



2022 Tower Foundation 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 a survey of families from Essex, Dukes, Barnstable, and Nantucket counties in Massachusetts in 2018. Sixty-six parents, guardians, or adult caregivers responded to the survey for a child with intellectual disabilities. At the beginning of 2020, forty parents, guardians, or adult caregivers responded to the survey, and in 2022, a follow-up survey was completed by 52 parents who reported that their child had an intellectual disability. Key differences between the 2018, 2020, and 2022 surveys are noted throughout this summary when changes are greater than 10 percentage points. 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 number of parents reporting on their children with intellectual disabilities is up in 2022 (52 parents) from parents who completed the survey in 2020 (40 parents), yet down from when parents reported on their children in 2018 (66 parents). The children were slightly older in 2022 as well, with a range of 5 to 26 years, compared to the range of 3 to 25 years in 2020. The children in 2018 were similar in age to the children in 2020 with a range of 2 to 26.

Because the number of completed surveys was relatively low in all 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 follow-up survey administered in 2022, two-fifths of parents agreed that it would be best for persons with intellectual disabilities to live and work in special communities (41%, up from 18% in 2020 and 14% in 2018). Fourteen percent of parents said they were unsure whether individuals with intellectual disabilities should live and work in special communities, similar to 2020 and 2018. Approximately half of parents in 2022 agreed that people with intellectual disabilities are treated fairly in our community compared to two thirds in 2018 (48%, down from 66% in 2018; 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.	2018	66	11%	55%	26%	8%	2%
	2020	39	5%	46%	39%	5%	5%
	2022	52	6%	42%	39%	10%	4%
It would be best for persons with intellectual disabilities to live and work in special communities.	2018	66	0%	14%	52%	27%	8%
	2020	40	0%	18%	43%	35%	5%
	2022	52	10%	31%	25%	21%	14%

Information and services to support youth with intellectual disabilities

In the 2022 follow-up survey, nearly half of the parents agreed that they had enough information to help plan services and supports for their child (49%), down notably from 72% in 2020 and 68% in 2018. Parents reported a substantial difference in the 2022 follow-up survey when compared to the 2020 survey concerning having enough information to understand their child's intellectual disability (70% compared to 83%), and receiving all needed services and supports for their child (31% compared to 18%). Additionally, there was a substantial difference in the 2022 follow-up survey compared to the 2018 survey regarding the ease of understanding supports and services they receive for their child (47% compared to 67%). It is notable that in 2022, while about half of parents have enough information to plan services and supports (49%), and they feel they understand their child's intellectual disability (70%), under one third report that they have received all of the needed services and supports for their child (31%). Over half of parents are not comfortable with the level of independence their child has (57%, similar to 2020 and 2018; Figure 2).

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.	2018	66	29%	50%	15%	5%	2%
	2020	39	39%	44%	15%	3%	0%
	2022	52	37%	33%	23%	6%	2%
You have enough information to help plan services and supports for your child.	2018	66	15%	53%	24%	3%	5%
	2020	39	28%	44%	23%	5%	0%
	2022	51	18%	31%	37%	12%	2%
The information about services and supports you receive for your child is easy to understand.	2018	66	11%	56%	29%	3%	2%
	2020	39	8%	38%	38%	13%	3%
	2022	52	8%	39%	39%	10%	6%
You have received all of the needed services and supports for your child.	2018	66	15%	18%	38%	27%	2%
	2020	39	8%	10%	59%	23%	0%
	2022	52	8%	23%	42%	25%	2%
You are comfortable with the level of independence your child has.	2018	66	8%	39%	32%	17%	5%
	2020	39	15%	28%	31%	23%	3%
	2022	52	8%	29%	40%	17%	6%

Educational experience

Among the families surveyed in 2022, 69 percent of children were currently enrolled in public school (Figure 3). When asked about their child's current educational setting, 83% were attending school in-person, while 11% were engaged in distance learning, and 6% were engaged in a hybrid model. (Figure 4).

3. Types of educational settings (N=36)

What kind of setting is your child currently being educated in?	Number	Percent checking this option
Public	25	69%
Private	11	31%

4. Types of educational settings (N=35)

What kind of setting is your child currently being educated in?	Number	Percent checking this option
In-person/face-to-face	29	83%
Remote/distance learning	4	11%
Hybrid	2	6%

Respondents reported their children had different levels of inclusion with students that do not have intellectual disabilities. Thirty-two percent of students in 2022 attended a school that only serves students with disabilities. The remaining students were either fully (36%), partially (23%, down from 40% in 2020), or not (7%) integrated into classrooms that included students with and without intellectual disabilities. (Figure 5).

