



2020 Tower Foundation COVID-19 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 at the beginning of 2020. Thirty parents, guardians, or adult caregivers from Essex, Dukes, Barnstable, and Nantucket counties in Massachusetts responded to the survey for a child with learning disabilities. With the disruption created by the COVID-19 pandemic, the Tower Foundation recognized the unique concerns that families of children with learning disabilities may have and decided to conduct a follow-up survey in fall 2020 to better understand current resources and needs. Key differences between the pre-COVID survey and the follow-up survey are noted. Throughout the summary, 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 30 parents who responded to the pre-COVID-19 survey in early 2020 said they had a total of 41 children, age 3-26, who have a learning disability. In second survey, sent out in fall 2020 during the COVID-19 pandemic, 12 parents, with children age 6-25 with a learning disability, completed the survey. Because the number of completed surveys was relatively low in both 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 COVID-19 survey, more than half of parents agreed that the community devotes enough resources to students with learning disabilities (59%, up from 38% before the pandemic). When asked whether community employers provide enough support or accommodations for employees with learning disabilities, slightly fewer parents disagreed in the later survey (33%, compared to 48% before the pandemic). However, in both surveys, more than a third of respondents 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.	Pre-COVID	29	3%	35%	41%	17%	3%
	COVID	12	17%	42%	25%	17%	0%
Employers in your community provide enough support or accommodation for employees with learning disabilities.	Pre-COVID	29	3%	14%	38%	10%	35%
	COVID	12	8%	17%	25%	8%	42%

Information and services to support youth with learning disabilities

In the survey administered during the COVID-19 pandemic, most parents agreed that they had enough information to understand their child's learning disability (83%). Slightly more agreed that they had enough information to help plan services and support during the pandemic than before (75%, compared to 65%), and that the information and supports are easy to understand (67%, up from 55%). More parents also agreed that they received all of the services and supports they needed for their child during the pandemic than before, although at both time points, less than half of the parents agreed with this statement (42% during the pandemic versus 31% prior, 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.	Pre-COVID	29	21%	55%	24%	0%	0%
	COVID	12	33%	50%	8%	0%	8%
You have enough information to help plan services and supports for your child.	Pre-COVID	29	17%	48%	24%	10%	0%
	COVID	12	25%	50%	17%	8%	0%
The information about services and supports you receive for your child is easy to understand.	Pre-COVID	29	7%	48%	38%	7%	0%
	COVID	12	17%	50%	25%	0%	8%
You have received all of the needed services and supports for your child.	Pre-COVID	29	7%	24%	48%	14%	7%
	COVID	12	25%	17%	42%	17%	0%

Educational supports

In the survey during the COVID-19 pandemic, seven of the eight children who were enrolled in school 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 (one respondent didn't know). Five of the seven parents and guardians agreed that the plan included all needed services and supports. Six of the seven agreed they were able to participate in developing the plan as much as they would have liked. Both of these figures were slightly higher than rates before COVID-19, although caution should be taken in interpreting the differences due to the small sample size (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.	Pre-COVID	24	17%	33%	21%	17%	13%
	COVID	7	2	3	2	0	0
You were able to participate as much as you would have liked in developing the plan.	Pre-COVID	24	21%	54%	21%	4%	0%
	COVID	7	2	4	1	0	0

Note: Responses are reported as numbers instead of percentages when the total number of respondents is fewer than 10.

Impact of COVID-19

In the later survey, parents were also asked about how the COVID-19 pandemic had impacted services and supports available to them. The majority of parents reported that their child had lost or experienced a decrease in services and supports during the COVID-19 pandemic (75%). One quarter also said that the format of services had changed, but not the amount or intensity of services (Figure 4). Parents who lost or decreased services reported face-to-face accommodations at school (6 of 8 parents) and opportunities for social-emotional connections (4 of 8 parents) 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	%
It has not affected the services and supports my child is receiving.	12	8%
It has changed the format of services received, but not changed the amount or intensity of services.	12	25%
My child has increased access to needed services and supports.	12	0%
My child has been able to access services not previously available (e.g., telehealth services or new opportunities).	12	8%
My child has lost or experienced a decrease in needed services and supports.	12	75%

5. Areas where youth have experienced a loss or decrease in services and supports

	N	%
Face-to-face accommodation at school	8	6
Social-emotional connections or opportunities	8	4
Community-based services	8	3
Paid employment	8	2
Insurance coverage	8	0
Child care	8	0
Other (please specify)	8	2

Other responses includes test accommodations and face-to-face supports at home.

When parents were asked how a loss or decrease in services and supports affected their child, parents mentioned negative impacts to their academic skills, such as losing academic support and falling behind in class (3 responses).

Her services had decreased in the amount of face to face learning sessions. This affects the fidelity of her learning and has long-term consequences to her academic knowledge and abilities.

He is having trouble keeping up in his classes as well as accessing extra help.

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 mentioned they liked the school's support and services during this time, including classes over Zoom as well as in-person schooling, limited homework during COVID-19, and presentations from school district about learning disabilities. One person also appreciated financial resources that were available, and three said there is nothing they appreciated about their community's support services during this time.

Parents mentioned they wished for changes to schooling, such as having in-person classes or meetings, more one-on-one time with teachers, more time for small groups, more proactive communication, and less screen time. One parent each also mentioned a pause in transition services and a desire for sports or other extracurricular activities for kids with learning/intellectual disabilities.

[I wish] they were still able to meet face to face. [My child] does not do well on Zoom, etc.

[I wish they provided services for] the individual and [did] small group sessions remotely as they do in school.

[I wish] services were provided. [My child] has been in communication with a transitional team, but his services have not been put into place. More communication is needed.

[I wish there were] sports and other extracurricular activities for kids with learning/intellectual disabilities. Activities and sports geared towards these kids that have a hard time listening and following directions would be a blessing.

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.

Parents were more likely to agree that their child has access to all of the needed services and supports, or that their child's educational service plan included all necessary services and supports. However, because of the small sample size in the second survey, 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 and opportunities for social-emotional connections. Given these responses, the following discussion questions may help plan services:

- How might schools safely support greater face-to-face, one-on-one, or small group support in schools for students with learning disabilities?
- How might communities build new opportunities for social-emotional connection during COVID-19?
- What supports do employers need for hiring and retaining individuals with diverse learning needs?
- How might schools and communities continue to ensure that young people with learning disabilities and their families have access to all the service and support systems they need?

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 pre-COVID survey:

- In fall 2019, 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 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 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.

Respondents who completed the survey in early 2020 were also asked to select if they would be interested in participating in later surveys. Respondents who selected "yes" were sent the late 2020 COVID-19 survey.

