

Ohio Parent Survey on Guardianship and Decision-Making

What Ohio parents told us about their experiences, choices, and needs

What is this brief about?

This brief shares what we learned from a survey of Ohio parents. These parents care for a family member with a disability. We asked them about making decisions, guardianship, and other ways to support a person in making their own choices.

This is a short summary. A longer report with all the details is also available.

What did we do?

We surveyed 619 people across Ohio between October 2025 and March 2026. Most were parents (about 86%). A smaller number were other family members — such as siblings, grandparents, aunts, or uncles — who act as a guardian or the main supporter. For simplicity, this brief uses the word “parents” for everyone who answered.

Each parent answered about one family member with a disability. We did not collect anyone’s name.

Parents answered in two groups:

- **Parents of youth in school.** 364 parents answered about a young person (ages 14 to 22) who is still in school and receives special education services. These young people have many different kinds of disabilities.
- **Parents of adults with IDD.** 255 parents answered about an adult (age 18 or older) who has an intellectual or developmental disability (IDD). IDD is a disability that affects learning and everyday skills and begins in childhood. These parents are the adult’s main supporter — they help with care, services, and decisions.

The two groups are not the same. The youth group includes many kinds of disabilities, while the adult group includes only people with IDD. So the numbers for each group are not a direct comparison.

Words to know

Guardianship: A court names a person to make some or all decisions for another adult.

Supported decision-making: The person makes their own decisions. People they trust help them understand the choices.

Power of attorney: The person picks someone they trust to help with certain decisions, such as money or health care.

Turning 18: At age 18, a person gains the legal right to make their own decisions.

What did we find?

1. Parents want more information.

Many parents said they knew only a little about guardianship and other options. Most wanted to learn more. More than half were very interested in topics like finding adult services and planning for the future.

2. Parents want more independence over time.

Right now, many of these family members need a lot of help to make decisions. But parents hope their family member will make more decisions on their own as time goes on. This was true for both young people and adults. The biggest gaps were in everyday choices, school, and community life.

3. Many parents made decisions without clear guidance.

The most common source of information was staff from developmental disability services. But about 1 in 4 parents of young people, and about 1 in 5 parents of adults, got no information at all. When parents did get advice, it was often mixed or unclear.

4. Worries shaped decisions about guardianship.

Parents who chose guardianship often worried about money decisions, medical decisions, safety, and the chance their family member could be taken advantage of. About half also said a professional had recommended it.

5. Parents who chose other options wanted to protect rights.

Parents who used options other than guardianship wanted to support independence and self-advocacy, respect their family member's right to make choices, and give help without taking away control. The most common options were supported decision-making agreements and power of attorney.

6. Parents faced barriers.

Common barriers were not being sure which option is best, finding the legal process confusing, not finding clear information, the cost of a lawyer, and not knowing where to start. About 1 in 3 parents said they had no problems.

What did people tell us they need?

The survey points to clear ways to better support Ohio parents and self-advocates:

- Share clear information earlier. Parents want plain information about all their options, sooner in the process.
- Help parents plan for more independence. Practical steps can close the gap between the support a person has now and their future goals.
- Support trusted helpers. Disability services staff, teachers, and doctors should have good, balanced information to share.
- Make alternatives easier to find and use. More people would consider options like supported decision-making if they were easier to learn about.
- Make the system easier to navigate. Parents want help knowing where to begin and how to find local resources.
- Keep listening to parents. Their experiences should guide new resources, services, and policies.

Where can I learn more?

Full report: Novak, J. (2026). Ohio parent survey on guardianship & decision-making: Understanding family experiences, choices, and needs. Bowling Green State University. <https://sdmno.org/decision-making-surveys>

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