



National Council on Disability

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

Estimating Population Size Benefited by the Health Extension and Accessibility for Developmentally Disabled and Underserved Population (HEADs UP) Act to Support Cost Estimates

In this analysis, NCD seeks to determine the number of people with Intellectual and Developmental Disabilities (I/DD) who require specialized medical and dental care in order to support efforts to estimate the cost implications of the Healthcare Extension and Accessibility for Developmentally Disabled and Underserved Population (HEADs UP) Act (HR 3380).

In order to estimate the number of people with I/DD who require specialized medical and dental care, it is necessary to first construct an estimate of the population of people with I/DD as a whole. Having done this, we then proceed to segment the identified population of people with I/DD into “acuity cells” in order to permit the extent of unmet need to vary by severity of impairment. We classify respondents into a series of 31 acuity cells for purposes of identifying specialized medical needs and 6 acuity cells for purposes of identifying specialized dental needs. Each acuity cell reflects a different severity level, as defined by program participation and population health survey data on health status and service utilization. We then make use of a combination of population health survey data, prior work and subject matter expertise to produce plausible estimates of unmet need within each cell, then construct a weighted sum of all cells in order to produce a realistic estimate of the number of people with I/DD with specialized medical and dental needs.

Within each cell, the number of persons with underserved needs is determined by the product of the cell size and the rate of unmet need within that particular cell. By summing these products from each cell, we can then produce a plausible national estimate of the underserved population of people with I/DD within each category.

Data Sources

We make use of the Social Security Administration (SSA) Supplement on Retirement, Pensions, and Related Content to the 2014 Survey of Income and Program Participation (SIPP) to identify people with I/DD. The SSA Supplement was commissioned by SSA to inform the agency’s policy micro-simulations, including the Financial Eligibility Model used to analyze and evaluate the SSI program and other federal programs relevant to persons with disabilities. Unlike other data sets, which typically identify people with disabilities using a limited number of questions regarding functional impairment (which make it difficult to distinguish between people with I/DD and other groups of people with disabilities), the SSA Supplement collects information on a broad range of specific

medical diagnoses. By linking the SSA Supplement with Wave 1 of the SIPP, we can also access information on each respondent's self- or proxy-reported health status as well as their participation in Supplemental Security Income (SSI) and Medicaid to measure unmet need within distinct acuity cells defined by program participation. All analyses were conducted with Stata 16 and use the survey weights provided with the SSA Supplement. Finally, to address misreporting of SSI program participation by survey respondents, we rely on data from the 2020 Supplemental Security Income Annual Report.

To estimate the scope of unmet dental need as part of the process of identifying the need for specialized dental care, we use data from our report, "Medicaid Oral Health Coverage for Adults with Intellectual & Developmental Disabilities – A Fiscal Analysis" (NCD Medicaid Oral Health report).¹ Produced using Medicaid claims data from the 2018 Transformed Medicaid Statistical Information System, the report includes detailed state-level information on the percentage of adults with I/DD who received basic dental care. For unmet dental need among children with I/DD, we use an estimate from Obeidat et al (2022).² As the SIPP does not include in their sampling frame individuals in institutions and other congregate residential settings, we make use of 2018 data from the University of Minnesota's Residential Information Systems Project to identify the number of people with I/DD in such settings.³

Though this present analysis is narrow in scope, NCD's research team consulted with two experts in the field of developmental medicine and dentistry to evaluate the plausibility of our estimates of the number of people with I/DD who require specialized medical and dental care needs and review estimates within this analysis and provide feedback. One expert's prior experience in building specialized medical care infrastructure for adults with I/DD makes him well qualified to evaluate the assumptions NCD undertook for this project.⁴ The other's expertise in health services research evaluating cost and quality of health care services for adults with I/DD makes her well qualified.⁵

¹ National Council on Disability, "Medicaid Oral Health Coverage for Adults with Intellectual & Developmental Disabilities – A Fiscal Analysis." <https://ncd.gov/publications/2022/medicaid-oral-health-coverage-adults-IDD>

² Obeidat R, Noureldin A, Bitouni A, Abdellatif H, Lewis-Miranda S, Liu S, Badner V, Timothé P. Oral health needs of US children with developmental disorders: a population-based study. *BMC Public Health*. 2022 Dec;22(1):1-0.

