

Learning More about Health of People with Intellectual and Developmental Disabilities (IDD)

An Easy Read Summary of Two Reports* from the Administration on Intellectual and Developmental Disabilities (AIDD) of the Administration for Community Living (ACL)

September 2019

The information in this paper comes from:

* Havercamp S, Krahn G, Larson S, and the National Health Surveillance for IDD Workgroup (2019). Working through the Data Conundrum: Identifying People with Intellectual and Developmental Disabilities in National Population Surveys.

* Bonardi A, Krahn G, Morris A, and the State and Local Administrative Data for IDD Workgroup (2019). Enriching our Knowledge: State and Local Data to Inform Health Surveillance of the Population with Intellectual and Developmental Disabilities.

Target audience:

This paper is developed for people with mild intellectual disability (ID) and some reading ability.

Development:

This paper was developed under contract by Gloria Krahn following the UK guidelines for Easy Read and US Department of Education guidelines (see below). The Disability Experience Expert Panel of the Nisonger Center’s Rehabilitation Research Training Center (RRTC) reviewed and provided valuable input.

UK Department of Health (2010). Making written information easier to understand for people with learning disabilities.

<https://www.gov.uk/government/publications/making-written-information-easier-to-understand-for-people-with-learning-disabilities-guidance-for-people-who-commission-or-produce-easy-read-information-revised-edition-2010>

US Department of Education (2014). Going public: Writing about research in everyday language.

<https://files.eric.ed.gov/fulltext/ED545224.pdf>

Recommended citation:

Administration for Community Living (2019). Learning More about Health of People with Intellectual and Developmental Disabilities (IDD): An Easy Read Summary.

I. THE PROBLEM: We don't know how healthy people are who have intellectual and developmental disabilities (IDD).

“IDD” means “intellectual and developmental disabilities”

We know a lot about how healthy people are in general. But, we don't know very much about how healthy people are if they have intellectual and developmental disabilities (IDD). From some studies, **we think people with IDD have more health problems** than others. But, we don't know if that is true for all people with IDD across the U.S.

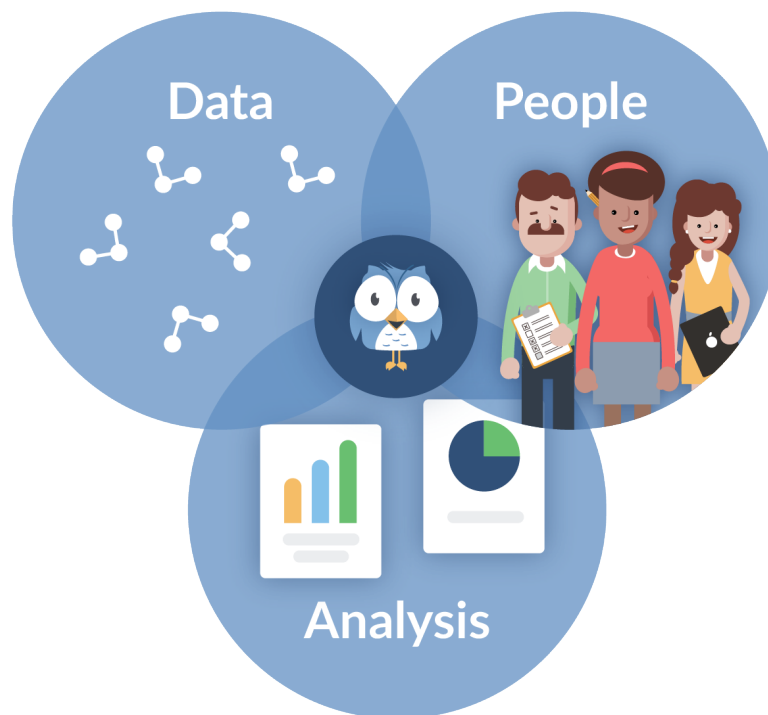
That is because people with IDD (intellectual and developmental disabilities) often are **left out of research studies and surveys**. That often happens for people who live in institutions. And, if they do participate in research surveys, researchers often don't know which answers came from people with IDD, so they can't develop facts about people with IDD.

