



2022 Tower Foundation Family Survey

Learning Disabilities Parent Results Essex, Dukes, Barnstable, and Nantucket 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 of families in 2018. Fifty-two parents, guardians, or adult caregivers from Essex, Dukes, Barnstable, and Nantucket counties in Massachusetts responded to the survey. At the beginning of 2020, thirty parents, guardians, or adult caregivers responded to another survey for their child with learning disabilities. A follow-up survey was completed in 2022 by 33 parents who reported that their child had a learning disability. Key differences between the 2018, 2020, and 2022 surveys are noted throughout the 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 33 parents who responded to the follow-up survey in 2022 said they had children aged 5-26 with a learning disability. The 30 parents who responded to the survey in 2020 said they had children aged 3-26 who have a learning disability. The 52 parents who completed the 2018 survey reported that they had children with a learning disability aged 2-26.

Because the number of completed surveys was relatively low in all instances, the results in this report may not represent the population of Barnstable, Dukes, Essex, or Nantucket 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, less than half of parents agreed that the community devotes enough resources to students with learning disabilities (45%), which is similar to previous surveys. When asked whether community employers provide enough support or accommodations for employees with learning disabilities, nearly half of parents disagreed in the 2022 and 2020 surveys (48%, at both time points) up from nearly one-quarter (23%) who disagreed in 2018. Also in the 2022 survey, fewer parents (12%) reported that they didn't know (Figure 1).

1. Parents' and residents' 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	52	12%	35%	37%	15%	2%
	2020	29	3%	35%	41%	17%	3%
	2022	33	3%	42%	30%	24%	0%
Employers in your community provide enough support or accommodation for employees with learning disabilities.	2018	52	4%	31%	15%	8%	42%
	2020	29	3%	14%	38%	10%	35%
	2022	33	0%	39%	36%	12%	12%

Information and services to support youth with learning disabilities

In the 2022 follow-up survey, many parents agreed that they had enough information to understand their child's learning disability (70%), down from the 2018 parent responses (86%). Three quarters of parents agreed that they had enough information to help plan services and supports in 2022 (76%), which is higher than they did in 2020 (65%). Nearly two-thirds of parents (61%) said that the information and supports are easy to understand, down from three-quarters of the parents (76%) who responded in 2018. More parents agreed that they received all of the services and supports they needed for their child in 2022 (49%) than in 2020 (31%), although at all three time points, less than half of the parents agreed with this statement (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	52	31%	55%	10%	4%	0%
	2020	29	21%	55%	24%	0%	0%
	2022	33	24%	46%	24%	6%	0%
You have enough information to help plan services and supports for your child.	2018	52	24%	51%	22%	4%	0%
	2020	29	17%	48%	24%	10%	0%
	2022	33	12%	64%	15%	9%	0%
The information about services and supports you receive for your child is easy to understand.	2018	52	16%	60%	20%	4%	0%
	2020	29	7%	48%	38%	7%	0%
	2022	33	3%	58%	27%	6%	6%
You have received all of the needed services and supports for your child.	2018	52	10%	38%	35%	17%	0%
	2020	29	7%	24%	48%	14%	7%
	2022	33	3%	46%	21%	21%	9%

Educational supports

Of the 27 children enrolled in school at the time of the 2022 follow-up survey, 85% 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. Most parents and guardians agreed in 2022 that the plan included all needed services and supports (82%, up from 50% in 2020 and 61% in 2018). Most parents also agreed they were able to participate in developing the plan as much as they would have liked (82%; 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	47	17%	44%	26%	13%	0%
	2020	24	17%	33%	21%	17%	13%
	2022	23	17%	65%	13%	4%	0%
You were able to participate as much as you would have liked in developing the plan.	2018	46	8%	66%	11%	4%	0%
	2020	24	21%	54%	21%	4%	0%
	2022	23	30%	52%	17%	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. Forty-two percent of parents reported that their child had lost or experienced a decrease in services and supports in 2022. One quarter of parents also reported that the format of services had changed, but not the amount or intensity of services, and nearly a third said the services and supports their child is receiving were not affected (Figure 4). Parents who lost or decreased services reported face-to-face accommodations at school (77%), opportunities for social-emotional connections (77%), and community-based therapies or services (62%) 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=33)

