

The I/DD Counts!

Project: What is it and Why is it Important?

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Katherine Cargill-Willis has been a Program Specialist at the Administration on Disabilities for almost twenty years. This is the part of the federal government that provides funding for SARTAC, Kathy has been the project officer working closely with SARTAC since the beginning.

Katherine is a champion of self-advocacy. She listens to us and takes us seriously. Kathy is strong advocate speaking up to make sure we are at the table when decisions about our lives are being made on a federal level. Thank you for all your hard work you continue to do.



Andrew is a consultant to Administration on Community Living (ACL) and used to work at ACL as a full-time time employee. Andrew has over 20 years of experience in the disability field (with a focus on health care and disability programs) working in multiple roles. He is also a person with disabilities.

SARTAC welcomes his expertise on gathering and analyzing data about people with intellectual and developmental disabilities.

We Have Two Problems

1. We do not know how many people with I/DD there are in the U.S.
1. We do not know how healthy people with I/DD are as a group.

Why are People with I/DD Left Out of the Data

- People with ID/DD are often left out of surveys and data.
- There is no way to tell if the person answering the questions has an ID/DD

Data means

- Another word for data is information. An example of health data from the Centers for Disease Control and Prevention is:
 - "Adults with disabilities are more likely to have diabetes. 16% of people with disabilities have diabetes compared to 8% of people without disabilities have diabetes."

Discussion Question

1. What information about being healthy do you need as a person with ID/DD?

What did the Administration on Disabilities (AoD) do first?

Two groups were formed with different agencies

- The groups held two large meetings with people with I/DD, researchers and more people from agencies
- We wrote reports about what people said at the meeting
- One of the reports was written in plain language

Another Thing AoD Did

We held focus groups (small group meetings) with

- People with I/DD
- Family members
- Researchers

All the Focus Groups said the Same Things

- Talking to the person is very important
- People with I/DD have unique needs
- We need more information about how healthy are people with I/DD
- The quality of life of people with I/DD is important
- What can I and my family members expect in my future?

Discussion Questions

2. What kinds of data about health does your organization want to know about?

3. What health issues are not being talked about enough?

The 2022 Summit

In 2022 there was another summit where people with I/DD, researchers, and people from different agencies came together to make recommendations.

Recommendations from the 2022 Summit

- 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.
- Let people know that progress has been made, but there is still missing information. This is also called “gaps in data.”

Recommendations from the 2022 Summit (continued)

- 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. These things can help us understand why some people have more health problems.
 - For example, people with I/DD are more likely to have diabetes. We need to know if this is true for both men and women.

Report from the 2022 summit (continued)

- A report and a plain language executive summary were written to discuss the recommendations of the summit.
 - https://acl.gov/sites/default/files/2023-05/ACL_IDD%20Counts%20Summit%20Executive%20Summary_05-18-23.pdf.pdf
- The Administration on Disability is sending out quarterly reports describing what is being done.
 - [I/DD Counts | ACL Administration for Community Living](#)

Future Issues

- Think about ways to use data collected by the states. Make sure it is reliable.
- There needs to be on-going work to find out how many people with I/DD are in the United States.
- How can self-advocates be more involved?

Discussion Questions

4. What data do you need for advocacy and self-advocacy (including health issues)?
4. What kind of data, in addition to health, interests you the most?

For More Information or Questions

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