



2020 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 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. 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. 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 30 parents who responded to the survey said they had a total of 41 children, age 3 to 26, who have a learning disability. The most frequently identified learning disabilities were dyslexia (32%), followed by dysgraphia (27%; Figure 1). Language processing was not a top learning disability, as it was among respondents in 2018.

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=21) |
|---|----|----------------|
| Dyslexia | 11 | 39% |
| Dysgraphia | 10 | 36% |
| Non-verbal | 7 | 27% |
| Dyscalculia | 7 | 26% |
| Language processing disorder | 6 | 22% |
| Visual perceptual or visual motor deficit | 5 | 18% |
| Auditory processing disorder (APD) | 3 | 12% |

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. Thirty-eight percent of parents or guardians agreed that the community devotes enough resources to students with learning disabilities, slightly higher than the 32% of community respondents who agreed. However, 41% of community respondents said they did not know, as opposed to 3% of the parents or guardians.

When asked whether community employers provide enough support or accommodations for employees with learning disabilities, 48% of parents disagreed, up from 23% in 2018. In addition, 35% said they did not know, an increase from 25% in 2018. The community survey results show 23% agreed there was enough support for employees with learning disabilities and 44% did not know (Figure 2).

2. 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. | Parents | 29 | 3% | 35% | 41% | 17% | 3% |
| | Overall community | 1,818 | 6% | 26% | 21% | 6% | 41% |
| Employers in your community provide enough support or accommodation for employees with learning disabilities. | Parents | 29 | 3% | 14% | 38% | 10% | 35% |
| | Overall community | 1,815 | 2% | 21% | 27% | 6% | 44% |

Information and services to support youth with learning disabilities

While a majority of parents and guardians agreed that they had enough information to understand their child's learning disability (76%) and to help plan services and support (65%), fewer found the information and supports easy to understand (55%), or agreed that they received all of the services and supports they needed for their child (31%, Figure 3). In addition, the proportion agreeing to each of these questions was down from 2018.

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 similarly likely to agree that they have enough information to understand their child's learning disability (70%), but were more likely to agree that they are receiving all of the needed services and supports (51%).

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 | 29 | 21% | 55% | 24% | 0% | 0% |
| | 2018 | 52 | 31% | 54% | 10% | 4% | 2% |
| You have enough information to help plan services and supports for your child. | 2020 | 29 | 17% | 48% | 24% | 10% | 0% |
| | 2018 | 52 | 23% | 50% | 21% | 4% | 2% |
| The information about services and supports you receive for your child is easy to understand. | 2020 | 29 | 7% | 48% | 38% | 7% | 0% |
| | 2018 | 52 | 15% | 60% | 19% | 4% | 2% |
| You have received all of the needed services and supports for your child. | 2020 | 29 | 7% | 24% | 48% | 14% | 7% |
| | 2018 | 52 | 10% | 35% | 33% | 15% | 8% |

Educational supports

Twenty-five of the children (83%) 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. Half of parents and guardians agreed that the plan includes all needed services and supports, down from 60% in 2018. Seventy-five percent agreed they were able to participate in developing the plan as much as they would have liked (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 | 24 | 17% | 33% | 21% | 17% | 13% |
| | 2018 | 47 | 17% | 43% | 26% | 13% | 2% |
| You were able to participate as much as you would have liked in developing the plan. | 2020 | 24 | 21% | 54% | 21% | 4% | 0% |
| | 2018 | 47 | 19% | 66% | 11% | 4% | 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 themes were around education and school (13 total comments).

The teachers within the schools are empowered to notice, test, and recommend solutions and opportunities to support my child.

That whomever we are talking to takes the time to get to know [my child] beyond her disability.

I was allowed to meet with her school psychologist and counselor to have input on the items in her 504 plan.

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, and improvements to school-based resources (5 responses each). The next most frequently mentioned wish was having easier access and not having to “struggle” to get access to services (4 responses).

[Services] seem selective and hidden, it is difficult to get any additional help or support without knowing the right person.

They were more complete. My daughter received support services as a resident of our town even though she attended a public school. However, I felt like there could have been more of an attempt to accommodate her schedule. In order to receive services, she often had to miss classes. I also think that more needs to be done to assist students with executive functioning deficits.

There would be more funds devoted to schools in order to hire more special education teachers.

I wish that the culture as a whole at the high school was not so punitive. This punitive culture strongly and adversely affects all students but especially students with disabilities who are really working harder than their peers.

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 less 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. This indicates that the community and the schools in the community may be having a more difficult time supporting children with learning disabilities, though the number of caregivers responding is quite small, particularly in 2020, 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 Essex County and 6,000 random addresses in Barnstable, Dukes, and Nantucket 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.

