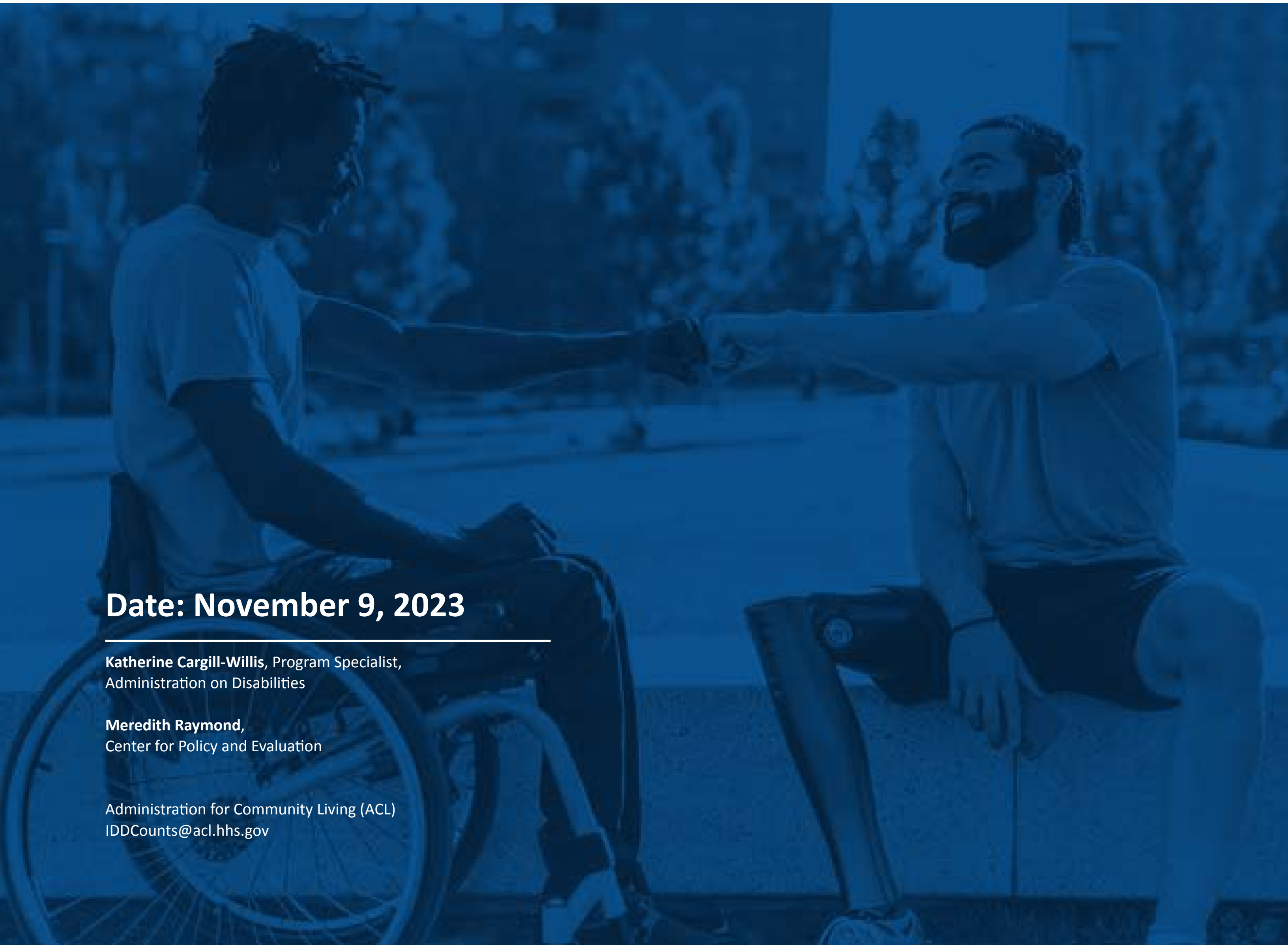
Administration for Community Living

I/DD COUNTS Quarterly Newsletter



Date: November 9, 2023

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I/DD Counts Initiative and Project Update:

The Administration for Community Living (ACL) is leading the ***I/DD Counts*** initiative in partnership with self-advocates, advocacy organizations, researchers, and U.S. Department of Health and Human Services agencies to:

1. Establish and maintain accurate data on the prevalence of intellectual and developmental disabilities (I/DD) in the United States and its territories, and;
2. Improve the collection, analysis and interpretation of the health-related data of people with I/DD.

