

# The Impact of Distance to Specialty and Primary Care on Health Outcomes and Service Use in Adults with Down Syndrome

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**Why this matters:** Adults with Down syndrome (DS) are living longer, and require healthcare to manage age related and co-occurring conditions. Two important health care resources for people with Down syndrome are specialty intellectual and developmental disability clinics and primary care providers. Specialty clinics provide comprehensive, multidisciplinary care tailored to people with Down syndrome, and primary care providers provide ongoing preventative and routine care. Studies suggest that few adults with Down syndrome in the US receive the healthcare that they need, and many intellectual and developmental disability clinics only serve children, leaving adults without specialty care. People with Down syndrome can live in health deprived areas where limited healthcare resources make it challenging to access the comprehensive care needed to support increasing life expectancy in this population. It is important to examine specialty clinics and primary care in context of what we know about how distance and access to healthcare impacts health.

**What we did:** We examined a near full cohort of 89,382 Medicaid enrolled adults with DS in 2019. in 20 million adults with IDD enrolled in Medicaid during 2022. We identified 27 specialty clinics that serve adults with DS in the US and used residential zip codes to estimate driving distance to the nearest clinic. We also evaluated the availability of primary care providers by county. We examined if distances to specialty clinics were associated with mortality, hospitalization, healthcare costs, and healthcare utilization.

**What we found:** We found that greater distance from specialty clinics was associated with higher mortality in our cohort. After adjusting for age, sex, rurality, poverty level, and state-level differences, mortality was 16% higher among enrollees in the third quartile of distance and 27% higher in those in the furthest quartile (Quartile IV), compared to those living within 48 miles of a specialty clinic. We also found significant distances in geographic variation in access to care. Specialty clinics were unevenly distributed across the US, and many areas had limited access to clinics for adults with DS. Our study did not find any associations with primary care provider availability and mortality or hospitalizations.

**What it means:** Our study highlighted the importances of equitable access to both primary and specialized care for adults with Down syndrome. Expanding specialty care clinics and strengthening primary care resources in underserved areas may help address geographic barriers and improve health outcomes.

**What to do next:** Please contact us at [salina26@bu.edu](mailto:salina26@bu.edu) or [erubens@bu.edu](mailto:erubens@bu.edu) for further questions or data requests.

Table 1. Demographic Table of Medicaid adults with Down syndrome in 2019 by Distance (Quartile) and Primary Care Availability.

