GRANT YEAR 2: 2022-2023

DS-TO-THE-MAX

Down syndrome towards optimal trajectories and health equity using Medicaid Analytic eXtract

Project funded by the National Institutes on Aging R01AG073179, R01AG073179-S1

What we've done
What we are doing
What we are going to do

A note from Eric

This year has been busy for the DS-TO-THE-MAX team. We have grown in size, both in team members and data. We have finalized our cohorts, which is this first step to finding out how to improve the health of adults with Down syndrome. We published four manuscripts, presented at conferences, and given invited talks. Our co-research team has been prolific, conducting a study on mental health and Down syndrome. Your support has been crucial to our success, and I want this opportunity to brag about the work done by this tremendous team. In this newsletter you will find research updates, study team updates, and next steps. I look forward to all the success and challenges of Grant Year 3!

-Eric

Team members

Investigators
- Eric Rubenstein (PI)
- Brian Skotko
- Yorghos Tripodis
- Matt Fox
- Jaimie Gradus
- Jennifer Weuve

Staff
- Ashley Scott
- Keryden Koeut-Futch
- Salina Tewolde
- Amy Michals
- Na Wang
- Kristina Astone
- Katie Hartlage
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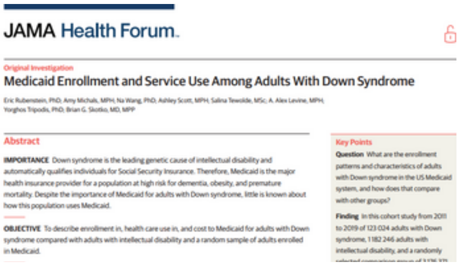
Co-researchers
- Gus Edouard
- Alexis Sokoloff
- Caley Versfelt
- Benjamin Golden
- Kaethe Sigelko
- Eden Rapp
- Stacy Christensen

Research Assistants
- Liam Quidore
- Alex Levine
- Prisha Sujin Kumar
- Emily Bock
- Ryan Gould
- Alyssa Santoso
- Ryan Zukowski

What we’ve done

Year 2 Publications


JAMA Health Forum.

Original Investigation

Medicaid Enrollment and Service Use Among Adults With Down Syndrome

Eric Rubenstein, PhD; Amy Michals, MPH; Na Wang, PhD; Ashley Scott, MPH; Salina Tewolde, MSc; A. Alex Levine, MPH; Yorghos Tripodis, PhD; Brian G. Skotko, MD, MPP

Abstract

IMPORTANCE Down syndrome is the leading genetic cause of intellectual disability and automatically qualifies individuals for Social Security Insurance. Therefore, Medicaid is the major health insurance provider for a population at high risk for dementia, obesity, and premature mortality. Despite the importance of Medicaid for adults with Down syndrome, little is known about how this population uses Medicaid.

OBJECTIVE To describe enrollment in, health care use in, and cost to Medicaid for adults with Down syndrome compared with adults with intellectual disability and a random sample of adults enrolled in Medicaid.

Key Points

Question What are the enrollment patterns and characteristics of adults with Down syndrome in the US Medicaid system, and how does that compare with other groups?

Finding In this cohort study from 2011 to 2019 of 123 024 adults with Down syndrome, 1 182 246 adults with intellectual disability, and a randomly

Medicaid Enrollment and Service Use Among Adults with Down Syndrome

Findings: From 2011 to 2019 of 123,024 adults with Down syndrome, 1,182,246 adults with intellectual disability, and a randomly selected comparison group of 3,176,371 individuals without developmental disabilities, adults with Down syndrome were more consistently enrolled in Medicaid and had higher costs and service use compared with the random sample

Link: rb.gy/pxkyr

Caregiver’s concerns and supports needed to care for adults with Down syndrome

Findings: We conducted a survey of 438 caregivers of adults with Down syndrome and asked about perspectives on surrounding caregiving and demographics. Most common concerns among care- givers were planning for future needs (72.1%) and what happens when they (the caregiver) are gone (68.3%). Concerns for the individual they cared for were employment (63.2%) and relationships (63.2%). We identified six themes about what clinical and research professionals should know to serve individuals with Down syndrome, their families, and those who support them.

Link: https://shorturl.at/qwW49


RESEARCH ARTICLE

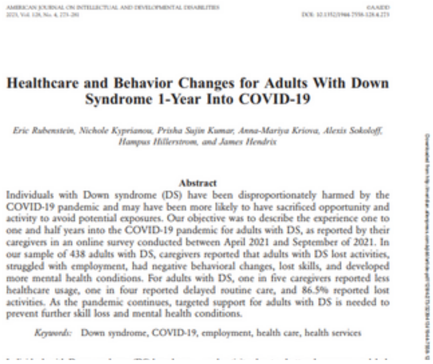
WILEY

Caregivers' concerns and supports needed to care for adults with Down syndrome

Erica De La Garza[1] | Ashley Scott[1] | Hampus Hillerstrom[2] | James Hendrix[3] | Eric Rubenstein[1]

