.*

Without access to preventive dental services, many Medicaid beneficiaries turn to the emergency department (ED) for dental care.

There are over two million ED visits for dental conditions annually, which total \$2.7 billion.<sup>38</sup> Medicaid is the most common payer for ED visits among adults, contributing 42.2 percent of the payment for these visits.<sup>39</sup> The remainder of payments are covered through out-of-pocket payments or private insurers.

Further, prior studies have demonstrated a link between good oral health and reductions in the cost of treating chronic health conditions, such as diabetes and coronary disease.<sup>40,41</sup> Thus, states could experience cost savings in their Medicaid programs if they provide accessible preventive

dental care to Medicaid enrollees, and adults with I/DD in particular.

*Medicaid Coverage and Potential Cost Reductions.* Prior research has demonstrated the potential for cost savings of providing more extensive dental benefits in Medicaid. When Medicaid beneficiaries received comprehensive dental benefits, costly ED visits and hospital admissions for nontraumatic dental care decreased.<sup>42–45</sup> These studies, however, primarily focus on the general adult population, not on people with I/DD. The exception is a recent Texas study that focused on people with disabilities.<sup>46</sup>

*Reimbursement Rates and Access to Dental Care.* Prior research has shown that increasing physicians' Medicaid reimbursement rates led to an increase in access to health care among adult Medicaid enrollees.<sup>47</sup> And a study found that increasing Medicaid reimbursement rates

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***There are over two million ED visits for dental conditions annually, which total \$2.7 billion.***

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***Medicaid is the most common payer for ED visits among adults, contributing 42.2 percent of the payment for these visits.***

for dentists led to an increase in children's receipt of dental care.<sup>48</sup> The literature review undertaken for this study

did not uncover any research on the relationship between Medicaid reimbursement rates and receipt of dental care among adults with I/DD. Furthermore, the literature review uncovered

no research that linked reimbursement rates for Medicaid dental providers to reductions in costs for ED visits or treatment of chronic disease.

People with disabilities deserve equitable health care access and health outcomes. There are ongoing opportunities for improvement through careful review of Medicaid coverage and programmatic policies that can lead to improved outcomes and lower costs.<sup>49</sup>

## Chapter 1: Research Questions and Methodology

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This report was motivated by an overarching question proposed by the National Council on Disability (NCD): “Should the Centers for Medicare and Medicaid Services [CMS] require state Medicaid agencies to implement Medicaid reimbursement and payment policies that promote access to dental care for adults with I/DD, and could that ultimately be a cost-effective option over the long term?” To answer this question, a range of state- and federal-level Medicaid policies and programs and their effects need to be assessed.

To date, very little research has delved into the receipt of dental services among adults with I/DD on Medicaid.<sup>50,51</sup> Further, no national studies have examined the relationship between states’ policies regarding provision of dental coverage

through Medicaid or Medicaid reimbursement rates and receipt of dental services among adults with I/DD. And as described in the Introduction, there is no publicly available data regarding reimbursement rates for Medicaid dental providers who provide services under an MCO contract.

Several research questions must be answered regarding barriers to the receipt of dental services, the status of states’ Medicaid policy, the relationship between states’ Medicaid policy and receipt of dental services, and the relationship between Medicaid reimbursement rates and receipt of preventive and emergency dental services. Specifically, this report addresses the following research questions:

### Research Questions Addressed in Report

#### *Barriers to Dental Care for Adults with I/DD*

- a. What are the key barriers to receipt of dental care among adults with I/DD who receive Medicaid?

#### *Status of State Medicaid Policy and Dental Services*

- b. How do states vary in the dental coverage they provide through Medicaid?
- c. What states expand dental coverage to patients with I/DD specifically through waiver programs?

*(continued)*

## **Research Questions Addressed in Report: *continued***

### *Receipt of Dental Services Among Adults with I/DD*

- d. Among adults with I/DD who receive Medicaid, what percentage receive preventive or routine dental services annually? (Henceforth, both preventive and routine dental services are referred to as “basic dental services.”)

### *Impact and Costs of Medicaid Dental Benefits*

- e. What is the relationship between states’ Medicaid policies for dental services and the likelihood of receiving basic dental services among adults with I/DD? Are waiver programs associated with receipt of basic dental services among adults with I/DD?
- f. What is the relationship between reimbursement rates for Medicaid health care providers and receipt of health care among Medicaid beneficiaries?
- g. What is the relationship between states’ Medicaid policy and receipt of dental care in the emergency room (ER)?
- h. What are the potential cost savings associated with providing Medicaid coverage for basic dental services for patients with I/DD?

### *Lessons Learned and Recommendations for Future Medicaid Dental Coverage*

- i. What can be learned, and potentially adopted as useful policy, from states that have innovative oral health care approaches for people with I/DD?
- j. What changes to Medicaid could be recommended at the federal and state levels to increase access to dental health services?
- k. Should reimbursement rates for Medicaid dental providers be increased to improve access?

The Surgeon General’s 2000 report on oral health care among people with disabilities noted the lack of available oral health and dental care data specific to the population with disabilities and urged for the equitable measurement, collection, and reporting of such information in the future.<sup>52</sup> Data on oral health care for adults with I/DD remains difficult to obtain, even twenty years later. Thus, to comprehensively answer these research questions, NCD collected both qualitative and quantitative data

from multiple sources. NCD hosted a virtual stakeholder meeting, conducted key informant interviews (KIIs), administered questionnaires to developmental disability (DD) agency leaders in all fifty states and Washington, DC, created a Medicaid Oral Health Policy Database (MOHPD), and analyzed Medicaid claims data from all fifty states, using CMS’ Transformed Medicaid Statistical Information System (T-MSIS) data. T-MSIS is a data and systems component of CMS containing utilization and claims data on





Medicaid and the Children’s Health Insurance Program (CHIP).

## **Research Methods**

### ***Virtual Stakeholder Meeting***

In November 2020, NCD held a virtual Zoom meeting with oral health practitioners, I/DD researchers, and advocates to introduce the study to key stakeholders and solicit their perspectives and advice on the study objectives and methods. Thirty-five individuals attended the summit, including four from NCD and five members of the research team, representing over twenty organizations. Attendees included self-advocates, dentists specializing in caring for people with I/DD, direct support professionals, oral health researchers, I/DD health and policy experts, and state Medicaid and DD agency

administrators. The agenda and list of attendees are provided in Appendix A.

The research team solicited feedback on four topics through two rounds of small breakout groups, giving each attendee the opportunity to participate in discussions on two topics. These topics were (1) innovative state Medicaid policies, (2) analytic approaches to Medicaid claims data, (3) coordination between Medicaid and state DD agencies and innovative DD agency practices, and (4) coverage and reimbursement of oral health care for people with I/DD and other important considerations. Other topics discussed included the importance of and general barriers to oral health care for the adult I/DD population. Summit proceedings were recorded and transcribed, with key stakeholders cited in this report anonymously. Transcripts were reviewed

for themes as they related to the research questions and integrated experts' ideas on ways to improve access to care in this report.

### ***Key Informant Interviews***

Interviews were conducted with twenty-two KIIIs between November 2020 and July 2021. Subject matter experts were identified during the discussions at the virtual stakeholder meeting, through KIIIs, and via research. The goals of the KIIIs were to (1) explore and learn about promising practices in oral health and state policy and (2) collect recommendations from key experts about approaches to improving oral health for adults with I/DD, including opportunities within Medicaid policy. The specific questions asked in the KIIIs were tailored to the expertise of the key informant but focused on the best use of Medicaid funding to improve access to dental services and promote oral and overall health. Each interviewee offered insights on other research questions for which they had professional experience and knowledge. Notes from each interview were reviewed, themes were identified as they relate to research questions, and findings were categorized by theme. This report integrates the learnings from these interviews.

### ***Questionnaire of Directors of State Developmental Disabilities Agencies***

A questionnaire was sent to DD agency leaders in all fifty states and Washington, DC. The purpose of the questionnaire was to identify any unique or innovative strategies employed by state DD agencies in their provision of oral health services for adults with I/DD, including how they coordinate with their state's Medicaid agency. The findings helped reveal current practices and potential recommendations for future policy that could benefit adults with I/DD.

The questionnaire was further reviewed by a state DD agency leader and leaders at the National Association of State Directors of Developmental Disabilities. The questionnaire was tailored to reflect the level of Medicaid oral health benefits (none, emergency only, limited, or extensive) offered by the state of the respondent, as classified in prior research produced by the National Academy for State Health Policy (NASHP).<sup>53</sup> (This classification is captured within the aforementioned fifty-state/Washington, DC, MOHPD, described in the next section.) The questionnaire was administered on the secure Qualtrics online platform.

The questionnaire asked directors how they coordinate health care services for adults with I/DD with the state Medicaid program and how they educate people served by their agency about additional oral health services, if applicable, outside of the general dental benefits their state Medicaid program offers. The questionnaire requested a description of any additional oral health-related services and activities for adults with I/DD outside of Medicaid, if applicable. Additionally, the questionnaire asked about the inclusion of consumers or patient advocates in agency meetings, and their perspectives on the main barriers to oral health care for adults with I/DD in their state. Nonrespondents were contacted multiple times by phone and by email. Twenty-eight leaders of state DD agencies completed questionnaires. The full questionnaire is available in Appendix B.

### ***Medicaid Oral Health Policy Database (MOHPD)***

The MOHPD contains the most recently available information about key Medicaid policy dimensions related to oral health for each state's Medicaid program. The data spans the years



2015–2021, depending on data availability. The term *dimension* is used to describe a specific aspect of a state Medicaid program that is variable, in other words, subject to state policy choices and not federally mandated, or those that vary across states (e.g., a state’s Federal Medical Assistance Percentage [FMAP] rates). Dimensions were deemed salient for inclusion through KIs, literature scan, and public availability of relevant information in a usable format. The dimensions include the level of Medicaid dental benefits for the general adult population as classified by the NASHP, state waivers that cover dental access specifically for people with I/DD, state FMAP levels, the fee schedules for key adult preventive oral health services, as well as other salient dimensions.<sup>54</sup> The full explanation of dimensions and sources is provided in Appendix C.

The MOHPD was analyzed to answer the research questions, and it was merged with the T-MSIS data to assess the relationship between current state Medicaid policies and receipt of dental services, described in more detail next.

### ***T-MSIS Data Analysis***

NCD undertook an analysis of the T-MSIS data set, which contains the state Medicaid claims data available for all Medicaid beneficiaries, through CMS. NCD received a sample of over 800,000 adults with I/DD who had a Medicaid claim in 2018, the most recent year of data available at the time of the data request. Each Medicaid claim in T-MSIS data is linked to a unique beneficiary ID to track the services each beneficiary received that were paid for by Medicaid. This data was used to assess receipt of dental services, location of receipt of that care,

and the association between state Medicaid policies and reimbursement rates and receipt of preventive oral health care, utilization of EDs for dental care, and the cost to states of providing oral health care to adults with I/DD. Because T-MSIS data is limited to Medicaid claims that were paid for by the Medicaid program, receipt of services does not include services that were paid for by other insurers or were received through charity programs. For ease of writing, the term *receipt of dental services* is used throughout the remainder of the report. Reimbursement rates in T-MSIS reflect FFS payments only, as described earlier, because MCOs do not consistently report to state Medicaid agencies about the fees that are paid to providers for services rendered, and reimbursements provided by MCOs are not included in the T-MSIS data.<sup>55</sup>

Adults with I/DD in the T-MSIS were identified by whether they had a diagnosis code, displayed in Appendix D, in their 2018 Medicaid claims data, which is associated with an I/DD. CMS identified 1,134,264 beneficiaries with I/DD who received Medicaid in 2018. Appendix E provides more detail about the sample. The first column in Appendix E provides the sample size by state of adults with I/DD. The second column provides the total number of adults with I/DD in each

state who receive Medicaid, as identified by CMS based on the diagnosis codes. The third column provides the percentage of adults with I/DD in the sample in each state. The fourth column provides the percentage of Medicaid beneficiaries in each state who had an I/DD.

A representative sample of claims records for adults with I/DD was randomly selected within each state. The analytic sample used in this report represents 73 percent of adults identified with I/DD who receive Medicaid across the nation in 2018. For twenty-five states (Alabama, Alaska, Arkansas, Colorado, Delaware, Hawaii, Idaho, Iowa, Kansas, Maine, Mississippi, Montana, Nebraska, Nevada, New Hampshire, New Mexico, North Dakota, Oklahoma, Oregon, Rhode Island, South Dakota, Utah, Vermont, West Virginia, Wyoming) and the District of Columbia, the sample includes all (100 percent) adults with I/DD who received Medicaid in that state.<sup>56</sup> On average, based on these data, 2.5 percent of Medicaid beneficiaries have an I/DD diagnosis; however, that percentage varies widely by state, from a low of 1 percent in Colorado to a high of 11 percent in Wyoming. It is possible that some adults with I/DD were not identified as having an I/DD because their I/DD diagnosis was not included in their Medicaid claims.



## Chapter 2: Barriers to Oral Health Care for Adults with I/DD

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Significant strides have been made toward expanding access to oral health care and raising awareness about and addressing barriers to care for people with I/DD. New standards and policies are being considered in or adopted by state and federal legislative bodies for dental education and dental practice. The federal Action for Dental Health Act was signed into law on December 11, 2018, which signified a need to improve access to oral health care for older adults and those with disabilities, among other underserved populations.<sup>57</sup> This bipartisan legislation, which authorizes close to \$32 million in spending annually from FY 2018 to FY 2022,<sup>58</sup> amends the Public Health Service Act to fund organizations to improve oral health education and dental disease prevention, facilitate the establishment of dental homes for children and adults, and implement initiatives<sup>59</sup> that reduce ED visits for certain dental services.<sup>60</sup>

Also in 2018, following NCD's recommendation, the American Dental Association (ADA) revised its Code of Professional Conduct to state that a patient cannot be denied treatment based on their disability status alone.<sup>61</sup> Because the ADA code of conduct is often used as the basis for state laws and regulations, this change had a ripple effect on dental practices.

In 2019, the Commission on Dental Accreditation (CODA), at the recommendation of NCD,<sup>62</sup> revised its standards to require graduating dental students, dental hygienists, and other oral health professionals to be competent in managing the treatment of people with I/DD and other disabilities. The aim of this revision is to better prepare a workforce that is comfortable with and trained to provide care to those with disabilities.

Finally, in 2020, ADA's Code on Dental Procedures and Nomenclature, or Current Dental Terminology (CDT) included codes for dental case management for patients with special needs.<sup>63</sup> The CDT is a standardized set of procedural codes for oral health services produced by the ADA and used in all fifty states and Washington, DC, to achieve "uniformity, consistency and specificity in accurately documenting dental treatment."<sup>64</sup> These codes allow dental care providers to bill for the additional and important work of ensuring coordination of care for patients with special needs.

Despite these efforts to raise awareness of, and address, barriers to dental care for adults with I/DD, barriers remain. The summit attendees for this report, state DD agency leaders, and key informants all uniformly described multiple ongoing barriers to receiving oral health care. Nearly all the key informant interview interviewees and the summit participants agreed

## Recent Significant Disability Policy Developments in the Dental Profession

- 2018 – Action for Dental Health Act signed into law.
- 2018 – American Dental Association (ADA) revised its Code of Professional Conduct to state that a patient cannot be denied treatment based on their disability status alone.
- 2019 – Commission on Dental Accreditation revised its standards to require graduating dental students, dental hygienists, and other oral health professionals to be competent in managing the treatment of people with I/DD and other disabilities.
- 2020 – ADA's Code on Dental Procedures and Nomenclature, or Current Dental Terminology included codes for dental case management for patients with special needs.

that increasing access to dental care for adults with I/DD was essential for improving quality of life for this population, especially regarding socialization and employment opportunities. They additionally confirmed many barriers described in the research literature that adults with I/DD face in accessing oral health care. Five main categories of systemic barriers and challenges emerged: lack of adult Medicaid dental coverage, lack of providers who accept Medicaid, lack of trained providers, difficulty in providing for specialized care needs, and transportation. (See Appendix F for detailed descriptions of the DD questionnaire responses about these barriers.)

