



2022 Tower Foundation Family Survey

Learning 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 learning disabilities, the Foundation conducted a survey with families in 2018. Twenty parents, guardians, or adult caregivers from Erie and Niagara counties in New York responded to the survey. At the beginning of 2020, twenty-three parents, guardians, or adult caregivers responded to another survey for a child with learning disabilities. A follow-up survey was completed in 2022 by 45 parents who reported that their child had a learning 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 **learning disabilities** as lifelong conditions that interfere with the ability to learn. They are neurological disorders that affect the ability of the brain to process, store, and respond to information.

Description of youths

The number of parents reporting on their children with learning disabilities is up in 2022 (45 parents) from 2020 (23 parents) and 2018 (20 parents). The children were slightly older in 2022 with an age range of 6-23 years, compared to the age range of 2-25 years in 2020 and 2-26 years in 2018.

Since 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 a learning disability. As such, we urge caution in generalizing these findings beyond the respondents who completed the survey.

Community resources

In the 2022 follow-up survey, about half of parents (49%) agreed that the community devotes enough resources to students with learning disabilities. Over a third of parents (37%) agreed that community employers provided enough support or accommodations for employees with learning disabilities, a notable increase from no parents agreeing in the 2020 survey, and one quarter of parents agreeing in the 2018 survey (25%). (Figure 1).

1. Erie and Niagara counties perspectives of learning disabilities

		N	Strongly agree	Agree	Disagree	Strongly disagree	Don't know
Your community devotes enough resources to students with learning disabilities.	2018	20	10%	45%	25%	20%	0%
	2020	23	4%	44%	26%	26%	0%
	2022	45	18%	31%	40%	9%	2%
Employers in your community provide enough support or accommodation for employees with learning disabilities.	2018	20	5%	20%	40%	10%	25%
	2020	23	0%	0%	30%	22%	48%
	2022	45	13%	24%	33%	9%	20%

Information and services to support youth with learning disabilities

In the 2022 follow-up survey, most parents agreed that they had enough information to understand their child's learning disability (80%, up from 65% in 2018). Most parents also felt that the information and supports were easy to understand (80%, up from 61% in 2020 and 45% in 2018). More parents felt they had enough information to help plan services and supports for their child in 2022 (76%) than in 2020 (61%) and 2018 (45%). Two-thirds of parents reported that they received all of the services and supports they needed for their child (67%), which is a notable increase from 2020 (39%) and 2018 (45%); Figure 2).

2. Information and services available for parents and guardians of youth with learning disabilities

		N	Strongly agree	Agree	Disagree	Strongly disagree	Don't know
You have enough information to understand your child's learning disability.	2018	20	10%	55%	25%	10%	0%
	2020	23	22%	61%	13%	4%	0%
	2022	45	24%	56%	16%	4%	0%
You have enough information to help plan services and supports for your child.	2018	20	15%	30%	35%	20%	0%
	2020	23	17%	44%	30%	9%	0%
	2022	45	20%	56%	20%	0%	4%
The information about services and supports you receive for your child is easy to understand.	2018	20	10%	35%	50%	5%	0%
	2020	23	13%	48%	39%	0%	0%
	2022	45	11%	69%	16%	4%	0%
You have received all of the needed services and supports for your child.	2018	20	15%	30%	40%	15%	0%
	2020	23	13%	26%	35%	22%	4%
	2022	45	16%	51%	22%	2%	9%

Educational supports

Of the 41 students who were enrolled in school in 2022, 76% had an educational service plan, such as an IEP, 504 plan, person-centered plan, or other plan for a primary, secondary, or post-secondary education. Seventy-one percent of parents and guardians agreed that the plan included all needed services and supports, which is similar to 2020 but a notable increase from 55% in 2018. Most parents in 2022 (87%) and 2020 (95%) said that they were able to participate in developing the plan as much as they would like. However, there was a substantial difference between parents reporting this in 2022 and 2018 (87% compared to 70%; Figure 3).

3. Educational supports for youth with learning disabilities

		N	Strongly agree	Agree	Disagree	Strongly disagree	Don't know
This educational service plan includes all needed services and supports.	2018	20	20%	35%	35%	10%	0%
	2020	20	15%	55%	25%	5%	0%
	2022	31	19%	52%	19%	0%	10%
You were able to participate as much as you would have liked in developing the plan.	2018	20	25%	45%	25%	5%	0%
	2020	20	25%	70%	5%	0%	0%
	2022	31	16%	71%	13%	0%	0%

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. Less than half of parents reported that COVID-19 had not affected the services and supports their child is receiving (44%). Under one-third of parents said that their child had lost or experienced a decrease in services and supports (31%). Eighteen percent also said that the format of services had changed, but not the amount or intensity of services (Figure 4). Of those who lost or decreased services, parents reported face-to-face accommodations at school (92%), opportunities for social-emotional connections (62%), and community-based services (39%) as areas where they had experienced the greatest loss in services and supports (Figure 5).

