EVERY SMILE MATTERS
NEVADA

March 2024

EVERY SMILE MATTERS

THE ORAL HEALTH NEEDS OF ADULTS WITH INTELLECTUAL AND/OR DEVELOPMENTAL DISABILITIES IN NEVADA

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The University of Minnesota Residential Information Systems Project (RISP)

ACKNOWLEDGEMENTS

Every Smile Matters is an oral health initiative aimed at improving the oral health of adults with intellectual and/or developmental disabilities in Nevada through research, outreach, oral health provider continuing education and community engagement. Information about Every Smile Matters and the work we do across the state can be found at www.everysmilemattersnevada.org.

This needs assessment was made possible by funding from the American Rescue Plan Act, and the leadership of the Division of Health Care Finance and Policy, the Nevada Aging and Disability Services Division, and the Nevada Oral Health Program. The project was led by Dr. Keith Benson, DMD, Nevada State Dental Health Officer; Kirsten Coulombe, Social Services Chief 3, Long Term Services and Support; and Jannette Gomez, Nevada State Public Health Dental Hygienist and Oral Health Program Coordinator.

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INTRODUCTION AND PURPOSE

Our health goals should be centered around one premise: Underserved shouldn't be a designation within our state.

Dr. Bryce Putman, DDS, NV Advisory Committee -State Program for Oral Health

Oral health care represents the most unmet health care need for adults with intellectual and/or developmental disabilities (ID/DD) in the United States. [1]

The data in this Nevada Oral Health Needs Assessment of Adults with Intellectual and/or Developmental Disabilities higher rates of oral disease in adults with ID/DD, the health disparities they experience, and how these disparities impact financial stability, overall health outcomes, employment, education, and quality of life. It is well documented throughout the literature that adults with ID/DD have a high burden of oral disease[2] made worse by comorbidities and other conditions.[3] The focus of this Needs Assessment is on working-age adults ages 18-64 with ID/DD and the significant oral health disparities they experience, and the policy, program, and practice changes to address them.

People with disabilities are the largest unrecognized minority group[4] in the United States, making up more than 27% of the population. According to U.S. Census Bureau American Community Survey (ACS) estimates, in 2022 there were 228,683 Nevadans ages 18-64 with a disability, and 95,639 adults with ID/DD, making up 41.8% of the population of Nevada adults with any disability.[5]

Throughout the Needs Assessment, data will be presented on Nevada adults with ID/DD who make up three specific subsets of the populations:

1. Adults with ID/DD ages 18-64 (estimated 95,639)
2. Adults with ID/DD ages 18-64 who rely on Medicaid (estimated 33,376)
3. Adults with ID/DD ages 21 and over enrolled in Medicaid and receiving expanded Medicaid dental benefits under the Home and Community Based Services (HCBS) Individuals with Intellectual or Developmental Disabilities Waiver (ID Waiver) (2,967)

This Assessment presents the main barriers to good oral health for adults with ID/DD nationally and in Nevada, and the data-driven recommendations to address those barriers through the understanding that ***oral health IS health***, that oral disease is almost always preventable, and that health prevention reduces healthcare costs.

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[1] Chavis, S. E., & Macek, M. (2022). Impact of disability diagnosis on dental care use for adults in the United States: Status matters. *Journal of the American Dental Association (1939)*, *153*(8), 797–804. https://doi.org/10.1016/j.adaj.2022.03.002

[2] Morgan, J. P., Minihan, P. M., Stark, P. C., Finkelman, M. D., Yantsides, K. E., Park, A., Nobles, C. J., Tao, W., & Must, A. (2012). The oral health status of 4,732 adults with intellectual and developmental disabilities. *Journal of the American Dental Association (1939)*, *143*(8), 838–846. https://doi.org/10.14219/jada.archive.2012.0288

[3] Williams, A.R., Yaqub, A., Glassman, P. & Phillips, V. (2023) Shortening-The-Line: Reducing the Need for Sedation and General Anesthesia for Dental Care for People with Disabilities, *Journal of the California Dental Association*, 51:1, DOI: 10.1080/19424396.2023.2253958

[4] National Institutes of Health. (2022). Advisory Committee to the Director Working Group on Diversity Subgroup on Individuals with Disabilities. *REPORT*. Retrieved from https://acd.od.nih.gov/documents/presentations/12092022_WGD_Disabilities_Subgroup_Report.pdf p. 8

[5] American Community Survey (ACS). 2022 1-year Estimates. Table S1810. Disability Status

Viewed through the lens of the Healthy People 2030 Framework[6] and the Social Determinants of Health model, adults with ID/DD face increased barriers due to their disability, compounding the problem of higher rates of oral disease and their impacts. Research has demonstrated that adults with ID/DD experience higher rates of poverty, lower rates of full-time, full-year employment, as well as higher rates of chronic disease such as diabetes, heart disease and obesity, making adults with ID/DD more likely to delay dental care if they are uninsured, and more likely to have complications if oral disease is left untreated. [7, 8, 9]

In order to gain an understanding of what barriers and challenges adult with ID/DD in Nevada face and to honor the motto of the ID/DD community internationally, "*Nothing about us without us,"*[10] Every Smile Matters—a program designed and supported by the Nevada Division of Health Care Finance and Policy, Nevada Aging and Disabilities Service Division, and the Nevada Oral Health Program, with American Rescue Act Plan funding—conducted interviews and surveys across the state with adults with ID/DD and their caregivers to ensure that their lived experience and first-person knowledge was included in the data presented, in addition to secondary data analysis. Survey results of oral health providers on their perspective, motivations, and barriers in treating this population are also included.

This Nevada Oral Health Needs Assessment of Adults with Intellectual and/or Developmental Disabilities is being completed against the national backdrop of Medicaid adult coverage that varies by state, and the trend toward expansion of benefits for adults, as well as for specific high-risk populations. Medicaid is the nation's public insurance program for people who are poor or low income and for people with disabilities and is the medical insurance provider for roughly 38% of adults with ID/DD across the country who rely on Medicaid coverage,[11] including an estimated 36,343 adults with ID/DD in Nevada.

Medicaid dental coverage for adults is not mandated for states by the Centers for Medicare & Medicaid Services (CMS) as it is for children,[12] resulting in variability of dental coverage for adults described above. Twenty-five states including Washington D.C. provide extensive dental coverage to Medicaid-enrolled adults, 14 provide limited coverage, 8 states including Nevada provide emergency only dental benefits, and 3 states provide no dental benefits.[13] Notably, while Nevada Medicaid medical insurance (general health coverage) continues seamlessly once a child, including one diagnosed with ID/DD turns 21, the Medicaid-funded dental insurance the child received from

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[6] U.S. Department of Health and Human Services. Office of Disease Prevention and Health Promotion. *Healthy People 2030 Framework*. Retrieved from https://health.gov/healthypeople/about/healthy-people-2030-framework

[7] Cornell University. *2022 Disability Status Report*. *Nevada.* Retrieved from https://www.disabilitystatistics.org/report/pdf/2022/2032000 p. 43

[8] Cornell University. *2022 Disability Status Report*. *Nevada.* Retrieved from https://www.disabilitystatistics.org/report/pdf/2022/2032000 pp. 32-37

[9] Centers for Disease Control and Prevention. Disability and Health Data System (DHDS). General Health Conditions, Chronic Conditions and Health Risks & Behaviors. Retrieved from https://www.cdc.gov/ncbddd/disabilityandhealth/dhds/index.html

[10] National Democratic Institute. (2022). *From "Nothing About Us Without Us" to "Nothing Without Us".* Retrieved from https://www.ndi.org/our-stories/nothing-about-us-without-us-nothing-without-us

[11] Drake, P, & Burns, A. (2024). *Working -Age Adults with Disabilities Living in the Community*. Retrieved from https://www.kff.org/medicaid/issue-brief/working-age-adults-with-disabilities-living-in-the-community/

[12] Centers for Medicare & Medicaid Services (CMS). 2014. *EPSDT – A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents*. Retrieved from https://www.hhs.gov/guidance/sites/default/files/hhs-guidance-documents/epsdt_coverage_guide_11.pdf

[13] National Academy for State Health Policy. (2022). *State Medicaid Coverage of Dental Services for General Adult and Pregnant Populations.* Retrieved from https://nashp.org/state-tracker/state-medicaid-coverage-of-dental-services-for-general-adult-and-pregnant-populations/

birth to 21 ends. Medicaid adult dental benefits coverage typically fall into four general categories:[14]

- **Extensive Coverage:** A comprehensive mix of services, including more than 100 diagnostic, preventive, and minor and major restorative procedures approved by the ADA; per-person annual expenditure cap is at least $1,000.
- **Limited Coverage:** Fewer than 100 diagnostic, preventive, and minor restorative procedures recognized by the American Dental Association (ADA); per-person annual expenditure for care is $1,000 or less.
- **Emergency Coverage Only:** Relief of pain under defined emergency situations.
- **No Coverage:** No adult dental benefits are provided.

Under Nevada Governor Joe Lombardo's leadership, Nevada took a significant step to address oral health disparities for adults with ID/DD enrolled in Medicaid by expanding dental benefits for 2,967 individuals ages 21 and over who qualify for the Home and Community Based Services (HCBS) for Individuals with Intellectual or Developmental Disabilities (ID Waiver). These benefits were piloted by the Nevada Division of Healthcare Financing and Policy and the Nevada Aging and Disability Services Division in 2023 with funding from the American Rescue Plan Act and were set to expire March 31, 2024. Governor Lombardo approved the continuation of these benefits through the 2024-2025 biennium as part of the Nevada Medicaid budget. This is the first-time adults with ID/DD with Medicaid coverage in Nevada have had access to expanded dental Medicaid benefits. Expanded benefits include:

- **Diagnostic and Preventative care:** Regular check-ups/radiographs and cleanings (prophy), fluoride and silver diamine fluoride treatments.
- **Restorative care**: amalgam, resin based composite fillings, stainless steel crowns, core build-ups
- **Endodontic care:** direct pulp caps, pulpotomy, root canal treatment on all teeth excluding only wisdom teeth.
- **Periodontic care**: gingivectomy, root planning and scaling, and full mouth debridement
- **Prosthodontic care:** Complete dentures and partial dentures including repairs
- **Oral surgery care**: extractions biopsy, alveoloplasty
- **Anesthesia care:** nitrous and IV sedation

As a result of expanded dental benefits for ID Waiver recipients, funded by ARPA, 147 dental providers across the state provided 4,520 procedures in dental office and care valued at $1,239,145.51 (HDR) ($392,298.90 DTL) to 855 unique patients in the 12 months of 2023. While this is incredible progress, the question for Nevada decision-makers remains whether there is a data-driven argument for expanding Medicaid dental benefits to the estimated 38% of adults with ID/DD (36,343) in Nevada who rely on Medicaid coverage,[15] not only to the 2,967 individuals on the ID Waiver.

[14] Center for Health Care Strategies, Inc. (2019). *Medicaid Adults Dental Benefits: An Overview.* Retrieved from https://www.chcs.org/media/Adult-Oral-Health-Fact-Sheet_091519.pdf

[15] Drake, P, & Burns, A. (2024). *Working -Age Adults with Disabilities Living in the Community*. from https://www.kff.org/medicaid/issue-brief/working-age-adults-with-disabilities-living-in-the-community/

Because my son is not easy to understand when he talks, his smile is the way he greets the world, and shows his joy. Nevada providing expanded Medicaid dental benefits to adults with ID/DD who previously did not have them is deeply personal, and to every one of us who loves someone with a disability, it is priceless.

Mother of 23-year-old adult son with ID/DD, Reno, NV

Nevada's expansion of dental benefits to adults on the ID Waiver, and the development and implementation of the Every Smile Matters initiative (www.everysmilemattersnevada.org), is directly aligned with the CMS Framework for Health Equity 2022-2023, which lays out its commitment to addressing the well-documented disparities for people with disabilities and other marginalized and historically underserved populations.

Numerous studies have found that providing Medicaid dental benefits for all adults, and especially for those at high risk of oral disease such as adults with ID/DD, reduced the burden on taxpayers and increased individual and public health outcomes.[16] Nevada specific research and fiscal analysis will need to be conducted to determine the return on investment for Nevada, and if these findings align with the National Council on Disability's findings for the costs and benefits to Nevada in its landmark study on this issue.

Aligned with the CMS Framework for Health Equity, for the 95,639 adults with ID/DD in Nevada,[17] and especially the 38%[18] who rely on Medicaid for their healthcare, ensuring that they are counted, and the disparities in their oral health are documented, analyzed, and data driven, recommendations are identified as the first step toward achieving health equity. This Needs Assessment and the data below tell the story of a population that has been, paraphrasing the National Council on Disability 2017 report, *neglected for far too long.*[19]

[16] National Council on Disability (NCD). (2022). *Medicaid Oral Health Coverage for Adults with Intellectual & Developmental Disabilities – A Fiscal Analysis.* Retrieved from https://www.nccp.org/wp-content/uploads/2022/03/NCD_Medicaid_Report_508.pdf

[17] American Community Survey (ACS), 2022 1-year Estimates. Table S1810, Disability Status.

[18] Drake, P, & Burns, A. (2024). *Working -Age Adults with Disabilities Living in the Community*. Retrieved from https://www.kff.org/medicaid/issue-brief/working-age-adults-with-disabilities-living-in-the-community/

[19] National Council on Disability. (2017). *Neglected for Too Long: Dental Care for People with Intellectual and Developmental Disabilities.* Retrieved from https://www.ncd.gov/report/neglected-for-too-long-dental-care-for-people-with-intellectual-and-developmental-disabilities/

METHODS AND APPROACH

The Nevada Oral Health Needs Assessment of Adults with Intellectual and/or Developmental Disabilities was conducted using an applied mixed methods model, which was selected to address the objectives of this project with specific focus on exploring available qualitative experiences and collecting quantitative data to assess and better understand the disparities facing adults with ID/DD with respect to dental needs, barriers, and oral health outcomes.

As introduced in the initial sections of this Needs Assessment and revisited throughout the discussions of data, limitations, experiences, and outcomes, there is an inherent need to understand the experiences, barriers to care, dental related issues, available treatment options, and insurance related claim data among adults with ID/DD in Nevada, those who are insured by Medicaid, as well as those who are enrolled in the Medicaid Home and Community Based Services ID Waiver program who accessed expanded dental services during the first year of benefits expansion for the Waiver population, 2023. Although dental health is often discussed as a component of overall health and wellness, the data systems and data collection procedures are quite different from general health data and there are numerous variances in terms of care options and insurance coverage that reduce access and limit care options, especially for adults with ID/DD.

Furthermore, there is an inherent need to examine the geo-locational disparities in terms of available providers, care options, dental procedures, dental visits, emergency dental care, insurance limitations, and a variety of other dental health related variables. Nevada, based on population diversity and dispersion, is a pragmatic pilot study state for assessing dental services and evaluating overall system operations through Applied Mixed Methods to understand and be able to explain the circumstances of the current landscape, expound upon impacts related to the implementation of the ID Waiver with data-derived narrative and recommendations, and align experiences from patients, caregivers, and providers to ultimately determine the efficacy of the ID Waiver and recommend adjustments to expand its deployment and utility to a larger population of individuals with ID/DD across Nevada. Comprehensive and holistic understanding from across the dental spectrum, system level to individual patient and provider level, is paramount to evaluating continued expansion initiatives.

Considering that most of the primary experiential data was gathered through surveys and facilitated interviews, the majority of that data was qualitative in nature. Quantitative data was collected from secondary sources both nationally and statewide as well as specifically from Medicaid and ID Waiver specific data requests from the Nevada State Office of Analytics. Both qualitative and quantitative data as well as applications thereof for research-based publications were limited in nature both within the state and the larger national literature, specifically in terms of standardized approaches, process, and data. The added focus on adults with ID/DD further confounded and compounded these observed limitations, which was postulated to fit within the Mixed Methods research lens and frameworks.

For this Needs Assessment, two surveys were distributed: the Every Smile Matters Individuals/Caregivers Survey and the Every Smile Matters Nevada Provider Perspectives Survey.

Surveys were designed and developed by Strategic Progress in collaboration with the Nevada Division of Health Care Finance and Policy, the Nevada Aging and Disability Services Division, and the Nevada Oral Health Program. See Appendix B for a copy of the surveys.

For the Individuals/Caregivers Survey, surveying and interviewing adults and their caregivers was driven by the recognition that input from key stakeholders is critical to describing challenges and identifying solutions to public health challenges. The Individuals/Caregivers Survey was informed by an extensive literature review of peer-reviewed journal articles and other research reports and publications. The objective of the literature review conducted before the Individuals/Caregivers Survey was designed was to help the researchers better understand:

- Individual and caregiver knowledge of oral health prevention strategies and home care
- The oral health related burdens on caregivers
- The oral health status of adults nationally with ID/DD and in Nevada
- The barriers to care faced by this vulnerable population
- Emergency department usage

The survey was deployed via email to a curated list of nonprofit agencies serving individuals with intellectual and/or developmental disabilities across Nevada, using the Survey Monkey survey tool. The survey was opened in May 2023 date and closed in February 2024. A total of 123 individuals with ID/DD and their caregivers completed the survey.

The Provider Perspectives Survey was informed by a wide ranging and extensive literature review of peer-reviewed journal articles and other research reports and publications on national provider perspectives on their readiness to provide care to adults with ID/DD, barriers to providing care in office as well as in a surgical setting, the benefits of specific education on caring for this population and the extent to which providers felt they received adequate training during their educational program, the benefit of continuing education and their participation in Medicaid, and barriers to enrolling as a Medicaid provider.

The survey was sent to three groups of dentists and hygienists, including:

1. Dentists on a Nevada dental provider list acquired by Complete Medical Lists.
2. Oral healthcare providers who attended a continuing education training on caring for adults with ID/DD at Truckee Meadows Community College in northern Nevada.
3. Oral healthcare providers who attended a continuing education training on caring for adults with ID/DD at Roseman University in southern Nevada.

Every Smile Matters surveyed dentists to understand the following:

- perceptions and readiness of oral health providers to provide care to adults with ID/DD
- barriers to the provision of preventative care and treatment to adult with ID/DD.
- the benefit of continuing education specific to caring for people with disabilities,
- the benefit of the two Nevada continuing education courses provided by Dr. Alan Wong on this topic specifically if they attended, and

- their perspectives on enrolling as a Medicaid provider as well as barriers to joining the Medicaid network.

The survey was deployed via email using the Survey Monkey survey tool and was opened in March 2023 and closed in March 2024. The survey was also posted on LinkedIn and Facebook and sent via email in August 2023. A total of 148 providers across Nevada had completed the survey.

Survey Analysis

Survey were beta tested prior to distribution in August of 2023. The data analyses for the Individuals/Caregivers Survey included descriptive statistics that provide insight into Nevada individuals with ID/DD and their caregivers perspectives on the challenges to accessing to care, the barriers faced for this population, the status of their oral health, and how they currently take care of their oral health. The data analyses for the Provider Perspectives Survey included descriptive statistics that provide insight into Nevada provider perspectives on caring for this population, which are designed to be used to inform future continuing education courses, and to help define the barriers and needs to improved oral health outcomes for adults with ID/DD.

Data Limitations, Challenges and Technical Notes - Shortage of Data on Health inequalities and Disparities for Adults with Intellectual and/or Developmental Disabilities In Nevada

In 2000, the Surgeon General released its seminal report, Oral Health in America, noting that no national studies had been conducted to determine the prevalence of oral health disease for individuals with disabilities. Unfortunately, that remains the case twenty years later.[20]

Christ, A, & Goldberg, J. in Justice in Aging

Nationally, and at the state level in Nevada, many health surveys exclude adults with ID/DD altogether or ask minimal questions and often lack critical demographic data within the ID/DD community. This lack of data not only precludes formulating data-driven policy, program, and practice change recommendations, but impedes Nevada is competing for federal grants and investments since population size and intensity of need are often critical factors for being awarded funding to build systems of care and programs that meet unmet needs. Additionally, due to the higher prevalence of disability within certain communities, the intersection of race and disability goes undocumented, perpetuating inequities for those who face multiple barriers.[21]

If national studies and estimates hold true for Nevada, then only 41% of adults with intellectual and/or developmental disabilities (IDD) are served through the developmental disabilities (DD) system in the State.[22] This poses unique challenge to identifying, counting, gathering data on, analyzing needs and forming policy recommendations that are data driven to address health and oral health disparities among adults with ID/DD in Nevada.

Fundamentally, there is a substantial shortage of data and limited connectivity of data for oral health of individuals with ID/DD. As a starting point for this discussion of data limitations, challenges, and technical notes it is imperative to stress the disparity of data observed in the literature, national and state secondary sources, and primary state sources (Medicaid enrollment, claim, and dental services data). Holistically, dental data is more limited than comparative health and even mental health data. Dental health comparatively has more direct health-related impacts (a tooth infection can spread beyond the mouth impacting overall health for example), but dental health records systems do not ascribe to the same parameters as similar health records systems and do not effectively or efficiently connect individuals across the Medicaid system. Furthermore, Medicaid does not require a standardized dental plan across states, which results in disparate and inconsistent available data nationally and at the state level. Systemically, these differences lead to an incomplete and inconclusive picture of dental health, dental services, and dental needs for all populations, and especially for the population of adults with ID/DD, where data is already limited.

[20] Christ, A., & Goldberg, J. (2020). Adding a Dental Benefit to Medicare: Addressing Oral Health Inequity Based on Disability. *Justice in Aging.* Issue Brief. Retrieved from https://justiceinaging.org/wp-content/uploads/2020/10/Adding-a-Dental-Benefit-to-Medicare-Disability.pdf p. 4

[21] Administration for Community Living. *I/DD Counts.* Retrieved from https://acl.gov/iddcounts

[22] Rosencrans, M., Tassé, M. J., Kim, M., Krahn, G. L., Bonardi, A., Rabidoux, P., Bourne, M. L., Havercamp, S. M., & Ohio State University Nisonger RRTC on Health and Function (2021). Invisible populations: Who is missing from research in intellectual disability?. *Research in developmental disabilities*, *119*, 104117. https://doi.org/10.1016/j.ridd.2021.104117

When gathering data and designing datasets that can be connected to "speak to each other" and for data to be shared across platforms, states and health care organization would need to use uniform disability identifiers that could be included in electronic health records, death certificates, and insurance claims for all patients, even if treatment sought is unrelated to the person's disability, in order to improve data availability and quality on adults with ID/DD in Nevada and their health outcomes.[23] Additionally, in order to assess what changes or policies would help Nevada to build out its Medicaid dental provider network, improved transparency in managed care reimbursement rates is critical to assessing what would cost-effectively expand the provider network of dentists who will treat adults with ID/DD on Medicaid.[24]

Part of this needs assessment include analysis of the outcomes of the expanded dental benefits for adults with ID/DD on the Home and Community Based Services Intellectual and Developmental Disabilities Waiver project. This project was funded by American Rescue Plan Act Funding in Nevada from January 1, 2023, through March 31, 2024. The authors chose to assess outcomes by requesting substantial raw data from the Nevada State Office of Analytics to include Personal Identifiable Information (PII) that enabled linkages between data from various reports to include dental treatment data, pharmacological data to include dental visit prescriptions, and Emergency Room visits for dental related issues to provide a snapshot of adults with ID/DD in Nevada who received these expanded dental benefits.

The primary focus of this report is to describe the extent to which adults with ID/DD have access to oral health care, and the health, poverty, and other social determinants of health that impact oral health status. As discussed and presented, national and state data does not always differentiate data by disability category, which results in substantial limitations in deploying available data to answer specific questions or address identified concerns within the project focus area. Whenever and wherever possible, data is presented specific to adults with ID/DD, but as the data is often not available at the state level for many of the key indicators and variables there are several areas that include data for disabilities (meaning all disability types) used. Additionally, numerous data sets use the term cognitive disabilities instead of intellectual and/or developmental disabilities, so in graphs and charts from those sources, the reference provided terms are adopted. Otherwise, the intellectual and/or developmental disabilities (ID/DD) term is operationalized and deployed for this report.

[23] National Council on Disability. (2023). *Framework to End Health Disparities of People with Disabilities.* Retrieved from https://www.ncd.gov/report/framework-to-end-health-disparities-of-people-with-disabilities/#:~:text=SCOPE%20AND%20PURPOSE%3A%20NCD%27s%20Framework,and%20the%20desire%20to%20address p. 8

[24] National Council on Disability (NCD). (2022). *Medicaid Oral Health Coverage for Adults with Intellectual & Developmental Disabilities – A Fiscal Analysis.* Retrieved from https://www.nccp.org/wp-content/uploads/2022/03/NCD_Medicaid_Report_508.pdf p. 12

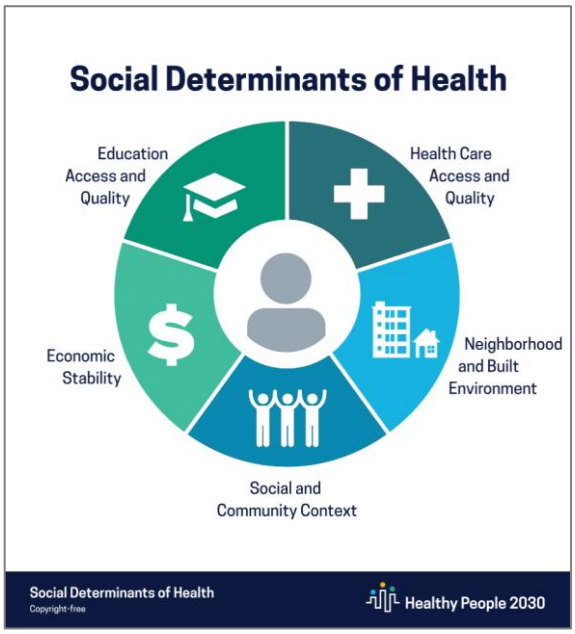
Population and Demographics of Adults with Intellectual and/or Developmental Disabilities

Health Equity Framework

This Needs Assessment analyzes the gaps and needs of adults with ID/DD in Nevada through the lens of social determinants of health (SDOH), describing the demographics, SDOH indicators and barriers this population experiences that impact their oral health.

The Centers for Medicare & Medicaid Services (CMS) defines health equity as *"the attainment of the highest level of health for all people, where everyone has a fair and just opportunity to attain their optimal health regardless of race, ethnicity, disability, sexual orientation, gender identify, socioeconomic status, geography, preferred language, or other factors that affect access to care and health outcomes."*[25] The CMS Framework for Health Equity[26] is consistent with the Healthy People 2030 Framework, which sets data-driven national objectives to improve health and well-being. Priority areas are based on the SDOH, which are the conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks.[27] SDOH can be grouped into 5 domains, including Economic Stability, Education, Health and Health Care, Neighborhood and Built Environment, and Social and Community Context (Figure 1).[28] [29]

Figure 1.Social Determinants of Health – 5 Domains



[25] U.S. Centers for Medicare & Medicaid Services (CMS). Health equity. Retrieved from https://www.cms.gov/pillar/health-equity
[26] U.S. Centers for Medicare & Medicaid Services (CMS). CMS Framework for Health Equity 2022-2032. Retrieved from https://www.cms.gov/files/document/cms-framework-health-equity-2022.pdf
[27] U.S. Centers for Medicare & Medicaid Services (CMS). CMS Framework for Health Equity 2022-2032. Retrieved from https://www.cms.gov/files/document/cms-framework-health-equity-2022.pdf p.13
[28] U.S. Department of Health and Human Services Office of Disease Prevention and Health Promotion. Social Determinants of Health. Retrieved from https://health.gov/healthypeople/priority-areas/social-determinants-health
[29] U.S. Department of Health and Human Services Office of Disease Prevention and Health Promotion. Social Determinants of Health. Retrieved from https://health.gov/healthypeople/priority-areas/social-determinants-health

In each of these domains, individuals with disabilities are more likely than their non-disabled counterparts to experience barriers and challenges, as seen in the disparities data below, as having a disability affects all areas of an individual's life, including employment, housing, transportation, social support, and education, and predict health outcomes.[30]

Nevada and United States Demographics of Adults with Intellectual and/or Developmental Disabilities

…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.'

An intellectual disability is often identified by an intellectual quotient (IQ) score of below seventy to seventy-five. 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.

National Council on Disability, 2022[31]

In 2022, there were an estimated 44.1 million Americans with disabilities, making up 13.4% of the civilian noninstitutionalized population. This group includes people with hearing, vision, cognitive, ambulatory, self-care, or independent living difficulties. There were 22.0 million working age adults ages 18-64 with any type of disability making up 20.9% of the total population ages 18-64. Nearly half of all adults with a disability ages 18-64 (approximately 10.4 million) have a cognitive disability. Adults ages 18-64 with a cognitive disability make up 5.2% of the total population in the United States, which is termed intellectual and/or developmental disabilities, or ID/DD, in this report.[32] The International Classification of Diseases (ICD) codes for the many conditions that have associated medical diagnosis codes for ID/DD are found in Appendix A.

In Nevada in 2022, there were 449,327 individuals of any age who had a disability, making up 14.3% of the civilian noninstitutionalized population of 3,139,304 in 2022. There were 228,683 working-age Nevada adults ages 18-64 with any type of disability, making up 22.7% of the total noninstitutionalized population ages 18-64.

[30] Association of University Centers on Disabilities. Social Determinants of Health. Retrieved from https://disabilityinpublichealth.org/social-determinants-of-health/

[31] National Council on Disability (NCD). (2022). *Medicaid Oral Health Coverage for Adults with Intellectual & Developmental Disabilities – A Fiscal Analysis.* Retrieved from https://www.nccp.org/wp-content/uploads/2022/03/NCD_Medicaid_Report_508.pdf p. 17

[32] American Community Survey (ACS). 2022 1-year Estimates. Table S1810. Disability Status

In 2022, there were 95,639 Nevada adults with a cognitive disability (ID/DD), making up 41.8% the adult population with disabilities (ages 18-64). The number of Nevadans of working-age (18-64) with a cognitive disability (ID/DD) grew from an estimated 72,846 in 2017 to 95,639 in 2022, an increase of 31.3% between 2017 and 2022.[33] The Nevada total civilian non-institutionalized population grew from 2,962,236 to 3,139,304 residents during that same time period, increasing by 6.0%.

American Community Survey (ACS) 1-year data have been selected to represent the estimated population of adults with ID/DD in Nevada (Table 1) due to the rapid growth of the state, making the five-year average less representative of the current population count.

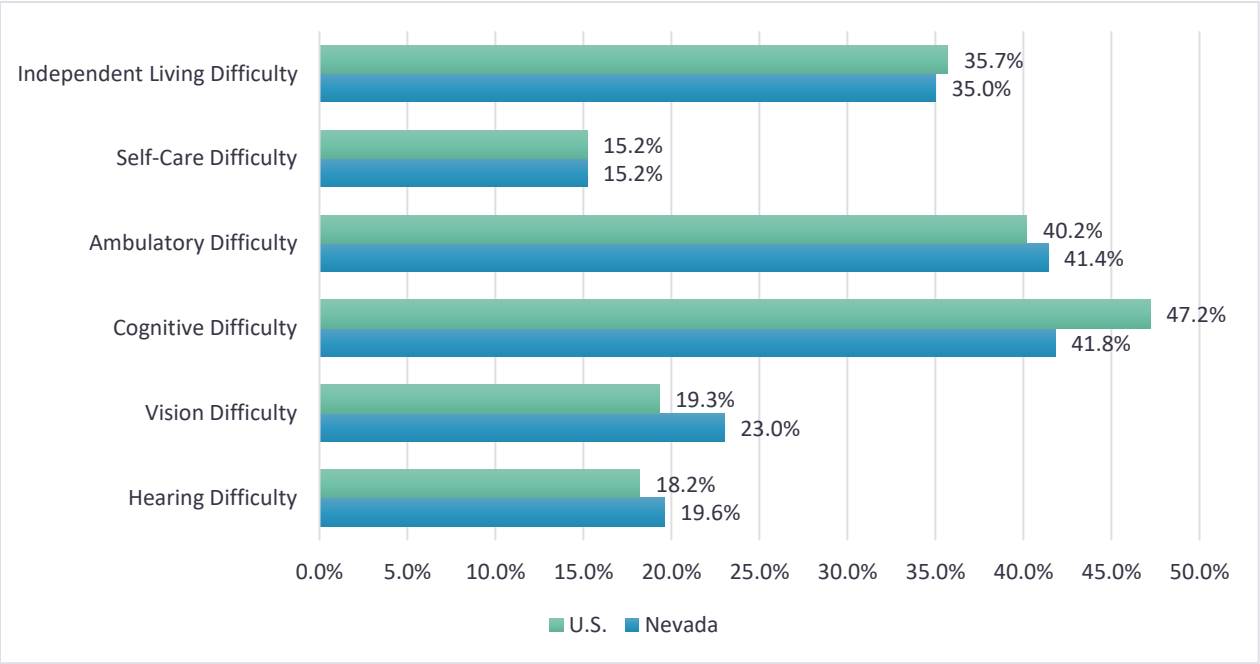
TABLE 1.AMERICAN COMMUNITY SURVEY 2017-2022 POPULATION COUNTS

	2017	2018	2019	2020	2021	2022
Total civilian non-institutionalized population	2,962,236	2,99,585	3,043,419	*	3,105,760	3,139,304
Adults age 18-64 with any disability	183,918	184,884	177,702	*	202,739	228,683
Adults age 18-64 with a cognitive disability	72,846	70,390	71,486	*	83,722	95,639

*Data from the American Community Survey for 2020 is not available.

In both Nevada and the United States, among adults ages 18-64 with a disability, nearly half report a cognitive disability (41.8% and 47.2%, respectively) (Graph 1), with multiple disabilities being reported as well.[34]

GRAPH 1. THE PERCENTAGE ADULTS AGES 18-64 WITH A DISABILITY BY TYPE OF DISABILITY, 2022 (ACS 1-YEAR ESTIMATES)



[33] American Community Survey (ACS). 2022 1-year Estimates. Table S1810. Disability Status
[34] American Community Survey (ACS). 2022 1-year Estimates. Table S1810. Disability Status

Table 2 below shows a breakdown of the total noninstitutionalized population ages 18-64 with any type of disability and those with cognitive disability by county. Nevada's rural counties, including Storey County (10.7%), Pershing County (8.9%), Mineral County (7.6%), Nye County (7.6%), and Lincoln County (6.6%) had a higher prevalence of individuals with disabilities[35] and face additional health disparities. These include limited access to specialized healthcare services, fewer community resources and support systems, transportation challenges, shortages of trained professionals and service providers, and social isolation. NOTE: The data below represents ACS 5-Year Estimates as the 1-Year estimates provided above were not available for all counties.[36]

TABLE 2. THE TOTAL NONINSTITUTIONALIZED POPULATION AGES 18-64, TOTAL WITH ANY TYPE OF DISABILITY AND WITH A COGNITIVE DISABILITY, AND PERCENT OF TOTAL POPULATION, NEVADA, BY COUNTY, 2022 (ACS 5-YEAR ESTIMATES)

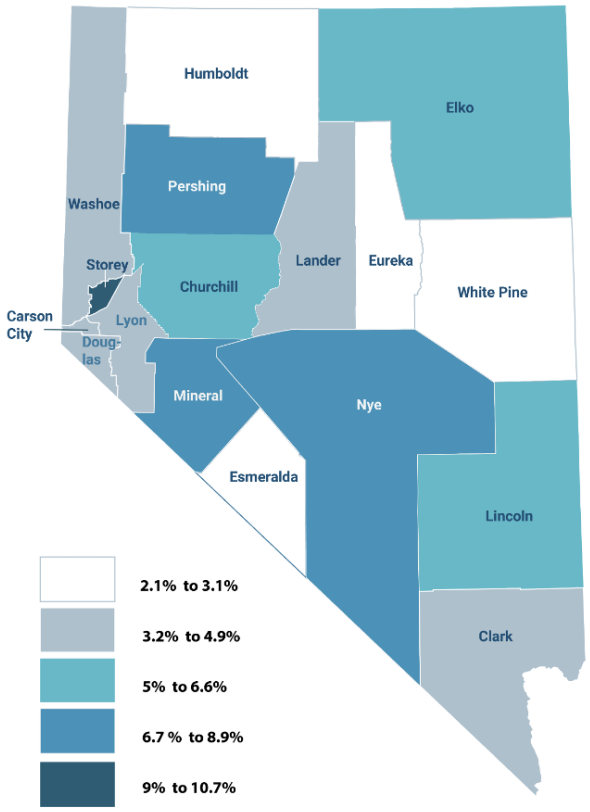
County	Total Population Ages 18-64	Population with a Disability Ages 18-64	Population with a Cognitive Disability Ages 18-64	% of Total Population Ages 18-64 with Cognitive Disability
Carson City	32,632	3,721	1,481	4.5%
Churchill County	13,580	2,211	782	5.8%
Clark County	1,385,619	141,393	57,069	4.1%
Douglas County	26,637	2,965	1,062	4.0%
Elko County	32,393	1,561	1,375	4.2%
Esmeralda County	620	141	15	2.4%
Eureka County	788	123	21	2.7%
Humboldt County	9,915	1,041	303	3.1%
Lander County	3,396	490	165	4.9%
Lincoln County	2,348	452	156	6.6%
Lyon County	34,065	4,679	1,612	4.7%
Mineral County	2,303	356	176	7.6%
Nye County	26,739	5,481	2,019	7.6%
Pershing County	2,752	469	244	8.9%
Storey County	1,871	334	200	10.7%
Washoe County	299,609	27,642	11,351	3.8%
White Pine County	4,073	281	86	2.1%
Nevada	**1,879,340**	**195,899**	**78,117**	**4.2%**

[35] National Council on Disability. (2023). *Framework to End Health Disparities of People with Disabilities.* Retrieved from https://www.ncd.gov/report/framework-to-end-health-disparities-of-people-with-disabilities/#:~:text=SCOPE%20AND%20PURPOSE%3A%20NCD%27s%20Framework,and%20the%20desire%20to%20address p. 2

[36] American Community Survey (ACS). 2022 5-year Estimates. Table S1810. Disability Status

Figure 2 below shows the density of the non-institutionalized population ages 18-64 with a cognitive disability in Nevada by county.

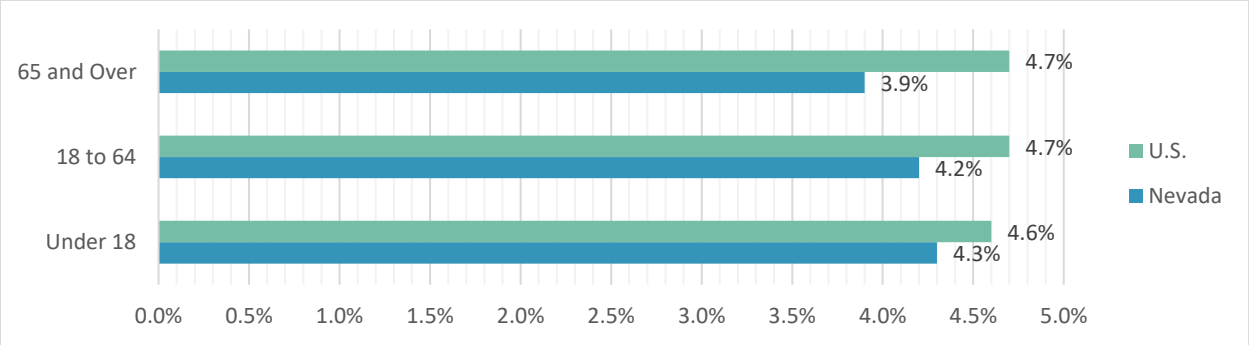
FIGURE 2. PERCENTAGE OF THE TOTAL CIVILIAN NONINSTITUTIONALIZED POPULATION AGES 18-64 WITH COGNITIVE DISABILITY IN NEVADA, BY COUNTY, 2022



AGE

In Nevada, 4.3% of the population under 18, 4.2% of the population 18 to 64, and 3.9% of the population 65 and over have a cognitive disability, compared to the United States at 4.6%, 4.7% and 4.7%, respectively (Graph 2).[37]

GRAPH 2. COGNITIVE DISABILITY BY AGE, NEVADA AND THE U.S., 2022 (ACS 5-YEAR ESTIMATES)

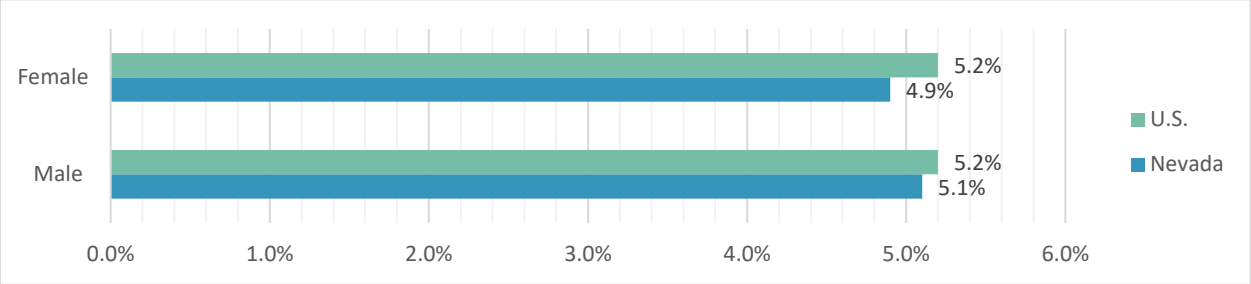


[37] American Community Survey (ACS). 2022 5-year Estimates. Table S1810. Disability Status

Gender and Gender Identity

There are more males (5.1%) than females (4.9%) with cognitive disabilities in Nevada, similar to national trends (Graph 3). [38] The higher prevalence of ID/DD in males can be attributed to various factors, including genetic and biological differences.

Graph 3. Cognitive Disability by Gender, Adults Ages 18-64, Nevada and the U.S., 2022 (ACS 5-Year Estimates)



Notably, self-reported disability rates are higher in the Lesbian, Gay, Bisexual, Transgender and Questioning (LGBTQ) population than in the non-LGBTQ population. [39] Table 3 below shows reported disability rates among adults in the United States by sexual orientation and gender identity for 2020.[40]

Table 3. Reported Disability Among U.S. Adults by Sexual Orientation & Gender Identity (2020)

Type of Disability	LGBTQ+	Transgender	Cisgender LGBQ+	Non- LGBTQ+
Any Disability	36%	52%	35%	24%
Cognitive	25%	35%	24%	9%
Hearing	5%	9%	5%	6%
Independent Living	12%	18%	12%	6%
Mobility	10%	19%	10%	12%
Self-care	3%	8%	3%	3%
Vision	7%	20%	6%	5%

Adapted from The Human Rights Campaign (HRC), Understanding Disability in the LGBTQ+ Community, Table 1.