³ Larson SA, van der Salm B, Pettingell S, Sowers M, Anderson LL. Long-term supports and services for persons with intellectual or developmental disabilities. Minneapolis (MN): University of Minnesota, Research and Training Center on Community Living; 2021.

⁴ Dr. Matt Holder, Global Medical Advisor and Chair of the Medical Advisory Committee for Special Olympics International and the past Executive Director of the American Academy of Developmental Medicine and Dentistry.

⁵ Dr. Priya Chandan is currently a clinical associate professor at the University Louisville School of Medicine.

Identifying People with I/DD

NCD identified people with I/DD based on responses to five questions in the SSA Supplement. Respondents are asked if they (or, for proxy respondents, the person for whom they are answering) have an intellectual disability (formerly known as mental retardation) and, in a separate question, if they have a developmental disability such as autism or cerebral palsy. Affirmative responses to either question result in a respondent being categorized as a person with I/DD. In addition, respondents are asked a series of questions regarding level of functional impairment, the presence of a condition that limits the kind or amount of work that can be done at a job or a business, and the nature of their health status. For respondents who report a functional impairment, a work-related disability or either fair or poor health, they are asked to provide their specific diagnosis, which interviewers then input based on a preset list of diagnostic codes. If respondents indicate the presence of Cerebral Palsy, Intellectual disability (formerly mental retardation), or Autistic or other developmental disorders (language as provided by the Census Bureau) then we categorize them as having a developmental disability. Question text is available in the 2014 Social Security Administration Supplement on Retirement, Pensions, and Related Content Users' Guide.⁶

NCD uses this data to reflect separate estimates of the prevalence of people with I/DD for adults and children. We estimate that 4.04% of US children and 1.96% of US adults have an I/DD. This estimate is close to estimates from prior research on this topic. We then apply each prevalence estimate to data from the Census Bureau's American Community Survey on the number of adults and children, respectively, in 2020 to account for population growth between 2014 and 2020. We thus produce an estimate of 5,030,575 US adults with I/DD and 2,942,013 US children with I/DD. This results in an estimate of 2.42% across all age groups. We believe our estimate to be well within the range of plausibility and appropriately consistent with prior work. Larson et al (2021) use a prevalence estimate of 2.17%, produced using a composite of prior research.⁷

While some differences exist, they are explainable due to changes in diagnostic trends over time and differences in the definitions used. Larson et al (2001) estimate that 1.49% of the US population has an I/DD using data from the 1994/1995 National Health

⁶ US Census Bureau. 2014 Social Security Administration Supplement on Retirement, Pensions, and Related Content (SSA Supplement). 2017. Available at: <https://www.census.gov/content/dam/Census/programs-surveys/sipp/methodology/SSA%20Supplement%20Users%20Guide.pdf>

⁷ Larson SA, van der Salm B, Pettingell S, Sowers M, Anderson LL. Long-term supports and services for persons with intellectual or developmental disabilities. Minneapolis (MN): University of Minnesota, Research and Training Center on Community Living; 2021.

Interview Survey's Disability Supplement.⁸ While this estimate is slightly below ours, it predates the increase in the use of the Autism Spectrum Disorder diagnosis and changes in the diagnostic criteria for autism under both the DSM-IV and DSM-V. Zablotsky et al (2017) produces a higher estimate of the incidence of I/DD in children of 6.99%. However, this estimate included children for whom parents had been told by a clinician that they had an unspecified developmental delay, a broad categorization that does not necessarily correspond to a need for specialized medical or dental care needs in most who receive it.⁹ Similarly, Zablotsky et al (2019) produces an estimate for children of 17.80%, owing to its inclusion of Attention Deficit Hyperactivity Disorder in its definition of I/DD.¹⁰