### (1) *Lack of adult Medicaid dental coverage:*

The lack of standardized Medicaid coverage for preventive services critical to serving this population, like silver diamine fluoride (SDF) application and use of nitrous oxide, limits dental care for adults with I/DD across states. Six DD questionnaire respondents and two key informants mentioned this as a barrier.

### (2) *Lack of providers who accept Medicaid:*

There is a lack of dental providers who serve Medicaid patients, due not only to the lack of training, but likely compounded by low Medicaid reimbursement rates. Medicaid FFS reimbursement rates are lower than those for private insurers.<sup>65</sup> As described in chapter 1, one study indicated that increasing the Medicaid reimbursement rates increased receipt of preventive dental care for children who are Medicaid beneficiaries.<sup>66</sup> Two prior studies, using rigorous quasi-experimental designs, demonstrated increases in access to medical care associated with higher reimbursement rates. The first of these studies demonstrated that increased Medicaid reimbursement, through both FFS and states' capitation rates<sup>67</sup> to managed care organizations, which were required under the Patient Protection and Affordable Care Act mandates, for certain nondental health services, led to decreases in patients' reports of physicians not accepting Medicaid beneficiaries, increases in utilization of care, and improvements in self-reported health.<sup>68</sup> The second study found that when this mandated rate increase expired in 2016, primary care appointment availability decreased for new Medicaid patients in the states that allowed their rates to decrease.<sup>69</sup>

While summit attendees cited low Medicaid reimbursement as a barrier to care, several attendees and key informants who



were interviewed mentioned that higher reimbursement does not necessarily lead to more dentists being willing to serve the I/DD population. Demonstrating this, nine DD questionnaire respondents cited a lack of providers who take Medicaid, while only four mentioned low reimbursement rates as barriers to care.

(3) *Training and education:* There is a lack of provider training and education and stigma associated with serving the I/DD population. Oral health care providers, particularly those who graduated before CODA revised its standards to include training on the management of the treatment of patients with disabilities, may be unaware of the unique needs of the I/DD population. They can find it difficult to spend the extra time and patience needed to care for patients with I/DD. Thirteen respondents to the DD questionnaire and three key informants cited a lack of trained providers and/or stigma about

treating people with disabilities as a barrier to oral health care.

(4) *Difficulties in accessing operating rooms (ORs) in hospitals for oral health procedures and providing specialized care:* Adults with serious I/DDs may require general anesthesia to receive preventive oral health care because

### **Barriers to Oral Health for Adults with I/DD**

- Lack of adult Medicaid dental coverage
- Lack of providers who accept Medicaid
- Lack of trained providers
- Difficulty in providing for specialized care needs
- Transportation

they cannot tolerate dental care otherwise. Thus, they must receive oral health care in a hospital setting or in outpatient dental surgery settings. Ten DD respondents mentioned an inability to provide specialized care as a barrier to oral health access. Research on access to oral health care for Medicaid enrollees with I/DD in California indicates that lack of access to general anesthesia for the dental care of patients with I/DD results from a lack of facilities that offer this service and accept Medicaid and hospitals'

prioritization of other surgeries over dental services in the OR.<sup>70</sup> Chapter 6 of this report addresses this issue in greater detail.

(5) *Transportation*: Even when a patient can locate a dentist who is willing to treat them, they may face barriers arranging transportation to the appointment or must drive long distances for dental care. Two DD questionnaire respondents cited transportation as a barrier to care, while four key informants mentioned the lack of providers and transportation as a barrier.



## Chapter 3: The Role of Medicaid in Providing Dental Services for Adults with I/DD

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**M**edicaid is a state-administered program that is supported by both state and federal funding. Each state agency has the authority to determine the structure of the program that best aligns with the needs and resources of its state population, as long as the state program complies with federal statutes and regulations. Although states are required to make dental care available to children and adolescents under age twenty-one years enrolled in Medicaid via the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT)

benefit, there is not a comparable mandate for adult dental benefits in Medicaid. As such, there is significant variation in Medicaid programs from state to state in terms of both eligibility

criteria and the covered services for adult dental benefits, which range from being nonexistent to extensive.<sup>71</sup> Among the general population of adults, those who live in states without an adult dental benefit in Medicaid are more likely to report that life is often “less satisfying due to the condition of mouth and teeth.”<sup>72</sup> Studies have shown that access to adult Medicaid dental benefits increases the probability of a dental visit within twelve months, underscoring the

importance of access to dental care through Medicaid.<sup>73,74</sup>

The NASHP categorized states’ adult dental benefits in Medicaid in July 2021 as no coverage, emergency only, limited, and extensive.<sup>75</sup> Twenty-three states and Washington, DC, provide extensive dental benefits for adults, with spending caps of at least \$1,000 per person per year and coverage for diagnostic, preventive, and major restorative dental services. Fourteen states

provide limited adult dental benefits with lower annual spending caps and coverage for diagnostic, preventive, and minor diagnostic dental services. Nine cover only emergency dental care for relief of

pain or infection in emergency situations. Three states do not offer any adult dental services (see Table 1). Variation in state Medicaid policy provides opportunities for studying the impact of these variations on receipt of dental care (see Appendix C and MOHPD). This classification system is used for this study and included in the MOHPD created for this study (see chapter 1).

Each state also has a distinct DDs services agency serving adults with DDs in the state.

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*Among the general population of adults, those who live in states without an adult dental benefit in Medicaid are more likely to report that life is often “less satisfying due to the condition of mouth and teeth.”*

**Table 1: Number of States’ Medicaid Programs Offering Different Levels of Dental Benefits for the General Adult Population, 2021<sup>76</sup>**

Level of Dental Benefits	Number of States
No coverage	3
Emergency only	9
Limited	15
Extensive	24

Many state Medicaid agencies, in conjunction with state DD agencies, administer 1915(c) home- and community-based services Medicaid waivers, some of which include provisions for dental care for adults with intellectual and developmental disabilities (I/DD; see Appendix C and MOHPD). The 1915(c) waivers are dependent

on funding, serving a limited number of people every year, and include specific target groups. Waiver enrollees must have met eligibility requirements for 1915(c) waivers, which means that not all adults with I/DD on Medicaid have access to dental benefits under these waivers. Additionally, some states have implemented section 1115 demonstrations that include an adult dental benefit.

Table 2 displays the states with and without waivers, in 2018, among states that provide no or emergency-only dental coverage through Medicaid. Both 1915 waivers and 1115 waivers are included in the table. Data from 2018 is displayed to align with the year of T-MSIS data used for this study. Seven of these states provided dental coverage for adults with I/DD through 1915 and/or 1115 waivers. People with I/DD in the states with Medicaid waivers (Table 2)

**Table 2: States with 1915 Waiver or 1115 Demonstration Coverage of Dental Benefits for Adults with I/DD, in 2018, Among States with No or Emergency-Only Medicaid Dental Benefits for the General Adult Population<sup>77</sup>**

State	Level of Dental Coverage for General Adult Population	Waiver Coverage of Dental Benefits for Adults with I/DD
Alabama	No coverage	N
Arizona	Emergency only	Y
Florida	Emergency only	Y
Georgia	Emergency only	Y
Hawaii	Emergency only	N
Maryland	No coverage	N
Nevada	Emergency only	N
New Hampshire	Emergency only	N
Oklahoma	Emergency only	Y
Tennessee	No coverage	Y
Texas	Emergency only	Y
Utah	Emergency only	Y

may be able to access Medicaid-covered dental care (if they fulfill waiver requirements and are enrolled in the waiver program), even though the Medicaid state plan does not cover basic dental care.

Adding further complexity to understanding state Medicaid programs, states set the reimbursement rates for medical and dental services for benefits under an FFS payment system, as described in the Introduction. According to the 2019 questionnaires conducted by Medicaid, Medicare, CHIP Services Dental Association, twenty-seven states delivered Medicaid dental services through FFS, and twenty-four states and Washington, DC, delivered Medicaid dental services through both FFS and managed care systems. These delivery models characterize adults' and children's access to dental services under Medicaid.<sup>78</sup> Under FFS, states directly pay providers for each covered service, while in managed care systems, the state pays a capitated fee per person enrolled in the plan to the MCO that delivers covered services. In a mixed system, states may contract with MCOs to deliver benefits to a certain population or provide specific services.<sup>79</sup> In key informant interviews, several stakeholders noted that states are moving toward more managed care delivery systems for

their Medicaid programs. Close to 70 percent of Medicaid enrollees nationwide are enrolled in managed care programs,<sup>80</sup> and 44 percent of Medicaid beneficiaries with disabilities were enrolled in managed care limited-benefit plans in 2018, which include dental benefits in many states.<sup>81</sup> Reimbursement rates under managed care systems may differ from Medicaid FFS fee schedules. Reimbursement rates under managed care plans are not required to be publicly available.<sup>82</sup>

State fee schedules are the Medicaid FFS maximum reimbursement rates to health care

providers or suppliers.

These are made publicly available by Medicaid agencies in each state. One 2016 study from the American Dental Association compared Medicaid

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*On average, for adult dental services, FFS rates are only 37 percent of those charged by dentists and 46 percent of private dental insurance reimbursement.*

FFS reimbursement rates for child and adult dental care services across states, additionally comparing them to private insurance reimbursement rates and the rates providers charge for these same services. The study found considerable variation in FFS rates for dental care across states and, overall, found Medicaid FFS reimbursement rates to be low. On average, for adult dental services, FFS rates are only 37 percent of those charged by dentists and 46 percent of private dental insurance reimbursement.<sup>83</sup>



## Chapter 4: Analysis of State Medicaid Dental Coverage, Medicaid Reimbursement Rates, and Receipt of Oral Health Care Among Adults with I/DD

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This chapter presents the results of the T-MSIS data analysis. NCD merged the Medicaid Oral Health Policy Database created for this study (see chapter 1) with the T-MSIS Medicaid claims data by the state of residence of the Medicaid beneficiary. The analysis was restricted to adults with I/DD, as identified by an I/DD diagnosis in the T-MSIS data. As noted in chapter 1, the T-MSIS analysis uses data from 2018, the most recent year available at the time of the T-MSIS data request.

NCD used three key pieces of data in the analysis: (1) Code on Dental Procedures and Nomenclature (CDT) codes to identify the dental care services that the beneficiary received in 2018; (2) an indicator of whether dental services were received in the emergency department (ED); and (3) *International Statistical Classification of Diseases and Related Health Problems, Tenth Revision (ICD-10)* codes to identify diagnoses. The first two variables are available for all medical or dental services that the beneficiary received in 2018. The *ICD-10* codes are available for services provided in hospitals, EDs, and ambulatory/urgent care centers. NCD presents state- and national-level analyses to address the research questions. The state data was weighted, based on the sampling design, to estimate an average across the nation. NCD then identified relationships between variables that are statistically significant.

Throughout the report, the shorthand “receipt of dental services” is used to mean receipt of dental services that were paid for by Medicaid. It is important to note that while the T-MSIS data includes only services that are paid by Medicaid, a Medicaid beneficiary may receive services that are not included in the T-MSIS data. The T-MSIS data does not include noncovered services or denied claims; therefore, it is possible for a Medicaid beneficiary to receive services through a federally qualified health clinic that did not submit a claim for noncovered services. Furthermore, if a Medicaid beneficiary received services through a charity (e.g., a Special Olympics dental clinic) or received services that were paid out-of-pocket or through another insurance plan, these services would not be included in the T-MSIS data. The estimates in this report may not include all dental services that an adult with I/DD received in 2018.

This chapter presents the following analyses for adults with I/DD: (1) the percentage of adults with I/DD who receive basic dental care by state; (2) the relationship between state Medicaid coverage of dental services and receipt of basic dental care; (3) the relationship between state Medicaid waivers that cover dental services and receipt of dental care in the ED; and (4) the potential return on investment (ROI) of expanding

dental care to adults with I/DD in states that do not currently do so, including estimates of the cost of expanding coverage relative to potential savings as a consequence of decreased ED use and reductions in cost of treatment of chronic diseases.

*Receipt of Basic Oral Health Care Among Adults with I/DD.* First, NCD examined the percentage of adults with I/DD who received basic oral health services by state in 2018. NCD then identified basic oral health services by CDT codes.<sup>84</sup> Basic dental services, as defined by CDT codes, were provided in four settings: ambulatory/urgent care, inpatient hospital setting, ED, or “other setting.” For this analysis, the focus was on basic dental services provided in “other settings,” which were likely dentists’ offices, capturing the type of dental care that is the focus of this report. Adults with I/DD may also receive basic dental care in an inpatient hospital or ambulatory care setting; however, some inpatient care may reflect admittance to the hospital after an ED visit for an oral health emergency, and some care provided in ambulatory or urgent care settings may reflect care resulting from an emergency. Thus, NCD focused on basic care offered in “other settings” in this section.<sup>85</sup>

These percentages ranged widely by state, with a low of 5 percent in Utah and a high of 71 percent in the District of Columbia (Table 3). This national average of 24 percent matches prior

estimates of use of dental benefits by Medicaid beneficiaries who live in states with extensive benefits.<sup>86</sup>

*Number of Adults with I/DD by State Policy.* Table 4 shows the number of adults with I/DD who live in states by the state Medicaid dental policy. NCD used the categorization of dental policies created by the NASHP described in chapter 3. Approximately three-quarters of adults with I/DD who receive Medicaid live

in states with either extensive or limited adult dental benefits. However, 23 percent (over 250,000 adults with I/DD who receive Medicaid) live in states

with either emergency-only or no coverage. In Tables 5 to 7, NCD calculated the cost and ROI of providing basic dental care for adults with I/DD in those states.

*State Medicaid Policy and Receipt of Preventive Care.* NCD examined the likelihood of receiving basic dental care among adults with I/DD by the Medicaid

policy for basic dental care of the state in 2018 in which they lived. The categorization of dental policies in 2018 was used to match the T-MSIS data. As shown in Figure 1, NCD found a strong association between states’ Medicaid policies and receipt of dental care. Adults with I/DD were over three times as likely to receive basic dental care if they lived in a state with extensive or limited Medicaid dental coverage, relative to states with no coverage, and 1.5 times as likely to receive

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***On average, 24 percent of adult Medicaid beneficiaries with I/DD nationwide received basic dental services during 2018.***

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***23 percent (over 250,000 adults with I/DD who receive Medicaid) live in states with either emergency-only or no coverage.***

**Table 3: Percentage of Adults with I/DD Who Received Basic Dental Care, by State, 2018<sup>87</sup>**

State	Percentage (%)	State	Percentage (%)
Alabama	5	Montana	56
Alaska	49	Nebraska	59
Arizona	25	Nevada	22
Arkansas	27	New Hampshire	14
California	27	New Jersey	48
Colorado	44	New Mexico	53
Connecticut	48	New York	22
Delaware	8	North Carolina	48
District of Columbia	71	North Dakota	64
Florida	27	Ohio	38
Georgia	17	Oklahoma	33
Hawaii	8	Oregon	48
Idaho	48	Pennsylvania	36
Illinois	25	Rhode Island	48
Indiana	55	South Carolina	42
Iowa	56	South Dakota	71
Kansas	36	Tennessee	26
Kentucky	40	Texas	21
Louisiana	8	Utah	5
Maine	17	Vermont	56
Maryland	14	Virginia	6
Massachusetts	57	Washington	43
Michigan	30	West Virginia	14
Minnesota	54	Wisconsin	41
Mississippi	21	Wyoming	40
Missouri	29	<b>National average (weighted)</b>	<b>24</b>

basic dental care, relative to states with emergency-only coverage. This relationship was statistically significant. Furthermore, Figure 2 demonstrates that the higher levels of receipt of basic dental care in the emergency-only

states, relative to the no-coverage states, are likely a consequence of waiver programs in the emergency-only states that provide dental services for some people with I/DD in those states.