Veterans

Veterans in Nevada have a higher prevalence of any type of disability (30.6%) than non-veterans (29.5%) (Graph 4).[41] Veterans often have a higher prevalence of disabilities, including Traumatic

[38] American Community Survey (ACS). 2022 5-year Estimates. Table B18104. Sex by Age by Cognitive Difficulty

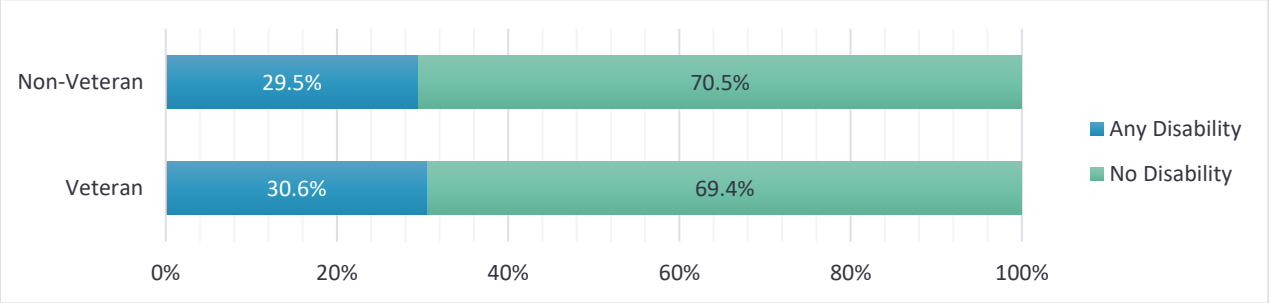
[39] Surfus, C. R. (2023). A Statistical Understanding of Disability in the LGBT Community. *Statistics and Public Policy, Taylor & Francis Journals*, vol. 10(1), pages 2188056-218, December. https://doi.org/10.1080/2330443X.2023.2188056

[40] The Human Rights Campaign (HRC). (2022). *Understanding Disability in the LGBTQ+ Community.* Retrieved from https://www.hrc.org/resources/understanding-disabled-lgbtq-people

[41] Centers for Disease Control. Disability and Health Data System (DHDS). Nevada Category: Disability Estimates. Veteran Status. Retrieved from https://dhds.cdc.gov/SP?LocationId=32&CategoryId=DISEST&ShowFootnotes=true&showMode=&IndicatorIds=STATTYPE,AGEIND,SEXIND,RACEIND,VETIND&pnl0=Chart,false,YR6,CAT1,BO1,,,,AGEADJPREV&pnl1=Chart,false,YR6,DISSTAT,,,,,PREV&pnl2=Chart,false,YR6,DISSTAT,,,,,AGEADJPREV&pnl3=Chart,false,YR6,DISSTAT,,,,,AGEADJPREV&pnl4=Chart,false,YR6,DISSTAT,,,,,AGEADJPREV&t=1709257402387

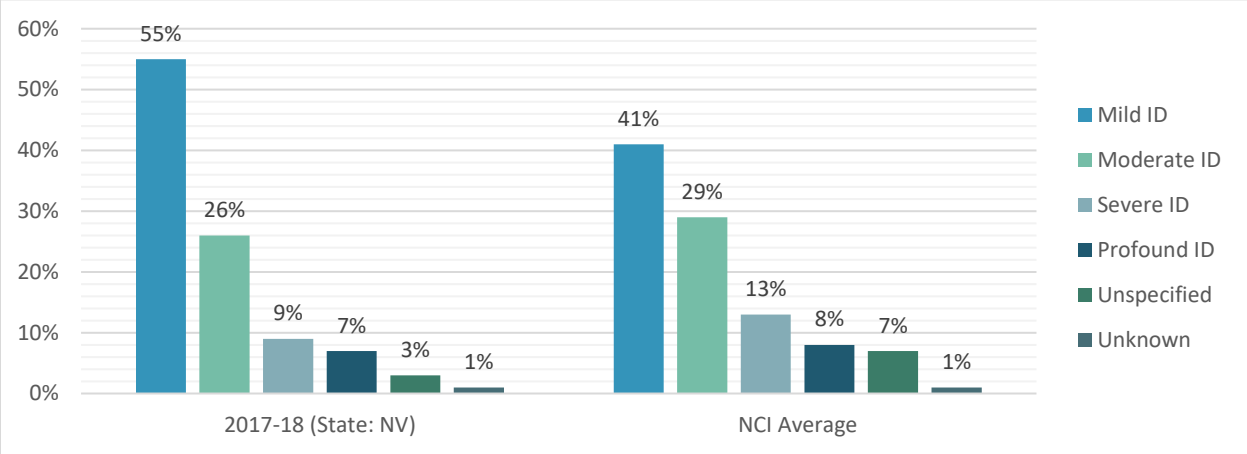
Brain Injury (TBI), due to combat exposure and occupational hazards. The combination of these factors results in a higher disability rate among veterans compared to non-veterans.

GRAPH 4. ADULTS AGES 18 YEARS OF AGE OR OLDER BY VETERAN STATUS, ANY DISABILITY AND NO DISABILITY, NEVADA 2021



The National Core Indicators Survey (NCI) State Report 2017-2018, which includes 374 individuals surveyed in Nevada, shows that 55% of Nevada respondents had Mild ID (ID/DD) versus 41% for the national NCI average, 26% Moderate ID in Nevada versus the 29% NCI average, 9% Severe ID in Nevada versus the 13% NCI average, 7% Profound ID in Nevada versus the 8% NCI average, 3% unspecified in Nevada versus 7% in the NCI average, and 1% Unknown for both the Nevada and NCI average (Graph 5). [42]

GRAPH 5. LEVEL OF INTELLECTUAL DISABILITY 2017-2018, NEVADA VS. NATIONAL CORE INDICATORS AVERAGE



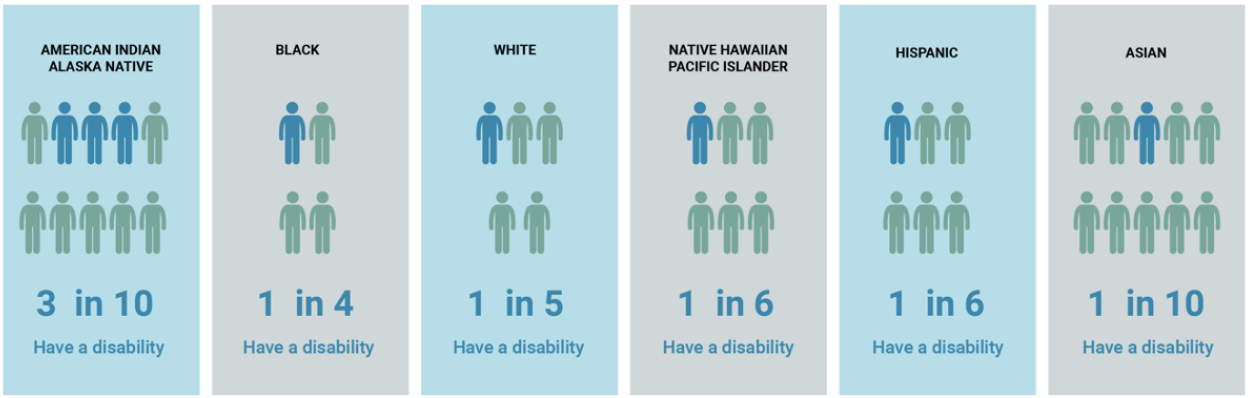
RACE/ETHNICITY

Americans in certain racial and ethnic groups are more likely to have a disability due to higher rates of poverty, limited access to healthcare, inadequate educational opportunities, and higher levels of environmental and occupational hazards, health disparities, cultural and linguistic barriers, discrimination and other adverse social determinants of health (Figure 3).[43]

[42] National Core Indicators (NCI). *Nevada. State Report: 2017-18.* Retrieved from https://legacy.nationalcoreindicators.org/states/NV/report/2017-18/

[43] The Centers for Disease Control and Prevention (CDC). (2020). Ethnicity and Race Infographic. Retrieved from https://www.cdc.gov/ncbddd/disabilityandhealth/materials/infographic-disabilities-ethnicity-race.html

FIGURE 3. ADULTS WITH DISABILITIES: ETHNICITY AND RACE

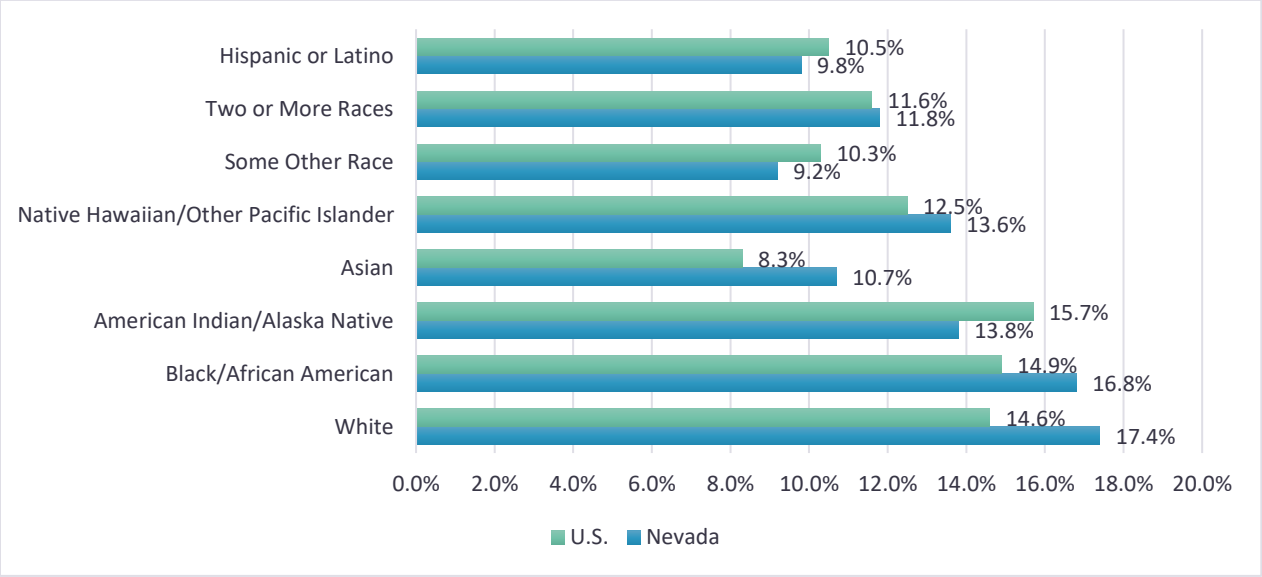


Adapted from the Centers for Disease Control and Prevention, Ethnicity and Race Infographic

In Nevada, American Indian/Alaska Natives make up 16% of the population that has a disability but make up only 1.7% of the total Nevada population, and Black individuals make up 14% of the Nevada population that has a disability, but only 10.8% of the total Nevada population, representing disparate rates of disability within these populations.[44, 45]

Of 449,327 individuals in Nevada that had a disability in 2022, 17.4% were White; 16.8% were Black/African American; 13.8% were American Indian/Alaska Native; 13.6% were Native Hawaiian/Other Pacific Islander; 11.8% were Two or More Races; 10.7% were Asian; 9.2% were Some Other Race; and 9.8% were Hispanic/Latino (Graph 6).[46] The data represent disability rates for each race/ethnicity, rather than a distribution of the disabled population by race/ethnicity.

GRAPH 6. ANY DISABILITY BY RACE, NEVADA AND THE U.S., 2022 (ACS 1-YEAR ESTIMATES)

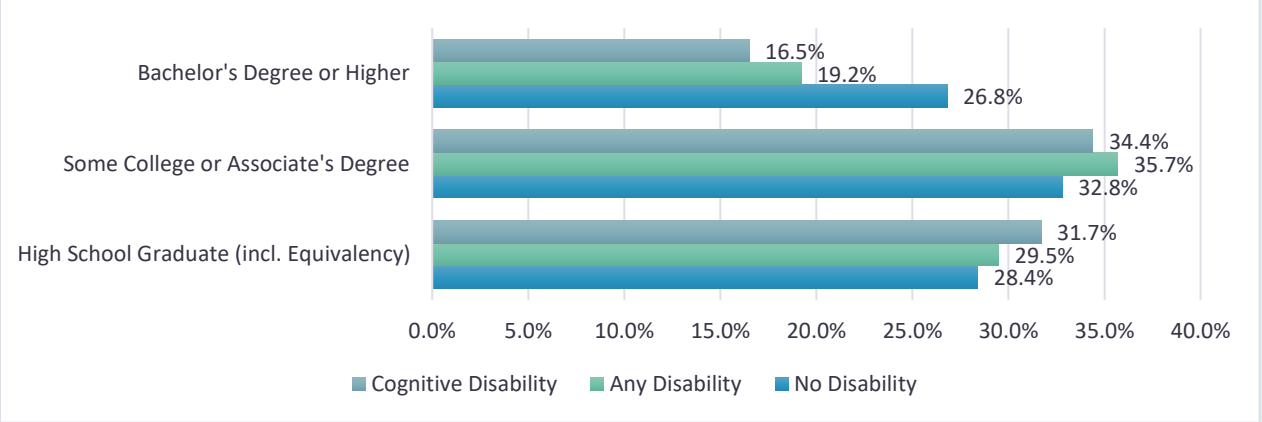


[44] American Community Survey (ACS). 2022 5-year Estimates. Table S1810. Disability Status
[45] U.S. Census Bureau. QuickFacts. Nevada. Retrieved from https://www.census.gov/quickfacts/fact/table/NV/PST045223
[46] American Community Survey (ACS). 2022 1-year Estimates. Table S1810. Disability Status

Educational Attainment

In 2022, the percentage of people ages 21 and over with a cognitive disability (ID/DD) with only a high school diploma or equivalent was 31.7%, compared to 29.5% for any disability, and 28.4% for no disability However, when it comes to post-secondary education, individuals with a cognitive disability with Bachelor's degree or higher was 16.5%, compared to 19.2% for any disability, and 26.8% for no disability (Graph 7).[47] Individuals with a cognitive disability often face challenges accessing post-secondary education due to insufficient support services, financial barriers, limited program availability to serve this population, social stigma, and transition difficulties.

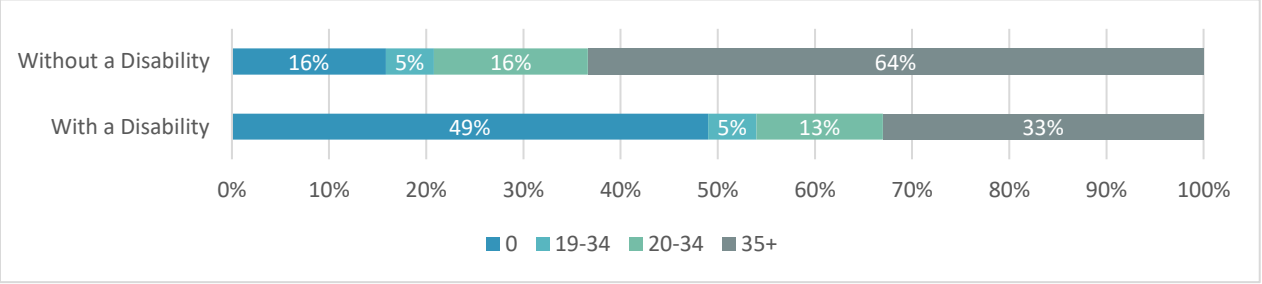
Graph 7. Educational Attainment, Population Ages 21 and Over, No Disability, Any Disability, and Cognitive Disability, Nevada, 2022



Employment

In the United States in 2022, working-age adults ages 18-64 with any type of disability were more than three times less likely to work than working-age adults without disabilities (49% and 16%, respectively) (Graph 8). Forty-nine percent of people with disabilities were unemployed 33% worked full time (35 or more hours per week), compared to over 64% of adults without a disability.[48]

Graph 8. Hours Worked Per Week, Working-Age Adults Ages 18-64 With Any Type of Disability and Without a Disability, 2022



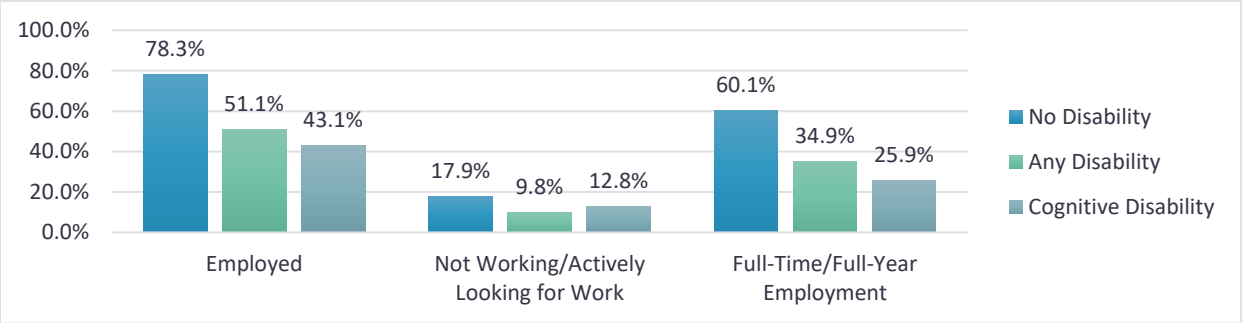
Source: Kaiser Family Foundation. Working -Age Adults with Disabilities Living in the Community. Figure 4.

[47] Cornell University. *2022 Disability Status Report. Nevada.* Retrieved from https://www.disabilitystatistics.org/report/pdf/2022/2032000 pp. 46-51

[48] Drake, P, & Burns, A. (2024). *Working -Age Adults with Disabilities Living in the Community*. Retrieved from https://www.kff.org/medicaid/issue-brief/working-age-adults-with-disabilities-living-in-the-community/

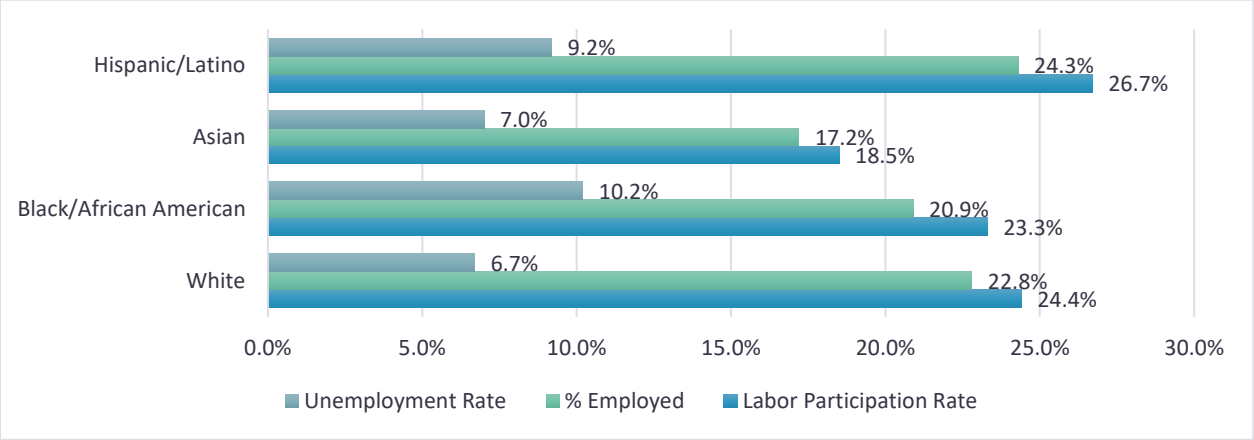
In Nevada in 2022, working-age adults with disabilities ages 21-64 and those with cognitive disabilities were employed at lower rate (51.1% and 43.1%, respectively) and less likely to have full-time, full-year employment (34.9% and 25.9%, respectively) than individuals with no disability (78.3% and 60.1%, respectively) (Graph 9). [49]

GRAPH 9. EMPLOYMENT STATUS OF WORKING-AGE ADULTS AGES 21-64, NO DISABILITY, ANY DISABILITY, AND COGNITIVE DISABILITY, NEVADA, 2022



The intersection of race and disability reveals significant disparities in employment statistics. Black and Latinx/Hispanic working-age adults with disabilities ages 16-64 experience higher unemployment rates compared to White individuals with disabilities, at 10.2% and 9.2%, in 2023, respectively. [50] Additionally, Black, and Asian individuals with disabilities are less likely to participate in the labor force compared to their White counterparts. While the overall labor force participation rate in the United States stands at 68.1% for individuals with no disability, it significantly drops to 26.7% of Hispanic/Latino individuals with disabilities, 24.4% of White individuals, 23.3% of Black individuals, 18.5% of Asian individuals who are part of the labor force (Graph 10).[51]

GRAPH 10. LABOR PARTICIPATION RATE, WORKING-AGE PEOPLE AGES 16-64 WITH ANY DISABILITY, 2023



[49] Cornell University. *2022 Disability Status Report. Nevada.* Retrieved from https://www.disabilitystatistics.org/report/pdf/2022/2032000 pp. 32-37

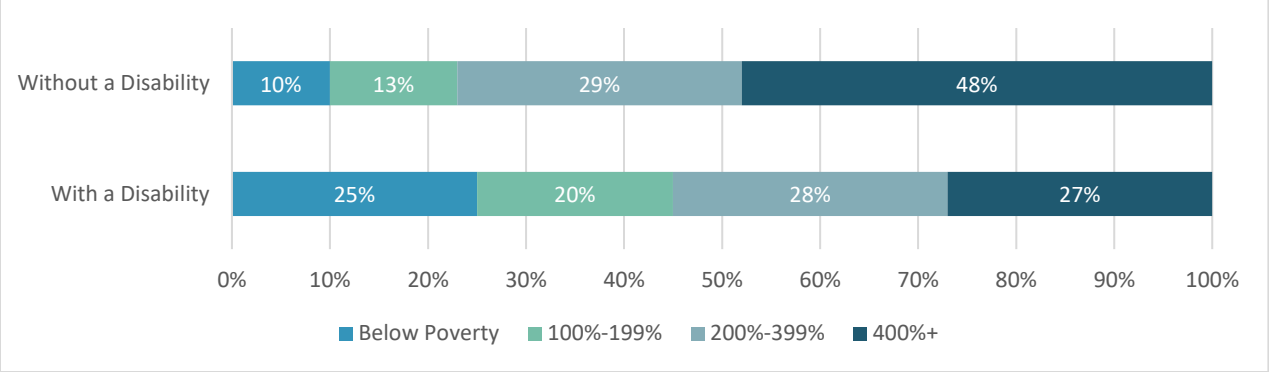
[50] U.S. Bureau of Labor Statistics. (2024). Economic News Release. *Persons with a Disability: Labor Force Characteristics Summary*. Table 1. Retrieved from https://www.bls.gov/news.release/disabl.t01.htm

[51] U.S. Bureau of Labor Statistics. (2024). Economic News Release. *Persons with a Disability: Labor Force Characteristics Summary*. Table 1. Retrieved from https://www.bls.gov/news.release/disabl.t01.htm

Poverty and Financial Stability

In the United States, working-age adults with disabilities are nearly twice as likely as those without disabilities to have incomes below 200% of the Federal Poverty Level (FPL). The income distribution for working-age adults with disabilities ages 18-64 is lower compared to their counterparts without disabilities with approximately one in four (25%) having incomes below the FPL threshold ($14,880 for an individual and $23,280 for a family of three on average in 2022) compared to one in ten (10%) working-age adults without disabilities reporting incomes below the FPL and almost half (48%) having incomes exceeding 400% of the FPL (Graph 11).[52]

Graph 11. Income Status for Working-Age Adults Ages 18-64 with a Disability and Without a Disability, 2022



Source: Drake, P, & Burns, A. (2024). Working -Age Adults with Disabilities Living in the Community. Figure 3.

Economic self-sufficiency for people with disabilities is distinctly different from that for people without disabilities. A person with a disability requires greater financial support for health care (durable medical equipment [DME], personal care assistance, hearing assistive technology, food that meets special dietary needs), transportation (accessible vehicles, specialized transportation), accessible housing (home ramps, smart home devices), adjustable clothing, and assistive technology (screen reader software, telecommunication devices for the Deaf and Hard of Hearing).

In other words, the costs associated with living with a disability require higher earnings and more financial support than prevailing earnings standards and poverty levels. Government and other public resources are vital to ensure that families with disabilities (children, working age adults, seniors) can offset these additional costs to reach and maintain economic self-sufficiency.[53]

National Council on Disability, 2023, p. 25

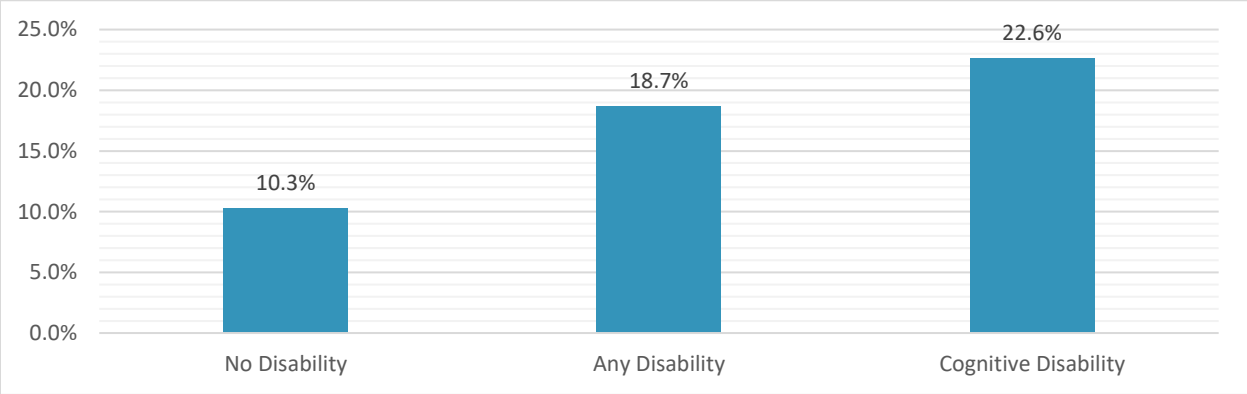
[52] Drake, P, & Burns, A. (2024). *Working -Age Adults with Disabilities Living in the Community*. Retrieved from https://www.kff.org/medicaid/issue-brief/working-age-adults-with-disabilities-living-in-the-community/

[53] National Council on Disability. (2023). *2023 Progress Report: Toward Economic Security: The Impact of Income and Asset Limits on People with Disabilities*. Retrieved from https://www.ncd.gov/report/2023-progress-report-toward-economic-security-the-impact-of-income-and-asset-limits-on-people-with-disabilities/ p. 25

Households with an adult member facing a work-limiting disability require approximately 28% more income, or an extra $17,690 annually, to maintain an equivalent standard of living compared to households without disabilities.[54]

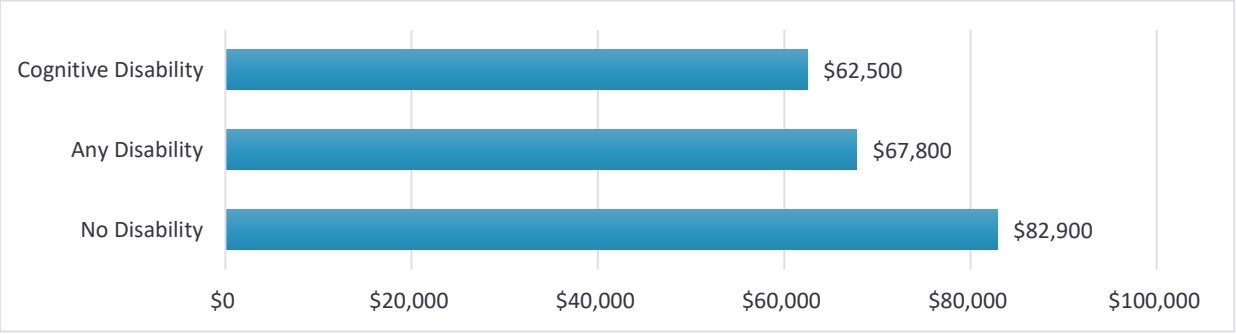
In Nevada, in 2022, the poverty rate for working-age adults ages 18 and over with any type of disability was 18.7%, compared to those with no disability at 10.3%. The poverty rate was even higher for working-age people with cognitive disabilities at 22.6%, showing that poverty rates for adults with cognitive disabilities are 17.3% higher than for adults with any type of disability, and 54.4% higher than working-age people with without disabilities (Graph 12).[55]

GRAPH 12. POVERTY RATES OF WORKING-AGE ADULTS AGES 18 AND OVER, NO DISABILITY, ANY DISABILITY, AND COGNITIVE DISABILITY, NEVADA, 2022



In 2022, the median household income of working-age adults ages 21 to 64 in Nevada was $82,900 for households with no disability; $67,800 for households with any disability; and $62,500 for households with a cognitive disability. The median household income for households with any adults with a cognitive disability was 24.6% lower than households with no disability, demonstrating the impact of a cognitive disability in the household on income (Graph 13).[56]

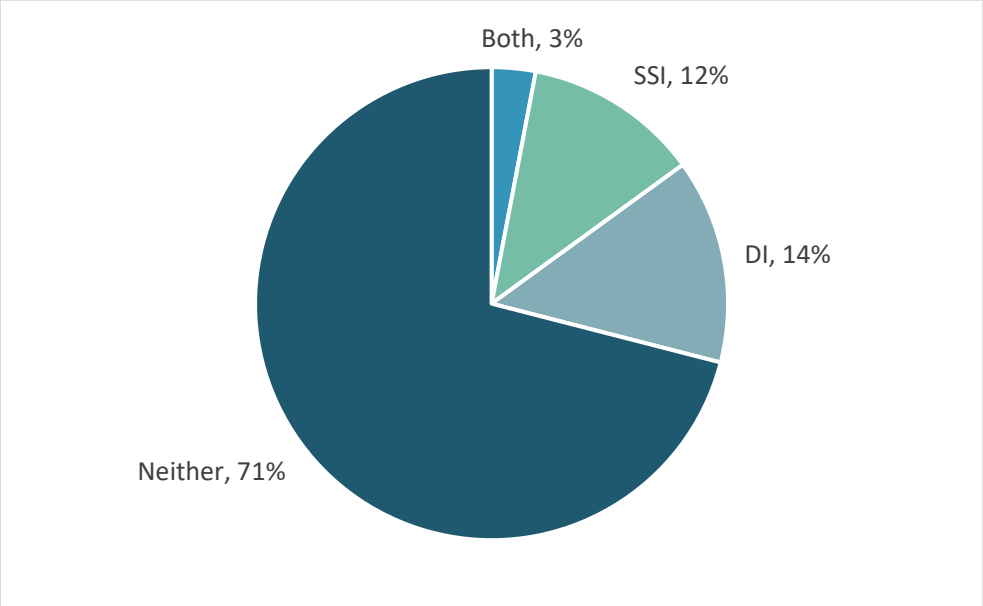
GRAPH 13. ANNUAL HOUSEHOLD INCOME FOR WORKING-AGE ADULTS AGES 21-64, NO DISABILITY, ANY DISABILITY, AND COGNITIVE DISABILITY, NEVADA, 2022



[54] Goodman, N., Morris, M., Morris, Z., & McGarity, S. (2020). *The Extra Cost of Living with a Disability in the U.S. – Resetting the Policy Table.* Retrieved form https://www.nationaldisabilityinstitute.org/wp-content/uploads/2020/10/extra-costs-living-with-disability-brief.pdf p. 1
[55] Cornell University. *2022 Disability Status Report. Nevada.* Retrieved from https://www.disabilitystatistics.org/report/pdf/2022/2032000 p. 43
[56] Cornell University. *2022 Disability Status Report. Nevada.* Retrieved from https://www.disabilitystatistics.org/report/pdf/2022/2032000 pp. 40-41

Among working-age adults with any disability ages 18-64 in the United States, 12% receive Social Security Insurance (SSI), 15% receive Social Security Disability Insurance (DI), and 3.9% receive benefits from both programs (Graph 14).[57]

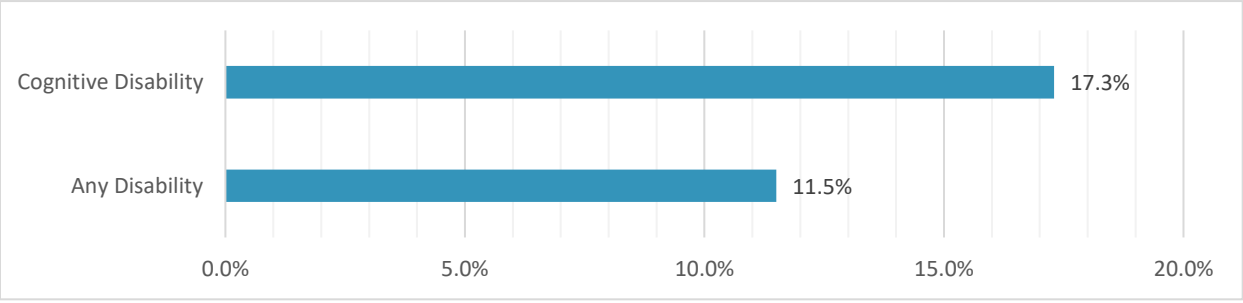
GRAPH 14. PERCENTAGE OF WORKING-AGE ADULTS AGES 18-64 WITH ANY DISABILITY WHO RECEIVE INCOME FROM SOCIAL SECURITY PROGRAMS



Adapted from Drake, P, & Burns, A. (2024). Working -Age Adults with Disabilities Living in the Community. Figure 6.

In Nevada, in 2022, 22,400 (11.5%) working-age adults with disabilities ages 21-64 and 15,700 (17.3%) with cognitive disabilities received SSI payments (Graph 15), [58] triggering automatic eligibility for Medicaid health insurance. Nationally, over one-third of Medicaid beneficiaries who qualify on the basis of a disability do so through receipt of SSI.[59]

GRAPH 15. WORKING-AGE PEOPLE AGES 21-64 WITH ANY DISABILITY AND COGNITIVE DISABILITY WHO RECEIVE SUPPLEMENTAL SECURITY INCOME (SSI) PAYMENTS IN NEVADA, 2022



[57] Drake, P, & Burns, A. (2024). *Working -Age Adults with Disabilities Living in the Community*. Retrieved from https://www.kff.org/medicaid/issue-brief/working-age-adults-with-disabilities-living-in-the-community/

[58] Cornell University. *2022 Disability Status Report. Nevada.* Retrieved from https://www.disabilitystatistics.org/report/pdf/2022/2032000 p. 44-45

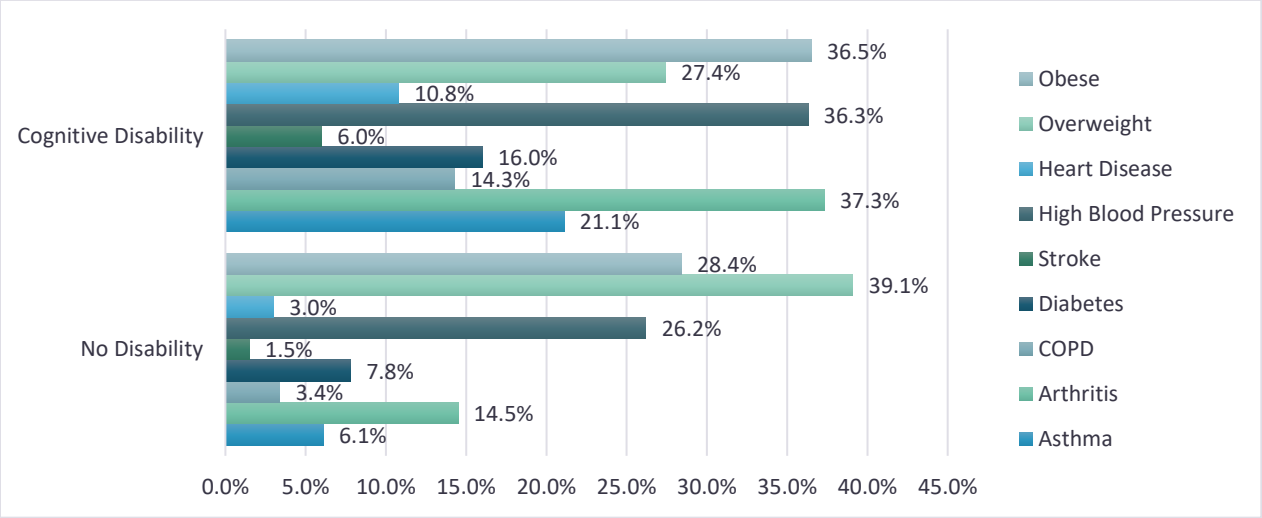
[59] Medicaid and CHIP Payment and Access Commission (MACPAC). *People with disabilities*. Retrieved from https://www.macpac.gov/subtopic/people-with-disabilities/

Health

Physical Health of Adults with Intellectual and/or Developmental Disabilities

People with a physical, intellectual and/or developmental disability have shorter life expectancies than those without ID/DD, and higher rates of chronic diseases.[60] In Nevada, compared to adults with no disability, adults with ID/DD ages 18 years of age or older have higher rates of asthma (21.1% vs. 6.1%), arthritis (37.3% vs. 14.5%), Chronic Obstructive Pulmonary Disease (COPD) (14.3% vs. 3.4%), diabetes (16.0% vs. 7.8%), stroke (6.0% vs. 1.5%), high blood pressure (36.3% vs. 26.2%), heart disease (10.8% vs. 3.0%), and higher rates of obesity (36.5% vs. 28.4%) (Graph 16).[61]

Graph 16. Percentage of Adults 18 Years of Age or Older with Chronic Conditions, No Disability, Disability, and Cognitive Disability, Nevada, 2021



Individuals with ID/DD are significantly more likely to have unmet medical, dental, and prescription needs. Research indicates that while people with ID/DD experience more chronic health conditions and comorbidities than the general population, they also experience avoidable health disparities and outcomes beyond those that are created by their primary disabling conditions.[62]

Mental and Behavioral Health of Adults with Intellectual and/or Developmental Disabilities

Adults with ID/DD often experience various mental and behavioral health conditions, including anxiety disorders, depression, bipolar disorder, schizophrenia, and attention-deficit/ hyperactivity disorder (ADHD). The combination of cognitive impairments, communication barriers, limited access to resources, and societal attitudes can exacerbate mental health challenges for adults with ID/DD, leading to more frequent episodes of feeling mentally unhealthy compared to individuals with other types of disabilities. In 2021 in Nevada, more than half (57.8%) of adults with ID/DD

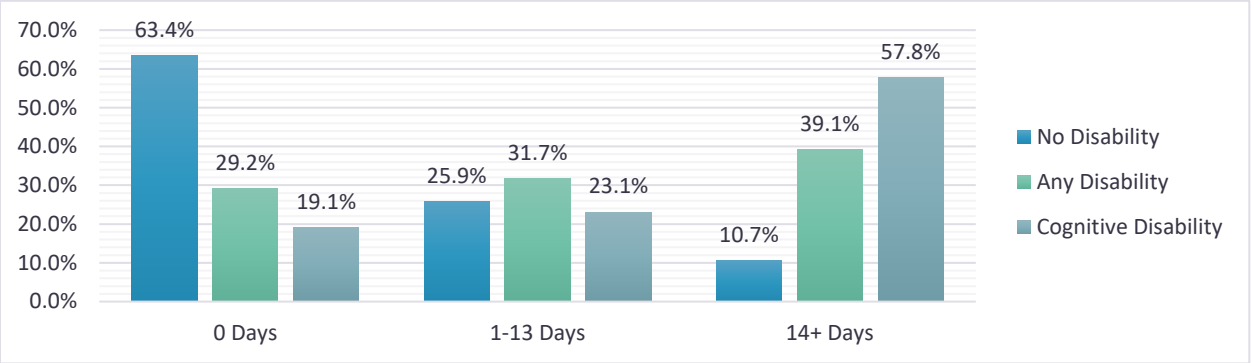
[60] Anderson, L. L., Humphries, K., McDermott, S., Marks, B., Sisirak, J., & Larson, S. (2013). The state of the science of health and wellness for adults with intellectual and developmental disabilities. *Intellectual and developmental disabilities*, *51*(5), 385–398. https://doi.org/10.1352/1934-9556-51.5.385

[61] Centers for Disease Control and Prevention. Disability and Health Data System (DHDS). *General Health Conditions, Chronic Conditions and Health Risks & Behaviors.* Retrieved from https://www.cdc.gov/ncbddd/disabilityandhealth/dhds/index.html

[62] Centers for Disease Control and Prevention. Disability and Health Promotion. *Disability Impacts Nevada.* Retrieved from https://www.cdc.gov/ncbddd/disabilityandhealth/impacts/nevada.html

ages 18 years of age or older had 14+ mentally unhealthy days compared to 39.1% with any disability, and 10.7% with no disability (Graph 17).[63]

GRAPH 17. PERCENTAGE OF MENTALLY UNHEALTHY DAYS IN PAST 30 DAYS, ADULTS AGES 18 YEARS OR OLDER, NO DISABILITY, ANY DISABILITY, AND COGNITIVE DISABILITY, NEVADA 2021



Many adults with ID/DD require behavior support services to help them improve adaptive skills and positive functioning (Table 4).

TABLE 4. RATES OF MENTAL HEALTH CONDITIONS AND BEHAVIORAL SUPPORT NEEDS IN ADULTS WITH INTELLECTUAL AND/OR DEVELOPMENT DISABILITIES, 2023

		Number	%
Mental Health Conditions	Mood Disorder	468	29.2%
	Anxiety Disorder	319	24.4%
	Psychotic Disorder	229	14.3%
	Other	139	8.7%
Behavior Support Needs	Disruptive Behaviors	748	46.6%
	Behavioral Condition	548	34.2%
	Destructive Behavior	509	31.7%
	Self-injurious Behavior	457	28.5%

Adapted from Lineberry et al (2023). Co-Occurring Mental Illness and Behavioral Support Needs in Adults with Intellectual and Developmental Disabilities, Table 1.

INSURANCE

Out-of-pocket costs and health expenditures for adults with disabilities are five to six times higher than adults with no disabilities due to the need for more frequent care for their primary disabling condition as well as additional comorbidities and chronic health conditions, even when they have

[63] Centers for Disease Control and Prevention. Disability and Health Data System (DHDS). Mental & Emotional Health. Retrieved from https://dhds.cdc.gov/SP?LocationId=32&CategoryId=MHLTH&ShowFootnotes=true&showMode=&IndicatorIds=DEPRESS,MHDAYS&pnl0=Chart,false,YR6,DISSTAT,,,,,AGEADJPREV&pnl1=Chart,false,YR6,DISTYPE,COGDIS,,,,AGEADJPREV&t=1708568039210

medical health insurance.[64] Adults with disabilities ages 19-64 have higher rates of public health coverage (50.7% in Nevada compared to 53.5% for the United States) than individuals with no disability (15% in Nevada compared to 14.3% for the United States). In Nevada, adults with a disability were 29.6% less likely to be uninsured than adults with no disability in 2022 (Table 5).[65]

TABLE 5. PERCENTAGE OF PEOPLE WITH A DISABILITY AND NO DISABILITY, AGES 19-64, WHO HAVE HEALTH INSURANCE, NEVADA AND THE U.S., 2022

Type of Insurance	Nevada	United States
With a Disability		
Private Health Insurance Coverage	49.7%	47.5%
With Public Health Coverage	50.7%	53.5%
No Health Coverage	11.2%	10.1%
No Disability		
Private Health Insurance Coverage	72.3%	76.2%
With Public Health Coverage	15.0%	14.3%
No Health Coverage	15.9%	12.4%

Note: The U.S. Census defines Public Health Insurance as plans funded by governments at the federal, state, or local level. The major categories of public health insurance are Medicare, Medicaid, the Children's Health Insurance Program (CHIP), CHAMPVA or VA coverage, State-specific plans and Indian Health Service (IHS).[66]

In the United States, the percentage of working-age adults with a disability ages 18-64 enrolled in Medicaid is more than double that of those without a disability. Specifically, 38% of working-age adults with a disability are covered by Medicaid (30% enrolled in Medicaid and an additional 8% who are dual-eligible and receive both Medicaid and Medicare). Estimates for adults with a cognitive disability ages 18-64 who rely on Medicaid range from 38% to 60%.[67]

The authors of this needs assessment have chosen to use the more conservative number of 38% due to lack of confirmed data for Nevada. In contrast, among individuals without disabilities, 13% are covered by Medicaid, with only 1% having both Medicare and Medicaid.[68]

As of September 2023, there were a total of 942,548 individuals enrolled in Medicaid Nevada, and 546,223 were ages 21 and older.[69]

[64] National Council on Disability. (2023). *2023 Progress Report: Toward Economic Security: The Impact of Income and Asset Limits on People with Disabilities.* Retrieved from https://www.ncd.gov/report/2023-progress-report-toward-economic-security-the-impact-of-income-and-asset-limits-on-people-with-disabilities/ p. 41

[65] American Community Survey (ACS). 2022 5-year Estimates. Table B18135. Age by Disability Status by Health Insurance Coverage Status

[66] U.S. Census Bureau. *Health Insurance Glossary.* Definition of Public Health Insurance. Retrieved from https://www.census.gov/topics/health/health-insurance/about/glossary.html#:~:text=or%20local%20level.-,The%20major%20categories%20of%20public%20health%20insurance%20are%20Medicare%2C%20Medicaid,Indian%20Health%20Service%20(IHS).