4. Impact of COVID-19 on the services and supports youth are receiving (N=45)

	N	%
It has not affected the services and supports my child is receiving.	20	44%
My child has lost or experienced a decrease in needed services and supports.	14	31%
It has changed the format of services received, but not changed the amount or intensity of services.	8	18%
My child has been able to access services not previously available (e.g., telehealth services or new opportunities).	4	9%
My child has increased access to needed services and supports.	2	4%

5. Areas where youth have experienced a loss or decrease in services and supports (N=13)

	N	%
Face-to-face accommodation at school	12	92%
Social-emotional connections or opportunities	8	62%
Community-based therapies or services	5	39%
Paid employment	1	8%
Insurance coverage	1	8%
Child care	0	0%
Other	1	8%

When parents were asked how a loss or decrease of services and supports affected their child, parents mentioned negative impacts to their health and well-being such as loss of interest in things, disconnection from others, challenges with learning due to the loss of one-on-one interaction and virtual methods, lack of academic support such as having to do school work on their own, and lack of social activity.

He has seemed to have lost a lot of interest in things he used to enjoy before COVID.

Built walls and shut people out.

Not being in school in person full-time at the beginning of this year, and 8th grade negatively affected his learning, grades and self-motivation.

It made it harder for him to learn when he wasn't one on one with his teacher.

He has pretty significant lags in reading and math due to online learning and remote reading intervention.

During the COVID time, all classes were virtual and she does not do as well virtually as in person. I feel her college could have done more to accommodate her disability.

He was able to graduate from college, but he really had to do it on his own.

He really missed getting together with friends and doing things in the community.

Life is more difficult and there is no social activity.

Community strengths and opportunities for improvement

Respondents were also asked about what they liked about current community support services for youth with learning disabilities. Parents said they liked the educational supports received from schools (8 responses) like chrome books, needed testing, and inclusive experiences for their children. Parents also liked the community support in general (5 responses). Some parents mentioned that services were taken seriously, the district was involved in important observations, and staff were concerned and caring (4 responses) while others appreciated having available supports in general (4 responses).

I like... that the community gives us good medical resources.

I like... the community resources to help me and my children.

I like... the chrome books for education apps.

I like... the fact that they did a lot of testing for my son when he was younger.

I like... that the high school in which my daughter attends is very inclusive of children with learning disabilities. She is in normal classes with other students and receives extra help as needed outside of the normal class time. She has even been able to participate in varsity sports with full inclusion and active play time.

I like... that they will help anyone and not make them feel different.

I like... the fact that the school district helped point out that my son may have ADHD.

I like... the compassion and empathy that educators and school staff exhibit.

I like... the helpfulness from others and access to information

Parents wished that children with learning disabilities would have improved supports and services, such as more explicit information about services and supports that help (6 responses). They also wished for opportunities to know more about services and support including education, awareness, and guidance (4 responses), while other parents wished for better school processes and practices such as better parent support, and working according to the needs of the student (3 responses).

I wish... that they were more readily available and we didn't have to advocate and fight so much for proper services.

I wish... that there were more after-school programs.

I wish... he had more face-to-face, and extra time for tests when needed.

I wish... there was more information available about how to get a diagnosis, what a diagnosis actually means, how best to treat the ADHD, more information regarding different treatment.

I wish... there were more events explaining all the supports or services my child could have. Without knowing these options how are you to know if she could possibly get other help.

I wish... the teachers would actually follow the 504 plans that are in place. [With] most teachers, once kids get into middle school [they] ignore 504 plans or don't take them seriously causing the kids to struggle more. When you bring it to their attention they follow it for 2 weeks and go back to ignoring it.

What the long term effects of my grandson's learning disability poses. Will he complete high school, will he attend college or will he be able to find gainful employment? I teach High School Equivalency classes and I fear that I may see my grandson in a class like mine someday. I feel that oftentimes that schools force out students that are "different" or can't finish the work required. It seems that graduation numbers count more than the struggling student.

Conclusions

The Tower Foundation conducted these surveys because of its commitment to address issues related to learning 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 learning disabilities, particularly during the pandemic.

In 2022, parents were more likely to report that employers provide enough support to employees with learning disabilities, they had enough information to help plan services and supports, and those services and supports were easy to understand. In addition, there was a notable increase in parents reporting they received all of the services and supports they needed for their child. Because of the small sample size in the surveys, caution is warranted in interpreting these increases. Parents also noted that the COVID-19 pandemic had resulted in a decrease in services and supports for their children, especially face-to-face supports in school, opportunities for social-emotional connections, and community-based supports. Given these responses, the following discussion questions may help plan services:

- How can we encourage employers to attract and better accommodate employees with learning disabilities?
- What can we do to grow the capacity and community awareness of community-based services for youth with learning disabilities?
- How can we make stronger connections between schools and community-based services for youth with learning disabilities?
- How can we enlist parents as advocates for more and better services for students with learning disabilities?

Methods and caveats

These two surveys were targeted to families of youth, age 26 or younger, who have a learning 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 2022 survey:

- In fall 2019 and 2021, the Tower Foundation mailed community surveys to 6,000 random addresses in Erie and Niagara counties (up from 4,000 in 2017) to gather community perspectives about available services and supports. 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.