**Table 4: Number and Percentage of Adults with I/DD by State Medicaid Benefits for the General Adult Population, 2018<sup>88,89</sup>**

	Population	Percentage (%)
Extensive	567,692	50
Limited	305,625	27
Emergency only	222,857	20
No coverage	38,090	3
<b>Total</b>	<b>1,134,264</b>	<b>100</b>

**Table 5: Estimated Total Cost and States' Share of Total Cost to Provide Extensive Dental Coverage to Adults with I/DD, in States with Emergency or No Coverage**

State	Total Cost	Cost to State
Alabama	\$2,290,420	\$628,033
Arizona	\$1,428,287	\$428,343
Florida	\$1,632,161	\$620,874
Georgia	\$2,549,957	\$840,721
Hawaii	\$579,963	\$272,466
Maryland	\$2,574,349	\$1,287,175
Nevada	\$616,038	\$226,086
New Hampshire	\$821,700	\$410,850
Oklahoma	\$162,916	\$52,150
Tennessee	\$1,252,377	\$424,556
Texas	\$4,716,186	\$1,801,111
Utah	\$969,234	\$314,807
<b>Total</b>	<b>\$19,593,588</b>	<b>\$7,307,172</b>

The analysis shows a clear trend. The more extensive the dental coverage provided by the state Medicaid program, the greater the likelihood that adults with I/DD would receive preventive dental services paid for by Medicaid. Chapter 5 describes the implications of these results for Medicaid policy reform.

It is important to note, however, that even in states with extensive dental benefits, two-thirds of adults with I/DD and who have Medicaid still do not receive basic dental care, paid for by Medicaid, as shown in Figure 1. This likely reflects the many barriers to dental care faced by people with I/DD, as described in chapter 2.



**Table 6: Estimated Total Cost Reductions and States' Share of Total Savings Resulting from Providing Basic Dental Coverage to Adults with I/DD, in States with Emergency-Only or No Coverage**

State	Total Cost Savings	Cost Savings to State
Alabama	\$3,475,205	\$952,901
Arizona	\$1,619,792	\$485,776
Florida	\$2,130,424	\$810,413
Georgia	\$3,735,944	\$1,231,741
Hawaii	\$649,142	\$304,967
Maryland	\$4,233,956	\$2,116,978
Nevada	\$700,984	\$350,492
New Hampshire	\$770,919	\$282,927
Oklahoma	\$210,330	\$67,327
Tennessee	\$1,626,656	\$551,436
Texas	\$6,511,649	\$2,486,799
Utah	\$1,615,682	\$524,773
<b>Total</b>	<b>\$27,280,683</b>	<b>\$10,166,530</b>

**Table 7: Total Return on Investment and Return on Investment by State of Providing Basic Dental Coverage in States that Currently Have No or Emergency-Only Medicaid Dental Coverage for Adults with I/DD**

State	Total Return on Investment (Cost – Cost Reduction)	Share of ROI for States
Alabama	\$1,184,785	\$324,868
Arizona	\$191,505	\$57,432
Florida	\$498,263	\$189,539
Georgia	\$1,185,988	\$391,020
Hawaii	\$69,180	\$32,501
Maryland	\$1,659,606	\$829,803
Nevada	(\$120,716)	(\$60,358)
New Hampshire	\$154,881	\$56,841
Oklahoma	\$47,414	\$15,177
Tennessee	\$374,279	\$126,881
Texas	\$1,795,463	\$685,687
Utah	\$646,448	\$209,966
<b>Total</b>	<b>\$7,687,095</b>	<b>\$2,859,358</b>

Figure 1. Percentage of Adults with I/DD Receiving Basic Dental Care, by State Policy Context, 2018<sup>90</sup>

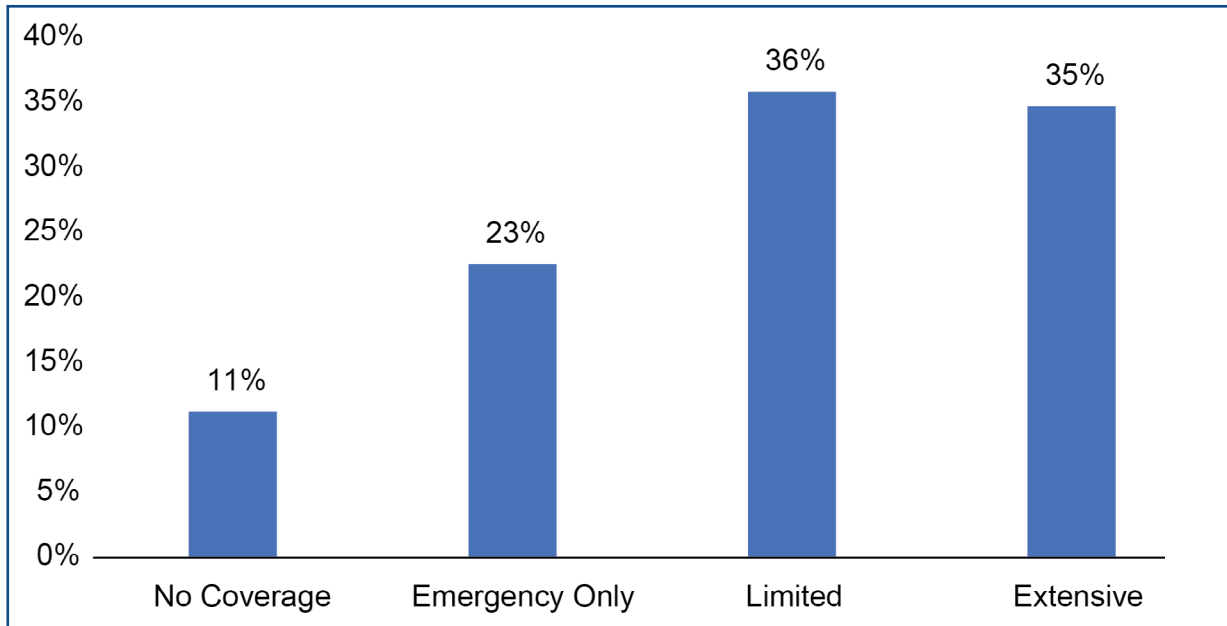
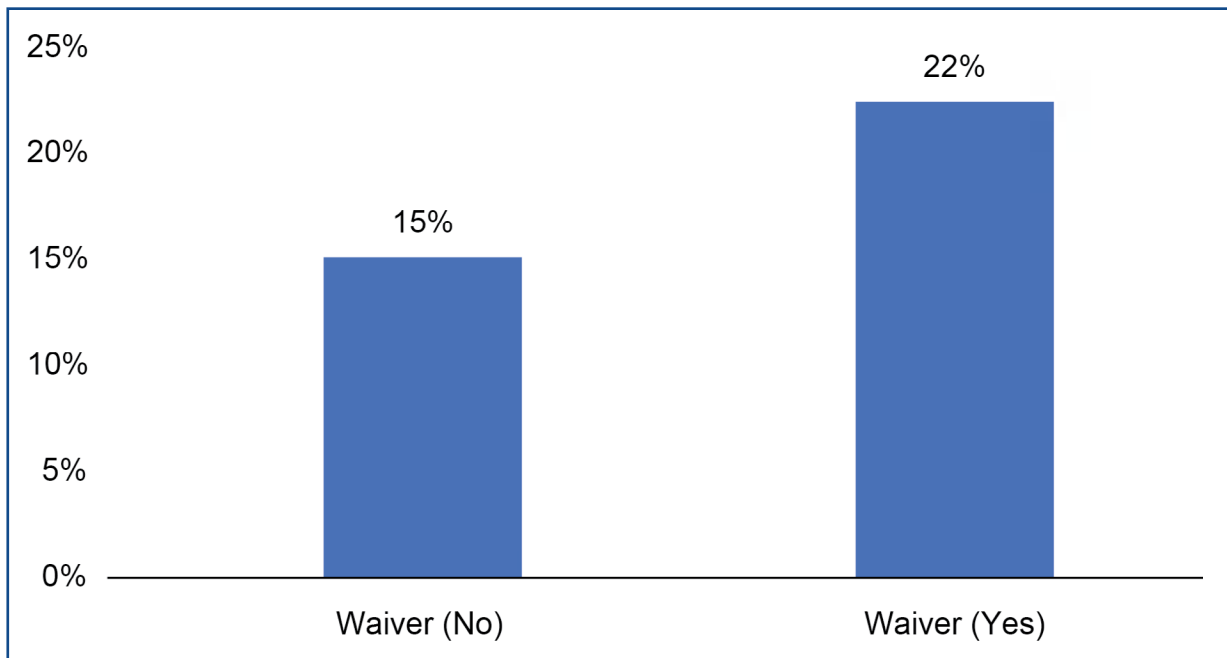


Figure 2. Percentage of Adults with I/DD Receiving Basic Dental Care in States with No or Emergency-Only Medicaid Dental Care, by Whether the State Has a Waiver Program<sup>91</sup>



*1915 Waivers and 1115 Demonstrations and Receipt of Preventive Services.* Adults with I/DD who live in states with 1915 waivers or 1115 demonstrations that cover dental care for adults with I/DD, as shown in Table 2, were 47 percent more likely to receive basic dental services (Figure 2) relative to states without waivers. This analysis was limited to the states that either have no coverage or emergency-only coverage, in 2018, because adults in these states do not otherwise have access to Medicaid coverage for basic dental services, except through waivers. Some of the waivers in these states provide extensive coverage for dental services; however, they typically do not cover the entire population of adults with I/DD in the state. This likely explains why waivers are associated with a 47 percent increase in receipt of dental services, compared to the larger increase in receipt of basic dental services that more expansive Medicaid benefits provide (Figure 1).

Six of the seven states with waivers provide emergency-only dental coverage for the general adult population. Only one of the seven states with waivers provides no dental coverage for the general adult population (see Appendix C for more information about the methodological approach to reviewing and classifying state

1915 waivers and 1115 demonstrations). Thus, this analysis suggests that Medicaid waivers for dental services for the I/DD population are associated with the higher receipt of basic dental care among adults with I/DD in states with emergency-only dental coverage (Figure 1), relative to adults in states with no dental

coverage.

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***[E]ven in states with extensive dental benefits, two-thirds of adults with I/DD and who have Medicaid still do not receive basic dental care, paid for by Medicaid . . .***

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***Medicaid waivers for dental services for the I/DD population are associated with the higher receipt of basic dental care among adults with I/DD in states with emergency-only dental coverage . . . , relative to adults in states with no dental coverage.***

*Reimbursement Rates and Receipt of Dental Care.* As described in the Introduction, prior research has shown that increased Medicaid rates led to increases

in receipt of dental care among child Medicaid beneficiaries and medical care among the general adult population of Medicaid beneficiaries.<sup>92</sup> These studies examined the effects of policies that raised Medicaid rates on changes in receipt of health care among Medicaid beneficiaries.

Because of data limitations, the T-MSIS data could not be used to measure the effects of reimbursement rates on the receipt of dental care among the adult I/DD population. The T-MSIS data does not include payment for services provided by Medicaid MCOs. As

mentioned in the Introduction, MCOs are not required to make their reimbursement rates public.<sup>93</sup> The MOHPD provides fee schedules for states with Medicaid dental benefits. As described in the Introduction, fee schedules are the maximum payment a Medicaid provider can

receive through FFS payment from the state Medicaid agency. The MOHPD also provides, when available, separate fee schedules or increased rates for dental services through waiver programs, for people with I/DD, relative to the general adult population. There is no systematic data source available for these separate fee schedules for waiver programs or the I/DD population. Dental fee schedules for the general adult population are not available for states with no Medicaid adult dental coverage.

*Receipt of Dental Care in the ED.* NCD examined the percentage of dental care that was received in the ED by state Medicaid policy environment

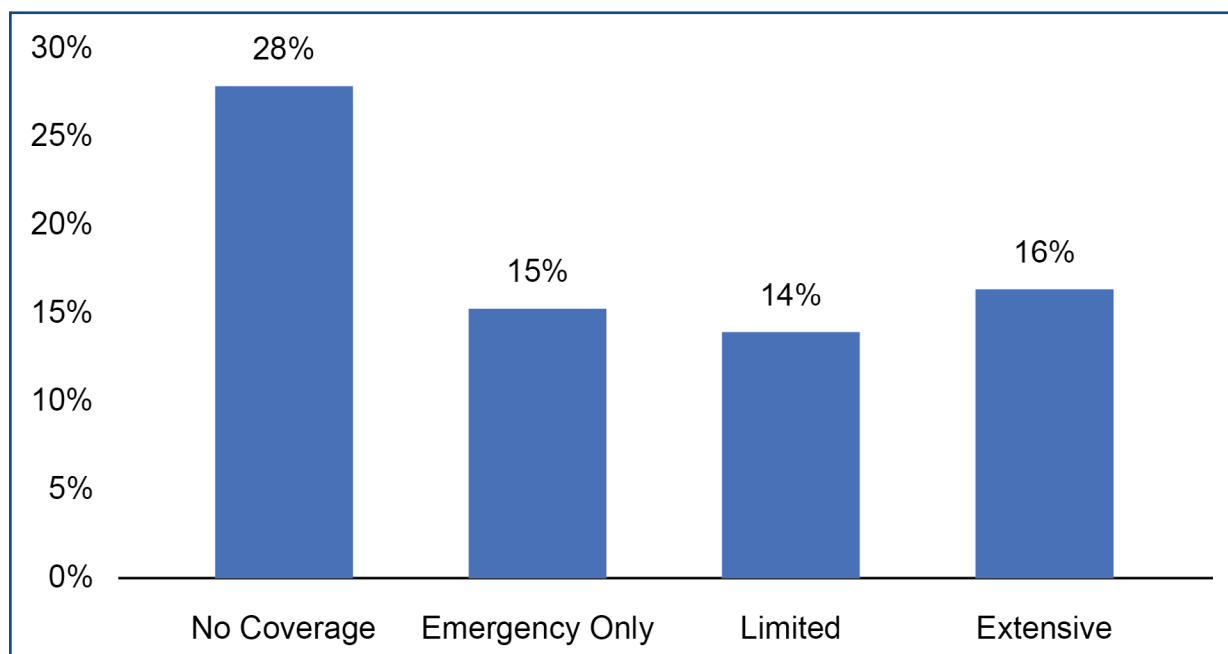
***NCD found that in states that provide no dental coverage in their Medicaid plans, a significantly higher proportion of dental care was provided in the [emergency department].***

(Figure 3). The sample was restricted to adults with I/DD who received some dental care in 2018, and *receipt of dental care* in the ED was defined as care for nontraumatic dental conditions provided in the ED, based on *ICD-10* codes.<sup>94</sup>

NCD found that in states that provide no dental coverage in their Medicaid plans, a significantly higher proportion of dental care was provided in the ED. Thus, although these states provide less dental care overall, more of that dental care takes place in a more costly environment of the ED.

*Potential Cost.* In this analysis, NCD first estimated the cost to federal and state

**Figure 3. Percentage of Adults with I/DD Who Received Dental Services in the ED, Among Adults with I/DD who Received Dental Services, by State Policy Context, 2018<sup>95</sup>**



governments of expanding Medicaid to include basic dental services for adults with I/DD in states that do not currently do so. NCD then analyzed the expected savings and the ROI to federal and state governments of providing this dental coverage to adults with I/DD.