5. Inclusiveness of school settings

Does/Did your child’s educational setting include students without disabilities	2018 (N=62)	2020 (N=38)	2022 (N=31)
Fully included	36%	32%	36%
Partially included	39%	40%	23%
Not included	3%	0%	7%
The school was only for students with disabilities	23%	29%	32%

Of the 36 youths in school in 2022, 86% had an IEP, 504 plan, person-centered plan, or other type of education service plan. Of those students with a plan, 57% of the parents said the educational service plan addressed all the supports their child needs (up from 47% in 2020). (Figure 6).

6. Development of educational plan

Did you and your child help develop the educational plan?	2018 (N=61)	2020 (N=39)	2022 (N=31)
Parent helped develop the plan	75%	56%	65%
Parent and child helped develop the plan	21%	20%	23%
Neither parent nor child helped develop the plan	0%	13%	3%
Child helped develop the plan	3%	3%	10%
Plan addresses all the support their child needs (of those with a plan)	60%	47%	57%

Parents were asked about equal education opportunities for youth with intellectual disabilities. In the 2022 follow-up survey, a greater proportion of parents agreed that youth with intellectual disabilities receive equal education opportunities (45%, up from 23% in 2020; 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.	2018	66	9%	36%	30%	23%	2%
	2020	39	8%	15%	56%	21%	0%
	2022	52	6%	39%	27%	27%	2%

Despite the majority of parents reporting that youth do not receive equal education opportunities, almost all parents (81%) were satisfied with the quality of the education their child received or is receiving in 2022 (up from 69% in 2018). (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?	2018	63	37%	32%	25%	6%	0%
	2020	38	13%	61%	18%	8%	0%
	2022	36	17%	64%	8%	11%	0%

Impact of COVID-19

In the 2022 follow-up survey, parents were also asked about how the COVID-19 pandemic had impacted services and supports available to them during the past year. Nearly half of the parents reported that COVID-19 had changed the format of services received (47%), but not the amount or intensity of services. Two fifths lost or experienced a decrease in services and supports (39%), while over a quarter of parents were able to access services not previously available (28%). (Figure 9).

Parents who lost or decreased services reported opportunities for social-emotional connections (80%), community-based therapies or services (75%), and face-to-face accommodations at school (65%) 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=51)

How has COVID-19 affected the services and supports your child is receiving?	Number	Percent checking this option
It has changed the format of services received, but not the amount or intensity of services.	24	47%
My child has lost or experienced a decrease in needed services and supports.	20	39%
My child has been able to access services not previously available (e.g., telehealth services or new opportunities).	14	28%
My child has increased access to needed services and supports.	7	14%
It has not affected the services and supports my child is receiving.	4	8%

Note: Respondents could select all that apply.

10. Areas where youth have experienced a loss or decrease in services and supports (N=20)

Please identify if your child has lost or experienced a decrease in any of the following specific types of services and supports.	Number	Percent checking this option
Social-emotional connections or opportunities	16	80%
Community-based therapies or services	15	75%
Face-to-face accommodations at school	13	65%
Child care	3	15%
Paid employment	2	10%
Insurance coverage	1	5%
Other	2	10%

When parents were asked how a loss or decrease of services and supports affected their child, parents most notably mentioned limited or lacking social opportunities (12 responses). This included not being able to go out in the community, not being able to socialize with peers, becoming isolated, and loss or less focus on social skills.

I believe these changes have affected his ability to socialize with others his age. The opportunities to build relationships outside of a school setting were hard to find.

It has isolated her and she hasn't been able to connect socially with fun activities she used to do.

His ability to socialize with peers was lost for a while and we are still looking to make gains in those areas.

Parents also mentioned various positive outcomes for their child, such as an increase in independence, overcoming health challenges, and being able to adapt (7 responses).

Increased motivation to be more independent.

My son actually overcame his severe anxiety during COVID and when he went back to his program in late 2021 the providers were stunned by how much he had positively changed.

Since he was able to do things where he was comfortable, he's become more independent and able to complete tasks.

