

OHIO PARENT SURVEY

ON

GUARDIANSHIP & DECISION-MAKING

UNDERSTANDING FAMILY EXPERIENCES,
CHOICES, AND NEEDS



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In partnership with
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Questions or comments

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About This Report

This report presents findings from a statewide survey of families in Ohio about decision-making for family members with disabilities as they approach or experience adulthood. It includes results on decision-making involvement, guardianship, alternatives such as supported decision-making, and the information, advice, and support families have received or need.

Survey responses were provided by parents and other family members who serve as guardians or primary supporters of a family member with a disability. Throughout the report, responses refer to the family member with a disability.

Results are presented separately for individuals who are still in school (Youth) and those who are no longer in school (Adults), where applicable.

The findings are intended to inform the development of resources for families, educators, professionals, and policymakers involved in transition and adult services.

What the Survey Asked

In addition to providing demographic information about themselves and their family member with a disability, respondents were asked about decision-making for their family member across several areas:

- **Decision-making understanding.** Whether the individual can understand the effects of their actions and decisions in different situations
- **Decision-making involvement and goals.** The extent to which the individual currently participates in decisions (such as daily living, health, finances, education, and housing) and the level of involvement families would like to see in the future
- **Guardianship status and plans.** Whether legal guardianship has been established or is being considered
- **Factors influencing guardianship decisions.** What has influenced families' decisions to pursue or not pursue guardianship
- **Use of alternatives to guardianship.** Whether families are using options such as supported decision-making, power of attorney, or other arrangements
- **Reasons for using alternatives.** Why families chose alternatives instead of guardianship
- **Information and advice received.** Whether families have received information or guidance about guardianship and alternatives, and from whom
- **Barriers to information or access.** Challenges families have faced in learning about or accessing guardianship or alternatives
- **Knowledge and interest in learning more.** How much families currently know about these topics and their interest in learning more

Overview of Responses

Several patterns emerged across family responses.

Many families reported needing more information about decision-making options. Across topics, families expressed interest in learning more about guardianship, alternatives such as supported decision-making, and how to plan for adult decision-making.

Families described a gap between their family member's current decision-making involvement and future goals, with many expressing a desire for greater independence over time.

Some families described making decisions with limited or unclear information. While a range of information sources was identified, not all families reported receiving guidance before making decisions, and advice was often mixed or inconsistent.

Decisions were influenced by concerns about independence, safety, individual rights, and the need for support in specific areas (e.g., financial, medical, or housing decisions), as well as input from professionals and others.

Barriers to understanding and accessing options were common. Families frequently noted difficulty finding clear, consistent information and navigating legal processes.

How to Read This Report

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

How results are organized

- Results are grouped into sections based on related survey questions.
- In the main results section, the survey question appears first, followed by the corresponding table(s).
- Each table or figure represents one survey question or a closely related set of items.

About the data

- All responses describe a family member with a disability and are based on respondent report.
- Information reflects respondents' understanding of their family member's demographics, diagnoses, and characteristics.

Youth and adult comparisons

- Results are shown separately for:
 - Youth (individuals still in school)
 - Adults (individuals no longer in school)
- Where applicable, Youth and Adult results are displayed side by side.
- The "All" column reflects combined responses across Youth and Adult samples when appropriate.
- Most survey items are identical across the two groups; when items differ, this is clearly noted.

- Some differences between Youth and Adult results may reflect where individuals are in the transition to adulthood (e.g., planning for future decisions vs. reflecting on decisions already made).

How to interpret percentages

- Tables report the percentage of respondents selecting each response option.
- Percentages are based on the number of respondents who answered each question; not all respondents answered every question.
- Totals may not equal 100% due to rounding.
- Some questions allowed respondents 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. At that time, they gain the legal right to make their own decisions in areas such as education, healthcare, finances, and housing. Some families consider whether additional supports or legal arrangements are needed to assist with decision-making.

One option is guardianship, a legal process in which a court appoints a person to make some or all decisions on behalf of another individual. The scope of guardianship can vary, with different levels of authority depending on the individual's circumstances.

Families may also consider alternatives to guardianship, which allow individuals to retain decision-making authority while receiving support. These may include supported decision-making, power of attorney, and other formal or informal arrangements. In these approaches, individuals typically continue to make their own decisions, with support or assistance from others as needed.

Decisions about guardianship and alternatives are often made during the transition to adulthood. Families may receive information or guidance from a range of sources, including schools, service providers, medical professionals, attorneys, and family members.

This report describes how families responded to survey questions about decision-making, guardianship, and alternatives, as well as the information and support they have received or need to make informed decisions.

Methods Overview

This survey was conducted to describe how Ohio families make decisions about guardianship and alternatives for family members with disabilities. It also aimed to identify the information and support families have received or may need to make informed decisions.

Two groups of family members participated. The first group included parents or family guardians of in-school youth (ages 14–22) with disabilities receiving special education services. The second group included parents or other family members of adults (age 18 or older) with an intellectual or

developmental disability who identified themselves as the primary supporter, responsible for coordinating care and services and assisting with decision-making.

Participants were recruited through community and professional networks across Ohio, including schools, disability organizations, and family support networks, as well as through online research panels. Data were collected using an online survey between October 2025 and March 2026. Responses were reviewed to remove incomplete or clearly invalid entries. Identifying information was not collected. A total of 619 responses were included in the analysis, including 364 responses about family members who are still in school (Youth) and 255 responses about family members who are no longer in school (Adults).

Most respondents identified as parents (86%), with a smaller number identifying as other family members (e.g., sibling, grandparent, aunt, or uncle). In total, 532 respondents were parents and 87 were other family members. Relationship to the individual is shown in Table 1. Additional respondent characteristics are provided in Appendix B.

Table 1. Participant Relationship to Family Member by Group

Relationship	Youth (<i>n</i> = 364)		Adult (<i>n</i> = 255)	
	<i>n</i>	%	<i>n</i>	%
Parent	336	92.3	196	76.9
Non-parent family member	28	7.7	59	23.1
Sibling	3	0.8	27	10.6
Grandparent	9	2.5	5	2.0
Aunt or uncle	12	3.3	19	7.5
Other (e.g., cousin, daughter, son)	4	1.1	8	3.1

Note. Percentages are based on total respondents within each group. “Youth” refers to respondents reporting on family members who are still in school, and “Adult” refers to respondents reporting on family members who are no longer in school. For Youth, non-parent family members were legal guardians; for Adults, non-parent family members were primary supporters.

Missing data were generally low (typically 0–3%), although some items had slightly higher levels of missing responses. Findings are based on descriptive summaries of the available responses.