Abstract

Research regarding caregivers for individuals with Down syndrome mainly focuses on outcomes for the pediatric population and not on the experience of caregivers themselves. Our objective was to understand caregiver-reported experiences and concerns for themselves and the individual they care for through a survey of caregivers of adults with Down syndrome. We conducted a survey of N = 438 caregivers of adults with Down syndrome and asked about the perspectives of the respondents surrounding caregiving and demographics. The most common concerns among caregivers were planning for future needs (72.1%) and what happens when they (the caregiver) are gone (68.3%). Concerns they had for the individual they cared for were employment (63.2%) and friendships/relationships (63.2%). We found no significant difference in responses based on caregiver education level. Our survey identified six themes for the feedback about what clinical and research professionals should know to better serve individuals with Down syndrome, their families, and those who support them. Many caregivers discussed topics including healthcare, coordination, competence, and ability. More efforts for research into the caregiver experience for adults with Down syndrome are needed.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Healthcare and Behavior Changes for Adults With Down Syndrome 1-Year Into COVID-19

Eric Rubenstein, Nichole Kyprianou, Prisha Sajin Kumar, Anna-Mariya Kriova, Alexis Sokoloff, Hampus Hillerstrom, and James Hendrix

Abstract

Individuals with Down syndrome (DS) have been disproportionately harmed by the COVID-19 pandemic and may have been more likely to have sacrificed opportunity and activity to avoid potential exposures. Our objective was to describe the experience one to one and half years into the COVID-19 pandemic for adults with DS, as reported by their caregivers in an online survey conducted between April 2021 and September of 2021. In our sample of 438 adults with DS, caregivers reported that adults with DS lost activities, struggled with employment, had negative behavioral changes, lost skills, and developed more mental health conditions. For adults with DS, one in five caregivers reported less healthcare usage, one in four reported delayed routine care, and 86.5% reported lost activities. As the pandemic continues, targeted support for adults with DS is needed to prevent further skill loss and mental health conditions.

Keywords: Down syndrome, COVID-19, employment, health care, health services

Healthcare and behavior change for adults with Down syndrome 1-year into COVID-19

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Link: https://shorturl.at/wDNQ4

Co-Research with the Experts Webinar

March 21, 2023

Our webinar was a dynamic event featuring the work of four research teams of individuals with and without disabilities that engage in co-research collaboratively. Co-research teams presented on:

- Developing quality of life measures - Brendan Durkin, Jacob Myer, and Dr. Ariel Schwartz
- Data collection methods - Dr. Jessica Kramer and her team members Fiorella Guerrero, Bianca Camacho, Cyril Nonga-Mann, and Elijah Thomas
- Research training and coping during the pandemic - Edward Kastern and Marquis Garner with Dr. Karla Ausderau
- Mental health for adults with Down syndrome - Kaethe Sigelko and Eden Rapp with Dr. Eric Rubenstein

Following these team presentations, lead investigators provided their perspectives on the significance of co-research in shaping their projects. The webinar ended with disability justice advocate and public health expert Mallory Cyr addressing the issue of ableism in academic research.

Learn more about the webinar and featured research projects here.


RESEARCH WITH THE EXPERTS: FINDINGS FROM CO-RESEARCHERS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES AND THE IMPORTANCE OF INCLUSION ON RESEARCH TEAMS WEBINAR

Learn about research projects with and about people with intellectual and developmental disabilities from co-researchers, research experts, and disability advocates across the US!

Join us in celebrating the work of co-researchers!

Tuesday, March 21st, 2023

12:00-1:30PM EST

What we are doing

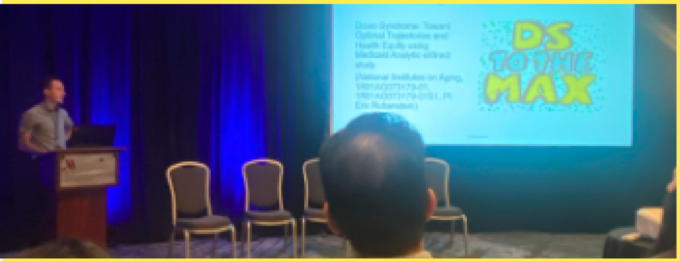
Co-Research team

This has been an amazing year for our co-research team! The year started with learning about research, practicing our skills, and deciding on our research topic- mental health. We designed a survey all about how people with Down syndrome manage their mental health. We had 60 adults with Down syndrome respond and are analyzing the data now. We are getting ready to share our exciting results.

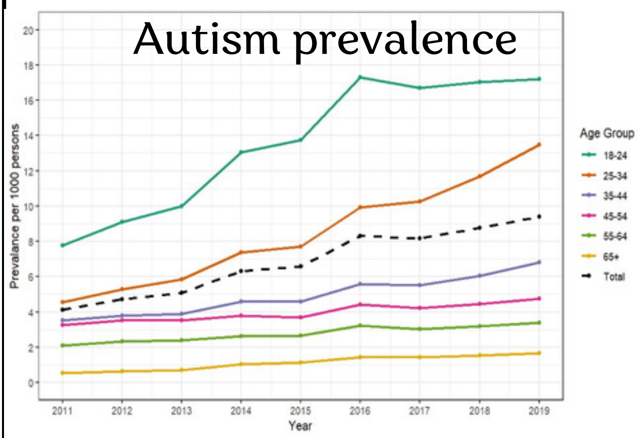
We had a lot of great speakers this year, including Drs. Brian Skotko, Setphanie Santoro, and Megann Lloyd; and Lori and Stephen Saux and Hampus Hillerstrom from LuMind IDSC. Eden, Kaethe, and Caley presented at the Co-Research Webinar, and Gus guest lectured in a class. Alexis and Benjamin wrote great blogs on our website and Staci joined our team from Utah. We recently started working on our interviewing skills

