
Addressing Dental-Care Underutilization in Adults with Intellectual and Developmental Disabilities (I/DD): A Policy Framework for Enhancing Access and Provider Engagement

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Research suggests that delivering preventive dental care to adults with intellectual and developmental disabilities (I/DD) is a cost-effective long-term strategy that can prevent oral-health conditions and mitigate the risk of more severe health issues. Improving dental care for adults with I/DD requires a multifaceted approach, involving policy adjustments and enhanced support for both providers and beneficiaries.

This brief evaluates recent reports and adopts an evidence-based approach to address the shortage in comprehensive dental-care coverage for adults with I/DD across various states. Key recommendation strategies include: 1) expanding coverage under a 1115 Demonstration Waiver, 2) establishing a federal regulation for all states to provide comprehensive dental care to adult Medicaid beneficiaries with I/DD, 3) adapting dental billing codes, 4) incentivizing providers with cost subsidies and fair reimbursement rates, and 5) advancing education and training in dental schools.

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Introduction

Medicaid, under which individuals with intellectual and developmental disabilities (I/DD) qualify across all states, offers comprehensive dental coverage for children with intellectual and developmental disabilities (I/DD) under the age of 21. However, for adults with I/DD, Medicaid dental-care utilization varies significantly by state, with some states providing minimal or no coverage, leaving more without adequate dental treatment.

Since over 4.5 million of the 7.3 million adults with I/DD depend on Medicaid, and specific data on their dental care access is lacking, Medicaid dental utilization data is used as a proxy to assess their dental access.¹ As of 2023, only 24 states reported Medicaid beneficiaries utilizing dental benefits, with coverage that may not fully include all necessary treatments. The remaining 36 states provide limited dental benefits with utilization levels as low as 0–0.05%.² Lack of dental utilization highlights access barriers, such as service–availability gaps and financial constraints. State-by-state dental-coverage levels, while difficult to track, have made small improvements since the Affordable Care Act (ACA) Section 1557 revisions were enacted in 2020. These revisions aimed to protect against disability discrimination and increase access to care in dental settings. However, despite increases in eligible coverage, individuals with I/DD struggle to utilize their dental benefits and receive actual care. This disparity highlights the need for targeted policy reforms to both expand and standardize dental coverage and address the contributors to underutilization among adults with I/DD across all states.

Background

Adults with I/DD are susceptible to poor oral health, and they experience significant barriers to obtaining dental care. In a systematic review evaluating health outcomes of adult dental patients with I/DD, a higher prevalence and severity of periodontal disease was reported, with this subpopulation facing consistently higher rates of untreated tooth decay.³ Another study suggests “the risk and need for routine and preventive dental services is greater in the I/DD population,” which signifies the need for preventive oral health programs and more frequent screenings.⁴

Despite the higher upfront costs in prioritizing preventive oral health in the short term, data from the National Council on Disability indicates that

providing dental care to adults with I/DD is highly cost-effective in the long term, since preventable oral health conditions are associated with (and are often a precursor to) more serious health conditions.⁵ Redirecting the focus away from emergency-only care and towards preventive care is within the authority of states. Lack of federal oversight over state dental spending has caused significant care discrepancies across various states.⁶ Variability in dental-care utilization is reflected through state-by-state differences as reported in **Figure 1**.

