2020 Tower Foundation COVID-19 Family Survey

Intellectual 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 intellectual disabilities, the Foundation conducted an additional survey of families in 2020. Forty parents, guardians, or adult caregivers from Essex, Dukes, Barnstable, and Nantucket counties in Massachusetts responded to the survey for a child with intellectual disabilities. With the disruption created by the COVID-19 pandemic, the Tower Foundation recognized the unique concerns that families of children with intellectual 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 **intellectual disabilities** as characterized by significant limitations both in mental capacity (e.g., learning, reasoning, and problem-solving), and adaptive behavior (e.g., conceptual skills, social skills, and daily living skills). Individuals on the autism spectrum are also included in this group.

Description of youths

Forty parents who completed the pre-COVID-19 survey in early 2020 had children age 3-25 with an intellectual disability. In the second survey, sent out in fall 2020 during the COVID-19 pandemic, 19 parents reported on their children age 11-26 with an intellectual disability. Because the number of completed surveys was relatively low in both instances, the results in this report may not represent the population of Essex, Dukes, Barnstable, and Nantucket county residents with a family member with an intellectual disability. As such, we urge caution in generalizing these findings beyond the respondents who completed the survey.

Community resources

In the survey administered during the COVID-19 pandemic, a third of parents agreed that it would be best for persons with intellectual disabilities to live and work in special communities (32%, up from 18% before the pandemic). Additionally, a larger percentage of parents said they did not know whether individuals with intellectual disabilities should live and work in special communities (16%, up from 5% before the pandemic). Roughly the same percentage of parents agreed that people with intellectual disabilities are treated fairly in our community in both surveys (53% in the COVID-19 survey, compared to 51% before the pandemic; Figure 1).

1. Parents' and residents' perspectives of intellectual disabilities

		N	Strongly agree	Agree	Disagree	Strongly disagree	Don't know
People with intellectual disabilities are treated fairly in our community.	Pre-COVID	39	5%	46%	39%	5%	5%
	COVID	19	11%	42%	42%	5%	0%
It would be best for persons with intellectual disabilities to live and work in special communities.	Pre-COVID	40	0%	18%	43%	35%	5%
	COVID	19	16%	16%	47%	5%	16%

Information and services to support youth with intellectual disabilities

In the survey administered during the COVID-19 pandemic, fewer parents agreed that they had enough information to help plan services and supports for their child (53%, down from 72% prior to the pandemic). Parents did not report a substantial difference during the pandemic when compared to prior to the pandemic on having enough information to understand their child's intellectual disability, finding information about services and supports they receive for their child is easy to understand, receiving all needed services and supports for their child, and being comfortable with the level of independence their child has (Figure 2). That being said, it is notable that while about half of parents have enough information to plan services and supports and they feel that the information about services and supports are easy to understand, far fewer report that they have received all of the needed services and supports for their child. In addition, over half of parents are not comfortable with the level of independence their child has.

2. Information and services available for parents and guardians of youth with intellectual disabilities

		N	Strongly agree	Agree	Disagree	Strongly disagree	Don't know
You have enough information to understand your child's intellectual disability.	Pre-COVID	39	39%	44%	15%	3%	0%
	COVID	19	47%	37%	11%	5%	0%
You have enough information to help plan services and supports for your child.	Pre-COVID	39	28%	44%	23%	5%	0%
	COVID	19	11%	42%	42%	5%	0%

2. Information and services available for parents and guardians of youth with intellectual disabilities (continued)

		N	Strongly agree	Agree	Disagree	Strongly disagree	Don't know
The information about services and supports you receive for your child is easy to understand.	Pre-COVID	39	8%	38%	38%	13%	3%
	COVID	19	11%	42%	32%	5%	11%
You have received all of the needed services and supports for your child.	Pre-COVID	39	8%	10%	59%	23%	0%
	COVID	19	0%	21%	37%	42%	0%
You are comfortable with the level of independence your child has.	Pre-COVID	39	15%	28%	31%	23%	3%
	COVID	19	11%	32%	32%	21%	5%

Educational experience

Among the families surveyed during the COVID-19 pandemic, 58% of children were currently enrolled in school (Figure 3). When asked about their child's current education setting during COVID-19, 55% were attending school in-person, while 27% were engaged in distance learning, and 18% were engaged in a hybrid model (Figure 4).