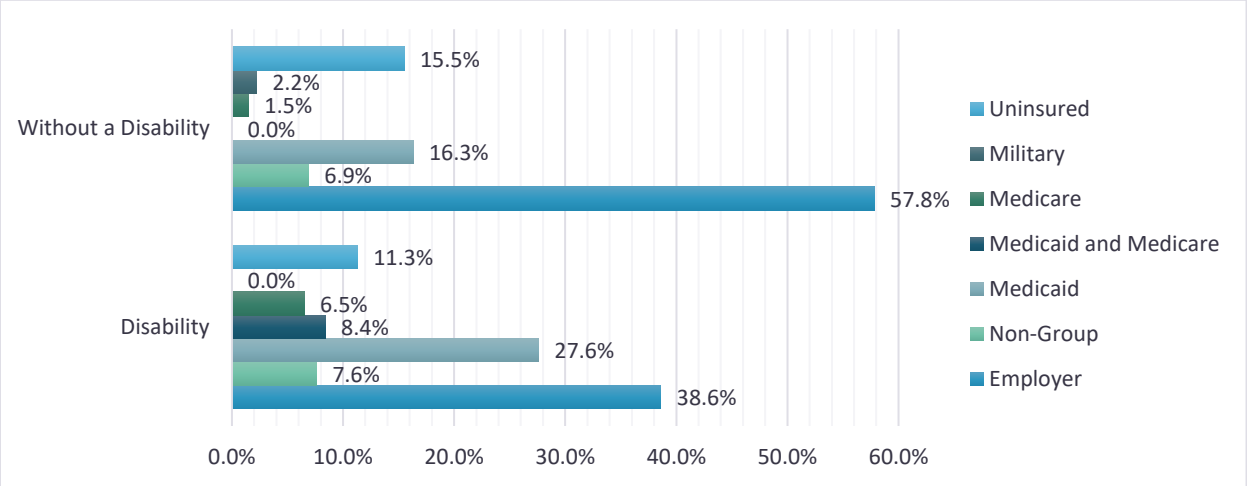
[67] National Council on Disability (NCD). (2022). *Medicaid Oral Health Coverage for Adults with Intellectual & Developmental Disabilities – A Fiscal Analysis.* Retrieved from https://www.nccp.org/wp-content/uploads/2022/03/NCD_Medicaid_Report_508.pdf p. 18

[68] Drake, P, & Burns, A. (2024). *Working -Age Adults with Disabilities Living in the Community*. Retrieved from https://www.kff.org/medicaid/issue-brief/working-age-adults-with-disabilities-living-in-the-community/

[69] Nevada Department of Health and Human Services Office of Analytics. Dental Overview Quarterly Reports. Nevada Medicaid (FFS/MCO). September, 2022 to September, 2023.

Individuals with disabilities in Nevada have higher rates of being enrolled in Medicaid (27.6%), Medicare (6.5%), and dual-eligible in Medicaid/Medicare (8.4%) than those with no disability (16.3%, 1.5%, and 0.0%, respectively) (Graph 18).[70, 71]

GRAPH 18. RATES OF INSURANCE COVERAGE FOR WORKING-AGE ADULTS AGES 18-64 WITH ANY DISABILITY AND WITHOUT A DISABILITY, NEVADA, 2022



INDIVIDUALS KNOWN TO AND SERVED BY THEIR STATE ID/DD AGENCY

According to the Centers for Medicaid & Medicare Services (CMS), in 2018, 21% of people of any age were known to, or served by, their state ID/DD agency, and 41% of adults were on a state ID/DD agency caseload nationally.[72] This means 59% of adults with ID/DD were not identified or known to a state ID/DD agency. By these estimates, 20,084 of the 95,639 adults with ID/DD in Nevada in 2023 should be known to, and served by, Nevada's DD agency, and 56,427 not known to the agency.

As of January 1, 2024, there were 2,967[73] Nevada Legislature approved slots for the ID Waiver for adults with ID/DD who are at risk of needing to live in an institution. As of February 28, 2023, Developmental Services reported serving approximately 7,500 individuals across the lifespan.[74] Many researchers have noted that if an individual is not known by a state ID/DD agency, they may not be as easily counted in state statistics; and therefore, health needs, gaps in care, and health

[70] Kaiser Family Foundation (KFF). State Health Facts. Distribution of Working-Age Adults with a Disability by Insurance Coverage. Nevada and the United States. Retrieved from https://www.kff.org/other/state-indicator/distribution-of-working-age-adults-with-a-disability-by-insurance-coverage/?currentTimeframe=0&selectedRows=%7B%22wrapups%22:%7B%22united-states%22:%7B%7D%7D,%22states%22:%7B%22nevada%22:%7B%7D%7D%7D&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D

[71] Kaiser Family Foundation (KFF). State Health Facts. Health Insurance Coverage of Adults 19-64. Nevada and the United States. Retrieved from https://www.kff.org/other/state-indicator/adults-19-64/?currentTimeframe=0&selectedRows=%7B%22wrapups%22:%7B%22united-states%22:%7B%7D%7D,%22states%22:%7B%22nevada%22:%7B%7D%7D%7D&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D

[72] Centers for Medicare & Medicaid Services (CMS). *State Spotlights: Supporting Adults with Intellectual and Developmental Disabilities and Their Aging Caregivers.* Retrieved from https://www.medicaid.gov/sites/default/files/2023-05/3-1_Adults_with_IDD_State_Spotlights-508%5B95%5D.pdf p. 1

[73] E.F. Wilcox (personal communication, March 8, 2024)

[74] The Nevada Department of Health and Human Services Aging and Disability Services Division. (2023). *Developmental Services Home & Community Based Services Waiver Renewal.* Retrieved from https://www.nvsilc.com/wp-content/uploads/2023/03/IDD-Waiver-Renewal-2023.pdf

status cannot be determined as well, and state programs cannot be as effectively tailored to address health disparities.

In Nevada, the Department of Health and Human Services Aging and Disability Services Division (ADSD) provides services to individuals with disabilities of any age. All consumers served by the three regional centers (Sierra Regional Center, Rural Regional Center, and Desert Regional Center) receive targeted case management/service coordination from agency service coordinators (Developmental Specialists).[75] ADSD operates the Nevada Medicaid waivers, including the ID Waiver approved by CMS. This waiver provides eligible recipients access to developmental services, Medicaid, eleven unbundled services (i.e., day habilitation, prevocational services, supported employment, career planning, residential support services and management, etc.) as well as certain extended Medicaid covered services unique to the waiver.[76, 77] Medicaid waivers, such as the 1115 Demonstration Waivers, 1915 (a, b, and b/c Managed Care Waivers) and 1915(c) Home and Community Based Waivers (HCBS), provide a range of supports (Figure 4).[78]

FIGURE 4. HOME- AND COMMUNITY-BASED SERVICES CATEGORIES AND EXAMPLES

Day Services	•Day habilitation (regularly scheduled activies to assist in acquiring, retaining, and improving self-help, socialization, and adaptive skills)
Home-Based Services	•Personal care (assistance with activities of daily living, such as bathing, dressing, and toileting, provided in a person's home and possibly other community settings) •Homemaker (performance of light housekeeping tasks)
Mental Health and Behavior Support Services	•Mental health assessment •Behavior support (services to encourage positive behaviors and to decrease challenging behaviors) •Counseling
Round-the-Clock Services	•Group home (supervision and assistance with acquiring and retaining skills provided in a home-like environment where multiple people with a disability live)
Supported Employment	•Assistance to locate and obtain employment •Assistance to maintain employment •Career planning

Adapted from United States Government Accountability Office Report to Congressional Requesters. (2023). MEDICAID Characteristics of and Expenditures for Adults with Intellectual or Developmental Disabilities. Figure 1.

[75] The Nevada Department of Health and Human Services Aging and Disability Services Division. *Developmental Services Regional Centers Monthly Report.* Retrieved from https://adsd.nv.gov/About/Reports/Developmental_Services_Reports/Developmental_Services_Monthly_Reports/

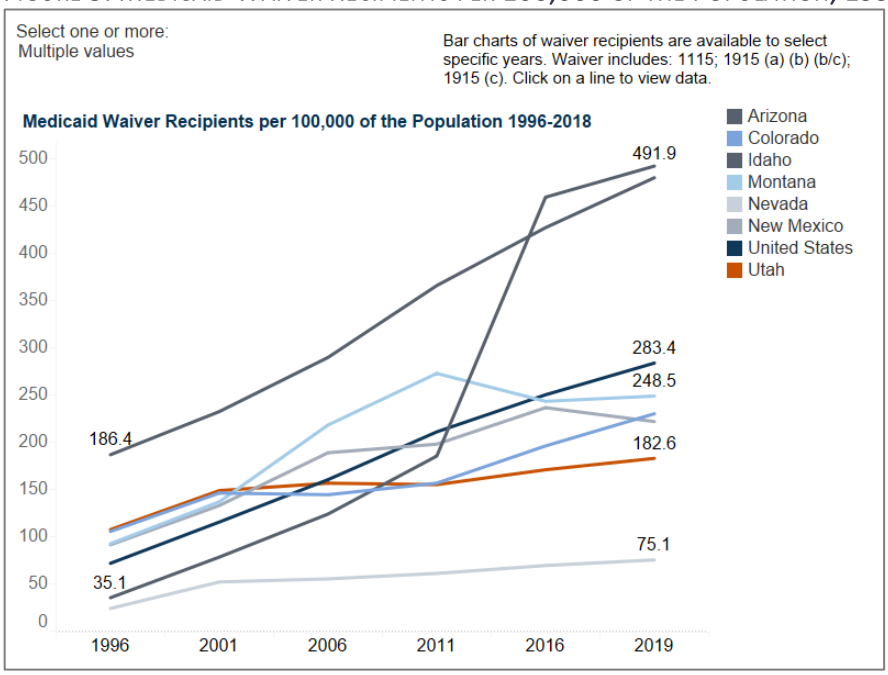
[76] Medicaid Services Manual Changes. *Chapter 2100 – Home and Community Based Services (HCBS) Waiver for Individuals with Intellectual and Developmental Disabilities* https://dhcfp.nv.gov/uploadedFiles/dhcfpnvgov/content/Resources/AdminSupport/Manuals/MSM/C2100/MSM_2100_23_01_01_ADA.pdf Section 2101 p. 1

[77] The Nevada Department of Health and Human Services Aging and Disability Services Division. (2023). *Developmental Services Home & Community Based Services Waiver Renewal*. Retrieved from https://www.nvsilc.com/wp-content/uploads/2023/03/IDD-Waiver-Renewal-2023.pdf

[78] United States Government Accountability Office Report to Congressional Requesters. (2023). *MEDICAID Characteristics of and Expenditures for Adults with Intellectual or Developmental Disabilities.* Retrieved from https://www.gao.gov/assets/gao-23-105457.pdf p. 7

Enrollment in Medicaid Waiver programs varies greatly for the Intermountain West states compared to the United States overall, as seen in Figure 5 below. From 1996-2018 (latest data available), Nevada served the lowest number of people through its waiver programs over the period of 22 years when compared to other Intermountain West states, and the United States average. In 2019, 75.1 people received waiver supports for every 100,000 people in Nevada, compared to 283 for United States overall, or 26.5% lower than the United States average.[79]

FIGURE 5. MEDICAID WAIVER RECIPIENTS PER 100,000 OF THE POPULATION, 1996-2018



LIVING SITUATION

A growing number of people with disabilities are now living in their community rather than an institutional setting. The majority of people with ID/DD (72%), live with their families or in a home of their own.[80]

Federal and state level Long-Term Services and Supports (LTSS) data provide a useful snapshot of adults with ID/DD. LTSS tends to support individuals with more significant service needs and those who need ongoing care due to age, physical or intellectual disability, or chronic illness. The Residential Information Systems Project (RISP) reports that in 2019, 60% of LTSS recipients with ID/DD in the United States lived with a family member, 11% lived in their own home, 5% lived in a host or foster family home, 16% lived in a group home shared by six or fewer people ID/DD, and 8% lived in larger facilities, nursing homes or psychiatric facilities.[81]

[79] Residential Information Systems Project. Minneapolis: University of Minnesota, RISP, Research and Training Center on Community Living, Institute on Community Integration. Retrieved from https://tableau.umn.edu/t/ICI/views/RISP2018viz-11_23_2018/a-waiver-recipients-100k-db?%3Aembed=y&%3Adisplay_count=n&%3AshowAppBanner=false&%3Aorigin=viz_share_link

[80] Barth, S., Lewis, S., & Simmons, T. (2020). *Medicaid Services for People with Intellectual or Developmental Disabilities – Evolution of Addressing Service Needs and Preferences*. Retrieved from https://www.macpac.gov/wp-content/uploads/2021/01/Medicaid-Services-for-People-with-Intellectual-or-Developmental-Disabilities-—-Evolution-of-Addressing-Service-Needs-and-Preferences.pdf p. 4

[81] Residential Information Systems Project. Living Arrangements for People with IDD. Minneapolis: University of Minnesota, RISP, Research and Training Center on Community Living, Institute on Community Integration. Retrieved from: https://risp.umn.edu

COMMUNITY WATER FLUORIDATION

Community water fluoridation is a population health program that can prevent dental caries for all socioeconomic groups.[82] Dental caries is the most prevalent chronic disease that disproportionately effects underserved communities, and community water fluoridation continues to decrease cavities by 25%.[83] In 2020, Nevada ranked 26th in the nation for water fluoridation.[84] As of April 2023, there are 233 total water systems in Nevada - 47 are fluoridated and 186 are non-fluoridated. Currently, 74.17% of the population is served by community water systems receiving fluoridated water and 25.84% are not (Table 6).[85]

TABLE 6. FLUORIDATION STATUS, NEVADA, 2023

			% Fluoridated		% of Total	
	Systems	Population	Systems	Population	Systems	Population
Fluoridated						
Adjusted	1	190	213	0.01	0.43	0.01
Natural	33	29,763	70.21	1.37	14.16	1.02
Variable/Other	0	0	0	0	0	0
Defluoridated	0	0	0	0	0	0
Consecutive	13	2,142,934	27.66	98.62	5.58	73.14
Multi-source	0	0	0	0	0	0
Total	**47**	**2,172,887**	**100**	**100**	**20.17**	**74.17**
Non-fluoridated						
Non-adjusted	152	556,026	--	--	65.24	18.98
Variable/Other	16	85,850	--	--	6.87	2.93
Defluoridated	0	0	--	--	0	0
Consecutive	14	42,402	--	--	6.01	1.45
Multi-source	4	72,634	--	--	1.72	2.48
Total	**186**	**756,911**	**--**	**--**	**79.84**	**25.84**

[82] Zokaie, T., & Pollick, H. (2022). Community water fluoridation and the integrity of equitable public health infrastructure. *Journal of public health dentistry*, *82*(3), 358–361. https://doi.org/10.1111/jphd.12480

[83] Zokaie, T., & Pollick, H. (2022). Community water fluoridation and the integrity of equitable public health infrastructure. *Journal of public health dentistry*, *82*(3), 358–361. https://doi.org/10.1111/jphd.12480

[84] Centers for Disease Control and Prevention. 2020 Water Fluoridation Statistics. Retrieved from https://www.cdc.gov/fluoridation/statistics/2020stats.htm

[85] Centers for Disease Control and Prevention. State Fluoridation Reports. Summary Report. Nevada. Retrieved from https://nccd.cdc.gov/DOH_MWF/Reports/Summary_Rpt.aspx

Nevada Medicaid ID Waiver Recipients – A Subset of Adults with Intellectual and/or Developmental Disabilities in Nevada

***Case Study - Denny's Visit to the Dentist:* With new access to expanded benefits, Denny, an adult with ID/DD enrolled in the ID Waiver, was able to visit the dentist for an exam and deep cleaning. While he was nervous, after the dentist found out that Denny loves baseball, he talked to him about baseball the entire time while he provided care, and the experience was an incredible success. Danny will return, covered now by Medicaid, every three months for care.**

Shared by mother of adult son with ID/DD on the Medicaid ID Waiver, Las Vegas, Nevada

Expanded Medicaid dental benefits for ID Waiver recipients were piloted with ARPA funding between January 1, 2023-March 31, 2024, and then included in the Medicaid 2024-2025 biennium budget under Governor Joe Lombardo's leadership. During calendar year 2023, according to Nevada State Office of Analytics SOURCE data, 885 unique individuals received dental care in a dental office, including preventative and restorative care, that up until January 1, 2023, was not covered under Medicaid.

Using data from the Nevada State Office of Analytics, a 6-year dataset of Medicaid data specific to dental ICD 10 codes, CPT codes, emergency room data related to dental issues or complaints, and prescriptions related to those visits, a total of 1,648 people had claims related to dental care in the dental office (paid for by expanded benefits or existing emergency only benefits), emergency room visits, or prescriptions that were coded as related to dental complaints in 2023. Although not all of these 1,648 individuals received care under the expanded benefits, there were an observed 4,520 cases (visits) associated with 885 ID Waiver individuals served at dental offices, which is the main provider area impacted by the expansion of Medicaid dental benefits for recipients on the Medicaid ID Waiver. Due to concerns about being able to confidently associate prescriptions to dental conditions, dental office visits and emergency room visit data will be focused on in this assessment, until a second phase of analysis of prescription medication usage can be completed.

The dental benefits provided in 2023 were much higher than in previous year, due to the expanded benefits available to ID Waiver recipients (Table 7). In total, there were 18,822 dental procedures provided in dental offices to 1,784 ID Waiver individuals across all 6-years of available data. Notably, nearly 50% of those visits occurred in 2023 when expanded benefits were available. Prior to 2023, emergency only benefits were available to this same set of individuals.

Table 7. Summary of Annual Dental Claims for ID Waiver Recipients, 2018-2023

	2018	2019	2020	2021	2022	2023	Total
Total Dental Claims	3,741	2,815	2,305	2,611	2,830	4,520	18,822
% of ALL Claims	19.9%	15.0%	12.2%	13.9%	15.0%	24.0%	100%
Total Distinct ID Waiver Individuals	635	619	542	559	613	885	1784
% of ALL Distinct ID Waiver Individuals	35.6%	34.6%	30.4%	31.3%	34.4%	49.6%	100%

Out of 6 years of data requested from the Nevada State Office of Analytics (2018-2023), there were a total of 56,014 dental related claims assigned to one of three claim areas: 1) dental offices, 2) emergency room, and 3) prescription drugs. Holistically, 91.2% of these cases were assigned to member zip codes within Nevada and 8.8% to member zip codes outside of Nevada. Due to concerns about being able to confidently associate prescriptions to dental conditions, dental office visits and emergency room visit data will be focused on in this assessment.

There were only 5 counties in Nevada with higher percentages of claims relative to the total population age 18-64 and the population of the same age with a Cognitive Disability (Table 8). Clark County, for example, had 73.7% of Total Population 18-64 and 73.1% of Population 18-64 with Cognitive Disability and 62.2% of ID Waiver Dental related claims. Additionally, a similar observation is seen in Carson City, which has 1.7% of the Total Population 18-64 and 1.9% of the Population 18-64 with Cognitive Disability and 5.6% of the Total ID Waiver Dental related claims. Five-year American Community Survey population estimates are used in the chart below.

TABLE 8. DISTRIBUTION OF ID WAIVER PATIENT CLAIMS, 2018-2023

County	ID Waiver Claims	Percentage of Claims	Total Population of 18-64	% of Total Population of 18-64	Population with a Cognitive Disability Ages 18-64	% of Population Ages 18-64 with Cognitive Disability
Carson City	3,129	5.6%	32,632	1.7%	1,481	1.9%
Churchill County	1,068	1.9%	13,580	0.7%	782	1.0%
Clark County	34,813	62.2%	1,385,619	73.7%	57,069	73.1%
Douglas County	257	0.5%	26,637	1.4%	1,062	1.4%
Elko County	870	1.6%	32,393	1.7%	1,375	1.8%
Esmeralda County	0	0%	620	0.0%	15	0.0%
Eureka County	92	0.2%	788	0.0%	21	0.0%
Humboldt County	477	0.9%	9,915	0.5%	303	0.4%
Lander County	0	0%	3,396	0.2%	165	0.2%
Lincoln County	14	0.0%	2,348	0.1%	156	0.2%
Lyon County	309	0.6%	34,065	1.8%	1,612	2.1%
Mineral County	24	0.0%	2,303	0.1%	176	0.2%
Nye County	295	0.5%	26,739	1.4%	2,019	2.6%
Pershing County	16	0.0%	2,752	0.1%	244	0.3%
Storey County	3	0.0%	1,871	0.1%	200	0.3%
Washoe County	9,640	17.2%	299,609	15.9%	11,351	14.5%
White Pine County	81	0.1%	4,073	0.2%	86	0.1%
Nevada	**51,088**	**91.2%**	**1,879,340**	**100.0%**	**78,117**	**100.0%**

AGE

The age distribution of ID Waiver patients in 2023 ranged from 11 to 83 with an average age of 37 and median age of 34. Compared to the total data set from 2018-2023, which included a distinct total population of 2,780 ID Waiver patients with an age distribution ranging from 8 to 94 with an average age of 39 and median age of 35.

The number of dental office visits over the 6 years of Medicaid dental claims for ID Waiver participants from 2018-2023 by age is shown in Table 9. Dental office visits increased considerably in 2023 for ID Waiver recipients (ages 21 and over) when they were able to access expanded Medicaid dental benefits.

TABLE 9. SUMMARY OF ANNUAL AND CUMULATIVE AGE GROUP DEMOGRAPHICS ID WAIVER RECIPIENTS, DENTAL OFFICE VISITS 2018-2023

Year of Service & Age Group	Under 18	18-24	25-34	35-44	45-54	55-64	65-74	75 or older	Total
2018	33	269	1,179	1,065	535	443	173	44	3,741
2019	36	380	899	612	361	318	182	27	2,815
2020	32	370	752	500	349	196	98	8	2,305
2021	60	433	792	622	327	200	161	16	2,611
2022	66	411	977	665	369	215	125	2	2,830
2023	56	678	1,505	1,230	564	311	154	22	4,520
Total	283	2,541	6,104	4,694	2,505	1,683	893	119	18,822
Dental Office Dataset Pearson Chi Square Tests for Independence: Value 435.377, df 35, Asymptotic Significance (2-sided) <0.001									

The summary of emergency room visits over the 6 years of Medicaid dental claims for ID Waiver participants from 2018-2023 by age is shown in Table 10. Emergency room visits increased slightly for all age groups in 2023 when ID Waiver recipients were able to access expanded Medicaid dental benefits. Ages 35-44 had the highest rate of emergency room visits.

TABLE 10. SUMMARY OF ANNUAL AND CUMULATIVE AGE GROUP DEMOGRAPHICS ID WAIVER RECIPIENTS, EMERGENCY ROOM VISITS 2018-2023

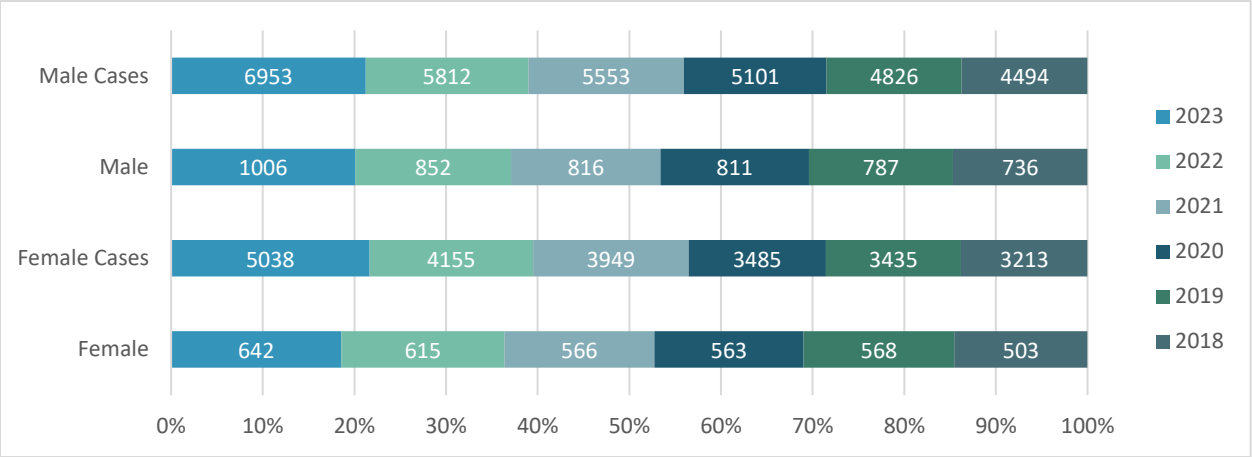
Year of Service & Age Group	Under 18	18-24	25-34	35-44	45-54	55-64	65-74	75 or older	Total
2018	5	22	242	222	98	118	40	19	766
2019	0	46	232	249	138	109	58	6	838
2020	1	84	238	161	96	75	44	16	945
2021	9	91	321	274	116	74	44	16	945
2022	2	100	345	215	76	86	20	13	857
2023	2	96	333	225	98	89	27	10	880
Total	19	439	1,711	1,346	622	551	253	71	5,012
Emergency Room Dataset Pearson Chi Square Tests for Independence: Value 219.103, df 35, Asymptotic Significance (2-sided) <0.001									

GENDER

Gender distribution among the ID Waiver population from the Nevada State Office of Analytics is consistent with the Nevada data in Graph 3 above, which shows a higher percentage of males with ID/DD. Among the ID Waiver population, there is also a higher representation of male patients (Graph 19).

In general, there is a higher prevalence of males and male cases reported annually. Furthermore, there was an increase in both case count and enrolled participants in 2023 for both males and females. This increase underscores the effectiveness and significance of expanding dental services through the ID Waiver, with nearly 20% of male and female patients seen in 2023 and over 20% of cases or visits recorded, compared to previous years where only 2022 saw more than 15% of male and female patients and cases or visits.

GRAPH 19. GENDER DISTRIBUTION OF ID WAIVER POPULATION, 2018-2023 (DISTINCT CLIENTS & ANNUAL CASES (VISITS)



The number of dental office visits over the 6 years of Medicaid dental claims for ID Waiver participants from 2018-2023 by gender is shown in Table 11. Dental office visits increased for both males and females in 2023 for males when ID Waiver recipients were able to access expanded Medicaid dental benefits.

TABLE 11. SUMMARY OF ANNUAL AND CUMULATIVE GENDER DEMOGRAPHICS ID WAIVER RECIPIENTS, DENTAL OFFICE VISITS 2018-2023

Year of Service & Gender	Female	Male	Total
2018	1,467	2,274	3,741
2019	1,211	1,604	2,815
2020	917	1,388	2,305
2021	1,069	1,542	2,611
2022	1,044	1,786	2,830
2023	1,779	2,741	4,520
Total	7,487	11,335	18,822

Dental Office Dataset Pearson Chi Square Tests for Independence: Value 24.504, df 5, Asymptotic Significance (2-sided) <0.001

The summary of emergency room visits over the 6 years of Medicaid dental claims for ID Waiver participants from 2018-2023 by gender is shown in Table 12. Emergency room visits increased slightly for both males and females in 2023 when ID Waiver recipients were able to access expanded Medicaid dental benefits. Males had a higher rate of emergency room visits.

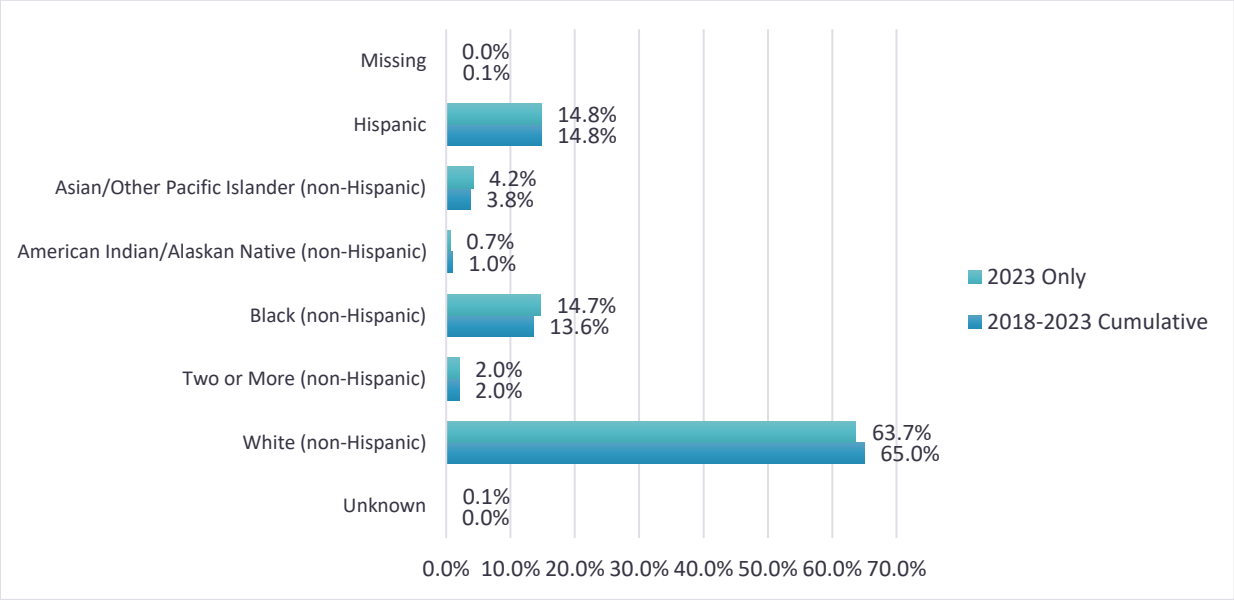
TABLE 12. SUMMARY OF ANNUAL AND CUMULATIVE GENDER DEMOGRAPHICS ID WAIVER RECIPIENTS, EMERGENCY ROOM VISITS 2018-2023

Year of Service & Gender	Female	Male	Total
2018	329	437	766
2019	317	521	838
2020	314	412	726
2021	403	542	945
2022	363	494	857
2023	390	490	880
Total	2,116	2,896	5,012
Emergency Room Dataset Pearson Chi Square Tests for Independence: Value 8.774, df 5, Asymptotic Significance (2-sided) 0.118			

RACE/ETHNICITY

The ID Waiver data presented in Graph 20 assesses the race and ethnicity as a function of the ID Waiver population in lieu of as a percentage of racial or ethnic group with a disability as shown in Figure 3 and Graph 6 above. The population of Nevada is distributed 72.1% White; 10.8% Black or African American; 1.7% American Indian or Alaska Native alone; 10.3% Asian, Native Hawaiian, or Other Pacific Islander; and 5.1% Two or More Races regardless of Hispanic ethnicity. When comparing state race and ethnicity percentages of the total population against race and ethnicity percentage in the ID Waiver population data, Graph 6, only White (non-Hispanic) and Black (non-Hispanic) subpopulations have higher rates of ID Waiver participation compared to their effective representation of the state general population. This observation substantiates the comorbid socio-economic disparities even within the available insurance and access to care as a function of minority racial and ethnic diversity.

GRAPH 20. ID WAIVER SUMMARY OF RACE AND ETHNICITY, 2018-2023 VS. 2023, PERCENT OF ID WAIVER RECIPIENTS



The number of dental visits over the 6 years of Medicaid dental claims for ID Waiver recipients from 2018-2023 by race and ethnicity is shown in Table 13. Notably, dental office visits jump considerably in 2023 when ID Waiver recipients were able to access expanded Medicaid dental benefits.

TABLE 13. SUMMARY OF ANNUAL AND CUMULATIVE RACE/ETHNICITY DEMOGRAPHICS ID WAIVER RECIPIENTS, DENTAL OFFICE VISITS 2018-2023

Year of Service & Race/Ethnicity	Missing	Hispanic	Asian-Pacific Islander	American Indian-Alaskan Native	Black	Two or More Races	White	Unknown	Total
2018	13	470	201	44	572	38	2,403	0	3,741
2019	13	303	115	23	483	29	1,849	0	2,815
2020	7	380	90	27	416	48	1,337	0	2,305
2021	0	379	92	19	404	41	1,676	0	2,611
2022	0	391	146	33	531	73	1,656	0	2,830
2023	0	751	168	9	796	74	2,722	0	4,520
Total	33	2,674	812	155	3,202	303	11,643	0	18,822

Dental Office Dataset Pearson Chi Square Tests for Independence: Value 231.535, df 30, Asymptotic Significance (2-sided) <0.001

The summary of emergency room visits over the 6 years of Medicaid dental claims for ID Waiver recipients from 2018-2023 by race and ethnicity is shown in Table 14. Emergency room visits increased slightly in 2023 when ID Waiver recipients were able to access expanded Medicaid dental benefits.

TABLE 14. SUMMARY OF ANNUAL AND CUMULATIVE RACE/ETHNICITY DEMOGRAPHICS ID WAIVER RECIPIENTS, EMERGENCY ROOM VISITS 2018-2023

Year of Service & Race/Ethnicity	Missing	Hispanic	Asian-Pacific Islander	American Indian-Alaskan Native	Black	Two or More Races	White	Unknown	Total
2018	0	81	12	25	123	10	515	0	766
2019	2	86	28	15	92	17	598	0	838
2020	0	65	8	9	96	20	528	0	726
2021	0	88	7	5	140	44	661	0	945
2022	0	83	35	14	164	35	526	0	857
2023	0	114	23	11	115	57	560	0	880
Total	2	517	113	79	730	183	3,388	0	5,012

Emergency Room Dataset Pearson Chi Square Tests for Independence: Value 150.373, df 30, Asymptotic Significance (2-sided) <0.001

ORAL HEALTH AND ORAL HEALTH DISEASE IN ADULTS WITH INTELLECTUAL AND/OR DEVELOPMENTAL DISABILITIES

ORAL HEALTH IS HEALTH

The divide between dental care and medical care is vast, (and) has significant consequences for patients, and is entirely our own making.
AJ Weil, Oral Health Affairs Journal, 2016[86]

Three key themes underpin this Needs Assessment including:

- Oral health IS health
- Nearly all oral health disease is preventable
- Investing in prevention saves money

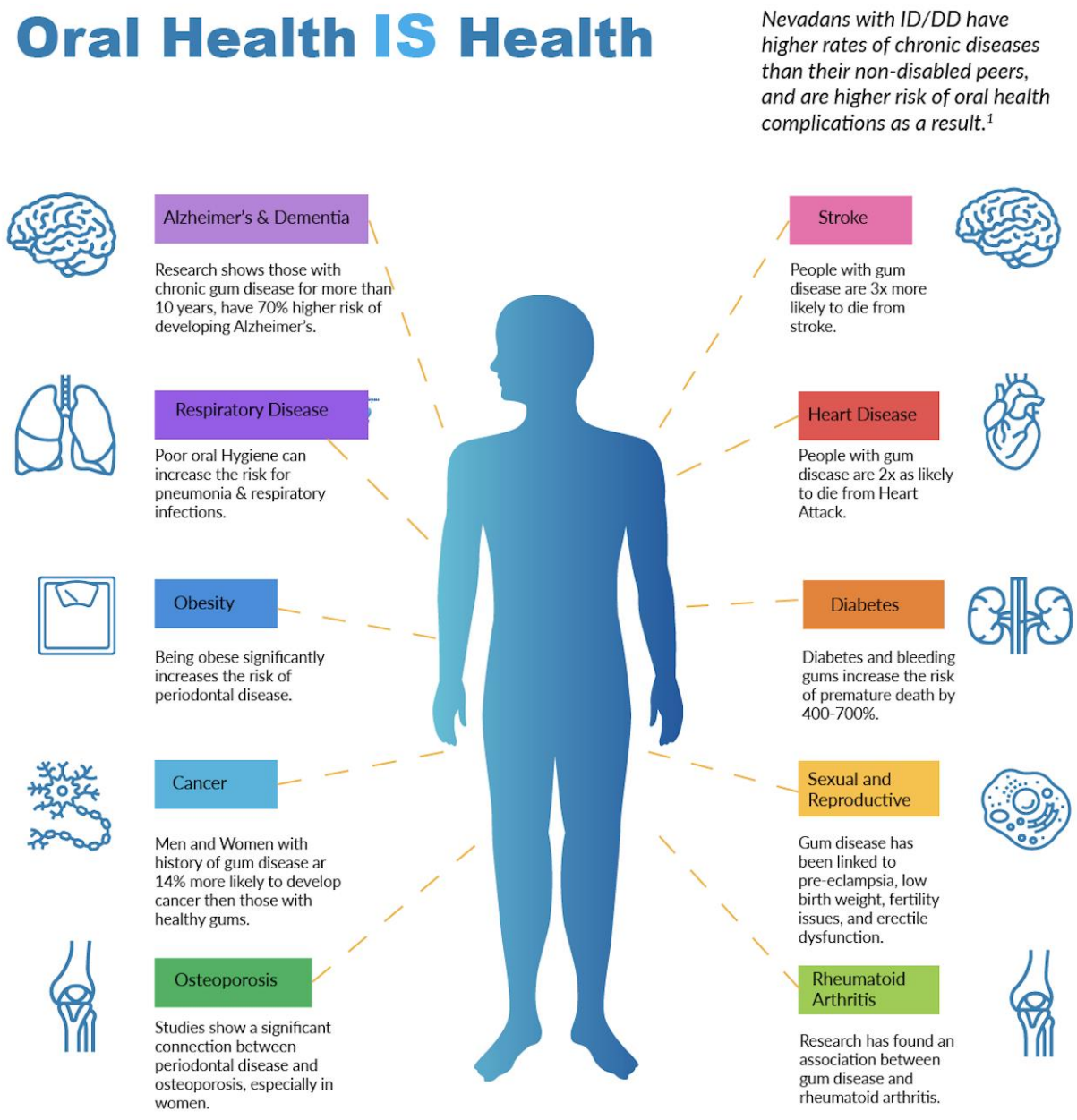
Nationally, states are working change policy, programs and practices to address historic and systematic health disparities in oral health among adults with ID/DD who experience worse oral health outcomes than the overall population. Oral health is integral to overall health, as oral disease can directly affect one's physical health and general well-being. Issues like gum disease and tooth decay can lead to serious health complications, including pain, inflammation, nutritional deficits, obesity, high blood pressure, cardiovascular diseases, diabetes, respiratory infections, and adverse pregnancy outcomes.

For example, poor oral health (periodontal disease) is directly linked to diabetes, which can impact life expectancy. Diabetes that is not well controlled leads to higher blood sugar (glucose) levels in the saliva, and a decreased production of saliva, which promotes the growth of pathogenic (bad) bacteria that can cause gum disease. Inflammation and reduced immune system functioning can lead to the breakdown of the supporting tissues around the teeth which is the hallmark of periodontal disease. On the other hand, infections from untreated periodontal disease can cause blood sugar to rise and make it more difficult to control diabetes. Therefore, for diabetics it is recommended that they complete a dental exam to determine if they have gingivitis and/or periodontal disease and if so, the dentist will prescribe a treatment plan to address their specific needs.

Consequently, individuals that do not have access to oral health care make chronic disease worse without proper periodontal treatments. All Smiles Shine and Project Accessible Oral Health created Figure 6[87] below that shows the impacts of oral disease on health and adverse outcomes of untreated oral disease.

[86]Weil, A. R. (2016). Oral Health. *Health Affairs.* Retrieved from https://www.healthaffairs.org/doi/10.1377/hlthaff.2016.1489
[87] Project Accessible Oral Health. *Oral Care Professionals Toolkit.* Retrieved from https://live-penn-dental-paoh.pantheonsite.io/wp-content/uploads/2021/11/PD-PAOH_Professionals-toolkit.pdf p. 3

FIGURE 6. ORAL HEALTH AND THE BODY



[1]*https://www.cdc.gov/ncbddd/disabilityandhealth/dhds/index.html*
Adapted from Dr. Tim Sulken and Dr. Yan Kinn- https://fostoriadentist.com/oral-systemic-link

The burden of untreated oral disease in adults with ID/DD extends beyond just oral health, significantly impacting overall health, educational attainment, employment opportunities, social interactions, and quality of life (Figure 7).[88]

[88] Heilmann, A., Tsakos, G., & Watt, R. G. (2015). Oral Health Over the Life Course. In C. Burton-Jeangros (Eds.) et. al., *A Life Course Perspective on Health Trajectories and Transitions*. (pp. 39–59). Springer. Retrieved from https://pubmed.ncbi.nlm.nih.gov/27683931/

FIGURE 7.IMPACT OF UNTREATED ORAL DISEASE

ORAL HEALTH DISPARITIES AND INTELLECTUAL AND/OR DEVELOPMENTAL DISABILITIES

Compared to those without disabilities, children and adults with disabilities are more likely to experience poor health and chronic conditions, and face a higher prevalence of comorbidities and heightened risks due to weakened immune systems or cardiac issues, increasing their susceptibility to conditions like endocarditis resulting from oral infections.[89] These disparities can be even greater for people with disabilities who have identities at the intersection of race and ethnicity or living in rural areas.