Results

The following sections present survey findings organized by topic. In addition to information about family members and the services they receive, results are grouped to reflect key areas of decision-making, guardianship, and information needs. Where applicable, tables present responses separately for individuals who are still in school (youth) and those who are no longer in school (adults), along with a combined “All” column.

Individual and Service Characteristics

Family Member Age

Table 2. Family Member Age

Age Group	Youth (<i>n</i> = 364)		Adult (<i>n</i> = 248)		All (<i>N</i> = 612)	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
14–15	176	48.4	–	–	176	28.8
16–17	107	29.4	–	–	107	17.5
18–19	45	12.3	69	27.8	114	18.6
20–22	36	9.9	46	18.5	82	13.4
23–25	–	–	28	11.3	28	4.6
26–30	–	–	39	15.7	39	6.4
31–40	–	–	36	14.5	36	5.9
41+	–	–	30	12.1	30	4.9

Family Member Gender

Table 3. Family Member Gender

Gender	Youth (<i>n</i> = 362)		Adult (<i>n</i> = 255)		All (<i>N</i> = 617)	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Male	207	57.2	155	60.8	362	58.7
Female	148	40.9	97	38.0	245	39.7
Non-binary/third gender	3	0.8	2	0.8	5	0.8
Prefers to self-describe	4	1.1	1	0.4	5	0.8

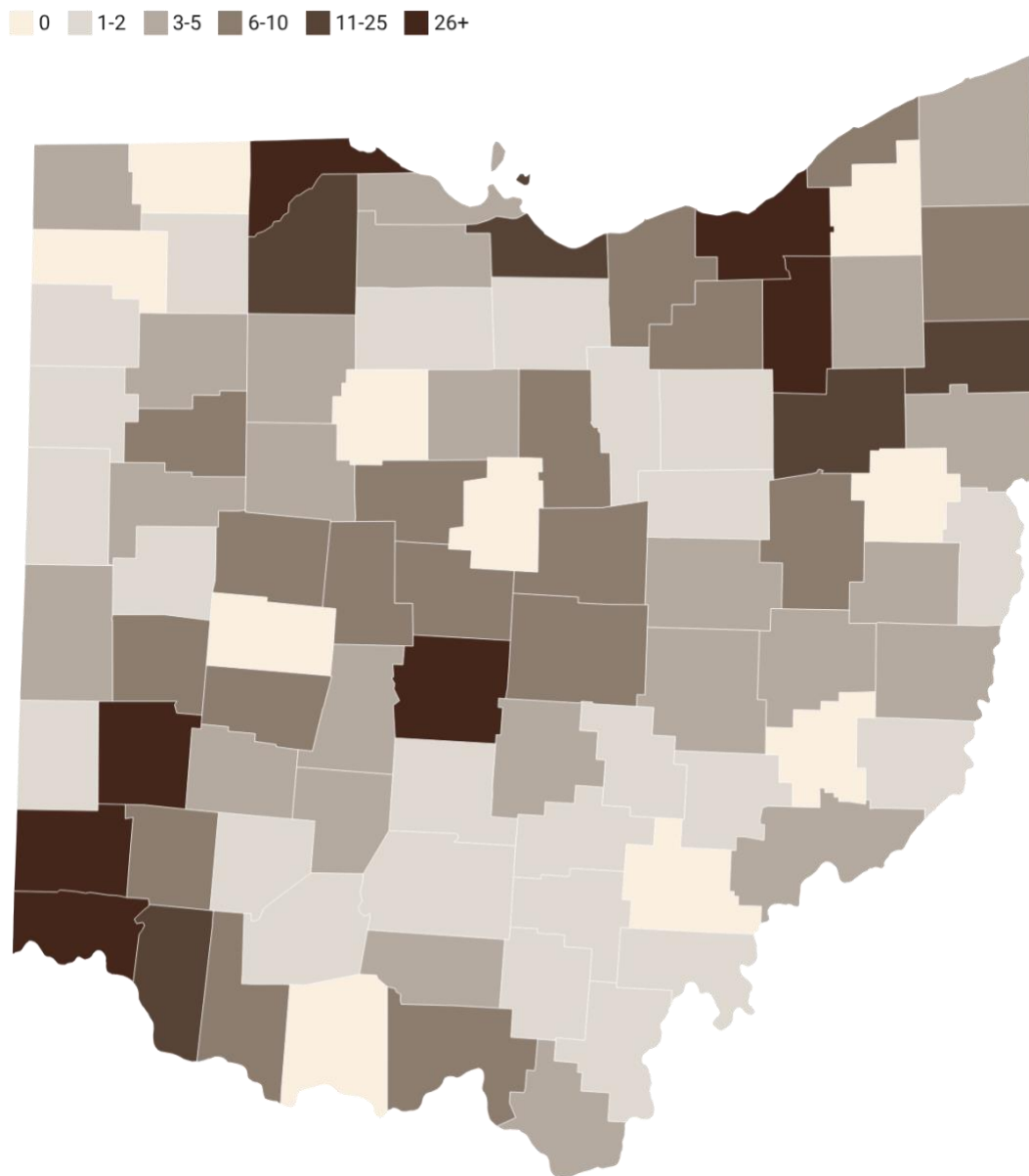
Family Member Race/Ethnicity

Table 4. Family Member Race/Ethnicity

Race/Ethnicity (Select all that apply)	Youth (<i>n</i> = 364)		Adult (<i>n</i> = 255)		All (<i>N</i> = 619)	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
White	301	82.7	212	83.1	513	82.9
Black or African American	64	17.6	41	16.1	105	17.0
Asian	5	1.4	9	3.5	14	2.3
American Indian or Alaska Native	6	1.6	4	1.6	10	1.6
Native Hawaiian or Other Pacific Islander	1	0.3	0	0.0	1	0.2
Hispanic/Latino	20	5.5	11	4.3	31	5.0
Prefer not to say	3	0.8	0	0.0	3	0.5

Note. Respondents could select more than one category; therefore, percentages may sum to more than 100%.

Figure 1. Number of Survey Responses by Family Member County of Residence



Family members resided in 78 of Ohio's 88 counties, spanning all five regions of the state. Counties containing Ohio's largest metropolitan areas accounted for nearly half of all responses (47%), closely reflecting their 48% share of the state's population. County-level response counts are provided in Appendix C.

Primary Disability Category (Youth)

Under what primary disability category does your family member receive special education services?