3. Types of education settings (N=11)

What kind of setting is your child currently being educated in?	Number	Percent checking this option
Public	8	73%
Private	3	27%

4. Types of education settings (N=11)

What kind of setting is your child currently being educated in?	Number	Percent checking this option
In-person/face-to-face	6	55%
Remote/distance learning	3	27%
Hybrid	2	18%

Respondents reported their children had different levels of inclusion with students that do not have intellectual disabilities. Twenty-nine percent of students prior to the pandemic attended a school that only serves students with disabilities. The remaining students were either partially (40%) or fully (32%) integrated into classrooms that included students with and without intellectual disabilities. During the COVID-19 pandemic, only those participating in in-person or hybrid education settings were asked about the inclusiveness of the setting. Six of eight parents reported that their child attended a school that only serves students with disabilities, while the remaining two parents reported their children were fully included in their education setting (Figure 5).

5. Inclusiveness of school settings

Does/Did your child’s education setting include students without disabilities	Pre-COVID (N=38)	COVID (N=8)
Fully included	32%	2/8
Partially included	40%	0/8
Not included	0%	0/8
The school was only for students with disabilities	29%	6/8

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

Of the 39 youths in school prior to the pandemic, 92% had an IEP, 504 plan, person-centered plan, or other type of education service plan. Of the 11 youths in school during the pandemic, all of them had such a plan (Figure 6). Of those with a plan, prior to the pandemic, 47% of the parents said the educational service plan addressed all the supports their child needs. This percentage increased to 64% during the pandemic.

6. Development of educational plan

Did you and your child help develop the education plan?	Pre-COVID (N=39)	COVID (N=11)
Parent helped develop the plan	56%	45%
Parent and child helped develop the plan	20%	36%
Neither parent nor child helped develop the plan	13%	9%
Child helped develop the plan	3%	9%
No plan	8%	0%
Plan addresses all the support their child needs (of those with a plan)	47%	64%

In both surveys, parents were asked about equal education opportunities for youth with intellectual disabilities. In the survey administered during the COVID-19 pandemic, a greater proportion of parents agreed that youth with intellectual disabilities receive equal education opportunities (37%, compared to 23% prior to the pandemic; Figure 7).

7. Equal education opportunities for youth with intellectual disabilities

		N	Strongly agree	Agree	Disagree	Strongly disagree	Don’t know
In general, people with intellectual disabilities receive equal education opportunities.	Pre-COVID	39	8%	15%	56%	21%	0%
	COVID	19	5%	32%	26%	37%	0%

Despite the majority of parents reporting that youth do not receive equal education opportunities, almost all parents (91%) were satisfied with the quality of the education their child received or is receiving during the pandemic. This is up from 74% prior to the pandemic (Figure 8).

8. Parents' satisfaction with quality of education

	Year	N	Very satisfied	Satisfied	Dissatisfied	Very Dissatisfied	Don't know
How satisfied are you with the quality of education your child received or is receiving?	Pre-COVID	38	13%	61%	18%	8%	0%
	COVID	11	27%	64%	0%	9%	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 (68%). A third of parents were able to access services not previously available (32%), while a fifth said that the format of services had changed, but not the amount or intensity of services (21%; Figure 9).

Parents who lost or decreased services reported opportunities for social-emotional connections (92%), face-to-face accommodations at school (75%), and community-based therapies or services (67%) as areas where they had experienced the greatest loss in services and supports (Figure 10).

9. Impact of COVID-19 on the services and supports youth are receiving

How has COVID-19 affected the services and supports your child is receiving?	Number	Percent checking this option
My child has lost or experienced a decrease in needed services and supports.	13	68%
My child has been able to access services not previously available (e.g., telehealth services or new opportunities).	6	32%
It has changed the format of services received, but not the amount or intensity of services.	4	21%
It has not affected the services and supports my child is receiving.	2	11%
My child has increased access to needed services and supports.	0	0%

Note: Respondents could select all that apply.

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

Please identify if your child has lost or experienced a decrease in any of the following specific types of services and supports.	Number (N=12)	Percent checking this option
Social-emotional connections or opportunities	11	92%
Face-to-face accommodations at school	9	75%
Community-based therapies or services	8	67%
Paid employment	2	17%
Child care	2	17%
Insurance coverage	0	0%
Other	0	0%

When parents were asked how a loss or decrease of services and supports affected their child, parents most notably mentioned negative impacts on their child's skill development (6 responses). This included regression in previously learned skills, as well as being unable to continue to learn new skills. A few parents also mentioned negative impacts on their child's mental health, such as an increase in depression or anxiety (3 responses), and their child feeling isolated or withdrawn from a lack of social opportunities (2 responses).