To estimate the costs of providing dental benefits to adults with I/DD living in states that currently provide no or emergency-only dental benefits, NCD multiplied the per person/per year cost of dental care by the estimated increase in the number of adults with I/DD who would access basic dental care, if states changed their Medicaid policy. More specifically, the annual additional costs to states were derived using the following equation:

$$\text{Annual additional costs to states} = \text{Ann est cost/ person} * [\text{EN} - \text{CN}] * (1 - \text{FMAP})$$

where

*EN* is the expected number of adults in a state that would receive basic dental care under a more comprehensive dental plan = [Number of adults with I/DD in a state] \* 35 percent<sup>96</sup>

*CN* is the current number of adults who receive basic dental care in a state<sup>97</sup>

*Ann est cost/person* is the estimated annual cost of providing dental care/per person/per year under a plan that covers basic dental care. This estimate comes from the cost of providing basic dental benefits specifically for adults with developmental disabilities through a recent state waiver program that covers basic dental services.<sup>98</sup> NCD adjusted this figure for annual inflation and state variation in the cost of providing dental services.<sup>99</sup>

*FMAP* is the Federal Medical Assistance Percentage, the percentage of Medicaid costs

that the Federal Government pays each state; 1-FMAP is the percentage of Medicaid costs paid by the state. These rates are provided in the MOHPD created for this project and vary by state.

Table 5 provides an estimate of the expected cost to states of providing extensive dental benefits (a term we use interchangeably with “basic dental coverage”) to adults with I/DD in states that currently provide no or emergency-only dental care. The total cost is estimated to be \$19.6 million. The total cost to states would be \$7.3 million. The cost to the Federal Government would be about \$12.3 million [Total Cost – State Share of Cost].

*Potential Cost Reduction.* Receiving preventive dental care can lead to cost reductions through reduced use of the ED, and resulting hospital admittance, for nontraumatic dental injuries. Improved oral health is also associated with reductions in chronic conditions and lower costs of treating chronic conditions. The Centers for Disease Control and Prevention’s 2019 umbrella review,<sup>100</sup> which is a comprehensive assessment of rigorous scientific studies,<sup>101</sup> identified diabetes, cardiovascular disease, cerebrovascular disease, chronic obstructive pulmonary disorder (COPD), dementia, psoriasis, and lung cancer as health conditions most closely associated with preventable oral health conditions. Furthermore, an analysis by the National Association of Dental Plans (NADP) indicates that medical costs for Medicaid beneficiaries who have access to dental benefits were lower for ten chronic conditions (coronary heart disease, diabetes, high blood pressure, heart attack, stroke, angina, other heart disease, cancer, high cholesterol, and asthma).<sup>102</sup>

## Health Conditions Most Closely Associated with Preventable Oral Health Conditions

- Diabetes
- Cardiovascular disease
- Cerebrovascular disease
- Chronic obstructive pulmonary disorder (COPD)
- Dementia
- Psoriasis
- Lung cancer

NCD estimate the cost reductions based on avoidance of ED and hospital use and reductions in treatment costs for people with these chronic conditions as follows:

Annual cost reductions for states = Ann est cost/ person \* est. percent of people to experience event/chronic condition \* [EN – CN] \* (1-FMAP)

The number of adults with I/DD who experience the chronic conditions by state was derived from analysis of T-MSIS data, where possible, and from national estimates, otherwise.<sup>103</sup> The estimated percentage of people who avoided hospital admission for nontraumatic dental care was obtained from an analysis completed by the Health Policy Institute, based on Texas Medicaid data.<sup>104</sup> The estimated percentage of people who would avoid an ED visit for a nontraumatic dental issue was obtained through analysis of T-MSIS data.<sup>105</sup> And the reduced costs of treatment for chronic conditions

were derived from estimates produced by the NADP, using data from the Medical Expenditure Panel Survey (MEPS).<sup>106</sup> These figures were adjusted for inflation.

The analysis demonstrated that the total cost reduction of implementing a dental benefit is \$27.3 million. The cost reduction to states is a combined \$10.2 million. The savings to the Federal Government is an estimated \$17.1 million. These estimates are likely conservative because, for many of the estimates of the frequency of chronic conditions, NCD drew from the NADP's MEPS analysis for the general adult population. People with disabilities tend to experience higher levels of chronic conditions than do people without disabilities.

*Return on Investment.* To calculate the ROI, NCD subtracted the cost of providing dental coverage from the savings that would result from providing dental coverage (Table 7). The estimates demonstrate that the total ROI would be \$7.7 million. States' share of the ROI would be close to \$3 million. States' ROIs vary substantially. For example, Oklahoma would have an ROI of about \$15,000, while Maryland would have an ROI of about \$830,000. In only Nevada would the cost of implementing a dental benefit exceed savings by a minimal amount. Nevada is estimated to spend only an additional \$60,000 from implementing a Medicaid dental benefit for adults with I/DD, in exchange for having the preventive dental care of its adult citizens with I/DD covered.

*Unmeasured Return on Investment.* It is important to note that the conversations with key informants and stakeholders encouraged an expansion of the definition of ROI. Outcomes that are not easily quantifiable should also be considered an ROI. For example, improved oral health would decrease chronic pain, improve

quality of life, and increase self-confidence to socialize and seek employment.

*Summary of TMSIS Analysis Results.* In summary, the key findings from the TMSIS analysis include the following: (1) covering basic dental care in Medicaid will likely lead to significantly greater receipt of dental care among adults with I/DD; (2) Medicaid waivers that cover basic dental care for

adults with I/DD are also likely to increase receipt of basic dental care, but not to the same extent as providing a general adult Medicaid dental benefit; and (3) even with dental coverage in Medicaid, approximately two-thirds of adults with I/DD who receive Medicaid did not receive basic dental care, paid for by Medicaid. This suggests significant barriers to dental care beyond states' Medicaid coverage that must be addressed.

Furthermore and vitally, regarding the cost, savings, and ROI for providing basic dental coverage, (1) the ROI of providing basic

Medicaid dental coverage for adults with I/DD for federal and state governments is estimated to total \$7.7 million, and states' share of that is estimated to be close to \$3 million; (2) the twelve states that currently do not provide extensive dental coverage would likely spend between \$52,000 (in Oklahoma) and \$1.8 million (in Texas) to provide such coverage to the

adult I/DD population; and (3) eleven of the twelve states that do not currently provide coverage of basic dental services in Medicaid would likely recoup all of these costs through the reduced cost of treating people with chronic

conditions and reductions in ED use and hospital stays for nontraumatic dental care.

It is important to note that the cost to quality of life of not having access to basic dental care is not counted in this ROI model. Basic dental care is essential for better life quality, and adults with I/DD are entitled to equitable supports to have a high quality of life.

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***[T]he ROI of providing basic Medicaid dental coverage for adults with I/DD for federal and state governments is estimated to total \$7.7 million, and states' share of that is estimated to be close to \$3 million.***





## Chapter 5: Opportunities and Recommendations for Change Within Medicaid

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This section presents findings from the KII, stakeholder group, and DD questionnaire responses about the best use of Medicaid funding to reduce preventable oral health issues; recent state changes in Medicaid oral health policy, including pilot, promising, and unique initiatives; and promising practices of state DD agencies regarding oral health care for the adults they serve. NCD also assesses the extent to which the expert, stakeholder, and state administrator opinions align with the quantitative data analysis.

### Opportunities in Medicaid

*Providing Comprehensive Coverage of Dental Services in Medicaid.* About one in four adults with I/DD who rely on Medicaid live in states that do not cover basic dental services in their Medicaid programs (Table 4). Key informants and stakeholders identified the lack of comprehensive dental benefits in all states as a major barrier to accessing dental care for adults with I/DD. Similarly, T-MSIS analysis showed a strong and clear association between states' Medicaid policy and the likelihood that an adult would receive basic dental care. Adults with I/DD living in states with coverage of dental care for the general adult population were substantially more likely to receive basic dental services, relative to adults with I/DD living in states with no dental care (Figure 1).

*Federal Legislation.* Comprehensive dental care could be mandated through legislation at the federal level for the adult Medicaid population, as was done for Medicaid-enrolled children in 1967 through the Medicaid EPSDT amendments, enacted as part of amendments to the Social Security Act.<sup>107</sup> Federal legislation would ensure that adult Medicaid beneficiaries with I/DD have ongoing access to dental coverage, regardless of whether states prioritize dental benefits for the general adult population in Medicaid in the future.

*State Policy Change.* Alternatively, the twelve states that do not currently require basic dental care could do so at the state level. Louisiana provides an example of a potential state pathway to coverage of dental services. Governor John Bel Edwards signed House Bill 172 into law, which extends comprehensive coverage of dental care for adults twenty-one years or older with I/DD who are enrolled in any Medicaid waiver program starting August 1, 2021. The coverage includes diagnostic, preventive, restorative, endodontic, periodontal, orthodontic, and prosthodontic services, oral and maxillofacial surgery, and emergency care.<sup>108</sup> Other states can follow this pathway by granting waiver enrollees with I/DD dental coverage through their state legislatures.

*State Waivers to Provide Dental Benefits.* States have the option to provide dental benefits through 1915(c), 1115 demonstrations, and 1915(i)

waivers. The MOHPD shows the states that have implemented 1915(c) home- and community-based services (HCBS) waivers and 1115 demonstrations to expand oral health benefits for the I/DD population. Additionally, twelve states and Washington, DC, have implemented 1915(i) state plan HCBS waivers to offer HCBS through the Medicaid state plan instead of through a waiver program. The 1915(i) waivers can target HCBS benefits to certain populations, increase financial eligibility for 1915(i) programs, establish a new Medicaid eligibility group for people eligible for state plan HCBS, and define the HCBS included in the benefit.<sup>109,110</sup> These waiver options offer an opportunity for Medicaid innovation and enhanced services for oral health for all or subsets of Medicaid enrollees. States can add dental services to existing 1915(c) or 1915(i) waivers or implement new waivers to provide increased coverage for oral health and expand services to specific populations, such as people with I/DD. The T-MSIS analysis demonstrated that waivers increase access to basic dental care in states without Medicaid dental coverage.

Texas provides an example of such waiver programs. Texas has several 1915(c) waiver programs and a 1115 demonstration program that offer enhanced dental benefits to adults with I/DD. A state-mandated dental study to evaluate these Medicaid waiver programs found that the dental benefits offered by the Community Living Assistance Services and Supports (CLASS) waiver were most cost effective in reducing nontraumatic dental condition (NTDC) ED visits. Compared to three other Texas Medicaid waiver

programs, people receiving CLASS services had lower ED utilization, while maintaining relatively low dental costs.<sup>111</sup> The state used these findings to inform which benefits should be offered in a state-mandated pilot program. Other states could use the Texas pilot as a model for extending dental benefits in their own states. A unique aspect of the state-mandated pilot program is it targets individuals with similar functional needs, rather than limiting it to people with a particular diagnosis.<sup>112</sup>

*Flexibility.* Owing to the wide range of functional and health needs within even a single I/DD diagnosis, like autism spectrum disorder, it is important for state and federal Medicaid

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***A unique aspect of the state-mandated pilot program is it targets individuals with similar functional needs, rather than limiting it to people with a particular diagnosis.***

policies to remain flexible and tailored to meet functional, rather than diagnosis-based, needs. Different patients, depending on type and/or severity of I/DD, may need different covered

services or different frequency of services. This type of flexibility can be incorporated into Medicaid coverage. For example, eligibility for some Texas waiver programs, described earlier, is based on functional capacity, not the individual's diagnosis.<sup>113</sup> While there are specific eligibility requirements to qualify for services under 1915(c) waivers, states have flexibility within these requirements, including in designating target populations and covered services.

*Incentives.* Key informants also noted the importance of ensuring there are incentives for expanding care to certain populations, such as people with I/DD. One such structure that could be implemented on the federal level would be to increase the FMAP for states that expand oral

health care to adults with I/DD. The FMAP is the percentage of state Medicaid expenditures the Federal Government contributes to the state.<sup>114</sup> The Patient Protection and Affordable Care Act (ACA) created a recent precedent for such incentives, the Balancing Incentive Program, which increased the FMAP to states that made structural changes to increase long-term care services in HCBS.<sup>115</sup> This mechanism could potentially be used to encourage increased training for oral health providers in treating patients with special needs.

*Expanding Medicaid-Covered Dental Services in States with Dental Benefits.* States that currently cover dental services in their Medicaid plans could expand reimbursement for certain dental codes to better serve adults with I/DD. Specific services that dental providers noted should be covered in Medicaid for adults with I/DD included (1) SDF application; (2) teledentistry; (3) house calls; and (4) desensitization and other behavior management techniques (e.g., use of a weighted blanket). The CDT codes developed by the American Dental Association that are used to bill insurers, including Medicaid, already contain codes related to these services, for which some states already reimburse providers. NCD's review of the most recently available Medicaid dental fee schedules for each state (fee schedules are from 2020 and 2021) found that twenty-five states reimburse for SDF application for adults (D1354-Interim Caries Medicament-Silver Diamine Fluoride Application—Arizona, Colorado, Connecticut, Delaware, Hawaii, Illinois, Iowa, Kentucky, Massachusetts, Michigan, Minnesota, Montana, Nebraska, Nevada, New Jersey, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, South Dakota,

Vermont, Virginia, Washington, Wisconsin), while far fewer states, just ten, reimburse for teledentistry (D9995 and/or D9996—Colorado, Massachusetts, Missouri, Montana, New Jersey, New Mexico, North Carolina, Oregon, Virginia, Washington). Twenty-four state Medicaid fee schedules contain fees above \$0 for D9410, the house/extended care facility call code (home visit), in their Medicaid fee schedules, but states have different restrictions on how providers can use this code. *D9410*. Some states, like Rhode Island, only allow providers to bill this code once per facility visit, regardless of the number of patients seen, while other states, such as Washington and California, are allowed to bill this code once per patient. The behavior management codes D9920 and D9997 are sometimes used by providers to bill for desensitization and other behavior management techniques. Thirteen states reimburse providers for behavior management (D9920-behavior management, by report) in their fee schedules for adults (Arizona, Connecticut, Massachusetts, Minnesota, Montana, New Jersey, New York, Oregon, Pennsylvania, Rhode Island, South Dakota, Vermont, Washington), and three states reimburse for dental case management—patients with special health care needs, D9997 (Connecticut, Missouri, Oregon).<sup>116</sup>

*Expanding Technical Assistance for Provision of Dental Services.* CMS could include guidance on providing care to adults with I/DD through technical assistance mechanisms, including hosting webinar series and learning collaboratives, supporting data reporting, and engaging in intensive one-on-one work with targeted states, including the development of waivers (see later in this chapter).<sup>117</sup> CMS already has technical assistance mechanisms in place.

In 2010, CMS launched the Oral Health Initiative to work with states to improve Medicaid-enrolled children’s use of preventive dental care.

*Increasing Reimbursement for Dental Providers.* Medicaid reimbursement emerged as a key barrier to accessing oral health care from Klls, stakeholders, and DD questionnaires. Some states have been advocating for better reimbursement to providers for the general adult Medicaid population, such as Michigan, where there has been no fee increase for decades.<sup>118</sup> Conversations revealed approaches that both states and the Federal Government could take to improve reimbursement in Medicaid to overcome barriers to access.

At the state level, mechanisms that could raise reimbursement rates include the following:

*Higher Reimbursement for Dental Care Provided to I/DD Patients.* States have the option, through 1915 waiver and 1115 demonstration programs, to set reimbursement rates for dental care provided to people with I/DD that are higher than the general adult population. For example, Colorado offers higher reimbursement rates in their dental fee schedule for HCBS-DD waiver participants (e.g., \$73.99 for a comprehensive oral evaluation versus \$37.72 for the general adult population). Similarly, Washington, DC, has a waiver program with higher fee-for-service reimbursement rates for treating patients with I/DD, relative to the general adult population. The literature review undertaken for this report found no evaluations of the impact of higher reimbursement rates on receipt of services in these states for this population.

