PETER & ELIZABETH **TOWER FOUNDATION**

2018 Tower Foundation Family Survey

Learning Disabilities Parent Results
Erie and Niagara 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 2017. To dig deeper into the experiences of families of youth with learning disabilities, an additional survey of families was conducted in 2018. Twenty parents, guardians, or adult caregivers from Erie and Niagara Counties in New York State 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 20 parents who responded to the survey said they had a total of 28 children age 2 to 26 who have a learning disability. Fourteen families had one child, four families had two children, and two families had three children with learning disabilities. The most frequently identified learning disabilities were dysgraphia, dyslexia, and auditory processing disorder. Almost 20% of the parents did not know if their child had either dysgraphia or language processing disorder (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
Dysgraphia	27	44%	37%	19%
Dyslexia	28	43%	61%	11%
Auditory processing disorder (APD)	28	43%	46%	11%
Language processing disorder	28	32%	50%	18%
Dyscalculia	27	33%	52%	15%
Non-verbal	27	30%	63%	7%
Visual perceptual or Visual motor deficit	26	27%	58%	15%

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. Fifty-five percent of parents or guardians agreed that the community devotes enough resources to students with learning disabilities, higher than the 29% of the community respondents who agreed. However, 37% of community respondents said they did not know, as opposed to none of the parents or guardians.

The responses for whether community employers provide enough support or accommodations for employees with learning disabilities were less disparate. Twenty-five percent of parents or guardians agreed there was enough support and 25% said they did not know. The remaining half disagreed. The community survey results show 19% agreed there was enough community support and 40% did not know. The remaining 40% disagreed (Figure 2).

2. Erie and Niagara Counties 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	20	10%	45%	25%	20%	0%
	Overall community	762	5%	24%	24%	10%	37%
Employers in your community provide enough support or accommodation for employees with learning disabilities	Parents	20	5%	20%	40%	10%	25%
	Overall community	762	2%	17%	30%	10%	40%

Information and services to support youth with learning disabilities

Two-thirds of parents and guardians agreed that they had enough information to understand their child's learning disability. Less than half (45%) agreed they had enough information to help plan services and supports or that they found the information and supports easy to understand. The same percentage 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=20)

	Strongly agree	Agree	Disagree	Strongly disagree
You have enough information to understand your child's learning disability.	10%	55%	25%	10%
You have enough information to help plan services and supports for your child.	15%	30%	35%	20%
The information about services and supports you receive for your child is easy to understand.	10%	35%	50%	5%
You have received all of the needed services and supports for your child.	15%	30%	40%	15%

Educational supports

All 20 of the children with learning disabilities parents chose to describe had an educational service plan. Fifty-five percent of parents and guardians agreed that the plan includes all needed services and supports. Seventy percent agreed that 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=20)

	Strongly agree	Agree	Disagree	Strongly disagree
This educational service plan includes all needed services and supports.	20%	35%	35%	10%
Were you able to participate as much as you would have liked in developing the plan?	25%	45%	25%	5%

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 theme was the support received from schools, medical community, parent networks, family, and friends. Some parents mentioned the helpful communications they receive from school staff, especially around scheduling IEP and other meetings. However, one parent or guardian said this was easier for them in a private school setting.

Others mentioned the opportunities for their child to be involved in social and recreational activities or services to help the child manage their learning disability. A few parents or guardians spoke about the benefits of having the schools and the medical community recognize different types of disabilities and work to include youth into activities with other children (Figure 5).

The second question asked parents and guardians about their wishes for community support for their child with learning disabilities. Parents and guardians requested ongoing support and education for families and a comprehensive listing of resources for families. They want services available close to home and accessible to everyone regardless of income. Specific services they mentioned include homework help, employment training, and individualized academic instruction for kids with learning differences. All of these should be developmentally appropriate for youth as they age. Two other requests from parents and guardians included more training for teachers and coaches who work with youth who have learning disabilities, and earlier diagnoses that are explained in a way parents understand (Figure 6).

5. Parent and guardian 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 . . .
The fact that they keep me posted at school. They send letters, they let me know about his IEP meetings. I attend meetings over the phone or in person. I will be attending his meeting on Wednesday because he is not meeting his goals.
I like the people that are involved with it, the people dealing with [child] right, the support they are giving him and us right now. Without them, I would be lost with my child.
That I'm able to bring an advocate with me to the IEP to speak on behalf of myself. There are groups on Facebook that were actually my help and support system in finding the extra services available to me unbeknownst to me. Friends and family were best advocates and not the school system. The school system did not help and thought he was doing great, that he was reading at a fifth grade level, he was actually reading at a first grade level.
The way the counselors at school reach out to ask you what you want for your child. They came right out and asked me, “What do you need for your child, what services do you want?” They helped me for a few things, like typing his papers because his handwriting is not legible, or extended time on tests.
I think about the town I live in and services depend heavily on where you live and which school district you're in. The support services he's receiving are top-notch and wonderful, the school district is saying what will benefit him the most and I haven't disagreed with them yet.
Parent involvement and input when it comes to planning child's education plan and necessary services.
The options I had once we went with private education.
Parent network [is a] resource for information and outreach for when there are problems. I like [organization] that does sports and ice skating for children. I would have to say [organization] for their behavior and their prospect and that is for if my son wants to go overnight places or if I want to go get other services from them. [organization].
When I see students with special needs incorporated into classrooms, sports teams, dance, and extracurricular activities.
I like how open they are about learning. It's easy to access services and ask questions and random information.
That they recognize the different disabilities and they try to make plans and changes to the education system.
That there's recognition of differences.
I like the medical and counseling providers. I think those providers are much more oriented to the child's needs, more than educational providers. Educational providers don't recognize the child's invisible disabilities as much.
There's not a lot of community support. The only support is from the school, not really community support. Getting support outside of school is really hard.
That you have an active role in the IEP. However, I felt my child was diagnosed late with his disability because he was 9 when tested and the school should have caught it earlier.
It’s really hard to answer that because when my son had learning disabilities in Erie County I was never offered any help. It's hard to like anything that was never offered.
Don't know (4)