[89] American Academy of Pediatric Dentistry. Management of dental patients with special health care needs. *The Reference Manual of Pediatric Dentistry.* Chicago, Ill.: American Academy of Pediatric Dentistry; 2023:33-44. Retrieved from https://www.aapd.org/globalassets/media/policies_guidelines/bp_shcn.pdf

One literature review described a 'cascade of disparities' for adults with ID/DD including: 1) higher rates of adverse health conditions, 2) less attention to care needs, 3) poorer preventive care and health promotion practices, and 4) inequitable access to health care, all of which can lead to poorer health outcomes.
NORC at the University of Chicago, 2021, p. 16[90]

As early as 1979, the National Conference on Dental Care for Handicapped (sic) Americans acknowledged *"one of the major unmet health needs in the United States is adequate dental care for the handicapped (sic)."*[91] Today, data continues to demonstrate that "***Oral health care represents the most unmet health care need***"[92] for individuals with ID/DD contributing to increased risks for poor overall health and more severe dental needs than for individuals without ID/DD.[93] The National Institute on Minority Health and Health Disparities defines disparities in health outcomes, categorized as:[94]

- Higher incidence and/or prevalence of disease, including earlier onset or more aggressive progression of disease
- Premature or excessive mortality from specific health conditions
- Greater global burden of disease, such as Disability Adjusted Life Years (DALY), as measured by population health metrics
- Poorer health behaviors and clinical outcomes related to the aforementioned; and
- Worse outcomes on validated self-reported measures that reflect daily functioning or symptoms from specific conditions

Being counted is a health equity and civil rights issue.
Administration for Community Living, 2024[95]

The challenges and health disparities faced by people with disabilities, many of which were exacerbated by the COVID-19 pandemic and its aftermath, cannot be overstated. A notable disparity highlighting the extent of health inequalities faced by adults with ID/DD lies in the insufficient data capturing their oral health status at national, state, and local levels. During the research conducted for this Needs Assessment, the authors found numerous studies from other countries describing the prevalence of caries, periodontal disease, edentulism, and other oral health conditions in adults with ID/DD but were unable to find similar data sets for adults with

[90] NORC at the University of Chicago. (2021). *Considerations for Building Federal Data Capacity for Patient-Centered Outcomes Research Related to Intellectual and Developmental Disabilities.* Retrieved from https://aspe.hhs.gov/sites/default/files/documents/83d1c45919c4794620ec9e1ab284ec4e/Data-Infrastructure-IDD-PCOR-White-Paper.pdf p. 16
[91] Waldman, H.B. and Perlman, S.P. (2002), Preparing to Meet the Dental Needs of Individuals with Disabilities. *Journal of Dental Education*, 66: 82-85. https://doi.org/10.1002/j.0022-0337.2002.66.1.tb03511.x
[92] Chavis, S. E., & Macek, M. (2022). Impact of disability diagnosis on dental care use for adults in the United States: Status matters. *Journal of the American Dental Association (1939), 153*(8), 797–804. https://doi.org/10.1016/j.adaj.2022.03.002
[93] Milano M. (2017). Oral Healthcare for Persons with Intellectual or Developmental Disabilities: Why Is There a Disparity?. *Compendium of continuing education in dentistry (Jamesburg, N.J.: 1995), 38*(10), e5–e8. Retrieved from https://www.aegisdentalnetwork.com/cced/2017/11/oral-healthcare-for-persons-with-intellectual-or-developmental-disabilities-why-is-there-a-disparity
[94] National Institute on Minority Health and Health Disparities. Health Disparity Outcomes. *Minority Health and Health Disparities Definitions.* Retrieved from https://hdpulse.nimhd.nih.gov/index.html
[95] Administration for Community Living. *I/DD Counts.* Retrieved from https://acl.gov/iddcounts

ID/DD in the United States. Studies were found that included oral health burden data on children or adolescents, as well as on adults with specific conditions like Down Syndrome or Rett Syndrome, but not on adult with ID/DD generally, or with population samples that were large enough to draw conclusions about the incidence of disease and its impact.

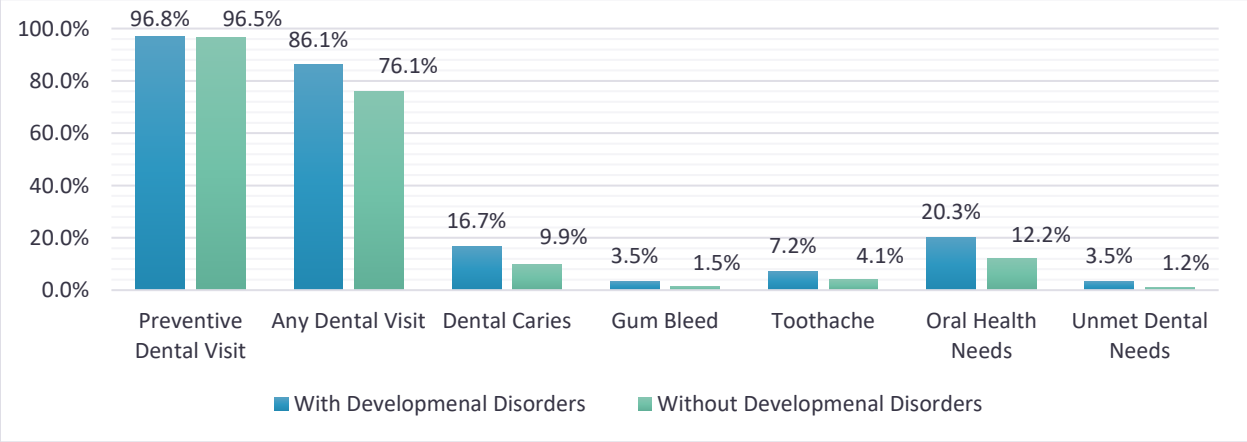
This lack of quality data describing the oral health status of adults with ID/DD at the national and state level is cited in academic journals and public health databases dealing with oral health and disabilities, and is a systemic, wide-ranging data gap that needs to be addressed to present high-quality and comprehensive burden data at the national and state levels for this underserved population. The lack of data on adults with ID/DD impedes efforts to identify inequities as well as creates barriers to measure progress in addressing them.

To estimate the extent of oral health disease in adults with ID/DD in Nevada, this report uses oral health burden statistics for all disabilities, as well as for individuals with ID/DD (often titled cognitive disabilities in various data sources) at the national level, North American level, and state and county levels, where available.

The disparities in the burden of oral health disease in adults with ID/DD begin in childhood, where the data show that with special health care needs have higher rates of dental caries (cavities), gum bleeds, toothaches, dental disease, and unmet needs.

In a cross-sectional study that utilized a sample of 30,530 noninstitutionalized children with and without developmental disorders/disabilities (DD) from the 2018 National Survey of Children's Health (NSCH), the prevalence of caries was 16.7% among children with developmental disabilities (DD) compared with 9.9% for children without DD; bleeding gums was 3.5% among children with DD and 1.5% among children without DD; and toothache was 7.2% among children with DD and 4.1% among those without DD. The rate of unmet dental needs was more than twice that for children with DD compared with children without DD (Graph 21).[96]

GRAPH 21. UTILIZATION OF DENTAL SERVICES, ORAL DISEASES, ORAL HEALTH NEEDS, AND UNMET DENTAL NEEDS FOR CHILDREN WITH AND WITHOUT DEVELOPMENTAL DISORDERS, 2018



[96] Obeidat, R., Noureldin, A., Bitouni, A. *et al.* Oral health needs of U.S. children with developmental disorders: a population-based study. *BMC Public Health* 22, 861 (2022). https://doi.org/10.1186/s12889-022-13237-2

The data illustrate disparities in the oral health of children with ID/DD, beginning at an early age, as described above, which then continue into adulthood.[97] Children with ID/DD face an enormous challenge as the data report they already suffer from higher rates of dental disease. When they reach the age of 21, they also lose comprehensive dental care and only qualify for emergency, palliative, and denture benefits. The funding of a comprehensive dental benefit for those 21 and over would require authority and funding to be granted to Nevada Medicaid by the Nevada Legislature.

For people with ID/DD who have high rates of oral disease, the dental caries, gum bleeds and tooth pain remain at higher levels due to their primary disabling condition and comorbidities through adulthood, even while they lose their Medicaid dental coverage.

In the *Special Populations Oral Health Survey* 2008 completed by Nevada Health and Human Services, which studied the oral health status and needs of 149 of Desert Regional Center adults with ID/DD, 65% of adults had visible oral decay and 20% had mouth pain. While this study is 16 years old, the oral health status findings are relevant even today due to the fact that there have been no material changes for this population in the last 16 years in terms of Medicaid dental benefits, until January 1, 2023, when ID Waiver recipients gained expanded dental benefits.[98]

Self-Rating of Oral Health in Households Experiencing Disability

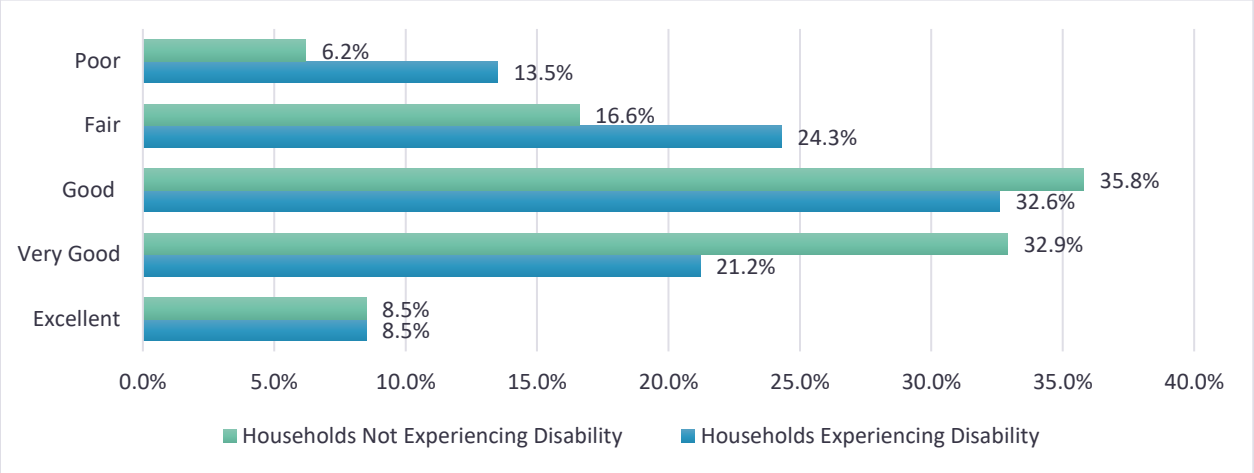
Of all forms of discrimination and inequalities, injustice in health is the most shocking and inhumane.
Dr. Martin Luther King, Jr., May 25, 1966

In a recent CareQuest Institute for Oral Health survey, respondents were queried about the presence of intellectual or physical disabilities within their households. Nearly 800 individuals (n=795, 4.5%) indicated "yes" and were classified as having a household member with an intellectual or physical disability.[99]

A greater proportion of individuals in households experiencing disability (38%) rate their oral health as fair or poor compared to households not experiencing disability.[100] These survey results underscore the continued relevance of oral health challenges within households affected by disability (Graph 22).

[97] Milano M. (2017). Oral Healthcare for Persons With Intellectual or Developmental Disabilities: Why Is There a Disparity?. *Compendium of continuing education in dentistry (Jamesburg, N.J.: 1995)*, *38*(10), e5–e8. Retrieved from https://www.aegisdentalnetwork.com/cced/2017/11/oral-healthcare-for-persons-with-intellectual-or-developmental-disabilities-why-is-there-a-disparity
[98] E.F. Wilcox (personal communication, March 8, 2024)
[99] CareQuest Institute for Oral Health. Family Affair. *A Snapshot of Oral Health Disparities and Challenges in Individuals and Households Experiencing Disability.* Retrieved from https://www.carequest.org/system/files/CareQuest_Institute_Family-Affair-Visual-Report_FINAL.pdf p. 1
[100] CareQuest Institute for Oral Health. Family Affair. *A Snapshot of Oral Health Disparities and Challenges in Individuals and Households Experiencing Disability.* Retrieved from https://www.carequest.org/system/files/CareQuest_Institute_Family-Affair-Visual-Report_FINAL.pdf p. 1

GRAPH 22. RATING OF ORAL HEALTH OF INDIVIDUALS IN HOUSEHOLDS EXPERIENCING [ANY] DISABILITY AND HOUSEHOLDS NOT EXPERIENCING DISABILITY



Source: CareQuest Institute for Oral Health. A Snapshot of Oral Health Disparities and Challenges in Individuals and Households Experiencing Disability.

THE BURDEN OF ORAL DISEASE IN ADULTS WITH INTELLECTUAL AND/OR DEVELOPMENTAL DISABILITIES

Adults with ID/DD demonstrate a higher burden of oral disease when compared to adults with no disability. They are at greater risk for a wide variety of oral health conditions that are associated with their disability and special healthcare needs, including but not limited to: [101, 102]

- poor oral hygiene
- build-up of calculus resulting in increased gingivitis and risk for periodontal disease
- edentulism (loss of teeth)
- enamel hypoplasia
- dental caries
- oral aversion and anxiety and behavioral challenges
- dental crowding
- malocclusion
- anomalies in tooth development, size, shape, eruption, and arch formation.
- bruxism and wear facets
- fracture of teeth or trauma
- dry mouth due to medications taken for chronic conditions
- special diets and liquid nutrition that is high in sugar content

[101] American Academy of Pediatric Dentistry. Management of dental patients with special health care needs. *The Reference Manual of Pediatric Dentistry*. Chicago, Ill.: American Academy of Pediatric Dentistry; 2023:33-44. Retrieved from https://www.aapd.org/globalassets/media/policies_guidelines/bp_shcn.pdf

[102] Morgan, J. P., Minihan, P. M., Stark, P. C., Finkelman, M. D., Yantsides, K. E., Park, A., Nobles, C. J., Tao, W., & Must, A. (2012). The oral health status of 4,732 adults with intellectual and developmental disabilities. *Journal of the American Dental Association (1939)*, *143*(8), 838–846. https://doi.org/10.14219/jada.archive.2012.0288

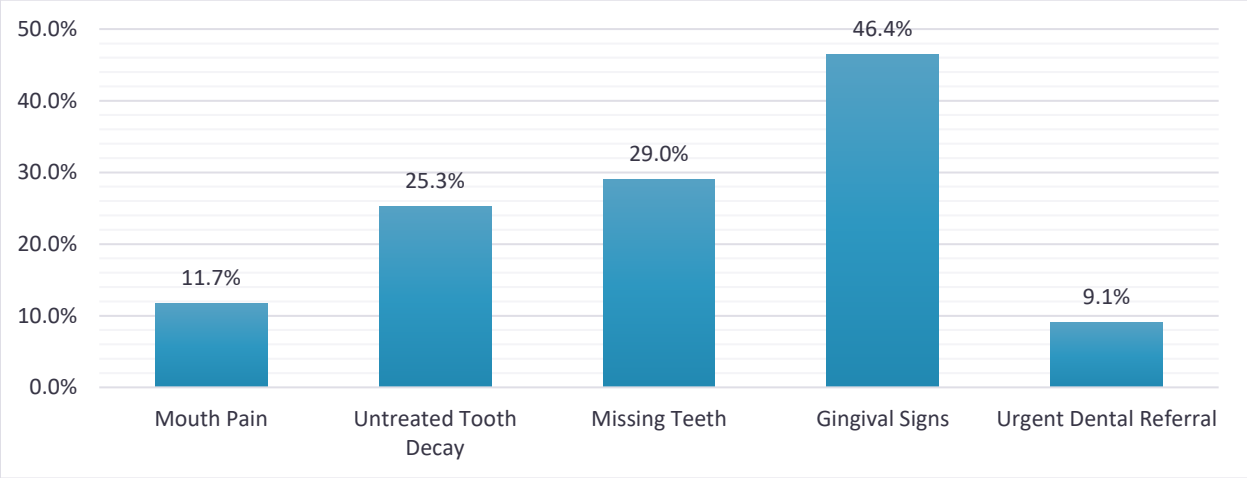
The Special Olympics dataset is most extensive collection of data concerning the physical health, including oral health, of individuals with ID/DD, specifically focusing on athletes served by their programs. This dataset encompasses health evaluations, oral health assessments, and records of preventative services rendered to over 900,000 individuals globally spanning from 2007 to 2018.

Notably, the Special Smiles program, which is the oral health component of Special Olympics, provides valuable insights into the oral health status of a significant segment of adults with ID/DD. The dataset predominantly represents active athletes and may not fully represent other subsets of the adult ID/DD population, such as those residing in institutions or individuals with severe and intricate medical conditions that might hinder their participation.

The Special Smiles Program assessed 123,129 individuals (eight years through adulthood) with ID/DD in North America between 2007-2018 and found the following (Graph 23): [103]

- 1 out of 4 (25.3%) individuals had untreated tooth decay
- Nearly 1 out of 2 (46.4%) had signs of gingivitis
- Nearly 3 out of 10 (29.4%) had missing teeth
- 1 out of 10 (11.7%) experienced mouth pain, and
- Nearly 1 out of 10 (9.1%) of athletes had oral health disease or a condition that was so severe that it necessitated an urgent referral for dental care, restoration or oral surgery.

GRAPH 23. ORAL HEALTH OF INDIVIDUALS SCREENED BY THE SPECIAL OLYMPICS SPECIAL SMILES PROGRAM 2017-2018



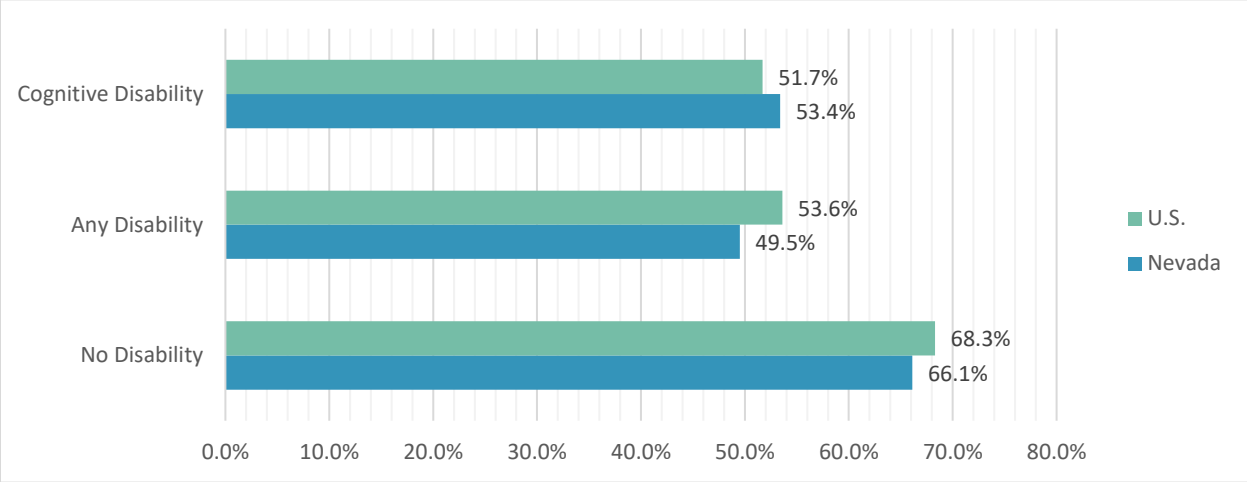
DENTAL VISIT RATES

Nevadans with disabilities ages 18 and older are not visiting the dentist at the same rates as their peers without disabilities. In 2020, only 49.5% of Nevadans with any disability and 53.4% of those

[103] Special Olympics Health. (2018). *Healthy Athletes 2018 Prevalence Report.* Retrieved from https://media.specialolympics.org/resources/research/health/2018-Healthy-Athletes-Prevalence-Report.pdf p. 34

with a cognitive disability had a dental visit in the past year, compared to 66.1% with no disability (Graph 24).[104]

GRAPH 24. ADULTS AGES 18 YEARS AND OLDER WHO VISITED A DENTIST IN THE PAST YEAR, ANY DISABILITY, COGNITIVE DISABILITY, AND NO DISABILITY, NEVADA AND THE U.S., 2020



MET AND UNMET DENTAL NEEDS

The percentage of adults with ID/DD across the United States experiencing unmet dental care needs differs from state to state, depending on whether the state offers Medicaid dental insurance benefits or not, as those with extensive coverage (34.45%) and limited coverage (35.63%) have higher rates of met dental care compared to those with emergency coverage (20.95%) no coverage (16.02%) (Table 15).[105]

TABLE 15. ADULTS WITH ID/DD DENTAL CARE NEEDS, BY NATIONAL ACADEMY FOR STATE POLICY (NASHP) BENEFITS CATEGORY

	Extensive Coverage	Limited Coverage	Emergency Coverage	No Coverage
% Met Dental Care	34.45%	35.63%	20.95%	16.02%
# of Adults with I/DD on Medicaid	1,159,170	672,870	557,297	129,824
# Met Dental Need	399,292	239,764	116,729	20,792
# Unmet Dental Need	759,878	433,107	440,569	109,031

Medicaid adult dental benefits coverage typically fall into four general categories:[106]

[104] Centers for Disease Control and Prevention. Disability and Health Data System (DHDS). Explore By Indicator. Category: Prevention & Screenings. Retrieved from https://dhds.cdc.gov/LP?CategoryId=PREVENT&IndicatorId=DENTIST&ShowFootnotes=true&View=Map&yearId=YR5&stratCatId1=DISSTAT&stratId1=DISABL&stratCatId2=&stratId2=&responseId=YESNO01&dataValueTypeId=AGEADJPREV&MapClassifierId=quantile&MapClassifierCount=5

[105] National Council on Disability (NCD). *Estimating Population Size Benefited by the Health Extension and Accessibility for Developmentally Disabled and Underserved Population (HEADs UP) Act to Support Cost Estimates.* Retrieved from https://www.ncd.gov/assets/uploads/reports/2023/ncd-heads-up-population-and-cost-analysis-2023.pdf p. 10

[106] Center for Health Care Strategies, Inc. (2019). *Medicaid Adults Dental Benefits: An Overview.* Retrieved from https://www.chcs.org/media/Adult-Oral-Health-Fact-Sheet_091519.pdf

- **Extensive Coverage:** A comprehensive mix of services, including more than 100 diagnostic, preventive, and minor and major restorative procedures approved by the ADA; per-person annual expenditure cap is at least $1,000.
- **Limited Coverage:** Fewer than 100 diagnostic, preventive, and minor restorative procedures recognized by the American Dental Association (ADA); per-person annual expenditure for care is $1,000 or less.
- **Emergency Coverage Only:** Relief of pain under defined emergency situations.
- **No Coverage:** No adult dental benefits are provided.

Nevada is an emergency only coverage state, which means Medicaid pays for extractions, palliative care and dentures in some cases. While the specific percentage is not available at the state level for Nevada, this data illustrates the greater unmet dental need in states that provide emergency only or no coverage (Nevada is an emergency only state) and no coverage.

The National Council on Disability, in their analysis on the dental health needs and costs for adults with ID/DD for the Health Extension and Accessibility for Developmentally Disabled and Underserved Population (HEADs UP) Act, estimated that 66% of adults covered by Medicaid with ID/DD had unmet dental care needs and would benefit from specialized dental care, notably a much higher estimate than the NASHP estimates presented above.[107]

Emergency Department Use and Costs For Non-Traumatic Dental Conditions

Individuals in households experiencing disability report visiting the emergency department (ED) for dental conditions at nearly three times the rate of their nondisabled counterparts (9.0% vs 3.1%).[108]

Adults with ID/DD in all states, including Nevada, who visit the ED for non-traumatic dental conditions (NTDC) use their Medicaid medical benefits for these visits. The national average cost of an ED visit for a dental condition is $1,286.33. This is costly to the health system, especially when 78%[109] of these issues could have been resolved in a dental office center for an average cost of between $90-$200.[110]

On average, in the United States in 2017, someone visited the ED every 15 seconds for a dental condition, totaling $2.7 billion in costs, with Medicaid paying for 42.2% of all adult visits.[111] These

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[107] National Council on Disability (NCD). *Estimating Population Size Benefited by the Health Extension and Accessibility for Developmentally Disabled and Underserved Population (HEADs UP) Act to Support Cost Estimates.* Retrieved from https://www.ncd.gov/assets/uploads/reports/2023/ncd-heads-up-population-and-cost-analysis-2023.pdf p. 10

[108] CareQuest Institute for Oral Health. Family Affair. *A Snapshot of Oral Health Disparities and Challenges in Individuals and Households Experiencing Disability.* Retrieved from https://www.carequest.org/system/files/CareQuest_Institute_Family-Affair-Visual-Report_FINAL.pdf

[109] Vujicic, M., Fosse, C., Reusch, C., and Burroughs, M. (2021). *Making the case for adults in all state Medicaid programs.* Health Policy Institute White Paper. American Dental Association in partnership with Community Catalyst and Families USA. https://www.ada.org/-/media/project/ada-organization/ada/ada-org/files/resources/research/hpi/whitepaper_0721.pdf%20page%204 p. 12

[110] Patel, N. A., Yun, J. K., & Afshar, S. (2020). Relieving Emergency Department Burden During COVID-19: Section 1135 Waivers for Dental Case Diversion. *Journal of oral and maxillofacial surgery: official journal of the American Association of Oral and Maxillofacial Surgeons*, *78*(12), 2110–2111. https://doi.org/10.1016/j.joms.2020.07.015

[111] Health Policy Institute. *Emergency Department Visits for Dental Conditions – A Snapshot*. Retrieved from https://www.ada.org/-/media/project/ada-organization/ada/ada-org/files/resources/community-initiatives/action-for-dental-health/emergency-department-referrals/ed_referral_hpi_infographic.pdf

visits are for non-traumatic dental conditions (NTDC), which are those not caused by accident or trauma.

EDs typically lack the necessary equipment and dental expertise to properly diagnose and treat dental conditions. Instead of definitive treatment, EDs typically provide temporary relief with antibiotics and painkillers, often opioids. This approach leads to recurring dental related ED visits, with 39% of ED dental patients returning once their medication has run out, and 21% returning multiple times within the year. ED providers are three times more likely than dentists to prescribe opioids for dental pain, and opioid painkillers account for 56% of medications prescribed after ED dental visits, contributing to the opioid epidemic in the United States.[112]

While Nevada data for ED visits for NTDC for all adults with ID/DD is not available, data for adults on the ID Waiver has been analyzed and can be found in the Emergency Department Use and Costs for Non-Traumatic Dental Conditions for ID Waiver Recipients section of this Needs Assessment. Nevada ED discharge data by age and gender for NTDC that include "any dental condition including traumatic injury (DEN001), Nontraumatic dental conditions (DEN002), Caries, periodontitis, and other preventable dental conditions (DEN003), Diseases of mouth; excluding dental (DIG003)" are found in Table 16[113] and by region in the Tables 17, 18, and 19.[114]

TABLE 16. NEVADA GENERAL ACUTE HOSPITALS BY GENDER AND AGE GROUP NON-TRAUMATIC DENTAL CONDITION EMERGENCY DEPARTMENT DISCHARGES AND AVERAGE BILL PER DISCHARGE, 2022

Nevada State Demographic	2022 Discharges	2022 Avg. Bill Per Discharge
Female	25,879	$2,453
Male	27,511	$4,736
Unknown	118	$7,050
Ages >1	4,001	$2,543
Ages 1-18	11,357	$3,159
Ages 19-34	16,213	$4,563
Ages 35-64	17,135	$5,446
Ages 65+	3,448	$9,771
Unknown	1,354	$2,160
State Total:	**53,508**	**$4,672**

[112] Association of State and Territorial Dental Directors (ASTDD). (2020). *Policy Statement: Reducing Emergency Department Utilization for Non-Traumatic Dental Conditions.* Retrieved from https://www.astdd.org/docs/reducing-emergency-department-utilization-for-non-traumatic-dental-conditions-january-2020.pdf p. 2

[113] Comagine Health and Nevada Department of Health and Human Services – Division of Health Care Financing and Policy. *Personal Health Choices. Calendar Year 2022. Book 3 – General Acute Care Hospitals. Outpatient Emergency Department Visits.* Retrieved from https://nevadacomparecare.net/reports/Transparency%20Reports/Personal%20Health%20Choices/Personal%20Health%20Choices%20-%20Emergency%20Department%20Visits%20Report%20PRELIM%2020231214.pdf page 11

[114] Comagine Health and Nevada Department of Health and Human Services – Division of Health Care Financing and Policy. *Personal Health Choices. Calendar Year 2022. Book 3 – General Acute Care Hospitals. Outpatient Emergency Department Visits.* Retrieved from https://nevadacomparecare.net/reports/Transparency%20Reports/Personal%20Health%20Choices/Personal%20Health%20Choices%20-%20Emergency%20Department%20Visits%20Report%20PRELIM%2020231214.pdf pages 12-13

TABLE 17. CLARK COUNTY GENERAL ACUTE HOSPITALS NON-TRAUMATIC DENTAL CONDITION EMERGENCY DEPARTMENT DISCHARGES AND AVERAGE BILL PER DISCHARGE, 2022

Clark County	2022 Discharges	2022 Avg. Bill Per Discharge
Centennial Hills Hospital Medical Center	2,296	$5,726
Boulder City Hospital	0	NR
Desert Springs Hospital Medical Center	1,728	$4,569
Dignity Health St. Rose Dominican Blue Diamond, LLC	568	$4,250
Dignity Health St. Rose Dominican Craig Ranch, LLC	1,798	$3,796
Dignity Health St. Rose Dominican Sahara, LLC	903	$3,514
Dignity Health St. Rose Dominican West Flamingo, LLC	367	$4,379
Henderson Hospital	4,275	$5,506
Mesa View Regional Hospital	411	$3,011
Mountain View Hospital	3,304	$6,998
North Vista Hospital	1,613	$2,583
South Hills Hospital and Medical Center	2,824	$5,968
Spring Valley Hospital Medical Center	2,563	$5,979
St. Rose Dominican Hospitals - Rose de Lima Campus	0	NR
St. Rose Dominican Hospitals - San Martin Campus	0	NR
St. Rose Dominican Hospitals - Siena Campus	0	NR
Summerlin Hospital Medical Center	2,092	$5,780
Sunrise Hospital and Medical Center	8.048	$6,185
University Medical Center of South Nevada	1,638	$5,602
Valley Hospital Medical Center	1,887	$6,306
Clark County Total	**36,324**	**$5,569**

TABLE 18. WASHOE CARSON CITY COUNTY GENERAL ACUTE HOSPITALS NON-TRAUMATIC DENTAL CONDITION EMERGENCY DEPARTMENT DISCHARGES AND AVERAGE BILL PER DISCHARGE, 2022

Washoe County Hospitals	2022 Discharges	2022 Avg. Bill Per Discharge
Carson Tahoe Medical Center	1,354	$2,160
Northern Nevada Medical Center	2,739	$3,513
Northern Nevada Sierra Medical Center	595	$3,489
Renown Regional Medical Center	5,034	$3,410
Renown South Meadows Medical Center	1,262	$2,882
Saint Mary's Regional Medical Center	1,768	$2,167
Washoe County Total	**12,752**	**$3,078**

TABLE 19. RURAL GENERAL ACUTE HOSPITALS NON-TRAUMATIC DENTAL CONDITION EMERGENCY DEPARTMENT DISCHARGES AND AVERAGE BILL PER DISCHARGE, 2022

Rural Hospitals	2022 Discharges	2022 Avg. Bill Per Discharge
Banner Churchill Community Hospital	1,149	$948
Battle Mountain General Hospital	0	NR
Carson Valley Medical Center	525	$2,674
Desert View Regional Medical Center	791	$2,828
Grover C Dils Medical Center	24	$2,039
Humboldt General Hospital	312	$1,391
Incline Village Community Hospital	0	NR
Mount Grant General Hospital	155	$1,367
Northeastern Nevada Regional Hospital	737	$2,577
Pershing General Hospital	140	$2,689
South Lyon Medical Center	191	$1,583
William Bee Ririe Hospital	408	$1,061
Rural Hospital Total	**4,432**	**$1,903**

ORAL HEALTH STATUS OF ID WAIVER RECIPIENTS– A SUBSET OF ADULTS WITH INTELLECTUAL AND/OR DEVELOPMENTAL DISABILITIES

It is noteworthy that 2023, after the expansion of dental benefits, there were increased services provided to ID Waiver recipients compared to other years of data within the 6-year period provided by the Nevada State Office of Analytics.

There are three series of data from the Nevada State Office of Analytics: 1) dental offices, 2) emergency room visits, 3) prescription medications. Consistently throughout the 6-years of requested data from 2018-2023, prescription medication claims were the most commonly reported "visit", followed by dental visits, and emergency room visits. In total there were 892 distinct providers based on NPI code for billing providers from 2018-2023 with 107 providers from the emergency room dataset, 301 providers from the dental visit dataset, and 532 prescription medication providers. Collectively, the NPI billing codes provided 56,009 claim-based services including a wide variety of comorbid services that could be coded as one of three major categories: ER only, Dental Office only, or Prescription only (26,167 visits); ER and Dental Office, ER and Prescription, or Dental Office and Prescription (24,426 visits); and ER, Dental Office, and Prescription in any order of service provision (5,416 visits). Due to concerns about being able to confidently associate prescriptions to dental conditions, dental office visits and emergency room visit data will be focused on in this assessment.

DENTAL VISIT RATES FOR ID WAIVER RECIPIENTS

The ID Waiver population, which included 2,967 individuals in 2023 during initial implementation, saw dental providers in a dental office substantially more in 2023 compared to the preceding 5-years. Comparatively, from 2018-2022, between 18.2% (2020) and 21.4% (2018) had at least one visit to a dental office with an average number of visits between 4.3 (2020) and 5.9 (2018).

From a dental visit perspective, ID Waiver recipients saw a dentist far less often than either peer populations of Nevadans with any disability, those with a cognitive disability, and those with no disability. In 2023, the initial year of the ID Waiver implementation, 29.8% saw a dentist or had a dental office visit with an annual average of 5.1 visits during the year per individual in 2023.

These initial observations substantiate the efficacy and need of the ID Waiver, and with expanded access and utilization of ID Waiver benefits, should lead to increased dental office or dentist visits among the ID Waiver participant population. It is also notable that even with the increased number of individuals visiting a dentist or dental office, the annual average number of visits did not stray from the observed range from 2018-2022.

Dental Office visits had the most variation across the 6-years of service data (Table 20). The expansion of dental benefits through the ID Waiver did lead to increased claims, 4,520 in 2023 compared to less than 3,000 annually from 2019-2022 and 3,741 in 2018 (an anomalous year within the 5-years of preceding data).

Additionally, the 885 served individuals in 2023 was the most by 250 compared to 2018 (highest total of preceding 5-years, but anomalous from a number of claims perspective as noted in the previous sentence) and by 266 compared to 2019 the highest among the remaining 4-preceding years.

The average annual representation of the cost data as a function of the ID Waiver population ranged from 18.3% in 2020 to 21.4% in 2018 with an average of 20.0% across the 5-years as compared to 29.8% in 2023. In total, 60.1% of ID Waiver recipients were served in Dental Offices. Cost data also showed dollar amounts in terms of HDR and DTL that were much higher in 2023, $1,239,145.51 (Header Level of a Claim or HDR) and $392,298.90 (Detailed Level of a Claim or DTL) than any other years, which ranged from $241,468.65 (HDR) in 2018 to $754,740.70 (HDR) in 2022 and $201,488.76 (DTL) in 2020 to $244,188.15 (DTL) in 2022. Across 6-years of claim data, annual cost data would be anticipated at 16.7% (HDL and DTL), which ranged from 5.5% HDR in 2018 (anomalous year) with the next lowest percentage at 13.3% in 2020 to 17.2% in 2022, compared to 28.2% HDR and 25.9% DTL in 2023.

TABLE 20. DENTAL OFFICE COST DATA, 2018-2023 ANNUAL AVERAGE AND CUMULATIVE SUMMARY, ID WAIVER RECIPIENTS

	2018		2019		2020		2021		2022		2023		Total	
	Paid Amount HDR	Paid Amount DTL	Paid Amount HDR	Paid Amount DTL	Paid Amount HDR	Paid Amount DTL	Paid Amount HDR	Paid Amount DTL	Paid Amount HDR	Paid Amount DTL	Paid Amount HDR	Paid Amount DTL	Paid Amount HDR	Paid Amount DTL
N	3,741	3,741	2,815	2,815	2,305	2,305	2,611	2,611	2,830	2,830	4,520	4,520	18,822	18,822
N Patients	635	635	619	619	542	542	559	559	613	613	885	885	1,784	1,784
n ($0)	23	40	28	34	30	35	42	48	50	57	71	89	244	303
n (>$0)	3,718	3,701	2,787	2,781	2,275	2,270	2,569	2,563	2,780	2,773	4,449	4,431	18,578	18,519
Mean	$64.5466	$60.6075	$235.8966	$76.7097	$318.4496	$87.4138	$289.0221	$90.1180	$266.6928	$86.2856	$274.1472	$86.7918	$233.14	$80.5411
Average (>$0)	$64.95	$61.26	$238.27	$77.65	$322.65	$88.76	$293.75	$91.81	$271.49	$88.06	$278.52	$88.54	$236.20	$81.86
Average (patients)	$380.27	$357.06	$1,072.78	$348.85	$1,354.29	$371.75	$1,349.98	$420.93	$1,231.22	$398.35	$1,400.16	$443.28	$2,459.68	$849.74
Std. Deviation	$134.26	$112.80	$339.05	$145.58	$511.39	$179.71	$408.22	$175.49	$388.61	$175.19	$457.11	$169.29	$395.36	$159.78
Range	$1,825.37	$1,332.50	$2,070.27	$1,481.04	$3,345.46	$2,439.36	$3,402.95	$2,439.36	$3,123.04	$2,874.30	$4,567.76	$2,788.37	$4,567.76	$2,874.30
Minimum	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00
Maximum	$1,825.37	$1,332.50	$2,070.27	$1,481.04	$3,345.46	$2,439.36	$3,402.95	$2,439.36	$3,123.04	$2,874.30	$4,567.76	$2,788.37	$4,567.76	$2,874.30
Sum	$241,468.65	$226,732.68	$664,048.95	$215,937.81	$734,026.43	$201,488.76	$754,636.72	$235,298.07	$754,740.70	$244,188.15	$1,239,145.51	$392,298.90	$4,388,066.96	$1,515,944.37

MET AND UNMET DENTAL NEEDS OF ID WAIVER RECIPIENTS

Based on the data from the Nevada State Office of Analytics, there is further evidence of more extreme needs among ID/DD population in Nevada. Considering at the height of participation in 2023, only 29.8% of ID Waiver recipients visited a dentist of dental office and the annual average from 2018-2022 was 20.0% of ID Waiver recipients visiting a dentist or dental office, there is extensive need among the ID/DD population in Nevada.

Assessing emergency room visits, during the period from 2018-2022, an annual average of 10.2% of ID Waiver recipients visited the emergency room annually with a range from 9.6% (2018) to 10.7% (2021). Comparatively in 2023, 10.7% of ID Waiver recipients visited the emergency room

an average of 2.8 visits per person during 2023. From an average number of emergency room visits, 2018-2022 annual average visits ranged from 2.49 (2020) to 2.98 (2021).

Further assessing medical care for dental issues, most of the care was provided through prescription medications with 37.9% of ID Waiver recipients receiving some form of prescription medication with an average of 5.9 "visits" per individual, which was the highest number of "visits" among ID Waiver individuals across the 6-years, but there were substantially more individuals receiving services through prescription medications in 2023 than previous years at 1,124 compared to 1,025 in 2022, which was the highest of the preceding 5-years.

From a distinct service perspective of those individuals with the ID Waiver, the highest number received some form of dental care in 2023 either at a dental office or with a dentist, in an emergency room, or through prescription medications and there were still more than 50% of ID Waiver individuals who did not receive any dental related care in 2023.

Although data is still limited in applicability for comparative analysis across all Medicaid recipients and there are inherent challenges with connecting datasets (dental offices, emergency rooms, and prescription medications), there is substantial evidence of unmet dental needs and unrealized access to care for more than half of the ID Waiver eligible population, which would be presumed to exist throughout Nevada's population of people with ID/DD at potentially higher rates among those not currently served by the ID Waiver.

From available ID Waiver data, the implications of limited preventative and prophylaxis dental care among individuals with ID/DD are quite profound, even with a single year of post-Waiver implementation data (Table 21).

TABLE 21. TOP 20 CPT CODES FROM DENTAL OFFICE VISITS, 2018-2023 ANNUAL AND CUMULATIVE SUMMARY, ID WAIVER RECIPIENTS

2023		Total		2022		2021		2020		2019		2018	
Rank	CPT Code	% of Total	Rank	% of Total	Rank	% of Total	Rank	% of Total	Rank	% of Total	Rank	% of Total	Rank	% of Total
1	LIMIT ORAL EVAL PROBLM FOCUS	10.4%	1	14.0%	1	15.6%	1	15.5%	1	15.9%	1	16.1%	1	13.5%
2	INTRAORAL PERIAPICAL EA ADD	10.0%	2	11.2%	2	11.1%	2	10.0%	2	10.4%	2	12.0%	2	13.0%
3	INTRAORAL PERIAPICAL FIRST	8.4%	3	8.6%	3	9.4%	3	8.2%	3	9.3%	3	9.5%	5	7.4%
4	BITEWINGS FOUR IMAGES	7.8%	4	7.3%	4	8.1%	4	6.7%	4	8.5%	4	7.9%	6	5.4%
5	COMPREHENSVE ORAL EVALUATION	6.3%	6	3.8%	5	4.6%	5	4.9%	5	4.9%	18	1.2%	22	0.7%
6	DENTAL PROPHYLAXIS ADULT	6.2%	15	2.0%	17	1.4%	16	1.5%	22	0.9%	118	0.0%	110	0.0%
7	PERIODIC ORAL EVALUATION	5.1%	13	2.2%	19	1.4%	14	1.7%	14	1.6%	21	1.0%	23	0.7%

2023			Total		2022		2021		2020		2019		2018	
Rank	CPT Code	% of Total	Rank	% of Total	Rank	% of Total	Rank	% of Total	Rank	% of Total	Rank	% of Total	Rank	% of Total
8	INTRAOR COMPREHENSIVE SERIES	3.5%	14	2.1%	11	2.4%	17	1.5%	26	0.7%	16	1.8%	12	1.9%
9	PANORAMIC IMAGE	3.2%	7	3.5%	6	4.5%	7	3.6%	8	3.2%	7	3.2%	7	3.4%
10	DENTAL CONSULTATION	2.7%	9	2.5%	10	2.5%	8	3.3%	7	3.3%	13	2.0%	16	1.3%
11	PERIODONTAL SCALING & ROOT	2.7%	24	0.9%	52	0.2%	59	0.2%	71	0.1%	50	0.2%	25	0.7%
12	REM IMP TOOTH W MUCOPER FLP	2.1%	5	4.1%	7	3.9%	6	3.8%	6	3.4%	9	2.6%	4	8.5%
13	ANESTH PROCEDURE ON MOUTH	2.0%	12	2.3%	9	2.6%	10	2.9%	13	2.0%	10	2.4%	10	2.0%
14	UNLISTED PX DENTALVLR STRUX	2.0%	11	2.4%	8	3.0%	11	2.3%	12	2.0%	8	2.9%	9	2.5%
15	POST 2 SRFC RESINBASED CMPST	1.8%	27	0.7%	54	0.2%	38	0.4%	38	0.4%	36	0.4%	27	0.5%
16	HOSPITAL/ASC CALL	1.6%	16	1.6%	13	1.8%	13	1.9%	19	1.4%	14	2.0%	17	1.1%
17	POST 1 SRFC RESINBASED CMPST	1.3%	28	0.6%	53	0.2%	43	0.3%	49	0.3%	41	0.3%	30	0.3%
18	FULL MOUTH DEBRIDEMENT	1.2%	10	2.4%	12	2.2%	9	3.0%	9	2.5%	6	3.6%	8	2.9%
19	DEEP ANEST, 1ST 15 MIN	1.1%	23	1.0%	14	1.5%	18	1.4%	18	1.4%	43	0.3%	33	0.3%
20	GENERAL ANESTH EA ADDL 15 MI	1.1%	18	1.3%	16	1.4%	20	1.3%	16	1.4%	22	0.9%	13	1.7%
10.5	Average Ranks/Cumulative %	80.7%	12.4	74.5%	15.8	7.9%	15.2	74.4%	17.15	73.5%	22.1	70.3%	19	67.8%

The Dental Office Top-20 CPT Codes were generally consistent with at least 13 shared Top-20 2023 CPT Codes found in all of the annual and the cumulative total presentations. However, there was less consistency in the cumulative percentage represented by the 2023 Top-20 CPT Codes across the other annual reported data and the cumulative total with percentages ranging from a low of 67.8% in 2018 to 80.7% in 2023.

