



2020 Tower Foundation Family Survey

Intellectual Disabilities Parent Results 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 community residents to respond to a survey in fall 2019. To dig deeper into the experiences of families of youth with intellectual disabilities, the Foundation conducted an additional survey of families in 2020. Sixty-eight parents, guardians, or adult caregivers from Erie and Niagara counties in New York State responded to the survey for a child with intellectual disabilities. Throughout the summary, the term “parents” includes all respondents and notable differences from the 2018 survey are noted.

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 in this group.

Description of youths

The 68 parents who completed the survey said they had a total of 83 children, age 1 to 26, with an intellectual disability. Most (85%) had one child with an intellectual disability. This summary describes the experiences of the 68 youths, age 2 to 20, whom parents focused on while completing the survey. The focus child was most frequently diagnosed with autism (77%; Figure 1).

1. Identified intellectual disabilities (N=68)

Disability	Percent of youth
Autism	77%
Down Syndrome	9%
Fetal Alcohol Syndrome	2%
Prader-Willi Syndrome	2%
Other diagnosis	19%
Don't know/refused	4%

Note: Youth may have more than one diagnosis, so the total may not equal 100%.

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 (49%) agreed that people with intellectual disabilities are treated fairly, 44% disagreed and 7% don't know (Figure 2). Forty-seven percent of community respondents agreed people with intellectual disabilities are treated fairly in their community and 28% disagreed. Twenty-nine percent said they did not know, which is much higher than parents.

A second question asked whether it would be best for people with intellectual disabilities to live and work in special communities. Twenty-four percent of parents agreed with this statement, a decline from last year when 34% agreed. Parent and community member responses were more similar in the most recent survey than they were in the previous survey, though community members were slightly less likely to agree with this statement even in the most recent survey (15%).

2. Parents' and residents' perspectives of intellectual disabilities

		N	Strongly agree	Agree	Disagree	Strongly disagree	Don't know
People with intellectual disabilities are treated fairly in our community.	Parents	68	2%	47%	32%	12%	7%
	Overall community	1,145	6%	41%	23%	5%	24%
It would be best for persons with intellectual disabilities to live and work in special communities.	Parents	68	8%	16%	49%	13%	13%
	Overall community	1,146	3%	12%	41%	26%	17%

Information and services to support youth with intellectual disabilities

A large majority of the parents (91%) agreed that they have enough information to understand their child's intellectual disability (Figure 3). Seventy-five percent have enough information to help plan services and supports for their child and half agreed that the information and supports were easy to understand. However, fewer parents agreed that they have received all the services and supports they need for their child (40%) or are comfortable with their child's level of independence (35%), both of which are also lower than in 2018.

Two of these questions were also asked of a subset of respondents who identified as parents of youth with intellectual disabilities on the community survey. In the broader community survey, parents of youth with intellectual disabilities were less likely to agree they have enough information to understand their child's learning disability (63%), but were similarly likely to agree that they are receiving all of the needed services and supports (40%).

3. Information and services available for parents and guardians of youth with intellectual disabilities

	Year	N	Strongly agree	Agree	Disagree	Strongly disagree	Don't know
You have enough information to understand your child's intellectual disability.	2020	68	28%	63%	7%	0%	2%
	2018	49	49%	45%	6%	0%	0%
You have enough information to help plan services and supports for your child.	2020	68	19%	56%	18%	7%	0%
	2018	49	27%	49%	18%	6%	0%
The information about services and supports you receive for your child is easy to understand.	2020	68	10%	40%	43%	7%	0%
	2018	49	18%	41%	35%	4%	2%
You have received all of the needed services and supports for your child.	2020	68	13%	27%	43%	16%	2%
	2018	49	12%	35%	31%	20%	2%
You are comfortable with the level of independence your child has.	2020	68	4%	31%	53%	10%	2%
	2018	49	6%	43%	39%	12%	0%

Educational experience

Among the families surveyed, 65 of the children were old enough to be in school (Figure 4). While most attended public schools (60%), this was fewer than in 2018 when 71% of respondent's children attended public schools. Forty-four percent of the youths attended private schools, and three (4%) were home-schooled. Some students attended multiple types of schools during their education experience.

4. Types of education settings (N=68)

What kind of setting was your child educated in?	Number	Percent checking this option
Public	41	60%
Private	30	44%
Home school	3	4%
Child is not yet in school	3	4%

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

The children had different levels of inclusion with students that do not have intellectual disabilities. Thirty-five percent attended a school that only serves students with disabilities, and 13% were in classrooms that did not include students without disabilities (Figure 5). The remaining students were either partially (33%) or fully (19%) integrated into classrooms that included students with and without intellectual disabilities. Compared to 2018, a larger percentage of students were in non-integrated classrooms (13% vs. 4%) and fewer were in fully integrated classrooms than in 2018 (19% vs. 28%).

5. Inclusiveness of school settings

Did your child's education setting include students without disabilities	2020 (N=63)	2018 (N=47)
Fully included	19%	28%
Partially included	33%	30%
Not included	13%	4%
The school was only for students with disabilities	35%	38%

Of the 65 youths in school, 94% had an IEP, 504 plan, person-centered plan, or other type of education service plan. Unlike in 2018 when all parents with a plan helped develop the plan, 81% of parents this year reported helping develop the plan and 11% of parents reported neither they nor their child helped in the plan development (Figure 6).

