



2022 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 dig deeper into the experiences of families of youth with intellectual disabilities, the Foundation conducted a survey with families in 2018. Forty-nine parents, guardians, or adult caregivers from Erie and Niagara counties in New York responded to the survey for a child with intellectual disabilities. At the beginning of 2020, sixty-eight parents, guardians, or adult caregivers responded to another survey for a child with learning disabilities. A follow-up survey was completed in 2022 by 50 parents who reported that their child had an intellectual disability. Key differences between the 2018, 2020, and 2022 surveys are noted throughout this summary when the changes are greater than 10 percentage points. The term “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 in this group.

Description of youths

The number of parents reporting on their children with intellectual disabilities in 2022 (50 parents) is down from parents who completed the survey in early 2020 (68 parents), but similar to 2018 (49 parents). The children were somewhat older in 2022 with an age range of 3 to 24 years, compared to the age range of 1 to 26 in 2020, and 2 to 26 in 2018.

Because the number of completed surveys was relatively low in all instances, the results in this report may not represent the population of Erie and Niagara county residents with a family member with an intellectual disability. As such, we urge caution in generalizing these findings beyond the respondents who completed the survey.

Community resources

In the follow-up survey administered in 2022, over a third of parents agreed that it would be best for persons with intellectual disabilities to live and work in special communities (38%, up from 24% in 2020). In 2022, most parents do not agree that people with intellectual disabilities are treated fairly in their community (54%, up from 44% in 2020; Figure 1).

1. 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.	2018	49	6%	47%	37%	10%	0%
	2020	68	2%	47%	32%	12%	7%
	2022	50	4%	32%	46%	8%	10%
It would be best for persons with intellectual disabilities to live and work in special communities.	2018	48	12%	22%	39%	18%	8%
	2020	68	8%	16%	49%	13%	13%
	2022	50	8%	30%	28%	20%	14%

Information and services to support youth with intellectual disabilities

In the 2022 follow-up survey, 76% of the parents agreed that they had enough information to help plan services and supports for their child. Parents reported a substantial difference in the 2022 follow-up survey when compared to previous surveys concerning having enough information to understand their child's intellectual disability (78%, down from 94% in 2018). In addition, it is notable that while the majority of parents said they have enough information to plan services and supports (76%), that they have enough information to understand their child's intellectual disability (78%), and that the information about services and supports are easy to understand (58%), fewer report that they have received all of the needed services and supports of their child (44%). (Figure 2).

2. Information and services available for families of youth with intellectual disabilities

		N	Strongly agree	Agree	Disagree	Strongly disagree	Don't know
You have enough information to understand your child's intellectual disability.	2018	49	45%	49%	6%	0%	0%
	2020	68	28%	63%	7%	0%	2%
	2022	50	22%	56%	16%	4%	2%
You have enough information to help plan services and supports for your child.	2018	49	27%	49%	18%	6%	0%
	2020	68	19%	56%	18%	7%	0%
	2022	50	18%	58%	18%	4%	2%
The information about services and supports you receive for your child is easy to understand.	2018	49	18%	41%	35%	4%	2%
	2020	68	10%	40%	43%	7%	0%
	2022	50	10%	48%	34%	8%	0%

2. Information and services available for families of youth with intellectual disabilities (continued)

		N	Strongly agree	Agree	Disagree	Strongly disagree	Don't know
You have received all of the needed services and supports for your child.	2018	49	12%	35%	31%	20%	2%
	2020	68	13%	27%	43%	16%	2%
	2022	50	12%	32%	36%	16%	4%
You are comfortable with the level of independence your child has.	2018	49	6%	43%	39%	12%	0%
	2020	68	4%	31%	53%	10%	2%
	2022	50	8%	34%	44%	12%	2%

Educational experience

Among the families surveyed in 2022, 78 percent of children were currently enrolled in school. The majority of students were evenly split between public and private settings, and the remaining students were home schooled (Figure 3). When asked about their child’s current education setting in 2022, 78% were engaged in in-person learning, and the remaining 22% were engaged in a hybrid model. No respondents reported engagement in distance learning (Figure 4).

3. Types of education settings (N=39)

What kind of setting is your child currently being educated in?	Number	Percent checking this option
Public	18	46%
Private	18	46%
Home	3	8%

4. Types of education settings (N=36)

What kind of setting is your child currently being educated in?	Number	Percent checking this option
In-person/face-to-face	28	78%
Hybrid	8	22%
Remote/distance learning	0	0%

The children had different levels of inclusion with students that do not have intellectual disabilities. Forty-four percent of students in 2022 attended a school that only serves students with disabilities. The remaining students were fully (6%, down from 19% and 28% pre-pandemic), partially (25%), or not integrated (22%, up from 4% in 2018) into classrooms that included students with and without intellectual disabilities (Figure 5).

