



# 2018 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 residents to respond to a survey in fall 2017. To dig deeper into the experiences of families of youth with learning disabilities, an additional survey of families was conducted in 2018. Fifty-two parents, guardians, or adult caregivers from Essex, Barnstable, Dukes, and Nantucket Counties in Massachusetts responded to the survey for a child with learning disabilities. Throughout the summary, 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 52 parents who responded to the survey said they had a total of 61 children age 2 to 26 who have a learning disability. Forty-two families had one child, eight families had two children, and one family had three children. The most frequently identified learning disabilities were dyslexia (42%) and language processing disorder (32%). A quarter of the youth were diagnosed with dysgraphia (26%) or being non-verbal (25%) (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	Yes	No	Don't know
Dyslexia	60	42%	53%	5%
Language processing disorder	57	32%	58%	11%
Dysgraphia	57	26%	63%	11%
Non-verbal	57	25%	70%	5%
Auditory processing disorder (APD)	54	22%	70%	7%
Dyscalculia	58	16%	71%	14%
Visual perceptual or Visual motor deficit	55	13%	82%	6%

## Learning disability resources

The first two questions on the survey of families of a child with a learning disability were the same as those asked in the broader community survey. Forty-seven percent of parents or guardians agreed that the community devotes enough resources to students with learning disabilities, higher than the 36% of the community respondents who agreed. However, 42% of community respondents said they did not know, as opposed to 2% of the parents or guardians.

The responses for whether community employers provide enough support or accommodations for employees with learning disabilities were less disparate. Thirty-five percent of parents or guardians agreed there was enough support and 42% said they did not know. The community survey results show 25% agreed there was enough community support and 47% did not know (Figure 2).

### 2. 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	52	12%	35%	37%	15%	2%
	Overall community	1,253	7%	29%	17%	6%	42%
Employers in your community provide enough support or accommodation for employees with learning disabilities	Parents	52	4%	31%	15%	8%	42%
	Overall community	1,255	2%	23%	24%	4%	47%

## Information and services to support youth with learning disabilities

Most parents (86%) agreed they had enough information to understand their child's learning disability. Three-quarters of the parents agreed they had enough information to help plan services and supports (75%) or that they found the information and supports easy to understand (76%). Less than half (48%) agreed that they received all of the services and supports they needed for their child (Figure 3).

### 3. Information and services available for parents and guardians of youth with learning disabilities (N=52)

	Strongly agree	Agree	Disagree	Strongly disagree
You have enough information to understand your child's learning disability.	31%	55%	10%	4%
You have enough information to help plan services and supports for your child.	24%	51%	22%	4%
The information about services and supports you receive for your child is easy to understand.	16%	60%	20%	4%
You have received all of the needed services and supports for your child.	10%	38%	35%	17%

## Educational supports

Ninety percent of the children with learning disabilities asked about in the survey had an educational service plan (47). Of the remaining five children, two did not have a plan, one was too young, one parent refused to answer the question, and one parent said they did not know if the child had an education plan. Sixty-one percent of parents or guardians agreed that the plan includes all needed services and supports. Seventy-four 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 (N=46-47)

	Strongly agree	Agree	Disagree	Strongly disagree
This educational service plan includes all needed services and supports.	17%	44%	26%	13%
Were you able to participate as much as you would have liked in developing the plan?	8%	66%	11%	4%

## 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 most prevalent theme was the support received from schools, medical community, and other families with similar situations. Some parents mentioned school choice which allows families to choose the best school system for their child or the team approach of multiple practitioners providing services for a child. Others mentioned the benefit of programs that have made accommodations for their child to participate.

A few parents provided thoughts on what can be improved. This included desires for additional funding and services, especially related to supporting basic skills and dyslexia (Figure 5).

The second question asked parents and guardians about their wishes for community support for their child with learning disabilities. Parents most frequently requested more services, including support groups for youth and families, recreation activities, and job training opportunities. A few specifically mentioned the need for more services in southeastern Massachusetts. Parents also requested consistent services that address their child's needs and more knowledge for parents about existing services and resources and how to access them.

Parents said they wished they did not have to fight so hard for services or diagnosis and that they could be more involved in decision-making for their child. They expressed frustration about schools deciding to delay testing or diagnosis in order to save money. Parents asked for more support and training for school staff, especially related to how to test children for learning disabilities (Figure 6).

## 5. Parent perspectives about what they like about their community's support for youth with learning disabilities

**Please finish this sentence: When I think about my community's support services for young people with learning disabilities, I like . . .**

[Organization] has been a huge resource for us outside the school. His IEP and teachers alone were not enough to give Kyle the support he needed. Through [Organization], we were able to get him a behavioral therapist, play therapist and therapeutic mentor, without which he would not have been as successful as he has been. He did have good supports in school, but the community is necessary to treat the whole child.

How responsive the team is.

I am just now getting access to things that I didn't even know existed. My son was recently diagnosed. I like the communication I have with the staff or anyone who provides care to him. Staff at school, they are the ones helping me get services that I didn't know existed.