What we need to know is:

- How many people in the U.S. have IDD (intellectual and developmental disabilities)?
- How healthy are they?
- What health problems do they have (like asthma, depression, diabetes)?
- What helps people with IDD be healthy?

People provide data for analysis. These data help governments and others know:

- What programs are needed to help people with IDD (intellectual and developmental disabilities) be healthy?
- Is money being spent for the right programs?
- How much does “where you live” matter for access to programs? (like group homes, or in the U.S. territories)



II. WHAT WE DID—Develop Workgroups to Learn More

A group of people met to talk about this in November 2017. It was people from:

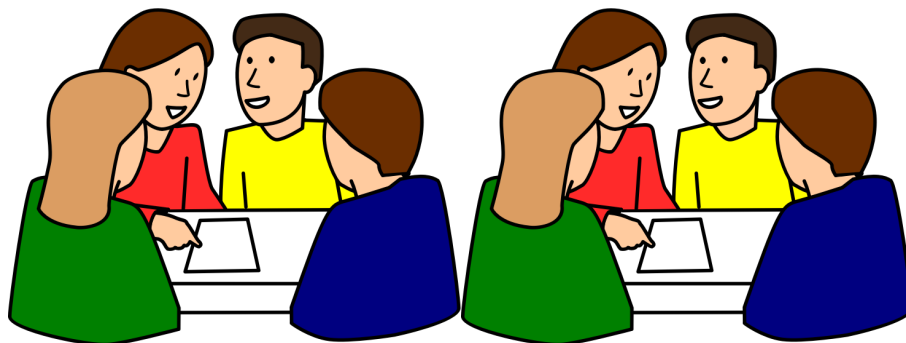
- Government agencies
- Advocacy groups and people with disabilities
- Researchers from around the U.S.

They agreed there are two ways to get this information:

- One way is from **U.S. national surveys**. We need to see what questions are needed so we can learn more about people with IDD (intellectual and developmental disabilities) across the U.S.
- The second way is from **state programs** like Developmental Disability (DD) services and education programs. Programs that already collect information on people with IDD include:
 - DD (Developmental Disability) Services
 - Education
 - Health care

In 2018, we formed **two national workgroups** to see **how** to do this:

1. National Survey Workgroup to look at US surveys.
2. State Data Workgroup to look at what data are available in states.



National Survey Group

State Data Group

III. WHAT THE WORKGROUPS LEARNED

A. U.S. NATIONAL SURVEYS

We can learn more about health of people with intellectual and developmental (IDD) from surveys that are already used. A survey is a set of questions that is asked of people around the country. Their answers are called data. The people who give their answers are called the sample.

A **Survey** is a set of questions that is asked of many people. A national survey asks people all around the country. One of the best surveys for health is the National Health Interview Survey.

The **Sample** is the people asked to answer the questions. It costs too much money to ask everyone. Instead, we choose people so that everyone has the same chance – like putting names into a basket and pulling out a few. If your name is pulled, you are part of the sample.

Data are the answers that people give to these questions. Answers are added up (or analyzed) to see how many people answer the same way.

Survey: Questions answered by Sample to give Data



Questions

+

Sample

=

Data

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1. WHAT WE LEARNED ABOUT SURVEYS:

Some surveys already have questions that ask:

- Are you able to see?
- Are you able to hear?
- Are you able to talk or sign so others understand you?
- Are you able to take care of yourself, like bathing and dressing?
- Are you able to earn money to pay for what you need?
- Are you able to walk or move around?

These questions help identify people with some kinds of disabilities (like vision, hearing, walking).