Constructing Acuity Cells for Unmet Medical Needs

With respect to unmet medical needs, respondents are first sorted based on every possible combination of SSI and Medicaid receipt. However, prior work has found that survey respondents may not accurately identify themselves as receiving SSI, potentially confusing the program with SSDI or other income sources. Using administrative data linked to the 1993 and 1996 SIPP panels, Huynh, Rupp & Sears (2013) found that the SIPP erroneously estimates SSI receipt. This is partially due to a high percentage of SSI recipients inaccurately reporting themselves as receiving no benefits or as receiving benefits only from the comparably less stigmatized Old Age Security and Disability Insurance (OASDI) program (some SSI recipients are concurrently enrolled in both programs). While fewer than 1 percent of OASDI-only recipients misreport themselves as receiving SSI only, the much smaller size of the SSI program means that this misreporting inflates the percentage of respondents reporting SSI receipt relative to the true value derived from administrative data.¹¹

To address this, we make use of data from the 2020 Supplemental Security Income Annual Report from SSA. We take state-year data on the number of SSI beneficiaries in the Autism spectrum disorders, Developmental disorders and Intellectual disorders categories for each state. We then adjust the population size of the SSI rate cells to match the administrative data and define the size of the non-SSI rate cells by subtracting the

⁸ Larson SA, Lakin KC, Anderson L, Kwak Lee N, Lee JH, Anderson D. Prevalence of mental retardation and developmental disabilities: estimates from the 1994/1995 National Health Interview Survey Disability Supplements. *American Journal on Mental Retardation*. 2001 May;106(3):231-52.

⁹ Zablotsky B, Black LI, Blumberg SJ. Estimated prevalence of children with diagnosed developmental disabilities in the United States, 2014-2016.

¹⁰ Zablotsky B, Black LI, Maenner MJ, Schieve LA, Danielson ML, Bitsko RH, Blumberg SJ, Kogan MD, Boyle CA. Prevalence and trends of developmental disabilities among children in the United States: 2009–2017. *Pediatrics*. 2019 Oct 1;144(4).

¹¹ Huynh M, Rupp K, Sears J. The assessment of Survey of Income and Program Participation (SIPP) benefit data using longitudinal administrative records. *Social Security Administration*. 2002 Jun.

SSI population by the total population as determined via the survey. As it is not possible to ascertain which respondents misreport their SSI status, levels of unmet need are still constructed using survey data. For non-SSI recipients, we determine the population size of Medicaid recipients using the NCD Medicaid Oral Health report's analysis of 2018 T-MSIS data for adults and SIPP survey data for children.

We define all individuals receiving SSI as Medicaid recipients. Prior work has demonstrated that survey responses often underreport Medicaid status, with many respondents erroneously indicating they have private insurance and a small number reporting themselves as uninsured^{12,13,14,15}. SSI recipients are automatically enrolled in Medicaid in 35 jurisdictions with SSA electronically informing state Medicaid agencies of their eligibility as soon as the disability determination process completes (these are often referred to as "1634 states", since Section 1634 of the Social Security Act permits states to enter into automatic-enrollment agreements with SSA).^{16,17} We explored the possibility of permitting the existence of a "SSI-No Medicaid" category for respondents who reported SSI enrollment but no Medicaid enrollment in non-1634 states, but ultimately found only 6 observations in the SSA Supplement reporting SSI status and no Medicaid receipt in non-1634 states, leading us to conclude that such a category would not be viable with available data.

We thus produce population estimates of three groups of people with I/DD by program participation: those receiving SSI and Medicaid ("SSI-Medicaid") those receiving Medicaid only ("No SSI-Medicaid") and those not participating in either program ("No SSI-No Medicaid"). For adults, we estimate that 22% of adults with I/DD or 1,094,892 people receive both SSI and Medicaid (a figure derived from the 1,094,892 adults with I/DD

¹² Davern M, Call KT, Ziegenfuss J, Davidson G, Beebe TJ, Blewett L. Validating health insurance coverage survey estimates: a comparison of self-reported coverage and administrative data records. *Public Opinion Quarterly*. 2008 Jan 1;72(2):241-59.

¹³ Call KT, Davidson G, Davern M, Nyman R. Medicaid undercount and bias to estimates of uninsurance: new estimates and existing evidence. *Health Services Research*. 2008 Jun;43(3):901-14.

