STUDY FACT SHEET

Medicaid enrollment and service use among adults with Down syndrome: comparisons to the intellectual disability population and other Medicaid enrollees, 2011-2019

Eric Rubenstein, Amy Michals, Na Wang, Ashley Scott, Salina Tewolde, A. Alex Levine, Yorghos Tripodis, Brian Skotko Published in JAMA Health Affairs (https://jamanetwork.com/journals/jama-health-forum/fullarticle/2808292)

Why is this important? **Medicaid** is the major health insurance provider for adults with Down syndrome in the US. People with Down syndrome are at high risk for health conditions like dementia and obesity, and are more likely to die prematurely. With longer lifespans, we aimed understand patterns in Medicaid use to ensure the health care needs of the Down syndrome population are met.

What we did: We created the **Down Syndrome Towards Optimal Trajectories and Health Equity using Medicaid Analytic eXtract**(DS-TO-THE-MAX) cohort of all Medicaid enrollees ≥18 years with Down syndrome. We looked at demographics, counted claims, costs and compared to other groups.



Adults with Down syndrome

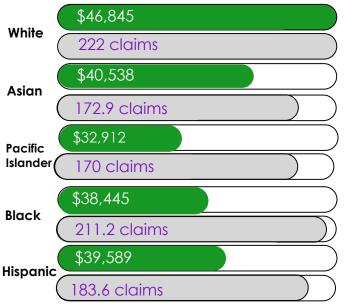
Were Hispanic ethnicity (20,000 people)

17% Were Black race (17,000 people)

Average age

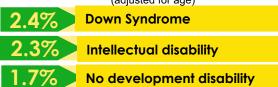
3.6% Older than 65 years in 2019

Costs and claims per person per year in the Down syndrome cohort by race and ethnicity:





Percent hospitalized per year: (adjusted for age)







Risk of death compared to people without Down syndrome (adjusted for age)

1.7X

Were enrolled in both Medicaid and Medicare 60%

Key Takeaway: Medicaid plays a key role in insuring adults with Down syndrome and facilitating access to health services. Given the consistent and near-universal enrollment, Medicaid data are a tremendous tool for understanding the health and well-being of the Down syndrome population and improving the quantity and quality of service is critical.