*Reimbursement Linked to Training.*

New Mexico provides added reimbursement to dentists who receive training and certification for treatment of people with I/DD. Similarly, AmeriHealth Caritas, a Medicaid MCO operating in the Philadelphia, Pennsylvania, area, has a separate reimbursement structure for dentists who receive additional training to treat people with I/DD within their Inclusive Dental Plan for treatment of patients with special needs; this incorporates and acknowledges the increased amount of time providers often must spend with a patient with I/DD.<sup>119</sup>

*Federal Legislative Mechanisms for Increasing Reimbursement.* At the federal level, a potential mechanism for raising reimbursement rates may be to include adults with I/DD in the medically underserved category.

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***New Mexico provides added reimbursement to dentists who receive training and certification for treatment of people with I/DD.***

The Healthcare Extension and Accessibility for Developmentally Disabled and Underserved Populations (HEADs UP) Act would

amend the Public Health Act to include those with I/DD as a “Special Medically Underserved Population” (SMUP). If passed, this would increase Medicaid reimbursement rates for providers.<sup>120</sup> This bill has been introduced in two previous Congresses and at the time of the writing of this report has been reintroduced in the 117th Congress (H.R. 6075).

*Increased Transparency in Reimbursement Rates.* To demonstrate the impact of raising reimbursement rates on access to dental care and the potential best mechanisms for raising reimbursement rates, more transparency about provider reimbursement is needed. Key informants and stakeholders described multiple

challenges to measuring and comparing Medicaid reimbursement rates across states, in large part because more states are opting to use MCOs to deliver Medicaid services. Without better publicly available data on actual reimbursement rates for providers, it is difficult to assess the optimal reimbursement rates to expand the Medicaid provider networks and increase access to dental care, while containing costs.

### **Medicaid-funded Initiatives to Expand Access to Services**

KIIs and summit attendees highlighted several promising practices worthy of further exploration, which are funded partially or fully through state Medicaid programs.

*Multidisciplinary Health Center.* Kentucky created the Lee Specialty Clinic, a statewide multidisciplinary health center that specializes in providing medical and dental care to people with I/DD. The health center is staffed by highly trained doctors and dentists, who solely treat people with I/DD. Their extensive experience treating people with I/DD, and their knowledge of behavioral modification and desensitization techniques, allows them to substantially reduce the need to use general anesthesia in the operating room to provide preventive dental services, thereby reducing overall costs. Many of their patients receive Medicaid coverage, which partially funds the center, in addition to other funds that come from the state. To date, efforts to expand this model to other states have been unsuccessful due to lack of state funding.

*Pilot Programs.* There are several states that have granted expanded oral health benefits for other select populations without disabilities. Knowledge gained from evaluations of these pilot projects could guide expanded dental coverage

for adults with I/DD. For example, Washington State's Oral Health Connections Pilot Project aims to test the effect of enhanced oral health services, for diabetic or pregnant Medicaid clients ages twenty-one to sixty-four years in three counties, on health outcomes and cost of care. New York's Medicaid program is exploring an SDF training program for caregivers of children. Such approaches could be expanded to include adults with disabilities. Similar small-scale experimental programs could be employed for adults with I/DD in states with less funding.

*Accessible Services.* The delivery of dental programs must be examined as well as the benefit itself. Pilot programs and all programs that expand coverage to adults should consider how people will be able to physically access care in the design of their projects. For example, California implemented a pilot program to provide additional treatment for people with higher risk of getting cavities. While this increased the covered services for patients with high caries risk, it required patients to come in person for up to four to five different visits for each product recommended to them under this pilot (e.g., fluoride varnish). They had to travel to a dental institution or dental school where the services were offered. As a result of the language in the pilot program guidelines, the process of receiving care was burdensome owing to the number of times patients were required to travel for services.<sup>121</sup> An example of a pilot program to increase access was implemented in partnership between New Hampshire's Division of Public Health Services, the state's Medicaid agency, and the Women, Infants, and Children (WIC) program. The *Pay for Prevention* program offers preventive dental services for children and pregnant women at WIC offices.<sup>122</sup> The program provided

comprehensive preventive oral health services, including dental sealants, fluoride varnish, and oral health education delivered via public health hygienists and dental assistants. The program also provided referrals to select, local, Medicaid enrolled dental providers. Of 857 pregnant women served by the program, 37 percent were referred to a dentist for urgent needs, and 75 percent received sealants, potentially avoiding more painful and costly dental issues. Improving access to oral health care by bringing oral health care directly to potential beneficiaries through state agency partnerships or mobile clinics could be replicated for the I/DD population. For example, Missouri and New Jersey have implemented mobile dental clinics, which can overcome transportation barriers to dental care faced by adults with I/DD, especially those living in rural areas or with limited transportation options.<sup>123,124</sup>

*Expanding Medicaid Provider Network*

*Experienced in Treating Adults with I/DD Through Enhanced Training.* There are also models for training Medicaid dental providers to work with the disability population, potentially expanding the provider network capable of treating adults with I/DD and increasing access. AmeriHealth Caritas's Inclusive Dental Plan, a plan of the previously mentioned Medicaid MCO in Pennsylvania, also partners with dental schools to train oral health providers in supporting the oral health needs of patients with disabilities.<sup>125</sup> The specialized continuing education extends beyond the training dental students receive in dental school under the revised Commission on Dental Accreditation (CODA) standards.

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*Missouri and New Jersey have implemented mobile dental clinics, which can overcome transportation barriers . . .*

*Ensuring Coordination Between DD Agencies and Medicaid.* Coordination between DD agencies and Medicaid MCOs will likely better facilitate utilization of managed care by adult Medicaid beneficiaries with I/DD. As described earlier in the report, more states are moving toward managed care delivery systems for Medicaid administration. Thus, it will be important to ensure that MCOs are familiar with the I/DD population and their needs.

DD agencies can provide key support to MCOs in serving their beneficiaries with special needs. For example, in New Jersey, adults with I/DD have an assigned case manager to help them navigate DD services and other community-based services. In addition, Medicaid MCOs may assign that same person a different care manager

to assist with insurance issues and access to medical and dental services. Coordination between these two points of contact facilitates access to

dental care. Accessing dental care for adults with I/DD requires not only the insurance coverage provided by the MCOs but also transportation and involvement of group home staff, services typically provided by DD contractors, requiring coordination between DD contractors and Medicaid providers.

The DD agency survey undertaken for this project provided examples of how some states pursue close coordination with MCOs. For example, the Delaware DD agency has established points of contact within the MCOs to improve coordination. The Connecticut DD agency reports being in frequent communication with the Connecticut Dental Health Partnership



MCO, which manages oral health benefits. In Pennsylvania, DD agency staff have developed relationships with dental providers who specialize in providing dental care for people with I/DD. In Louisiana, representatives from the DD agency and Medicaid MCOs participate in a dental task force with I/DD advocates in the state.

DD agencies take a range of approaches to coordinating oral health services with their states' Medicaid programs, according to the survey responses. Some states have regularly scheduled meetings or ad hoc meetings to coordinate benefits with the state's Medicaid agency, sometimes facilitated by the agencies being housed in the same department. Two agencies (Louisiana and Washington, DC) noted they have a memorandum of understanding (MOU) or a memorandum of agreement (MOA) with the lead Medicaid agency. In Washington, DC, the

agencies coordinate weekly (if not daily) through the MOA and MOU to provide waiver services to the I/DD population. Similarly, both agencies in Washington state coordinate to resolve oral health care issues.

*Incorporating Patient Feedback.* States may also institute processes for incorporating feedback on their programs from adults with I/DD and their families. The DD survey revealed that some states have no formal process for receiving input about the patient experience. Most states, however, mentioned receiving patient feedback through one of the following means: surveys, care coordinators, advocacy organizations, public commission or council meetings, and an advisory body. Additional practices included a complaint hub in Florida that handled complaints from patients and public forums held by the Ohio DD agency and the Ohio Department of Medicaid.



## Chapter 6: Opportunities Outside of Medicaid

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**B**eyond the Medicaid program, other actors are working to expand access to oral health care for people with special needs. For example, legislation was introduced in the 117th Congress to include dental benefits in Medicare, including the Medicare Dental, Vision, and Hearing Act of 2021 (H.R. 4311) that would add a dental benefit to Medicare Part B.<sup>126</sup> If this or similar legislation were

passed, enacted, and funded, adults with I/DD across the United States who are eligible for Medicare would receive dental benefits coverage.

Other smaller-scale initiatives should be assessed to determine whether they would be cost effective for Medicaid. For example, a pilot program implemented in the Virginia VA Community Living Center required nursing staff to brush the teeth of residents once a day. This program resulted in reducing the incidence of pneumonia by approximately 90 percent and an estimated savings of \$9.4 million over three years, as of July 2019.<sup>127</sup>

Community dental centers, housed at universities and teaching hospitals, provide

dental students opportunities to serve a wide range of patients, including those with disabilities and I/DD. Examples of this model are the Community Dental Center at Harvard that uses students as dental providers and assistants, and clinics at Temple University, Rutgers, and NYU.<sup>128–131</sup> Dental schools in Washington, Arizona, and New York offer

fellowships and residencies for providers interested in serving patients with special needs. State and local boards can also require board-certified dentists to take continuing dental education courses on treatment of patients with special needs.

Some promising practices aim to increase

coordination between medical and dental providers. For example, the Arc of Mercer County in New Jersey currently runs a medical center offering medical, behavioral, and podiatry care to people with I/DD and soon will be offering dental care, all under one roof.<sup>132</sup>

The University of Buffalo has been exploring the creation of a dentist and occupational therapist program. The program would aim

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*[A] pilot program implemented in the Virginia VA Community Living Center required nursing staff to brush the teeth of residents once a day. This program resulted in reducing the incidence of pneumonia by approximately 90 percent and an estimated savings of \$9.4 million over three years.*

to incorporate dental hygiene into training for occupational therapists to help patients with daily oral hygiene maintenance and educating dentists on how to handle their patients.<sup>133</sup>

Beyond these promising practices, summit attendees and key informants provided other insights into improving access to oral health care for adults with I/DD.

*Patient-Centered Care.* Interviewees described patient-centered care that includes asking patients about their goals for care, as an approach that improves care. Relatedly, one stakeholder noted the importance of promoting sensory accommodations (i.e., light dimmers, softer colors, weighted blankets) as an accommodation covered under the Americans with Disabilities Act, along with more obvious accommodations for people with physical disabilities like chair lifts and wider doorways.

*Training Caregivers on Oral Hygiene.* Interviewees also noted the importance of training direct support professionals (DSPs) and others of the home health aide workforce about oral hygiene. Often this workforce is responsible for daily hygiene activities for many people with disabilities, including maintenance of oral health. New Jersey provides an example of implementing this approach. In 2021, the New Jersey chapter of the American Academy of Pediatrics began working with the developmental disabilities agency to include oral health information in DSPs' training as part of the Improving Oral Health across the Lifespan Program.<sup>134</sup>

## Areas for Future Research

NCD's research has highlighted key gaps in overall research and data that should be addressed to ensure that Medicaid policy and programs best address the oral health disparity experienced by adults with I/DD in a cost-effective manner.

### *Data on Reimbursement Rates.*

Reimbursement levels provided by managed care organizations to health care providers are not publicly available, making it virtually impossible for researchers to gather accurate data about actual reimbursement rates. As

described earlier, prior research on the impact of reimbursement rates on receipt of health care has compared receipt of health care before and after policy changes that directed Medicaid agencies to increase

reimbursement rates, rather than examining reimbursement rates directly. This data could be used to pinpoint the optimal reimbursement rates that both ensure adequate Medicaid participation among health care providers and are cost effective.

*Ongoing Evaluation of Pilot Programs.* As noted earlier, innovative and promising publicly funded state and local pilot programs should be evaluated for effectiveness and cost-effectiveness to inform Medicaid policy and payment structures.

*Effects of Specific Benefits.* Future studies should examine the specific benefits within waiver programs that are most associated with cost-effective outcomes. Most evaluations of

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*In 2021, the New Jersey chapter of the American Academy of Pediatrics began working with the developmental disabilities agency to include oral health information in DSPs' training . . .*

waiver programs examine packages of benefits. To the extent possible, disentangling the impact of specific elements of these programs would improve knowledge about effective interventions to improve oral health outcomes for adults with I/DD.

*Medicaid Policy for the General Adult Population.* It is vital that there is ongoing research to examine the impact on adults with I/DD of new or proposed Medicaid policies targeted at the general adult population. For example, a University of Michigan study examined the potential impact of the state's 1115 waiver work requirements. The study found that 94 percent of Medicaid beneficiaries who were unable to work had chronic physical or mental health conditions, and nearly 50 percent had impaired mental functions that did not allow them to work.<sup>135</sup> A federal court in 2020 struck down work requirements in state Medicaid 1115 waivers as unlawful, in part owing to their restrictions on access to care.<sup>136</sup>

*Dental Treatment in the Operating Room.* As described in chapter 2 some adults with I/DD

receive oral health treatment in the OR because they require general anesthesia to tolerate the treatment. Adults with I/DD who receive routine dental care in the OR often are among the most vulnerable of adults with I/DD. Many are nonverbal and unable to articulate experiences of oral pain. There are many drawbacks to providing basic or routine dental treatment in the OR, including the dangers of general anesthesia, the expense, the difficulty of coordinating this type of care, and the typically long wait times for OR care. There is very little research available on the rates of receipt of dental care in the OR, the average wait time for routine dental care, the trends in availability of ORs for dental care, effective dental practices to treat these patients outside the OR, and the cost-effectiveness of investing in training of dental providers to reduce the need for OR care. As described in chapter 5, highly trained dental providers may be able to reduce the need for OR care. More research is needed about the best approaches to addressing the dental needs of adults with the most serious forms of I/DD.



## Conclusions

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This report used a mixed-methods approach to address the overarching research question: should CMS require state Medicaid agencies to implement Medicaid reimbursement and payment policies that promote access to dental care for adults with I/DD, and could that ultimately be a cost-effective option over the long term? Because Medicaid adult dental benefits vary widely by state, and there is a dearth of research on how the Medicaid program should be structured to best address oral health disparities for adults with I/DD, NCD assessed multiple aspects of the Medicaid program, at the state and federal levels.

The research examined the relationship between state Medicaid dental benefits and receipt of basic dental care among adults with I/DD and the estimated cost and potential savings of implementing basic dental Medicaid benefits in states that do not currently do so. Further, NCD examined the role of coordination between DD agencies and Medicaid agencies for improving access to dental care and promising Medicaid-funded state strategies and privately funded local strategies for expanding dental care for adults with I/DD.

*Key Findings* from the research presented in this report follow.

The total estimated cost of providing extensive dental benefits to adults with I/DD in the twelve states that do not currently provide dental benefits would be about \$19.6 million annually, with the Federal Government responsible for approximately \$12.3 million of that cost. However, total cost reductions from implementing a dental benefit, through reductions in emergency department use and hospital admissions and in the cost of treating chronic diseases exacerbated by poor oral health, would be \$27.3 million. In total, introducing a dental benefit would lead to an estimated \$7.7 million return on investment.

Adults with I/DD are substantially more likely to receive basic dental care if they live in states with Medicaid dental benefits for adults, relative to adults with I/DD that live in states without these benefits. In the twelve states that do not provide Medicaid dental benefits to adults, seven have Medicaid waivers that expand dental benefits for adults with I/DD. Adult Medicaid beneficiaries with I/DD in these waiver states were 50 percent more likely to receive basic dental care, compared to adult Medicaid beneficiaries with I/DD in states without waivers.

Even in states with extensive dental benefits, only one-third of adult Medicaid



beneficiaries with I/DD received basic dental care, paid for by Medicaid, in a year. Many barriers to receiving dental care for adults with I/DD remain. Among these barriers is the lack of dental providers who participate in Medicaid. Medicaid reimbursement rates are significantly lower than reimbursement rates provided by

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*Even in states with extensive dental benefits, only one-third of adult Medicaid beneficiaries with I/DD received basic dental care, paid for by Medicaid, in a year.*

private insurers. Although data is unavailable to thoroughly assess the impact of raising reimbursement rates on the participation of dental care providers providing treatment to patients with I/DD in Medicaid, prior research indicates that policies that increased Medicaid reimbursement rates increased access to medical care for Medicaid beneficiaries.