Telehealth provided weekly socialization communication therapy.

Other parents reported that their child regressed in skills pertaining to school and vocational work, and self-care (5 responses). Fewer reports included challenges with accessing services and supports, adapting to new ways of living, and regression in general.

He has lost most of his skills for vocational work.

His therapies have changed and decreased dramatically. He has regressed and lost some of his self-care knowledge that I am afraid he won't be able to get back.

He has not progressed in his growth [nor] learned new skills to assist in his thriving in the classroom.

Work experience

In the 2022 follow-up, seven parents (14%) said their child had a job for which they earn pay on a regular basis. Four parents reported that their child earns at least minimum wage, two said their child has integrated employment, three parents reported that their child was self-employed, while five parents reported job satisfaction. Similarly, seven parents (21%) in 2020 and five parents (8%) in 2018 said their child had a job for which they earn pay on a regular basis.

In 2022, 18% of parents agreed that people with intellectual disabilities receive equal employment opportunities (Figure 11). This is similar to previous survey results.

11. 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.	2018	66	2%	12%	35%	30%	21%
	2020	39	3%	8%	46%	23%	20%
	2022	52	10%	8%	44%	27%	12%

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 said they liked specific program or support services (4 responses), sports and recreation clubs such as Cape Cod Challenger and Special Olympics (3 responses), support they got from schools (3 responses), the fact that there were services available (3 responses), and the caring and kind people (3 responses).

I like... that there is an online community and resources without them I would be lost. I also like that there are private services available to bridge all the gaps in the ones that are offered as public. I also love the federation for students with special needs. They were a life saver for my son.

I like... that he's back to his day program but only 3 days are offered.

I like... the Cape Cod Challenger Club offers some activities appropriate for my son.

I like... how responsive her school was to setting up a plan before starting school.

I like... the services and support our local community college offers.

I like... the calm, caring and confident adults who are committed to the mission of supporting youth with ID.

I like... that parents and teachers and YMCA staff are very kind to our family.

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 quite a few recommendations for improvement in how their communities support their children during COVID-19. The most common response was more or better resources, services, and support available in general (10 responses). Another common response was that there could be more inclusive and supportive opportunities for kids with disabilities such as activities outside of school including sports and recreation, and daytime community programs (5 responses). Other responses involved specific support for parents and families, and help for kids with unique needs (5 responses). Parents also mentioned more social development opportunities for their children such as making friends with kids of the same age with similar interests and challenges, and having social activities or programs (5 responses). Fewer responses included more information or education about disabilities for parents, children and the community (4 responses). Four parents also noted that they wished they knew more, that more information was given to them, and that they were told about services that could help their child.

I wish...it would be more inclusive with outside of school activities.

I wish... more could be offered - physical activities are all adult driven.

I wish... they provided more support for parents and families.

I wish... more day time community based programs for people not in DDS day programs.

I wish... there were more individuals of like age and interests who live with similar challenges so that my son could have friendships and job opportunities in a group setting.

I wish... there were more opportunities for social development.

I wish... that any services that could help my son would be told to me. I don't understand how I am still learning about services now, just from conversations with other parents that I wouldn't know about otherwise.

I wish... there were more and I knew about more. Everything we are involved in is word of mouth.

I wish... I was provided with more information regarding intellectual disabilities such as autism.

I wish... there was some more information available to me regarding intellectual disabilities.

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.

In 2022, parents were less likely to agree that they have enough information to help plan services and supports for their child, and very few continued to agree that the community provides equal employment opportunities for youth with intellectual disabilities. However, they were more likely to agree that they are receiving all needed services and supports for their child; that their child's education plan is addressing all needed supports; 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 in 2022. 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, community-based therapies or services, and face-to-face supports in school. Given these responses, the following discussion questions may help plan services:

- How can we encourage employers to provide more and better employment opportunities for people with intellectual disabilities?
- How can schools and communities better ensure that young people with intellectual disabilities and their families have easily understandable information about available services and supports?
- How can schools and communities encourage and support appropriate levels of independence for people with intellectual disabilities?

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 follow-up 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 and 2021 (up from 4,000 in 2017), 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 and 2020 were sent the results from those surveys and were invited to participate again in subsequent years.

Tower Foundation and Wilder Research staff designed outreach and recruitment materials for local organizations and schools to share with families to increase participation.

