



2018 Tower Foundation Family Survey

Parents of Youth with Intellectual Disabilities Erie and Niagara Counties

Like so many families, the Tower family has been affected by intellectual disabilities, learning disabilities, mental health issues, and substance use disorders. To learn how these issues affect the community and help guide local efforts to address them, the Tower Foundation asked residents to respond to a survey in fall 2017. To dig deeper into the experiences of families of youth with intellectual disabilities, an additional survey of families was conducted in 2018. Forty-nine parents, guardians, or adult caregivers of children with intellectual disabilities from Erie and Niagara Counties in New York State responded to the survey. Throughout the summary, parents includes all respondents.

The Tower Foundation defines **intellectual disabilities** as characterized by significant limitations both in mental capacity (e.g., learning, reasoning, and problem-solving), and adaptive behavior (e.g., conceptual skills, social skills, and daily living skills). Individuals on the autism spectrum are also included here.

Description of youths

The 49 parents who completed the survey said they had a total of 113 children, age 2 to 26. Some families had multiple children with intellectual disabilities, but they provided inconsistent data about how many children or what type of intellectual disabilities.

This summary describes the experiences of the 49 youths, age 2 to 20, whom parents focused on while completing the survey. Parents reported in an open-ended question that these youths were most frequently diagnosed with autism (36). Youth were most likely to live at home with their parents (84%) (Figure 1).

1. Child's living situation (N=49)

Where does your child currently live?	Number	Percent checking this option
At home with parent or guardian	41	84%
With another family member	2	4%
In a supervised group home or a residence specifically for people with disabilities	5	10%
Hospital	1	2%

Perceptions of intellectual disabilities

The family survey included a few questions that mirrored those asked on the broader community survey. The first asked about how people with intellectual disabilities are treated in the community. About half the parents (53%) agreed that people with intellectual disabilities are treated fairly, and the remaining 47% disagreed (Figure 2). Forty-two percent of community respondents agreed people with intellectual disabilities are treated fairly in their community and 31% disagreed. Twenty-eight percent said they did not know.

A second question asked whether it would be best for people with intellectual disabilities to live and work in special communities. Thirty-four percent of parents agreed with this statement, 57% disagreed, and 8% did not know. Community members were more likely than parents to disagree (66%) or say they did not know (18%) about this statement. Sixteen percent of community members agreed it would be best for persons with intellectual disabilities to live and work in special communities.

2. Perceptions of people with intellectual disabilities

		N	Strongly agree	Agree	Disagree	Strongly disagree	Don't know
People with intellectual disabilities are treated fairly in our community.	Parents	49	6%	47%	37%	10%	0%
	Overall community	762	4%	38%	26%	5%	28%
It would be best for persons with intellectual disabilities to live and work in special communities.	Parents	48	12%	22%	39%	18%	8%
	Overall community	762	2%	14%	47%	19%	18%

Information and services to support parents of youth with intellectual disabilities

Almost all of the parents (94%) agreed they have enough information to understand their child's intellectual disability (Figure 3). Seventy-six percent agreed they have enough information to help plan services and supports, and 59% agreed they found the information and supports easy to understand. Fewer parents agreed they have received all the services and supports they need for their child (47%) or are comfortable with their child's level of independence (49%).

3. Information and services available for parents of youth with intellectual disabilities (N=49)

	Strongly agree	Agree	Disagree	Strongly disagree	Don't Know
You have enough information to understand your child's intellectual disability.	45%	49%	6%	0%	0%
You have enough information to help plan services and supports for your child.	27%	49%	18%	6%	0%
The information about services and supports you receive for your child is easy to understand.	18%	41%	35%	4%	2%
You have received all of the needed services and supports for your child.	12%	35%	31%	20%	2%
You are comfortable with the level of independence your child has.	6%	43%	39%	12%	0%

Educational experience

Forty-seven of the youths were old enough to be in school (Figure 4). Most of them attended public schools (71%). A third of the youths (36%) attended private schools, and two (4%) were home-schooled. Some students had multiple types of schools during their education experience.

4. Types of education settings (N=49)

What kind of setting was your child educated in?	Number	Percent checking this option
Public	35	71%
Private	18	36%
Home school	2	4%
Child is not yet in school	2	4%

Note: Child could have attended multiple types of school settings.

The youths had different levels of inclusion with students that do not have intellectual disabilities. Thirty-eight percent attended a school that only serves students with disabilities, and 4% were in classrooms that did not include students without disabilities (Figure 5). The remaining students were either partially (30%) or fully (28%) integrated into classrooms that included students with and without intellectual disabilities.