## Key Recommendations

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**B**ased on the research presented in this report, the key recommendations are as follows:

### **Congress:**

- NCD recommends that Congress pass legislation that would require state Medicaid programs to provide extensive adult dental benefits for people with I/DD or create financial incentives for states to do so. States should have flexibility in implementing dental benefits to ensure they address the needs of their I/DD population. Evaluations of existing state programs should inform the design and implementation of these benefits.
- States should create greater transparency concerning managed care reimbursement rates. The lack of dental providers who participate in Medicaid remains a barrier to receipt of dental care. There is a lack of publicly available data about Medicaid Managed Care Organization reimbursement rates for dental care providers and creating policies that incentivize dental providers to participate requires an analysis of current rates.

### **States:**

- As we acknowledge that federal legislation can require a lengthy process for passage, NCD also recommends that states should add dental benefits for adults with I/DD to existing or new 1915(c) and 1915(i) waivers or 1115 demonstrations. States can refer to waivers in other states that extend dental coverage to adults with I/DD as a starting point or template to design their own programs. States should consider available data about and evaluations of these waiver programs to prioritize the types of dental services and target populations to include in their own waivers. States can use available data as guidance to maximize access to key, cost-effective dental services while balancing available funding.
- States should fund additional programs that would improve oral healthcare for people with I/DD. Other barriers to oral health care must be addressed and could be funded through the Medicaid program, including expanding the dental workforce whose members have expertise in treating adults with I/DD through continuing education programs, implementing programs that improve daily oral care provided by caregivers, and improving education and support for good oral hygiene for adults with I/DD. Additionally, states must address

transportation barriers. States should coordinate services between DD agencies and Medicaid providers.

### **U.S. Department of Health and Human Services**

- The U.S. Department of Health and Human Services, through the Administration on Community Living, should conduct additional research to offer policy insights and recommendations that would reduce the need for the receipt of dental care in the OR and to improve access to the OR for

people with I/DD. Many adults with serious I/DD receive basic dental care under general anesthesia in hospital ORs. Providing basic dental care in the OR is expensive. Further, adults with I/DD typically face long waiting lists to receive such care, owing to the shortage of available OR space for these procedures. More research is needed to pinpoint clear policy recommendations that would reduce the need for the receipt of dental care in the OR and to improve access to the OR for these vulnerable adults who face serious challenges.

# Appendices

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## Appendices: Contents

Appendix A: Agenda and Attendee List for Virtual Stakeholder Meeting . . . . .	65
Appendix B: Questionnaire to State Directors of Developmental Disabilities Agencies . . . . .	69
Appendix C: Details About the Fifty-State and DC Medicaid Oral Health Policy Database . . . . .	73
General Medicaid Characteristics . . . . .	74
Waivers . . . . .	79
Medicaid Fee-for-Service Fee Schedules . . . . .	82
Medicaid Fee Schedule and Frequency Sources . . . . .	83
CDT Code Descriptors . . . . .	83
Appendix D: <i>ICD-10</i> Diagnosis Codes for Autism Spectrum Disorder, Intellectual Disability and Related Conditions, Cerebral Palsy, and Other Developmental Delays . . . . .	85
Appendix E: Details About T-MSIS Sample . . . . .	87
Appendix F: Developmental Disabilities Agency Leader Questionnaire Responses About Barriers to Oral Health . . . . .	89



# Appendix A: Agenda and Attendee List for Virtual Stakeholder Meeting

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**Making Sufficient Oral Health Care for People with I/DD a Cost-Effective Reality:  
Examining the Medicaid Reimbursement Rate  
Tuesday, November 17, 2020 | 10:00 AM–12:30 p.m. EST  
National Center for Children in Poverty, Bank Street Graduate School of Education  
Health Policy Institute, American Dental Association  
Funded by the National Council on Disability**

## Agenda

*\*Times in Eastern*

1. National Council on Disability introduction to study goals and background (10:00–10:10 a.m.)\*
2. Introduction to the study team (10:10–10:15 a.m.)
3. Presentation of our study methods (10:15–10:30 a.m.)
  - i. Research questions
  - ii. Methods
  - iii. Timeline
4. First round of breakout discussions (10:30–11:00 a.m.)
  - a. Introductions within breakouts
  - b. Obtaining feedback on key aspects of the study
    - i. Innovative state Medicaid policies and Medicaid policy dimensions
    - ii. Medicaid claims data methodology and analysis advice
    - iii. Coordination of state DDD and Medicaid agencies and innovative oral health care practices in DDD agencies
    - iv. Comments on study goals and research questions and other important considerations for oral health care access for the I/DD population
5. Transition to second round of breakout rooms (11:00–11:05 a.m.)
6. Second round of breakout discussions (11:05–11:30 a.m.)
  - a. Introductions within breakouts
  - b. Obtaining feedback on key aspects of the study

- i. Innovative state Medicaid policies and Medicaid policy dimensions (1 of 2)
  - ii. Innovative state Medicaid policies and Medicaid policy dimensions (2 of 2)
  - iii. Coordination of state DDD and Medicaid agencies and innovative oral health care practices in DDD agencies
  - iv. Comments on study goals and research questions and other important considerations for oral health care access for the I/DD population
7. Report out to the group (11:30 a.m.–12:00 p.m.)
8. Next steps (12:00–12:15 p.m.)

### Attendees

Name	Title	Organization
Steve Beetstra	President	Special Care Dentistry Association (SCDA)
Alixé Bonardi	Senior Policy Specialist	Human Services Research Institute
Melissa Burroughs	Senior Oral Health Campaign Manager	Families USA
Natalia Chalmers	Chief Dental Officer	Centers for Medicare & Medicaid Services
Stacey Chazin	Director of Capacity Building and Technical Assistance	Oral Health Progress and Equity Network (OPEN)
Carrie Coffield	Assistant Professor of Pediatrics	The Boggs Center on Developmental Disabilities, Rutgers RWJMS
Jack Dillenberg	Dentist, Dean Emeritus	Arizona School of Dentistry and Oral Health
Marty Ford	Senior Advisor	The Arc
David Fray	Dentist	American Academy of Developmental Medicine & Dentistry (AADMD)
Brooke Fukuoka	Dentist	American Dental Association (ADA) Council on Advocacy for Access and Prevention (CAAP)
Dena Gassner	PhD candidate/Board Member	Adelphi University/Board of Directors, The Arc
Carrie Hanlon	Project Director	National Academy for State Health Policy (NASHP)
Matthew Holder	ABDM Liaison	American Academy of Developmental Medicine and Dentistry (AADMD)
Greg Howe	Senior Program Officer	Center for Health Care Strategies
Joseph Macbeth	President and CEO	National Alliance for Direct Support Professionals (NADSP)
Mike Monopoli	Vice President of Grant Strategy	DentaQuest



Name	Title	Organization
Steven Perlman	Global Clinical Advisor and Founder	Special Olympics Special Smiles
Madeline Pucciarello	Program Officer	Center for Health Care Strategies
Gary Pickard	Director of Government and Industry Services	Pacific Dental Services Foundation
Colin Reusch	Senior Advisor for Oral Health Policy	Community Catalyst
Bonnie T. Stanley	Dental Director	Dental Director NJ Family Care
John Tschida	Executive Director	Association of University Centers on Disabilities (AUCD)
Barbie Vartanian	Executive Director	Project Accessible Oral Health (PAOH)
Bridget Walsh	Senior Policy Analyst	Medicaid Matters (New York State)
Allen Wong	President	American Academy of Developmental Medicine and Dentistry (AADMD)
Christine Wood	Executive Director	Association of State and Territorial Dental Directors (ASTDD)
Billy Altom	Council Member	National Council on Disability
Joan Durocher	General Counsel & Director of Policy	National Council on Disability
Rick Rader	Council Member	National Council on Disability
Amged Soliman	Attorney Advisor	National Council on Disability
Emma Browse	Graduate Research Assistant	National Center for Children in Poverty, Bank Street College of Education
Chelsea Fosse <b>(Co-PI)</b>	Senior Health Policy Analyst	Health Policy Institute, American Dental Association
Jennifer Hernandez	Graduate Research Assistant	National Center for Children in Poverty, Bank Street College of Education
Heather Koball <b>(Co-PI)</b>	Codirector	National Center for Children in Poverty, Bank Street College of Education
Akilah Moore	Administrative Assistant	National Center for Children in Poverty, Bank Street College of Education
Suma Setty	Senior Research Associate	National Center for Children in Poverty, Bank Street College of Education



## Appendix B: Questionnaire to State Directors of Developmental Disabilities Agencies

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**Purpose:** This fifty-state (and Washington, DC) questionnaire is sponsored by the National Council on Disability and is meant to aid in better understanding how DD agencies coordinate care for adults with intellectual and developmental disabilities (IDD). We are also interested in learning about oral health benefits conferred to adults with IDD served by DD agencies in your state.

**Background:** The Bank Street Graduate School of Education and the Health Policy Institute at the American Dental Association are conducting a ten-month study funded by the National Council on Disability. The study focuses on Medicaid policies that cover oral health services and aims to identify best Medicaid-related practices and policies related to oral health care for adults with IDD.

**Security:** Qualtrics, this questionnaire platform, uses Transport Layer Security (TLS) encryption (also known as HTTPS) for all transmitted data (visit the website <https://www.qualtrics.com/security-statement/> for more details). Findings from this questionnaire may be reported at the national or state levels. We will only identify your state/agency name in our final report with your permission.

Q3 First and Last Name

---

Q4 Title/Role

---

Q5 Agency Name

---

*End of Block: Default Question Block*

*Start of Block: State*

Q6 In which state do you currently reside?

▼ Alabama . . . Wyoming

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## *End of Block: State*

### *Start of Block: Block 2*

*Display Question 7: If Q6 = California Or Q6 = Colorado Or Q6 = Connecticut Or Q6 = Delaware Or Q6 = District of Columbia Or Q6 = Idaho Or Q6 = Illinois Or Q6 = Iowa Or Q6 = Massachusetts Or Q6 = Montana Or Q6 = New Jersey Or Q6 = New Mexico Or Q6 = New York Or Q6 = North Carolina Or Q6 = North Dakota Or Q6 = Ohio Or Q6 = Oregon*

Q7 Our understanding is that your state provides extensive dental benefits to adults who are covered by Medicaid (see *DentaQuest's Jan 2020 Report* for more details on what constitutes "extensive").

If adults with IDD served by your agency receive additional oral health services compared to the general Medicaid adult population (e.g., more dental cleanings covered by Medicaid, publicly funded clinics), how do you educate the people served by your agency and their family members and caregivers about these additional services?

If adults with IDD served by your agency do not receive additional oral health services, please type "N/A or none."

---

## *End of Block: Block 2*

### *Start of Block: Block 3*

*Display Question 8: If Q6 = Alaska Or Q6 = Arizona Or Q6 = Arkansas Or Q6 = Florida Or Q6 = Georgia Or Q6 = Hawaii Or Q6 = Indiana Or Q6 = Kansas Or Q6 = Kentucky Or Q6 = Louisiana Or Q6 = Maine Or Q6 = Michigan Or Q6 = Minnesota Or Q6 = Mississippi Or Q6 = Nebraska Or Q6 = Nevada Or Q6 = New Hampshire Or Q6 = Oklahoma Or Q6 = Pennsylvania Or Q6 = South Carolina Or Q6 = South Dakota Or Q6 = Texas Or Q6 = Utah Or Q6 = Vermont Or Q6 = Virginia Or Q6 = West Virginia Or Q6 = Wyoming*

Q8 Our understanding is that your state provides limited or emergency-only dental benefits to adults who are covered by Medicaid (see *DentaQuest's Jan 2020 Report* for more details on what constitutes "limited and emergency-only").

If adults with IDD served by your agency receive additional oral health benefits compared to the general Medicaid adult population (e.g., additional covered dental cleanings), how do you educate the people served by your agency and their family members and caregivers about these additional services?

If adults with IDD served by your agency do not receive additional oral health services, please type "N/A or none."

---

### ***End of Block: Block 3***

### ***Start of Block: Block 6***

*Display Question 9: If Q6 Alaska Or Q6 = Arizona Or Q6 = Arkansas Or Q6 = California Or Q6 = Colorado Or Q6 = Connecticut Or Q6 = Delaware Or Q6 = District of Columbia Or Q6 = Florida Or Q6 = Georgia Or Q6 = Hawaii Or Q6 = Illinois Or Q6 = Indiana Or Q6 = Iowa Or Q6 = Kansas Or Q6 = Kentucky Or Q6 = Louisiana Or Q6 = Maine Or Q6 = Massachusetts Or Q6 = Michigan Or Q6 = Minnesota Or Q6 = Mississippi Or Q6 = Missouri Or Q6 = Montana Or Q6 = Nebraska Or Q6 = Nevada Or Q6 = New Jersey Or Q6 = New Mexico Or Q6 = New York Or Q6 = North Carolina Or Q6 = North Dakota Or Q6 = Ohio Or Q6 = Oklahoma Or Q6 = Oregon Or Q6 = Pennsylvania Or Q6 = Rhode Island Or Q6 = South Carolina Or Q6 = South Dakota Or Q6 = Texas Or Q6 = Utah Or Q6 = Vermont Or Q6 = Virginia Or Q6 = Washington Or Q6 = West Virginia Or Q6 = Wisconsin Or Q6 = Wyoming*

Q9 How does your agency coordinate health care services for adults with IDD, particularly oral health care, with your state’s Medicaid agency (e.g., Do you have an MOU in place? Are there regularly scheduled meetings between the agencies? Are there regulations related to this coordination?)?

---

### ***End of Block: Block 6***

### ***Start of Block: Block 4***

*Display Question 10: If Q6 = Alabama Or Q6 = Maryland Or Q6 = Tennessee*

Q10 Our understanding is that your state does not provide dental benefits to adults who are covered by Medicaid (see *DentaQuest’s Jan 2020 Report*, available at <https://www.carequest.org/system/files/CareQuest-Institute-Health-Mouths-Why-They-Matter-for-Adults-and-State-Budgets-Brief.pdf>).

If adults with IDD served by your agency receive additional oral health services compared to the general population of adults covered by Medicaid, how do you educate the people served by your agency and caregivers about these additional services?

If adults with IDD do not receive additional oral health benefits please type “N/A or none.”

---

### ***End of Block: Block 4***

### ***Start of Block: Block 5***

Q11 If your agency has a budget for oral health-related services and activities for adults with IDD, please describe these services and activities and funding sources.

---

Q12 From your perspective, what are the main barriers to oral health care for adults with IDD in your state?

---

Q13 How do you go about including patients, and receiving their input, at your agency and intra-agency meetings concerning “the patient experience”?

---

Q14 Would you be willing to speak with us over the phone for approximately thirty minutes about oral health issues for adults with IDD in your state? Or is there someone else in your agency you would recommend we speak with (please add contact information below)?

---

Q15 Thank you for contributing your time to this important project to better understand oral health care services for adults with IDD.

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**For more information about this survey, please contact Suma Setty at [ssetty@bankstreet.edu](mailto:ssetty@bankstreet.edu).**

## Appendix C: Details About the Fifty-State and DC Medicaid Oral Health Policy Database

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The Medicaid Oral Health Policy Database (MOHPD) contains information relevant to Medicaid state policy and the oral health of adults with intellectual and/or developmental disabilities (I/DD) in each state and the District of Columbia (DC). The MOHPD compiles original data collected from Centers for Medicare and Medicaid Services (CMS) waiver applications and other materials and state Medicaid fee schedules, and consolidates relevant data from leading sources of information about oral health and Medicaid research, including the Kaiser Family Foundation, the American Dental Association's Health Policy Institute, the Medicaid/Medicare/CHIP Services Dental Association, and the U.S. Bureau of Labor Statistics.