¹⁴ Davern M, Klerman JA, Baugh DK, Call KT, Greenberg GD. An examination of the Medicaid undercount in the Current Population Survey: preliminary results from record linking. *Health services research*. 2009 Jun;44(3):965-87.

¹⁵ Klerman JA, Davern M, Call KT, Lynch V, Ringel JD. Understanding The Current Population Survey's Insurance Estimates And The Medicaid 'Undercount' People can't accurately recall their insurance status when asked by the Census Bureau's survey takers—so these widely quoted estimates may be substantially off. *Health Affairs*. 2009;28(Suppl1):w991-1001.

¹⁶ MACPAC. Exhibit 37: Medicaid Income Eligibility Levels as a Percentage of the FPL for Individuals Age 65 and Older and PWD By State, 2021. Available at: <https://www.macpac.gov/wp-content/uploads/2015/01/EXHIBIT-37.-Medicaid-Income-Eligibility-Levels-as-a-Percentage-of-the-Federal-Poverty-Level-for-Individuals-Age-65-and-Older-and-Persons-with-Disabilities-by-State-2021.pdf>

¹⁷ Rupp K, Riley GF. State Medicaid eligibility and enrollment policies and rates of Medicaid participation among disabled supplemental social security income recipients. *Soc. Sec. Bull.*. 2016;76:17.

receiving SSI reported in the 2020 SSI Statistical Report), that 77% of adults with I/DD or 3,896,311 people receive neither SSI nor Medicaid (a figure derived from subtracting the number of adults with I/DD enrolled in Medicaid calculated from the NCD Medicaid Oral Health report from the total number of adults with I/DD), and that 1% of adults with I/DD or 39,372 receive Medicaid but not SSI (a figure derived from subtracting both of the prior figures from the total number of adults with I/DD). For children, we estimate that 18% of children with I/DD or 528,451 people are receiving SSI and Medicaid (a figure derived from the 528,451 children with I/DD receiving SSI reported in the 2020 SSI Statistical Report), that 61% of children with I/DD or 1,808,357 people receive neither SSI nor Medicaid (a figure derived from SIPP survey data), and that 21% of children with I/DD or 605,205 people receive Medicaid but not SSI (a figure derived from subtracting both of the prior figures from the total number of children with I/DD).

Having produced estimates of the size of each of these program participation groups using a combination of SIPP survey data and administrative data, we then rely exclusively on SIPP survey data to estimate the distribution of respondents' self-reported health. Wave 1 of the SIPP asks respondents to provide a rating of their health status (or for proxy respondents, that of the person for whom they are answering). Respondents may classify their health status as Excellent, Very Good, Good, Fair or Poor.

Though this measure is deceptively simple, a large body of research has found that it and similar self-reported measures of health are associated with mortality risk and service utilization.^{18,19,20,21,22} While concern has been raised that such measures may conflate functional impairment and health status when asked to people with I/DD or their proxy respondents,^{23,24} this problem does not present an issue in our analysis, as both functional impairment and health status are predictors of our intended outcome of a need for specialized medical care.

¹⁸ Idler EL, Benyamini Y. Self-rated health and mortality: a review of twenty-seven community studies. *Journal of health and social behavior*. 1997 Mar 1;21:37.

¹⁹ Gallagher JE, Wilkie AA, Cordner A, Hudgens EE, Ghio AJ, Birch RJ, Wade TJ. Factors associated with self-reported health: implications for screening level community-based health and environmental studies. *BMC public health*. 2016 Dec;16(1):1-5.

²⁰ Miilunpalo S, Vuori I, Oja P, Pasanen M, Urponen H. Self-rated health status as a health measure: the predictive value of self-reported health status on the use of physician services and on mortality in the working-age population. *Journal of clinical epidemiology*. 1997 May 1;50(5):517-28.

²¹ Benjamins MR, Hummer RA, Eberstein IW, Nam CB. Self-reported health and adult mortality risk: an analysis of cause-specific mortality. *Social science & medicine*. 2004 Sep 1;59(6):1297-306.

