



Nothing About Me Without Me

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

— survey participant

Decision-Making Perspectives
of Ohio Adults with Intellectual
and Developmental Disabilities

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In partnership with
Supported Decision-Making Network of Ohio

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Questions or comments

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About This Report

This report shares findings from a statewide survey of adults with intellectual and developmental disabilities (IDD) in Ohio about decision-making in their daily lives. The survey asked individuals about how they make decisions—who helps them, what kinds of support they have, and what they know about supported decision-making (SDM). People with and without legal guardians took the survey, so the findings reflect a wide range of experiences.

Survey responses were provided directly by adults with IDD. Some people had help from a trusted person (like a family member, staff member, or friend) to read or understand the questions, but the answers came from the individuals themselves. The report title, “Nothing About Me Without Me,” comes from a direct quote shared by a survey participant and reflects the spirit of the disability rights message “Nothing About Us Without Us.”

The survey was designed to be accessible and flexible; details about its design are described in the Methods Overview.

The findings in this report reflect the perspectives and lived experiences of individuals with IDD across a range of areas, including daily decisions, major life choices, and the role of support from others.

The report is intended to inform resources, supports, and policies that center the voices of people with disabilities.

What the Survey Asked

In addition to basic information about themselves (such as age, gender, and living situation), people who took the survey were asked about their experiences with decision-making and support across several areas:

- **Experiences with support.** Who helps individuals make decisions (such as family members, friends, staff, or service providers), the types of help they receive, and whether they feel they have the right amount of support.
- **Decision-making involvement.** How individuals are involved in decisions across everyday and major life areas, including daily routines, health, social activities, housing, work, and spending money.
- **Perceptions of autonomy and independence.** How important it is to individuals to make their own choices, how they feel about the level of control they have in their lives, and what decisions they would like to make in the future.
- **Awareness and use of supported decision-making.** Whether individuals have heard of supported decision-making, how they understand it, whether they use it in their lives, and how it has affected their ability to make decisions.

Individuals were also invited to share their experiences in their own words, including descriptions of important or difficult decisions they have had to make, the support they received, and how those decisions turned out.

Overview of Responses

Several patterns emerged across responses from individuals with IDD.

Most individuals reported that making their own choices is important. Responses emphasized independence, having a voice, and being able to control what happens in their lives.

Many individuals described actively participating in decisions across daily life areas. A majority reported making some decisions on their own, particularly in areas such as daily routines, social activities, and spending money, while others described making decisions with support or, in some cases, having decisions made for them.

Support was common and came from a range of people, including family members, friends, staff, and service providers. Many individuals reported that they receive help when making decisions and that this support often involves explaining options, giving advice, or helping them think through choices. Most individuals indicated that they are satisfied with the amount of help they receive, though some reported wanting more or less support.

Individuals shared a range of experiences with important or difficult decisions, including decisions about where to live, relationships, work, health, and education. These experiences often involved weighing options, seeking advice, and making final decisions themselves, sometimes with support from others.

Awareness of supported decision-making (SDM) was relatively high among individuals who took the survey. Many reported that they had heard of SDM and described it as getting help from people they trust while still making their own decisions. A majority also indicated that they use supported decision-making in their lives and described positive impacts, such as increased independence, confidence, and control.

At the same time, responses highlighted variability in experiences. Some individuals described challenges related to limited options, access to information, or navigating systems and services. Others emphasized the importance of being heard, having access to support that fits their needs, and maintaining control over decisions.

Overall, responses reflect a strong emphasis on autonomy, supported decision-making, and the importance of having both choice and support in navigating everyday and major life decisions.

How to Read This Report

This report presents survey results by question. Each section corresponds to a specific survey topic, and tables and figures show how individuals responded.

