



COVID-19 Survey: Experiences of Parents of Young People Living with Intellectual and Learning Disabilities

Background

The Tower Foundation works to help improve the quality of life for young people living with intellectual and learning disabilities and their families in parts of Western New York and Eastern Massachusetts. To understand these families' experiences and their reactions to services, the Foundation conducted an initial survey in early 2020 of 68 parents of children, ages 26 or younger, living with a disability. The Foundation conducted a second survey following the onset of the COVID-19 pandemic to see how opinions and experiences may have changed. Of the 68 families initially surveyed, 33 responded back in Autumn 2020. This summary shares some of those findings. Due to the relatively small sample size in the second survey, we urge that readers use caution in generalizing these results.

Findings

Four key themes emerged from the survey related to changes parents experienced due to COVID-19:

1. The state of community supports during the pandemic depended on where you live.
2. The pandemic created more barriers to education and socialization.
3. Opportunities for employment became more difficult for young people living with a disability.
4. Despite limited opportunities and services, parents responded positively about how their communities treat young people living with disabilities.

Differences in Support/Services

Access to community supports and services, like face-to-face accommodations at school and community-based services, during the COVID-19 pandemic depended on location.

- In parts of Eastern Massachusetts, the number of parents strongly disagreeing their child has the community supports he or she needs nearly doubled over the course of the pandemic from 23 percent to 42 percent.
- The survey tells a different story in parts of Western New York. The percentage of parents saying their children receive needed community support rose from 40 percent to 44 percent of respondents.

Education/Socialization Barriers

Parents said the onset of the pandemic presented more barriers to their child's ability to socialize with peers.

- More than nine in 10 (92%) parents of a child with an intellectual disability in parts of Eastern Massachusetts reported their child lost "social-emotional connections or opportunities."
- In parts of Western New York, 70 percent of parents with children who have learning disabilities reported their children lost "face-to-face accommodations at school" due to the pandemic.

Employment

The pandemic created a disproportionate burden on employment for the children of the families surveyed, but parents' satisfaction with their children's education increased.

- Prior to the pandemic, 21 percent of parents in parts of Eastern Massachusetts said their child with an intellectual disability had a job for which they earn pay on a regular basis. The onset of the pandemic halved that number to 11 percent.
- The proportion of parents who strongly disagree with the statement that "people with intellectual disabilities receive equal employment opportunities" in parts of Eastern Massachusetts nearly doubled during the pandemic from 23 percent of respondents in early 2020 to 42 percent in August 2020.
- Despite the difficulties surrounding in-person education and socialization opportunities during the pandemic, most parents (91%) in parts of Eastern Massachusetts were satisfied with the quality of the education their child with an intellectual disability has received during the pandemic, an increase from 74 percent prior to the pandemic.

Community Value/Awareness

Parents reported an increase in community value and awareness for their family experiences, even while supports themselves decreased.

- Before the pandemic, 5 percent of parents in parts of Eastern Massachusetts strongly agreed that "people with intellectual disabilities are treated fairly in their community." That mid-pandemic number more than doubled to 11 percent of respondents.

Conclusion

Families of children living with intellectual and learning disabilities face pandemic challenges similar to those faced by families of children without a disability. Social isolation wears on the opportunities to see others and community-build, but appreciation for those who go out of their way to be inclusive and kind to others going through hard times is seen now more than ever.

The Tower Foundation believes these findings are critical to understanding the populations it serves and the best ways to address their needs. The survey also provides a crucial opportunity to give voice to an often underheard population.

Methodology and Caveats

The Tower Foundation contracted with Wilder Research to conduct the two surveys of families of youth, ages 26 or younger, who live with 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:

1. 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.
2. Families who participated in a similar survey in 2018 were sent the results from that survey and were invited to participate again in 2020.
3. 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 August 2020 COVID-19 survey.

To view the individual pre- and post-COVID-19 survey findings, [click here](#).