



2020 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 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 2019. 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. Throughout the summary, the term “parents” includes all respondents and notable differences from the 2018 survey are noted.

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 40 parents who completed the survey said they had a total of 44 children, age 3 to 25, with an intellectual disability. Most (95%) had one child with an intellectual disability. This summary describes the experiences of the 40 youths, age 3 to 25, whom parents focused on while completing the survey. The focus child was most frequently diagnosed with autism (65%; Figure 1).

1. Identified intellectual disabilities (N=40)

Disability	Percent of youth
Autism	65%
Down Syndrome	8%
Fragile X Syndrome	3%
Prader-Willi Syndrome	3%
Cerebral Palsy	3%
Other diagnosis	38%
Don't know	5%

Note: Youth may have more than one diagnosis, so the total may not equal 100%.

Perceptions of intellectual disabilities

The family survey included a few questions that mirrored those asked on the broader community survey. The first asked about how people with intellectual disabilities are treated in the community. About half of parents (51%) agreed that people with intellectual disabilities are treated fairly, down from 66% in 2018, while 44% disagreed and 5% didn't know (Figure 2). Fifty-two percent of community respondents agreed that people with intellectual disabilities are treated fairly in their community and 19% disagreed. Twenty-nine percent said they did not know, which is much higher than parents.

A second question asked whether it would be best for people with intellectual disabilities to live and work in special communities. Eighteen percent of parents agreed with this statement. Overall, parent and community member responses were similar, though community members were more likely to say they didn't know (19% compared to 5%).

2. 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.	Parents	39	5%	46%	39%	5%	5%
	Overall community	1,809	8%	44%	16%	3%	29%
It would be best for persons with intellectual disabilities to live and work in special communities.	Parents	40	0%	18%	43%	35%	5%
	Overall community	1,814	3%	11%	43%	24%	19%

Information and services to support youth with intellectual disabilities

A large majority of the parents (83%) agreed that they have enough information to understand their child's intellectual disability (Figure 3). Seventy-two percent have enough information to help plan services and supports for their child, and 43% are comfortable with their child's level of independence. Down from 67% in 2018, 46% agreed that the information and supports were easy to understand. In addition, just 18% of parents agreed that they have received all the services and supports they need for their child, also down from 33% in 2018.

Two of these questions were also asked of a subset of respondents who identified as parents of youth with intellectual disabilities on the community survey. In the broader community survey, similar proportions of parents of youth with intellectual disabilities were likely to agree that they have enough information to understand their child's learning disability (82%) and that they are receiving all of the needed services and supports (19%).

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

	Year	N	Strongly agree	Agree	Disagree	Strongly disagree	Don't know
You have enough information to understand your child's intellectual disability.	2020	39	39%	44%	15%	3%	0%
	2018	66	29%	50%	15%	5%	2%
You have enough information to help plan services and supports for your child.	2020	39	28%	44%	23%	5%	0%
	2018	66	15%	53%	24%	3%	5%
The information about services and supports you receive for your child is easy to understand.	2020	39	8%	38%	38%	13%	3%
	2018	66	11%	56%	29%	3%	2%
You have received all of the needed services and supports for your child.	2020	39	8%	10%	59%	23%	0%
	2018	66	15%	18%	38%	27%	2%
You are comfortable with the level of independence your child has.	2020	39	15%	28%	31%	23%	3%
	2018	66	8%	39%	32%	17%	5%

Educational experience

Among the families surveyed, all but one child were old enough to be in school (Figure 4). A large majority of these youth attended public schools (85%). A quarter attended private schools, and two were home-schooled. Some students attended multiple types of schools during their education experience.

4. Types of education settings (N=68)

What kind of setting was your child educated in?	Number	Percent checking this option
Public	34	85%
Private	10	25%
Home school	2	5%
Child is not yet in school	1	3%

Note: Child could have attended multiple types of school settings.

The children had different levels of inclusion with students that do not have intellectual disabilities. Twenty-nine percent attended a school that only serves students with disabilities (Figure 5). The remaining students were either partially (40%) or fully (32%) integrated into classrooms that included students with and without intellectual disabilities.

5. Inclusiveness of school settings

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

Of the 39 youths in school, 92% had an IEP, 504 plan, person-centered plan, or other type of education service plan. While 76% of parents helped develop a plan this year, this was down from 2018 when 94% reported they did so (Figure 6).