To date, this is the only database that consolidates key information about Medicaid dental waiver programs and available Medicaid maximum fee-for-service (FFS) fees for select Code on Dental Procedures and Nomenclature (CDT) from all fifty states and DC. The information on Medicaid dental waiver programs shows which states have decided to expand dental services for adults with I/DD, what dental benefits beyond those in the state plan are available under the waiver programs, and specifics about the populations granted expanded dental benefits under the waiver. For most 1915 waivers, there is additional information on the cost cap of dental services allowed per waiver enrollee and the number of enrollees per waiver year. FFS fees show whether a state has listed an amount for CDT codes relevant to the oral health of adults with I/DD, like behavior management (D9920), in their Medicaid fee schedule and the maximum reimbursement rate Medicaid will reimburse providers who bill for this service.

While the purpose of the CDT code is to “achieve uniformity, consistency and specificity in accurately documenting dental treatment,”<sup>137</sup> codes may be applied differently state by state. For example, in New Mexico, the D9920-behavior management code is reserved for use by dental providers who have completed a special needs care training program, which is not the case in other states.<sup>138</sup> Another example is Massachusetts, where fees for some dental codes are listed as Individual Consideration, or IC, meaning that some procedures would be reimbursed based on several factors such as the time required to perform the procedure and the severity and/or complexity of the patient's condition, among others.<sup>139</sup> In addition, some states may have different fee schedules for waiver program enrollees than the general population and/or different fees depending on the region of the state (e.g., Hawaii). The MOHPD displays FFS fees for the general adult population as found on publicly available Medicaid fee schedules. No Medicaid FFS dental fee schedules for the general adult population exist for states with no dental coverage for the general adult population, and fees were listed as n/a, or not applicable.

The CDT Codes selected for inclusion in the MOHPD were as follows:

1. the most common procedure codes for adults, as identified in prior research of the American Dental Association's Health Policy Institute<sup>140</sup>;
2. related to prevention and/or arrest of dental disease such as nutritional and oral hygiene counseling, topical fluoride application, and silver diamine fluoride (SDF); and/or
3. adjunctive services that—when offered and paid for—promote access to oral health care for the I/DD population, such as behavior management, case management, and teledentistry.

The remainder of this appendix provides a brief explanation of relevant dimensions contained in the database.

### *Database Sections (correspond with tabs in Excel spreadsheet):*

General Medicaid Characteristics

Waivers

Medicaid Fee-for-Service Fee Schedules

Medicaid Fee Schedule and Frequency Sources

CDT Code Descriptors

### **General Medicaid Characteristics**

1. Medicaid fee-for-service (FFS) reimbursement rates for adult dental care services as percentage of fees charged by dentists, 2016
  - a. Column B
  - b. Field: Percentage
  - c. Source of Data: N. Gupta, C. Yarbrough, M. Vujcic, A. Blatz, and B. Harrison, *Medicaid Fee-For-Service Reimbursement Rates for Child and Adult Dental Care Services for All States, 2016* (Chicago: Health Policy Institute, American Dental Association, 2017).
  - d. Explanation: Higher reimbursement rates may mean more dentists are available to serve Medicaid patients. Only collected for those classified as extensive dental benefits in 2016
2. Medicaid FFS reimbursement rates for adult dental care services as percentage of private reimbursement for dental services, 2016
  - a. Column C
  - b. Field: Percentage
  - c. Source: Gupta et al., *Medicaid Fee-For-Service Reimbursement, 2017*.
  - d. Explanation: Higher reimbursement rates may mean more dentists are available to serve Medicaid patients.



3. As of September 8, 2021, has the state expanded Medicaid to 138 percent of Federal Poverty Level for Adults?
  - a. Column D
  - b. Field: Yes or No
  - c. Source: Kaiser Family Foundation, *Status of State Medicaid Expansion Decisions: Interactive Map* (October 1, 2020), accessed October 15, 2020, <https://www.kff.org/medicaid/issue-brief/status-of-state-medicaid-expansion-decisions-interactive-map/>.
  - d. Explanation: More people being served by Medicaid
4. Date of Medicaid expansion implementation, if applicable
  - a. Column E
  - b. Source: Kaiser Family Foundation, *Status of State Medicaid Expansion Decisions: Interactive Map* (October 1, 2020), accessed October 15, 2020. <https://www.kff.org/medicaid/issue-brief/status-of-state-medicaid-expansion-decisions-interactive-map/>.
5. Is dental access delivered via fee for service, managed care, or both?
  - a. Column F
  - b. Fields: Fee For Service (FFS) and/or Managed Care (MC)
  - c. Source: Medicaid/Medicare/CHIP Services Dental Association (MSDA), *2019 National Policy, 2019*, accessed October 2020. <https://www.msdanationalprofile.com/profiles/2019/national/all/policy> (free account creation required to access).
  - d. Note about the MSDA source: MSDA surveys all fifty states and DC Medicaid and CHIP Oral Health Programs. MSDA data collected in the MOHPD reflects the answers from that survey of state representatives. The latest available data is from 2019. This column describes the delivery models for dental services to adults and children. If a state appears in the list for “Dental access under FFS,” then it was classified as FFS. If a state appears in the list for “Dental Access under Managed Care,” then it was classified as MC. If it appeared in both lists, it was classified as FFS and MC. In states classified as FFS and MC, some dental services are delivered FFS, and/or different populations may receive dental services through different delivery methods (FFS or MC).
  - e. Explanation: Reimbursement rates for dental services delivered via managed care are not publicly available. Medicaid fee schedules reflect fees for dental services delivered via FFS.
6. 2021 NASHP classification of Medicaid adult dental coverage
  - a. Column G
  - b. Fields: No Coverage, Emergency, Limited, Extensive

- c. Source: National Academy for State Health Policy, *State Medicaid Coverage of Dental Services for General Adult and Pregnant Populations* (2021), accessed September 2021, <https://www.nashp.org/state-medicaid-coverage-of-dental-services-for-general-adult-and-pregnant-populations/>.
  - d. Explanation: This is the latest classification of adult Medicaid dental benefits across all fifty states and DC.
7. 2018 CHCS classification of Medicaid adult dental coverage (general dental benefits for adults)
- a. Column H
  - b. Fields: No coverage, Emergency Only, Limited, Extensive
  - c. Source: *Medicaid Adult Dental Benefits: An Overview* (Hamilton, NJ: Center for Health Care Strategies, Inc., July 2018), [https://www.chcs.org/media/Adult-Oral-Health-Fact-Sheet\\_072718.pdf](https://www.chcs.org/media/Adult-Oral-Health-Fact-Sheet_072718.pdf).
  - d. Explanation: The 2018 classification was used for Transformed Medicaid Statistical Information System (T-MSIS) analysis to align with the year of T-MSIS claims data.
8. Is behavior management covered for special populations?
- a. Column I
  - b. Fields: Yes/No
  - c. Source: Medicaid/Medicare/CHIP Services Dental Association (MSDA), *MSDA National Profile: Benefits, D9920-Behavior Management* (2019), accessed October 2020, <https://www.msdanationalprofile.com/profiles/2019/national/all/benefits/dental-codes/37?chip=0> (free account creation required to access).
  - d. Explanation: It is a measure that would benefit patients with I/DD and may increase the likelihood of patients returning for dental visits. This may decrease the likelihood of advanced dental complications. Desensitization is folded into this (no separate code).
9. Is case management covered for special populations? (Y/N)
- a. Column J
  - b. Fields: Yes/No and any qualitative information about the populations covered
  - c. Source: *Medicaid/Medicare/CHIP Services Dental Association (MSDA), MSDA National Profile: Benefits, D9991-9994 Case Management Codes Coverage* (2019), accessed October 2020, <https://www.msdanationalprofile.com/profiles/2019/national/all/benefits/dental-codes/39?chip=0> (free account creation required to access).
  - d. Explanation: It is a preventative measure that would decrease the likelihood of advanced dental complications.
10. Is fluoride varnish covered and for which populations (D1206)?
- a. Column K
  - b. Fields: Not covered/Adults/Children/Pregnant women/Medicaid Expansion/etc., and any qualitative information about the populations covered and frequencies allowed

- c. Source: Medicaid/Medicare/CHIP Services Dental Association (MSDA), *MSDA National Profile: Benefits, D1206-Fluoride Varnish Coverage* (2019), accessed October 2020, <https://www.msdanationalprofile.com/profiles/2019/national/all/benefits/dental-codes/12?chip=0> (free account creation required to access).
  - d. Explanation: It is a preventative measure that would decrease the likelihood of advanced dental complications.
11. Fluoride varnish coverage description
- a. Column L
  - b. Fields: Contains information about what populations are eligible for the benefit as well as frequency limitations to the benefit
  - c. Source: Medicaid/Medicare/CHIP Services Dental Association (MSDA), *MSDA National Profile: Benefits, D1206-Fluoride Varnish Coverage* (2019), accessed October 2020, <https://www.msdanationalprofile.com/profiles/2019/national/all/benefits/dental-codes/12?chip=0> (free account creation required to access).
12. Is fluoride treatment covered and for which populations (D1208)?
- a. Column M
  - b. Fields: Not covered/Adults/Children/Pregnant women/Medicaid Expansion/etc., and any qualitative information about the populations covered and frequencies allowed
  - c. Source: Medicaid/Medicare/CHIP Services Dental Association (MSDA), *MSDA National Profile: Benefits, D1208-Fluoride Treatment Coverage* (2019), accessed October 2020, <https://www.msdanationalprofile.com/profiles/2019/national/all/benefits/dental-codes/11?chip=0> (free account creation required to access).
  - d. Explanation: It is a preventative measure that would decrease the likelihood of advanced dental complications.
13. Fluoride treatment coverage description
- a. Column N
  - b. Contains information about what populations are eligible for the benefit as well as frequency limitations to the benefit
  - c. Source: Medicaid/Medicare/CHIP Services Dental Association (MSDA), *MSDA National Profile: Benefits, D1208-Fluoride Treatment Coverage* (2019), accessed October 2020, <https://www.msdanationalprofile.com/profiles/2019/national/all/benefits/dental-codes/11?chip=0> (free account creation required to access).
14. Is silver diamine fluoride application covered and for which populations (D1354)?
- a. Column O
  - b. Fields: Not covered/Adults/Children/Pregnant women/Medicaid Expansion/etc., and any qualitative information about the populations covered and frequencies allowed

- c. Source: Medicaid/Medicare/CHIP Services Dental Association (MSDA), *MSDA National Profile: Benefits, Silver Diamine Fluoride* (2019), accessed October 2020, <https://www.msdanationalprofile.com/profiles/2019/national/all/policy/silver-diamine-flouride> (free account creation required to access).
  - d. Explanation: It is a preventative measure that would decrease the likelihood of advanced dental complications.
15. Silver diamine fluoride application coverage description
- a. Column P
  - b. Contains information about what populations are eligible for the benefit as well as frequency limitations to the benefit
  - c. Source: Medicaid/Medicare/CHIP Services Dental Association (MSDA), *MSDA National Profile: Benefits, Silver Diamine Fluoride* (2019), accessed October 2020, <https://www.msdanationalprofile.com/profiles/2019/national/all/policy/silver-diamine-flouride> (free account creation required to access).
16. State FMAP Fiscal Year 2021 rates
- a. Column Q
  - b. Fields: Percentages
  - c. Source: Kaiser Family Foundation, *Federal Medical Assistance Percentage (FMAP) for Medicaid and Multiplier, FY 2021*, accessed September 29, 2021, <https://www.kff.org/medicaid/state-indicator/federal-matching-rate-and-multiplier/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>.
  - d. Explanation: Federal Medical Assistance Percentage (FMAP) is the rate of federal Medicaid money allocated to each state. This is used in TMSIS analysis. *Note:* These rates do not include the 6.2 percent increase as legislated in the Families First Coronavirus Response Act (FFCRA).
17. 2018 mean hourly wage for general dentists
- a. Column R
  - b. Field: Dollar (\$) amount
  - c. Source: Bureau of Labor Statistics, *Occupational Employment and Wage Statistics, State* (May 2018), <https://www.bls.gov/oes/tables.htm>.
  - d. Explanation: This information was captured to create average weights for fees across states.
18. 2018 annual median wage for general dentists
- a. Column S
  - b. Field: Dollar (\$) amount
  - c. Source: Bureau of Labor Statistics, *Occupational Employment and Wage Statistics, State* (May 2018), <https://www.bls.gov/oes/tables.htm>.

19. Buy-in for working people with disabilities
  - a. Column T
  - b. Fields: Yes, No
  - c. Source: M. Musumeci, P. Chidambaram, and M. O'Malley Watts, *Appendix Table 1: State Adoption of Key Option Pathways to Full Medicaid Eligibility Based on Old Age or Disability, 2018* (Washington, DC: Kaiser Family Foundation, 2020), <https://www.kff.org/report-section/medicaid-financial-eligibility-for-seniors-and-people-with-disabilities-findings-from-a-50-state-survey-appendix-tables/>.
  - d. Explanation: Many state Medicaid programs allow individuals with disabilities who are under the age of sixty-five years who earn more than the allowable amount under Medicaid to purchase Medicaid coverage by paying premiums (<https://www.dol.gov/sites/dolgov/files/odep/topics/medicaidbuyinqaf.pdf>). These programs allow individuals with disabilities to work and retain Medicaid health benefits. Many states will temporarily allow recipients to stay on the program after losing employment (e.g., for six months), allowing participants in this Medicaid option to retain Medicaid while they reapply for Supplemental Security Income or seek other employment. In states with buy-in programs, more people with disabilities have opportunities to be covered by state Medicaid programs.

## Waivers

### *Detailed waiver review methodology*

NCD reviewed waiver programs only for states that were not classified as having comprehensive adult dental benefits in 2018. For 1915 waivers, NCD reviewed approved waiver applications available on the CMS website.<sup>141</sup> However, 1115 waivers did not follow a standardized format; therefore, some columns have missing fields. For information about 1115 waivers, several documents available on the CMS website were reviewed, including quarterly reports, CMS approval letters, and fact sheets. Only the most recent versions of waiver materials listed on CMS were reviewed, as prior versions of waiver materials were not consistently available across all states. NCD also cross-checked CMS information with information from MSDA survey results from 2019. When MSDA data indicated that a state has dental coverage via waivers (column B), NCD expanded the search of the state's waivers to include pending waiver applications (e.g., Utah). NCD did not review expired or terminated waivers. The 1915 waiver applications also contain standardized information about the number of people the waiver will serve per year of the approval period and the cap on the monetary amount they will spend on dental services, so these were collected as well from waiver reviews for 1915 waiver programs.

