2022

I/DD COUNTS SUMMIT REPORT

Executive Summary
March 2023

ACL
Administration for Community Living

BACKGROUND ON THE ISSUE

Reliable health data is important to supporting people with intellectual and developmental disabilities (I/DD). Being counted is a health equity and civil rights issue.

Although data collection about people with disabilities generally has improved in recent decades, there is still not enough information on how many people with I/DD live in the U.S., how healthy they are, and what things affect their health. Many health surveys exclude questions about I/DD altogether, and when information about people with I/DD is collected, often it lacks other important information like age, sex, ethnicity, and race. In addition, the way data are collected varies widely among states and even within states. In many cases, I/DD is not tracked at all unless a person is receiving services through a state or federally funded program. We have known about this problem for decades, but the COVID-19 pandemic has shown how important it is to have data.

Since 2016, the Administration for Community Living (ACL) has been working with federal agencies and other stakeholders to address these issues through the I/DD Counts initiative. I/DD Counts is a cross-agency initiative to improve how information about health of people with I/DD is collected, analyzed, and understood. I/DD Counts created and updated the 2030 Roadmap for Health Data Equity for Persons with I/DD.

ABOUT THE 2022 SUMMIT

In November 2022, ACL organized a national summit that included representatives from federal agencies, people with I/DD, advocacy groups, researchers, and health care providers. The group discussed progress in implementing the roadmap, remaining gaps, and priorities for the future. The summit focused on six areas:

Data needed by federal agencies

Data needed by advocacy groups

What federal agencies are doing to improve data

What other organizations are doing to improve data

How to share information from improved data

Tools and skills needed to improve data

This report summarizes the key ideas from the summit and next steps for the I/DD Counts initiative.

KEY IDEAS

- Include people with I/DD from the start on all projects about their health.

- Make sure everyone with I/DD is included – not just "easy to reach" groups.

- Use a common definition of I/DD so that data from different surveys can be compared.

- Major progress has been made, but there are still gaps in data.

- Collect more data on those things that affect health (like where you live or if you can get health care) so changes can be made to improve health.

- Collect data on things like race, ethnicity, gender identity, where a person lives, and income to understand how these things may lead to differences in the health of people with I/DD.
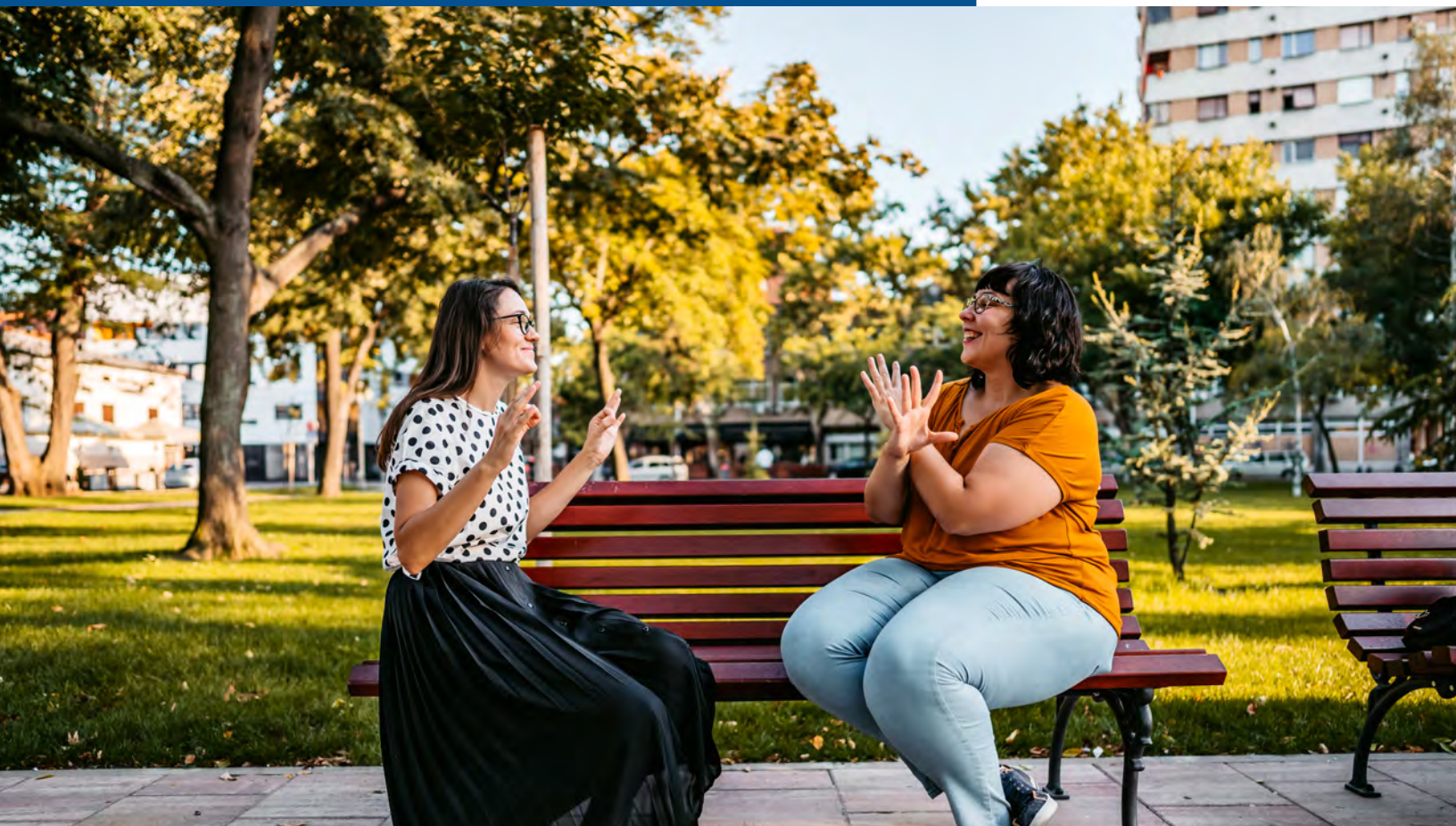
NEXT STEPS

The summit recommended actions in five areas:

Partnerships

- Include people with I/DD in all steps of the process.
- Build strong partnerships with federal and state government agencies, health insurers, and organizations that have health data.

Survey Data

- Use the same definition of I/DD across surveys.
- Help people with I/DD self-report.
- Make guidelines about self-reporting by people with I/DD and when other people can report on behalf of people with I/DD (proxy-reporting).

Administrative Data

- Make these data easier to use and make guidelines for how to use them.
- Understand how different states collect data and try to make it easier to compare data across states.

Tools and Skills for Analyses

- Look at how things like race, ethnicity, or gender affect health of people with I/DD.
- Consider creating more supports for better data collection and analysis. These could include a Center of Excellence and more training for people at the state level.

Sharing Information

- Develop information that is useful for different audiences like policymakers, self-advocates, researchers, and health care providers.
- Develop guidelines for making information easy to understand, actionable, and in plain language.

If these next steps are followed, we should have improved data by 2030 on how many people live with I/DD, their health, and their health needs.