|                                |                  | Distance to specialty clinic, by quartiles |                                     |                                       |                                   | Primary care provider availability |                                   |                                |
|--------------------------------|------------------|--------------------------------------------|-------------------------------------|---------------------------------------|-----------------------------------|------------------------------------|-----------------------------------|--------------------------------|
|                                |                  | Quartile I (0-48 mi)<br>N=22,310           | Quartile II (49-123 mi)<br>N=22,373 | Quartile III (124-245 mi)<br>N=22,352 | Quartile IV (>246 mi)<br>N=22,347 | High availability<br>(N=35,547)    | Medium availability<br>(N=18,938) | Low Availability<br>(N=17,258) |
| Deaths in 2019                 | Total: 2,863     | 449 (2.27)                                 | 758 (3.45)                          | 773 (3.70)                            | 683 (3.29)                        | 1111 (46.4)                        | 639 (26.7)                        | 643 (26.8)                     |
| Age at study enrollment (2019) | 18-25            | 5060 (22.7)                                | 4609 (20.6)                         | 4534 (20.3)                           | 4956 (22.2)                       | 7756 (21.8)                        | 4062 (21.4)                       | 3285 (19.0)                    |
|                                | 26-34            | 5689 (25.5)                                | 5386 (24.1)                         | 5281 (23.6)                           | 5581 (25.0)                       | 8563 (24.1)                        | 4540 (24.0)                       | 4008 (23.2)                    |
|                                | 35-44            | 4044 (18.1)                                | 4085 (18.3)                         | 4269 (19.1)                           | 4484 (20.1)                       | 6421 (18.1)                        | 3498 (18.5)                       | 3426 (19.9)                    |
|                                | 45-54            | 3653 (16.4)                                | 3939 (17.6)                         | 4057 (18.2)                           | 3691 (16.5)                       | 6229 (17.5)                        | 3366 (17.8)                       | 3127 (18.1)                    |
|                                | 55-64            | 3109 (13.9)                                | 3479 (15.5)                         | 3350 (15.0)                           | 2952 (13.2)                       | 5322 (14.9)                        | 2790 (14.7)                       | 2736 (15.9)                    |
|                                | 65-89            | 755 (3.4)                                  | 875 (3.9)                           | 861 (3.9)                             | 683 (3.1)                         | 1256 (3.5)                         | 682 (3.6)                         | 676 (3.9)                      |
| Race†                          | White            | 14,251 (65.2)                              | 16,822 (76.2)                       | 17,405 (79.9)                         | 15,690 (72.0)                     | 25856 (74.5)                       | 13784 (74.7)                      | 14326 (84.7)                   |
|                                | Black            | 4,008 (18.3)                               | 3,209 (14.5)                        | 3,049 (14.0)                          | 2,267 (10.4)                      | 6243 (18.0)                        | 2822 (15.3)                       | 1733 (10.2)                    |
|                                | Pacific Islander | 137 (0.6)                                  | 101 (0.5)                           | 109 (0.5)                             | 425 (2.0)                         | 219 (0.6)                          | 180 (1.0)                         | 86 (0.5)                       |
|                                | Asian            | 1,225 (5.6)                                | 730 (3.3)                           | 274 (1.3)                             | 937 (4.3)                         | 943 (2.7)                          | 522 (2.8)                         | 158 (0.9)                      |
|                                | Native American  | 45 (0.2)                                   | 86 (0.3)                            | 140 (0.6)                             | 456 (2.1)                         | 220 (0.6)                          | 152 (0.8)                         | 151 (0.9)                      |
|                                | Mixed            | 2,209 (10.1)                               | 1,119 (5.1)                         | 807 (13.1)                            | 2,030 (9.3)                       | 1244 (3.6)                         | 981 (5.3)                         | 459 (2.7)                      |
| Ethnicity††                    | Non-Hispanic/    | 17,216 (78.7)                              | 18,374 (83.3)                       | 18,946 (87.0)                         | 16,875 (77.4)                     | 29903 (86.1)                       | 15246 (82.7)                      | 15198 (90.0)                   |
|                                | Latino           | 4,659 (21.3)                               | 3,693 (16.7)                        | 2,838 (13.0)                          | 4,930 (22.6)                      | 4822 (13.9)                        | 3195 (17.3)                       | 1715 (10.1)                    |
| Sex                            | Male             | 11,419 (51.1)                              | 11,585 (51.8)                       | 11,788 (52.7)                         | 11,678 (52.2)                     | 18871 (53.0)                       | 9857 (52.0)                       | 9118 (52.8)                    |
|                                | Female           | 10,891 (48.9)                              | 10,788 (48.2)                       | 10,564 (47.2)                         | 10,669 (47.7)                     | 16,676 (47.0)                      | 9081 (48.0)                       | 8140 (47.1)                    |
| Region                         | Northeastern     | 5035 (22.6)                                | 9360 (41.8)                         | 4297 (19.2)                           | 1166 (5.2)                        | 7386 (20.8)                        | 6777 (35.8)                       | 4552 (26.3)                    |
|                                | Midwest          | 5949 (26.7)                                | 4677 (20.9)                         | 5974 (26.7)                           | 4039 (18.1)                       | 10686 (30.1)                       | 4717 (24.9)                       | 5143 (29.8)                    |
|                                | South            | 4943 (22.2)                                | 5082 (22.7)                         | 9744 (43.6)                           | 8773 (39.2)                       | 14937 (42.0)                       | 5780 (30.5)                       | 6079 (35.2)                    |
|                                | West             | 6379 (28.6)                                | 3249 (14.5)                         | 2331 (10.4)                           | 8366 (37.4)                       | 2530 (7.1)                         | 1661 (8.8)                        | 1481 (8.6)                     |
| Eligibility type (ever)        | Disability       | 17275 (77.4)                               | 17799 (79.6)                        | 18220 (81.5)                          | 16926 (75.7)                      | 28246 (80.0)                       | 14784 (78.0)                      | 13811 (79.8)                   |
|                                | Income           | 13181 (59.1)                               | 12282 (54.9)                        | 12467 (55.8)                          | 13935 (62.4)                      | 19221 (54.9)                       | 10992 (58.3)                      | 8644 (50.1)                    |
| Dual enrollment Medicare       | Yes              | 12113 (54.3)                               | 13416 (60.0)                        | 13914 (62.2)                          | 12749 (57.1)                      | 21350 (60.1)                       | 11349 (59.9)                      | 11095 (64.3)                   |
|                                | No               | 10197 (45.7)                               | 8957 (40.0)                         | 8438 (37.8)                           | 9598 (42.9)                       | 14197 (39.9)                       | 7589 (40.1)                       | 6163 (35.7)                    |

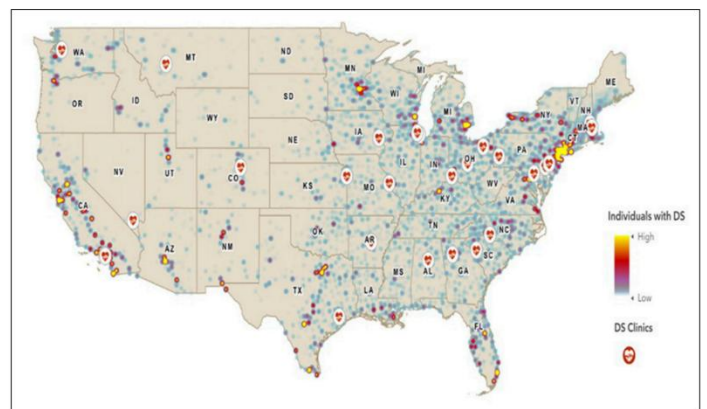


Figure 1. Intellectual and developmental disability specialty clinic locations and density of adults with Down syndrome in 2019 in the continental US.