Table 5. Primary Disability Category

Primary Disability Category	<i>n</i>	%
Intellectual Disability	28	7.8
Multiple Disabilities	41	11.4
Autism	111	30.9
Specific Learning Disability	29	8.1
Other Health Impairment (e.g., ADHD)	84	23.4
Orthopedic Impairment	9	2.5
Speech or Language Impairment	17	4.7
Deafness	2	0.6
Hearing Impairment	9	2.5
Visual Impairment, including Blindness	3	0.8
Deaf-Blindness	2	0.6
Emotional Disturbance	12	3.3
Traumatic Brain Injury	8	2.2
Unsure	4	1.1

Note. *n* = 359.

Intellectual Disability Status

Does your family member have an intellectual disability?

Description provided to respondents

Intellectual disability is a diagnosed condition involving significant limitations in learning, reasoning, and adaptive skills, with onset before age 18. In older school or medical records, it may be listed as “mental retardation.” It is distinct from autism, ADHD, or a learning disability, although some individuals may have more than one diagnosis.

Table 6. Intellectual Disability Status

Response	Youth (<i>n</i> = 364)		Adult (<i>n</i> = 255)		All (<i>N</i> = 619)	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Yes	214	58.8	168	65.9	382	61.7
No	150	41.2	87	34.1	237	38.3

Comparisons between families of youth and families of adults should be interpreted with caution, as the populations represented in each group differ. Families of adults were limited to those with an intellectual or developmental disability, whereas families of youth included individuals across a

broader range of disability categories (e.g., specific learning disability, speech or language impairment, and other health impairment).

In addition, results are based on self-report. Although a description of intellectual disability was provided, some respondents may have relied on their own understanding of the term when responding.

Table 7. Level of Intellectual Disability

Level	Youth (<i>n</i> = 188)		Adult (<i>n</i> = 194)		All (<i>n</i> = 382)	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Mild	36	19.1	47	24.2	83	21.7
Moderate	96	51.1	104	53.6	200	52.4
Severe	46	24.5	36	18.6	82	21.5
Profound	6	3.2	6	3.1	12	3.1
Unsure	4	2.1	1	0.5	5	1.3

Note. Percentages are based only on respondents who indicated that the individual has an intellectual disability; thus, this table reflects a subset of the full sample. The “All” column reflects the combined subset of families of youth and families of adults (*n* = 382).

The current samples include higher proportions of individuals described as having moderate or more significant support needs relative to national estimates, which generally indicate that most individuals with intellectual disability fall within the mild range. These differences may reflect characteristics of the sample, including who chose to participate and how participants were recruited. As with the previous question, level of intellectual disability was based on respondent report and was not verified through formal evaluation or records.

Eligibility for County Board of Developmental Disabilities Services

Is your family member eligible for services from a county board of developmental disabilities?

Table 8. Eligibility for County Board of Developmental Disabilities Services

Response	Youth (<i>n</i> = 362)		Adult (<i>n</i> = 255)		All (<i>N</i> = 617)	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Yes	247	68.2	185	72.5	432	70.0
No	41	11.3	32	12.5	73	11.8
Unsure	74	20.4	38	14.9	112	18.2

Decision-Making Understanding and Involvement

This section presents findings related to decision-making understanding and involvement across key domains.

Ability to Understand the Effects of Actions and Decisions

Is your family member able to understand the effects of their actions and decisions in specific situations?

Table 9. Ability to Understand the Effects of Actions and Decisions

Level of Understanding	Youth (<i>n</i> = 361)		Adult (<i>n</i> = 255)		All (<i>N</i> = 616)	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Yes, in most situations	139	38.5	93	36.5	232	37.7
Yes, but only in certain situations	156	43.2	103	40.4	259	42.0
No, they have difficulty understanding	66	18.3	56	22.0	122	19.8
I'm not sure	—	—	3	1.2	3	0.5

Current Decision-Making Involvement and Future Goals

For each area below, indicate how much your family member is currently involved in making decisions and what you hope their decision-making will be like in the future.

Description provided to respondents

Decision-making areas:

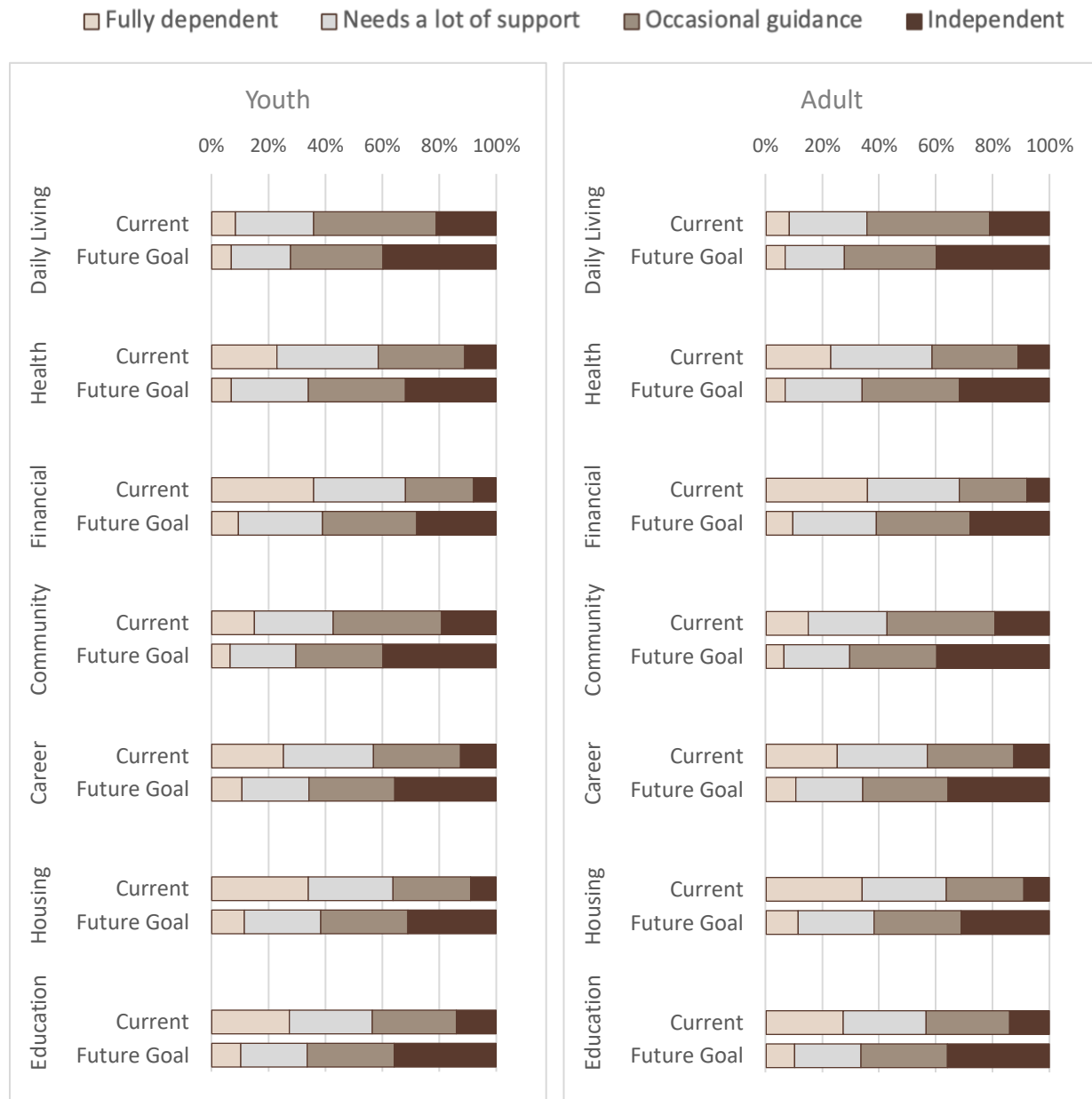
- **Daily living decisions** (choosing when to wake up and go to bed, deciding what to eat for meals, picking clothing for the day)
- **Health-related decisions** (deciding how to manage symptoms, choosing exercise activities, deciding whether to take recommended medications)
- **Financial decisions** (budgeting for entertainment, making purchase decisions, selecting banking methods)
- **Community and social participation decisions** (deciding whether and when to visit family or friends, choosing clubs or groups to join, picking social events to attend)
- **Work or career decisions** (identifying personal preferences and interests, choosing a career path, selecting jobs to apply for)
- **Housing decisions** (choosing where to live, selecting roommates, determining how to handle household tasks)
- **Education-related decisions** (selecting courses, deciding about participation in school activities, selecting a career training program)

