PETER & ELIZABETH **TOWER FOUNDATION**

2024 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 first conducted a survey of families from Essex, Dukes, Barnstable, and Nantucket counties in Massachusetts with a child age 26 or younger with a learning disability in 2018. This survey has been repeated every two years since, with the most recent round in 2024. Key differences between the 2018, 2020, 2022, and 2024 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 number of parents reporting on their children with learning disabilities is up in 2024 (44 parents), compared to 2022 (33 parents) and 2020 (30 parents). The 2018 survey yielded the highest number of respondents (52 parents). The ages of the children in 2024 ranged from 2 to 25, with a median of 14.5. The median age was similar to that in 2020 (14) and varied slightly from 2022 (16) and 2018 (13).

Because the number of completed surveys was relatively low in all instances, the results in this report may not fully represent the population of Essex, Dukes, Barnstable, or Nantucket county residents having 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 2024 survey, less than half of parents agreed that the community devotes enough resources to students with learning disabilities (43%), which is similar to previous surveys (Figure 1). When asked whether employers provide enough support or accommodations for employees with learning disabilities, nearly half of parents disagreed in the 2024 (45%), 2022 (48%), and 2020 (48%) surveys, up from roughly one-quarter who disagreed in 2018 (23%). Additionally, a greater share of parents in 2024 reported that they didn't know if employers provide enough support compared to 2022 (30% vs. 12%).

1. Parents' 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%
	2024	44	2%	41%	36%	21%	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%
	2024	44	0%	25%	34%	11%	30%

Information and services to support youth with learning disabilities

In 2024, two-thirds of parents agreed that they had enough information to understand their child's learning disability (68%, similar to 70% in 2022; Figure 2). Fifty-four percent of parents in 2024 reported having enough information to help plan services and supports – a marked decrease from previous years (75% in 2018, 65% in 2020, and 76% in and 2022). Roughly half of parents agreed that information about services and supports are easy to understand (49%, down from 61% in 2022 and 76% in 2018). A smaller proportion of parents agreed that they received all of the services and supports that they needed for their child in 2024 (38%) than in 2022 (49%).

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%
	2024	43	14%	54%	23%	9%	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%
	2024	43	7%	47%	30%	14%	2%
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%
	2024	43	2%	47%	40%	7%	5%
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%
	2024	43	5%	33%	42%	19%	2%

Educational supports

Of the 39 children enrolled in school at the time of the 2024 survey, all but one (97%) 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. Two-thirds of parents agreed in 2024 that the plan included all the needed services and supports (66%, down from 82% in 2022, up from 50% in 2020; Figure 4). Three-fourths of parents also felt they were able to participate in developing the plan as much as they would have liked (76%), similar to previous survey years.

3. Educational service plan

Does your child have an educational service plan?	2018 (N=50)	2020 (N=29)	2022 (N=27)	2024 (N=39)
Yes	94%	86%	85%	97%
No	4%	14%	15%	0%
Don't know	2%	0%	0%	3%

Note: The language of this question changed from asking if their child ever had an educational service plan in 2018 and 2020 to asking if their child currently has an educational service plan in 2022 and 2024.

4. 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%
	2024	38	11%	55%	24%	8%	3%
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%
	2024	38	18%	58%	18%	5%	0%

Impact of COVID-19

In the 2024 survey, parents were also asked about how the COVID-19 pandemic has affected services and supports available to them in the past year. Just under half of parents in 2024 report that the services and supports their child is receiving have not been affected (46%), while nearly one-third of parents say their child has lost or experienced a decrease in services and supports (29%; Figure 5). One in 10 parents reports that the format of services had changed, but not the amount or intensity of services (10%). Access to services not previously available and an increase in needed supports and services were each reported by 7% of parents. Parents who lost or saw decreases in services most commonly reported face-to-face accommodations at school (73%), opportunities for social-emotional connections (55%), and community-based therapies or services (55%) as areas where they had experienced a loss in supports (Figure 6).