Emergency Department Use and Costs For Non-Traumatic Dental Conditions for ID Waiver Recipients

The Emergency Room data presented in Table 22 shows comprehensive cost data from 2018-2023 as well as cumulative cost data. Cumulatively the Emergency Room Cost data includes 5,012 claims associated with 1077 patients, which represents 36.3% of the ID Waiver recipients over 6 years of claims data. Additionally, the average annual patients served ranged from 9.6% in 2018 to 10.7% in 2021 and 2023 and an annual average of 10.2% between 2018-2022, indicating limited variance in Emergency Room utilization rates.

Fundamentally, while Emergency Room cost data had some changes to cost data, Dental Office related cost data was substantially higher in 2023 following the implementation of the ID Waiver

expanded benefits program. Cost data is suggestive and supportive of potential correlation or connection between the expanded ID Waiver dental benefits, reach, care provided, and reimbursable costs associated with dental care, which supports the rationale and expectation of the ID Waiver from a systemic vision, mission, and goal perspective.

TABLE 22. EMERGENCY ROOM COST DATA, 2018-2023 ANNUAL AVERAGE AND CUMULATIVE SUMMARY, ID WAIVER RECIPIENTS

	2018		2019		2020		2021		2022		2023		Total	
	Paid Amount HDR	Paid Amount DTL	Paid Amount HDR	Paid Amount DTL	Paid Amount HDR	Paid Amount DTL	Paid Amount HDR	Paid Amount DTL	Paid Amount HDR	Paid Amount DTL	Paid Amount HDR	Paid Amount DTL	Paid Amount HDR	Paid Amount DTL
N	766	766	838	838	726	726	945	945	857	857	880	880	5,012	5,012
N Patients	284	284	315	315	292	292	317	317	309	309	316	316	1,077	1,077
n ($0)	290	597	342	467	266	363	346	453	327	413	338	447	1,909	2,740
n (>$0)	476	169	496	371	460	363	599	492	530	444	542	433	3,103	2,272
Mean	$712.27	$13.64	$886.67	$42.03	$965.86	$53.29	$1,091.71	$51.99	$1,117.45	$50.08	$1,334.50	$47.70	$1,028.24	$43.57
Average (>$0)	$1,146.22	$61.85	$1,498.04	$94.93	$1,524.38	$106.58	$1,722.32	$99.86	$1,806.89	$96.67	$2,166.71	$96.94	$1,660.82	$96.12
Average (patients)	$1,921.13	$36.80	$2,358.82	$111.81	$2,401.42	$132.49	$3,254.48	$155.00	$3,099.20	$138.90	$3,716.32	$132.84	$4,785.07	$202.78
Std. Deviation	$3,603.65	$35.93	$3,319.02	$59.71	$3,468.98	$70.48	$6,392.40	$72.45	$4,749.54	$74.54	$4,264.96	$64.23	$4,510.39	$65.94
Range	$47,500.00	$267.69	$39,000.00	$267.69	$33,836.00	$267.69	$112,419.00	$535.38	$77,400.00	$1,070.76	$47,488.00	$317.68	$112,419.00	$1,070.76
Minimum	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00	$0.00
Maximum	$47,500.00	$267.69	$39,000.00	$267.69	$33,836.00	$267.69	$112,419.00	$535.38	$77,400.00	$1,070.76	$47,488.00	$317.68	$112,419.00	$1,070.76
Sum	$545,599.82	$10,451.84	$743,027.88	$35,219.98	$701,215.16	$38,686.89	$1,031,670.24	$49,133.43	$957,654.08	$42,919.56	$1,174,357.25	$41,977.01	$5,153,524.43	$218,388.71

BARRIERS TO GOOD ORAL HEALTH FOR ADULTS WITH INTELLECTUAL AND/OR DEVELOPMENTAL DISABILITIES

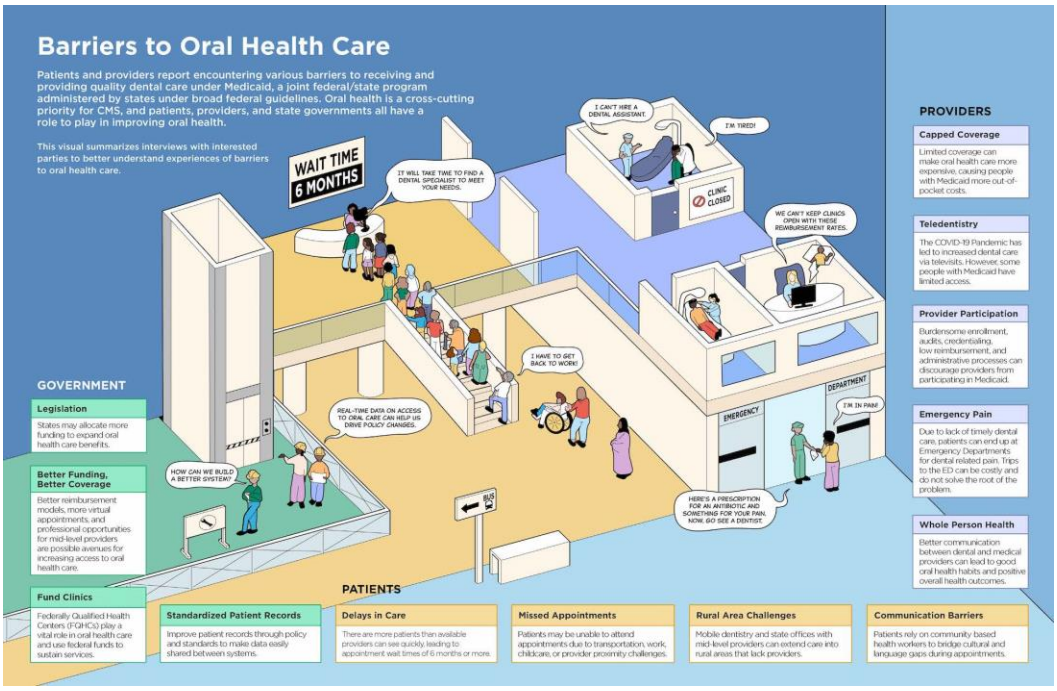
Let's take the 'silent' out of 'silent epidemic.' Virtually every shortcoming in the safety net has at its root a failure to understand or value oral health.
American Dental Association[115]

Ensuring good oral health is essential for overall well-being, yet adults with ID/DD often face significant barriers in maintaining optimal oral hygiene and oral health. Adults with ID/DD encounter unique challenges that hinder access to dental care and preventive measures, exacerbating their risk of oral diseases. In this section, we explore the various obstacles that impede good oral health for adults with ID/DD in Nevada, including:

- Individual Barriers to Good Oral Health
- Barriers to Accessing Oral Healthcare
- Policy and System Barriers

The Centers for Medicare & Medicaid Services (CMS) and external partners co-created the "Barriers to Oral Health" illustration [116] (Figure 8) that encapsulates the perspectives of stakeholders and underscores the primary hurdles encountered by individuals seeking or providing oral health care services.

FIGURE 8. BARRIERS TO ORAL HEALTH ILLUSTRATION



[115] American Dental Association. (2011). *Breaking Down Barriers to Oral Health for All Americans: Repairing the Tattered Safety Net.* Retrieved from https://www.cds.org/docs/default-source/foundation/barriers-paper_repairing-tattered-safety-net.pdf?sfvrsn=c5f5cb51_0 p. 20
[116] Centers for Medicare & Medicaid Services (CMS). Barriers to Oral Health Illustration. Retrieved from https://www.cms.gov/priorities/key-initiatives/burden-reduction/about-cms-office-burden-reduction-health-informatics/barriers-oral-health-care-illustration

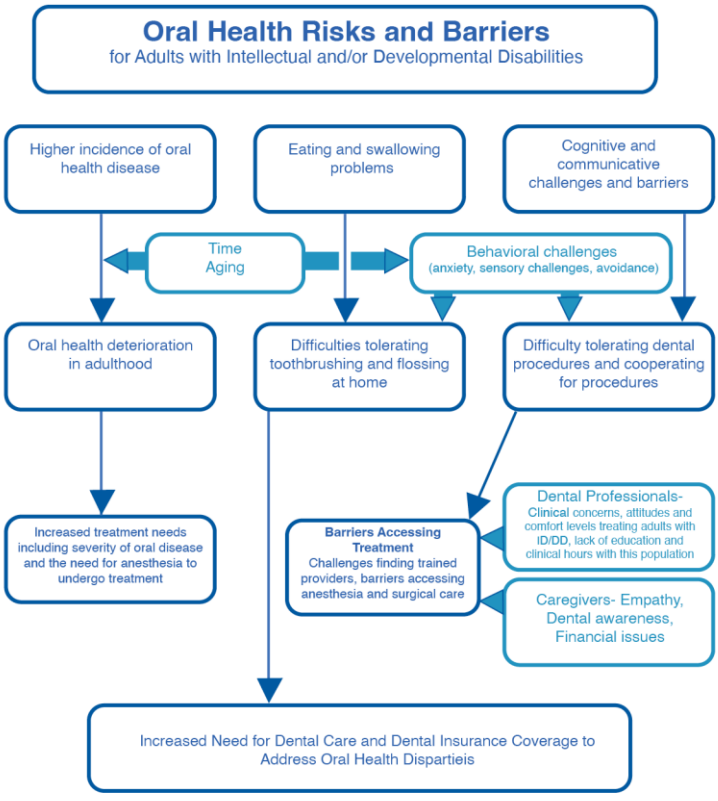
INDIVIDUAL BARRIERS TO GOOD ORAL HEALTH

Treating the existing disease without educating the patient is a wasted opportunity, making it likely that the disease will recur.
The Centers for Disease Control and Prevention (CDC)[117]

PATIENT-CENTERED BARRIERS

Patient-centered barriers include anxiety, communication difficulties, physical and cognitive barriers, sensory sensitivities, and behavioral challenges. Age and severity of the disability as well as experiencing multiple disabilities (e.g., intellectual and/or physical) and chronic health conditions also play a large role in managing oral hygiene at home and creating barriers to dental care at the dental office. While most patients with ID/DD can be treated in the office, some cannot tolerate treatment without sedation or anesthesia. When surgical care and anesthesia are needed, patients face significant barriers to accessing this care due to the out-of-pocket cost burden as well as lack of operating room availability, resulting in delays in care, increased pain, and worsening oral health outcomes. Figure 9[118] shows the oral health risks and barriers for adults with ID/DD.

FIGURE 9. ORAL HEALTH RISKS AND BARRIERS



Adapted from Lee, J., Chang, J. BMC Oral Health 21, 538 (2021). https://doi.org/10.1186/s12903-021-01896-3 Figure 1.

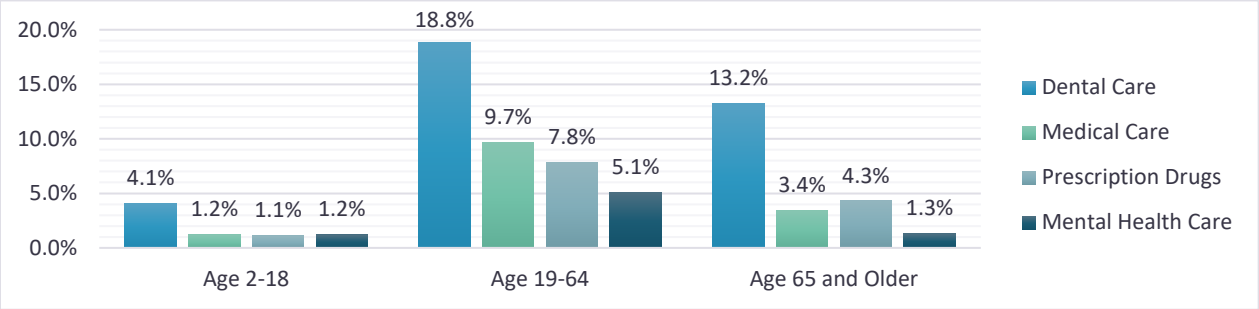
[117] American Dental Association. (2011). *Breaking Down Barriers to Oral Health for All Americans: Repairing the Tattered Safety Net.* Retrieved from https://www.cds.org/docs/default-source/foundation/barriers-paper_repairing-tattered-safety-net.pdf?sfvrsn=c5f5cb51_0

[118] Lee, J., Chang, J. Oral health issues of young adults with severe intellectual and developmental disabilities and caregiver burdens: a qualitative study. *BMC Oral Health* 21, 538 (2021). https://doi.org/10.1186/s12903-021-01896-3

For all age groups, data suggest that financial barriers to dental care are more significant than for any other health service... [119]
Vujicic, M., and Fosse, C., in AMA J Ethics

The financial barrier to dental care is the number one factor[120] for every age group for individuals with ID/DD - greater than the barriers to medical care, prescription drugs and mental health care (Graph 25). The benefits age cliff – loss of Medicaid dental benefits that occurs when an individual reaches adulthood - is dramatic, as financial barriers to dental increase from 4.1% of individuals with ID/DD ages 2-18 to 18.8% ages 19-64 and 13.2% ages 65 and older. [121]

GRAPH 25. FINANCIAL BARRIERS TO DENTAL CARE AND OTHER TYPES OF HEALTH CARE, 2019



CAREGIVERS BARRIERS

Brushing and flossing is difficult for many individuals with ID/DD due to motor challenges or sensory challenges, and it can also be challenging for caregivers to assist with brushing and flossing. Supporting an adult with ID/DD in their oral hygiene is also a challenge for care staff at residential facilities. One study found that that individuals with severe to profound intellectual disabilities made up 72% of all individuals with ID/DD in public residential facilities, indicating that staff support for, and training in, oral hygiene is key to maintaining good oral health.[122]

BARRIERS TO ACCESSING CARE ORAL HEALTHCARE

Access to quality health care is a basic human right. It is unacceptable that in 2023, every person in the United States of America does not have that access. Research to understand the barriers and unmet needs faced by people with disabilities, and to develop effective interventions to address them, is needed…to improve access to healthcare and health outcomes for all people.
Secretary Xavier Becerra, The U.S. Department of Health and Human Services

[119] Vujicic, M., and Fosse, C. (2022). Time for Dental Care to Be Considered Essential in the US Health Care Policy. *AMA J Ethics*. 2022;24(1): E57-63. doi: 10.1001/amajethics.2022.57. Retrieved from https://journalofethics.ama-assn.org/article/time-dental-care-be-considered-essential-us-health-care-policy/2022-01
[120] Vujicic, M., and Fosse, C. (2022). Time for Dental Care to Be Considered Essential in the US Health Care Policy. *AMA J Ethics.* 2022;24(1): E57-63. doi: 10.1001/amajethics.2022.57. Retrieved from https://journalofethics.ama-assn.org/article/time-dental-care-be-considered-essential-us-health-care-policy/2022-01
[121] Vujicic, M., and Fosse, C. (2022). Time for Dental Care to Be Considered Essential in the US Health Care Policy. *AMA J Ethics*. 2022;24(1): E57-63. doi: 10.1001/amajethics.2022.57. Retrieved from https://journalofethics.ama-assn.org/article/time-dental-care-be-considered-essential-us-health-care-policy/2022-01
[122] Rosecrans, M. et al. (2021). Invisible populations: Who is missing from research in intellectual disability? *Research in Developmental Disabilities*, Volume 119, 2021, 104117, ISSN 0891-4222, https://doi.org/10.1016/j.ridd.2021.104117

Another significant barrier to obtaining care, even for those on the Nevada ID Waiver who have access to expanded dental benefits, is finding a dentist who not only takes Medicaid but is also trained, experienced, and willing to care for adults with ID/DD.

The Oral Health Workforce Research Center (OHWRC) found that while 14% of parents or caregivers with children under 6 years old encountered challenges in locating a dental provider, 44% of parents or caregivers of adults with ID/DD ages 23 to 26 faced challenges locating a provider. These obstacles persist regardless of whether an individual is covered by Medicaid or private insurance, though they may be more pronounced for those reliant on Medicaid. [123]

Why does age alone dictate whether society deems oral health essential?

Marko Vujicic, PhD and Chelsea Fosse, DMD, MPH, in AJA J Ethics[124]

Access to care barriers often start as the patient with ID/DD transitions from pediatric dental care to adult care. Pediatric dentists are provided with extensive training to manage the care of young children, and their behaviors, fears, and to facilitate treatment effectively. While many pediatric dentists continue to care for an adult patient that has been in their practice past the age of 18, due to the different oral healthcare needs of adults, the American Dental Association has recommended that adults with ID/DD be transitioned to general practice adult dentists. [125] However, this is a challenge for many patients, as the system of care for adults with ID/DD is underdeveloped across the country, as many providers have not been adequately trained or received clinical access to training while in educational programs.

The American Dental Association states that of the 5 million transition-age youth across the country with special health care needs and disabilities, only 17% received adequate planning for the transition to an adult provider from their current providers.[126] The goal of a robust system of dental care for adults with ID/DD is best illustrated by what Dr. Keith Benson, DMD, Nevada State Dental Officer, described as "a system where every adult dentist would be trained, qualified and ready to care for that adult with ID/DD and specialty clinics would be needed only in those cases that required more complex interventions".[127]

In addition to the challenges in locating a dental provider willing and able to care for adults with ID/DD, individuals with disabilities have struggled to maintain good health as a result of a healthcare system that has failed them. The systemic barriers that include institutional discrimination and ableism and a "resistance" to incorporating training on cultural competency

[123] Oral Health Workforce Research Center. (2020). *Contributions of General and Specialty Dentists to Provision of Oral Health Services for People with Special Needs.* Retrieved from https://www.oralhealthworkforce.org/wp-content/uploads/2020/05/OHWRC_Provision_of_Oral_Health_Services_for_People_With_Special_Needs_20204.pdf p. 15

[124] Vujicic, M., and Fosse, C. (2022). Time for Dental Care to Be Considered Essential in the US Health Care Policy. *AMA J Ethics.* 2022;24(1): E57-63. doi: 10.1001/amajethics.2022.57. Retrieved from https://journalofethics.ama-assn.org/article/time-dental-care-be-considered-essential-us-health-care-policy/2022-01

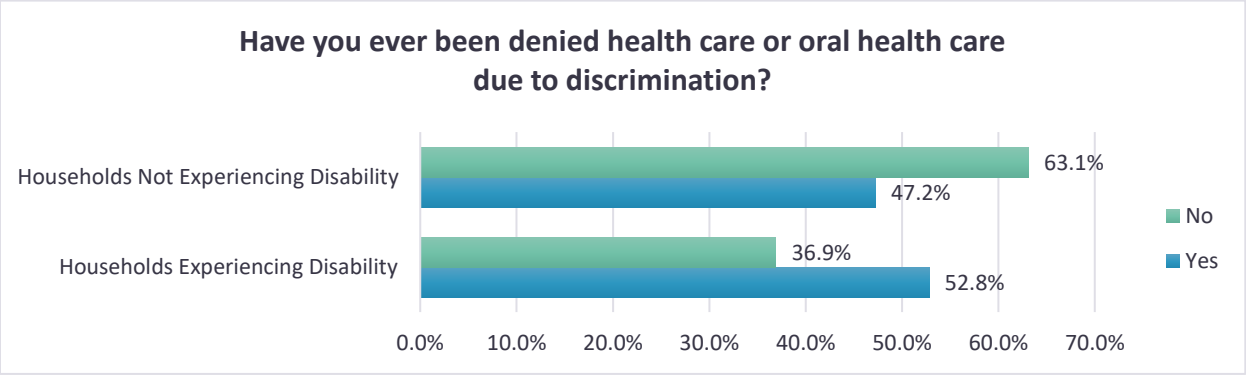
[125] American Academy of Pediatric Dentistry. Policy on transitioning from a pediatric to an adult dental home for individuals with special health care needs. *The Reference Manual of Pediatric Dentistry.* Chicago, Ill.: American Academy of Pediatric Dentistry; 2023:173-6. Retrieved from https://www.aapd.org/media/Policies_Guidelines/P_Transitioning.pdf p. 1

[126] American Academy of Pediatric Dentistry. Policy on transitioning from a pediatric to an adult dental home for individuals with special health care needs. *The Reference Manual of Pediatric Dentistry.* Chicago, Ill.: American Academy of Pediatric Dentistry; 2023:173-6. Retrieved from https://www.aapd.org/media/Policies_Guidelines/P_Transitioning.pdf p. 1

[127] K. Benson, DMD (personal communication, March 29, 2024)

when treating individuals with disabilities has contributed to longstanding and significant health disparities for this community.[128] In a recent CareQuest Institute for Oral Health report, 52.8% of households experiencing disabilities report being denied healthcare or oral healthcare due to discrimination, versus 36.9% in households not experiencing disability (Graph 26).[129]

GRAPH 26. RATING OF ORAL HEALTH DISCRIMINATION OF INDIVIDUALS IN HOUSEHOLDS EXPERIENCING A DISABILITY AND NOT EXPERIENCING A DISABILITY



Source: CareQuest Institute for Oral Health. A Snapshot of Oral Health Disparities and Challenges in Individuals and Households Experiencing Disability.

For people of color who also have disabilities, including ID/DD, discrimination and historical marginalization are even more significant. Studies show that a lack of trust in communities of color in medical and dental care, driven by historical abuses, results in barriers to individuals seeking care. A scholarly review of the literature conducted in 2021 shows that mistrust in the system was one of the primary healthcare barriers for Black and Latinx individuals with ID/DD, while it was not cited by White individuals as a barrier.[130]

In a strong dental care system, a dental home would provide culturally competent care for adults with ID/DD in order to ensure effective service delivery, continuity of care and integration of care between physicians and the dental care team and improve both short- and long-term oral health outcomes of the patient. A dental home that is successful in meeting patient needs and overcoming barriers to care would:

- Provide language interpretation for patients whose primary language is not English.
- Ensure access to American Sign Language translation or facilitate communication with Deaf and hard of hearing patients and/or their caregivers through a variety of methods including interpreters, written materials, and lip-reading.
- Ensure that offices are Americans with Disabilities Act (ADA) compliant. The ADA guidelines[131] state that dental practices must offer "full and equal access to their health care services and facilities", which includes physical access (accessible parking, wheelchair

[128] National Council on Disability. (2022). *Health Equity Framework for People with Disabilities.* Retrieved from https://www.ncd.gov/assets/uploads/reports/2022/ncd_health_equity_framework.pdf p. 1
[129] CareQuest Institute for Oral Health. Family Affair. *A Snapshot of Oral Health Disparities and Challenges in Individuals and Households Experiencing Disability.* Retrieved from https://www.carequest.org/system/files/CareQuest_Institute_Family-Affair-Visual-Report_FINAL.pdf
[130] Williamson, L. D., & Bigman, C. A. (2018). A systematic review of medical mistrust measures. *Patient education and counseling*, *101*(10), 1786–1794. https://doi.org/10.1016/j.pec.2018.05.007
[131] National Network. *Federal ADA Regulations and Standards.* Retrieved from https://adata.org/ada-law-regulations-and-design-standards

ramps, elevators, wide doors/hallways, spacious treatment rooms), communication access (alternative formats for written communication, communication aids, and accessible email and website options), and both mental and emotional access (reasonable accommodations and support during procedures).

- Be knowledgeable about the requirements of guardianship and informed medical content and their applications for adults with ID/DD to avoid delays in care.
- Coordinate care with general physician, working to integrate medical and dental care to improve outcomes and reduce risks of procedures and surgical interventions.
- Work to desensitize the patients to dental care by introducing them to the office on a "tour" or "meet and greet" only appointment before care or procedures to calm anxiety.
- Demonstrate what each instrument does in easy-to-understand, plain language, speaking to the adult with ID/DD directly, engaging them in their own care.
- Use techniques that can facilitate dental care for people with ID/DD including keeping the dental chair more upright as teeth are cleaned or restored, using weighted blankets during treatment to help calm sensory issues, and providing fidgets for clients to hold or sunglasses to wear during treatment.
- Provide families and/or caregivers with Patient Care Preference Cards (see example at www.everysmilemattersnevada.org) enabling the dentists or hygienist to tailor treatment and build rapport and trust with the patient.

The state of Washington worked to improve access to a dental home and qualified provider by establishing an online directory found at https://www.wsda.org/public/special-needs-directory.

Virtual Dental Homes (VDH) can also work to address access barriers by providing intervention and prevention services through telehealth by registered dental hygienists (RDHs) under the general supervision of a licensed dentist who need not be physically present. RDHs provide education, preventive and simple therapeutic services, and collect dental charts as well as dental and medical histories of patients. RDHs then confer with partnering dentists through tele-dentistry technology about the patient's condition, course of treatment, and any necessary referrals. Pilot projects between 2010 and 2016 demonstrated that underserved and vulnerable populations could be successfully treated using the VDH delivery approach.[132] According to a brief from the Resources for Integrated Care, the benefits of using telehealth for this population include the following examples:[133]

- Reduced emergency department utilization and increased cost savings
- Overcoming transportation barriers
- Improved access to specialists
- Increased patient satisfaction
- Improved health outcomes

[132] Legislative Analyst's Office. (2018). *Improving Access to Dental Services for Individuals with Developmental Disabilities.* Retrieved from https://lao.ca.gov/reports/2018/3884/dental-for-developmentally-disabled-092718.pdf p. 9

[133] Resources for Integrated Care. (2023). *Brief. People with Intellectual/Developmental Disabilities (I/DD): Telehealth Overview.* Retrieved from https://www.resourcesforintegratedcare.com/wp-content/uploads/2023/02/People-with-Intellectual-Developmental-Disabilities-IDD-Telehealth-Overview.pdf

POLICY AND SYSTEM BARRIERS

Navigating the landscape of oral health care for adults with ID/DD is often fraught with policy and system barriers that impede access to dental care. Adults with ID/DD encounter unique challenges including lack of adults Medicaid dental benefits (except for ID Waiver recipients), insufficient provider networks equipped to address their specialized needs, and regulatory hurdles that complicate the delivery of comprehensive oral care. As a result, adults with ID/DD frequently face disparities in accessing timely and appropriate dental treatments, exacerbating their risk of oral diseases, and compromising their overall health outcomes.

Lack of Adult Medicaid Dental Coverage

A recent report from the National Council on Disability (NCD), "Medicaid Oral Health Coverage for Adults with Intellectual & Developmental Disabilities – A Fiscal Analysis", [134] was motivated by a central research question, *"Should the Centers of 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 ID/DD and would doing so be cost-effective over the long-term?"* For both questions, the answer was ***"absolutely yes".*** [135]

Dental benefits are federally mandated for all Medicaid-enrolled children. However, state Medicaid programs are not required to cover dental care services and dental coverage for adults – this coverage is optional in each state and varies between comprehensive coverage to no coverage. Medicaid adult dental benefits coverage typically fall into four general categories:[136]

- **Extensive Coverage:** A comprehensive mix of services, including more than 100 diagnostic, preventive, and minor and major restorative procedures approved by the ADA; per-person annual expenditure cap is at least $1,000.
- **Limited Coverage:** Fewer than 100 diagnostic, preventive, and minor restorative procedures recognized by the American Dental Association (ADA); per-person annual expenditure for care is $1,000 or less.
- **Emergency Coverage Only:** Relief of pain under defined emergency situations.
- **No Coverage:** No adult dental benefits are provided.

Nevada is an emergency only coverage state, which means Medicaid pays for extractions, palliative care and dentures in some cases.

Figure 10[137] illustrates what adult Medicaid benefits were available in each state of as early 2021.

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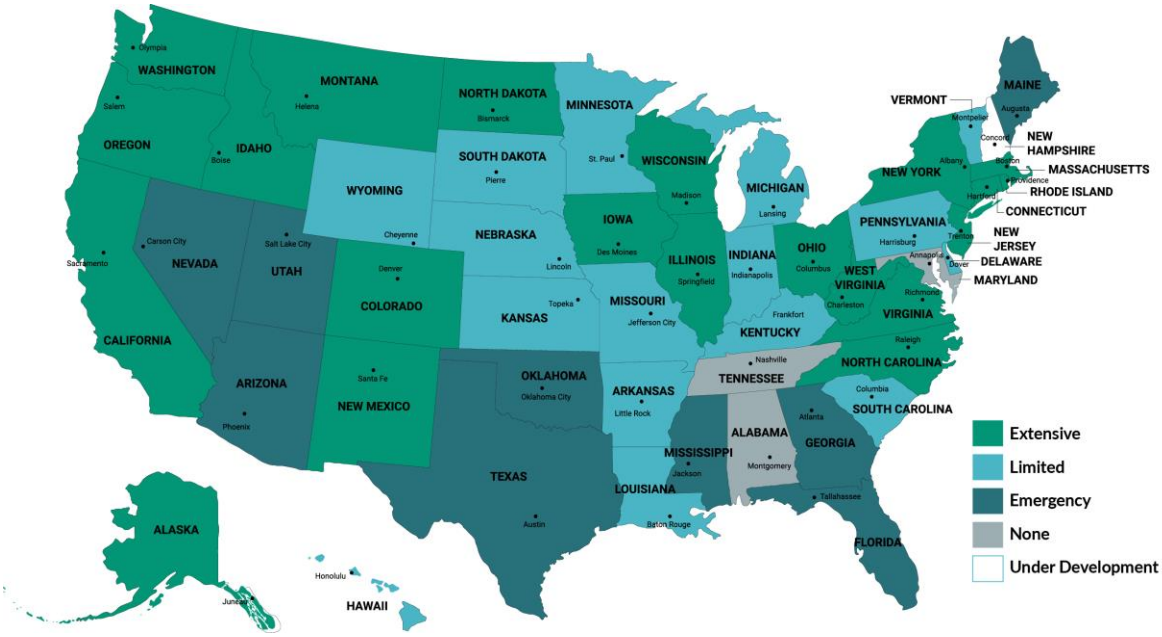
[134] National Council on Disability (NCD). (2022). *Medicaid Oral Health Coverage for Adults with Intellectual & Developmental Disabilities – A Fiscal Analysis.* Retrieved from https://www.nccp.org/wp-content/uploads/2022/03/NCD_Medicaid_Report_508.pdf

[135] National Council on Disability (NCD). (2022). *Medicaid Oral Health Coverage for Adults with Intellectual & Developmental Disabilities – A Fiscal Analysis.* Retrieved from https://www.nccp.org/wp-content/uploads/2022/03/NCD_Medicaid_Report_508.pdf

[136] Center for Health Care Strategies, Inc. (2019). *Medicaid Adults Dental Benefits: An Overview.* Retrieved from https://www.chcs.org/media/Adult-Oral-Health-Fact-Sheet_091519.pdf

[137] Vujicic, M., Fosse, C., Reusch, C., and Burroughs, M. (2021). *Making the case for adults in all state Medicaid programs.* Health Policy Institute White Paper. American Dental Association in partnership with Community Catalyst and Families USA. https://www.ada.org/-/media/project/ada-organization/ada/ada-org/files/resources/research/hpi/whitepaper_0721.pdf%20page%204 p. 5

FIGURE 10. ADULT MEDICAID BENEFITS AVAILABLE IN 2021



Between 2020 and 2022, there was a significant expansion of Medicaid adult benefits across the country. As of the end of 2022, the number of states that expanded benefits grew to seven states (Alaska, Iowa, Maine, Montana, New Jersey, Oregon, and Wisconsin) and the District of Columbia.[138]

During the same time, six states (Delaware, Kansas, Maine, Oklahoma, Virginia, and West Virginia) implemented dental benefits for all adults for the first time or significantly expanded their existing benefits. [139] Four states began providing an enhanced package of benefits to certain groups of beneficiaries, including postpartum adults (Alabama, Maryland, and Tennessee) and adults with ID/DD (Louisiana), where the return on investment for expanding dental coverage can be documented.[140]In 2023, Hawaii, Maryland, Michigan, New Hampshire, and Tennessee expanded benefits to all adults.

As mentioned, Nevada has also recently expanded oral health benefits to adults with ID/DD on the Home and Community Based Services Waiver for Individuals with Intellectual or Developmental Disabilities (ID Waiver). This waiver serves adults with ID/DD through 2,967 Nevada Legislature approved slots with ID/DD in Nevada as of January 1, 2024.
In terms of the fiscal impact to states of expansion of dental benefits to adults with ID/DD through ID Waiver programs, the National Council on Disability found cost savings to states that varied between states, [141] therefore, in order to determine costs and projected realized savings, Nevada

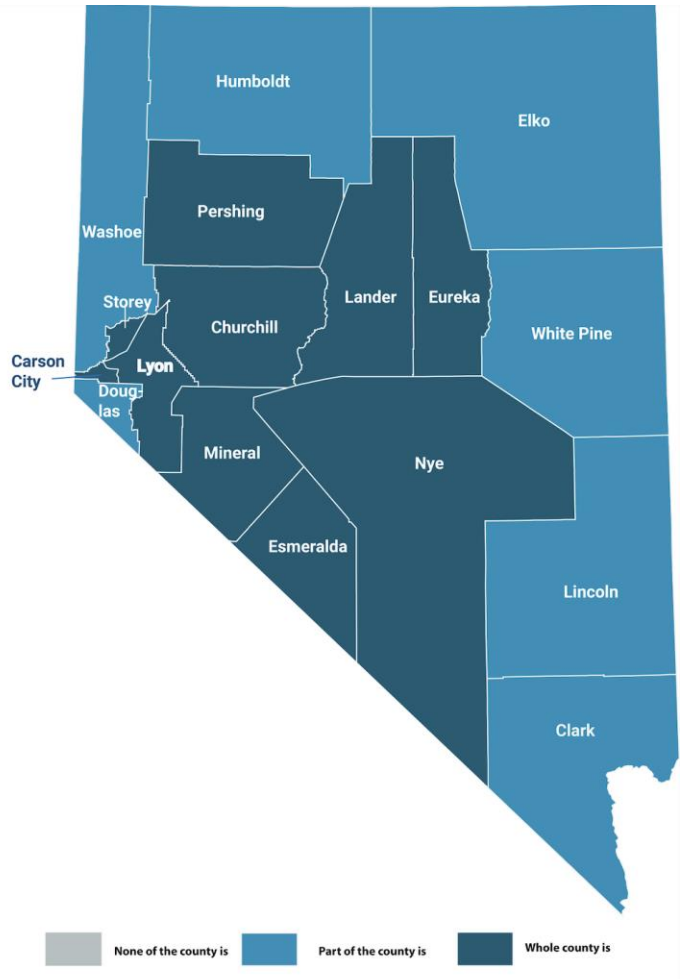
[138] Auger, S. (2023). *Five Key Takeaways about Medicaid Adult Dental Benefits in 2023.* Retrieved from https://www.carequest.org/about/blog-post/five-key-takeaways-about-medicaid-adult-dental-benefits-2023
[139] CareQuest. (2023). *Medicaid Adult Benefits.* Retrieved from https://www.carequest.org/system/files/CareQuest_Institute_Medical-Adult-Dental-Benefits_1.12.24.pdf p. 2
[140] CareQuest. (2022). *Medicaid Adult Dental Benefits.* Retrieved from https://www.carequest.org/system/files/CareQuest_Institute_Medical-Adult-Dental-Benefits_1.12.24.pdf p. 2
[141] National Council on Disability (NCD). (2022). *Medicaid Oral Health Coverage for Adults with Intellectual & Developmental Disabilities – A Fiscal Analysis.* Retrieved from https://www.nccp.org/wp-content/uploads/2022/03/NCD_Medicaid_Report_508.pdf

specific research and fiscal analysis will need to be conducted to determine the return on investment for Nevada and if these findings align with the National Council on Disability's findings for the costs and benefits to Nevada in its landmark study on this issue that found that expanding dental benefits to adults was valuable and provided a high return on investment.

Dental Provider Shortages and Shortages of Providers Who Accept Medicaid

All Nevadans live in a Dental Care Health Professional Shortage Area (HPSA), either whole or partial (Figure 11). [142] Eight of the 17 the Nevada counties are whole county Dental HPSAs with residents living without easy access to routine dental care, especially notable in the rural areas of the state. In Nevada, only 30.1% of the need for dental care is met, with 191 additional practitioners needed to remove the health HPSA designation. [143] The number of dentists per 1,000 population is 1,560:1, compared to the U.S at 1,380:1 in 2023.[144]

FIGURE 11. NEVADA DENTAL HEALTH PROFESSIONAL SHORTAGE AREAS BY COUNTY



[142] Rural Health Information Hub. Health Professional Shortage Areas. Retrieved from https://www.ruralhealthinfo.org/charts/9?state=NV
[143] Kaiser Family Foundation. Dental Health Care Professional Shortage Areas (HPSAs). Retrieved from https://www.kff.org/other/state-indicator/dental-care-health-professional-shortage-areas-hpsas/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D
[144] County Health Rankings. Retrieved from https://www.countyhealthrankings.org/explore-health-rankings/nevada?year=2023

The shortage of dental providers is even greater when looking at providers enrolled in Medicaid, resulting in a critical shortage, not just in Nevada but across the country.[145] The enrollment numbers for Medicaid dental providers in Nevada with the specialty types listed for calendar year 2023 are shown in Table 23[146].

TABLE 23.PROVIDER ENROLLMENT BY NEVADA COUNTY, , 2023

County	Dental	Total Medicaid Population	Nevada Population
Carson City	20	16,466	58,923
Churchill	7	7,735	26,940
Clark	891	828,718	2,361,285
Douglas	9	7,440	54,343
Elko	17	13,196	52,538
Esmeralda	0	209	1,067
Eureka	0	445	1,776
Humboldt	1	4,989	17,696
Lander	0	1,434	6,121
Lincoln	0	1,146	4,808
Lyon	9	16,841	63,179
Mineral	1	1,870	4,892
Nye	15	19,907	52,478
Pershing	0	1,406	7,464
Storey	0	236	4,454
Washoe	120	117,656	508,759
White Pine	0	2,502	10,005
Out-Of-State	109	27,414	?
Grand Total	**1,197**	**1,069,618**	**3,241,678**

The number of Nevada Medicaid dentists has only grown from 1,128 in calendar year 2020 to 1,197 in 2023.[147] The shortage of dental providers who accept Medicaid is a significant challenge, marked by difficulties in attracting dentists to participate in the program. Even in states that provide extensive Medicaid dental benefits, two out of three adults with ID/DD still do not receive basic dental care, paid for by Medicaid, due to the difficulty finding a provider to treat them and other access barriers.[148] Eight tribal clinics and two Federally Qualified Health Centers with three locations across Nevada provide dental services on a sliding scale to help address access barriers.