I like that we have programs for continued services well, I also have kids that are in special programs during school which are I like that the team is willing to work with external people. For instance when my son had major depression and was hospitalized and the school worked with a psychologist to help negotiate to get him back to school.

My pediatricians office's support, education, and referrals

Nantucket STAR

I like that community organizations will make accommodations for his needs, particularly Boy Scouts, when he was younger he played baseball when he was in baseball league. And yeah, I would say that would be it, there hasn't been much support.

Our high school was very supportive.

Parent involvement

School choice which allowed me to move my child to a district better able to support her needs

That we were placed in an out of district school that could provide an appropriate education.

School's support and involvement in providing my child's accommodations

That my community has a lot of resources that I could collaborate with.

That there are other families struggling with the same issues

That they are visible and involved with the tasks.

That we are included in every decision and our input is paramount in the final solution.

That we have a lot of options including programs like Title I, reading recover, and [staff]. The structure of the RTI model is also helpful.

The ability to communicate via email freely.

The excellent services provided by the school, particularly in terms of her special education coordinator and teacher, and the mixed classes and pull out session.

The fact that the town has ample resources to fulfill these [educational] plans. You can mix and match his educational plan to be partial inclusion or as needed, and when they get to the higher grades, there is different options for individualized education, and accredited night school for kids that want to work.

The ground level staff that are doing their best with limited resources at the school. A few teachers and therapists that give it their all and go above and beyond.

The integrated support within the elementary school system.

**5. Parent perspectives about what they like about their community's support for youth with learning disabilities (continued)**

**Please finish this sentence: When I think about my community's support services for young people with learning disabilities, I like . . .**

The [local] schools have a very proactive approach when it comes to disabilities. They are the ones that noticed her eyes were not tracking correctly when she reads and we ended up getting her glasses.

The organizations on Cape Cod such as: KDC, Cape Cod Challenger Club, Special Olympics and CORD.

The school is very inclusive and provides opportunities in our community for [child]

The staff working with her are caring and trying their best to help her.

The support in the [local] school system

The team approach.

The team effort put forth by our school system.

The team's commitment to be there for us.

The way all important factors are considered.

They are willing to have parental involvement and hear what parents have to say.

They helped with getting him into school. He had Early intervention which gave us support to get into the public preschool.

Opportunities for improvements

[Child] does not receive any services (therefore the respondent didn't feel like she could answer the question)

I honestly can't say I like anything because there isn't much support in the community.

I like to see more funding going towards basic skills.

Would love to see more community based services for children with dyslexia. In addition, I would love all schools to have dyslexia specialist in place. 1 in 5 children struggle to learn how to read! Dyslexia is the most common learning disability yet the one that is least identified. The emotional and financial burden is placed on the parents and child.

That improvements are hopefully coming in the future. I believe dyslexia is the new autism and that it will become more recognized and accommodated for the next generation.

I like very little. The school has a terrible ability to meet kid's needs, parents need to hire outside neuropsychologists for testing and pay for education advocacy to get access to the right programs.

Don't know. (11)

**6. Parent perspectives about what they wish for to support youth with learning disabilities**

**Please finish this sentence: When I think about my community's support services for young people with learning disabilities, I wish . . .**

Any family that struggles should use the resources available to them, as I did. I educated myself, knowing who the key players were on the special education team. I was constantly interacting with teachers and school officials and very involved in creating [child's] educational plan]

Communication was better and services were more consistently provided

Dyslexia was a legal word that schools used and recognized. That transferring out is not fought constantly but offered early and encouraged.

## 6. Parent perspectives about what they wish for to support youth with learning disabilities (continued)

**Please finish this sentence: When I think about my community's support services for young people with learning disabilities, I wish . . .**

I wish that parents could be more involved, have more of a say than we usually do. We're not told a lot of things, but more hearing it from other people about different programs that could help and what's out there. Schools and doctors, you think they would tell you but they don't. Instead you hear from other people who have kids with disabilities and that shouldn't be the way because it's hard enough to begin with. When you're fighting for your child for their needs to survive, and you don't hear or know stuff that could help, it could have been different.

I wish the school would educate special education staff on how to progress monitor using effective testing- using diagnostic measures. They often times give false reporting to parents which make parents feel their children are making gains- when they aren't

I wish we had more support services locally- there are services but they are all very far away

It was more, people were made more aware that things (services) were available, for example in a lot of places you need certain insurance to get services easier and faster. There is not enough out there, it is not something that comes up right away, like my child has to suffer and suffer until you find out about the services that are available.

Parents did not have to be the "squeaky wheel" to get services so that our children will make progress

School would offer more help for teachers.

That I did not have to pay 25% of this very expensive education

That I would've gotten a little more. When I got him tested at the public school, they didn't admit anything was wrong with him because they didn't want to pay for it. Because he was homeschooled, it was easy to say that he is all yours. I guess I wished they would have admitted that there was something wrong instead of refusing to admit it so they wouldn't have to give any services.