Response options:

- Depends completely on others to make decisions for them
- Helps make decisions but needs a lot of support
- Makes decisions on their own with occasional guidance
- Make most decisions on their own without help

Figure 2 displays respondents' ratings of current decision-making involvement and their future goals across seven decision-making domains. Table 10 provides the complete percentage distributions for each domain.

Figure 2. Current Involvement and Future Goals Across Decision-Making Domains



Note. Each bar shows how respondents answered, with sections representing different response options.

Across all domains, respondents' ratings of current decision-making involvement more often reflected reliance on support or others, whereas future goals reflected a greater emphasis on independence. This pattern was consistent for both youth and adults, with the largest differences between current ratings and future goals observed in daily living, education, and community/social decisions. Differences between youth and adult patterns were minimal.

Table 10. Current Involvement and Future Goals Across Decision-Making Domains

Decision-Making Domain	Group	Timeframe	Level of Decision-Making Involvement			
			Fully dependent	Needs a lot of support	Occasional guidance	Independent
Daily Living	Youth	Current	7.4	34.2	41.6	16.8
		Future Goal	5.5	18.5	32.8	43.3
	Adult	Current	8.2	27.5	43.1	21.2
		Future Goal	6.7	20.9	32.4	39.9
Health	Youth	Current	24.7	36.8	29.4	9.1
		Future Goal	6.1	24.6	29.3	39.9
	Adult	Current	22.9	35.6	30.4	11.1
		Future Goal	6.7	27.2	34.3	31.9
Financial	Youth	Current	36.5	34.3	22.0	7.2
		Future Goal	9.4	24.6	30.1	35.9
	Adult	Current	35.8	32.3	24.0	7.9
		Future Goal	9.4	29.5	33.1	28.0
Community	Youth	Current	14.1	32.1	37.1	16.6
		Future Goal	4.7	18.7	30.1	46.5
	Adult	Current	14.9	27.8	38.0	19.2
		Future Goal	6.3	23.2	30.7	39.8
Career	Youth	Current	23.5	35.9	32.6	8.0
		Future Goal	6.7	19.5	31.5	42.3
	Adult	Current	25.1	31.8	30.6	12.5
		Future Goal	10.6	23.5	30.2	35.7
Housing	Youth	Current	39.2	31.5	21.3	8.0
		Future Goal	11.0	18.7	33.1	37.2
	Adult	Current	33.9	29.9	27.2	9.1
		Future Goal	11.4	26.8	30.7	31.1
Education	Youth	Current	23.5	32.7	32.4	11.4
		Future Goal	7.1	18.8	30.7	43.5
	Adult	Current	27.2	29.2	29.6	14.0
		Future Goal	10.1	23.4	30.6	35.9

Note. Values represent the percentage of respondents selecting each response option within each decision-making domain.

Guardianship and Decision-Making

This section presents findings related to guardianship and decision-making and includes items asked of different respondent groups based on whether the family member was still in school or out of school. The first three items apply only to families of in-school youth, while the fourth applies only to families of out-of-school adults. As a result, sample sizes (n) vary across tables and reflect only those respondents for whom each item was applicable.

Conversations About Guardianship and Other Options (Youth)

Has your family member been involved in conversations about guardianship, supported decision-making, or other decision-making options?

Table 11. Conversations About Guardianship and Other Options

Response	<i>n</i>	%
Yes	164	45.2
No	178	49.0
Unsure	21	5.8

Note. *n* = 363.

Plans to Pursue Guardianship at Age 18 (Youth)

Do you plan to pursue guardianship for your family member when they reach 18?

Table 12. Plans to Pursue Guardianship at Age 18

Response	<i>n</i>	%
Yes, I plan to pursue guardianship	105	37.4
No, I do not plan to pursue guardianship	71	25.3
I am unsure at this time	105	37.4

Note. *n* = 281. This question was asked only of respondents whose family member was under age 18. Values represent the percentage of respondents who answered this question.

Guardianship Status at Age 18 (Youth)

Did you establish guardianship for your family member when they turned 18?

Table 13. Guardianship Status at Age 18

Response	<i>n</i>	%
Yes, I have established guardianship or am in the process of doing so	32	39.5
No, I did not establish guardianship	35	43.2
No, but I might or plan to establish it in the future	14	17.3

Note. *n* = 81. This item was asked only of respondents whose family member had reached age 18. Values represent the percentage of respondents who answered this question.

Current Guardianship Status (Adult)

Have you established legal guardianship for your family member?

Table 14. Current Guardianship Status

Response	<i>n</i>	%
Yes	145	56.9
No	110	43.1

Note. *n* = 255.