> *She has regressed in many ways due to not being able to access anything outside of home for a long time. Once school started back up she did better but she does not have the ability to do Zoom classes due to her functioning level.*
>
> *It has [been] more difficult for him to learn new skills; he needs as an adult.*
>
> *Increased anxiety over loss of all regular activities. Withdrawn since so much time at home and no social opportunities. OCD tendencies increased. Anxiety/fear about getting sick.*

Work experience

During the pandemic, two parents (11%) said their child had a job for which they earn pay on a regular basis, both of which reported their child earns at least minimum wage and is satisfied with the job. Prior to the pandemic, seven parents (21%) said their child had a job for which they earn pay on a regular basis. Six had jobs that pay at least minimum wage and are in an integrated environment where they are competitively employed in a setting not specifically for people with disabilities (one parent did not respond).

Both prior to and during the pandemic, 11% of parents agreed people with intellectual disabilities receive equal employment opportunities (Figure 9).

9. Equal employment opportunities for youth with intellectual disabilities

		N	Strongly agree	Agree	Disagree	Strongly disagree	Don't know
In general, people with intellectual disabilities receive equal employment opportunities.	Pre-COVID	39	3%	8%	46%	23%	20%
	COVID	19	0%	11%	37%	42%	11%

Community strengths and opportunities for improvement

To better understand their experiences navigating supports for their children with intellectual 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 intellectual disabilities during the COVID-19 pandemic. Parents most often said they liked that some programs were creative in finding ways to remain accessible during COVID-19 (7 responses). This could be transitioning to remote options through platforms like Zoom or finding ways to make in-person options safe. A few parents also noted they appreciated schools having in-person classes (2 responses) and the dedication of some school staff or service providers to being present for their child (2 responses). Three parents said there was nothing they liked about their community's supports during this time.

> ***I like...*** *That there are efforts to engage the youth, virtually. I like that educators and coaches are visible and ensuring safety.*
>
> ***I like...*** *That they are available online via Zoom, etc. My son is more comfortable with this interaction.*
>
> ***I like...*** *That [organization] prioritized getting students like my son back into the schools because remote learning is not a real viable option for him.*
>
> *There was none. My child and children like him were left with nothing suddenly in March, disrupting their routines and schedules, causing regression in a lot of cases. The school 'tried' but with schools not allowed to be open and his inability to do remote learning he was left with no school and no therapies for over 6 months.*

The second question asked parents and guardians about their wishes for community support for their child with intellectual disabilities during the COVID-19 pandemic. Parents had a few ideas for improvement in how their communities support their children during COVID-19. The most common response was more opportunities for social interactions, such as small group activities, either in-person or remote (5 responses). Another common response was that the community would be more understanding toward families with children with intellectual disabilities and take their needs into consideration (4 responses). This included having special hours at local stores for shopping or a greater understanding for the amount of anxiety present in this population. A few parents also noted a desire for schools to resume in-person classes (3 responses), more information about available services or resources (2 responses), and more programs or services in general (2 responses).

> ***I wish...*** *All community-based day programs provided more options for in-person small groups and a wider variety of Zoom classes with local friends. Some programs offer a lot but only to their clients and not the rest of the community. I would like to have someone create a local 'map' of the resources available and to create a network of people with [intellectual disabilities] who share similar interests.*
>
> ***I wish...*** *That we would be back in-person for school. I wish that we could offer small group activities.*
>
> ***I wish...*** *That our children were considered and thought about in a greater context.*
>
> ***I wish...*** *More services were available in my area for my son's age group.*

Conclusions

The Tower Foundation conducted these surveys because of its commitment to address issues related to intellectual 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 intellectual disabilities, particularly during the pandemic.

During the pandemic, parents were less likely to agree that they have enough information to help plan services and supports for their child. However, they were more likely to agree that they are satisfied with the quality of education their child is receiving; that in general, people with intellectual disabilities receive equal education opportunities; and that it would be best for persons with intellectual disabilities to live and work in special communities during the pandemic, as well. Because of the relatively 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 opportunities for social-emotional connections, face-to-face supports in school, and community-based therapies or services. Given these responses, the following discussion questions may help plan services:

- How might communities build new opportunities for social-emotional connection during COVID-19?
- How might schools safely support greater face-to-face, one-on-one, or small group support for students with learning disabilities?
- How might schools and communities continue to ensure that young people with learning disabilities and their families have access to all the information, services, and support systems they need?

Methods and caveats

These two surveys were targeted to families of youth, age 26 or younger, who have an intellectual 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:

- 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.

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.

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