[145] Health Policy Institute. (2020). *Dentist Participation in Medicaid or CHIP.* Retrieved from https://www.ada.org/-/media/project/ada-organization/ada/ada-org/files/resources/research/hpi/hpigraphic_0820_1.pdf

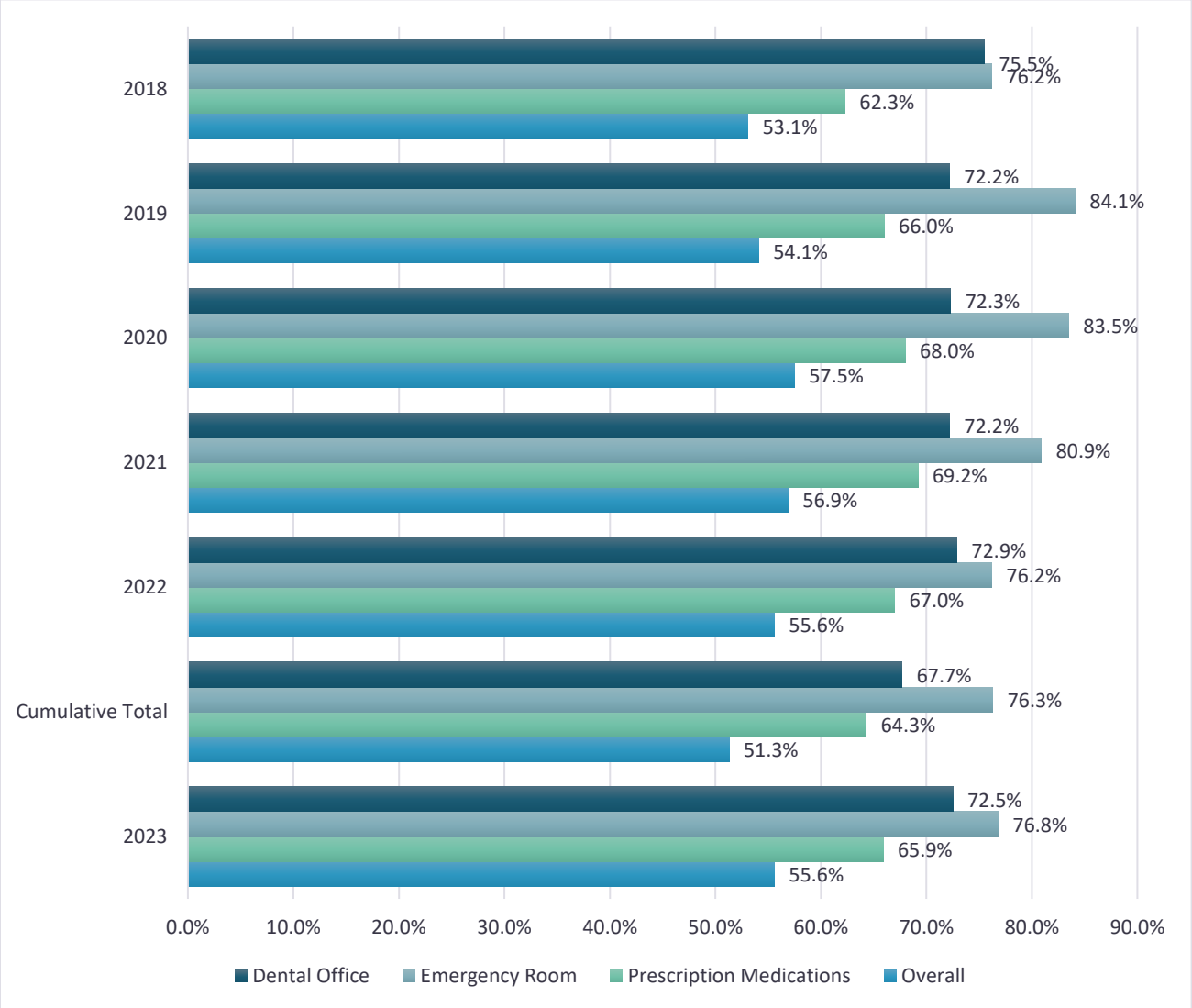
[146] The Nevada Division of Health Care Financing and Policy. (2024). *A Plan to Monitor Healthcare Access for Nevada Medicaid Recipients.* Retrieved from https://dhcfp.nv.gov/uploadedFiles/dhcfpnvgov/content/Resources/MCandQ/DRAFT%20Access%20to%20Care%20Monitoring%20Review%20Plan%202024.pdf p. 12

[147] The Nevada Division of Health Care Financing and Policy. (2024). *A Plan to Monitor Healthcare Access for Nevada Medicaid Recipients.* Retrieved from https://dhcfp.nv.gov/uploadedFiles/dhcfpnvgov/content/Resources/MCandQ/DRAFT%20Access%20to%20Care%20Monitoring%20Review%20Plan%202024.pdf

[148] National Council on Disability (NCD). (2022). *Medicaid Oral Health Coverage for Adults with Intellectual & Developmental Disabilities – A Fiscal Analysis.* Retrieved from https://www.nccp.org/wp-content/uploads/2022/03/NCD_Medicaid_Report_508.pdf

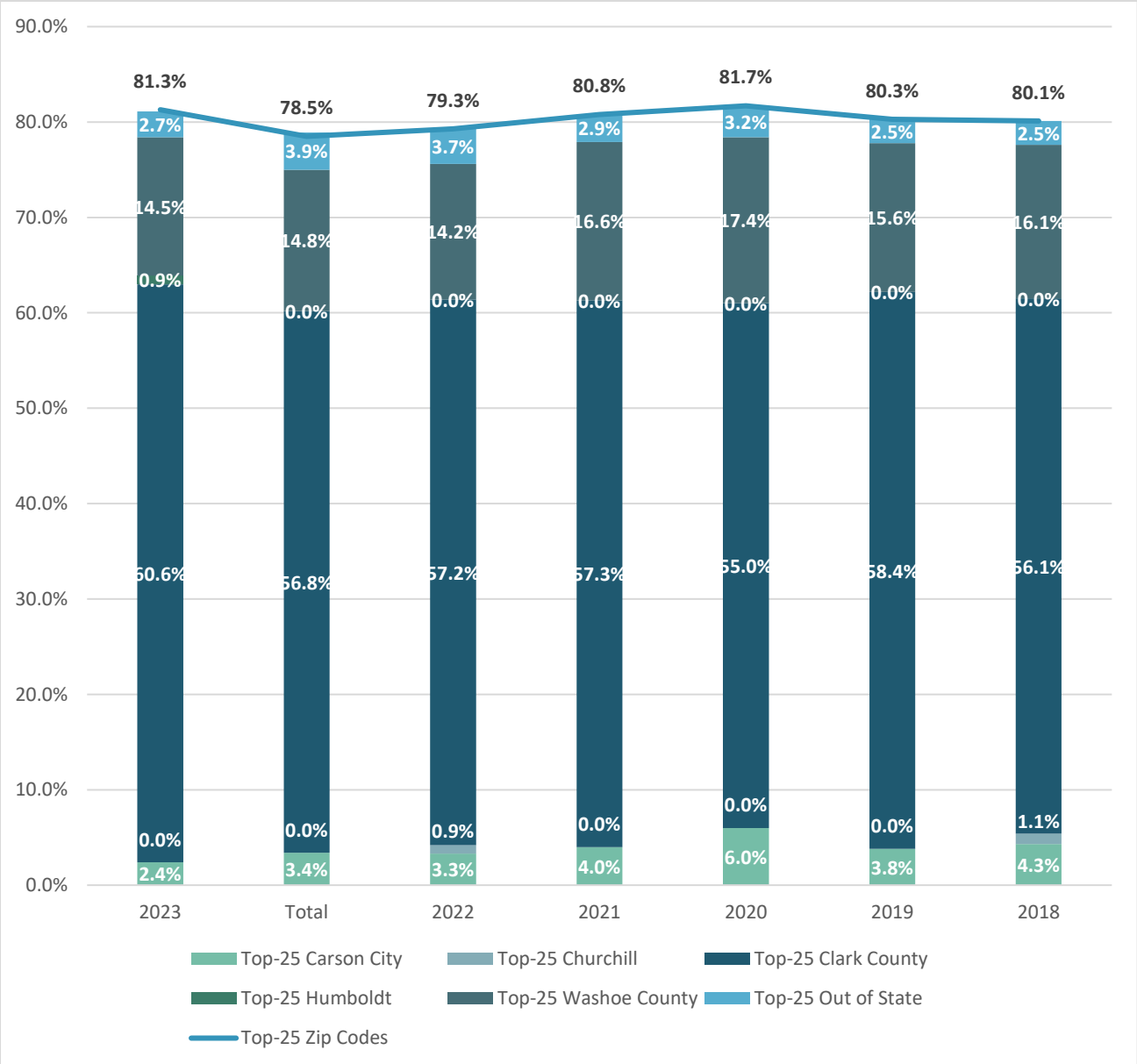
In terms of the ID Waiver population claims data, data gathered from the Nevada State Office of Analytics provides further clarity into the provider shortage for adults with ID/DD who have Medicaid, as presented in Figure 12 and Table 23 through both distribution of National Provider Identification (NPI) codes for the cumulative data request period, 2018-2023, and each year independently. Holistically, there were 892 distinct NPI codes reported as the billing NPI, which does not include the smaller subsets of data for preferred providers and referring providers. Although data was available for these subsets, the focus of the analysis for this Needs Assessment was on the billing NPI. Future studies or follow-on analyses could be augmented with the subset provider data, which would presumedly indicate even more disparate provider distributions across the state. NPI data from the Nevada State Office of Analytics specifically for ID Waiver recipients (Graph 27) further substantiates the increased disparity between the statewide disparity and the statewide ID Waiver disparity.

GRAPH 27.SUMMARY OF TOP-20 NPI CODES OVERALL AND CATEGORICAL, 2018-2023 ANNUAL AND CUMULATIVE TOTALS, ID WAIVER RECIPIENT CLAIMS



Furthermore, Graph 28 provides a summary of the NPI billing zip codes for the cumulative data request period for ID Waiver recipients enrolled in Medicaid, 2018-2023, and each year independently. Collectively, Graph 27 and Graph 28 illustrate the current landscape (2023) with historical data (2018-2022) in Nevada for ID Waiver recipients from a dental provider perspective regardless of provider type (includes dental offices, emergency rooms, and prescription medications – all related to dental care).

GRAPH 28. SUMMARY OF TOP-25 OVERALL NPI BILLING CODES BY ZIP CODES, 2018-2023 ANNUAL AND CUMULATIVE TOTALS



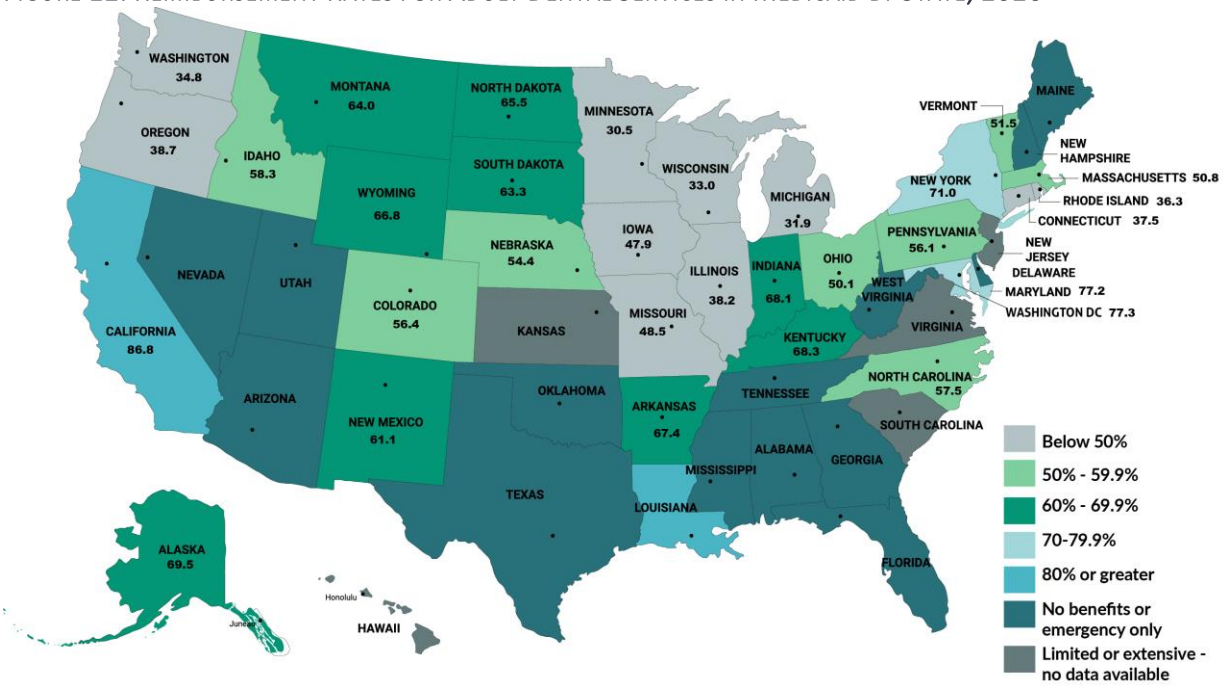
While efforts to grow the Medicaid provider network in Nevada and across the country are ongoing, providers cite a number of reasons for not enrolling in Medicaid, including: low reimbursement rates, administrative burdens, high no-show rates, and a lack of knowledge of the

benefits of being a Medicaid provider.[149] In states that provide preventive dental services as part of their expanded benefits to adults, the National Council on Disability found that reimbursement rates for fee for service (FFS) dental services were substantially lower than reimbursement rates provided by private insurance companies.[150] FFS rates for adults were only 37% of those charged by dentists and 46% of private dental insurance reimbursement.[151] The study concluded that while rates varied across state, that overall, Medicaid FFS reimbursement rates were too low and were a barrier to building the Medicaid provider network. In Nevada, ID Waiver patients who have access to expanded benefits receive those benefits through FFS plans, and rates have been increased 10% as an incentive to care for these patients and to offset the longer appointment times and care management often required.[152]

Medicaid Rates as Percentage of Private Insurance Reimbursement

The reimbursement rates for adult Medicaid dental services vary by state (Figure 12).[153] For limited or extensive adult dental services, the average Medicaid reimbursement was 53.3% of private insurance reimbursement. California had the highest reimbursement rate (86.8%) while Minnesota had the lowest (30.5%). Nevada does not provide basic adult dental coverage (except for emergency, palliative care, and dentures) under Medicaid.

FIGURE 12. REIMBURSEMENT RATES FOR ADULT DENTAL SERVICES IN MEDICAID BY STATE, 2020



[149] Hinton, E., & Paradise, J. (2016). *Access to Dental Care in Medicaid: Spotlight on Nonelderly Adults*. Retrieved from https://www.kff.org/medicaid/issue-brief/access-to-dental-care-in-medicaid-spotlight-on-nonelderly-adults/

[150] National Council on Disability (NCD). (2022). *Medicaid Oral Health Coverage for Adults with Intellectual & Developmental Disabilities – A Fiscal Analysis.* Retrieved from https://www.nccp.org/wp-content/uploads/2022/03/NCD_Medicaid_Report_508.pdf p. 19

[151] National Council on Disability (NCD). (2022). *Medicaid Oral Health Coverage for Adults with Intellectual & Developmental Disabilities – A Fiscal Analysis.* Retrieved from https://www.nccp.org/wp-content/uploads/2022/03/NCD_Medicaid_Report_508.pdf p. 33

[152] K. Benson, DMD (personal communication, March 29, 2024)

[153] American Dental Association. (2021). *Reimbursement Rates for Child and Adult Dental Services in Medicaid by State.* Retrieved from https://www.ada.org/-/media/project/ada-organization/ada/ada-org/files/resources/research/hpi/hpigraphic_1021_1.pdf

In order to incentivize providers to meet the unmet needs of the ID Waiver recipients in Nevada who now have expanded dental benefits, Nevada Medicaid added a 10% increase to the rates paid to providers who care for ID Waiver patients, increased the yearly dental benefit to $2500 and reduced prior authorization requirements to streamline anesthesia care and reduce administrative burden on patients and dental providers.[154] Incentives states provide to improve access to care for adults with ID/DD include: tuition payback based on Medicaid care participation, fee incentives for rural practice establishment, increased fees tied to care in high need microenvironments and with populations of individuals with special healthcare needs and disabilities, preferred prior authorization status, fast-track credentialing, tax incentives and other creative ways to credit dentists who provide Medicaid care.[155]

Shortage of Trained Providers

In addition to the barriers in accessing a Medicaid enrolled provider, adults with ID/DD face challenges as many oral health providers have not received adequate amounts of training to provide high quality care to people with disabilities.[156]

The National Council on Disability (NCD) in 2017 urged the Commission on Dental Accreditation (CODA) to require more thorough training to dental education students in the care of patients with ID/DD. [157] As recommended by the NCD, CODA recently implemented a new standard in the education of students in treating patients with the ID/DD, which now requires all dental education programs to train their students to treat patients with ID/DD. The accompanying statement of intent states for pre-doctoral education standards is as follows: [158]

> "*An appropriate patient pool should be available to provide experiences that may include patients whose medical, physical, psychological, or social situations may make it necessary to consider a wide range of assessment and care options. As defined by the school, these individuals may include, but are not limited to, people with developmental disabilities, cognitive impairment, complex medical problems, significant physical limitations, and the vulnerable elderly. Clinical instruction and experiences with the patients with special needs should include instruction in proper communication techniques including the use of respectful nomenclature, assessing the treatment needs compatible with the special need, and providing services or referral as appropriate."*

While pediatric dentists treat both children and adults with ID/DD, adults have different dental needs than children, and the American Dental Association has encouraged the growth of the adult

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[154] K. Benson, DMD (personal communication, March 29, 2024)

[155] Casamassimo, P., Czerepak, C., & Lee, J. Y. (2021). To work toward oral health care equity, start with Medicaid. *Journal of the American Dental Association (1939)*, *152*(7), 495–499. https://doi.org/10.1016/j.adaj.2021.04.002

[156] National Council on Disability (NCD). (2023). *Incentivizing Oral Health Care Providers to Treat Patients with Intellectual and Developmental Disabilities.* Retrieved from https://www.ncd.gov/report/incentivizing-oral-healthcare-providers-to-treat-patients-with-intellectual-and-developmental-disabilities/

[157] National Council on Disability (NCD). (2017). *Neglected for Too Long: Dental Care for People with Intellectual and Developmental Disabilities.* Retrieved from https://ncd.gov/sites/default/files/NCD_Dental%20Brief%202017_508.pdf

[158] Oral Health Workforce Research Center. (2020). *Contributions of General and Specialty Dentists to Provision of Oral Health Services for People with Special Needs.* Retrieved from https://www.oralhealthworkforce.org/wp-content/uploads/2020/05/OHWRC_Provision_of_Oral_Health_Services_for_People_With_Special_Needs_20204.pdf

dental system to meet those needs, provide the care this population needs, and importantly to reduce the use of anesthesia the way that specialty centers of excellence in treating adults with ID/DD across the country are able to do, thereby reducing the risk of complications as well as reducing cost. [159]

A 2017 brief issued by National Council on Disability, "Neglected for Too Long: Dental Care for People with Intellectual and Development Disabilities",[160] revealed the following:

- According to a series of studies, 50% of dental students reported no clinical training in the care of patients with such specific care requirements, and 75% of dental students reported little to no preparation in providing care to people with ID/DD.
- A national study of dental hygiene programs reported similar finds for treatment of people with disabilities in that 48% of 170 programs offered 10 hours or less of didactic training (including 14% with 5 hours or less); and 57% of programs reported no clinical experience.

In a 2023 National Council on Disability survey of 900 oral health care providers, made up of 72.1% general dentists, 8.5% pediatric dentists, 7% oral and maxillofacial surgeons, 4.2% dental hygienists and 8.2% of dental specialties, respondents provided the following reasons for not treating people with ID/DD:[161, 162]

- Lack of training and expertise in caring for this population
- Concerns about managing patient behaviors associated with their disability
- Lack of specialized equipment
- Transportation issues for patients resulting in broken appointments
- Time factors including extra time needed for appointments
- Operatory limitations and treatment room logistics
- Lack of available sedation to enable care provision
- Insufficient trained staffing to support care
- Poor Medicaid reimbursement

When asked what supports were needed to render dental care, the respondents cited the following (Table 24): [163]

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[159] Oral Health Workforce Research Center. (2020). *Contributions of General and Specialty Dentists to Provision of Oral Health Services for People with Special Needs.* Retrieved from https://www.oralhealthworkforce.org/wp-content/uploads/2020/05/OHWRC_Provision_of_Oral_Health_Services_for_People_With_Special_Needs_20204.pdf p. 10

[160] National Council on Disability (NCD). (2017). *Neglected for Too Long: Dental Care for People with Intellectual and Developmental Disabilities.* Retrieved from https://beta.ncd.gov/assets/uploads/reports/2017/ncd_dental-brief-2017.pdf

[161] National Council on Disability (NCD). (2023). *Incentivizing Oral Health Care Providers to Treat Patients with Intellectual and Developmental Disabilities.* Retrieved from https://www.ncd.gov/report/incentivizing-oral-healthcare-providers-to-treat-patients-with-intellectual-and-developmental-disabilities/ p. 36

[162] Oral Health Workforce Research Center. (2020). *Contributions of General and Specialty Dentists to Provision of Oral Health Services for People with Special Needs.* Retrieved from https://www.oralhealthworkforce.org/wp-content/uploads/2020/05/OHWRC_Provision_of_Oral_Health_Services_for_People_With_Special_Needs_20204.pdf

[163] National Council on Disability (NCD). (2023). *Incentivizing Oral Health Care Providers to Treat Patients with Intellectual and Developmental Disabilities.* Retrieved from https://www.ncd.gov/report/incentivizing-oral-healthcare-providers-to-treat-patients-with-intellectual-and-developmental-disabilities/ p. 36

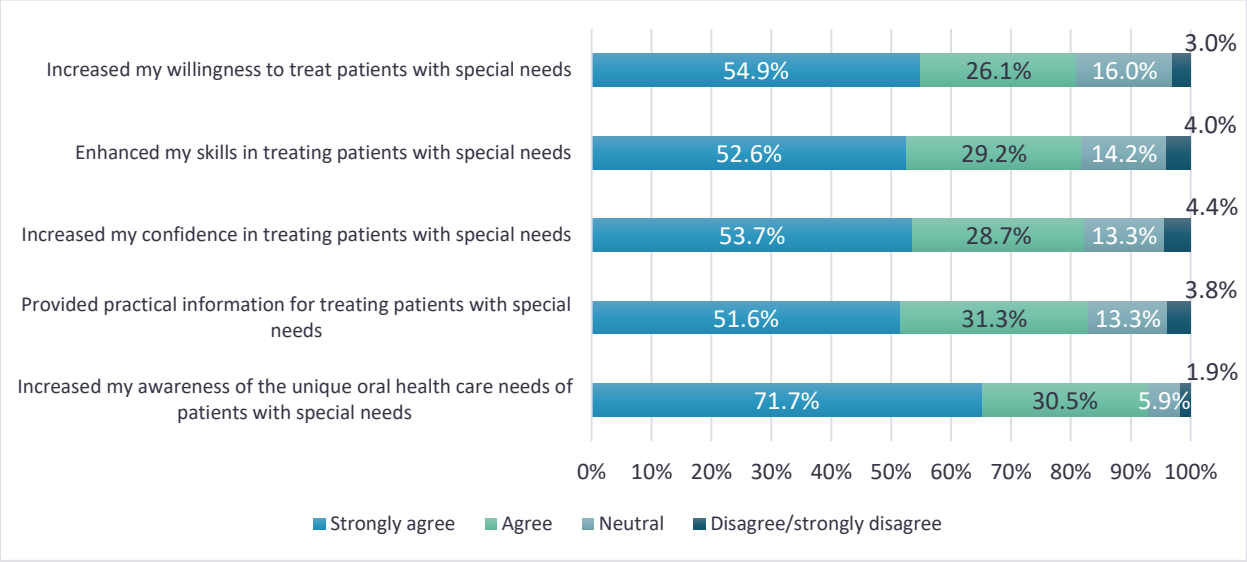
TABLE 24. SUPPORTS NEEDED TO RENDER DENTAL CARE

	Supports Needed
Physical Infrastructure	Wheelchairs with a head rest Bariatric dental chairs Larger operatories with open floor plans Quiet spaces without lots of noise and distraction Wheelchair-accessible treatment Panorex and three-dimensional scanning machines with wheelchair capability Portable x-rays Regular access to the operating room Papoose boards
Behavioral	Use of IV sedation Access to anesthesiologist Sedation via Certified Registered Nurse Anesthetist (CRNA) Oral conscious sedation Sedation Outreach facilitator
Treatment/Other	Additional education and training Policy that supports general practitioner use of IV sedation Sedation support staff Compensation for increased treatment time Ability to use sedatives More staff to support patient care and safety Better reimbursement Initial consultation with parent/caregiver Medical consultation prior to treatment Policy approval for use of papoose boards

In a 2020 Oral Health Workforce Research Center (OHWRC) study, respondents *"strongly agreed or agreed that education, training, or other experiences working with people with special needs increased their awareness (92.2%), confidence (82.4%), and willingness (81.0%) to treat people with special needs and that it provided practical information (82.9%) and/or enhanced their skills (81.8%) in treating people with special needs"* (Graph 29)."[164]

[164] Oral Health Workforce Research Center. (2020). *Contributions of General and Specialty Dentists to Provision of Oral Health Services for People with Special Needs.* Retrieved from https://www.oralhealthworkforce.org/wp-content/uploads/2020/05/OHWRC_Provision_of_Oral_Health_Services_for_People_With_Special_Needs_20204.pdf p. 24

GRAPH 29. PROVIDER PERCEPTIONS OF THEIR EDUCATION AND PREPAREDNESS TO PROVIDE TREATMENT TO PATIENTS WITH SPECIAL NEEDS (SIC)



Adapted from Contributions of General and Specialty Dentists to Provision of Oral Health Services for People with Special Needs by Oral Health Workforce Research Center, Figure 1, p. 24.

Respondents expressed a preference for learning in clinical settings rather than through didactic instruction only, which was linked to enhanced self-efficacy in treating individuals with disabilities and an increased intention to work with this population in future practice.[165] Similar data describe the same benefits for dental hygienists.[166]

In Nevada, the University of Nevada Las Vegas General Practice Residency and the Roseman University Advanced Education in General Dentistry programs provide access for dental students to obtain hands-on experience caring for individuals with ID/DD. Notably, there are no residency programs in northern Nevada.

Increased opportunities for clinical rotations to care for patients from a community pool of individuals with the special healthcare needs are needed to increase access to quality care. Examples of how states and communities have met this need include:

- Specialty hospital clinics can offer an interdisciplinary approach to caring for individuals with ID/DD, aiming to minimize the necessity for anesthesia through effective behavioral management techniques and best practices. These clinics can also ensure access to sedation, anesthesia, and surgical care when required, while simultaneously providing valuable operatory clinical experience for students.
- University Dental Clinics have the opportunity to utilize their dental chair capacity or collaborate with community agencies, such as Community Health Centers or Federally

[165] Oral Health Workforce Research Center. (2020). *Contributions of General and Specialty Dentists to Provision of Oral Health Services for People with Special Needs.* Retrieved from https://www.oralhealthworkforce.org/wp-content/uploads/2020/05/OHWRC_Provision_of_Oral_Health_Services_for_People_With_Special_Needs_20204.pdf pp. 24

[166] Spolarich, A.E., Gohlke, E., Fallone, K., & Curtis Bay, R. (2023). Training Dental Hygiene Students to Care for Patients with Disabilities. *Journal of Dental Hygiene.* Retrieved from https://jdh.adha.org/content/97/5/43

Qualified Health Centers, to expand dental care access. These partnerships can facilitate dental students' provision of care to patients either through privileges granted at the center or by renting space during off-hours. Collaboration allows for the recruitment of clients by the educational program, enhancing access to dental services for underserved populations.

- Special Olympics and their dental screening, preventative services, and educational program can provide an access point for dental education students to assess individuals with ID/DD and provide care in communities where clinical access points are limited.
- Dental education programs can leverage disability serving agencies in the community and provide screenings and assessments to clients of these programs, providing students with an opportunity to work with adults with ID/DD.

Barriers to Anesthesia and Surgical Care

Many individuals with ID/DD require general anesthesia or sedation to receive preventive oral health care due to anxiety and the inability to tolerate dental care, and therefore, must receive oral health care in a hospital or outpatient dental surgery setting. However, the impact of low reimbursement rates is starkly evident in the challenges faced by pediatric dentists and oral surgeons in accessing hospital operating rooms.

This issue has worsened during the COVID-19 pandemic and is expected to deteriorate further due to increasing case backlogs. Many hospitals cannot afford to grant operating room access to dentists at the Medicaid facility fee reimbursement rate in numerous states. Furthermore, reimbursement for dental procedures performed under general anesthesia is significantly lower compared to general surgical procedures, averaging just over $200 nationally compared to well over $2,000.[167]

Nationwide, dentists report delays in accessing operating rooms due to high demand for services compared with limited supply which results in people being placed on waiting lists, issues with accessibility, accommodation, affordability, acceptability, in office-based treatment settings, and inadequate training and reimbursement for dental providers. In addition, dental anesthesiologists have cited restrictive state regulation of equipment and transportation of sedatives as constraints for providing timely, appropriate dental care to those with developmental disabilities.[168]

Figure 13[169] below highlights a number of these barriers.

[167] Casamassimo, P., Czerepak, C., & Lee, J. Y. (2021). To work toward oral health care equity, start with Medicaid. *Journal of the American Dental Association (1939)*, *152*(7), 495–499. https://doi.org/10.1016/j.adaj.2021.04.002

[168] Williams, A.R., Yaqub, A., Glassman, P. & Phillips, V. (2023) Shortening-The-Line: Reducing the Need for Sedation and General Anesthesia for Dental Care for People with Disabilities, *Journal of the California Dental Association*, 51:1, DOI: 10.1080/19424396.2023.2253958

[169] Virginia Board for People with Disabilities. (2023). *Assessment of Virginia's Disability Services System: Accessibility of Dental Care.* Retrieved from https://www.vbpd.virginia.gov/downloads/Dental%20Care%20Assessment%202023-Final.pdf p. 24

FIGURE 13. DIFFERENT BARRIERS THAT LIMIT DENTAL PROVIDER ACCESS TO SEDATION AND ANESTHESIA

Adapted from Virginia Board for People with Disabilities, Assessment of Virginia's Disability Services System: Accessibility of Dental Care, Figure 9.

The Special Care Dentistry Association (SCDA) has acknowledged that many patients with ID/DD treated with sedation or general anesthesia could have preserved their oral health in other ways if alternative strategies had been available, utilized, and reimbursable.[170] Examples include the use of fluoride varnish, silver diamine fluoride (SDF), resin sealants, chlorohexidine, chemo-mechanical caries removal and atraumatic restorative treatment and behavioral and environmental modifications.[171] Additionally, for Nevada adults with ID/DD who have expanded Medicaid dental coverage, Nevada could expand reimbursement to cover teledentistry, house calls, and desensitization in alignment with guidance from the National Council on Disability to better care for this population.[172]

Dr. Alan S. Wong, an internationally renowned expert and trainer in special healthcare needs dentistry, has adapted the Special Olympics "Let me win, but if I cannot win, let me be brave at the attempt,"[173] to "Let me treat, but if I cannot treat, let me be brave at the attempt," to encourage dentists and hygienists to attempt care and treatment first, using minimally invasive techniques and behavior management strategies, before resorting to the use of anesthesia and surgical care, unless surgery is already necessary to address existing issues that cannot be treated in the office.

Patients with ID/DD are at increased risk for complications with sedation and anesthesia due to other medical comorbidities, abnormal gag reflexes, hyperextension resulting in lower oxygenation during treatment. Additionally, some patients experience complications due taking

[170] Williams, A.R., Yaqub, A., Glassman, P. & Phillips, V. (2023) Shortening-The-Line: Reducing the Need for Sedation and General Anesthesia for Dental Care for People with Disabilities, *Journal of the California Dental Association*, 51:1, DOI: 10.1080/19424396.2023.2253958
[171] Williams, A.R., Yaqub, A., Glassman, P. & Phillips, V. (2023) Shortening-The-Line: Reducing the Need for Sedation and General Anesthesia for Dental Care for People with Disabilities, *Journal of the California Dental Association*, 51:1, DOI: 10.1080/19424396.2023.2253958
[172] National Council on Disability (NCD). (2022). *Medicaid Oral Health Coverage for Adults with Intellectual & Developmental Disabilities – A Fiscal Analysis.* Retrieved from https://www.nccp.org/wp-content/uploads/2022/03/NCD_Medicaid_Report_508.pdf p. 49
[173] Special Olympics. Frequently Asked Questions. Retrieved from https://www.specialolympics.org/about/faq

multiple medications for their disability and related conditions, which can result in delayed recovery from sedation.[174]

Lack of Transportation

For many families with members who have ID/DD, and who are poor or low-income and therefore Medicaid eligible or enrolled, transportation barriers are a challenge, especially if they do not own a vehicle. Transportation can be even more challenging for those in wheelchairs without private transportation, as well as for rural individuals who have to travel long distances to find a Medicaid dentist who is also trained to treat adults with ID/DD. This, is coupled with the fact there are significant disparities in the prevalence of disability that exist by levels of urbanization within a state, with rural residents having the highest prevalence of disability, and the access of dental care being limited create notable challenges.[175]

In addition, many adults with ID/DD or their caregivers may not be aware that Medicaid covers rides, or non-emergency medical transportation, for eligible individuals to and from the doctor's office, the hospital, or another medical office for Medicaid-approved care. Coverage for these rides may differ depending on the individual's situation and needs.[176]

[174] Williams, A.R., Yaqub, A., Glassman, P. & Phillips, V. (2023) Shortening-The-Line: Reducing the Need for Sedation and General Anesthesia for Dental Care for People with Disabilities, *Journal of the California Dental Association,* 51:1, DOI: 10.1080/19424396.2023.2253958

[175] Zhao, G., Okoro, C. A., Hsia, J., Garvin, W. S., & Town, M. (2019). Prevalence of Disability and Disability Types by Urban-Rural County Classification-U.S., 2016. *American journal of preventive medicine*, *57*(6), 749–756. https://doi.org/10.1016/j.amepre.2019.07.022

[176] Centers for Medicare & Medicaid (CMS). *Fact Sheet. Let Medicaid Give You a Ride.* Retrieved from https://www.cms.gov/medicare-medicaid-coordination/fraud-prevention/medicaid-integrity-education/downloads/nemt-factsheet.pdf

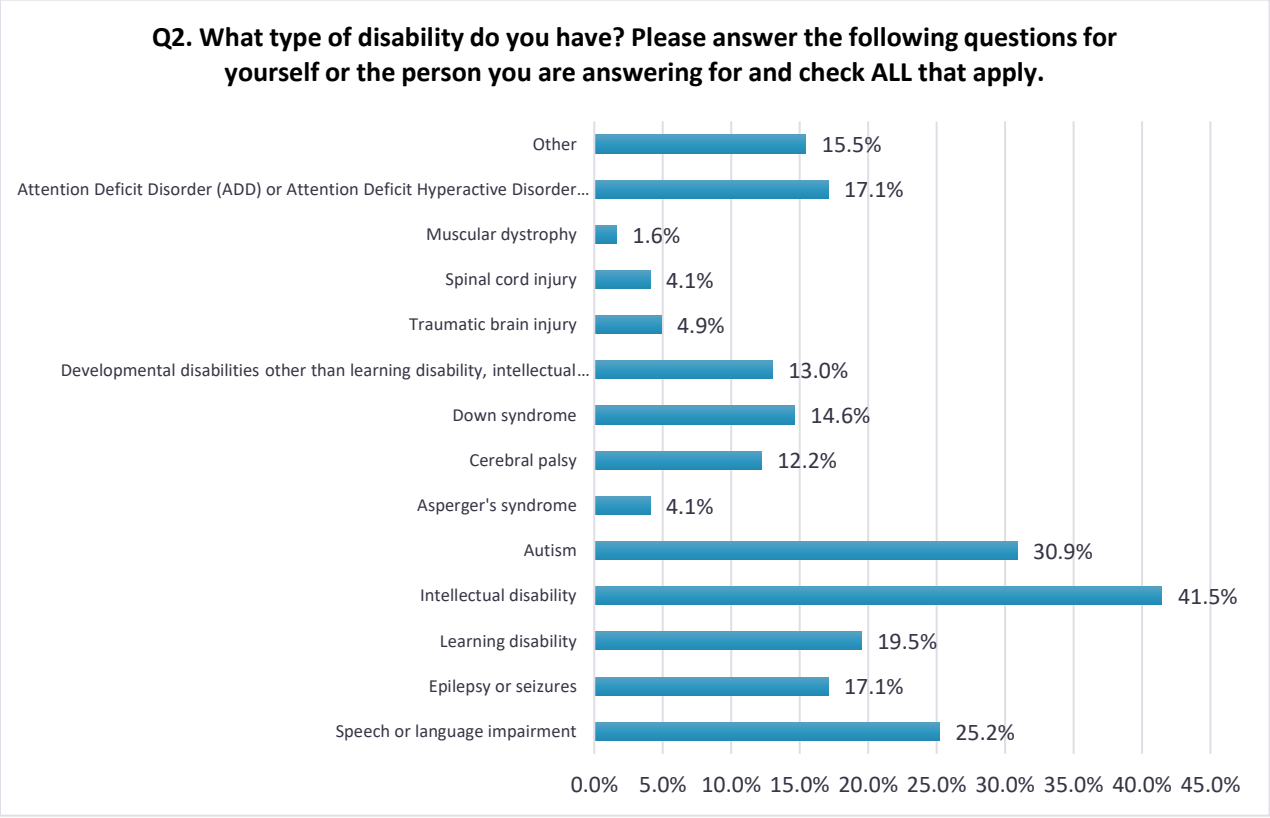
Nevada Individuals with Intellectual and/or Developmental Disabilities and Caregivers Survey And Interview Results

Key Survey Findings

The Individuals/Caregivers Survey was designed by the authors in collaboration with the Division of Health Care Finance and Policy, the Aging and Disability Services Division, and the Nevada Oral Health Program, and informed by an extensive literature review of peer-reviewed journal articles and other research reports and publications. The objective of the literature review conducted before the Individuals/Caregivers Survey was designed was to help the researchers better understand the oral health status of adults with ID/DD and the barriers to care faced by this vulnerable population. The survey was opened in May 2023 and was closed in March 2024. Survey Monkey was the survey tool used to disseminate the survey and analyze results.

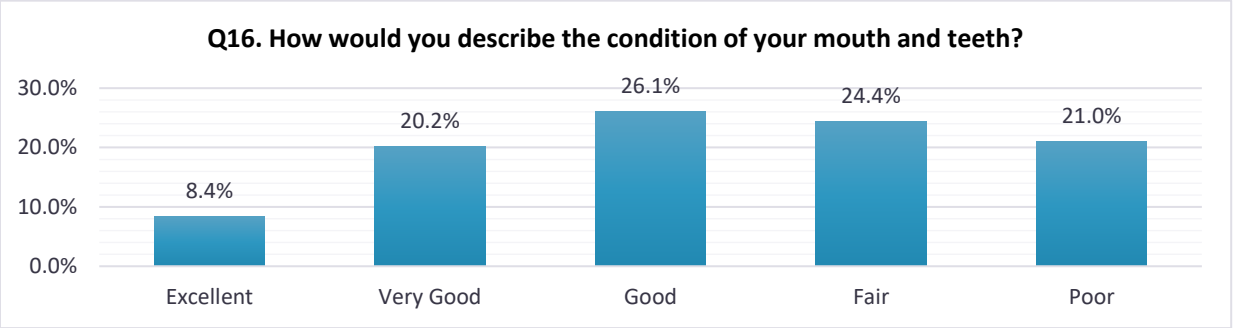
Of the 123 Nevadans who completed the survey, 29.3% were adults with ID/DD, 42.3% were parents, 18.7% were caregivers, and 9.8% responded as other. In addition, 47.2% of respondents indicated they were enrolled in the Medicaid Home and Community Based Services ID Waiver, 32.5% indicated they were not, and 20.3% indicated they did not know if they were enrolled. The largest percentage of respondents were from Clark County (50.4%), followed by Washoe County at 30.9%, Elko County at 4.1%, Douglas County at 2.4% and Lincoln, Lyon and Story Counties at 0.8% of total respondents. When asked for the type of disability, respondents could choose more than one disability, if appropriate. The breakdown of disabilities is shown in Graph 30.

Graph 30. Type of Disability



When asked how they would describe the condition of their mouth and teeth, respondents indicated that the condition was excellent (8.4%), very good (20.2%), good (26.1%), fair (24.4%) or poor (21.0%) (Graph 31).

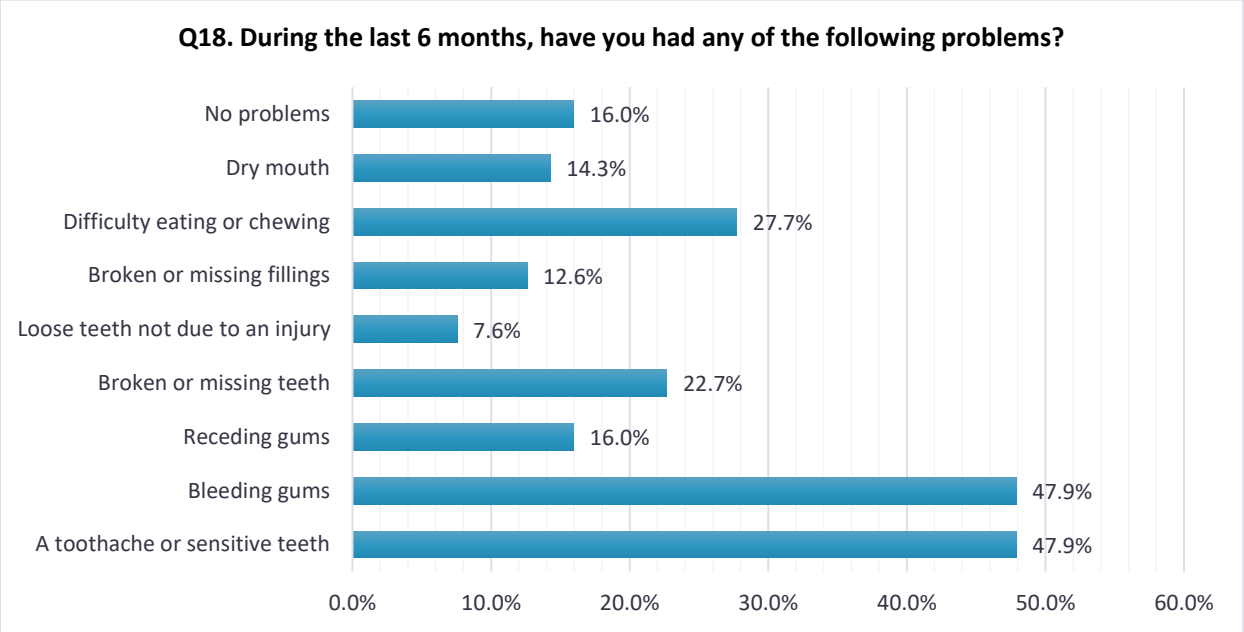
GRAPH 31. INDIVIDUAL WITH ID/DD REPORTED CONDITION OF MOUTH AND TEETH



When asked about their preventative oral hygiene routines at home, the majority of respondents (63.0%) indicated they brush their own teeth, while approximately 1 in 4 indicated that their parent/caregiver helps (37.0%) The majority of respondents (84.9%) brush their teeth daily, with 45.4% brushing twice a day and 39.5% brushing once a day, while 15.1% indicated they don't brush regularly. The majority of respondents do not floss regularly (39.5%) or cannot tolerate flossing (24.4%), while 18.5% indicated they floss once a day and 17.7% floss twice a day.

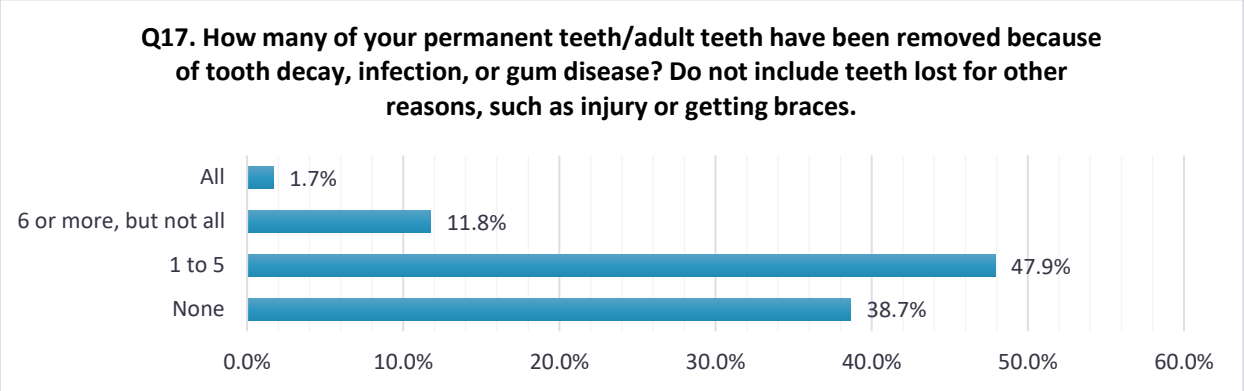
When asked about their oral health and what problems they had experienced during the last 6 months at the time of the survey, respondents indicated that they experienced a toothache or sensitive teeth (47.9%); bleeding gums (47.9%), difficulty eating or chewing (27.7%), broken or missing teeth (22.7%), receding gums (16.0%), dry mouth (14.3%), broken or missing fillings (12.6%), and loose teeth (7.6%) (Graph 32).

GRAPH 32. ORAL HEALTH PROBLEMS IN THE LAST 6 MONTHS



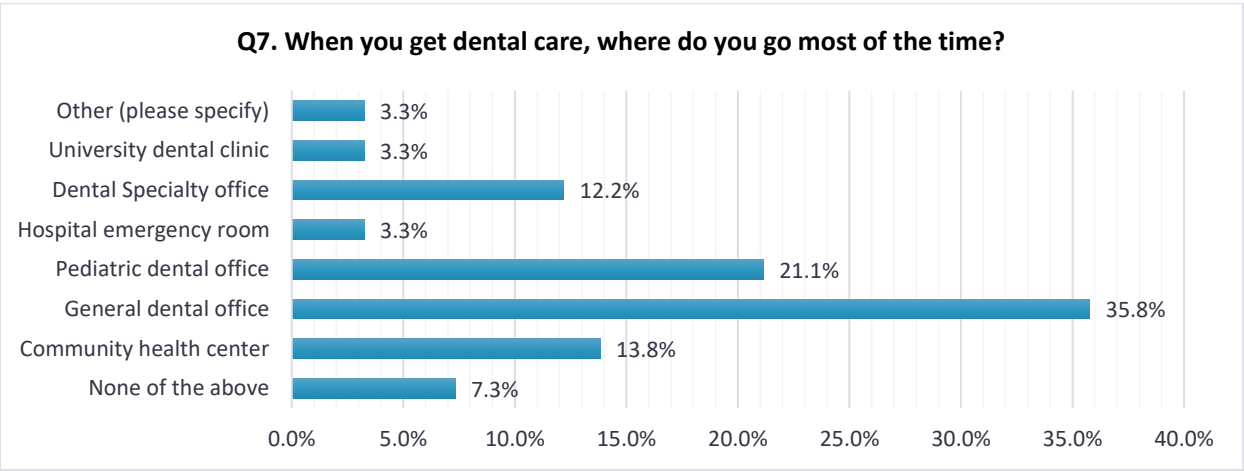
Notably, the majority of respondents (61.4%) indicated they had some form of tooth removal due to tooth decay, infection, or gum disease, including 47.9% indicated 1 to 5 removed; 11.8% indicated 6 or more but not all removed, and 1.7% indicated that all were removed, while 38.7% had no teeth removed (Graph 33).