That my son could have better services to access than what he's currently having right now. I can give an example. When accommodations at UMass for a reader for testing or exams, his major is Kinesology. So there are many med terms and tech terms and Latin words that need to be pronounced out loud and he has never had a reader that would pronounce the words correctly for him. The readers find it to be annoying. He's hesitated to advocate for that because he doesn't think they will be able to find anyone who can do it better. He's already being accommodated by getting a different time to take it. He's already accommodated with someone reading the test.

That my son received services earlier. In middle school he was turned down. I'm relieved that both the high school and community college gave him services. I feel he would have excelled if it had happened much earlier in his education.

That the school setting wouldn't look at just the money that is spent but the impact that the skills he would learn would be far-reaching at the moment. It comes down to how much money it costs, if they had identified him earlier and provided the systematic approach to reading earlier, he would have had the opportunity to be remedied earlier and not still struggle as a junior. That might be changing because the governor has a bill on his desk that would screen children earlier and research shows that the brain can be changed and it will cost less money in the long run. He was identified in kindergarten when he was 6. I identified him when he was 4. In fifth grade, the school district filed against us saying he didn't need specialized services anymore. We invoked stay put through the Board of Education appeals and were ruled in our favor that my son still needed those specialized services. In our state, state law is stronger than federal law and states that you have to educate to the student's potential. Are you familiar with special education? It's such a daunting task.

That they were more accessible, you did not have to fight so hard to get, they were giving to the kids in need and not just the kids whose parents couldn't. My son had some friends who should have gotten some intervention in primary school, but since their parents did not fight as much, they did not get it.

The IEP process was more understandable for parents, had even more options available for students depending on their needs.

The schools were more cooperative and understanding

6. Parent perspectives about what they wish for to support youth with learning disabilities (continued)

**Please finish this sentence: When I think about my community's support services for young people with learning disabilities, I wish . . .**

The schools were not so overwhelmed and incapable of meeting the students' needs.

There was less focus on [standardized testing] and more focus on the job training programs and internships. I wish there were more intermural sports and activities to participate in to build self-esteem and friendships

There was more

There was more assistance regarding the mental health part of the learning disability, particularly my daughter really pushes back against reading as she has a reading disability.

There was more outreach for students like Gabe who are twice exceptional.

There was more properly trained support staff

There was more support outside of school, when we have concerns or need to talk to people to ask questions.

There was more understanding from typical peers.

There was more!

There were more available activities for all children with special needs.

There were more available and more reliable information

There were more avenues for job training and transition services here in the Nantucket. Members of the community are starting a task force to look into this, but there is no residential program for our kids to live independently away from home, without having to move off island. For the Nantucket Community especially, I would consider this a crisis.

There were more camps and after school programs on Cape Cod.

There were more options for higher education.

There were more services available through community volunteers.

There were more support and if there were more teachers that were knowledgeable about learning disabilities so they can teach them the proper way. Maybe like support groups for parents to get together to discuss things. Support groups for the kids with the disabilities so that they can get together and not feel alone or know that they are alone in this. Learning opportunities for the parents too.

There were more volunteer opportunities in town.

They could be more direct with suggestions (without giving a diagnosis) to what learning disability the child has rather than let the problem go on for years and years. A lot of parents can't afford a private psych evaluation and getting some direction from the school team that is with the child all day in a learning environment would be helpful.

They had more answers and more resources themselves.

They understood dyslexia and dyscalculia better. My daughter did not show signs of improvement until I moved her to a place that understood how to better teach her and then she thrived. Unfortunately intellectual disabilities and learning disabilities are grouped together in our school system and they couldn't be more different and they style of learning needed couldn't be more different. Children with language based learning disabilities are falling through the cracks!

They would learn about my son's disability, provide appropriate therapeutic support as stated by his neuropsychologist. Since this is not possible, I wish they would pay for a therapeutic school that could give my son the support he needs to get an excellent education, address his social isolation, and transition to college.

They would recognize that kids who "look normal" may be struggling.

We had more children psychotherapist and psychologist available for psychological support

We had more services and support.

Don't know (9)



## 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.

Given that over half of the respondents did not feel that they had enough information to help plan services and supports for their child and information available is not easy to understand, 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?
- How might schools, employers, and community-based agencies build their capacity to provide person-centered support for people with learning disabilities?
- 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.

Two primary methods were used to invite families to participate:

- When the Tower Foundation mailed community surveys to 4,000 random addresses in Essex County and to 4,000 random addresses in Barnstable, Dukes, and Nantucket Counties in fall 2017, the mailing included information for residents to register for an additional family survey specific to learning disabilities and intellectual disabilities. When Wilder staff completed the phone survey with those who registered, families were asked for names of other parents or guardians who might be interested in completing the survey, and referred families were contacted.
- Tower Foundation and Wilder Research staff designed outreach and recruitment materials for local organizations and schools to share with families to increase participation. Facebook promoted posts were also used. Families were directed to a website to complete the survey online or request a phone interview.

The outreach methods were not as successful as we had hoped. Future data collection efforts will consider alternative options for reaching families of youth with learning disabilities. Because of the low number of respondents, the results may not be representative of the entire population of families of youth with learning disabilities.