20. MSDA: Dental programs operating under Medicaid waiver
  - a. Column B
  - b. Fields: 1115, 1915(b), 1915(c)

- c. Source: Medicaid/Medicare/CHIP Services Dental Association (MSDA), *2019 National: Policy. Dental Programs Operating Under Medicaid Waiver* (2019), accessed October 2020, <https://www.msdanationalprofile.com/profiles/2019/national/all/policy/medical-waivers> (free account creation required to access).
  - d. Explanation: States self-reported this measure and indicated whether the waiver was 1115, 1915(b), 1915(c), combination, or left blank.
21. Waiver name
    - a. Column C
  22. Waiver type
    - a. Column D
    - b. Fields: For example, 1115, 1915(b), 1915(c), etc.
  23. Does the waiver provide dental coverage for adults with I/DD beyond that covered for the general adult population?
    - a. Column E
    - b. Fields: Y/N
    - c. Note: Maryland provides dental care for adults ages twenty-one to sixty-four years who are dually eligible for Medicaid and Medicare through a pilot dental program. This is not specific to adults with I/DD and, thereby, was not counted as a waiver program for 2018 T-M SIS analysis. The fee schedule for this program is available at <https://health.maryland.gov/mmcp/Documents/Overview.pdf>.
  24. Does the waiver provide dental coverage for the general adult population?
    - a. Column F
    - b. Fields: Y/N
  25. Was the waiver in effect in 2018?
    - a. Column G
    - b. Fields: Y/N
    - c. Marked as Y if 2018 fell between the waiver approval date of initial application and the waiver expiration date. This was used in analysis of 2018 T-M SIS data.
  26. Initial application/approval date
    - a. Column H
    - b. On CMS website
  27. Date the latest approved/pending application was effective
    - a. Column I
    - b. On CMS website

28. Waiver expiration date
  - a. Column J
  - b. On CMS website
29. Approval period
  - a. Column K
  - b. For 1915 waivers, this information is in Section 1C of approved waiver applications.
30. Number of people served by the waiver
  - a. Column L
  - b. For 1915 waivers, this information is in Appendixes B and J of approved waiver applications.
31. Cost cap per waiver participant per year for dental services covered in the waiver plan
  - a. Column M
  - b. For 1915 waivers, this information is usually in Appendix C of approved waiver applications.
32. Dental services covered under the waiver
  - a. Column N
  - b. For 1915 waivers, this information is usually in Appendix C of approved waiver applications.
33. Populations granted expanded dental benefits under the waiver
  - a. Column O
  - b. For 1915 waivers, this information is usually in the waiver description and Appendix B of approved waiver applications.
34. Other notes and resources
  - a. Column P

Detailed steps for determining whether a waiver covered dental benefits for the general adult population or the adult population with I/DD were as follows:

1. If at least one term listed under items a and b appeared in the waiver text, they were flagged for further review:
  - a. "Intellectual disability"/"Developmental disability"/"Mental retardation"/"Autism"
    - i. In 1915 waiver applications/renewals, there is usually a grid of populations that are the "target group" for the waiver in Appendix B (covered populations) or sometimes populations included/excluded are listed in Part I: E, "Populations Included in Waiver."
  - b. "Oral health" (space before "oral")/"Dental"/"Dentistry"
    - i. Also in 1915 waiver applications, Appendix C (covered services) contains information about any benefits included in the waiver program.

2. If oral health and I/DD search terms were present, the approved waiver application materials were reviewed in depth for the above information.
3. If the waiver specifically named the I/DD population as eligible for oral health benefits under the waiver, column E was marked as “Y”; as providing the I/DD population with additional dental benefits. Otherwise, the field was marked “N”. Sometimes I/DD populations are specifically excluded in some waivers (e.g., Indiana), which would also require “N” within this column.
4. The waiver was marked as “Y” in column F only if the waiver extended oral health benefits beyond the state plan for the general adult population.

### **Medicaid Fee-for-Service Fee Schedules**

1. NASHP classification of adult dental benefit coverage in Medicaid
  - a. Column B
  - b. Source: National Academy for State Health Policy, *State Medicaid Coverage of Dental Services for the General Adult and Pregnant Populations*, accessed September 22, 2021, <https://www.nashp.org/state-medicare-coverage-of-dental-services-for-general-adult-and-pregnant-populations/>.
2. Date of input into spreadsheet
  - a. Column C
3. Date of fee schedule
  - a. Column D
4. Medicaid maximum fee for service fees for twenty-six relevant CDT codes for adult dental services
  - a. Columns E–AC
  - b. Frequency limitations for the below relevant twenty-six CDT codes
  - c. Columns AD–BB
5. Was a separate fee schedule for individuals with intellectual disabilities found?
  - a. Column BC
  - b. While this was not specifically sought for by NCD researchers, it was recorded when researchers came across a separate fee schedule for individuals with I/DD, usually only available if the state has a waiver granting additional or expanded dental benefits to adults with I/DD in the state.
6. Notes
  - a. Column BD
  - b. Provides some clarity on fee schedule or additional information about fees within the sheet



### *Methodological notes on fee schedules*

- Fees are for FFS dental benefits to the general adult population unless otherwise noted. It was assumed that for states where the fee schedule was not clear about whether the rates were for children or adults that the rates were the same for both populations.
- States without a Medicaid dental benefit for the general adult population do not publish a Medicaid fee schedule for dental services, and the FFS are listed as n/a or not applicable in these states.
- Frequency limitations related to relevant CDT codes were not found for New Mexico, Oregon, Tennessee, or Virginia.
- Actual frequency limitations and fees may vary depending on whether dental services are delivered via managed care organizations and may differ between managed care organizations, if there are multiple.

### **Medicaid Fee Schedule and Frequency Sources**

1. Link to fee schedule
  - a. Column B
  - b. The latest version of the Medicaid fee schedule was referenced.
2. Link to provider manual or other frequency limitation source
  - a. Column C
  - b. Frequency limitations were not always stated within the fee schedule; thus, sources for the frequency limitations often came from Medicaid dental provider manuals, state statutes, or state websites.
3. Notes
  - a. Column D
  - b. Provides additional information about methods and approach

### **CDT Code Descriptors**

This tab contains the relevant codes and descriptions of CDT codes for which fees and frequency limitations were collected in the Medicaid fee-for-service fee schedules. Codes that begin with D0 are for diagnostic services, D1 = preventive, D2 = endodontics, D4 = periodontics, and D9 = adjunctive general services.

1. D0120 - Periodic oral evaluation—established patient
2. D0140 - Limited oral evaluation—problem focused
3. D0150 - Comprehensive oral evaluation—new or established patient
4. D0220 - Intraoral—periapical first radiographic image

5. D0230 - Intraoral—periapical each additional radiographic image
6. D0274 - Bitewings—four radiographic images
7. D1110 - Prophylaxis—adult
8. D1206 - Topical application of fluoride varnish
9. D1208 - Topical application of fluoride—excluding varnish
10. D1310 - Nutritional counseling for control of dental disease
11. D1330 - Oral hygiene instructions
12. D1354 - Interim caries arresting medicament application—per tooth
13. D1355 - Caries preventive medicament application—per tooth
14. D2391 - Resin-based composite—one surface, posterior
15. D2392 - Resin-based composite—two surfaces, posterior
16. D4910 - Periodontal maintenance
17. D9410 - House/extended care facility call
18. D9430 - Office visit for observation (during regularly scheduled hours)—no other services performed
19. D9920 - Behavior management, by report
20. D9991 - Dental case management—addressing appointment compliance barriers
21. D9992 - Dental case management—care coordination
22. D9993 - Dental case management—motivational interviewing
23. D9994 - Dental case management—patient education to improve oral health literacy
24. D9995 - Teledentistry—synchronous; real-time encounter
25. D9996 - Teledentistry—asynchronous; information stored and forwarded to dentist for subsequent review
26. D9997 - Dental case management—patients with special health care needs

Source: *Current Dental Terminology* (Chicago: American Dental Association, 2021).

## Appendix D: ICD-10 Diagnosis Codes for Autism Spectrum Disorder, Intellectual Disability and Related Conditions, Cerebral Palsy, and Other Developmental Delays

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The Transformed Medicaid Statistical Information System (T-MSIS) sample consisted of adults with intellectual and developmental disabilities (I/DD). If a claim in T-MSIS had one or more of the following *International Classification of Diseases (ICD)* codes, the person associated with the claim was considered someone with an I/DD.

E78.71, E78.72	Barth syndrome
F70.0, F70.1, F70.8, F70.9	Mild mental retardation
F71, F71.0, F71.1, F71.8, F71.9	Moderate mental retardation
F72, F72.0, F72.1, F72.8, F72.9	Severe mental retardation
F73, F73.0, F73.1, F73.8, F73.9	Profound mental retardation
F78, F78.0, F78.1, F78.8, F78.9	Other mental retardation
F79, F79.0, F79.1, F79.8, F79.9	Unspecified mental retardation
F81.9	Developmental disorder unspecified, scholastic skills
F82	Specific developmental disorder of motor function
F84.0	Autistic disorder
F84.1	Atypical autism
F84.2	Rett's syndrome
F84.3, F84.4	Pervasive developmental disorder
F84.5	Asperger's syndrome
F84.8	Other pervasive developmental delay
F84.9	Pervasive developmental delay not otherwise specified
F88	Other disorders of psychological development
F89	Unspecified disorder of psychological development

(continued)

G80.0, G80.1, G80.2, G80.3, G80.4, G80.8, G80.9	Cerebral palsy
P04.3	Fetal alcohol syndrome
Q86.0	Congenital malformation syndrome due to exogenous factors
Q86.1	Fetal hydantoin syndrome (primarily physical, may include mild developmental disability)
Q86.2	Dysmorphism due to warfarin
Q86.8	Other congenital malformation, unknown cause
Q87.0	Congenital malformation primarily affecting the face
Q87.1	Other specified congenital malformation syndromes affecting multiple systems
Q87.11	Prader-Willi syndrome
Q87.19, Q87.2, Q87.3, Q87.5, Q87.8	Other specified congenital malformation syndromes affecting multiple systems
Q87.81	Alport syndrome (may include ID)
Q87.89	Other specified congenital malformation syndromes, not elsewhere classified
Q89.7	Multiple congenital malformations, not otherwise specified
Q89.8	Other specified congenital malformation syndromes affecting multiple systems
Q90.0, Q90.1, Q90.2, Q90.9	Down's syndrome
Q91.0, Q91.1, Q91.2, Q91.3, Q91.4, Q91.5, Q91.6, Q91.7	Edward's syndrome and Patau's syndrome
Q92.0, Q92.1, Q92.2, Q92.5, Q92.7, Q92.8, Q92.9	Trisomy
Q92.61	Marker chromosomes in normal individual
Q92.62	Marker chromosomes in abnormal individual
Q93.0, Q93.1, Q93.2, Q93.3, Q93.4, Q93.5, Q93.51, Q93.8, Q93.1, Q93.2, Q93.529, Q93.6, Q93.7, Q93.8, Q93.81, Q93.88, Q93.89, Q93.9	Monosomies and deletions from autosomes, not elsewhere classified
Q95.2	Balanced autosomal rearrangement in abnormal individual
Q95.3	Balanced sex autosomal rearrangement in abnormal individual
Q99.2	Fragile X

## Appendix E: Details About T-MSIS Sample

The table displays the number of people in the 2018 Transformed Medicaid Statistical Information System (T-MSIS) population and for the T-MSIS sample analyzed for this study. Column A displays the number of adults with intellectual and developmental disabilities (I/DD) in the sample analyzed for this study. Adults with I/DD were randomly selected within each state from the population of adults with I/DD identified in T-MSIS. Column B displays the number of adults with I/DD in the 2018 T-MSIS population. Column C is the ratio of column A to column B, converted into a percentage. Column C shows the percentage of adults with I/DD in each states' T-MSIS population who were randomly selected for the T-MSIS sample for this study. Column D shows the percentage of all adults, by state, in the T-MSIS population who were identified as having an I/DD in 2018.

State	A. Adults with I/DD in sample	B. Adults with I/DD in population	C. Percent of sample in population	D. Percent of Medicaid recipients in each state who had an I/DD
<b>Alabama</b>	13,622	13,623	100	3.64
<b>Alaska</b>	2,558	2,558	100	2.41
<b>Arizona</b>	16,915	21,145	80	1.78
<b>Arkansas</b>	12,562	12,564	100	2.11
<b>California</b>	72,543	145,095	50	1.57
<b>Colorado</b>	11,872	11,872	100	1.27
<b>Connecticut</b>	13,661	17,078	80	2.86
<b>Delaware</b>	4,323	4,323	100	2.78
<b>District of Columbia</b>	3,106	3,107	100	1.59
<b>Florida</b>	27,530	34,413	80	1.97
<b>Georgia</b>	20,033	25,041	80	2.89
<b>Hawaii</b>	3,489	3,489	100	1.43
<b>Idaho</b>	6,960	6,960	100	5.87
<b>Illinois</b>	34,602	43,262	80	2.35
<b>Indiana</b>	15,150	18,937	80	1.98
<b>Iowa</b>	13,161	13,167	100	3.24
<b>Kansas</b>	7,374	7,374	100	4.76

*(continued)*

State	A. Adults with I/DD in sample	B. Adults with I/DD in population	C. Percent of sample in population	D. Percent of Medicaid recipients in each state who had an I/DD
Kentucky	14,817	18,524	80	1.93
Louisiana	13,849	17,311	80	1.74
Maine	8,818	8,818	100	5.37
Maryland	20,260	25,326	80	2.92
Massachusetts	30,267	37,835	80	2.92
Michigan	34,658	43,322	80	2.53
Minnesota	26,576	33,227	80	4.86
Mississippi	11,304	11,305	100	3.55
Missouri	20,574	25,720	80	5.33
Montana	3,149	3,150	100	1.84
Nebraska	3,618	3,619	100	3.50
New Hampshire	5,554	5,555	100	4.07
New Jersey	24,527	30,667	80	2.70
New Mexico	7,086	7,087	100	1.39
New York	53,855	107,716	50	2.56
Nevada	6,288	6,288	100	1.36
North Carolina	26,363	32,956	80	3.49
North Dakota	2,342	2,342	100	6.33
Ohio	38,885	64,814	60	3.37
Oklahoma	10,966	10,966	100	3.12
Oregon	10,526	10,526	100	1.46
Pennsylvania	38,033	63,397	60	3.19
Rhode Island	5,380	5,381	100	2.41
South Carolina	13,186	16,482	80	3.12
South Dakota	3,683	3,684	100	7.93
Tennessee	16,114	20,144	80	2.41
Texas	33,230	55,389	60	3.52
Utah	7,600	7,600	100	5.16
Vermont	4,362	4,362	100	4.33
Virginia	17,816	22,270	80	4.51
Washington	12,559	15,700	80	1.32
West Virginia	7,522	7,522	100	1.91
Wisconsin	14,632	18,291	80	2.50
Wyoming	2,960	2,960	100	11.01

## Appendix F: Developmental Disabilities Agency Leader Questionnaire Responses About Barriers to Oral Health

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The following table shows which states responded to the Developmental Disability Agency Questionnaire and the types of issues they cited within the questionnaire as barriers to oral health care for adults with intellectual and developmental disabilities (I/DD) in their state. The original question text was: “Q12 From your perspective, what are the main barriers to oral health care for adults with I/DD in your state?”

State	State Responded	Lack of Transportation	Medicaid Coverage Limits	Lack of Funds	Lack of Providers Trained to Work with Patients with I/DD	Lack of Providers Who Accept Medicaid	Low Reimbursement Rate	Specialized Care	Accessibility	Psychosocial Barriers
AL	N	-	-	-	-	-	-	-	-	-
AK	Y	-	-	-	-	-	-	-	-	-
AZ	Y	Y	Y	-	-	-	-	Y	-	Y
AR	N	-	-	-	-	-	-	-	-	-
CA	N	-	-	-	-	-	-	-	-	-
CO	Y	-	-	-	Y	Y	-	-	-	-
CT	Y	-	-	-	-	-	-	Y	-	-
DE	N	-	-	-	-	-	-	-	-	-
DC	Y	-	-	-	-	-	-	Y	-	Y
FL	Y	-	-	-	Y	-	-	Y	-	-
GA	Y	-	Y	-	-	-	-	-	-	-
HI	Y	-	Y	-	Y	-	-	Y	-	-
ID	Y	-	-	-	-	-	Y	Y	-	-
IL	N	-	-	-	-	-	-	-	-	-
IN	N	-	-	-	-	-	-	-	-	-
IA	Y	Y	-	-	-	Y	-	Y	-	-
KS	N	-	-	-	-	-	-	-	-	-
KY	N	-	-	-	-	-	-	-	-	-
LA	Y	-	-	-	Y	-	Y	Y	-	-
ME	N	-	-	-	-	-	-	-	-	-
MD	Y	-	-	Y	Y	-	-	-	-	-
MA	N	-	-	-	-	-	-	-	-	-
MI	N	-	-	-	-	-	-	-	-	-
MN	N	-	-	-	-	-	-	-	-	-







## Endnotes

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