GRAPH 33. NUMBER OF PERMANENT TEETH/ADULT TEETH REMOVED DUE TO TOOTH DECAY, INFECTION, OR GUM DISEASE



Of the 123 respondents, 63.4% indicated that they had a dentist that they see for care every year, 30.1% responded that they did not have a dentist they see every year, and 6.5% responded "other". Additionally, 56.1% said they had seen the dentist in the last 12 months, with 23.6% responding they had seen a dentist in the last 1-2 years, 10.6% within the past 5 years, and 8.1% more than 5 years ago. When asked in what setting they mostly received care, responses included those seen in Graph 34 below:

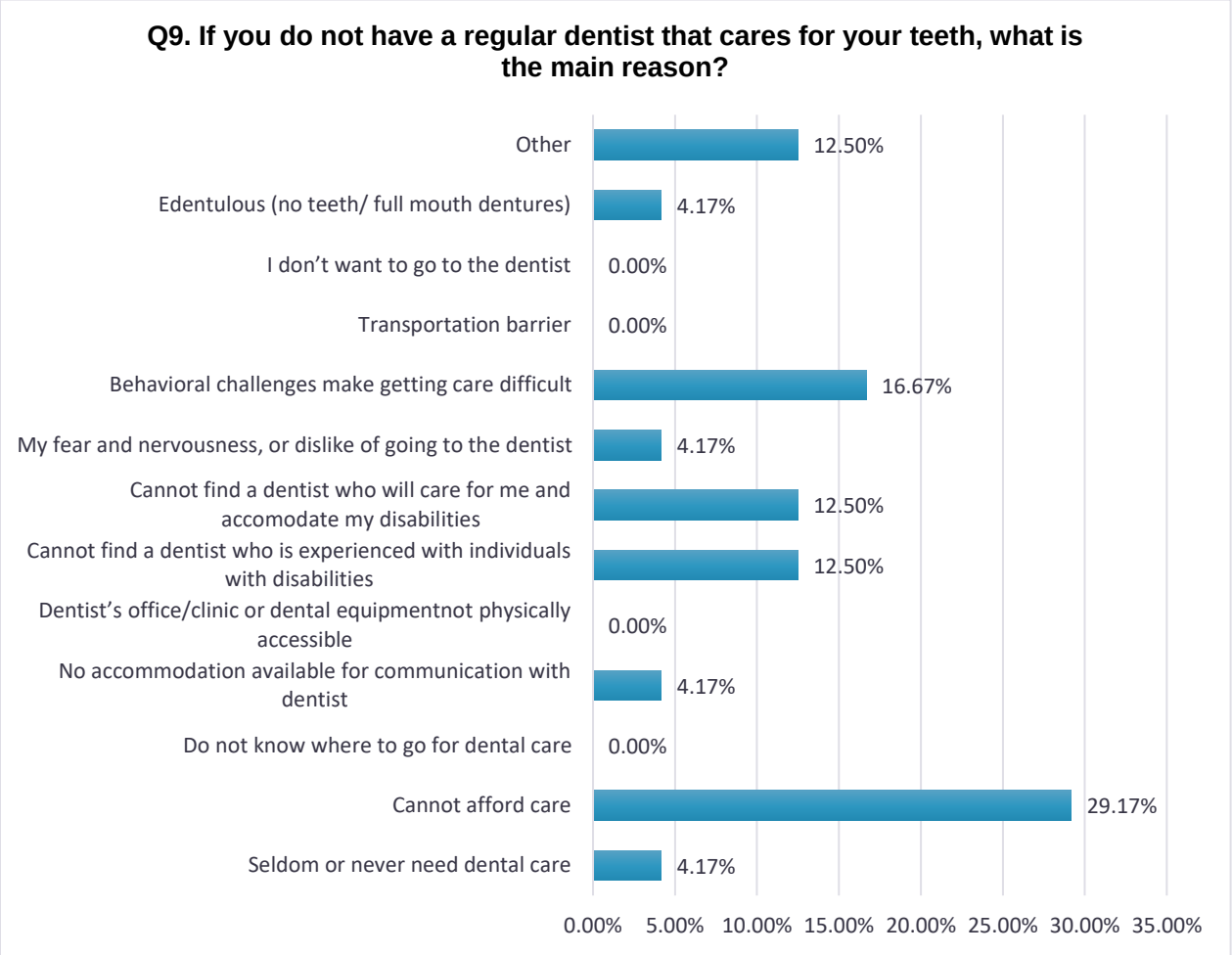
GRAPH 34. DENTAL VISIT LOCATIONS



Of the respondents that indicated that they did not have a regular dentist to care for their oral health, almost one-third (29.2%) indicated that they cannot afford care as the main reason they did not have a regular dentist that cares for their teeth. Behavioral challenges (16.7%) was the next highest chosen reason (Graph 35). Respondents who chose "Other" (12.5%) commented: all of the above, no dentist to take or provide care for Medicaid and Medicare, no health insurance

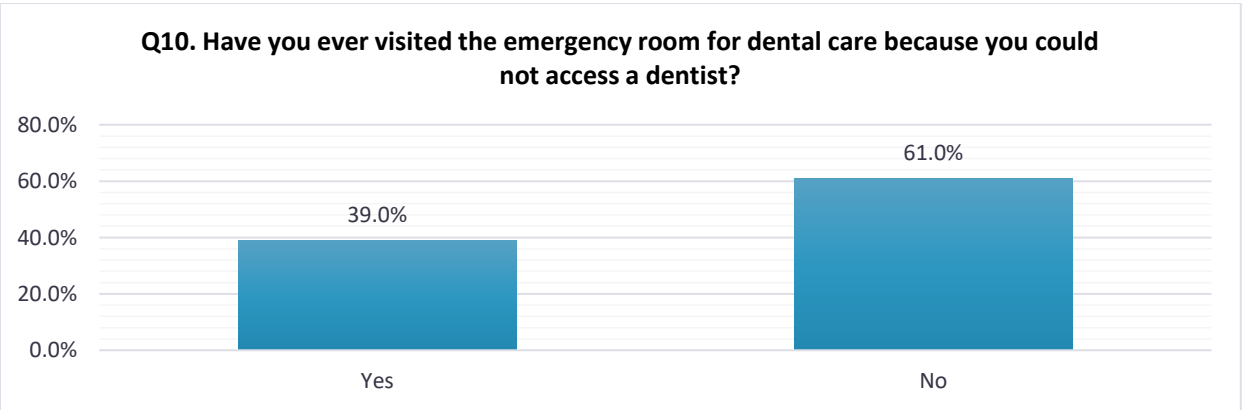
coverage from Medicaid and Medicare, needs a lot of dental work that waiver does not cover, no dental insurance.

GRAPH 35. REASONS FOR NOT VISITING THE DENTIST



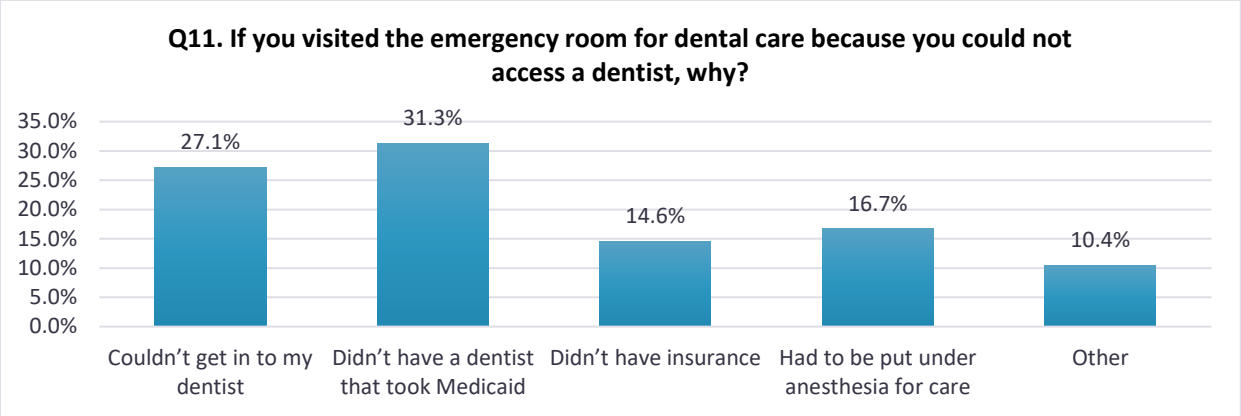
Approximately 1 in 4 (39.0%) have visited the emergency room for dental care because of the inability to access a dentist for care (Graph 36).

GRAPH 36. VISITS TO EMERGENCY ROOM TO ACCESS CARE



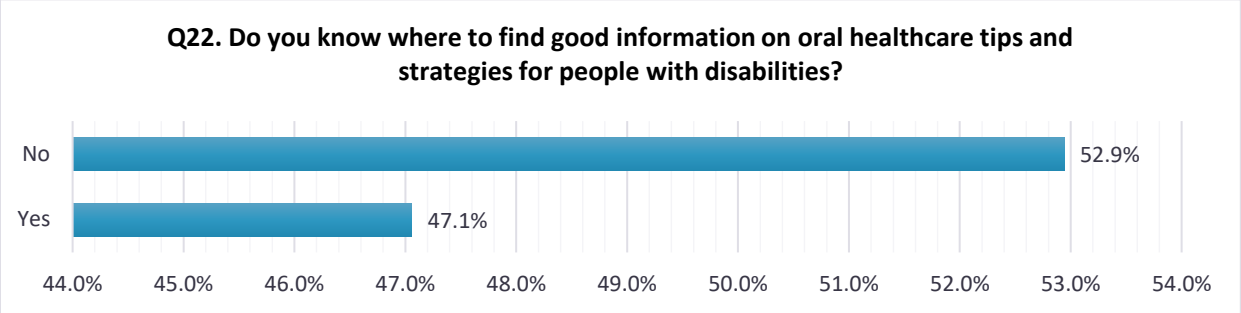
The main reasons individuals indicated for visiting the emergency room for dental care was they didn't have a dentist that took Medicaid (31.3%), they couldn't get into their dentist (27.1%), they had to be put under anesthesia (16.7%) or they didn't have insurance (14.6%) (Graph 37). Respondents who chose "Other" (10.4%) commented: all of the above, admitted through emergency room for psychosis and diagnosed with severe gingivitis, to have teeth pulled, for an infection/abscess, and was forced to allow the dental condition to become worse before it was treated.

GRAPH 37. REASON FOR VISITING THE EMERGENCY ROOM



Over half of respondents (52.9%) did not know where to find good information on oral healthcare tips and strategies for people with disabilities (Graph 38).

GRAPH 38. KNOWING WHERE TO FIND GOOD INFORMATION ON ORAL HEALTH CARE



INTERVIEW FINDINGS

A total of 41 interviews were conducted across the state, 23 in English and 18 in Spanish. Of the English interviewees, 11 participants were adults with ID/DD, 29 were parents or caregivers.

It is important to note that while the needs of the participants who only speak Spanish and the ones who speak English are very similar or the same in most issues, the language barrier is a unique challenge for the Spanish speaking interview participants. For Spanish speaking parents who did not speak English, or felt more comfortable communicating in Spanish, if their adult children were nonverbal, it created a significant barrier that hindered communication between the parent/guardian and the dental professionals. In addition, they shared that there is a lack of sensitivity in helping them fill out paperwork if they do not understand what is required.

Nevada Interview findings include:

- Most caregivers and persons with ID/DD shared that their smile is important because it helps them connect to others; without dental care, that is not possible.
- 15 reported good or fair dental health; 11 had major dental health issues,
- 12 participants reported having precarious dental health, including the need to be sedated for routine exams.
- 28 participants reported brushing daily, some struggled with doing so and needed close supervision from caregivers or caregiver assistance.
- 3 reported not being able to brush their teeth
- All participants shared that flossing is difficult due to sensory issues or other mobility limitations.
- The most reported challenges related to their disability were sensory, behavioral, and having limitations due to mobility, tremors, or being in a wheelchair.
- Most experience fear or stress during dental visits. Caregivers shared that proceeding with X-rays is difficult and creates a lot of anxiety.
- 22 of the 38 reported access to and using special or electric toothbrushes.
- 18 of the participants reported having a dentist that they visit regularly, and 20 of them do not have access to a regular dentist due to a variety of reasons: not having insurance, financial hardship, lack of training from the dentist part, or lack of a conducive environment in the dental office.
- Some caregivers reported that they never had to take their loved ones to the operating room for general anesthesia due to dental pain, while others visited the operating room several times to access care. In many cases, accessing the operating room for anesthesia is not easy and costly.
- While some caregivers felt they had enough information and training to assist their loved one, most participants feel that they need more information and help to take care of their or their loved ones' dental needs. Specifically, Spanish speaking participants requested access to more information in Spanish and access to training and education about helping their children with sensory issues.
- Parents and caregivers would like access to a list of providers that treat people with ID/DD, more access to dentists who accept Medicaid, information about caring techniques and special toothbrushes for their children, and more empathetic, trained, and compassionate.

Data from our surveys and interviews align with national findings. Key themes from national and Nevada interviews include:

- Experiencing financial barriers to accessing dental care.
- Experiencing behavioral challenges that make getting care difficult and experiencing anxiety about going to the dentist.
- Finding a dentist who takes Medicaid and is trained and willing to care for adults with ID/DD is a serious challenge.
- Many interviewees stated they had to visit the emergency room for dental care because of the inability to access a dentist for care or afford the dental care out of pocket costs.

- Needing sedation or general anesthesia for dental treatment and experiencing barriers accessing sedation and anesthesia.
- Accessing high-quality dental care from a provider trained to care for their loved one is a challenge in the community.
- It was common for adults with ID/DD to have teeth removed due to tooth decay, infection, or gum disease, and to report the condition of the mouth as fair or poor.
- Oral health disease impacts included oral health problems including toothache or sensitive teeth, bleeding gums, difficulty eating or chewing, and broken or missing teeth.
- The majority of interviewees reported difficulty flossing.

QUOTES FROM NEVADA INDIVIDUALS WITH ID/DD AND THEIR CAREGIVERS

"I haven't been to the dentist in 5 years. I need braces, dental cleaning, and X-rays; I have cavities that probably need root canals and fillings. I live with severe pain. I live on social security and have straight Medicaid, and because I'm 26 years old, I have to pay out of pocket. I don't have money for that, but I only make $914.00 per month, so it is difficult to face the cost of my dental needs." (Adult with ID/DD)

"We need more caring dentists to help adults with disabilities; we need special attention, and normal dentists are not as nice and talk too fast. They can be scary." (Adult with ID/DD)

"In 2013, I had an abscessed tooth. As you know, an abscessed tooth is a painful infection at the root of a tooth. The dentist recommended that the tooth be extracted. The dentist felt I would benefit from having the tooth extracted during outpatient surgery under general anesthesia. I agreed that I did not wish to be awake for this procedure as it caused me a lot of anxiety. I was experiencing a lot of pain and wanted to have the tooth removed as quickly as possible. While working with the dentist's staff to schedule this procedure, we were told that the first possible date would be at least five months away. We were told that because I was my own guardian, only one facility in town would honor that and that there was only one anesthesiologist in Reno who would work with an individual with intellectual developmental disabilities who have their own guardianship. I was devastated that I would have to wait that long to have this infected tooth removed." (Adult with ID/DD)

"We need more caring dentists to help adults with disabilities; we need special attention, and normal dentists are not as nice and talk too fast. They can be scary." (Adult with ID/DD)

"All individuals with ID/DD should be covered for life. Dental problems are an indicator of bigger physical health issues. Why does it have to get to that point? Preventative care is a must! My son has major behaviors where he beats himself up, beats me up, has seizures all day long, etc. How am I supposed to work? My husband doesn't have insurance, so how are we supposed to get insurance for our son outside of Medicaid? My son doesn't speak very well, so when he beams his beautiful smile, others can see how soft and kind he is."

"Finding a Medicaid dentist who gives the same attention to adults on the spectrum will be difficult, if not impossible. The sensory issue is the hardest for normal dental offices to deal with; they are not educated in sensory issues." (Caregiver)

"Dentists need training from the time they are in dental school. The importance of our population being treated as human beings, not others. We need training for sedation!" (Caregiver)

"My son has been at the same dentist since he was 1. He is 22, and I have just been told that dental visits are no longer covered. There is a waiting list for the waiver, and I now have to search for an adult dentist. What am I supposed to do? How does the state cut off dental care for an individual at a certain age, but the parents are unaware of this? Nobody tells the parents!" (Caregiver)

"If Medicaid does not even cover preventative, then why would I even take him in? I am shocked that Medicaid/Medicare does not pay for preventative dental care. He is still seeing a pediatric dentist (he is 30 years old). I get overwhelmed with the thought of how he would even get into a dentist's office. He can't get out of his wheelchair, so finding a dentist to accommodate him would be daunting." (Caregiver)

"More training is needed for dentists to understand the patient with Autism. Adults with Autism have the right to seek services from an adaptive trained professional." (Caregiver)

"Our loved ones deserve to have healthy teeth and gums, and there can often be sensory issues, fine motor skill issues, and other barriers for individuals with disabilities. This is another area where people need to understand that there should not be a disparity in level and access to care. There can be different struggles, and dental is not an area where there seems to be much support or help for families." (Caregiver)

"Please give us more options for our children and adults with disabilities. Please make it mandatory for these specialists to take training so that they understand how to treat individuals with disabilities while making an experience that should be easier make it very difficult. Please give us more coverage, especially those with Medicare with disabilities, because we don't have many options, and please have empathy for our children with autism." (Caregiver)

"Everything is so difficult for individuals with IDD during these few years of transition into adulthood. Why does one more thing have to be a struggle? Everything from financial barriers to special needs trusts to guardianship/supported decision making, housing availability limitations, lack of work opportunities and day programs, and healthcare transition. Everything is a struggle beyond the age of 22 for individuals with IDD. Give them one thing that is covered and can protect their health." (Caregiver)

ORAL HEALTH PROVIDER SURVEY RESULTS

SURVEY RESULTS

The Every Smile Matters Nevada Provider Perspectives Surveys was conducted on behalf of the Nevada Division of Health Care Finance and Policy as part of a larger initiative that includes a Needs Assessment, secondary and primary research on barriers, gaps and needs of adults with intellectual and/or developmental disabilities (ID/DD) in Nevada, and strategies to improve oral health outcomes for this underserved population.

This survey was informed by a wide ranging and extensive literature review of peer-reviewed journal articles and other research reports and publications on national provider perspectives on their readiness to provide care to adults with ID/DD, barriers to providing care in office as well as in a surgical setting, the benefits of specific education on caring for this population and the extent to which providers felt they received adequate training during their educational program, the benefit of continuing education and their participation in Medicaid, and barriers to enrolling as a Medicaid provider.

Every Smile Matters surveyed dentists to understand the following:

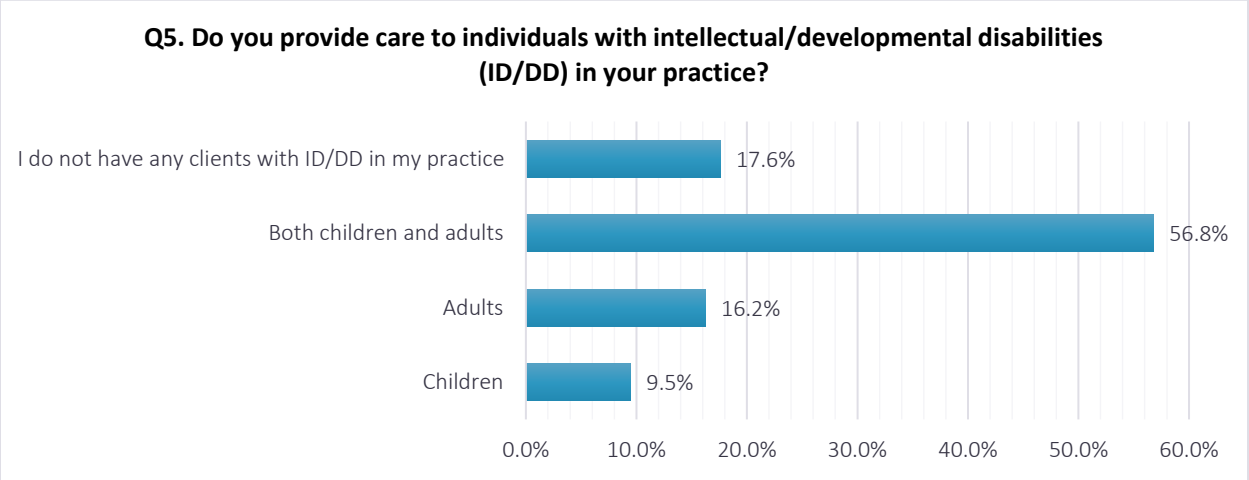
- The perceptions and readiness of oral health providers to provide care to adults with ID/DD;
- The barriers to the provision of preventative care and treatment to adult with ID/DD;
- The benefit of continuing education specific to caring for people with intellectual disabilities;
- The benefit of the two Nevada continuing education courses provided by Dr. Alan Wong on this topic specifically if they attended; and
- The perspectives on enrolling as a Medicaid provider as well as barriers to joining the Medicaid network.

A total of 148 Nevada oral health providers completed the survey, who were mostly from Clark and Washoe County, 40.5% and 43.2% respectively. Others were from Carson City (10.1%), Douglas County (3.4%), Lyon County (2.0%), and Nye County (0.7%)

Providers who completed the survey were mostly Hygienists (68.2%), General Practice Dentists (19.6%), and Pediatric Dentists (6.1%). Over half of the providers (54.7%) reported they had been in practice for 10+ years. The majority of providers were either from a private dental practice (67.8%), an educational supported practice (providing are at a dental school or residency) (12.8%), or a public supported practice (FQHC, community, etc.).

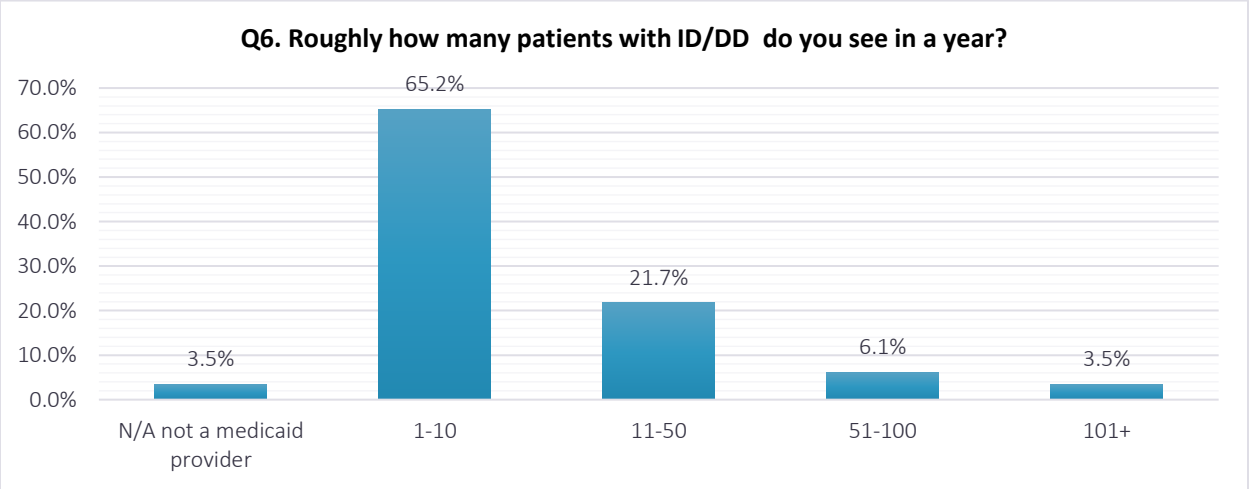
Over half of the providers (56.8%) indicated that they care for both children and adults with ID/DD, while 16.2% care for adults only; 9.5% care for children only; and 17.6% do not have any clients with ID/DD in their practice (Graph 39). Of the providers that provide dental care for individuals with ID/DD, 65.2% see between 1-10 patients with ID/DD per year; 21.7% see between 11-50 patients with ID/DD per year, 6.1% see between 51-100 patients with ID/DD per year; and 3.5% see between 101+ patients with ID/DD per year.

GRAPH 39. PROVISION OF DENTAL CARE



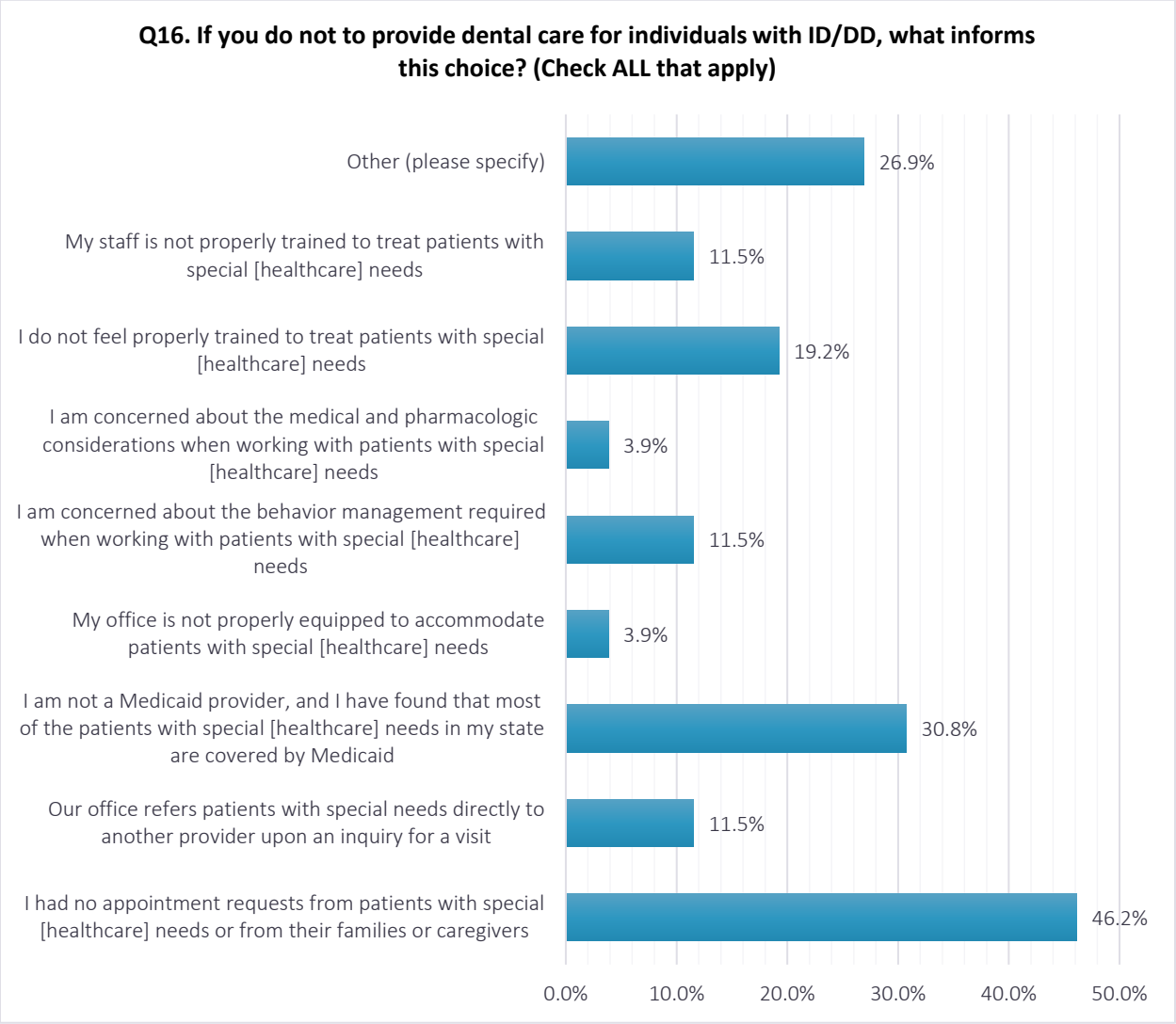
Of the providers that provide dental care for individuals with ID/DD, 65.2% indicated that they see between 1-10 patients with ID/DD per year; 21.7% see between 11-50 patients with ID/DD per year, 6.1% see between 51-100 patients with ID/DD per year; and 3.5% see between 101+ patients with ID/DD per year (Graph 40).

GRAPH 40. NUMBER OF PATIENTS WITH ID/DD SERVED IN A YEAR



Providers indicated the reasons for not providing dental care for individuals with ID/DD was that there were no appointment requests from patients with ID/DD or their caregivers/families (46.2%) they were not a Medicaid provider (30.8%), they felt they were not properly trained to treat patients with special [healthcare] needs (19.2%); their staff is not properly trained to treat patients with special [healthcare] needs (11.5%); they are concerned about the behavior management required when working with patients with special [healthcare] needs (11.5%); their office refers patients with disabilities or special healthcare needs directly to another provider upon and inquiry for a visit (11.5%); their office is not properly equipped to accommodate patients with special [healthcare] needs (3.9%); and they are concerned about the medical and pharmacologic considerations when working with patients with disabilities (3.9%) (Graph 41).

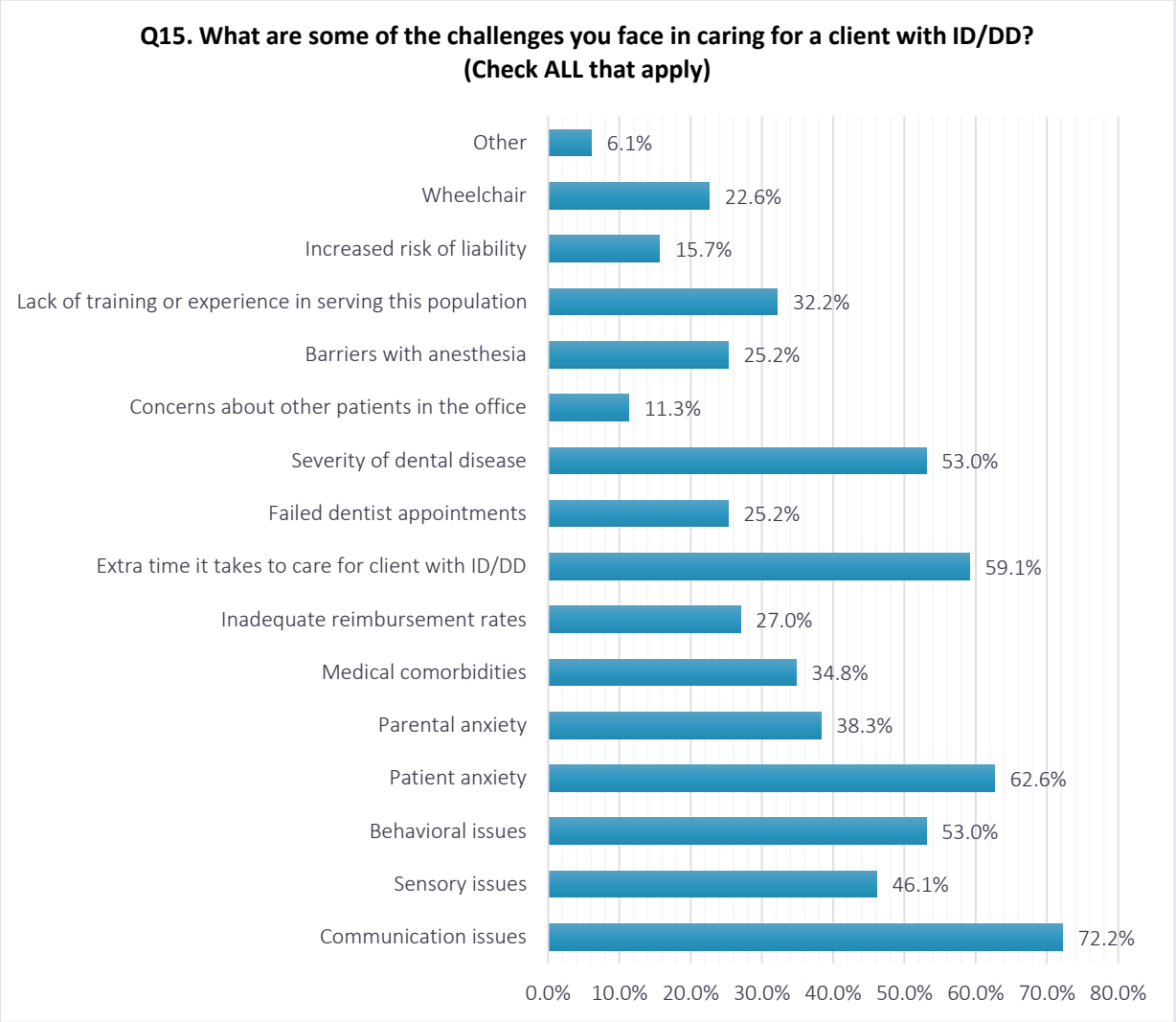
GRAPH 41. REASONS FOR NOT PROVIDING DENTAL CARE FOR INDIVIDUALS WITH ID/DD



Providers indicated that the main challenges faced in caring for a client with ID/DD were communication issues (72.2%), patient anxiety (62.6%), extra time it takes to care for clients with ID/DD (59.1%), behavioral issues (53.0%), severity of dental disease (53.0%), sensory issues (46.1%), parental anxiety (38.3%), medical comorbidities (34.8%), and lack of training to serve this population (32.2%).

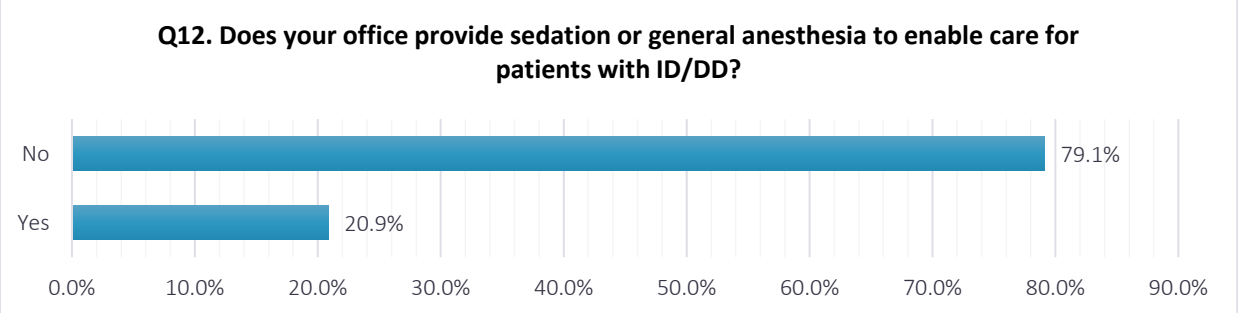
Other reasons included inadequate reimbursement rates (27.0%), barriers to anesthesia (25.2%), failed dentist appointments (25.2%), wheelchair (22.6%), increased risk of liability (15.7%), and concerns about other patients in the office (11.3%) (Graph 42).

GRAPH 42. CHALLENGES FACED BY DENTAL PROVIDERS IN TREATING CLIENTS WITH ID/DD



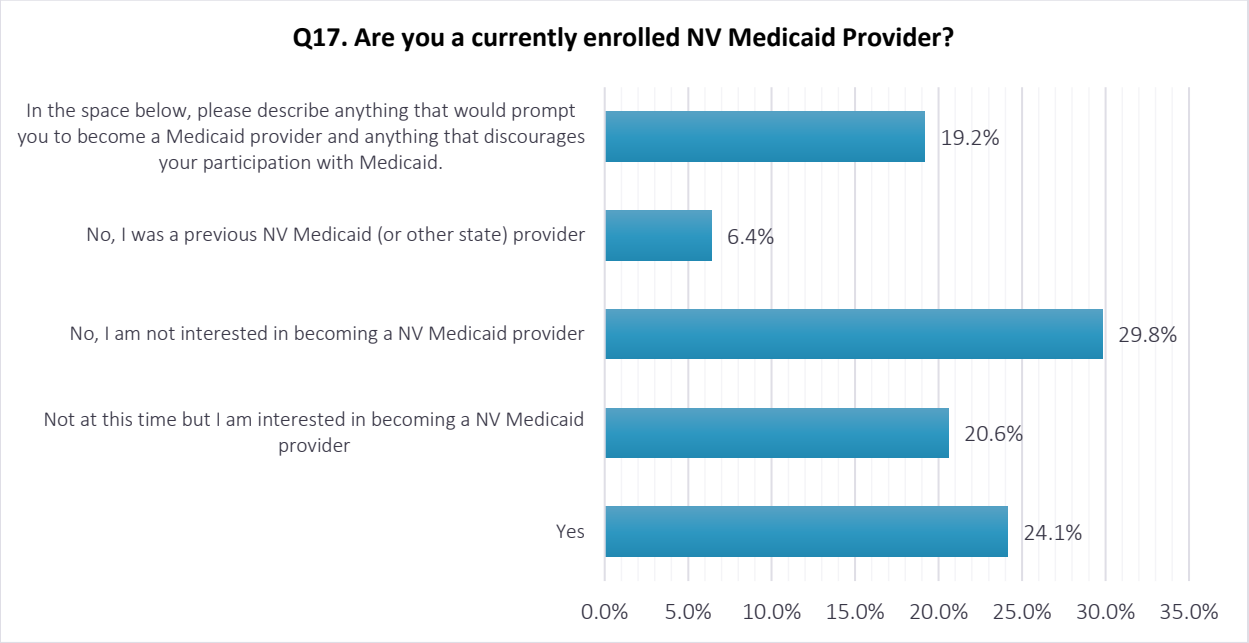
The majority of providers (79.1%) indicated that they do not provide sedation or general anesthesia to enable care to patients with ID/DD (Graph 43).

GRAPH 43. PROVISION OF SEDATION OR GENERAL ANESTHESIA



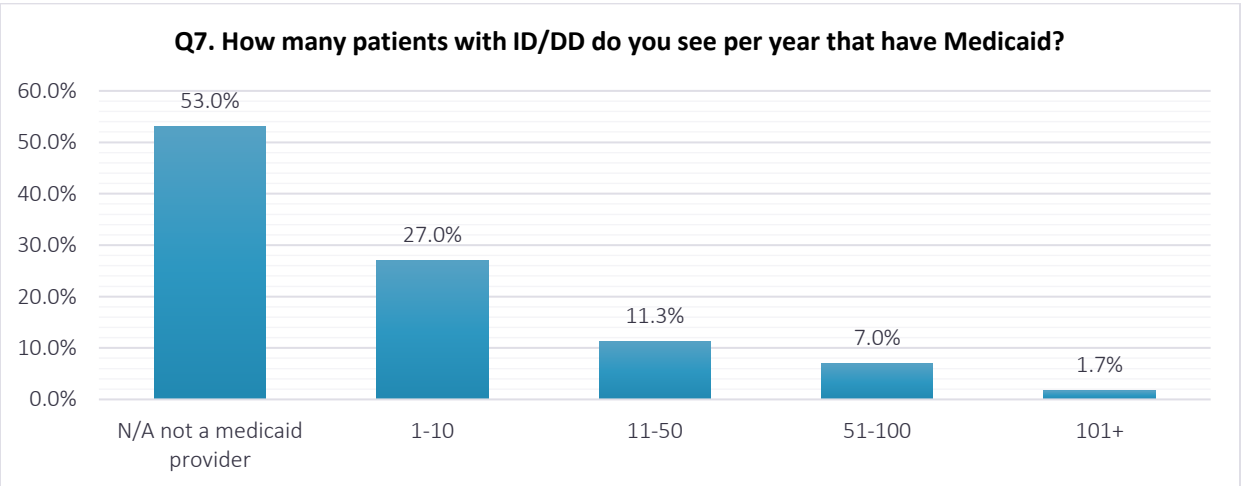
Approximately 1 in 4 providers (24.1%) indicated that they are currently enrolled in NV Medicaid, 20.6% indicated that they are not enrolled but interested in becoming a NV Medicaid provider, and almost 29.8% indicated that they are not currently in NV Medicaid and are not interest in becoming a NV Medicaid provider (Graph 44).

GRAPH 44. ENROLLMENT IN NV MEDICAID



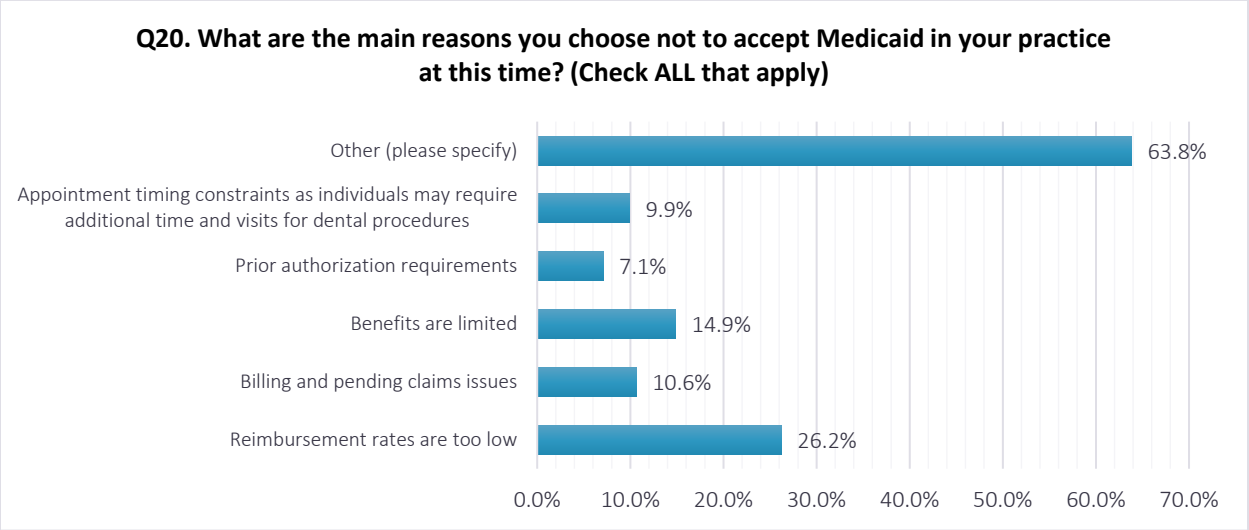
Over half of providers (53.0%) indicated that they are not a Medicaid provider. For those who are currently Medicaid providers, 27.0% indicated that they see 1-10 patients with ID/DD per year that have Medicaid; 11.3% see 11-50 patients with ID/DD per year that have Medicaid; 7.0% see patients with ID/DD per year that have Medicaid; and 1.7% see patients with ID/DD per year that have Medicaid (Graph 45).