5. Inclusiveness of school settings (N=47)

Did your child's education setting include students without disabilities	Number	Percent checking this option
Fully included	13	28%
Partially included	14	30%
Not included	2	4%
The school was only for students with disabilities	18	38%

Of the 47 youths in school, 43 (91%) had an IEP, 504 plan, person-centered plan, or other type of education service plan. Eighty-three percent of the parents said the educational service plan addresses all the supports their child needs (Figure 6). All parents helped develop the plan; 14% also involved children in the plan development (Figure 7).

6. Educational plan for youth with intellectual disabilities (N=42)

	Number	Percent checking "Yes"
The educational service plan addresses all the supports the child needs.	35	83%

7. Development of educational plan (N=43)

Did you and your child help develop the education plan?	Number	Percent checking this option
Parent helped develop the plan	37	86%
Parent and child helped develop the plan	6	14%

Both parents and community members were asked about equal education opportunities for youth with intellectual disabilities. Ninety-two percent of community respondents agreed that youth with intellectual disabilities should receive equal education opportunities. However, fewer than half of the parents (45%) agreed this happens (Figure 8).

8. Equal education opportunities for youth with intellectual disabilities

		N	Strongly agree	Agree	Disagree	Strongly disagree	Don't know
In general, people with intellectual disabilities (should) receive equal education opportunities. ^a	Parents	49	2%	43%	41%	14%	0%
	Overall community	762	45%	47%	4%	0%	3%

^a In the community survey, the word **should** was included in the question to get their opinions of what should happen. For the family survey, the question was asking whether the statement actually happened.

Despite their perspectives on whether youth receive equal education opportunities, most parents were satisfied with the quality of the education their child received or is receiving. One-third of the parents (33%) were “very satisfied” and half (49%) were “satisfied” with their child’s experience (Figure 9).

9. Parents’ satisfaction with quality of education (N=45)

	Very satisfied	Satisfied	Dissatisfied	Very Dissatisfied
How satisfied are you with the quality of education your child received or is receiving?	33%	49%	7%	11%

Work experience

Three parents (1%) said their child had a job for which they earn pay on a regular basis. One is competitively employed and earns at least minimum wage in a setting not specifically for people with disabilities, one works at household chores, and one works as on-call or seasonal labor.

Both parents and community members were asked about equal employment opportunities for youth with intellectual disabilities. Eighty-five percent of community respondents agreed youth with intellectual disabilities should receive equal employment opportunities. However, 10% of the parents agreed this happens (Figure 10).

10. Equal employment opportunities for youth with intellectual disabilities

		N	Strongly agree	Agree	Disagree	Strongly disagree	Don't know
In general, people with intellectual disabilities (should) receive equal employment opportunities. ^a	Parents	48	0%	10%	48%	31%	10%
	Overall community	762	35%	50%	8%	1%	7%

^a In the community survey, the word **should** was included in the question to get their opinions of what should happen. For the family survey, the question was asking whether the statement actually happened.

Conclusions

The Tower Foundation conducted this survey because of its commitment to address issues related to intellectual disabilities in the communities it serves. Foundation staff and Trustees will look at these results in connection with results from community-level data to help organizations in Erie and Niagara Counties look into what they can do to better support families and youth experiencing intellectual disabilities. The following questions can help guide future discussions and decisions:

- What services and supports do families need to help their child reach their highest potential?
- How might communities create or connect youth with intellectual disabilities to opportunities to achieve appropriate levels of independence?
- How can respondents' positive attitudes about equity in education and employment be leveraged to ensure youth with intellectual disabilities are treated fairly?

Methods and caveats

This survey targeted families of youth, age 26 or younger, who have an intellectual disability. Any parent, guardian, or caregiver who completed the survey received a \$20 gift card.

Two primary methods were used to invite families to participate:

- When the Tower Foundation mailed community surveys to 4,000 random addresses in Erie and Niagara Counties in fall 2017, the mailing included information for residents to register for an additional family survey specific to learning disabilities and intellectual disabilities. When Wilder staff completed the phone survey with those who registered, families were asked for names of other parents or guardians who might be interested in completing the survey; those referred families were also contacted.
- Tower Foundation and Wilder Research staff designed outreach and recruitment materials for local organizations and schools to share with families to increase participation. Facebook promoted posts were also used. Families were directed to a website to complete the survey online or request a phone interview.

The outreach methods were not as successful as we had hoped. Future data collection efforts will consider alternative options for reaching families of youth with intellectual disabilities. Because of the low number of respondents, the results may not be representative of the entire population of families of youth with intellectual disabilities.