5. Inclusiveness of school settings

Does/Did your child's education setting include students without disabilities	2018 (N=47)	2020 (N=63)	2022 (N=36)
Fully included	28%	19%	6%
Partially included	30%	33%	25%
Not included	4%	13%	22%
The school was only for students with disabilities	38%	35%	44%

Of the 39 youths in school, 85 percent had an IEP, 504 plan, person-centered plan, or other type of education service plan. Of those with a plan, 76% of the parents in 2022 said the educational service plan addressed all the supports their child needs; very similar to percentages from 2020 and 2018. (Figure 6).

6. Development of educational plan

Did you and your child help develop the education plan?	2018 (N=42)	2020 (N=63)	2022 (N=33)
Parent helped develop the plan	86%	64%	73%
Parent and child helped develop the plan	14%	17%	18%
Neither parent nor child helped develop the plan	0%	11%	6%
Child helped develop the plan	0%	3%	3%
Plan addresses all the support their child needs (of those with a plan)	83%	80%	76%

Parents were also asked about equal education opportunities for youth with intellectual disabilities. In the survey administered during 2022, a similar proportion of parents agreed that youth with intellectual disabilities receive equal education opportunities (44%, compared to 40% in 2020 and 45% in 2018; 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 receive equal education opportunities.	2018	49	2%	43%	41%	14%	0%
	2020	68	3%	37%	40%	19%	2%
	2022	50	4%	40%	38%	16%	2%

Despite the majority of parents reporting that youth do not receive equal education opportunities, most parents (84%) were satisfied with the quality of the education their child received or is receiving in the 2022 follow-up. A similar portion of parents reported satisfaction with education quality in 2020 and 2018. (Figure 8).

8. Parents' satisfaction with quality of education

		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?	2018	45	33%	49%	7%	11%	0%
	2020	65	32%	51%	8%	8%	2%
	2022	38	21%	63%	11%	0%	5%

Impact of COVID-19

In the 2022 follow-up survey, parents were also asked about how the COVID-19 pandemic had impacted services and supports available to them in the past year. Over a third of parents reported that their child had lost or experienced a decrease in services and supports (36%), and the format of services received changed but not the amount or intensity of services (36%). Twenty percent said that services and supports had not been affected (Figure 9).

Parents who lost or decreased services reported opportunities for social-emotional connections (72%), community based therapies or services (72%), and face-to-face accommodations at school (67%) as areas where they had experienced the greatest loss in services and supports (Figure 10).

9. Impact of COVID-19 on the services and supports youth are receiving (N=50)

How has COVID-19 affected the services and supports your child is receiving?	Number	Percent checking this option
My child has lost or experienced a decrease in needed services and supports.	18	36%
It has changed the format of services received, but not the amount or intensity of services.	18	36%
It has not affected the services and supports my child is receiving.	10	20%
My child has increased access to needed services and supports.	4	8%
My child has been able to access services not previously available (e.g., telehealth services or new opportunities).	1	2%

Note: Respondents could select all that apply.

10. Areas where youth have experienced a loss or decrease in services and supports (N=18)

Please identify if your child has lost or experienced a decrease in any of the following specific types of services and supports.	Number	Percent checking this option
Social-emotional connections or opportunities	13	72%
Community-based therapies or services	13	72%
Face-to-face accommodations at school	12	67%
Child care	7	39%
Insurance coverage	0	0%
Paid employment	0	0%
Other	2	11%

When parents were asked how a loss or decrease in services and supports affected their child, parents most notably mentioned difficulty with the virtual method. Examples of this are lack of focus or challenges with participation, learning that occurred much more slowly or was lost, and the overall inappropriateness of the virtual method for school and therapy (8 responses). Nearly as many parents mentioned the disadvantages of their child not participating in social activities in-person or in the community. This included lost or limited opportunities to socialize, reduced social and learning skills, and isolation (7 responses). Fewer parents noted that their child regressed in their skills and mental health, including becoming more depressed, anxious, or self-injurious (4 responses). Other parents reported difficulties with changes to routine. (3 responses).

It was very hard to use a virtual method for her therapy sessions due to her not having the same materials that her therapists were using as well as she did not want to sit at a table and focus on the laptop.

Learning online was a significant setback, but now that she is back in school she is doing well.

Lack of socialization and opportunities to learn.

Loss in opportunity has created more social isolation/ boredom for her and this has escalated behaviors.

Less exposure to other people. Slower learning and learning loss.

The lack of routine at a school setting escalated his aggression and self-injury, and eventually resulted in his removal from the school.

He definitely regressed, increased stress and depression. He missed his school, his peers and his teachers. Routine is extremely important to him. His life was turned upside down

Regression in skills, increased anxiety, loss of community access and decreased socialization.

It has moved many appointments with therapists and specialists online via zoom.

He had to change from receiving in person therapy to teletherapy. He really struggled to get any sort of benefit from that. We spent most of his sessions chasing him around the house to try and get him to participate.

Work experience

In the 2022 follow-up, seven parents (14%) said their child had a job for which they earn pay on a regular basis. Of these, two parents reported their child has integrated employment. Three parents said their child is employed through facility-based paid employment. Six of the seven respondents reported their child earned at least minimum wage for their work, and that their child is satisfied with their current employment.

