

Nothing About Me Without Me

What Ohio adults with IDD said about making their own choices



What is this brief?

This is an Easy Read brief.

It shares what adults with IDD in Ohio said about making their own choices.

A longer report has all the details.

What did we do?

We did a survey.

134 adults with IDD in Ohio took the survey.

They were between 18 and 81 years old.

Some people had a guardian. Some people did not.

People answered for themselves. Some had help to read the questions.

Words to know

IDD: This stands for intellectual and developmental disabilities. A person with IDD may learn differently or need help with some everyday skills. These differences begin when a person is young.

Guardian: A person who a judge chooses to make some decisions for another person.

Supported decision-making: You get help from people you trust. You still make your own choices.

What did we find?



1. Making your own choices matters.

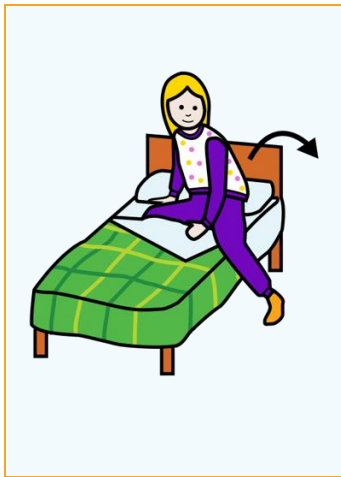
Almost everyone said it is very important to make their own choices.

People want to be independent, have a voice, and feel in control of their lives.

IN THEIR OWN WORDS

"I can be independent, and happier, and have a better life. When I make my own decision, I can stay out of the system."

"Nothing about me without me — it's my life to live."



2. People make many choices every day.

Many people choose things by themselves. For example, when to get up, what to eat, and when to see family and friends.

They have more help with some choices. For example, taking medicine, spending money, and where to live.



3. People get help from people they trust.

Help comes from family, SSAs, staff, friends and guardians.

Help can mean explaining choices, giving advice, or talking things through.

About 1 in 10 people said no one helps them.



4. People talk with others before making big decisions.

For big decisions, like home, work, or health, people ask others for ideas.

But they still make the final choice themselves.



5. People who use supported decision-making like it.

They said it helps them be more independent and confident.

IN THEIR OWN WORDS

"It's like asking someone to hold your ladder while you climb high to replace a lightbulb."

"Supported decision-making saved me from guardianship. I also was able to take back my life and have autonomy in my decisions."

"Being able to make my own choices without people doing it for me and still have my voice heard."



6. Some people still face barriers.

Some people cannot get the services or information they need.

Some said information is not in a way they can use.

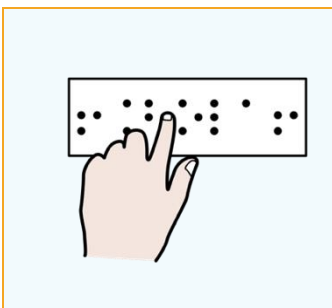
Some people feel left out.

What did people say should happen?



Tell more people about supported decision-making.

More people should learn that they can get help and still make their own choices.



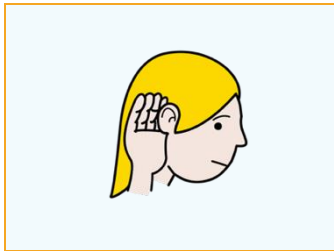
Make information easier to understand.

Use plain language, Braille, and other formats people can use.



Give people real choices.

This means real choices about home, work, friends, and community life.



Keep listening to people with IDD.

Nothing about us without us.

Checked by self-advocates

✓ People with IDD checked this brief. They were part of the team that helped make the survey.

Where can I learn more?

Full report: Novak, J. (2026). Nothing about me without me: Decision-making perspectives of Ohio adults with intellectual and developmental disabilities. Bowling Green State University.

<https://www.sdmno.org/decision-making-surveys>

Questions: Jeanne Novak, jnovak@bgsu.edu

Funding acknowledgement. The contents of this brief were developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number 90SFGE0079-01-00). NIDILRR is a center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents do not necessarily represent the policy of NIDILRR, ACL, or HHS, and you should not assume endorsement by the Federal Government.

Symbol attribution. Pictographic symbols used in this document are owned by the Government of Aragón and created by Sergio Palao for ARASAAC (arasaac.org). License: CC BY-NC-SA 4.0.