²² Grant MD, Piotrowski ZH, Chappell R. Self-reported health and survival in the Longitudinal Study of Aging, 1984–1986. *Journal of clinical epidemiology*. 1995 Mar 1;48(3):375-87.

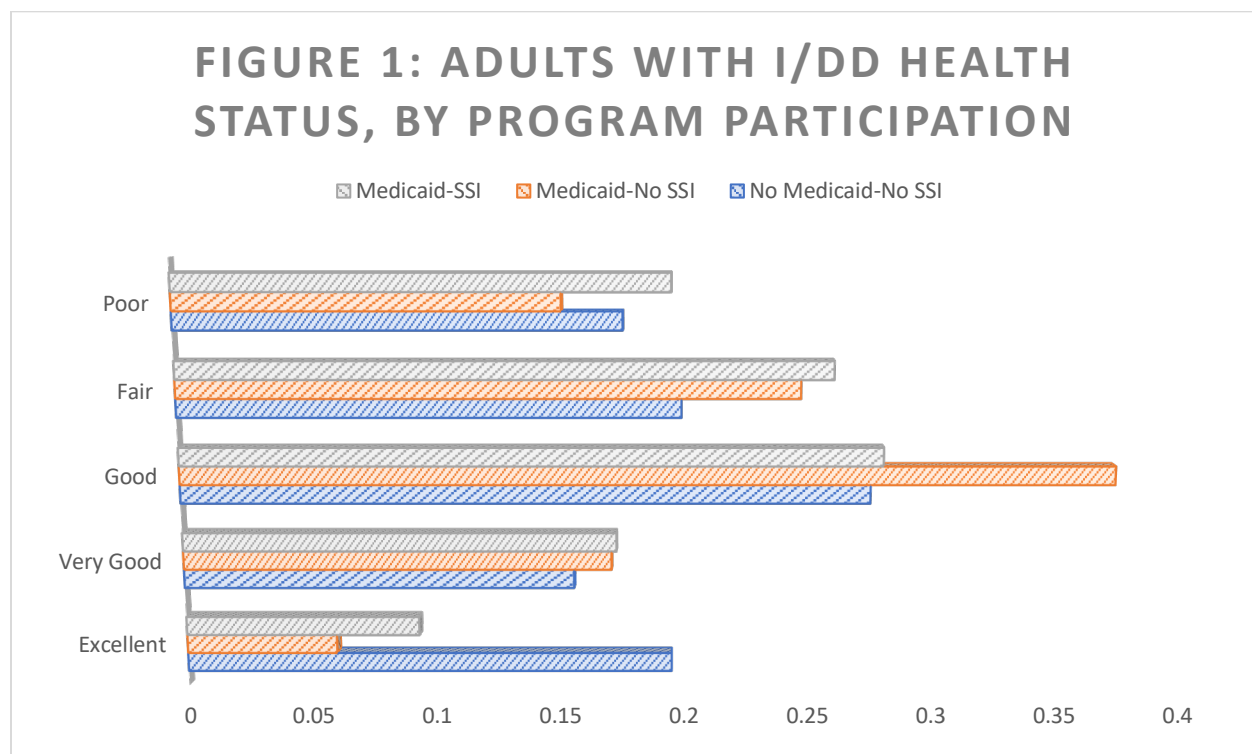
²³ Fujiura GT, RRTC Expert Panel on Health Measurement. Self-reported health of people with intellectual disability. *Intellectual and developmental disabilities*. 2012 Aug;50(4):352-69.

²⁴ Krahn GL, Fujiura G, Drum CE, Cardinal BJ, Nosek MA, RRTC Expert Panel on Health Measurement. The dilemma of measuring perceived health status in the context of disability. *Disability and Health Journal*. 2009 Apr 1;2(2):49-56.