Co-Research Team One Year Celebration

Research in progress

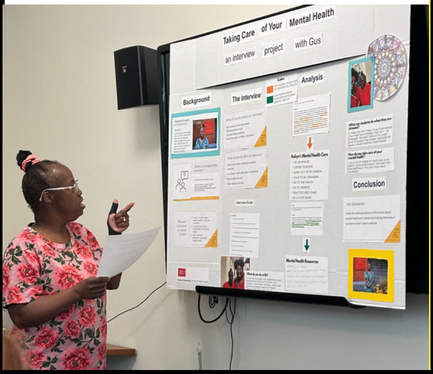


Alex Levine, PhD candidate, is researching how Home and Community Based Service waivers are administered and whether they improve health outcomes for people with intellectual and developmental disabilities. They presented their findings at two national conferences

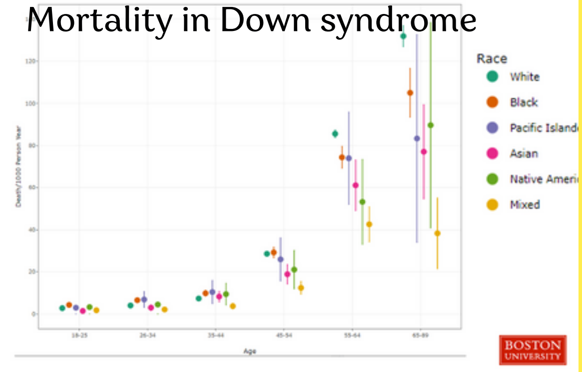


We examined autism prevalence in Medicaid. 403,028 unique adults had autism claims in their Medicaid records. Three fourths were male, 74.2% were white, 16.8% were black, and 87.8% were non-Hispanic. Across all ages, autism prevalence went from 4.2/1000 enrollees in 2011 to 9.5/1000 enrollees in 2019. The largest increase over the 9 years was in the 25-34 age range (195% increase). Prevalence of white enrollees was at least 2 times that of the prevalence of every other racial group in all age categories.Despite difficulties in identifying autism in adults, there is a considerable and growing population of autistic adults in Medicaid. This paper is in press at JAMA Psychiatry

Gus Edouard presenting her summer internship interview project



Salina Tewolde and Ashley Scott have examined whether minoritized people with Down syndrome have greater mortality and hospitalization risk than white people with Down syndrome, and whether that differs from white-non-white disparities in the general population. They presented this work at the Disability Health Equity Research Network Summer meeting

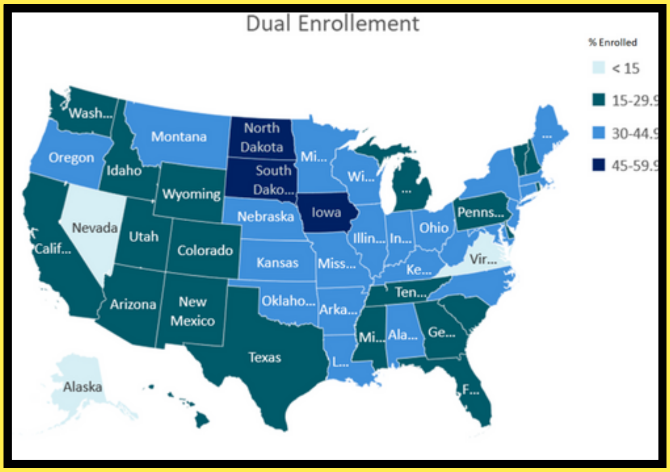


What we are going to do

2023-2024 Projects

Dementia and sleep apnea

This year, we will focus on documenting, understanding, and predicting dementia and sleep apnea using Medicaid and Medicare data. First, we will describe who has these conditions, when they develop symptoms, and whether factors like where someone lives impacts disease. We also will explore what treatments people with Down syndrome use and whether there are differences by race, ethnicity, and sex.



Mapping Down syndrome

Where you live has major impacts on your health. We want to know how community level factors and access to Down syndrome clinics impact folks with Down syndrome. We have already mapped health insurance by state, but now will map how far people live to Down syndrome clinics, what types of areas people with Down syndrome live (e.g., rural, urban, rich, poor) and whether those factors are associated with health.

Conferences

national down syndrome society
ADULT SUMMIT
CINCINNATI • 2023

This November, we will present at the NDSS Adult Summit. BU staff and co-researchers will present on all things mental health, Down syndrome, and co-research. See you in Cincinnati!

We are also excited to go to the T21RS conference in Rome in June and the IASSID conference in Chicago.

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