But surveys **don't have questions that identify people with intellectual disabilities.** So, surveys need to **add questions** that ask:

- **Do you have problems with learning or remembering?**
- **Do you need help to do things outside your home, like going shopping or seeing a doctor?**
- **How old were you when you first started having these problems?**

Some surveys ask about **seeing, hearing, talking, walking** or **moving,** and **taking care of yourself at home.**

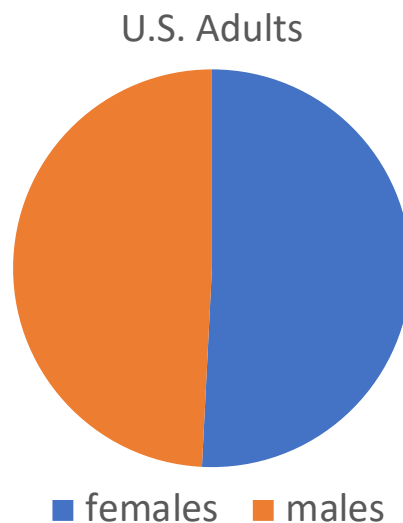
But, surveys usually do NOT ask about **learning, needing help outside of home,** and **age when these problems started.**

If surveys have these extra questions, they can help us know how many people in the U.S. have IDD (intellectual and developmental disabilities). This is called the **prevalence** of IDD (intellectual and developmental disabilities). Prevalence is a specific kind of percent or ratio.

Prevalence is a specific kind of percent or ratio. It is a number that says:

“of all the people in the country, how many are like this?”

For example, the prevalence of females in the U.S is 50.8%, or about 51 of every 100 adults is a female.



2. IDEAS FOR SURVEY NEXT STEPS:

- The National Health Interview Survey is one of the most useful surveys on health of people in the U.S. Work with people from the National Health Interview Survey to develop these new questions. Test the new questions to see if they work.
- Use and analyze these questions every year to track any changes that might happen over time. These questions should be used in other surveys too.
- Continue to have government agencies work together on this.
- Not all people from the U.S. Territories are part of surveys now. The U.S. Territories are American Samoa, Guam, the Northern Mariana Islands, Puerto Rico, and the U.S. Virgin Islands. People who live in the Territories need to be added to the sample of people who answer the surveys.

B. STATE PROGRAMS

The second way to learn about health of people with IDD (intellectual and developmental disabilities) is by looking at state programs. These programs already collect data on the people they serve. These are called **administrative data**.

Administrative data are the information that programs collect to show what they do and whom they serve.

These are programs like:

- **Special Education** –how many children and youth get special education services in school?
- **State Developmental Disabilities Services**—how many adults get different services for disabilities? This includes National Core Indicators data.
- **Public health insurance** (Medicaid and Medicare)—how many people have their health care paid by the government because they have IDD (intellectual and developmental disabilities)?

By looking at data in these programs, we can learn more about:

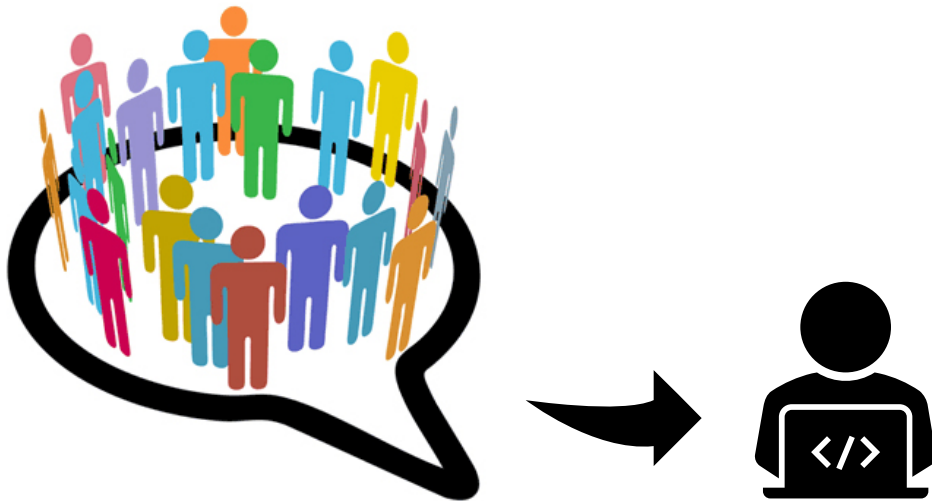
- Who are the people getting these services, like their race and age?
- What other disabilities do they have?
- What health services do they use?
- What is the rest of their life like that helps them be healthy, such as “where are they living?”