We reflect the distribution of health status within each program participation group for adults in Table 1 and for children in Table 2. We also reflect each graphically in Figures 1 and 2.

| Table 1: Health Status Distribution for Adults with I/DD | | | |
|---|--------------------|-----------------|--------------|
| Health Status | No Medicaid-No SSI | Medicaid-No SSI | Medicaid-SSI |
| Excellent | 0.195 | 0.0602 | 0.0935 |
| Very Good | 0.156 | 0.171 | 0.173 |
| Good | 0.274 | 0.371 | 0.279 |
| Fair | 0.199 | 0.246 | 0.259 |
| Poor | 0.176 | 0.152 | 0.195 |

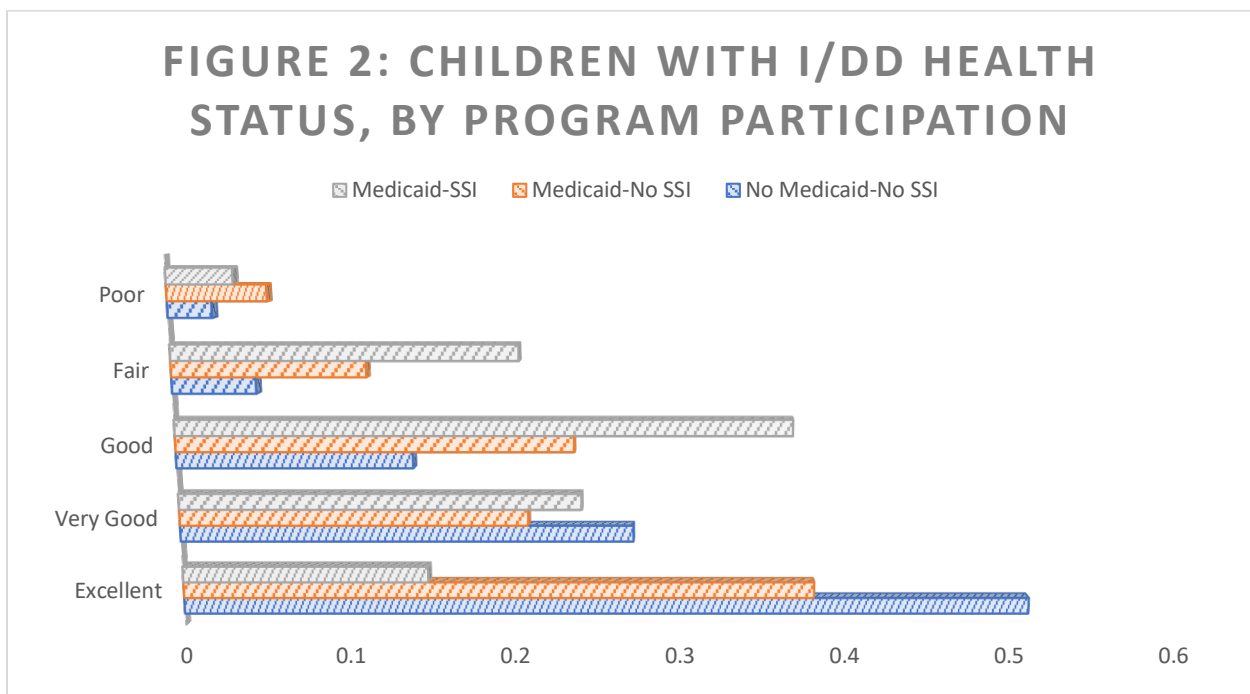
Figure 1: Adults With I/DD Health Status, By Program Participation:



As shown in Table 1 and Figure 1, for adults with I/DD, health status is substantially better for the No Medicaid-No SSI group, consistent with expectations. As shown in Table 2 and Figure 2, for children with I/DD, the No Medicaid-No SSI group has the best health status, while the Medicaid-No SSI group has substantially better health status than the Medicaid-SSI group. These results validate our strategy of using program participation as one dimension through which the acuity of people with I/DD may vary.

| Health Status | No Medicaid- No SSI | Medicaid-No SSI | Medicaid-SSI |
|----------------------|--------------------------------|------------------------|---------------------|
| Excellent | 0.511 | 0.381 | 0.148 |
| Very Good | 0.272 | 0.209 | 0.241 |
| Good | 0.141 | 0.237 | 0.367 |
| Fair | 0.050 | 0.115 | 0.205 |
| Poor | 0.026 | 0.059 | 0.039 |