Factors Influencing the Decision to Pursue Guardianship

What factors influenced your decision to pursue guardianship? (Select all that apply)

Table 15. Factors Influencing the Decision to Pursue Guardianship

Factor	Youth (n = 137)		Adult (n = 145)		All (n = 282)	
	n	%	n	%	n	%
Fears or concerns about their ability to make financial decisions	90	65.7	83	57.2	173	61.3
Fears or concerns about their ability to make medical decisions	83	60.6	88	60.7	171	60.6
Fears or concerns about their safety	88	64.2	81	55.9	169	59.9
Fears or concerns that they may be taken advantage of	80	58.4	85	58.6	165	58.5
Recommendations from professionals	73	53.3	69	47.6	142	50.4
To prevent them from making harmful or risky decisions	74	54.0	67	46.2	141	50.0
To remain involved in important decisions about their life	73	53.3	63	43.4	136	48.2
My own research	71	51.8	50	34.5	121	42.9
To ensure I can stay involved in their education decision-making after they turn 18	67	48.9	51	35.2	118	41.8
Advice from family or friends	44	32.1	35	24.1	79	28.0
Other	7	5.1	9	6.2	16	5.7

Note. Respondents could select more than one factor; percentages therefore sum to more than 100%.

The most frequently endorsed factors across both groups were concerns about financial and medical decision-making, safety, and vulnerability to exploitation. About half of respondents also cited professional recommendations and a desire to prevent harmful or risky decisions.

Alternatives to Guardianship Being Used or Considered

Tables 16 and 17 present responses separately for families of in-school youth and families of out-of-school adults, as the items were worded differently across groups.

YOUTH: *What alternatives to guardianship, if any, are you using or planning to use for your family member? (Select all that apply)*

Table 16. Alternatives to Guardianship Being Used or Considered

Alternative	<i>n</i>	%
Supported decision-making agreement	128	35.2
Power of attorney	108	29.7
Direct deposits or automatic payments	89	24.5
Authorized decision maker	71	19.5
Limited guardianship	67	18.4
Representative payee	61	16.8
Protective services or orders	30	8.2
Other	3	0.8

Note. *n* = 364. Respondents could select more than one alternative; percentages may sum to more than 100%. This item was asked of all families of youth and includes both alternatives currently in use and those being considered or planned.

ADULT: *What alternatives to guardianship, if any, are you using for your family member? (Select all that apply)*

Table 17. Alternatives to Guardianship Currently Used

Alternative	<i>n</i>	%
Supported decision-making agreement	40	36.4
Power of attorney	29	26.4
Direct deposits or automatic payments	25	22.7
Authorized decision maker	20	18.2
Limited guardianship	7	6.4
Representative payee	28	25.5
Protective services or orders	3	2.7
Other	8	7.3

Note. *n* = 110. Respondents could select more than one alternative; percentages may sum to more than 100%. This item was asked only of families of adults who did not establish guardianship and reflects alternatives currently in use.

Across both groups, supported decision-making agreements and power of attorney were among the most frequently reported alternatives. Results for youth and adults are not directly comparable due to differences in question wording and sample composition.

Reasons for Using Alternatives to Guardianship

If you are using or considering alternatives to guardianship, what are your reasons? (Select all that apply)

Table 18. Reasons for Using Alternatives to Guardianship

Reason	Youth (n = 227)		Adult (n = 110)		All (n = 337)	
	n	%	n	%	n	%
To encourage their independence and self-advocacy	128	56.4	48	43.6	176	52.2
They have the right to make their own decisions as an adult.	85	37.4	40	36.4	125	37.1
Alternatives like supported decision-making can provide guidance without taking away their autonomy.	81	35.7	38	34.5	119	35.3
To avoid court involvement in my relationship with them through guardianship	57	25.1	30	27.3	87	25.8
They don't need a guardian.	47	20.7	23	20.9	70	20.8
To avoid the ongoing court reporting and oversight required under guardianship	38	16.7	18	16.4	56	16.6
Other	2	0.9	8	7.3	10	3.0

Note. Respondents could select more than one reason; percentages may sum to more than 100%. This item was applicable to respondents who reported they did not and do not plan to establish guardianship.

Across both groups, the most endorsed reasons for using alternatives to guardianship center on promoting independence, respecting the individual's right to make decisions, and maintaining autonomy while providing support.

Information, Advice, and Barriers

This section presents findings related to information, advice, and barriers associated with guardianship and decision-making options.

Information or Training Received About Guardianship and Alternatives

Has anyone given you information or training about guardianship, supported decision-making, or other alternatives to guardianship? (Select all that apply)

Table 19. Information or Training Received About Guardianship and Alternatives

Source of Information/Training	Youth (n = 364)		Adult (n = 255)		All (N = 619)	
	n	%	n	%	n	%
Developmental disability services staff	109	29.9	90	35.3	199	32.1
Family member or family friend	93	25.5	67	26.3	160	25.8
Medical professional	91	25.0	66	25.9	157	25.4
Teachers or school staff	95	26.1	49	19.2	144	23.3
Advocacy organization representative	50	13.7	42	16.5	92	14.9
Social worker	49	13.5	37	14.5	86	13.9
Attorney	39	10.7	47	18.4	86	13.9
Special needs trust advisor or financial advisor	48	13.2	35	13.7	83	13.4
Judge or court staff	12	3.3	20	7.8	32	5.2
Other	4	1.1	7	2.7	12	1.9
No one has given me information or training	93	25.5	52	20.4	145	23.4

Note. Respondents could select more than one source; percentages may sum to more than 100%.

Across both groups, developmental disability services staff were the most reported source of information about guardianship and alternatives. Approximately one-quarter of respondents in each group reported receiving information from medical professionals or family members. Notably, about one in four youth-family respondents and one in five adult-family respondents indicated that they had not received any information or training on these topics.

Advice Received About Guardianship and Alternatives

What advice did you receive about guardianship, supported decision-making, or other alternatives?

Table 20. Advice Received About Guardianship and Alternatives

Type of Advice Received	Youth (n = 264)		Adult (n = 197)		All (n = 461)	
	n	%	n	%	n	%
Advised to pursue guardianship	64	24.2	82	41.6	146	27.0
Advised to pursue alternatives, like power of attorney or supported decision-making	52	19.7	32	16.2	84	15.6
Received mixed advice	82	31.1	52	26.4	134	24.8
Received information but no specific recommendation	66	25.0	31	15.7	97	18.0

Note. This item was applicable to respondents who reported receiving information or training about guardianship, supported decision-making, or other alternatives.