1. STATE EXAMPLES:

Many states are doing things to get better data about people with IDD (intellectual and developmental disabilities).

The workgroup described a few examples of states doing **new things to understand health of people with disabilities:**

A. Washington State has a program that **reaches out** to find people with disabilities who are **not getting disability services**. This gives information on what the needs are of people who are NOT getting services.



B. South Carolina and Ohio link data from different programs to learn more about people with disabilities.

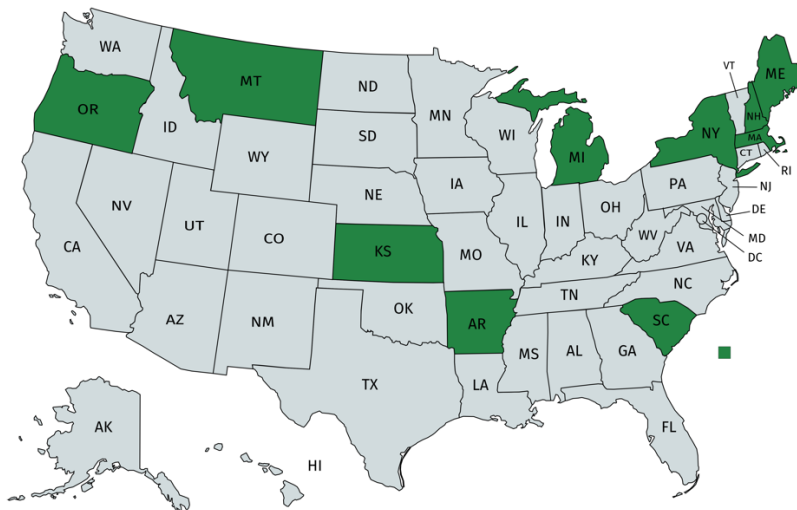
Data from one program (like DD Services) is linked with data from another program (like Education) to learn more about people with IDD (intellectual and developmental disabilities).



- c. **California is looking at race and language** of people with disabilities to see what helps some people be healthier. This study can also see if some groups of people are not as likely to get services.



- D. **Ten states are looking at the public health insurance** (Medicaid) data to learn about the diseases and health care that people with disabilities get. Those states are in green below:



2. IDEAS FOR NEXT STEPS FOR STATE DATA:

- Have different programs use the **same ways to identify people with IDD** (intellectual and developmental disabilities)—this would let us compare data across programs.
- Do **more research** to answer key questions, like what are the **best practices** across states.
- **Train more people to use data** to show state programs what is needed.
- **Get the word out** to more people on the health of people with IDD.

IV. SUMMARY:

- A. To plan services, governments and others need good data on:
- how many people have IDD (intellectual and developmental disabilities)?
 - how healthy are people with IDD?
 - What helps them be healthy?
- B. Two ways to get better data are:
- Add new questions to surveys so we can see who has IDD.
 - Use data that states already collect about people getting services for IDD.

*Better Data about people with IDD can mean
Better Services and
Better Health!*

What the Words Mean—Glossary:

Administrative data is the information that programs collect to show what they do and whom they serve.

Data are the answers that people give to questions. Data are the answers added up to see how many people answer the same way.

Prevalence is a number that says, of all the people in the country, how many are like this?

Sample is the people who are asked to answer the questions.

A **Survey** is a set of questions that is asked of many people all around the country.