How results are organized

- Results are grouped into sections based on related topics (such as support, decision-making, and supported decision-making)
- In the main results section, the survey question appears first, followed by the corresponding table(s) and/or figure(s)
- Each table or figure represents one survey question or a closely related set of items

About the data

- All responses reflect the perspectives of individuals with intellectual and developmental disabilities (IDD)
- In some cases, individuals may have received help from a trusted person to read or understand the questions, but responses reflect the individual's own views

How to interpret percentages

- Tables and figures report the percentage of individuals selecting each response option
- Percentages are based on the number of individuals who answered each question; not all individuals answered every question
- Totals may not equal 100% due to rounding

Questions with multiple responses

- Some questions allowed individuals to select more than one answer
- Percentages for these items may sum to more than 100%

Background and Context

In Ohio, individuals reach the age of majority at 18 and gain the legal right to make their own decisions in areas such as healthcare, finances, housing, education, and daily life. Adults with intellectual and developmental disabilities (IDD) may make decisions on their own or with input from others, depending on their preferences and circumstances.

Some individuals have a legal guardian. Guardianship is a court-ordered arrangement in which another person is authorized to make some or all decisions on behalf of the individual. Others do not have a guardian and retain full legal decision-making authority. Alternatives to guardianship are also available. These include approaches such as supported decision-making (SDM), power of attorney, and informal supports, which are intended to assist individuals in making decisions while maintaining their involvement in the process.

Most of us rely on others when making important decisions. People with IDD are no different. Individuals may seek input from family members, friends, staff, or service providers to help understand information, consider options, or communicate their choices.

Having opportunities to participate in decision-making can be important for individuals both with and without guardians. Access to clear information, opportunities to express preferences, and involvement in decisions may support autonomy and self-determination.

This report describes how individuals with IDD in Ohio experience decision-making and support, including the role of others, awareness and use of supported decision-making, and perspectives on autonomy and independence.

Methods Overview

This study used an accessible online survey to understand how adults with intellectual and developmental disabilities (IDD) in Ohio experience decision-making in their daily lives. The survey was developed using a community-engaged approach, with input from self-advocates and supporters to ensure clarity and accessibility. Self-advocates who contributed to this work received honorariums.

Participants were adults (age 18 or older) with IDD living in Ohio. The final analytic sample included 134 individuals, including individuals both with and without legal guardians. Participants were recruited through community networks across the state.

Data were collected between October 2025 and March 2026. Most participants completed the survey online. Approximately one-third completed the survey at a self-determination conference, where individuals could use an iPad and receive support from a member of the research team.

The survey was designed to be accessible and to support participation from individuals with a range of communication preferences and support needs. It used plain language, was compatible with screen readers, and could be completed with assistance. Participants could choose between a shorter or longer version and could skip any questions or stop at any time.

Participants reviewed consent information (in writing or by watching a video) and completed questions to demonstrate understanding before continuing. Additional procedures were used to confirm permission for individuals with legal guardians when required.

Findings are based on descriptive summaries of responses, including percentages for closed-ended items and selected open-ended responses. More detailed information about how the survey was designed, how consent was obtained, and how responses were reviewed is provided in the Appendix.

Results

The following sections present survey findings organized by topic. Results focus on key areas of decision-making, support, and awareness and use of supported decision-making (SDM).

Participant Characteristics

Guardianship Status and Type of Guardian

Table 1. Guardianship Status and Type of Guardian

Guardianship Status and Type	<i>n</i>	Percent
Has a legal guardian	49	36.6
Parent	20	41.7
Other family member	5	10.4
Professional guardian	23	47.9
Does not have a legal guardian	85	63.4

Note. Percentages for guardianship status are based on the full sample ($N = 134$). Percentages for guardian type are based on individuals who answered the guardian-type question ($n = 48$).

Most individuals who took the survey did not have a legal guardian, while about one-third reported having a guardian. Among individuals with guardians, guardians were most often professional guardians or parents.

Eligibility for County Board Services

Do you get services from your county Board of Developmental Disabilities? (Choose “Yes” if the board has ever said you can get services—even if you don’t get help from them right now.)

Table 2. Eligibility for County Board of Developmental Disabilities Services

Response	<i>n</i>	Percent
Yes	104	77.6
No	20	14.9
Not sure	10	7.5

Over three-quarters of individuals reported that they are eligible for services from their county Board of Developmental Disabilities, while a smaller number reported that they are not eligible or were unsure. Individuals with guardians were more likely to report receiving county board services than those without guardians.