As shown in Table 16, approximately one-quarter of respondents reported receiving no information or training. Among those who did receive information, patterns in the type of advice reported varied by group. Families of youth most often reported receiving mixed advice or general information without a specific recommendation, while families of adults most often reported being advised to pursue guardianship. Overall, responses were more evenly distributed among families of youth, whereas families of adults reported advice to pursue guardianship at a noticeably higher rate than other advice types. These patterns are presented descriptively and should be interpreted in light of differences in the populations represented in each sample.

Barriers to Understanding or Pursuing Guardianship and Alternatives

What barriers have you faced in understanding or pursuing guardianship or other decision-making options? (Select all that apply)

Table 21. Barriers to Understanding or Pursuing Guardianship and Alternatives

Barrier	Youth (n = 364)		Adult (n = 255)		All (N = 619)	
	n	%	n	%	n	%
Unsure which option is best	131	36.0	67	26.3	198	32.0
The legal process is confusing	76	20.9	66	25.9	142	22.9
Cannot afford an attorney	70	19.2	36	14.1	106	17.1
Not given enough clear information	72	19.8	29	11.4	101	16.3
Do not know where to start or who to ask	60	16.5	38	14.9	98	15.8
Other	18	4.9	21	8.2	39	6.3
Have not experienced any challenges	112	30.8	94	36.9	206	33.3

Note. Respondents could select more than one response; percentages may sum to more than 100%.

The most reported barrier was being unsure which option is best, followed by confusion about the legal process. Approximately one-third of respondents reported not having experienced any challenges. Relatedly, over half of the responses categorized as “Other” indicated that the item was not applicable or that no barriers were experienced. These responses may reflect respondents for whom guardianship or alternative decision-making options are not relevant—for example, those whose family member does not require substantial decision-making support.

Knowledge and Interest in Learning More

This section presents findings related to respondents' current knowledge and interest in learning more about decision-making, guardianship, and related topics.

Current Knowledge and Interest in Learning More

For each topic below, rate how much you already know and how interested you are in learning more.

Table 22. Current Knowledge and Interest in Learning More

Topic	Group	Current Knowledge			Interest in Learning More		
		No	Basic	Extensive	Not	Some-what	Very
Establishing guardianship	Youth	17.0	68.4	12.1	20.8	34.9	44.2
	Adult	8.5	59.3	32.3	21.9	39.2	38.8
Exploring alternatives to guardianship	Youth	24.5	58.8	14.6	18.0	33.8	48.2
	Adult	26.6	52.5	20.9	18.6	38.8	42.6
Understanding the transfer of legal rights at age 18	Youth	23.4	56.6	18.1	19.7	32.6	47.8
	Adult	16.5	49.2	34.3	23.3	38.8	37.9
Using supported decision-making	Youth	21.4	59.3	17.6	17.2	34.1	48.7
	Adult	14.0	57.0	28.9	18.4	41.6	40.0
Advocating for the individual	Youth	14.0	58.0	26.4	13.8	36.3	49.9
	Adult	5.2	46.8	48.0	16.7	39.7	43.5
Navigating adult services and supports	Youth	21.4	56.6	22.3	12.8	32.7	54.5
	Adult	11.4	62.2	26.4	11.6	36.4	52.1
Protecting the individual's well-being	Youth	13.5	54.4	32.1	13.2	33.0	53.8
	Adult	4.5	40.9	54.7	10.3	38.8	50.8
Encouraging self-determination and self-advocacy	Youth	10.4	52.2	37.4	10.7	33.2	56.0
	Adult	7.3	48.8	43.9	12.4	39.7	47.9
Planning for long-term housing, financial stability, and daily support	Youth	26.1	54.4	19.5	18.7	36.3	45.1
	Adult	18.6	56.7	24.7	16.1	42.1	41.7
Restoring rights after guardianship	Youth	48.4	42.9	8.8	25.3	36.3	38.5
	Adult	44.1	44.1	11.7	23.8	39.3	36.8

Across topics, respondents most often reported having basic knowledge, particularly among families of youth, for whom basic knowledge exceeded 50% across most areas. Families of adults more frequently reported extensive knowledge, especially for advocating for the individual and protecting their well-being. For both groups, restoring rights after guardianship was associated with relatively high proportions reporting no knowledge and few reporting extensive knowledge.

Interest in learning more was consistently high across both groups. For most topics, many respondents reported being somewhat or very interested, with relatively few indicating no interest. “Very interested” responses often exceeded 40% and reached over half of youth respondents for several topics, including navigating services, protecting well-being, and encouraging self-determination.

These patterns suggest that, even where some foundational knowledge is present, families seek additional information and guidance related to guardianship, alternatives, and broader decision-making supports.

Key Findings and Implications

What We Learned

The survey responses highlight several important patterns in how Ohio families experience decision-making, guardianship, and planning for adulthood for family members with disabilities.

Families reported a need for more information about decision-making options and adult services

Many families reported having only basic knowledge of guardianship and alternatives such as supported decision-making. Most families were interested in learning more. Interest was especially high for topics like navigating adult services and planning for the future, with more than half of families reporting they were very interested in these areas.

Families reported a gap between current decision-making involvement and future goals

Families often reported that their family members currently need substantial support to make decisions. Families hope those individuals will take on a more active and independent role in decision-making over time. This pattern was consistent across both youth and adult groups and was especially noticeable in areas such as daily living, education, and community participation.

Families reported making decisions with limited or inconsistent guidance

Families reported receiving information from a range of sources, most often developmental disability services staff. About one-quarter in each group also reported receiving information from medical professionals or from family members or friends. At the same time, about one in four families of youth and one in five families of adults reported receiving no information at all. Among those who did receive information, advice was often mixed.

Families identified multiple factors influencing decisions to pursue guardianship

Decisions were most often influenced by concerns about financial and medical decision-making, safety, and vulnerability to exploitation. About half of families also cited recommendations from professionals, as well as a desire to prevent harmful or risky decisions and to remain involved in important aspects of their family member's life.

Families identified multiple reasons for using alternatives to guardianship

Among those using or considering alternatives, common reasons included promoting independence and self-advocacy, respecting the individual's right to make decisions, and maintaining autonomy while still providing support. Supported decision-making agreements and power of attorney were among the most frequently reported approaches across both groups.

Families reported barriers to accessing and understanding decision-making options

Families frequently described uncertainty about which option is best, confusion about the legal process, and difficulty finding clear and consistent information. Legal costs and not knowing where

to begin were also commonly noted. About one-third of families reported not experiencing challenges.

What These Findings Suggest

These findings point to several opportunities to better support Ohio families as they navigate decision-making for family members with disabilities.