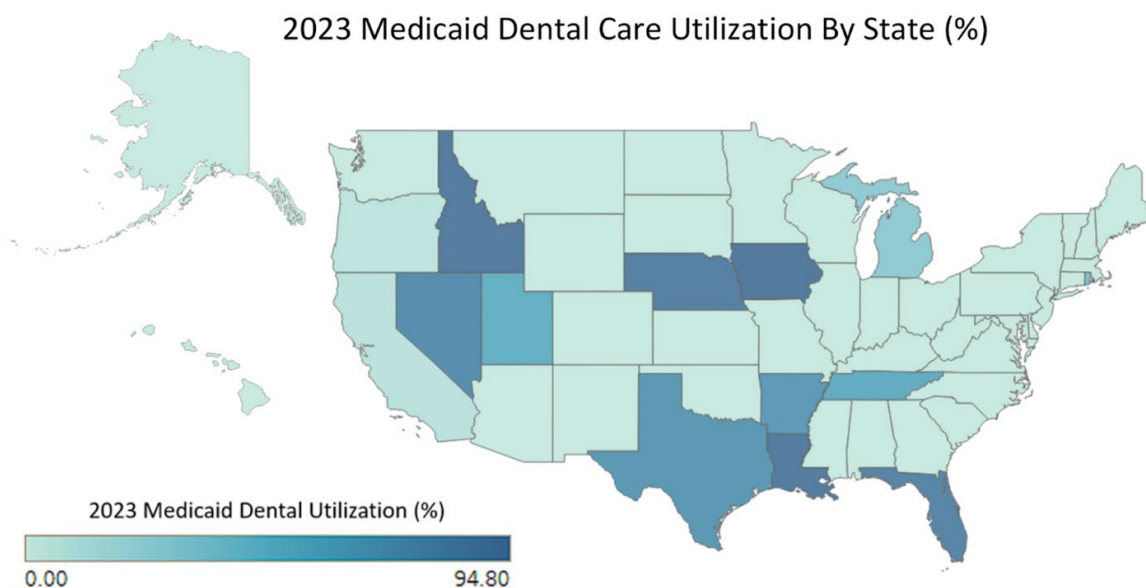


Figure 1. Medicaid dental-care utilization by U.S. state. Percentages by state are displayed in accordance with the data in MACStats: Medicaid and CHIP Data Book² (2023, pp. 89–91). The color legend reflects differences in dental utilization ranging from 0.00% (reported minimum, in light blue) through 94.80% (reported maximum, in dark blue). A figure of 0.0% indicates an amount less than 0.05% that rounds to zero. See Appendix for [accessible version](#).

Another factor to consider for patients with I/DD is their greater need for sedation practices. Compared to the general adult population, which spends \$199.92 for routine preventive care (including dental exam, x-rays, cleaning), adults with I/DD spend \$199.92–\$272.92, without in-office sedation, and around \$3,649.92 with sedation.⁷

In addition to financial barriers stemming from the higher cost of care, adults with I/DD face obstacles accessing services at dental offices. These challenges are compounded by the fact that many dentists choose not to participate in the Medicaid

program for three primary reasons: 1) low reimbursement rates, 2) frequency of broken appointments and patient noncompliance, and 3) higher administrative burdens.⁸

Unfavorable perceptions and lack of educational preparation among dentists contributes to hesitance to treat disabled patients. Minimal didactic and clinical dental education on disability dentistry further compounds this issue. A 2010 survey of 22 U.S. and Canadian dental schools revealed that special-needs courses were offered in only 64% of programs, with only 37% of programs having a designated clinical area to learn how to treat disabled patients.⁹ Despite the National Council on Disability’s (NCD) push for dental schools to revamp disability curricula and the American Dental Association’s revision to the code of ethics to prevent discrimination of disabled patients,¹⁰ a recent study published in 2023 acknowledged that “only 41% of students felt confident treating special needs patients upon graduation” from a dental school.¹¹ With a projected 65% increase in the number of disabled individuals in the U.S. by 2030,¹² it is crucial to prepare systems, practitioners, and institutions to meet the growing demand for care.



Proposed Policy Solutions



Section 1: 1115 Demonstration Waiver

Under a 1115 Demonstration Waiver, states can pilot innovative approaches to Medicaid coverage, including dental care. These waivers are granted at the discretion of the HHS secretary and reviewed on a case-by-case basis by CMS. Piloting a new model for providing dental care and expanding coverage is pertinent to improving equity in dental care across states for adults with I/DD and improving population health outcomes. This waiver should advocate for a comprehensive dental-care package tailored to the preventive needs of adults with I/DD. Given the elevated risk profile of this population, the proposed recommendations go beyond standard American Dental Association guidelines to ensure appropriate and effective care.