Help Completing the Survey

Is someone helping you with this survey? If yes, who is helping you?

Table 3. Help Completing the Survey

Response	<i>n</i>	Percent
Yes	63	47.0
No	71	53.0

About half of individuals completed the survey independently, while about half received help. Among those who received help, the most common sources of support were research team members (12%) and support staff (11%), followed by guardians (9%) and family members (8%).

Living Situation

Where do you live?

Table 4. Living Situation

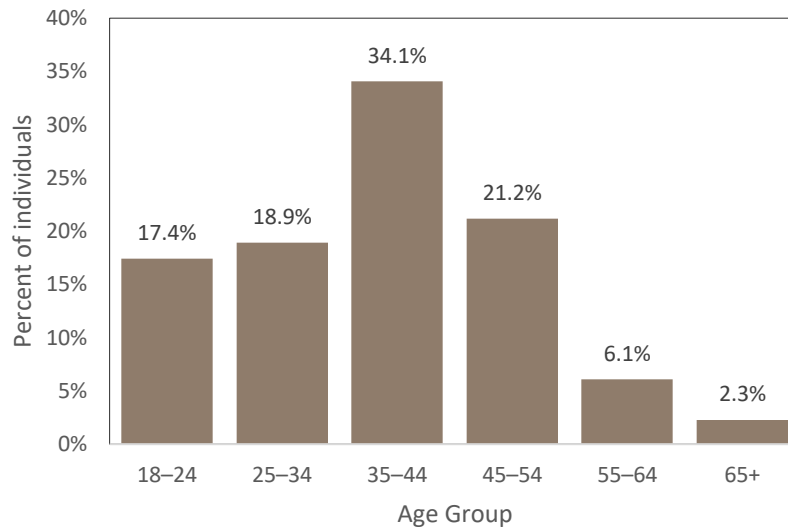
Response	<i>n</i>	Percent
In my own house or apartment	67	50.0
With family	48	35.8
In a group home	11	8.2
Other	6	4.5

About half of individuals reported living in their own house or apartment, while over one-third lived with family. A smaller number lived in group homes or other settings.

Living situation differed for individuals with and without guardians. Individuals without guardians were more likely to live in their own home or apartment, while individuals with guardians were more likely to live in a group home.

Age

Figure 1. Age Distribution



Note. $n = 132$.

Individuals ranged in age from 18 to 81, with representation across all age groups. The largest proportion of individuals were between the ages of 35 and 44, followed by those ages 45 to 54.

Gender

Table 5. Gender

Gender	<i>n</i>	Percent
Male	43	32.3
Female	86	64.7
Non-binary	1	0.8
Prefer not to say	3	2.3

Two-thirds of individuals identified as female, while about one-third identified as male. A small number identified as non-binary or preferred not to say.

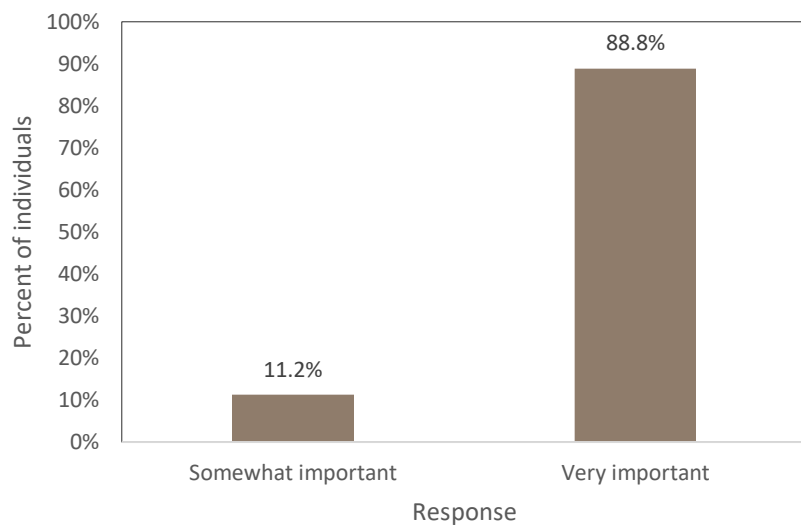
Importance of Decision-Making

This section focuses on how individuals view the importance of making their own decisions and why it matters in their lives.

