2020 Tower Foundation COVID-19 Family Survey

Intellectual 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 intellectual disabilities, the Foundation conducted an additional survey of families in 2020. Sixty-eight parents, guardians, or adult caregivers from Erie and Niagara counties in New York 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

The 68 parents who completed the pre-COVID survey in early 2020 had children, age 1-26, with an intellectual disability. In the second survey, sent out in fall 2020 during the COVID-19 pandemic, 33 parents reported on their children age 4-25 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 Erie and Niagara 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, over a third of parents agreed that people with intellectual disabilities are treated fairly in their community (36%, down from 49% before the pandemic; Figure 1). Most parents at both time points did not feel that individuals with intellectual disabilities should be living and working in special communities (72-75%).

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	68	2%	47%	32%	12%	7%
	COVID	33	3%	33%	39%	15%	9%
It would be best for persons with intellectual disabilities to live and work in special communities.	Pre-COVID	68	8%	16%	49%	13%	13%
	COVID	33	6%	12%	45%	30%	6%

Information and services to support youth with intellectual disabilities

In the survey administered during the COVID-19 pandemic, a greater percentage of parents agreed the information about services and supports they receive for their child is easy to understand (61%, up from 50% prior to the pandemic; Figure 2). Parents did not report a substantial difference during the pandemic when compared to before on having enough information to understand their child's intellectual disability, having enough information to help plan services and supports for their child, 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 the majority of parents said they have enough information to plan services and supports and many feel that the information about services and supports are easy to understand, fewer report that they have received all of the needed services and supports of 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	68	28%	63%	7%	0%	2%
	COVID	33	52%	39%	3%	6%	0%
You have enough information to help plan services and supports for your child.	Pre-COVID	68	19%	56%	18%	7%	0%
	COVID	33	27%	55%	6%	12%	0%
The information about services and supports you receive for your child is easy to understand.	Pre-COVID	68	10%	40%	43%	7%	0%
	COVID	33	21%	39%	24%	12%	3%

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
You have received all of the needed services and supports for your child.	Pre-COVID	68	13%	27%	43%	16%	2%
	COVID	33	24%	21%	27%	24%	3%
You are comfortable with the level of independence your child has.	Pre-COVID	68	4%	31%	53%	10%	2%
	COVID	33	9%	33%	39%	18%	0%

Educational experience

Among the families surveyed during the COVID-19 pandemic, 79 percent of children were currently enrolled in school, with 62% in public schools and 38% in private schools (Figure 3). When asked about their child's current education setting during COVID-19, 64% were engaged in a hybrid of distance and in-person learning, and 36% were engaged in distance learning. No respondents reported attending school in person (Figure 4).

3. Types of education settings (N=26)

What kind of setting is your child currently being educated in?	Number	Percent checking this option
Public	16	62%
Private	10	38%

4. Types of education settings (N=25)

What kind of setting is your child currently being educated in?	Number	Percent checking this option
Hybrid	16	64%
Remote/distance learning	9	36%
In-person/face-to-face	0	0%

The children had different levels of inclusion with students that do not have intellectual disabilities. Thirty-five percent of students prior to the pandemic attended a school that only serves students with disabilities. The remaining students were fully (19%), partially (33%), or not (13%) 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. Forty percent of parents reported that their child attended a school that only serves students with disabilities, while the remaining parents reported their children were fully (27%), partially (20%), or not (13%) 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=63)	COVID (N=15)
Fully included	19%	27%
Partially included	33%	20%
Not included	13%	13%
The school was only for students with disabilities	35%	40%

Of the 65 youths in school, 94% had an IEP, 504 plan, person-centered plan, or other type of education service plan. Of the 26 youths in school during the pandemic, 25 of them had such a plan (one respondent did not answer the question; Figure 6). Of those with a plan, 80% of the parents said the educational service plan addressed all the supports their child needs prior to the pandemic, while 76% said so during the pandemic.

6. Development of educational plan

Did you and your child help develop the education plan?	Pre-COVID (N=63)	COVID (N=25)
Parent helped develop the plan	64%	80%
Parent and child helped develop the plan	17%	12%
Neither parent nor child helped develop the plan	11%	8%
Child helped develop the plan	3%	0%
No plan	5%	0%
Plan addresses all the support their child needs (of those with a plan)	80%	76%

In both surveys, parents were asked about equal education opportunities for youth with intellectual disabilities. In the survey administered during the COVID-19 pandemic, the proportion of parents agreeing that youth with intellectual disabilities receive equal education opportunities did not differ substantially from those prior to the pandemic (33%, compared to 40% 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	68	3%	37%	40%	19%	2%
	COVID	33	3%	30%	39%	24%	3%

During the pandemic, 68% of parents were satisfied with the quality of the education their child received or is receiving. This is down from 83% prior to the pandemic (Figure 8).