Comprehensive Dental Package Proposal

Preventive Care
<p>Routine Dental Cleanings (Prophylaxis): 3-4 per year</p> <p><i>Increase covered benefit from 2 per year to 3-4 per year. Many adults with I/DD classify as high-risk caries patients and should have coverage for >2 cleanings a year (if needed).</i></p>
<p>Dental Examinations: 3-4 per year</p> <p><i>Increase covered benefit from 2 per year to 3-4 per year. Adults with I/DD may require a more frequent dental exam schedule every 3-4 months (if needed).</i></p>
<p>Fluoride Treatments: Minimum of 2 per year</p> <p><i>Adults with a history of frequent cavities, dry mouth, or other risk factors would benefit from more frequent treatments (if needed).</i></p>
<p>X-rays (Radiographs): 1 per year</p> <p><i>Beneficiaries should be eligible for bitewings and periapical x-rays annually (if needed).</i></p>


Dental professionals and insurance companies should collaboratively re-evaluate coverage frequencies for restorative care, cosmetic procedures, and early interventions to alleviate patients' financial burdens and enhance access to dental services.

Examples of procedures and/or strategies for restorative care, cosmetic procedures, and early intervention are listed in the table below.

Restorative Care	Cosmetic Procedures	Early Intervention
Fillings (Composites) Root Canals Extractions Crowns & Bridges Dentures & Implants Oral Surgery Mouthguard & Retainers	Braces & Clear Aligners Teeth Whitening Botox Treatment	Oral Health Products (Toothbrushes, Prescription Toothpastes, Rinses) Scaling & Root Planing Oral Screening Routine Cleanings/Exams

 **Section 2: Federal Regulation Establishing Minimum Coverage Across States**

Requiring all states to include comprehensive dental coverage—encompassing preventive care, restorative treatments, and specialized procedures that may be required more frequently for individuals with I/DD—will promote consistency in access to dental care for adults with I/DD across all states. This policy adjustment aims to provide a baseline level of coverage while balancing state autonomy to set maximums and addresses the growing need for comprehensive dental benefits. Setting this minimum threshold will not only improve geographical dental equity, but substantially reduce patient out-of-pocket costs.

 **Section 3: Adapting CDT (Current Dental Terminology) Billing Codes**

To incentivize dentists to provide care for this underserved I/DD population, enhancements to CDT codes could lead to reimbursement more reflective of services rendered. This may entail introducing new CDT codes recognizing the unique challenges of treating adults with I/DD. These would account for use of specialized equipment, staffing, techniques, or additional time required, particularly with patients presenting with communication, behavioral, or physical challenges. Because this population has a greater need for sedation and anesthesia, better differentiating the more complex services through tiered coding would be beneficial. Tiered coding would more accurately account for the additional time, risk, and expertise required to safely sedate patients who present with comorbid conditions or heightened anxiety.

Adults with I/DD typically work with multiple healthcare providers, such as primary care physicians, neurologists, or caregivers. As such, the extra time and resources to ensure coordination of care can better be reflected through improvements in CDT codes tailored to I/DD dental treatment services.



Section 4: Funding Reallocation

Funding for the 1115 Demonstration Waiver must be approved and follow proper guidelines.¹³ Lack of utilization of Medicaid dental services in past years may warrant the reallocation of resources towards alternate means. Unused funds from beneficiaries with unmet caps or who have not utilized their allotted dental services might be reallocated in two beneficial ways:

- 1) Medicaid program: reallocated to improve dental benefits
- 2) State General Fund: reallocated to improve dental education



Section 5: Addressing Dental Providers and Incentivization

Unused funds can address gaps in training, resources, and awareness among dental providers. They can also help improve dental education by enhancing curricula on treating underserved populations, including individuals with I/DD.

Part 1: Dentists

Many dentists deny treatment to Medicaid beneficiaries due to low reimbursement rates. According to the American Dental Association, only 33% of dentists in the United States are estimated to treat Medicaid patients.¹⁴ One way to incentivize the acceptance of Medicaid patients for offices with high overhead costs is to subsidize equipment and provide fair reimbursement rates.