Making One's Own Decisions

How important is it to you to make your own choices?

Figure 2. Importance of Making One's Own Decisions



Note. Response options included “very important,” “somewhat important,” and “not important at all.” No individuals selected “not important at all.”

Individuals overwhelmingly reported that making their own decisions is very important.

Why Decision-Making is Important

Why do you think making your own choices is important?

Figure 3. Perspectives on Why Decision-Making is Important



Note. This figure includes selected representative responses from individuals who completed the longer version of the survey ($n = 46$). Responses are presented unchanged to reflect individuals' own words and perspectives.

Responses most often emphasized independence, having a voice, and being able to control what happens in their lives. Many individuals also described decision-making as connected to personal rights, self-confidence, responsibility, and pursuing the life they want.

Decision-Making Involvement

This section focuses on the extent to which individuals are involved in everyday decisions in their lives, including decisions related to routines, health, housing, work, and relationships. Participants were also asked about the people who help them make decisions.

Decision-Making in Daily Life

Participants were asked who makes decisions in different areas of their lives. Response options included:

- “I choose by myself”
- “I choose with a little help”
- “Someone else chooses for me”

Table 6. Who Makes Different Life Decisions?

Decision Area	I choose by myself	I choose with a little help	Someone else chooses for me
When to wake up and go to bed	84.1	12.9	3.0
What to eat each day	71.4	24.8	3.8
If and when to take medicine	57.1	30.8	12.0
How to take care of home or room	55.6	34.6	9.8
When to see friends or family	75.2	20.3	4.5
Where to live	60.9	22.6	16.5
Who to live with	69.9	14.3	15.8
What kind of job to have	58.6	21.8	3.0
What clubs or events to go to	75.2	21.8	3.0
How to spend money on fun things or shopping	57.1	37.6	5.3

Note. Values are percentages. For the job question, 16.5% selected “This question does not apply to me.”

Participants most often reported making decisions independently in areas related to daily routines and social activities, such as when to wake up and go to bed, what clubs or events to attend, and when to see friends or family.

Decisions involving health, finances, housing, and employment were more likely to involve support from others, especially decisions about taking medication, where to live, and how to spend money.

Across all areas, relatively few individuals reported that someone else completely makes decisions for them. However, this was more common for decisions related to housing, living arrangements, and medication.

People Who Help Make Decisions

Who helps you make decisions? (You can choose more than one.)

Table 7. People Who Help Individuals Make Decisions

Source of support	<i>n</i>	Percent
Family members	87	64.9
SSA, service coordinator, or case manager	68	50.7
Staff or caregivers	52	38.8
Friends	48	35.8
Guardians	37	27.6
Someone I work with	16	11.9
Someone else	11	8.2
No one helps me	15	11.2

Note. SSA = service and support administrator. Participants could select more than one response option.

Individuals reported receiving decision-making support from a range of people. Family members were the most reported source of support, followed by service and support administrators (SSAs), service coordinators, or case managers, staff or caregivers, and friends. At the same time, over one in ten individuals reported that no one helps them make decisions.

Experiences with Hard Decisions

Think about a hard decision you have made. This could be about where to live, work, school, health, relationships, money, or something else important in your life. What was the hard decision about? Did anyone help you with the decision? What did they say or do to help you? Who made the final choice, and how did that happen? How did you feel afterward?

Figure 4. Topics of the Hard Decision



Note. n = 38. Larger words reflect topics that appeared more often in individuals' responses. Individuals described hard decisions across a range of major life areas, with many focusing on where to live, what to do for work or school, and how to handle important personal or medical issues.