GRAPH 45. NUMBER OF PATIENTS WITH MEDICAID SERVED IN A YEAR



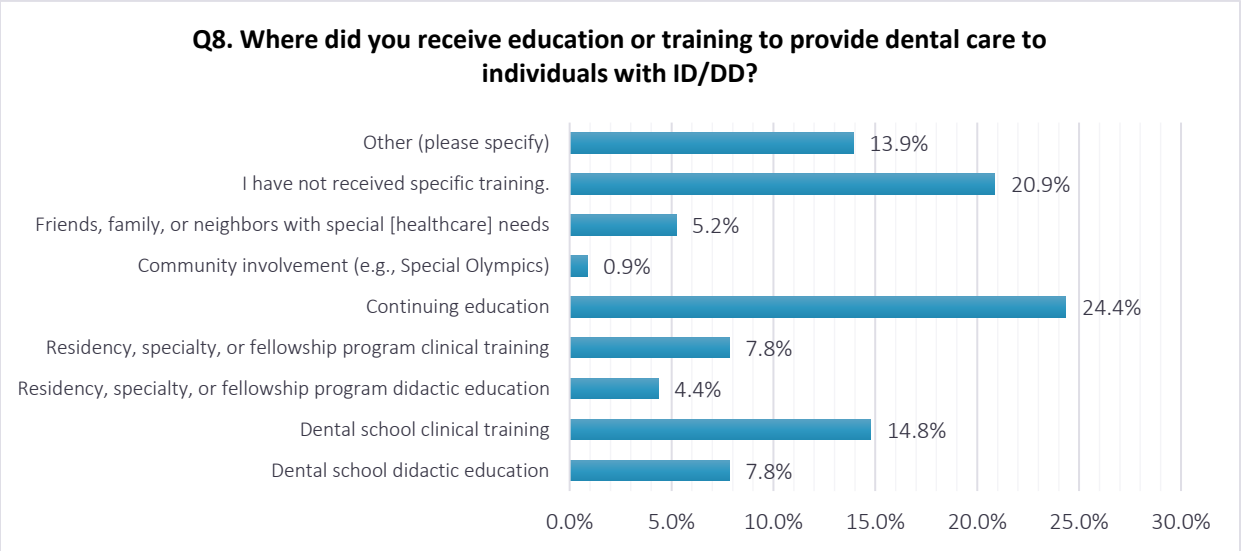
Providers indicated that one of the main reasons for not choosing to accept Medicaid in their practice was reimbursement rates are too low (26.2%), benefits are limited (14.9%), billing and pending claims issues (10.6%), appointment timing constraints as individuals may require additional time and visits for dental procedures (9.9%), and prior authorization requirements (7.1%) (Graph 46). For those who chose "Other", comments included: limited adult benefits, office does not accept Medicaid, high no-show rates, don't take insurance in education setting, we see Medicaid patients below 21 years old, and decision of dentist.

GRAPH 46. REASONS FOR NOT CHOOSING TO ACCEPT MEDICAID IN THE DENTAL PRACTICE



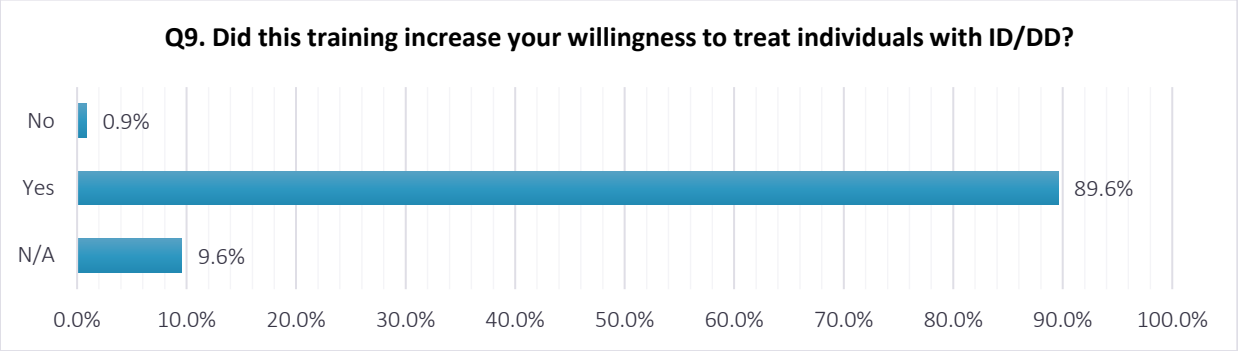
Providers that care for individuals with ID/DD received training through continuing education (24.4%); dental school clinical training (14.8%); dental school didactic education (7.8%); residency, specialty, or fellowship program clinical training (7.8%); while 20.9% did not receive specific training (Graph 47).

GRAPH 47. LOCATION OF DENTAL CARE EDUCATION AND TRAINING



Nine out of ten (89.6%) providers who received training reported an increase in the willingness to treat individuals with ID/DD (Graph 48).

GRAPH 48. INCREASE IN WILLINGNESS TO TREAT INDIVIDUALS WITH ID/DD DUE TO TRAINING



Data from our surveys align with national findings, in that providers demonstrate motivation to care for individuals with ID/DD but many feel unprepared to provide the level of care needed due to lack of specific education during dental programs, and barriers including managing behavior and addressing issues related specifically to the patients primary disability and comorbidities. Key themes found in the Nevada oral health provider survey include:

- Barriers noted were provider concerns about how to manage challenging behaviors, patient anxiety, communication and sensory issues, medical comorbidities.
- Reasons for not providing dental care for individuals with ID/DD included not feeling properly trained to treat patients with special needs; staff is not properly trained to treat patients with special needs; being concerned about the behavior management required when working with patients with special needs; office is not properly equipped to accommodate patients with special needs; and being concerned about the medical and pharmacologic considerations when working with patients with disabilities.
- Nearly 21% of the respondents reported they did not receive training during their dental education to work with people with ID/DD, lack of training to care for individuals with ID/DD during their educational program, and 24.4% reported they received their training through continuing education courses.
- The majority of providers who cared for patients with ID/DD cared for 1-10 patients per year.
- Poor Medicaid reimbursement rates and limited benefits are main reasons for not choosing to accept Medicaid. Other reasons include prior authorization requirements, billing and pending claims issues, and appointment timing constraints.
- Receiving training and education to serve this population increases provider confidence to provide care, with nearly 90% of respondents reporting that the continuing education course they attended taught by Dr. Alan S. Wong in Reno and in Las Vegas, increased their willingness to treat individuals with ID/DD.

QUOTES FROM PROVIDERS

Question 10 from the survey asked oral health providers, *"What motivates you to provide dental care to individuals with extra needs/disabilities?"* A sample of the responses is included below:

"I have always loved this population. It is always my goal to have the patient leave happier than when they walked in. Helping this population be more motivated in their oral care is definitely a bonus."

"I think everyone should have access to dental care, especially preventative care."

"Everyone needs care, and it shouldn't be dictated by insurance."

"I feel this is an underserved community, but their needs are just as important as any other patient demographic."

"I have always had a special place in my heart for this population. I am always filled with gratitude to be a part of creating better health for all my patients, but especially those that may not have a voice."

"Helping give them build confidence about being in the dental office and to help improve their quality of life."

"People with intellectual disabilities urgently need access to care."

"The simple fact that I might be able to provide a positive experience and contribute to better oral health for any patient in my chair."

"I would like to reach out to, educate, and improve the oral health of anyone who has not been properly taught, who has not been treated with compassion or respect. I feel every human being deserves to have a healthy smile, no matter their race, gender, religion, social status, or their physical appearance."

NEEDS ASSESSMENT KEY FINDINGS

The key findings from the research conducted from this needs assessment includes:

- "***Oral health care represents the greatest unmet health care need***"[177] for adults with ID/DD across the United States, who consistently rate the unmet need for dental care as greater than the unmet needs for physical health or mental health care.
- People with disabilities are the largest unrecognized minority group in the United States, making up more than 27% of the population.[178]
- In 2022, there were 228,683 Nevadans ages 18-64 with any type of disability, and 95,639 adults with ID/DD.[179]
- Adults with ID/DD have a high burden of oral disease[180] made worse by comorbidities and other conditions.[181]
- Adults with ID/DD in Nevada experience significantly higher rates of poverty at 22.6% versus 10.7% for people without a disability, making out-of-pocket costs for dental care a significant barrier.[182]
- Working-age individuals with cognitive disabilities in Nevada are employed at lower rate (43.1%) compared to their nondisabled counterparts (78.3%).[183]
- Using the most conservative estimate of 38%, 36,434 Nevada adults with ID/DD rely on Medicaid (38% of the 95,639 adults with ID/DD less the 2,967 on the ID Wavier).
- An estimated 33,376 Medicaid enrolled Nevada adults with ID/DD not on the ID Waiver still do not have access to Medicaid basic preventative dental benefits.
- Only 2,967 adults with ID/DD in Nevada who are on the ID Waiver have access to expanded dental benefits, leaving 33,467 without dental benefits.
- Rural residents were more likely to experience disability than their urban counterparts (14.7% versus 12.6%)[184] and have poorer health outcomes, and face additional health barriers. In Nevada's rural and frontier regions, access to oral health care due to provider shortages and transportation challenges is even more challenging.
- Roughly 41% of adults with ID/DD are known to or served by their state DD agency[185], in Nevada, the Aging and Disabilities Services Division, meaning an estimated 59% of adults with ID/DD are not being connected to services they could benefit from, and often not being

[177] Chavis, S. E., & Macek, M. (2022). Impact of disability diagnosis on dental care use for adults in the United States: Status matters. *Journal of the American Dental Association (1939)*, *153*(8), 797–804. https://doi.org/10.1016/j.adaj.2022.03.002

[178] National Institutes of Health. (2022). Advisory Committee to the Director Working Group on Diversity Subgroup on Individuals with Disabilities. *REPORT*. Retrieved from https://acd.od.nih.gov/documents/presentations/12092022_WGD_Disabilities_Subgroup_Report.pdf p. 8

[179] American Community Survey (ACS). 2022 1-year Estimates. Table S1810. Disability Status

[180] Morgan, J. P., Minihan, P. M., Stark, P. C., Finkelman, M. D., Yantsides, K. E., Park, A., Nobles, C. J., Tao, W., & Must, A. (2012). The oral health status of 4,732 adults with intellectual and developmental disabilities. *Journal of the American Dental Association (1939)*, *143*(8), 838–846. https://doi.org/10.14219/jada.archive.2012.0288

[181] Williams, A.R., Yaqub, A., Glassman, P. & Phillips, V. (2023) Shortening-The-Line: Reducing the Need for Sedation and General Anesthesia for Dental Care for People with Disabilities, *Journal of the California Dental Association,* 51:1, DOI: 10.1080/19424396.2023.2253958

[182] Cornell University. *2022 Disability Status Report. Nevada*. Retrieved from https://www.disabilitystatistics.org/report/pdf/2022/2032000 p. 43

[183] Cornell University. *2022 Disability Status Report. Nevada*. Retrieved from https://www.disabilitystatistics.org/report/pdf/2022/2032000 pp. 32-37

[184] U.S. Census Bureau. (2023). *Disability Rates Higher in Rural Areas Than Urban Areas.* Retrieved from https://www.census.gov/library/stories/2023/06/disability-rates-higher-in-rural-areas-than-urban-areas.html

[185] Centers for Medicare & Medicaid Services (CMS). *State Spotlights: Supporting Adults with Intellectual and Developmental Disabilities and Their Aging Caregivers.* Retrieved from https://www.medicaid.gov/sites/default/files/2023-05/3-1_Adults_with_IDD_State_Spotlights-508%5B95%5D.pdf p. 1

counted in state surveillance or service data, as most adults with ID/DD are "counted" in datasets as a result of the provision of publicly funded services and supports.

- The proportion of working-age adults with disabilities enrolled in Medicaid is more than double that of those without disabilities.[186]
- The financial burden of dental care, including not having dental insurance and therefore high out-of-pocket costs, is consistently listed as the number one factor when assessing barriers to good oral health for adults with ID/DD. [187]
- Financial barriers cause many individuals to forego preventative and restorative oral health care, leading to more severe oral health disease, increased pain, decreased wellness and health, and lower quality of life.[188]
- In states like Nevada that do not provide basic dental benefits to adults on Medicaid, individuals without dental insurance often end up using the emergency room for care.[189]
- Households with a person with an intellectual disability visit the emergency department (ED) at three times the rate of households who do not include a person with ID/DD.[190]
- ED care for non-traumatic dental conditions costs an average $1,286.33 per visit versus $90-$200 in the dental office,[191] and does not solve the problem, as ERs typically only prescribe antibiotics and pain medication, including opioids, and refer the patient back to the community for dental procedures.
- 39% of ER dental patients return once their medication is finished; 21% return multiple times within a year.[192]
- 78%[193] of all dental ER visits could have been treated and addressed in a dental office.
- Nevada would realize a return on investment for expansion of dental benefits to all adults with ID/DD on Medicaid that includes the following:
    - Decreased Medicaid emergency room dental visit expenditures
    - Decreased healthcare costs for oral health related chronic disease impacts
    - Improved individual oral health outcomes
    - Improved public health outcomes

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[186] Drake, P., & Burns, A. (2024). *Working-Age Adults with Disabilities Living in the Community.* Retrieved from https://www.kff.org/medicaid/issue-brief/working-age-adults-with-disabilities-living-in-the-community/

[187] Vujicic, M., Fosse, C., Reusch, C., and Burroughs, M. (2021). *Making the case for adults in all state Medicaid programs.* Health Policy Institute White Paper. American Dental Association in partnership with Community Catalyst and Families USA. https://www.ada.org/-/media/project/ada-organization/ada/ada-org/files/resources/research/hpi/whitepaper_0721.pdf%20page%204 p. 12

[188] Vujicic, M., and Fosse, C. (2022). Time for Dental Care to Be Considered Essential in the US Health Care Policy. *AMA J Ethics.* 2022;24(1):E57-63. doi: 10.1001/amajethics.2022.57. Retrieved from https://journalofethics.ama-assn.org/article/time-dental-care-be-considered-essential-us-health-care-policy/2022-01

[189] National Council on Disability. (2022). *Medicaid Oral Health Coverage for Adults with Intellectual & Developmental Disabilities – A Fiscal Analysis.* Retrieved https://www.nccp.org/wp-content/uploads/2022/03/NCD_Medicaid_Report_508.pdf

[190] CareQuest Institute for Oral Health. *Family Affair. A Snapshot of Oral Health Disparities and Challenges in Individuals and Households Experiencing Disability.* Retrieved from https://www.carequest.org/system/files/CareQuest_Institute_Family-Affair-Visual-Report_FINAL.pdf

[191] Patel, N. A., Yun, J. K., & Afshar, S. (2020). Relieving Emergency Department Burden During COVID-19: Section 1135 Waivers for Dental Case Diversion. *Journal of oral and maxillofacial surgery: official journal of the American Association of Oral and Maxillofacial Surgeons*, 78(12), 2110–2111. https://doi.org/10.1016/j.joms.2020.07.015

[192] Association of State and Territorial Dental Directors (ASTDD). (2020). *Policy Statement: Reducing Emergency Department Utilization for Non-Traumatic Dental Conditions.* Retrieved from https://www.astdd.org/docs/reducing-emergency-department-utilization-for-non-traumatic-dental-conditions-january-2020.pdf

[193] Vujicic, M., Fosse, C., Reusch, C., and Burroughs, M. (2021). *Making the case for adults in all state Medicaid programs*. Health Policy Institute White Paper. American Dental Association in partnership with Community Catalyst and Families USA. https://www.ada.org/-/media/project/ada-organization/ada/ada-org/files/resources/research/hpi/whitepaper_0721.pdf%20page%204 p. 12

- Even if Medicaid dental benefits for adults with ID/DD are expanded beyond the ID Waiver recipients, there are still multiple barriers, including system- and policy-level barriers, that impact the ability to obtain care, including:
    - Patient-centered barriers which include anxiety, communication difficulties, sensory sensitivities, behavioral challenges, medical comorbidities, financial and transportation barriers and barriers to anesthesia and surgical care.
    - Caregiver-centered barriers include caregiver burden; issues of guardianship and documentation for informed consent; and lack of awareness and education on how to support the individual with ID/DD in their oral health care at home.
    - Provider-level barriers include shortage of clinical access during oral health education programs; not enough education on treating adults with ID/DD during dental education; and a lack of incentives to serve this population due to the extra time and cost barriers.
    - Policy and systemic barriers and challenges include lack of adult Medicaid basic dental coverage, shortage of providers who accept Medicaid, shortage of providers trained to care for adults with ID/DD, and difficulty in providing for specialized care needs.
    - Data barriers—nationally, and in Nevada, many health surveys exclude adults with ID/DD altogether or ask minimal questions and often lack critical demographic data that are needed to inform policy decisions and investment to address health disparities.

CONCLUSION AND RECOMMENDATIONS

CONCLUSION

People with I/DD remain the largest minority population with unmet oral healthcare needs. To achieve health equality for people with I/DD, policymakers need to examine the shortcomings of current policy against the backdrop of national goals for people with disabilities.

Shawn Kennemer, Council Member, National Council on Disability[194]

If we consider that oral health is the top unmet need for adults with ID/DD in both the United States and Nevada, along with the clear evidence of oral health disparities in this group, it raises questions about why federal and state policies have not adequately addressed this issue. This population faces numerous barriers to accessing dental care, including higher rates of poverty, increased comorbid medical conditions, multi-level barriers to accessing care, and systemic challenges. The primary barrier to accessing dental services for adults with ID/DD across the country is financial, and the primary issue for providers when surveyed for not treating this population is also a financial issue. Providers also cite lack of adequate education and clinical access during their educational programs, low Medicaid rates and high administrative barriers, and high number of client appointment cancellations as the reasons they do not treat any adults with ID/DD or treat more. Changes have been made at the national level requiring more education on caring for this population, but the lack of clinical access for oral health students is one that persists nationally and in Nevada.

Neglecting oral health care leads to poor overall health outcomes, costly surgical procedures, and unnecessary emergency department visits. The evidence indicates that individuals with low income and no insurance are prone to seeking expensive emergency department care, thereby exacerbating costs and straining an already overwhelmed emergency healthcare system. This issue is particularly pronounced among adults with ID/DD, who are three times as likely as those without ID/DD to use the emergency room for dental issues. When states do not provide access to preventative care and timely treatment for those populations that have disproportionate rates of oral disease like adults with ID/DD, taxpayers foot the bill for more costly emergency department care that could have been prevented. By addressing these issues, we can prevent unnecessary costs and improve health outcomes.

According to the American Dental Association, research consistently demonstrates that expanding dental coverage can lead to overall reductions in medical costs, including decreased reliance on emergency department services. [195] By redirecting care to dental offices, where treatments are covered and provided by trained professionals, patients receive more appropriate care for their nontraumatic dental conditions.

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[194] National Council on Disability (NCD). Council Members. Retrieved from https://www.ncd.gov/council-members/

[195] Vujicic, M., Fosse, C., Reusch, C., and Burroughs, M. (2021). *Making the case for adults in all state Medicaid programs*. Health Policy Institute White Paper. American Dental Association in partnership with Community Catalyst and Families USA. https://www.ada.org/-/media/project/ada-organization/ada/ada-org/files/resources/research/hpi/whitepaper_0721.pdf%20page%204 p. 4

Expanding Medicaid dental benefits for adults with ID/DD is a crucial step towards addressing the long-standing disparities in oral health for this population. While it may not be the sole solution, it holds significant potential for improving oral health outcomes. The fiscal, public health and individual health outcomes of expansion of dental benefits include, but are not limited to:[196]

- Improved oral health for adults with ID/DD, including the ability to eat and communicate, and a reduction in pain from untreated oral health disease and decay.
- A reduction of complications and comorbidities associated with poor oral health, and their associated costs, including diabetes and heart disease. [197, 198]
- Reduction in costs of care related to untreated dental conditions including infection as well as more costly procedures requiring anesthesia and oral surgery.
- Improved individual and family financial stability due to coverage for dental care as opposed to paying out of pocket, a considerable burden given higher poverty and lower employment rates among this population.
- Fewer visits and readmittance to emergency rooms, as well as Medicaid medical payments, for nontraumatic dental conditions (NTDC), 78%[199] of which could have been treated and addressed in the office for $90-$200 instead of an average of $1,286.33.[200]
- Improved ability to work or attend school due to fewer missed days of work due to untreated oral disease and pain.

In Nevada, where 38% of individuals with ID/DD rely on Medicaid, the expansion of dental benefits is especially impactful. Thanks to funding from the American Rescue Plan Act and the advocacy of Governor Lombardo, expanded dental benefits have been implemented for the first time in Nevada's history, providing much-needed access to care. Across the country, other states have similarly recognized the importance of expanding Medicaid dental benefits to high-risk populations, including those with ID/DD. Research indicates that such expansions lead to significantly higher rates of basic dental care utilization among adults with ID/DD, highlighting the effectiveness of these initiative.

Expanding benefits for ID Waiver participants, launching the Every Smile Matters project, and conducting this Needs Assessment all aim to enhance Nevada's understanding of the needs of adults with ID/DD and improve their access to necessary care. However, significant data challenges persist, highlighting the need for federal and state efforts to accurately assess the population and their requirements. Dr. Keith Benson, DMD, Nevada State Dental Health Officer, emphasizes the importance of "measuring what matters" to inform data-driven policy decisions for enhancing

[196] National Council on Disability (NCD). (2022). *Medicaid Oral Health Coverage for Adults with Intellectual & Developmental Disabilities – A Fiscal Analysis.* Retrieved from https://www.nccp.org/wp-content/uploads/2022/03/NCD_Medicaid_Report_508.pdf

[197] Williams, A.R., Yaqub, A., Glassman, P. & Phillips, V. (2023) Shortening-The-Line: Reducing the Need for Sedation and General Anesthesia for Dental Care for People with Disabilities, *Journal of the California Dental Association*, 51:1, DOI: 10.1080/19424396.2023.2253958

[198] Williams, A.R., Yaqub, A., Glassman, P. & Phillips, V. (2023) Shortening-The-Line: Reducing the Need for Sedation and General Anesthesia for Dental Care for People with Disabilities, *Journal of the California Dental Association*, 51:1, DOI: 10.1080/19424396.2023.2253958

[199] Vujicic, M., Fosse, C., Reusch, C., and Burroughs, M. (2021). *Making the case for adults in all state Medicaid programs*. Health Policy Institute White Paper. American Dental Association in partnership with Community Catalyst and Families USA. https://www.ada.org/-/media/project/ada-organization/ada/ada-org/files/resources/research/hpi/whitepaper_0721.pdf%20page%204 p. 12

[200] Patel, N. A., Yun, J. K., & Afshar, S. (2020). Relieving Emergency Department Burden During COVID-19: Section 1135 Waivers for Dental Case Diversion. *Journal of oral and maxillofacial surgery: official journal of the American Association of Oral and Maxillofacial Surgeons*, 78(12), 2110–2111. https://doi.org/10.1016/j.joms.2020.07.015

health equity among adults with ID/DD in Nevada. Access to oral healthcare remains a crucial health equity issue for the majority of adults with ID/DD, necessitating a comprehensive government approach aligned with the Centers on Medicaid and Medicare Services Health Equity Plan 2022-2023 to address personal, provider, and systemic barriers and achieve better public health outcomes for this vulnerable group.

This statewide oral health needs assessment for adults with ID/DD in Nevada, one of the few of its kind nationally, and one of very few published nationally that aim to describe the unmet needs of this underserved population, provides crucial data and recommendations (below) for policymakers, families and caregivers, disability serving agencies, advocates, health researchers, elected officials, and community leaders to establish policy, program and practice changes that are needed to address the longstanding oral health inequalities faced by Nevadans with ID/DD. As described by the National Council on Disability, this population has been "neglected for too long.[201]

RECOMMENDATIONS

BUILDING THE ORAL HEALTH SAFETY SYSTEM

Adults with ID/DD with Medicaid in Nevada need an oral health safety net in order to address the longstanding oral health disparities in access, treatment, and health outcomes they face. A strong oral health safety net will require investments at multiple levels, and engagement and collaboration across state agencies and systems, and will produce a high return on investment in terms of improving individual and public health outcomes, and result in cost savings that occur when oral health treatment is unavailable or delayed.

Four key points that drive oral health public health messaging and investments are:

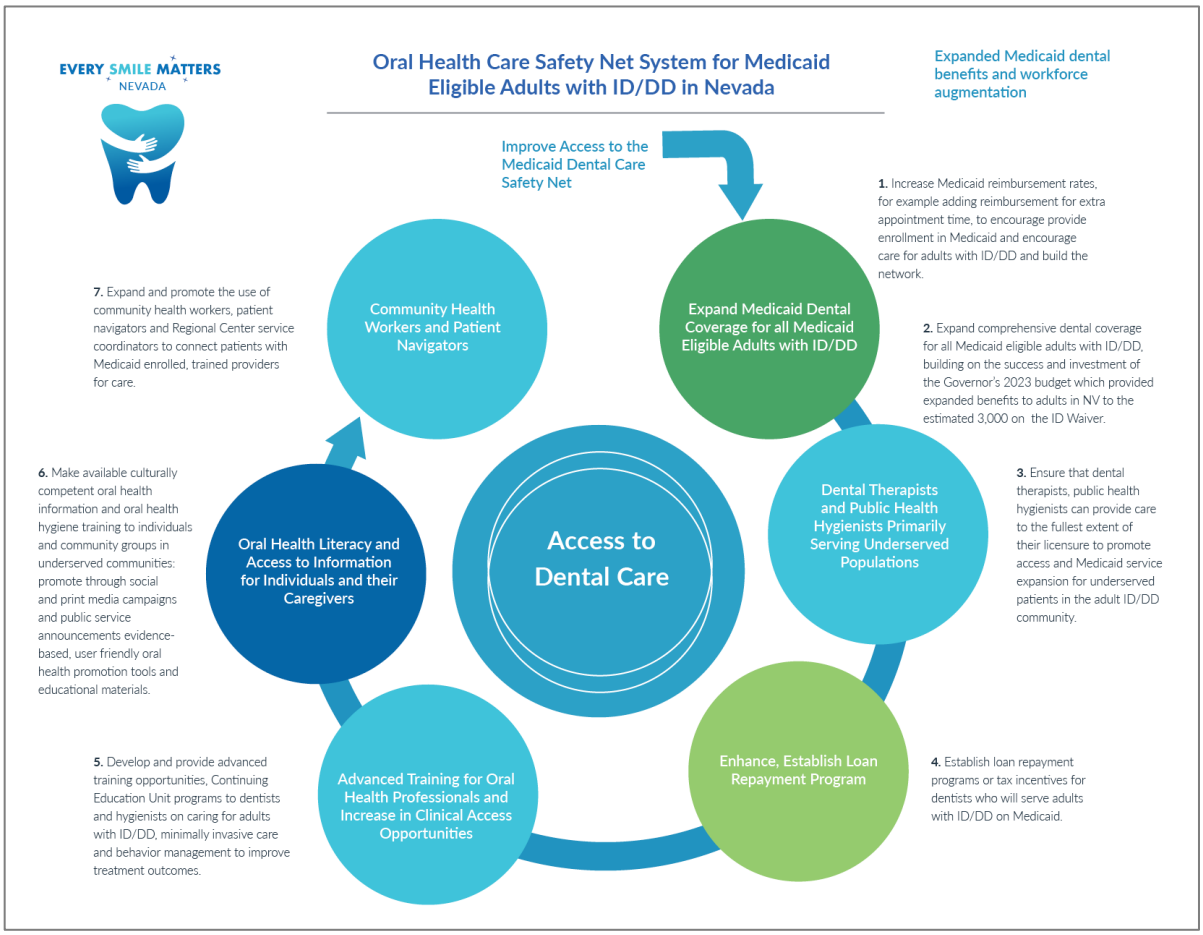
1. **Oral health IS health**
2. **Nearly all oral health disease is preventable**
3. **Investing in prevention saves taxpayer money**
4. **Adults with ID/DD in Nevada have higher rates of disease, more health complications of oral disease, and more costly interventions when prevention and care is not accessible**

A strong oral health safety net that improves oral health outcomes for adults with ID/DD is necessary in Nevada to address unmet needs and current high rates or oral disease and would include elements like those shown in Figure 14 below. [202]

[201] National Council on Disability. (2017). *Neglected for Too Long: Dental Care for People with Intellectual and Developmental Disabilities.* Retrieved from https://www.ncd.gov/report/neglected-for-too-long-dental-care-for-people-with-intellectual-and-developmental-disabilities/

[202] Davis AL, Zare H, Kanwar O, McCleary R, & Gaskin DJ. Programs and Policies Targeted to Improve Access to Dental Care for Low Income Adults and Children in the US: An Integrative Literature. *J Dent & Oral Disord*. 2021; 7(3): 1166. Retrieved from https://austinpublishinggroup.com/dental-disorders/fulltext/jdod-v7-id1166.pdf

FIGURE 14. IMPROVING THE ORAL HEALTH CARE SAFETY NET SYSTEM IN NEVADA



As Nevada works to design and implement improvements to the oral health safety net system, there are existing assets that can be deployed (Table 25).[203]

TABLE 25. SAFETY NET SYSTEM COMPONENTS

Clinical Services
▪ Community Non-profit and volunteer programs such as Special Olympics Special Smiles Program
▪ Dental and dental hygiene schools
▪ Free and reduced cost dental service providers including Federally Qualified Health Centers, Community Health Centers, and Rural Health Centers
▪ Hospital emergency departments and related triage and diversion programs
▪ Indian Health Service and 8 tribal clinics in Nevada
▪ Local health departments
▪ Long-term care
▪ Non-dental providers (i.e., physicians, nurses)
▪ Private practice (Medicaid, pro bono in-office care)
▪ Public health endorsed dental hygienists (PHEDH)
▪ Residency programs in hospitals and dental schools
▪ Telehealth and virtual dental care

[203] American Dental Association. (2011). *Breaking Down Barriers to Oral Health for All Americans: Repairing the Tattered Safety Net.* Retrieved from https://www.cds.org/docs/default-source/foundation/barriers-paper_repairing-tattered-safety-net.pdf?sfvrsn=c5f5cb51_0 p.4

Nonclinical Support Services
▪ Federal Oral Health Programs (e.g. HRSA workforce grants)
▪ Social services (case management and patient navigation)
▪ State Medicaid
▪ Nevada State Oral Health Program

Adapted from American Dental Association. (2011). Breaking Down Barriers to Oral Health for All Americans: Repairing the Tattered Safety Net. Table on page 4.

Improving Oral Health Prevention at Home

Educate individuals and their caregivers about oral hygiene and prevention strategies at home.

a. Continue to develop and maintain the Every Smile Matters Nevada website that is targeted to improve oral health outcomes for adults with ID/DD and support caregivers.
b. Implement an oral health educational campaign and outreach strategy for nonprofit and community organizations, general practitioners, and state agencies serving individuals with ID/DD aimed at disseminating crucial information (accessing treatment, utilizing adaptive oral health products, employing behavioral management techniques, and preparing dental visits) to adults with ID/DD, parents, families, and caregivers.
c. Provide training to Regional Center service coordinators on oral hygiene and prevention techniques and strategies to share with caregivers.
d. Implement oral-health-provider-led trainings at adult ID/DD Residential Care Homes to advance outcomes for clients living in Medicaid-supported living arrangements.

Increasing Access to Dental Preventative Care and Treatment

Invest in existing dental programs and pilot new programs that increase access to care for Medicaid clients with ID/DD, provide additional training as needed.

a. Develop and maintain an online directory of Medicaid providers and private dentists who care for adults with ID/DD to help individuals and their caregivers find providers trained and ready to treat them.
b. Increase funding and support to Federally Qualified Health Centers and Community Health Centers to provide dental care to poor and low-income adults with ID/DD. Include additional training on serving adults with ID/DD for participating dentists.
c. Build connections and implement MOUs between community-based organizations with clinical space that can be used during non-business hours for screening clinics staffed by dental students.
d. Increase utilization of freestanding Outpatient Surgery Centers (OSC)/Ambulatory Surgery Centers (ASC)– Dentist-owned OSCs/ASCs with ORs fully outfitted with dental equipment.
e. Increase the utilization of in-office General Anesthesia, either administered by a licensed dentist or another qualified dental professional trained in anesthesia, or by engaging a nurse anesthetist for anesthesia delivery. This approach offers benefits such as immediate access to dental tools and resources, simplified appointment scheduling, familiarity with the dental team, decreased travel time, and expedited patient appointments.
f. Increase dental surgery facility rates that remove the financial disincentives for hospitals and surgical centers to schedule dental surgeries.

g. Work with hospitals and ambulatory surgical centers to promote dental surgery access during off peak hours.
h. Increase the awareness of, and use of, minimally invasive treatment, including long-term preventatives such as topical fluorides, high-fluoride dentifrices, and the application of silver diamine fluoride.
i. Increase support for and investment in mobile dentistry programs to reach adults with ID/DD in underserved areas including rural and frontier regions. Provide screenings on-site at disability-related community events.
j. Pilot and evaluate a telehealth model staffed by an in-person dental hygienist and a supervising dentist via telehealth, increasing the use of Virtual Dental Homes to improve oral health.
k. Increase the utilization of public health endorsed dental hygienists (PHEDH) to go to residential facilities and group homes to provide education and Medicaid-funded treatment to adults with ID/DD.
l. Educate individuals with ID/DD with Medicaid and their caregivers about Medicaid-supported transportation to dental appointments.
m. Promote private dental insurance reform so that private insurance would pay for hospital treatment and have a max allowance that could support this care.

Improving Oral Health Provider Education

Increase continuing education opportunities and improve clinical access for dental students, and create mentoring and professional support for providers caring for adults with ID/DD.

Improving Provider Expertise in Serving Adults with ID/DD

a. Increase the skill and number of oral health providers (caregivers, hygienists, and dentists) who are trained and have spent clinical time caring for individuals with ID/DD through advanced educational/training opportunities, including continuing education (CE) credit courses held at dental clinical locations, to provide not only topical training but clinical care demonstrations for adult patients with ID/DD.
b. Publicize and host CE courses and public speakers who are experts in caring for adults with ID/DD. Course components include:
    1. Didactic learning with local speakers
    2. Hands-on experience in clinic and operating room settings
    3. Networking opportunities following CE courses to encourage case presentations and second opinions.
    4. In-service learning opportunities for staff, family members, and residents of facilities for persons with disabilities.
c. Implement an educational campaign to educate dentists and hygienists on the needs of this population, with emphasis that the majority of adults with ID/DD can typically undergo treatment in-office without sedation. Highlight the importance of establishing a robust oral healthcare infrastructure, which would enable general dentists in the community to effectively treat most adults with ID/DD. Provide insights into behavior management techniques and the utilization of adaptive tools for improved patient care, and the

Americans with Disability Act requirements for accessible care and strategies (https://www.ada.gov/resources/medical-care-mobility/).

Increase Clinical Access Points for Dental Provider Training to Improve Care Outcomes and Access

a. Fund clinics attached to hospitals and/or universities to create clinical care knowledge centers that provide treatment for adults with ID/DD and provide clinical access opportunities for dental students.
b. Establish a general practice residency or advanced education in general dentistry in northern Nevada with a strong ID/DD hospital component to not only train dentists to serve this population but be a hub in the for patients to receive treatment.
c. Establish specialized clinics in northern and southern Nevada for individuals with disabilities and/or utilize community programs and locations for increasing clinical access and providing care, such as Federally Qualified Health Care Centers, Community Health Centers, and partnerships with the Special Olympics and other ID/DD-serving organizations.

Increase Professional Development and Mentoring to Advance Provider Knowledge and Treatment Outcomes

a. Create a professional support organization for oral health professionals (including pediatric, adult, specialty, hygienists) who treat adults with ID/DD to share case studies, troubleshoot care, and grow the number of providers in Nevada.
b. Implement a mentoring program for health professionals who are new to treating this population, with mentors who have experience treating adults with ID/DD, supporting providers new to this population or wanting to deepen their knowledge and advance their skills.

Policy and Systems Change to Improve Oral Health Outcomes for Adults with Intellectual and/or Developmental Disabilities

Expand Medicaid to provide dental benefits to all adults with ID/DD on Medicaid, in addition to those already covered under the ID Waiver.

Build the Medicaid provider network through targeted outreach and provider incentives to meet unmet needs for treatment and care.

a. Conduct a feasibility study to assess the costs of expansion to the adult ID/DD population and calculate the return on investment, building off the assessment and outcomes described by the National Council on Disability in their March 2022 study, *Medicaid Oral Health Coverage for Adults with Intellectual & Developmental Disabilities- A Fiscal Analysis.*
b. Evaluate the ID Waiver expanded-benefits program to assess care usage rates, costs, and health outcomes over time, compared to adults with ID/DD on Medicaid who are not receiving expanded dental benefits.
c. Assess Medicaid rates for adequacy in terms of expanding and maintaining the Medicaid network, with consideration of adequacy of rates for the extra time and staff it takes to provide care to adults with ID/DD.

d. Decrease the number of broken appointments cited by dental providers as a barrier to enrolling in Medicaid by utilizing Medicaid funding to help with patient coordination and transportation support.

Build the Medicaid Enrolled Provider Service Network

a. Expand services after the new regulations for dental hygienists are published by the Nevada State Board of Dental Education for dental hygienists who receive additional training to allow then to provide basic dental restorative and therapeutic services as dental therapists to care for adults on Medicaid with ID/DD in underserved areas.
b. Conduct an internal assessment on messaging and marketing to potential Medicaid dentists who are considering joining the network targeted to address the main reasons found in this assessment and in other studies, where providers cite low rates, administrative burdens, and canceled appointments as primary impediments.
c. Advance a provider incentive program that issues grants and loans to expand dental practices that serve adults with ID/DD on Medicaid, and/or student loan forgiveness and repayment programs for providers who serve this population.
e. Develop strategies for greater integration of care between dental and primary care professionals to bridge gaps between these professions and create partnerships in care for adults on Medicaid with ID/DD.

Ensure that Adults with ID/DD are Counted

a. Conduct a survey of existing Nevada data sources on adults with ID/DD to assess what state-level data on this population exists, how it is coded, and how it can be shared. Include data from state and county agencies, hospitals, and insurers to map what data are gathered, and what terms are used, for ex. I/DD, ID/DD, intellectual disability, developmental disability, cognitive disability, etc.
b. Develop data standards for identifying this population so that datasets can be connected to provide quality data on population numbers, prevalence of specific disabilities and demographics.
c. Create a roadmap that details how data can be connected or shared across systems using unique identifiers, which can be used to drive public policy and service decisions and investments and identify needs.
d. Increase utilization of data by creating plans for dissemination, publication, and accessible documents for different audiences, such as individuals with ID/DD, caregivers, legislators and decision-makers, medical and oral health providers, communities using American Sign Language, and culturally and linguistically isolated communities.
e. Work to create greater transparency concerning managed care reimbursement rates so that Nevada can assess the adequacy of rates across both fee-for-service and managed care organizations as the state works to build its Medicaid provider networks.

Develop the Leadership and Strategies to Address Oral Health Disparities for Adults with ID/DD Across Nevada

a. Develop a statewide strategic plan with detailed activities and benchmarks to address the documented health disparities in adults on Medicaid with ID/DD in Nevada to address that gaps and needs identified in this Needs Assessment, and those identified by key stakeholders, advocates, and public health leaders.
b. Establish oral health and ID/DD benchmarks for dental visits, burden of disease, and access to treatment and care, against which change can be measured.
c. Fund the Nevada Oral Health Program to conduct health surveillance, convene stakeholders, reach out to Medicaid oral health providers, and implement the strategic plan to address the high burden or oral disease in adult Nevadans with ID/DD.
d. Increase the focus on individuals with disabilities, including ID/DD, in Office of Minority Health reports, studies, and initiatives to promote the understanding that this population has been underserved and under-counted, and is experiencing health and oral health inequities across the state.
e. Conduct and publish a public health needs assessment at the state level every three years that is focused on the physical, mental, and oral health of individuals with ID/DD, and/or all disabilities with ID/DD carved out. The assessments can be used to drive investments across agencies that serve this population.

About the Authors

Strategic Progress, LLC is a Nevada-based company specializing in public policy research and data analytics, federal grant development and strategic positioning of large-scale initiatives. This project was researched, written, and produced by Strategic Progress, LLC.

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APPENDICES

APPENDIX A. TMSIS- ID/DD ICD-10 DIAGNOSIS CODES

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

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
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 B. SURVEYS

APPENDIX C. PATHWAYS TO MEDICAID

TABLE 1. Eligibility Pathways for People with Disabilities

Eligibility group	Federal statutory and regulatory requirements	State plan options
Disabled individuals (under age 65)	**Disabled individuals receiving SSI** • States must cover individuals determined disabled receiving SSI and mandatory state supplementary payments.[1] **Working disabled** • States must cover individuals who are severely impaired and had received SSI and Medicaid previously, but whose earnings make them ineligible for SSI. **Disabled adult children** • States must cover individuals over 18 years old who had a disability prior to age 22, and lost eligibility for SSI.	**SSI-related pathways</span** • Other optional individuals with disabilities can be covered under certain SSI-related provisions. **Optional poverty and low-income-related pathways** • States have the option to cover individuals with disabilities up to 100 percent FPL or people receiving optional state supplemental payments. • States also have the option under the special income group option to cover institutionalized individuals with incomes not exceeding 300 percent of SSI (approximately 222 percent FPL). **Working disabled** • States can allow certain working individuals with disabilities to buy into Medicaid. **Individuals with disabilities receiving services in the community** • States have the option to cover individuals not otherwise eligible for Medicaid (under Section 1915(i)) or who would be eligible for Medicaid if institutionalized (under Sections 1915(c) and (d) waivers) who are receiving home and community-based services (HCBS).
Medically needy		**Medically needy option[2]** • States can cover individuals with high medical expenses where the expenses incurred are deducted from income for purposes of determining eligibility (also referred to as spend-down).

Notes: FPL is federal poverty level. Aid to Families with Dependent Children (AFDC) is the cash assistance program that was replaced by Temporary Assistance to Needy Families (TANF) in 1996. SSI is Supplemental Security Income.

[1] Rather than conferring automatic Medicaid eligibility on all SSI recipients, states (referred to as 209b states) can use more restrictive criteria to determine Medicaid eligibility.

[2] States can choose to cover medically needy individuals that would be categorically eligible, except for their incomes. Specifically, states can cover individuals with incomes above categorically needy income levels up to 133 percent of the state's 1996 AFDC level. This includes individuals age 65 and older, individuals with disabilities, as well as parents, pregnant women, and children. If states choose to cover individuals under the medically needy pathway, then states are required to cover children under 18 and pregnant women during the course of their pregnancy.

Source: MACPAC, 2017, *Federal Requirements and State Options: Eligibility*.

[204] Medicaid and CHIP Payment and Access Commission (MACPAC). People with disabilities. Retrieved from https://www.macpac.gov/subtopic/people-with-disabilities/