Part 2: Private Dental-Insurance Companies

Increasing annual maximums and expanding coverage through tailored coverage plans for essential procedures will reduce out-of-pocket costs for patients with I/DD that opt for private dental insurance. Making these adjustments may expand the dentist's network of patients, potentially helping to increase reimbursement after negotiation. Dental-insurance companies should also consider streamlining claims processing to lower administrative costs and redirect efforts toward expanding coverage.

Part 3: Dental Schools

Dental schools should reevaluate their education programs for students in both didactic and clinical years to ensure a well-rounded curriculum that adequately prepares them to treat patients with disabilities upon graduation. Utilizing state general funds to increase the presence of disability oral-health centers would not only benefit school reputation and attract patients but, more importantly, offer greater opportunities for affordable care. School-specific loan-repayment programs for people who commit to serving adults with I/DD in school-sponsored clinics would incentivize dental students and improve health outcomes among this population.

Conclusion

Addressing the gaps in dental coverage for adults with I/DD is not only a matter of equity but also a strategic approach for improving overall health outcomes and reducing long-term costs. Current Medicaid dental benefits for adults with I/DD are insufficient in many states, leaving many individuals with inadequate access to necessary care.

This policy brief highlights the urgent need for comprehensive reform, including expanding coverage under the 1115 Demonstration Waiver, setting minimum-coverage requirements, and adapting dental codes to better represent the needs of individuals with disabilities. Additionally, incentivizing dental providers to accept more adult I/DD patients, many of whom are covered through Medicaid, and enhancing dental education are crucial steps toward improving care delivery.

This coordinated strategy including policy adjustments, funding reallocations, and educational advancements will help establish a more equitable and effective dental-care framework.

How to Cite This Brief

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Appendix

Medicaid Dental-Care Utilization by U.S. State: Accessible Version

This table presents the raw data used to generate the heatmap shown above in **Figure 1**. The table lists dental-care utilization percentages for each state, with values ranging from 0.0% to 94.8%. The data is sourced from the *MACStats: Medicaid and CHIP Data Book*² (2023, pp. 89–91) and reflects the proportion of Medicaid enrollees who utilized dental-care services.

Note: Values of 0.0% indicate utilization rates of less than 0.05%, which are rounded to zero.

State	Medicaid Enrollees	Dental (%)	State	Medicaid Enrollees	Dental (%)
Alabama	1,198,510	0.0	Missouri	1,048,083	0.0
Alaska	242,176	0.0	Montana	309,776	0.0
Arizona	2,244,273	0.0	Nebraska	336,290	88.1
Arkansas	1,069,577	67.6	Nevada	847,650	77.1
California	14,150,266	6.3	New Hampshire	239,439	0.0
Colorado	1,499,303	0.0	New Jersey	1,892,091	0.0
Connecticut	1,106,169	0.0	New Mexico	941,830	0.0
Delaware	276,475	0.0	New York	7,145,884	0.0
District of Columbia	285,297	0.0	North Carolina	2,557,593	0.0
Florida	4,871,362	83.1	North Dakota	125,354	0.0
Georgia	2,539,039	0.0	Ohio	3,238,849	0.0
Hawaii	420,033	0.0	Oklahoma	1,065,121	0.0
Idaho	421,589	92.8	Oregon	1,286,095	4.7
Illinois	3,467,588	0.0	Pennsylvania	3,292,313	0.0

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State	Medicaid Enrollees	Dental (%)	State	Medicaid Enrollees	Dental (%)
Indiana	1,870,171	0.0	Rhode Island	339,276	37.7
Iowa	749,862	94.8	South Carolina	1,446,070	0.0
Kansas	461,405	0.0	South Dakota	137,268	0.0
Kentucky	1,584,976	0.0	Tennessee	1,717,984	54.1
Louisiana	1,894,676	92.8	Texas	4,928,655	69.6
Maine	331,396	0.0	Utah	424,565	51.1
Maryland	1,780,886	0.0	Vermont	191,240	0.0
Massachusetts	2,091,955	0.0	Virginia	1,852,563	0.0
Michigan	2,900,801	28.1	Washington	2,008,655	0.0
Minnesota	1,253,815	0.0	West Virginia	599,336	0.0
Mississippi	776,482	0.0	Wisconsin	1,484,746	0.0