Additionally in 2022, more parents agreed people with intellectual disabilities receive equal employment opportunities (18%, up from 6% in 2020; Figure 11). However, most parents did not agree with this statement at all-time points.

11. Equal employment opportunities for youth with intellectual disabilities

		N	Strongly agree	Agree	Disagree	Strongly disagree	Don't know
In general, people with intellectual disabilities receive equal employment opportunities.	2018	48	0%	10%	48%	31%	10%
	2020	67	0%	6%	43%	30%	21%
	2022	50	0%	18%	42%	26%	14%

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 during the COVID-19 pandemic. When parents were asked what they liked most about their community's support services during this time, the most common response was how many options there were for resources and services (10 responses). Fewer parents mentioned the network of families or other parents who have stepped up and been supportive (3 responses), while other parents mentioned specific programs or services, such as community healthcare resources, and therapy or treatment (3 responses). Other parents appreciated that the schools connect with parents, and coordinate care with other entities such as the county (2 responses), while two more parents like the inclusive sports and recreation opportunities that were formed.

I like... that there are a lot more events for younger kids to be able to do activities like sports for example.

I like... that there are a variety of services available.

I like... that they are available and that my child is able to participate in them.

I like... the support others in the community give us; from other experienced parents/caregivers.

I like... the parents of children and family members with disabilities who have stepped up to make a difference.

I like... the Daeman Cause program the most because he gets to socialize and learn from college students, and feel accepted.

I like... I like how in contact the school is with me. They send me a daily report showing his progress.

I like... that the school system and county coordinate care.

I like... the choices for recreation, such as Challenged Athletes Participating in Sports program.

I like... that more special needs sports groups are formed.

The second question asked parents and guardians about their wishes for community support for their child with intellectual disabilities during the COVID-19 pandemic. A large number of parents said they wanted more respect and acceptance for individuals with disabilities (6 responses), such as paying attention and understanding in order to help them, and accepting those who are able to work. In addition, parents wished there were generally more opportunities for social engagement in the community, including being with their peers, and others with intellectual disabilities (4 responses). Similarly, parents wished for opportunities for employment (4 responses), and more workers or staff to provide services (4 responses). Fewer parents wanted easier access to services (3 responses), and more or better resources, services and support (3 responses). Two parents mentioned having more information or education about disabilities for better understanding.

***I wish...** I wish that companies not only said that they were inclusive but also acted upon those claims. Too many places talk about being inclusive but when others from the general population make statements or do things to make us feel excluded, most companies throw their hands up in the air and act as if there is nothing that they can do about it.*

***I wish...** people were more understanding when my child is struggling.*

***I wish...** there was more awareness, education, inclusion and support.*

***I wish...** there were more “social” settings for young adults.*

***I wish...** there were social activities available for him with other teenagers that have intellectual disabilities.*

***I wish...** she could have a job working from home that she would be able to do.*

***I wish...** for him to have some sort of job. He loves to help out. I want his life to have meaning and a purpose.*

***I wish...**there were enough workers for the services that are offered, we have been on a wait list for respite for years.*

***I wish...** that there was more information for people to understand what it really means when someone has intellectual disabilities and explain that they just learn differently than everyone else.*

***I wish...** that while I understand, through assessments and evaluations, my son has difficulties and special needs, I do not fully understand his condition or what would lead to an official diagnosis.*

Conclusions

The Tower Foundation conducted these surveys 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 youth and community-level data to help community organizations explore what they can do to better support families and youth experiencing intellectual disabilities.

In 2022, parents were less likely to agree that people with intellectual disabilities are treated fairly in their community or that they have enough information to understand their child's intellectual disability. However, most other perceptions were similar between surveys, including consistently low numbers of parents reporting that there are equal education and employment opportunities for youth with intellectual disabilities and that they have received all of the needed services and supports for their child. Parents also noted that the COVID-19 pandemic resulted in a decrease in services and supports for their children, especially opportunities for social-emotional connections, community-based therapies or services, and face-to-face supports in school. Given these responses, the following discussion questions may help plan services:

- How can communities ensure that people with intellectual disabilities are (and feel) treated fairly?
- How can schools and communities better ensure that young people with intellectual disabilities and their families have easily understandable information about available services and supports?
- How can we encourage employers to provide more and better employment opportunities for people with intellectual disabilities?
- What can communities do to improve educational opportunities for youth with intellectual disabilities? In addition, how can schools build more fully-inclusive educational opportunities for students with intellectual disabilities?

Methods and caveats

These two surveys were 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 in the 2022 survey:

- When the Tower Foundation mailed community surveys to 6,000 random addresses in Erie and Niagara counties in fall 2019 and 2021 (up from 4,000 in 2017), 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 and 2020 were sent the results from those surveys and were invited to participate again in subsequent years.
- Tower Foundation and Wilder Research staff designed outreach and recruitment materials for local organizations and schools to share with families to increase participation.