6. Parent and guardian 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 . . .
That there were more services to offer to kids and to adults. He has been diagnosed with a disability since he was little and I only ever dealt with it through school, and he was in counseling for a little bit. I feel like there could be more services that he could be offered to explain [his disability] better. They just send a paper home, but they never really explain what it means, I think when he was younger they would explain it better and when he was older they just send it in the mail. Maybe a center, or more resources, somewhere where he can get homework help, and now I have to fight with him to do homework, and that puts stress on me and the household. A place where I can take him and he can be offered more information about his disability, because I am lost on what they do and don't have.
I knew of more employment help.
I wish that all the schools had the services [because] it's not fair and he lives in Buffalo and he has to be transferred to the east side of Buffalo to get the help that he needs. The kids have to travel like an hour on the bus to get to the schools to get the services that they need.
There's more openness and availability of services and where to go for help.
The school would have let me know at a younger age. The teachers had suggested he had a disability, but when the school tested him they said he did not have a disability. And when he got older, I had a friend who said that he had ADHD and another said he had a disability. If I had known when he was younger, I wouldn't have been ripping my hair out trying to get my son to do his homework, and I would've known what to do about it. For instance, in Kindergarten every day I would see him sitting on the bench because he hadn't finished his homework, so every day he did not get to play as much as the other kids did because he had to finish his work.
That more was explained regard the specific case because I knew my child was diagnosed with delays at 3 but didn’t fully understand what it meant and he was not diagnosed with a learning disability until six years later.
I wish there were more training programs for coaches and teachers to be aware of it, to be more aware of the behaviors from non-regular children.
That educators had more training beyond what they currently have. Sensitivity, stigma, incorporating techniques into the classroom, person-centered approach.
The services are out there, but when it comes to the services we need, it's very vague unless it's an agency. It's frustrating to get around some services and resources. You get services up until they're 7 or 8 and once they're 8 and up, it's very short on them for the support that they need. There is also a need for community employers to not just all businesses and other employers want to hire and train individuals with special needs. And with agencies feeding them with behavior modification if needed. My son can speak and do stuff, but his behavior, he gets frustrated and he's not focused so he needs someone to help him focus again. I mean, he can do stuff but he needs that extra help. We live in a community that has a lot of services, but it's hard to get to with certain behaviors.
That there were more resources for both parents and the youths and that they're easily available so that the parents do not have to spend hours and hours and hours trying to find out the information. And it would be great if those resources would be available to everyone and not just to those who financially qualify.
I wish there were more support groups not just for parents but for students with disabilities, or if there are support groups available, that they were better advertised for people to access them.
I wish we were in the process of getting Medicaid it took years, to get adaptive equipment it took months. I wish the process could be sped up a bit. (else) That is really it.
I wish there was more access to specific topics, not like a generalized topic. Like, just how to have your child interact with peers, routine type things at home, like sleep routines and eating.
There was more support in private/Catholic school systems.

6. Parent and guardian 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 . . .
They were made available to my son. Children are typically not tested formally for learning disabilities until age 8. He was in special education in public school when he was 5 but because he was not formally diagnosed, he was never offered the services. He's also on the autism spectrum and if he had a higher level of speech therapy, I would have made sure he had those services if I had known about them. It wasn't until I took him to a special school for kids with language-based learning disabilities, the #1 school for kids with language-based learning disabilities, that he got the services he needed. My son was able to learn through this special program where they break down language using the Latin and Greek root to teach students how to read. I wish that all children who struggle with learning disabilities like dyslexia could attend a school like [School], it's 4:1 (4 students to 1 teacher), because students get lost in the shuffle. All students should have access to an education. Most people can't afford to spend $63,000 a year to educate their children. I spent hundreds of thousands to educate my son but not everyone can afford that, especially if they have other children and other children who have learning disabilities.
I really wish the educational system recognized learning differences rather than disabilities and could individualize instruction. I wish they understood strengths-based learning rather than disabilities. The whole system is backwards. It starts at the community. The community doesn't understand the difference. Change happens at the policy level and until we have somebody at the top who understands what we're doing is not working, nothing really changes. Outcomes do not change for the betterment of the individual.
I wish there were more ongoing services. Like my daughter has a lot of physical services, whereas they don't have a lot of ongoing services for my son which is more of a learning disability they do not provide as much.
I wish there would be better resources for knowing everything that is available and more assistance for navigation for what's available. (why) Because it doesn't currently exist. All of the systems are very fragmented, there is no single source that you can go to, to see what's available. Even though there are people there who can help with navigating, there is still a lot of things families need to do that they don't know which could be a barrier.
There were seminars on all the help available to the youth and help with developing support or information for the youth when heading to college.
Don't know.

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 Erie and Niagara 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.