



2018 Tower Foundation Family Survey

Parents of Youth with Intellectual Disabilities 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 residents to respond to a survey in fall 2017. To dig deeper into the experiences of families of youth with intellectual disabilities, an additional survey of families was conducted in 2018. Sixty-six parents, guardians, or adult caregivers of children with intellectual disabilities from Essex, Dukes, Barnstable, and Nantucket Counties responded to the survey. Throughout the summary, 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 here.

Description of youths

The 66 parents who completed the survey said they had a total of 137 children, age 2 to 26. Some families had multiple children with intellectual disabilities, but they provided inconsistent data about how many children or what type of intellectual disabilities.

This summary describes the experiences of the 65 youths, age 2 to 26, whom parents focused on while completing the survey. Parents reported in an open-ended question that these youths were most frequently diagnosed with autism (38). Youth were most likely to live at home with their parents (91%) (Figure 1).

1. Child's living situation (N=65)

Where does your child currently live?	N	Percent checking this option
At home with parent or guardian	59	91%
In their own home or apartments	1	2%
In a supervised group home or a residence specifically for people with disabilities	3	5%
At a residential school	2	3%

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. Two-thirds of parents (66%) agreed that people with intellectual disabilities are treated fairly (Figure 2). Fifty-four percent of community respondents agreed people with intellectual disabilities are treated fairly in their community and 18% disagreed. Twenty-seven percent said they did not know.

A second question asked whether it would be best for people with intellectual disabilities to live and work in special communities. Fourteen percent of parents agreed with this statement, 79% disagreed, and 8% did not know. Community members were slightly less likely than parents to disagree (69%), but slightly more likely to say they did not know (15%) about this statement. Seventeen percent of community members agreed it would be best for persons with intellectual disabilities to live and work in special communities.

2. Perceptions of people with intellectual disabilities

		N	Strongly agree	Agree	Disagree	Strongly disagree	Don't know
People with intellectual disabilities are treated fairly in our community.	Parents	66	11%	55%	26%	8%	2%
	Overall community	1,240	8%	46%	15%	3%	27%
It would be best for persons with intellectual disabilities to live and work in special communities.	Parents	66	0%	14%	52%	27%	8%
	Overall community	1,245	4%	13%	47%	22%	15%

Information and services to support parents of youth with intellectual disabilities

Most parents (79%) agreed they have enough information to understand their child's intellectual disability, while 20 percent disagreed (Figure 3). Two-thirds agreed they have enough information to help plan services and supports (68%) and the information and supports are easy to understand (67%). Fewer parents agreed they have received all the services and supports they need for their child (33%) or are comfortable with their child's level of independence (47%).

3. Information and services available for parents of youth with intellectual disabilities (N=66)

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

Educational experience

Nearly all (95%) of the youths were old enough to be in school (Figure 4). Most of them attended public schools (82%). A third of the youths (32%) attended private schools, and four (6%) were home-schooled. Some students had multiple types of schools during their education experience.

4. Types of education settings (N=66)

What kind of setting was your child educated in?	Number	Percent checking this option
Public	54	82%
Private	21	32%
Home school	4	6%
Child is not yet in school	3	5%

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

The youths had different levels of inclusion with students that do not have intellectual disabilities. Twenty-three percent attended a school that only serves students with disabilities, and 3% were in classrooms that did not include students without disabilities (Figure 5). The remaining students were either partially (39%) or fully (36%) integrated into classrooms that included students with and without intellectual disabilities.

5. Inclusiveness of school settings (N=62)

Did your child's education setting include students without disabilities	Number	Percent checking this option
Fully included	22	36%
Partially included	24	39%
Not included	2	3%
The school was only for students with disabilities	14	23%

All of the 63 youth in school had an IEP, 504 plan, person-centered plan, or another type of education service plan. Sixty percent of the parents said the educational service plan addresses all the supports their child needs (Figure 6). Nearly all parents helped develop the plan (96%); 24% said their children were involved in the plan development (Figure 7).

6. Educational plan for youth with intellectual disabilities (N=63)

	Number	Percent checking "Yes"
The educational service plan addresses all the supports the child needs.	38	60%

7. Development of educational plan (N=61)

Did you and your child help develop the education plan?	Number	Percent checking this option
Parent helped develop the plan	46	75%
Child helped develop the plan	2	3%
Parent and child helped develop the plan	13	21%

Both parents and community members were asked about equal education opportunities for youth with intellectual disabilities. Ninety-one percent of community respondents agreed that youth with intellectual disabilities should receive equal education opportunities. However, fewer than half of the parents (45%) agreed this happens (Figure 8).

8. 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. ¹	Parents	66	9%	36%	30%	23%	2%
	Overall community	1,244	46%	45%	4%	1%	3%

¹ 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, the majority of parents were satisfied with the quality of the education their child received or is receiving. About one-third of the parents each were very satisfied (37%) or satisfied (32%) with their child's experience (Figure 9).

9. Parents' satisfaction with quality of education (N=63)

	Very satisfied	Satisfied	Dissatisfied	Very Dissatisfied
How satisfied are you with the quality of education your child received or is receiving?	37%	32%	25%	6%

Work experience

Parents said five youth (8%) had a job for which they earn pay on a regular basis. Three are competitively employed and earn at least minimum wage in a setting not specifically for people with disabilities and one works in a paid sheltered workshop environment. Four of the youth received at least minimum wage for their work.

Both parents and community members were asked about equal employment opportunities for youth with intellectual disabilities. Eighty-three percent of community respondents agreed youth with intellectual disabilities should receive equal employment opportunities. However, 14% of the parents agreed this happens (Figure 10).

10. 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. ¹	Parents	66	2%	12%	35%	30%	21%
	Overall community	1,245	34%	49%	10%	1%	6%

¹ 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.

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 organizations in Essex, Barnstable, Dukes, and Nantucket Counties look into what they can do to better support families and youth experiencing intellectual disabilities. 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 targeted 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.

Two primary methods were used to invite families to participate:

- When the Tower Foundation mailed community surveys to 4,000 random addresses in Essex County and 4,000 random addresses in Barnstable, Dukes, and Nantucket Counties in fall 2017, the mailing included information for residents to register for an additional family survey specific to learning disabilities and intellectual disabilities. When Wilder staff completed the phone survey with those who registered, families were asked for names of other parents or guardians who might be interested in completing the survey; those referred families were also contacted.
- Tower Foundation and Wilder Research staff designed outreach and recruitment materials for local organizations and schools to share with families to increase participation. Facebook promoted posts were also used. Families were directed to a website to complete the survey online or request a phone interview.

The outreach methods were not as successful as we had hoped. Future data collection efforts will consider alternative options for reaching families of youth with intellectual disabilities. Because of the low number of respondents, the results may not be representative of the entire population of families of youth with intellectual disabilities.