5. Impact of COVID-19 on the services and supports youth are receiving (N=41)

	N	%
It has not affected the services and supports my child is receiving.	19	46%
My child has lost or experienced a decrease in needed services and supports.	12	29%
It has changed the format of services received, but not changed the amount or intensity of services.	4	10%
My child has been able to access services not previously available (e.g., telehealth services or new opportunities).	3	7%
My child has increased access to needed services and supports.	3	7%

6. Areas where youth have experienced a loss or decrease in services and supports (N=11)

Area	N	%
Face-to-face accommodation at school	8	73%
Social-emotional connections or opportunities	6	55%
Community-based therapies or services	6	55%
Other	2	18%
Child care	1	9%
Paid employment	0	0%
Insurance coverage	0	0%

Note. Other responses include 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 negative impacts on their child's learning, skills, and disability overall (4 responses), struggles with online formats and the lack of face-to-face support (3 responses), shortages of school support staff and providers (3 responses), and limited or lacking services and supports in general (3 responses). A few parents noted that online options made accessing services easier.

> *My child has trouble learning online. She needs one-on-one attention when she has trouble. She needs to be able to ask questions and be more hands on.*
>
> *Negative impact on his ability to find success with his academics as he struggled to find consistent care, routine of care, and holding those services accountable for providing services on his treatment plan.*
>
> *They need to be seen more and can't, they need more supports that are just not there.*
>
> *He is even more far behind than before. Sometimes staffing is an issue for receiving services.*
>
> *Appointments are easier to attend, especially if I have to work or they are [outside of community].*

Community strengths and opportunities for improvement

Respondents were also asked what they liked about current community support services for youth with learning disabilities. Parents share positive comments about the ability to obtain and be involved in shaping an educational plan for their child (5 responses) and the support provided by their child's school and teachers (5 responses). Parents also appreciated how comprehensive services are and the effort put in to ensure they are helpful (4 responses), as well as the care and awareness of others in their community (4 responses).

> ***I like…*** that the school involves me in all decisions made for [child]. They put a lot of time into making the plan for her needs.
>
> ***I like…*** the support, understanding, and programs in place. I appreciate the effort and hard work everyone exerts.
>
> ***I like…*** that the stigma is lessening, that many parents can relate because of the uptick in needs and diagnoses after COVID.
>
> ***I like…*** that there is often a team-based mentality and they allow parents to be an equal member of that team.

Parents wished for improvements to the supports and guidance for parents navigating their child's learning disability and needed services (8 responses), as well as to the resources and options offered by schools (7 responses). Parents also expressed wanting more or a greater variety of supports overall (6 responses), more opportunities for employment and vocational programs (5 responses), increased information and education about available services (4 responses), and more community awareness around learning disabilities (4 responses).

> ***I wish…*** employers were more open to hiring kids with learning differences. Plus, there are very few social opportunities for our population of young adults.
>
> ***I wish…*** there was money to help my son who does not go to public school. Once we were able to request services, there has been no money left in the budget, so we pay for all of his care out of pocket. This is a huge drain for a middle-class family.
>
> ***I wish…*** that I didn't have to fight so hard or wait so long to get services. I had to hire an advocate and fight each step to get the services on her IEP.
>
> ***I wish…*** there were more people willing to take the time to help parents navigate the complexities of the needed services.
>
> ***I wish…*** there was more support for the people supporting these kids and more training, as well as individual support for each student that would be more consistent. … If trained psychologists and therapists can be part of the team, that would be great too. Career training and weekly or daily therapy sessions would be great.

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.

In 2024, the majority of parents that responded to the survey felt they had enough information to understand their child's learning disability. In addition, the majority of parents whose child had an educational service plan agreed that the plan included all needed services and supports and that they were able to participate in developing the plan as much as they would have liked. However, only 54% of parents agreed that they have enough information to help plan services and supports and only 49% agreed that information about services is easy to understand. Only 25% of parents in 2024 reported that employers provide enough support or accommodations for employees with learning disabilities. Only 43% agreed that the community devotes enough resources to students with learning disabilities, and only 38% agreed that they have received all of the services and supports that they needed for their child.

Parents also noted that the COVID-19 pandemic has continued to result 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 therapies or services. 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 access of community- and school-based services for youth with learning disabilities?
- How can schools and communities support parents in making the best decisions for their child and in receiving necessary information on available services?
- How can schools better ensure that young people with learning disabilities receive the appropriate support and attention needed in a format that works for them?

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 in the 2024 survey:

- In fall 2019, 2021, and 2023, 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 previous years 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.