Figure 2: Children With I/DD Health Status, By Program Participation:



After estimating the distribution of health in each program participation category, we then use this data to estimate the number people with I/DD in every combination of the three program participation categories and the five health categories, resulting in 15 acuity cells for adults and 15 acuity cells for children. Finally, we reflect an additional acuity cell for individuals with I/DD of any age residing in congregate care settings using a prevalence estimate calculated from 2018 data available from the Residential Information Systems Project, adjusted to reflect population growth between 2018 and 2020 using data from the Census Bureau’s American Community Survey. The use of a distinct cell for individuals residing in congregate care settings is necessary as individuals in congregate care are not included within the sampling frame for the SIPP, meaning that our survey

data is not representative of this population. We estimate the number of people with I/DD residing in congregate care settings at 317,532 people.

Relying on subject matter expertise, we assume that the proportion of people with I/DD requiring specialized medical care is 5% for people with I/DD reporting Excellent health, 10% for those reporting Very Good health, 15% for those reporting good health, 70% for those reporting fair health, 80% for those reporting poor health and 90% for individuals residing in congregate care settings. These assumptions were assessed by NCD's consulting experts and found to be consistent with the medical care needs of adults with I/DD. Relying on these assumptions, we estimate that 1,804,006 community-dwelling adults with I/DD, 495,000 community-dwelling children with I/DD and 285,779 people with I/DD of all ages residing in congregate care settings require specialized medical care, yielding a total estimate of 2,584,785 people with I/DD requiring specialized medical care, corresponding to 0.78% of the general population.

Constructing Acuity Cells for Unmet Dental Needs

With respect to unmet dental needs, we make use of the NCD Medicaid Oral Health report to understand the extent of unmet needs for adults with I/DD on Medicaid. The report includes claims-data derived estimates of the percentage of adults with I/DD who receive basic dental care in each state.

Unfortunately, the SIPP is not representative at a state level and includes too few adult respondents with I/DD to permit reliable estimates of the number of adults with I/DD in each state. To address this, we segment states into four broad categories determined by the National Academy for State Health Policy (NASHP)'s categorization of state Medicaid dental coverage (extensive, limited, emergency and none).²⁵ We then produce estimates of the percentage of adults with I/DD receiving basic dental care in each of these four groupings of states by averaging the percentage for each state in a category, weighting states by the number of adults with I/DD identified in claims data. These estimates of met dental need are then applied to estimates of the number of adults with I/DD on Medicaid produced via SIPP data in each of the four groupings of states to produce estimates of the number of adults with I/DD with met dental need. (In our analysis of the number of adults with I/DD on Medicaid in each of the four state groupings, we categorize respondents' state of residence by their residence in the first month of their SIPP reference period.) We are then able to determine the number of adults with I/DD with unmet dental needs by subtracting this prior number from the total.

²⁵ National Academy for State Health Policy. State Medicaid Coverage of Dental Services for General Adult and Pregnant Populations. Updated August 2022. Available at: <https://www.nashp.org/state-medicare-coverage-of-dental-services-for-general-adult-and-pregnant-populations/>

These estimates are reflected in Table 3. Note that they differ from corresponding estimates in the NCD 2022 report, “*Medicaid Oral Health Coverage for Adults with Intellectual & Developmental Disabilities – A Fiscal Analysis*”, as NCD made use of states’ NASHP categorizations from 2018 while we make use of them from 2022. Consistent with expectations, Table 3 shows the proportion of adults with I/DD with met dental care needs was highest in states with Extensive and Limited Medicaid Dental Coverage relative to states with Emergency or No Coverage.

| | Extensive Coverage | Limited Coverage | Emergency Coverage | No Coverage |
|-----------------------------------|--------------------|------------------|--------------------|-------------|
| % Met Dental Care Need | 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 | 440,568 | 109,031 |

We then assume that 66% of adults with I/DD on Medicaid with unmet dental care needs would benefit from specialized dental care. We also assume that adults with I/DD most likely to require specialized dental care are all or substantially all on Medicaid. This estimate was originally 33% but was revised upward after consultation with NCD’s research team. This produces an estimate of 1,150,105 adults with I/DD with specialized dental care needs.

