



# 2020 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 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 learning disabilities, the Foundation conducted an additional survey of families in 2020. Twenty-three parents, guardians, or adult caregivers from Erie and Niagara counties in New York State responded to the survey for a child with learning disabilities. Throughout the summary, the term “parents” includes all respondents and notable differences from the 2018 survey are noted

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 23 parents who responded to the survey said they had a total of 29 children, age 2 to 25, who have a learning disability. The most frequently identified learning disabilities were non-verbal (50%) and dyslexia (43%), followed by dysgraphia (30%) and dyscalculia (30%). Auditory processing was not a top learning disability, as it was among respondents in 2018 (Figure 1).

For the remaining questions, parents and guardians were asked to respond with their experiences associated with one child with learning disabilities.

#### 1. Identified learning disabilities

Disability	N	Percent (N=19)
Non-verbal	12	41%
Dyslexia	11	38%
Dysgraphia	8	28%
Dyscalculia	7	24%
Language processing disorder	6	21%
Auditory processing disorder (APD)	6	21%
Visual perceptual or visual motor deficit	4	14%

Note: Children could have more than one identified learning disability, so percentages do not add up to 100%.

The first two questions on the survey of families with a child having a learning disability were the same as those asked in the broader community survey. Forty-eight percent of parents or guardians agreed that the community devotes enough resources to students with learning disabilities, higher than the 36% of community respondents who agreed. However, 32% of community respondents said they did not know, as opposed to none of the parents or guardians.

When asked whether community employers provide enough support or accommodations for employees with learning disabilities, no parents agreed, and about half (52%) disagreed. However, nearly half (48%) said they did not know, an increase from 25% in 2018. The community survey results show 24% agreed there was enough community support and 36% did not know. The remaining 40% disagreed (Figure 2).

**2. 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.	Parents	23	4%	44%	26%	26%	0%
	Overall community	1,152	6%	30%	25%	8%	32%
Employers in your community provide enough support or accommodation for employees with learning disabilities.	Parents	23	0%	0%	30%	22%	48%
	Overall community	1,151	4%	20%	32%	8%	36%

**Information and services to support youth with learning disabilities**

Eighty-three percent of parents and guardians agreed that they had enough information to understand their child’s learning disability, an increase from two-thirds in 2018. Sixty-one percent agreed they had enough information to help plan services and supports or that they found the information and supports easy to understand, both increased from 45% in 2018. Thirty-nine percent agreed that they received all of the services and supports they needed for their child (Figure 3).

Two of these questions were also asked of a subset of respondents who identified as parents of youth with learning disabilities on the community survey. In the broader community survey, parents of youth with learning disabilities were less likely to agree that they have enough information to understand their child’s learning disability (68%), but were similarly likely to agree that they are receiving all of the needed services and supports (43%).

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

	Year	N	Strongly agree	Agree	Disagree	Strongly disagree	Don't know
You have enough information to understand your child's learning disability.	2020	23	22%	61%	13%	4%	0%
	2018	20	10%	55%	25%	10%	0%
You have enough information to help plan services and supports for your child.	2020	23	17%	44%	30%	9%	0%
	2018	20	15%	30%	35%	20%	0%
The information about services and supports you receive for your child is easy to understand.	2020	23	13%	48%	39%	0%	0%
	2018	20	10%	35%	50%	5%	1%
You have received all of the needed services and supports for your child.	2020	23	13%	26%	35%	22%	4%
	2018	20	15%	30%	40%	15%	1%

## Educational supports

Twenty of the children with learning disabilities 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 percent of parents and guardians agreed that the plan includes all needed services and supports, up from 55% in 2018. All but one caregiver (95%) agreed they were able to participate in developing the plan as much as they would have liked, an increase from 75% in 2018 (Figure 4).

### 4. Educational supports for youth with learning disabilities

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

## Community strengths and opportunities for improvement

To better understand their experiences navigating supports for their children with learning 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 learning disabilities. The most prevalent theme was school-based support (5 responses), followed by the number of resources and options available for families (3 responses). Specifically, caregivers mentioned Special Olympics and support for disabled athletes, therapeutic horseback riding, school counselors and teachers that support their children's education, and financial support for programming.

*That I live near The Gow School and was awarded enough financial aid for [my child] to go there.*

*How her programming provides a budget for her through self-directed service funding to go out in the community and do fun and educational activities that [my child] likes to do. It is a better fit for her currently than her [name] programming, which due to staff limitations, sometimes cannot do the fun activities [my child] likes to do.*

*Our school district is one of four districts in the state to have a unified athletic program for the disabled. Special Olympics has recognized our district and we were presented with an official banner for the school.*

*The counselors and teachers and school and their continued support in his education*

The second question asked parents and guardians about their wishes for community support for their child with learning disabilities. Parents and guardians most wished for more community support services and options for their children (6 responses). The next most frequently mentioned “wishes” included (3 responses each): shorter waitlists and less paperwork, more information about what is available both in and outside of school, and job opportunities for their children. Caregivers specifically mentioned supports both in the classroom and at home, more supports at private schools, and general community awareness of the talents and strengths of kids with learning disabilities.

*I wish there wasn't a wait list for young adults. I'm one of the lucky few who has services for my adult son.*

*They would reach out to parents of children with learning disabilities to advise what support services they offer and what is available. I have a daughter with a learning disability and goes to college. I found out what help is available from a friend who had help for her daughter from Access VR. No one advised me this financial help was available I also pay extra for tutors for her at college and it is quite a bit of money. I wish extra tutoring was available to youth with learning disabilities. I do not understand why extra help stops with high school. The learning disability does not go away once they start college. Also when they get a job, management should be more aware that the individuals possibly need more time to learn the job. They should be given more instruction if needed and be patient with the person with the learning disability.*

*There was more resources for parents to understand how to help our kids outside of school.*

*More services would be available to those in private schools.*

*That there were more diverse opportunities with better pay as well as occupational training for jobs of interest such as computers/technical school that were offered.*

*There were more job opportunities suited to what [my child] wants to do.*

*There was more resources for parents and children living with disabilities to help everyone to live more fulfilled lives. More education for community members who don't live with learning disabilities how to better understand those who do.*

## Conclusions

The Tower Foundation conducted this survey 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.

This year, compared to 2018, caregivers were more likely to agree that the community devotes enough resources to students with learning disabilities and that they personally had enough information to understand their child's learning disability. A higher proportion also said that their child's educational service plan had all the needed services and supports. This indicates that the community and the schools in the community may be better supporting children with learning disabilities, though the number of caregivers responding is quite small and does not reflect the experiences of all children with learning disabilities in the region.

Given that over half of the respondents still do not feel they have received all of the services and supports they need for their child, and based on the recommendations made for improving the system, the following discussion questions may help plan services:

- How might communities ensure that youth with learning disabilities are aware of community-based resources to assist them (including educational and recreational supports)?
- How might schools and communities help young people with learning disabilities and their families navigate service and support systems?
- What supports do employers need for hiring and retaining individuals with diverse learning needs?

## Methods and caveats

This survey was 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:

- 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.