These quarterly updates provide information from ACL and its collaborators on progress toward the 10-year plan to guide the development of the health surveillance system for people with I/DD.

The I/DD counts team wanted to hear directly from people with I/DD about what matters to them when researchers and policy makers use their health information. This includes how the information is collected and used to understand how people with I/DD are doing in the United States. The I/DD Counts team organized three focus groups to gather that information. A total of 16 adults with I/DD participated in the focus groups.

A member of the I/DD Counts team helped write a paper that was published in October 2023 about what the researchers learned. The important messages are below:

- ***Privacy is important to people with I/DD.*** They may not want to share all information with support providers, and they may not let strangers know that they have a disability. Relying only on reports by others (also called proxy reporting) may not give the full picture of their health. Some health care professionals have negative attitudes about people with I/DD and that makes it hard to talk with them.
- ***There is a need for better data on the health of people with I/DD.*** This includes information to improve health care and information about what they can expect as they get older (also called longitudinal data). This data should include information on mental health, dental health and difficulties accessing health care.
- ***It is important to gather data about where and with whom people live.*** Health is influenced by people's living situations.

- ***Self-determination and choice are very important.*** People with I/DD should be part of the decisions about their care.

The I/DD Counts team hopes that the lessons from the paper will be shared with policy-makers, advocates, support providers, and program staff and health care providers.

For more details on the study and its findings, see:
Krahn, Cargill-Willis, Bersani, Moore & Johnson. (2023). Recruiting the voices of persons with intellectual and developmental disabilities in policy development: Priorities for health equity data. Intellectual and Developmental Disabilities, October 2023.

Federal Interagency Workgroup on I/DD Administrative Data

Quick Summary:

- This workgroup brings together people who work in different federal agencies. Workgroup members share information about ways their agencies are collecting or using data that describes the health of people with intellectual and developmental disabilities. The group also shares information about projects that their agencies are working on that will improve health related data.
- We are learning more about people with intellectual disabilities in the United States by looking into information that is collected when people use public services like education and health care. This kind of information is called "administrative data" because it is collected to help provide or "administer" public services.
- This quarter, a representative from the Office of Special Education Programs, U.S. Department of Education, joined the workgroup. The workgroup learned about publicly available data profiles that can be used to discover how many children and young adults get special education services in each state, what kind of disability they have, race and ethnicity, gender, and whether they are English language learners. Referred to as "IDEA Section 618" data, these data profiles are on the Department of Education website.
- This type of data is helpful in understanding more about the young people receiving special education services who have intellectual disabilities.
- **Point of contact:** Alixe Bonardi, abonardi@hsri.org; Amanda Reichard, Amanda.Reichard@acl.hhs.gov

Assessing Outcomes Relevant for Patient-Centered Outcomes Research Among Adults Aged 18–64 with Disabilities and Federal Data Infrastructure Opportunities

Quick Summary:

- This report identifies individual-level measures for conducting patient-centered outcomes research (PCOR) important to adults with disabilities, aged 18–64 years. It identifies six broad outcome domains important to PCOR for this population from prior research, including: (1) social and community engagement; (2) choice and control; (3) employment and self-sufficiency; (4) privacy, rights, and human security; (5) health-related social needs; and (6) health and wellbeing. Additionally, the report identifies 32 sources of measures across the domains that include standardized tools/instruments, routinely fielded surveys, and administrative datasets.
- Access the full report and inventory here.
- **Point of contact:** Madjid Karimi, Madjid.Karimi@hhs.gov

Institute for Exceptional Care's Project/Research Updates

Quick Summary:

- We have recruited data scientists from Epic, the largest electronic health record company in the country, and over 15 self-advocates with I/DD and family members to join our Making I/DD Visible team. This team is developing a machine learning tool that can detect the health records for people with I/DD, even if they don't have a diagnosis of I/DD in their record. The team has decided to focus on a series of steps to detect autism, and separately, intellectual disability. We submitted an abstract to ARPA-H for potential funding, and are planning to submit an NIH grant proposal as well.
- We have begun a study with Milliman, the healthcare actuarial firm, to estimate the number of people with I/DD by reviewing commercial health insurance records. We will compare what we learn to estimates of the number of people with I/DD based on other research including CDC ADDM monitoring, NHIS data, and (old) surveys of adults. We will describe the data based on types of I/DD, age, sex, and geography.