Most individuals who answered this set of questions reported receiving help with the decision. When describing that help, individuals often said that others gave advice, explained options, helped compare choices, or talked through possible outcomes.

Responses also suggest that individuals often remained actively involved in the process and, in many cases, made the final choice themselves. Afterward, many described feeling good, happy, confident, or empowered, although some reported mixed feelings or frustration.

Example

One individual described a difficult decision about whether to leave a sheltered workshop to pursue work in the community. The person said that their sister recognized it was a big decision, offered advice, and emphasized that the choice was ultimately theirs. The individual later interviewed for a job, was hired, and said they felt both excited and nervous afterward. They described it as the best decision they had ever made.

Supported Decision-Making

Many individuals described getting help when making decisions. This section focuses on supported decision-making (SDM), described in the survey as getting help from people you trust to understand your options, think about your choices, and make your own decisions.

Awareness of Supported Decision-Making

Have you heard of supported decision-making?

Table 8. Awareness of Supported Decision-Making

Response	<i>n</i>	Percent
Yes, I've heard of it	105	79.5
No, I haven't heard of it before	18	13.6
I'm not sure	9	6.8

Note. n = 132.

Most individuals reported that they had heard of supported decision-making. A smaller number said they had not heard of it before or were unsure. Because many participants were recruited through self-advocacy networks and a self-determination conference, these findings may reflect greater awareness of supported decision-making than would be expected among adults with IDD statewide.

Where Individuals Heard About Supported Decision-Making

Where did you hear about it?

Table 9. Where Individuals Heard About Supported Decision-Making

Source	<i>n</i>	Percent
SSA, service coordinator, or case manager	42	40.0
Family member	27	25.7
Friend	24	22.9
Provider or caregiver	24	22.9
Guardian	18	17.1
Other	26	24.8

Note. $n = 105$. Participants could select more than one response option. Most “other” responses referred to state or local self-advocacy networks or groups in Ohio.

Individuals reported learning about supported decision-making from a range of sources. SSAs, service coordinators, or case managers were the most reported source, followed by family members, friends, and providers or caregivers.

How Individuals Described Supported Decision-Making

How would you describe supported decision-making to a friend?

Figure 5. Perspectives on Supported Decision-Making



Note. $n = 34$. This question was open-ended. The figure includes representative responses presented unchanged to reflect individuals' own words and perspectives.

Responses most often described supported decision-making as getting help from trusted people while still making your own decisions. Individuals emphasized advice, support, and talking through options, while keeping the final choice with the person making the decision.

Use of Supported Decision-Making

Do you use supported decision-making in your life? This could be for little decisions or for big decisions.

Table 10. Use of Supported Decision-Making

Response	<i>n</i>	Percent
Yes	83	83.0
No	9	9.0
I'm not sure	8	8.0

Note. *n* = 100.

Among individuals who answered this question, most reported that they use supported decision-making in their lives. A smaller number said they do not use it or were unsure.

Difference Supported Decision-Making Has Made

Has supported decision-making made a difference in your life? If so, how? You can describe any ways it has helped—or not helped—you.

Figure 6. Difference Supported Decision-Making Has Made



Note. $n = 31$. This question was open-ended. The figure includes representative responses presented unchanged to reflect individuals' own words and perspectives.

Responses most often emphasized greater independence, more confidence, more freedom, and feeling able to make choices while still receiving support.

Barriers to Accessing Supports for Making Decisions

Is there anything else you want to share about making your own choices or getting help with decisions? (n = 22)

The final survey question invited individuals to share anything else about making decisions or getting help. While some responses reiterated positive experiences with supported decision-making, others reflected variability in access and ongoing barriers that some individuals continue to face, including limited access to services, difficulty obtaining information in accessible formats, and gaps in systems and services.

Some individuals described feeling excluded from conversations about supported decision-making or lacking access to services altogether.

I have a developmental disability, and I am older and because I don't get county board services people like me get excluded from conversations on supported decision making...my husband makes a lot of decisions for me and it's hard sometimes. I feel like if I had supported decision making in place maybe it help me be more independent also be more free to choose.