	N	%
My child has lost or experienced a decrease in needed services and supports.	14	42%
It has not affected the services and supports my child is receiving.	10	30%
It has changed the format of services received, but not changed the amount or intensity of services.	9	27%
My child has been able to access services not previously available (e.g., telehealth services or new opportunities).	2	6%
My child has increased access to needed services and supports.	1	3%

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

	N	%
Face-to-face accommodation at school	10	77%
Social-emotional connections or opportunities	10	77%
Community-based therapies or services	8	62%
Child care	1	8%
Other	1	8%
Paid employment	0	0%
Insurance coverage	0	0%

Other responses includes structure in a school setting and vocational activities.

When parents were asked how a loss or decrease in services and supports affected their child, parents mentioned difficulty connecting with staff and service providers (3 responses), and that services and supports were limited or delayed (3 responses).

I feel like everyone is really disconnected and that these types of services have fallen to the wayside.

It made it far more difficult to connect with teachers and assistants and specialists.

It took time before services were able to be provided online - so there was a significant gap where limited services were provided.

He was in private treatment and the limits on outside activities severely limited the entire program and expected results.

Community strengths and opportunities for improvement

Respondents were also asked what they liked about current community support services for youth with learning disabilities. Parents mentioned they liked the educational support, services, and staff during this time, including understanding the IEP, and staff meeting the needs of students (11 responses). Some parents liked the available services and supports in general (5 responses).

I like... that students with significant disabilities seem to receive the services they need without a great deal of fighting.

I like... that the school had one person who provided a safe environment for a new kid in the school system to feel at ease at any time during the day when it felt stressful.

I like... that we feel support at school as we navigate the IEP but also know that I have a clear understanding of what it entails or know who to ask if I have questions or concerns.

I like... that there is a dedicated team of educators and parents working hard to meet the needs of students with learning disabilities.

Parents mentioned they wished for improvements to accessing services in general (9 responses), and an easier process to accessing services (5 responses). Some parents wished for improvements to available services in terms of being better equipped to serve their children or being more comprehensive, while other parents wished for more knowledge about services (4 responses).

***I wish...** it did not take two years for Community Services to have an available therapist; that there was someone who was familiar with special needs schools or could steer one to proper support while grappling with daily trauma.*

***I wish...** it had come a lot sooner; when my son was young. Early intervention is key. I realize professionals were still learning about autism during his early childhood. But, I still wonder how much closer he would be towards achieving his goals and gaining self-confidence & self-advocacy skills had things been different.*

***I wish...** there were more educators for the students.*

***I wish...** I wish that there was more comprehensive services that were easier to access.*

***I wish...** I understood more about other services. I do not know what services I should be asking for. The school suggests x and y services but I don't know if there are other things we should be asking for. For example, we did not know to ask for a language based classroom until we had a report done in 5th grade that recommended it. Then the school told us about the language based program in the same district. Not sure why the school did not recommend the program earlier when the testing showed that she was a 5th grader reading at 2nd grade level.*

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.

Parents in 2022 were more likely than in 2020 to agree that they had enough information to plan services and supports, their child has access to all of the needed services and supports, and that their child's educational service plan included all necessary services and supports. However, fewer than half of parents reported that their child has access to all needed services and supports at all time points. 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 and opportunities for social-emotional connections. 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 more can our community do to provide culturally relevant information about learning disabilities and resources/supports to families in their primary language?
- How can social emotional learning be better integrated with 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 the 2022 survey:

- In fall 2019 and 2021, the Tower Foundation mailed community surveys to 6,000 random addresses in Essex County and 6,000 random addresses in Barnstable, Dukes, and Nantucket 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.