For children with I/DD, we make use of only a single acuity cell reflecting all children with I/DD. We rely on Obeidat et al (2022), which uses data from the 2018 National Survey of Children’s Health to estimate that 3.5% of children with I/DD have unmet dental care needs as compared to 1.2% of children without I/DD.²⁶ We use the difference between these numbers (2.3%) as an estimate of the number of children with I/DD who require specialized dental care. This produces an estimate of 67,666 children with I/DD with specialized dental care needs. Although the percentage of specialized dental care need we use for children with I/DD is substantially lower than the percentage of adults with I/DD identified in our analysis, we believe this to be appropriate given that adults with I/DD are generally higher-acuity than children with I/DD due to the frequency with which individuals with less functional impairment no longer report service needs in adulthood.

Finally, we use the same process for estimating the number of persons with I/DD in congregate care settings as we undertook in our analysis of specialized medical care

²⁶ Obeidat R, Nouredin A, Bitouni A, Abdellatif H, Lewis-Miranda S, Liu S, Badner V, Timothé P. Oral health needs of US children with developmental disorders: a population-based study. BMC Public Health. 2022 Dec;22(1):1-0.

needs, applying the same estimate of the size of the congregate care population and the same assumption of 90% need in this cell. This produces an estimate of 285,779 people with I/DD residing in congregate care settings who require specialized dental care.

Overall, we estimate that 1,503,551 people with I/DD require specialized dental care, making up 19% of the total population of people with I/DD. This estimate is in line with data from Special Olympics International, which reports that 25% of the 123,000 young adults with I/DD who participated in Special Olympics dental screening from 2007-2018 have untreated tooth decay while 12% report pain in their mouth.²⁷ This population is slightly younger and is likely to have somewhat less severe functional impairment than the total population of people with I/DD, but provides a useful range that confirms the plausibility of our 19% estimate of specialized dental care need. This estimate was also reviewed by NCD's consulting experts and found to be plausible and consistent with their subject matter expertise.

Conclusions

Overall, we conclude that 2,584,785 people with I/DD have specialized medical care needs and that 1,503,551 people with I/DD have specialized dental care needs. These estimates identify distinct needs in overlapping populations and should be treated as separate figures for distinct purposes. Further work to estimate the total cost of implementing the HEADs UP Act will depend on the acquisition of cost data for the existing populations covered under the Federal Government's Medically Underserved Population categorization. Determining per capita cost data for the existing special MUP populations is an important next step in exploring cost. Rather than a set per capita figure for existing MUP populations, in consulting the Health Resources and Services Administration, NCD learned that the per capita figure for a new designated population as proposed in HEADs UP, would be the result of the funds appropriated to such an effort by policymakers.

To that end, NCD sought to further explore additional factors to inform policymakers' consideration of appropriations. In consultation with relevant subject matter experts, we have concluded that a 2-3x multiplier could reasonably be applied to per capita estimates of the cost of serving people in existing MUP populations, to account for the more intensive service needs of people with I/DD relative to existing groups with a special MUP designation. To produce a cost estimate, the per capita cost estimate should have applied a 2-3x multiplier, and then multiply it by the size of the population with specialized medical care needs.

²⁷ Special Olympics. Special Olympics Releases New Oral Health Resources with The Smile Generation. Available at: <https://www.specialolympics.org/stories/news/special-olympics-releases-new-oral-health-resources-with-the-smile-generation>

As the existing MUP designation does not include the dental care programs encompassed by the HEADs Up Act, this analysis should not include the dental figures arrived at in this analysis. We note also that our estimate of specialized dental care need includes a population that is likely to substantially overlap the population with specialized medical care need – as such, these two estimates should under no circumstances be added together as this would result in a substantial overestimate of relevant costs.

NCD staff have an Excel file with relevant figures already plugged into it to enable the quick estimate of a cost score for the HEADs Up Act's special MUP designation for people with I/DD as soon as the requested per capita cost data is assessed, ready to provide to interested congressional offices. Please email Amged Soliman, Senior Attorney Advisor, at asoliman@ncd.gov for more information.