Provide clearer, more accessible information earlier. Many families described making decisions — including decisions about guardianship — with limited or inconsistent guidance. Making clear, plain-language information about guardianship, supported decision-making, and other options more widely available, and doing so earlier in the transition process, could help families make more informed choices.

Support families in planning for greater independence. Families consistently described hoping for more independence for their family members over time. Resources and conversations that help families identify practical steps toward greater involvement — across areas like daily living, health, and community participation — could help bridge the gap between current support needs and longer-term goals.

Strengthen the role of trusted sources. Developmental disability services staff were the most common source of information for families. Equipping these professionals — as well as educators, medical providers, and others families turn to — with accurate, up-to-date information about the full range of decision-making options could help ensure that families receive consistent and balanced guidance.

Make alternatives to guardianship more visible and easier to access. Families who used alternatives to guardianship described doing so for reasons rooted in respect for their family member's rights and a desire to promote independence. Increasing awareness of these options — and reducing barriers such as legal costs and unclear processes — could help more families consider approaches that preserve individual autonomy.

Reduce barriers to navigating the system. Families frequently described not knowing where to begin or how to find clear information. Tools that help families understand their options, navigate legal processes, and connect with local resources could reduce confusion and make the process more manageable.

Continue to include family perspectives in planning and policy. This survey demonstrates that families have important insights into what their family members need and what supports are missing. Ongoing efforts to include family voices in the development of resources, services, and policies can help ensure that those supports are practical, accessible, and responsive to real-world experiences.

Appendices

Appendix A. Study Methods

Study Purpose

This statewide survey examined how Ohio families make decisions about guardianship and less restrictive alternatives, such as supported decision-making, as their family members with disabilities approach or navigate adulthood. The study focused on families' knowledge of these options, the factors that influence their decisions, the information and guidance they receive, and the barriers they encounter.

Survey Development

Survey development was guided by an advisory board connected to the Supported Decision-Making Network of Ohio (SDMNO). The board included self-advocates; family members of individuals with intellectual or developmental disabilities; and representatives of state education, county-board, parent-information, advocacy, and service organizations with expertise in guardianship, supported decision-making, transition, and family support. Over six meetings, board members helped identify key topics, reviewed draft questions for clarity and relevance, and provided feedback used to refine wording, navigation, and accessibility.

Two versions of the survey were developed for family respondents: one for those reporting on in-school youth with disabilities and a second for those reporting on adults with intellectual or developmental disabilities. Most questions were the same in both versions, with a small number tailored to the family member's disability characteristics and whether respondents were planning for future decisions or reporting on decisions already made. Both versions were built in Qualtrics, a platform compatible with screen readers, and were available in English and Spanish.

Because the two versions were largely identical, the families-of-youth version was pretested in person through individual cognitive-interview sessions with five parents of in-school youth with disabilities. During these sessions, parents reviewed the survey while explaining how they understood the questions and response options. They also provided feedback about wording, clarity, navigation, and ease of completion. Their feedback resulted in minor wording and navigation revisions to the final survey versions.

Recruitment and Data Collection

Families were recruited across Ohio through community and professional networks. SDMNO and its member organizations supported outreach efforts. Recruitment partners shared study information and invitations to participate through family, education, developmental-disability, and advocacy networks. Information was distributed through newsletters, social media, listservs, direct outreach, conferences, and other community channels.

To supplement community-based recruitment, additional respondents were recruited through a sample vendor that drew from multiple online panels. The vendor used initial screening to identify potential respondents reporting on a family member living in Ohio and technical safeguards to reduce duplicate and fraudulent entries. This approach broadened recruitment beyond existing community and professional networks.

Community recruitment ran from October 1, 2025, through March 27, 2026. Online-panel recruitment was added partway through the project and ran on a shorter schedule: December 12, 2025, through January 19, 2026 for families of youth, and February 11 through February 23, 2026 for families of adults.

Following response review, the final analytic sample included 619 responses: 364 families of youth (104 recruited through community outreach and 260 through online panels) and 255 families of adults (90 recruited through community outreach and 165 through online panels).

IRB Review and Participant Protections

This study was reviewed and determined to be exempt by the Bowling Green State University Institutional Review Board (IRBNet #2278402). The protocol was amended during the study to add online-panel recruitment and additional data-quality procedures.

Before beginning the survey, respondents reviewed information about the study, including its purpose, procedures, risks, privacy protections, and voluntary nature. Respondents indicated consent by choosing to continue to the survey. They could skip questions or stop participating at any time.

To be eligible, respondents needed to be at least 18 years old. The family member they reported on needed to live in Ohio. Respondents reporting on in-school youth also needed to be a parent or other family member serving as a guardian of a family member ages 14–22 who was still in school and receiving special education services. Respondents reporting on adults needed to be a parent or other family member serving as a guardian or primary supporter of an adult age 18 or older with an intellectual or developmental disability who was no longer in school. Respondents who did not meet these criteria were screened out before beginning the main survey.

The main survey did not ask respondents to provide names, email addresses, or other direct identifying information. Survey responses were kept confidential. Contact information for incentives, when provided, was stored separately from survey responses and was not included in the analytic dataset.

Incentives

Participants recruited through community channels could choose to enter a drawing for a \$50 electronic gift card, with approximately a 1 in 25 chance of winning. The first 150 eligible participants in each survey group also received a guaranteed \$10 digital gift card. These study-funded incentives were initially offered to participants recruited through social media as well. After

a pattern of fraudulent entries linked to incentivized social-media posts was identified, the incentives were discontinued for that recruitment channel. Participants recruited through online research panels were compensated through the vendor's reward system rather than through the study's gift cards.

Response Review

Responses were reviewed before analysis to confirm that they met the study's eligibility criteria and reflected genuine, valid survey participation. The review included checks for eligibility, survey completion time, duplicate submissions, consistency across related questions, the quality of open-ended responses, and technical indicators of automated or fraudulent submissions.

For example, a response was flagged for the consistency check if it showed a pattern of reporting a family member's future decision-making independence as substantially lower than their current level — an unlikely pattern suggesting low-quality responding. Technical information used for these checks, such as IP addresses, was temporary and removed before the final analytic dataset was created.

Responses were excluded when they were ineligible, duplicate, insufficiently complete, completed unusually quickly, showed multiple unlikely response patterns, or contained other converging indicators that the response was not valid.

Data Analysis

Findings in this report are based on descriptive summaries of survey responses and are presented as frequencies and percentages. Most findings are shown separately for families of youth and families of adults because the groups represented different stages of the transition to adulthood and different disability populations.