Others described challenges accessing information in accessible formats.

The lack of accessibility in Braille information impacts my ability to make decisions independently. For example, Ohio Medicaid refuses to put information in Braille for me so I can't even understand my Medicaid benefits...I feel like accessibility of information also impacts my ability to make decisions and also understanding what services are out there.

Some individuals also identified gaps in systems and services, including the need for more support workers and greater flexibility in service planning:

I would like this evidence to also be used as evidence that we need support workers in our life.

I would like SDM to be added to the Ohio ISP service plans

These responses reflect the importance of ensuring that supported decision-making is accessible to all adults with IDD in Ohio, regardless of age, service eligibility, or communication needs.

Key Findings and Implications

What We Learned

The survey responses highlight several important themes about how adults with intellectual and developmental disabilities (IDD) experience decision-making in their daily lives.

Making one's own choices is highly valued.

Nearly everyone who took the survey emphasized the importance of having a voice and control in their lives, with a large majority reporting that making their own choices is very important.

Most participants are actively involved in decisions across daily life.

Many reported making decisions by themselves, while others reported making decisions with a little help. A smaller group reported that someone else makes certain decisions for them, particularly in areas such as where to live and who to live with.

Support is common and typically comes from trusted people.

People described getting help from a range of supporters, including family members, service coordinators, staff, and friends. This help often included explaining options, giving advice, or talking through decisions together.

Many people get support with important decisions while still making the final choice.

When people described more complex decisions, such as those involving housing, work, relationships, or health, many said they ask others for input but still make the final decision themselves.

Many participants are familiar with supported decision-making.

People described supported decision-making as getting help from trusted people while still making their own choices. Many shared positive experiences with this approach, including feeling more independent, confident, and in control.

Experiences vary, and some individuals face barriers.

While many people shared positive experiences, others described barriers such as limited options, difficulty getting clear information, and challenges navigating systems and services.

What These Findings Suggest

These findings point to several ways to better support decision-making for adults with IDD in Ohio.

Increase awareness of supported decision-making.

Many people reported using and valuing supported decision-making, but awareness and access were not the same for everyone. More outreach and education about SDM—especially through service and support administrators (SSAs), family members, and other trusted supporters—could help more people learn about and use this approach.

Make information easier to understand and use.

Some people described difficulty finding information, understanding their options, or navigating services. Clearer information in plain language and other accessible formats could help people make more informed decisions.

Support the people who provide help with decisions.

Because many adults with IDD rely on family members, staff, service coordinators, and friends for support, it is also important to help these supporters understand how to provide assistance in ways that preserve the person's voice and choice. Practical guidance and training could help supporters encourage choice while still providing needed help.

Expand real opportunities for choice.

Some responses suggest that barriers may involve not only decision-making support, but also the availability of meaningful options. Expanding choice in areas such as housing, employment, relationships, and community life may help more people exercise greater control over their lives.

Keep including the voices of people with IDD.

This survey shows that adults with IDD can share important perspectives about their own lives and experiences. Continued efforts to include people with IDD in research, policy, and program development are essential to making sure supports reflect what people actually want and need.

Appendix. Detailed Methods

Study Purpose

This survey was conducted to describe how adults with intellectual and developmental disabilities (IDD) in Ohio experience decision-making in their daily lives. The study focused on individuals' involvement in decisions, support from others, and awareness and use of supported decision-making (SDM) and related approaches.

Survey Development

The project used a community-engaged approach. Self-advocates and supporters from the Supported Decision-Making Network of Ohio (SDMNO) helped develop survey topics and questions, provided feedback to improve clarity and accessibility, and offered input on interpretation of the findings. Self-advocates who contributed to this phase of the work received honorariums.

After the survey was drafted, members of a county self-advocacy group pretested the consent materials and survey through a series of cognitive interviewing meetings. Participants were asked to explain what each question meant to them and identify anything confusing or unclear about the wording, response options, or overall format. They also tested the survey on computers, iPad, and cell phones, including with screen readers. Their feedback informed revisions to improve the clarity and accessibility of the final survey.

