PETER & ELIZABETH **TOWER FOUNDATION**

# 2020 Tower Foundation COVID-19 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 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 Erie and Niagara counties in New York 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

Twenty-three parents who responded to the pre-COVID-19 survey in early 2020 had children age 2-25 with a learning disability. In second survey, sent out in fall 2020 during the COVID-19 pandemic, 13 parents reported on their children age 6-21 with a learning disability. Because the number of completed surveys was relatively low in both instances, the results in this report may not represent the population of Erie and Niagara 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, about half of parents agreed that the community devotes enough resources to students with learning disabilities. Few parents (15%) agreed that community employers provided enough support or accommodations for employees with learning disabilities, though it is still a notable increase from no parents agreeing in the pre-COVID survey. In both surveys, a third to a half of respondents reported that they didn't know (Figure 1).

**1. 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. | Pre-COVID | 23 | 4% | 44% | 26% | 26% | 0% |
| | COVID | 13 | 15% | 31% | 8% | 46% | 0% |
| Employers in your community provide enough support or accommodation for employees with learning disabilities. | Pre-COVID | 23 | 0% | 0% | 30% | 22% | 48% |
| | COVID | 13 | 0% | 15% | 8% | 46% | 31% |

## Information and services to support youth with learning disabilities

In the survey administered during the COVID-19 pandemic, about three-quarters of parents agreed that they had enough information to understand their child's learning disability. Fewer parents felt that the information and supports were easy to understand during the pandemic (39%) than before (61%), and that they received all of the services and supports they needed for their child (23%, down from 39%). No parents strongly agreed with these statements in the most recent survey. However, slightly more parents felt they had enough information to help plan services and support for their child during the pandemic than before (75%, compared to 61%; 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 | 23 | 22% | 61% | 13% | 4% | 0% |
| | COVID | 13 | 0% | 77% | 23% | 0% | 0% |
| You have enough information to help plan services and supports for your child. | Pre-COVID | 23 | 17% | 44% | 30% | 9% | 0% |
| | COVID | 13 | 25% | 50% | 17% | 8% | 0% |
| The information about services and supports you receive for your child is easy to understand. | Pre-COVID | 23 | 13% | 48% | 39% | 0% | 0% |
| | COVID | 13 | 0% | 39% | 46% | 15% | 0% |
| You have received all of the needed services and supports for your child. | Pre-COVID | 23 | 13% | 26% | 35% | 22% | 4% |
| | COVID | 13 | 0% | 23% | 46% | 31% | 0% |

## Educational supports

Eleven of the twelve 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. Seventy-three percent of parents and guardians agreed that the plan included all needed services and supports, which is about the same as it was prior to COVID. Fewer parents reported they were able to participate as much as they would have liked in developing the plan (82%, compared to 95% before COVID-19; 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 | 20 | 15% | 55% | 25% | 5% | 0% |
| | COVID | 11 | 9% | 64% | 9% | 9% | 9% |
| You were able to participate as much as you would have liked in developing the plan. | Pre-COVID | 20 | 25% | 70% | 5% | 0% | 0% |
| | COVID | 11 | 9% | 73% | 18% | 0% | 0% |

## 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 (77%). Fifteen percent also said that the format of services had changed, but not the amount or intensity of services (Figure 4). Of those who lost or decreased services, parents reported face-to-face accommodations at school (70% of parents), community-based services (40%) and opportunities for social-emotional connections (40%) 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

| Blank | N | % |
|---|---|---|
| My child has lost or experienced a decrease in needed services and supports. | 13 | 77% |
| It has changed the format of services received, but not changed the amount or intensity of services. | 13 | 15% |
| It has not affected the services and supports my child is receiving. | 13 | 8% |
| My child has increased access to needed services and supports. | 13 | 0% |
| My child has been able to access services not previously available (e.g., telehealth services or new opportunities). | 13 | 0% |

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

| Blank | N | % |
|---|---|---|
| Face-to-face accommodation at school | 10 | 70% |
| Community-based services | 10 | 40% |
| Social-emotional connections or opportunities | 10 | 40% |
| Paid employment | 10 | 0% |
| Insurance coverage | 10 | 0% |
| Child care | 10 | 0% |
| Other (please specify) | 10 | 20% |

Other responses included summer services, occupational therapy, speech therapy and in-home hospice services.

When parents were asked how a loss or decrease of services and supports affected their child, parents mentioned negative impacts to their academic skills, such as falling behind in class and a regression in skill development. Parents also mentioned the loss of social interaction, depression, and increased aggression.

> *He is less successful academically and is lonely with little to no social interaction.*
>
> *[My child] has severe disfluency of speech and his stuttering has increased a lot since March. He is supposed to receive speech therapy 3X a week according to his IEP and now he is only receiving therapy twice per 12 day cycle.*

## 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 said they liked the effort made by teachers during this time and the continued communication. A couple of other parents said there was nothing they liked or that they were unsure of services available in the community.

> *[I like] teacher interactions. Feedback on concerns and progress.*
>
> *Not sure there are community services really.*

Parents wished that children with learning disabilities would have more intensive education opportunities during this time, such as being able to go back to school in-person or having more one-on-one instruction. They also wished more support services were available, including respite, increased social opportunities, and improved accommodations from employers.

> *[I wish] there was full time in-person school or a private tutor to help.*
>
> *[I would like to] get out to visit family and friends.*
>
> *[I wish] I had a helpful respite worker.*

## 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.

Since the beginning of the COVID-19 pandemic, parents were less likely to agree that their child has access to all of the needed services and supports, or that services and supports they received were easy to understand. However, because of the small sample size in the two surveys, 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, community-based supports, and opportunities for social-emotional connections. Given these responses, the following discussion questions may help plan services:

- How might schools safely support greater one-on-one or in-person support for students with learning disabilities?
- How might communities build new opportunities for social-emotional connection during COVID-19, for both parents and their children with learning disabilities?
- 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 Erie and Niagara 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 electronically.