Of those with a plan, 80% of the parents said the educational service plan addresses all the supports their child needs, similar to the 83% in 2018.

6. Development of educational plan

Did you and your child help develop the education plan?	2020 (N=63)	2018 (N=47)
Parent helped develop the plan	64%	78%
Parent and child helped develop the plan	17%	13%
Neither parent nor child helped develop the plan	11%	NA
Child helped develop the plan	3%	NA
No plan	5%	91%
Plan addresses all the support their child needs (of those with a plan)	80%	83%

Both parents and community members were asked about equal education opportunities for youth with intellectual disabilities. Ninety-four percent of community respondents agreed that youth with intellectual disabilities should receive equal education opportunities. However, fewer than half of the parents (40%) agreed that this happens (Figure 7).

7. 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	68	3%	37%	40%	19%	2%
	Overall community	1,155	45%	49%	3%	<1%	2%

^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 (32%) were “very satisfied” and half (51%) were “satisfied” with their child’s experience (Figure 8).

8. Parents’ satisfaction with quality of education

	Year	N	Very satisfied	Satisfied	Dissatisfied	Very Dissatisfied	Don’t know
How satisfied are you with the quality of education your child received or is receiving?	2020	65	32%	51%	8%	8%	2%
	2018	45	33%	49%	7%	11%	0%

Work experience

Four parents (10%) said their child had a job for which they earn pay on a regular basis. All of these jobs pay at least minimum wage and are in an integrated environment where they are competitively employed in a setting not specifically for people with disabilities.

Both parents and community members were asked about equal employment opportunities for youth with intellectual disabilities. Eighty-four percent of community respondents agreed that youth with intellectual disabilities should receive equal employment opportunities. However, 6% of the parents agreed this happens (Figure 9).

9. 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	67	0%	6%	43%	30%	21%
	Overall community	1,146	34%	50%	8%	1%	6%

^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.

Community strengths and opportunities for improvement

To better understand their experiences navigating supports for their children with intellectual disabilities, parents and guardians were asked to respond to two open-ended questions. The first question explored what parents and guardians like about their community’s support of youth with intellectual disabilities. The most prevalent theme was the number of resources and options available for families (9 responses), specifically the qualities of staff and professionals in the programs (e.g., trustworthy, kind, caring, dedicated, and patient; 5 responses). Parents also mentioned the increased level of awareness, understanding, and acceptance in the community (6 responses).

*That the people who are responsible for her development are trustworthy and caring.
The teachers and therapists my son has had.*

I like that they exist. I like the diversity of services that seem to be available.

That everything is readily available to him and that the school district is willing to give us everything he needs.

The fact that the number of non-government funded programs has been increasing.

The second question asked parents and guardians about their wishes for community support for their child with intellectual disabilities. Parents and guardians most wished for more information about the services that are available (12 responses) and easier access to services (9 responses).

I had been [given] more information about community services through the school and the many counselors we went to. [My child] missed out on so many service because I wasn't told about them.

There was a class, at initial diagnosis, that I could have taken to explain the process and services that are available to us.

There were places to get help for parents and young adults to discern what opportunities could be available within the community. My children will be growing old in this community and want to be productive citizens, I wish there were places to help them to become included. I wish employers would be more open to trying to hire a person with an intellectual disability. Even attempting to find opportunities for volunteering has been difficult.

I wish that the amount of effort required to access these services was not so huge. I wish that we paid the people that deliver the services more. I wish that the wait list to access these services was not so long. I wish that programs advertised as developing independent living skills for young people with autism did not exclude individuals who are "too autistic" and "not independent enough". I also wish that youth with intellectual disabilities didn't have to spend so much time and energy having to learn how to conform to neuro-typical norms just to exist safely in the world.

It was easier to access and was more advertised.

The language and processes were not so complicated.

Next most frequently, caregivers "wished for" (8 responses each): more or better school-based support, and more community awareness, caring, and inclusivity.

That more businesses would be understanding, and train their employees to have understanding, and knowledge, and the ability to help without judgements.

The community was more inclusive and accepting.

More was available for all students with needs, at all schools.

The school board offered more in the sense of year round school (full day).

The schools were more sensitive to intellectual disabilities.

There were more school opportunities/options and/or that the district we live in provided better school opportunities for varying needs of children. Schooling for her is not very appropriate.

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 community organizations explore what they can do to better support families and youth experiencing intellectual disabilities.

This year, compared to 2018, caregivers were less likely to report they have received all of the supports and services they need and they are comfortable with their child's independence. In addition, the majority of parents at both time points have expressed that individuals with intellectual disabilities do not have access to equal educational and employment opportunities. Given these findings, 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 was targeted to 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.

Three primary methods were used to invite families to participate:

- When the Tower Foundation mailed community surveys to 6,000 random addresses in Erie and Niagara counties in fall 2019, the mailing included information for residents to complete an additional family survey specific to learning disabilities and intellectual disabilities. When parents completed the survey, they were asked to share the survey link with other eligible families.
- Families who participated in the survey in 2018 were sent the results from that survey and were invited to participate again in 2020.
- Tower Foundation and Wilder Research staff designed outreach and recruitment materials for local organizations and schools to share with families to increase participation.