Interpreting the Findings

The survey included families from communities across Ohio and provides important information about the experiences, concerns, and information needs of participating families.

Participants were recruited through community networks and online panels rather than through a random statewide sample. Therefore, the findings describe the experiences of the families who took part and may not represent the experiences of all Ohio families of people with disabilities.

Results for families of youth and families of adults are presented separately because the groups represented different populations and different points in the decision-making process. Families of youth were often planning for future decisions and included family members across IDEA disability categories. Families of adults were more often reflecting on decisions already made and were limited to those with an intellectual or developmental disability.

Despite these considerations, the survey offers valuable insight into how Ohio families experience decision-making, guardianship, and support during the transition to adulthood.

Appendix B. Respondent Characteristics

This appendix presents additional respondent characteristics, including age, gender, race/ethnicity, education, and household income. Respondents' relationship to their family member is presented in Table 1 in the Methods Overview section.

Table 23. Respondent Age

Age Group	Youth (<i>n</i> = 360)		Adult (<i>n</i> = 252)		All (<i>N</i> = 612)	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
30 or younger	20	5.6	19	7.5	39	6.4
31–40	105	29.2	47	18.7	152	24.8
41–50	142	39.4	73	29.0	215	35.1
51–60	70	19.4	71	28.2	141	23.0
61–70	18	5.0	34	13.5	52	8.5
71–80	5	1.4	8	3.2	13	2.1

Table 24. Respondent Gender

Gender	Youth (<i>n</i> = 359)		Adult (<i>n</i> = 252)		All (<i>N</i> = 611)	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Male	119	33.1	57	22.6	176	28.8
Female	239	66.6	195	77.4	434	71.0
Prefers to self-describe	1	0.3	0	0.0	1	0.2

Table 25. Respondent Race/Ethnicity

Race/Ethnicity (Select all that apply)	Youth (<i>n</i> = 364)		Adult (<i>n</i> = 255)		All (<i>N</i> = 619)	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
White	306	84.1	218	85.5	524	84.7
Black or African American	48	13.2	35	13.7	83	13.4
Asian	3	0.8	5	2.0	8	1.3
American Indian or Alaska Native	5	1.4	5	2.0	10	1.6
Native Hawaiian or Other Pacific Islander	0	0.0	0	0.0	0	0.0
Hispanic/Latino	18	4.9	8	3.1	26	4.2
Prefer not to say	2	0.5	0	0.0	2	0.3

Note. Respondents could select more than one category; therefore, percentages may sum to more than 100%.

Table 26. Respondent Education

Highest Level of Education	Youth (<i>n</i> = 361)		Adult (<i>n</i> = 252)		All (<i>N</i> = 613)	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
No high school diploma or GED	5	1.4	4	1.6	9	1.5
High school diploma or GED	73	20.2	56	22.2	129	21.0
Vocational school or certificate program	27	7.5	14	5.6	41	6.7
Some college	91	25.2	52	20.6	143	23.3
College degree or higher	165	45.7	126	50.0	291	47.5

Table 27. Respondent Household Income

Household Income	Youth (<i>n</i> = 359)		Adult (<i>n</i> = 251)		All (<i>N</i> = 610)	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
No earned income	12	3.3	10	4.0	22	3.6
Up to \$35,000	61	17.0	37	14.7	98	16.1
\$35,001–\$40,000	34	9.5	20	8.0	54	8.9
\$40,001–\$70,000	95	26.5	68	27.1	163	26.7
\$70,001–\$115,000	85	23.7	61	24.3	146	23.9
Over \$115,000	53	14.8	39	15.5	92	15.1
Prefer not to say	19	5.3	16	6.4	35	5.7

Note. Household income excludes state or federal benefits such as SSI or SSDI.

Appendix C. Family Member County of Residence

This appendix provides the county-level data shown in Figure 1 in accessible tabular form.

Table 28. Family Member County of Residence

County	Region	Responses
Allen County	Northwest	6
Ashland County	Northeast	2
Ashtabula County	Northeast	4
Auglaize County	Northwest	5
Belmont County	Southeast	4
Brown County	Southwest	6
Butler County	Southwest	27
Clark County	Southwest	6
Clermont County	Southwest	13
Clinton County	Southwest	1
Columbiana County	Northeast	3
Coshocton County	Southeast	3
Crawford County	Central	5
Cuyahoga County	Northeast	53
Darke County	Southwest	3
Delaware County	Central	8
Erie County	Northwest	11
Fairfield County	Central	3
Fayette County	Central	3
Franklin County	Central	53
Gallia County	Southeast	2
Greene County	Southwest	3
Guernsey County	Southeast	3
Hamilton County	Southwest	34
Hancock County	Northwest	3
Hardin County	Northwest	3
Harrison County	Northeast	4
Henry County	Northwest	2
Highland County	Southwest	1
Hocking County	Southeast	2
Holmes County	Northeast	1

Huron County	Northwest	1
Jackson County	Southeast	1
Jefferson County	Northeast	2
Knox County	Central	7
Lake County	Northeast	8
Lawrence County	Southeast	4
Licking County	Central	8
Logan County	Southwest	6
Lorain County	Northeast	10
Lucas County	Northwest	45
Madison County	Central	4
Mahoning County	Northeast	14
Marion County	Central	7
Medina County	Northeast	9
Meigs County	Southeast	1
Mercer County	Northwest	1
Miami County	Southwest	6
Monroe County	Southeast	1
Montgomery County	Southwest	27
Morgan County	Southeast	1
Muskingum County	Southeast	5
Ottawa County	Northwest	3
Paulding County	Northwest	2
Perry County	Southeast	1
Pickaway County	Central	1
Pike County	Southeast	4
Portage County	Northeast	5
Preble County	Southwest	2
Putnam County	Northwest	3
Richland County	Central	10
Ross County	Central	2
Sandusky County	Northwest	3
Scioto County	Southeast	6
Seneca County	Northwest	1
Shelby County	Southwest	1
Stark County	Northeast	24
Summit County	Northeast	34

Trumbull County	Northeast	7
Tuscarawas County	Northeast	9
Union County	Central	6
Van Wert County	Northwest	1
Vinton County	Southeast	1
Warren County	Southwest	9
Washington County	Southeast	4
Wayne County	Northeast	2
Williams County	Northwest	3
Wood County	Northwest	17

Note. $N = 606$. No family members were reported as residing in the remaining 10 Ohio counties: Adams, Athens, Carroll, Champaign, Defiance, Fulton, Geauga, Morrow, Noble, Wyandot.