Of those with a plan, 47% of the parents said the educational service plan addresses all the supports their child needs, down from 60% in 2018.

6. Development of educational plan

Did you and your child help develop the education plan?	2020 (N=39)	2018 (N=63)
Parent helped develop the plan	56%	73%
Parent and child helped develop the plan	20%	21%
Neither parent nor child helped develop the plan	13%	3%
Child helped develop the plan	3%	3%
No plan	8%	0%
Plan addresses all the support their child needs (of those with a plan)	47%	60%

Both parents and community members were asked about equal education opportunities for youth with intellectual disabilities. Ninety-three percent of community respondents agreed that youth with intellectual disabilities should receive equal education opportunities. However, only a quarter of the parents (23%) agreed that this happens (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 (should) receive equal education opportunities. ^a	Parents	39	8%	15%	56%	21%	0%
	Overall community	1,821	51%	42%	3%	0%	3%

^a In the community survey, the word should was included in the question to get their opinions of what should happen. For the family survey, the question was asking whether the statement actually happened.

Despite their perspectives on whether youth receive equal education opportunities, most parents (74%) were satisfied with the quality of the education their child received or is receiving (Figure 8). Fewer parents were dissatisfied in 2020 compared to 2018.

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?	2020	38	13%	61%	18%	8%	0%
	2018	63	37%	32%	25%	6%	0%

Work experience

Seven parents (21%) said their child had a job for which they earn pay on a regular basis. Six have 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). One parent was very dissatisfied with their child's current work situation.

Both parents and community members were asked about equal employment opportunities for youth with intellectual disabilities. Eighty-five percent of community respondents agreed that youth with intellectual disabilities should receive equal employment opportunities. However, 11% of the parents agreed this happens (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 (should) receive equal employment opportunities. ^a	Parents	39	3%	8%	46%	23%	20%
	Overall community	1,820	40%	45%	9%	1%	6%

^a In the community survey, the word **should** was included in the question to get their opinions of what should happen. For the family survey, the question was asking whether the statement actually happened.

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. The most prevalent theme was the inclusive, supportive sports and recreation programs (9 responses), followed by (3 responses each): general programming and support, the kind and respectful community members, and school-based support. About twelve respondents, however, said nothing or that supports were inadequate.

The many inclusive playgrounds, making it accessible for her abilities.

The network of families I have met who are committed to helping their loved ones thrive and grow into productive adults. Some incredible Special Olympics programs and coaches.

There is community support for out of school activities, like the [club] and the [club], through the recreation department.

The second question asked parents and guardians about their wishes for community support for their child with intellectual disabilities. Parents and guardians most wished for (5 respondents each): easier access to services, more or improved school-based support, a wider variety of programming, and supports for older youth. Some specific ideas they mentioned were: adaptive sports, sidewalks, social activities, investment in ASL, life skills training, housing for young adults with intellectual disabilities, or a website with a directory of resources.

PCAs and DPH respite programs are vital and helpful, but there is a whole enrichment piece that's missing. Most if not all social and enrichment programs are geared to higher functioning children. I also think there is a real need for heavy investment in ASL as a means of communicating to non-verbal children.

A dedicated person/s to develop these opportunities in [community]. Networking and coordination is huge and often falls to (tired) parents and (tired) teachers. Networking and developing natural supports would be amazing and provide such benefits to our local and extended community!

There were more options for adaptive sports, swimming, accessible community events. I'd like to see a stronger network of parents, parent groups for support and sharing tips/advice.

The school system would concentrate on life skills, safety skills, addressing puberty and social skills instead of educating through a modified grade level curriculum she will never use.

Conclusions

The Tower Foundation conducted this survey 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 community-level data to help community organizations explore what they can do to better support families and youth experiencing intellectual disabilities.

Given the lower number of responses this year, it is difficult to compare to 2018. However, caregivers were less likely to report they have received all of the supports and services they need in 2020. In addition, the majority of parents at both time points have expressed that individuals with intellectual disabilities do not have access to equal educational and employment opportunities. Given these findings, the following questions can help guide future discussions and decisions:

- What services and supports do families need to help their child reach their highest potential?
- How might communities create or connect youth with intellectual disabilities to opportunities to achieve appropriate levels of independence?
- How can respondents' positive attitudes about equity in education and employment be leveraged to ensure youth with intellectual disabilities are treated fairly?

Methods and caveats

This survey was 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:

- 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.