8. Parents' satisfaction with quality of education

		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	65	32%	51%	8%	8%	2%
	COVID	25	28%	40%	28%	4%	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 (64%). Eighteen percent said that the format of services had changed, but not the amount or intensity of services (Figure 9).

Parents who lost or decreased services reported opportunities for social-emotional connections (86%) and face-to-face accommodations at school (76%) 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 (N=33)

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.	21	64%
It has changed the format of services received, but not the amount or intensity of services.	6	18%
My child has been able to access services not previously available (e.g., telehealth services or new opportunities).	3	9%
It has not affected the services and supports my child is receiving.	3	9%
My child has increased access to needed services and supports.	1	3%

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=21)	Percent checking this option
Social-emotional connections or opportunities	18	86%
Face-to-face accommodations at school	16	76%
Community-based therapies or services	12	57%
Child care	6	29%
Insurance coverage	2	10%
Paid employment	1	5%
Other[a]	3	14%

[a] Other options included: camps and respite, social connection, lower reimbursement by self-direction (1); major delay in the application process for getting desperately needed services (1); restriction in access to family and friends (1).

When parents were asked how a loss or decrease in services and supports affected their child, parents most notably mentioned a regression of skills (8 responses). This included speech skills, social skills, and general life skills. Parents also noted negative impacts to their child's mental health, including becoming more depressed, agitated, or self-injurious (4 responses). A few parents also mentioned a particular loss of social activities and programming (3 responses) and a loss of their child's daily routine (2 responses).

> *[My child] doesn't understand the extreme changes and his behaviors have increased in all areas, including aggressive to others, self-injurious, and destructive to property. The lack of in-person services for school has led to regression and his speech and occupational therapies have been reduced. Virtual learning does not work for him so he is receiving about 40% of the education he should be getting as listed in his IEP.*
>
> *Regression seen in social skills and signs of depression.*
>
> *She is much more distressed and agitated. She will not wear a mask so cannot go anywhere in the community. Her world became very small.*

Work experience

During the pandemic, three parents (9%) said their child had a job for which they earn pay on a regular basis. Of these, two parents reported their child has integrated employment, while the third reported their child is employed through facility-based paid employment. Two of the three respondents reported their child earned at least minimum wage for their work. Prior to the pandemic, four parents (10%) said their child had a job for which they earn pay on a regular basis. All of these jobs 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. During the pandemic, 15% 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	67	0%	6%	43%	30%	21%
	COVID	33	0%	15%	39%	39%	6%

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. When parents were asked what they liked most about their community's support services during this time, the most common response was nothing – that there was a lack of support services (7 responses). Other parents did note that they appreciated the school's general support and services to families (6 responses), such as the education services they continued to offer students.

Parents also appreciated the service providers or organizations that were remaining dedicated to their children by going above and beyond to offer support (5 responses).

> ***I like…*** *Nothing. No support. We are completely on our own.*
>
> ***I like…*** *Nothing, as support services for my son have been virtually zero due to lack of his ability to wear a face mask.*
>
> ***I like…*** *That the schools are still trying to find a way to meet the IEP needs.*
>
> ***I like…*** *Small nonprofit groups have risen to the challenge to have some services to "fill in the gap" left by day programs and schools being closed.*
>
> ***I like…*** *That her respite program came to our home. It provided some much needed social interaction and familiarity.*

The second question asked parents and guardians about their wishes for community support for their child with intellectual disabilities during the COVID-19 pandemic. A large number of parents said they wanted more support services in general (6 responses), though didn't specify what type of support services would be helpful. In addition, parents often wished there were generally more opportunities for social interaction in the community, including organized activities or chances to build social skills (6 responses). Similarly, parents expressed a desire for places to stay open (4 responses), including 2 parents who wished schools would resume in-person classes. Parents also wanted more services available for teens or adults with disabilities to build independent living, vocational, and social skills (4 responses).

> ***I wish…*** *There was a way for my son to have in-person interaction with others in a contained environment with a "bubble" of 5-6 others with similar circumstances.*
>
> ***I wish…*** *That our district would just resume full day, in-school, classes. I feel like half the material is being covered with these half days, and that the kids are all falling behind academically, and socially.*
>
> ***I wish…*** *Services were available to help kids transition from teenagers to young independent adults.*
>
> ***I wish…*** *That there was more support because we have seen much regression.*

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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 people with intellectual disabilities are treated fairly in their community or that they are satisfied with the quality of education their child is receiving. However, they were more likely to agree that the information about services and supports they receive for their child is easy to understand. Because of the relatively small sample size in the second survey, caution is warranted in interpreting these changes. 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 and face-to-face supports in school. 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 for students with intellectual disabilities?
- How might schools and communities continue to ensure that young people with intellectual disabilities and their families have access to easily understandable information about services and supports 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 Erie and Niagara 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.