Recruitment and Data Collection

Participants were recruited through community and professional networks across Ohio, including disability organizations, advocacy groups, service providers, and self-advocacy networks.

Data were collected between October 2025 and March 2026. Approximately one-third of participants completed the survey at a self-determination conference. At that event, individuals could complete the survey on an iPad with support from a member of the research team. Other participants completed the survey online.

Because many participants were recruited through self-advocacy networks and a self-determination conference, the sample likely included individuals who were more familiar with decision-making supports such as supported decision-making.

Consent and Eligibility Procedures

Participants reviewed consent information presented in accessible language, either by reading it or watching a video.

To support informed participation, individuals completed three questions to demonstrate understanding:

- If you don't want to do the study, do you have to?

- If you want to stop, can you stop answering the questions?
- Who should answer the survey questions—you or someone else?

If an individual did not answer all three questions correctly, the information was reviewed again (in writing or video), and they had a second opportunity to answer the questions correctly before continuing.

For individuals who indicated that they had a legal guardian, the survey included the following instruction: “Please ask your guardian if it is okay for you to do this survey.” Participants were then asked whether their guardian said yes. Only individuals who indicated that their guardian gave permission were permitted to continue with the survey.

IRB Approval and Confidentiality

This study was reviewed and approved by the Institutional Review Board at Bowling Green State University (IRBNet #2343003). All participation was voluntary, and confidentiality of responses was maintained throughout the study.

Survey Design and Accessibility

The survey was designed to support participation from individuals with a range of communication preferences and support needs. Key features included:

- plain language wording
- compatibility with screen readers
- option to complete the survey with assistance from a trusted person or researcher
- choice between a short version and a longer version

The figure below shows the question participants were asked when choosing between the short and long versions of the survey.

Figure 7. Choice Between the Short and Long Versions of the Survey

★ **Please read this carefully – it's a very important question:**
Do you want to take the short or long version of the survey?

☐ ☐ Short version – It's faster and doesn't ask for long answers.

☐ ☐ Long version – I want to share more about how I make choices.

Individuals who selected the longer version were asked both multiple-choice and open-ended questions, while those who selected the shorter version were asked only multiple-choice questions.

Incentives

Participants had the option to enter a drawing for a \$50 electronic gift card, with 1 in 25 participants selected to receive a gift card. Contact information for the drawing was collected separately from survey responses to maintain confidentiality.

Response Review and Final Sample

A total of 181 responses were received. Responses were reviewed and excluded if they met one or more of the following criteria:

- Did not provide consent to participate ($n = 6$)
- Did not correctly answer one or more eligibility questions after a second attempt ($n = 29$)
- Guardian did not give permission to participate ($n = 1$)
- Did not proceed beyond the eligibility questions ($n = 9$)
- Completed less than 50% of the survey content items ($n = 2$)

After applying these exclusion criteria, the final analytic sample included 134 adults with IDD living in Ohio. The sample included people both with and without legal guardians and reflected a range of living situations, support needs, and service experiences.

Data Analysis

Findings are based on descriptive summaries of survey responses. Results are presented using frequencies and percentages for closed-ended items.

Open-ended responses were reviewed to identify common themes and to provide examples of individuals' experiences. Selected responses are included in the report to reflect individuals' perspectives in their own words.

Interpreting the Findings

The survey included adults with IDD from communities across Ohio and provides important insight into participants' experiences with decision-making, support, and supported decision-making.

Results are based on what participants shared about their own lives and experiences. Some individuals completed the survey independently, while others received help from a trusted person or member of the research team to read or understand the questions. Responses were intended to reflect each participant's own views.

Participants were recruited through community networks, including self-advocacy groups and a self-determination conference, rather than through a random statewide sample. As a result, the findings describe the experiences of the adults who took part and may not represent all adults with IDD in Ohio. Awareness and use of supported decision-making may be higher in this group than would be expected statewide.

Despite these considerations, the survey offers valuable insight into how adults with IDD in Ohio experience decision-making and support in their daily lives.