- At the same time, we are planning an analysis with Mathematica Policy Research using TMSIS (the “Transformed Medicaid Statistical Information System’’) data on people who are eligible for both Medicare and Medicaid. This project will also look at differences in I/DD prevalence based on whether specific states have policies related to educational or healthcare benefits that make certain I/DD diagnoses more favorable (for example, policies that ensure learning accommodations only for children who have autism or ADHD, etc.). We will also examine differences in the prevalence of “substitute” diagnoses such as oppositional behavior disorder, which do not result in eligibility for public benefits and that people think could be more common among Black/Brown children than white children.
- **Point of contact:** Mai Pham, mai.pham@ie-care.org

National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)

Update from NIDILRR

Quick Summary:

- The National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) funded seven new research grants addressing topics of interest for people with intellectual and developmental disabilities (I/DD). These research studies started September 1, 2023 and are described below:
    - Developing approaches to support employment for people with I/DD using computer-generated sound or sight supplement to assist with job tasks.
    - Developing a new research center focused on improving opportunities for people with I/DD to participate in community living.
    - Understanding whether minority youth are prepared for the changes in health care that will take place when they become adults.
    - Training supervisors to work with individuals with I/DD to improve the employment experiences.
    - Making a new way for youth and young adults with I/DD to improve community participation by improving accessible travel options for them.

  - Studying ways to do research with individuals with I/DD when researchers and subjects people are in different locations and are using tools like video conference to communicate. Developing a new way to make employment better for adults with Autism.
- **If you have questions contact:** Amanda Reichard, Amanda.Reichard@acl.hhs.gov

Centers for Disease Control and Prevention, Prevention Research Center, NYU/CUNY, Special Interest Project: Four State Disability and Health Data Analysis Collaborative

Update from CDC

Quick Summary:

- A project team funded by the Centers for Disease Control/National Center on Birth Defects and Developmental Disabilities includes partners from Massachusetts, Kansas, South Carolina and New York will form a Disability and Health Data Collaborative (DHDC). The team is building on twelve years of work. The goal of the current study is to compare the ways that different groups use health services. Those groups are:
  - People with I/DD and severe mental illness;
  - People with severe mental illness without I/DD and;
  - People with I/DD without severe mental illness.
- The project used two different data sources; the first source is Medicaid reimbursement files and the second is Center for Medicaid and Medicare (CMS) combined Medicaid and Medicare files, for people from birth to age 45. The analysis will look at differences in health services used by people who live in cities and those who live elsewhere. This is a two-year project that began in October 2022 and will go until October 2024. The audience for the research is the National Center on Birth Defects and Developmental Disabilities, the four state Medicaid agencies, the disability agencies in the four states, and advocates for people with I/DD and those with serious mental illness.

- **Key Initiatives:**
    - Review data from the two data sources.
    - Identify gaps and establish the diagnosis that will be included when doing the data analysis in rural areas.
    - Ensure that the data are organized to allow the researchers to compare how the three groups use health services and understand how living in urban or rural settings or other demographic characteristics may affect health care use.
- **Issues or Challenges**
    - One of the four states has not provided Medicaid data yet. This issue is being addressed.
- **Next Steps:**
    - Since we meet every two weeks, we expect to stay on target and accomplish the stated goals during the next quarter.
- **Point of contact:** Suzanne McDermott, Suzanne.Mcdermott@sph.cuny.edu

Centers for Medicare & Medicaid Services (CMS): Disparities in Health Care in Medicare Advantage Associated with Dual Eligibility or Eligibility for a Low-Income Subsidy and Disability Stratified Report

Update from CMS

Quick Summary:

- The Centers for Medicare & Medicaid Services' Office of Minority Health (CMS OMH) released a report in July 2023 detailing the kind of care that people in the Medicaid Advantage program received. *The Disparities in Health Care in Medicare Advantage Associated with Dual Eligibility or Eligibility for a Low-Income Subsidy and Disability* report shares information on people with Medicare Advantage in 2020. This report compares care for four groups of people in Medicare Advantage who have (1) dual eligibility for Medicare and Medicaid or eligibility for a Part D Low-Income Subsidy (LIS) and/or (2) a disability.

- This report is based on an analysis of data from medical records and administrative data about care that Medicare Advantage enrollees received for many medical issues, including diabetes, cardiovascular disease, and chronic lung disease.
- Access more information here.
- **Point of contact:** Sarah Johaningsmeir, sarah.johaningsmeir@cms.hhs.gov

Conference Updates

The I/DD Counts team will be presenting and having discussions with collaborators at these upcoming national meetings. Come find us!

- AUCD Conference (November 6 - 8, Washington D.C.)
- APHA Conference (November 12 - 14, Atlanta GA)
- TASH 2023 Conference (November 30 - December 3, Baltimore MD)

Contribution from:

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