

# Tower Foundation

## FAMILY SURVEY GUIDE Barnstable, Dukes, and Nantucket Counties

This document provides partners with information and guidelines for recruiting families for the Tower Foundation's Survey to better understand the experiences of families and guardians of youth with intellectual disabilities or learning disabilities.

The Tower family, like so many others, has members who have intellectual disabilities or learning disabilities. Because of this, the Tower Foundation funds organizations in Barnstable, Dukes, and Nantucket Counties working to better meet the needs of young people and their families affected by these issues.

The survey is being funded by The Peter and Elizabeth C. Tower Foundation and conducted by Wilder Research.

### Recruiting families

Thank you for your help recruiting families and youth for this survey project. All of the surveys will be completed by phone by trained interviewers from Wilder Research.

The Foundation needs your help to guide families to register online at <http://towerfdn.link/surveysignup>. Anyone who completes the survey will receive a **\$20 gift card** to Amazon, Target, or Walmart.

**Please share the link** via email, Twitter, Facebook, newsletters, or other ways you communicate with program participants.

**We have also provided flyers** that can be posted in your organization, emailed, or handed to families, and language to use in a variety of communications.

Finally, there is an FAQ document that answers key questions people may have about the survey. Please familiarize yourself with the questions and answers in case people ask. Also, please share this with families if they have questions.



If you have any further questions, you can contact **Don Matteson**, Chief Program Officer at the Tower Foundation, at [dwm@thetowerfoundation.org](mailto:dwm@thetowerfoundation.org) or **716-689-0370 x207**. If you are having technical difficulties with the online registration, please call **1-888-328-2972** and ask for **Terry Franklin**.

Barnstable, Dukes,  
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The Peter and Elizabeth C. **TOWER** Foundation

## Example messaging you can customize for outreach to families

### Community Newspaper

The Peter and Elizabeth C. Tower Foundation is conducting a survey to help better understand the needs of families and youth with intellectual disabilities or learning disabilities in Barnstable, Dukes, and Nantucket Counties.

The Tower Foundation works with agencies who provide services and resources for families and youth with intellectual disabilities or learning disabilities in Barnstable, Dukes, and Nantucket Counties.

If you have a family member with intellectual disabilities or learning disabilities up to age 26, live in Barnstable, Dukes, or Nantucket Counties, and are interested in completing a 20 minute phone survey, please register at <http://towerfdn.link/surveysignup>

Surveys will be conducted by Wilder Research through June 2018. Anyone completing the survey will receive a \$20 gift card to Amazon, Target, or Walmart.

Information provided will be used to identify priorities for improving services and resources available for families and youth with intellectual disabilities or learning disabilities.



#### Twitter or text message for both types of disabilities

Live in Barnstable, Dukes, or Nantucket Counties? Have a child with intellectual disabilities or learning disabilities? Register at <http://towerfdn.link/surveysignup> to complete survey and earn \$20.

#### Twitter or text message for Intellectual Disabilities

Live in Barnstable, Dukes, or Nantucket Counties? Have a child with intellectual disabilities? Register at <http://towerfdn.link/surveysignup> to complete survey and earn \$20.

#### Twitter or text message for Learning Disabilities

Live in Barnstable, Dukes, or Nantucket Counties? Have a child with learning disabilities? Register at <http://towerfdn.link/surveysignup> to complete survey and earn \$20.



#### Agency Newsletters and Facebook for Intellectual Disabilities

[Our Agency] is helping The Peter and Elizabeth C. Tower Foundation recruit families to complete a survey in order to better understand the needs and experience of families and youth with intellectual disabilities.

If you have a family member with intellectual disabilities up to age 26, live in Barnstable, Dukes, or Nantucket Counties, and are interested in completing a 20-minute phone survey, please register at <http://towerfdn.link/surveysignup> Anyone completing the survey will receive a \$20 gift card to Amazon, Target, or Walmart.

The valuable information provided will be used to identify priorities for improving services and resources available for families and youth with intellectual disabilities.

Surveys will be conducted by Wilder Research through June 2018.



#### Agency Newsletters and Facebook for Learning Disabilities

[Our Agency] is helping The Peter and Elizabeth C. Tower Foundation recruit families to complete a survey in order to better understand the needs and experience of families and youth with learning disabilities.

If you have a family member with intellectual disabilities up to age 26, live in Barnstable, Dukes, or Nantucket Counties, and are interested in completing a 20-minute phone survey, please register at <http://towerfdn.link/surveysignup> Youth with learning disabilities age 14 to 26 are also invited to participate in a separate survey about their experiences. Anyone completing the survey will receive a \$20 gift card to Amazon, Target, or Walmart.

The valuable information provided will be used to identify priorities for improving services and resources available for families and youth with intellectual disabilities.

Surveys will be conducted by Wilder Research through June 2018.

**THANK YOU!!**

# Why do we want to know about Intellectual Disabilities and Learning Disabilities?

## FREQUENTLY ASKED QUESTIONS

### ✓ Why is this survey being done?

The Peter and Elizabeth C. Tower Foundation wants to understand the experiences families have when seeking services for youth with intellectual disabilities or learning disabilities. The Foundation and the organizations it supports will use this information to help improve services provided to families and youth with intellectual disabilities or learning disabilities. The Tower Foundation has contracted with Wilder Research to complete these interviews.

### ✓ Do I get anything for participating?

In appreciation of your time, we are offering a \$20 gift card to Amazon, Target, or Walmart. The gift card will be emailed (Amazon) or mailed (Target or Walmart) after the interview has been completed. Completing the survey will NOT qualify you for additional benefits or services from specific providers or the Tower Foundation.

### ✓ Who can participate?

If you have a youth up to age 26 who has an intellectual disability or learning disability and you live in Barnstable, Dukes, or Nantucket Counties, you are eligible to complete the survey. Youth with learning disabilities age 14-26 are also invited to participate in a separate survey about their experiences.

### ✓ What are you going to ask me about?

The survey has questions about experiences families and youth have had in seeking services for an intellectual disabilities or learning disabilities. The questions address types of disabilities, experience accessing supports, and experience with education and employment situations.

An **intellectual disability** is characterized by significant limitations both in mental capacity, such as learning, reasoning, and problem solving, and in adaptive behavior such as conceptual skills, social skills, and daily living skills. The Tower Foundation also includes the autism spectrum under this definition.

### ✓ How can I take the survey?

The surveys will be completed by an interviewer from Wilder Research. Please register for the survey at <http://towerfdn.link/surveysignup>. Once registered, families will be contacted by phone by an interviewer. If you do not have access to a computer to register online, please call **1-888-328-2972** and ask for **Terry Franklin** to register and complete the survey over the phone. Surveys will start in March 2018. The interview will take about 15 minutes.

A **learning disability** is a condition that interferes with the ability to learn. It is a neurological disorder that affects the ability of the brain to process, store, and respond to information.

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✓ **Do I have to participate?**

The study is completely voluntary. Participation (or lack thereof) will not affect your relationship with the Foundation or any other entities. Participation in the study also will not directly connect you to benefits or services for which you may be eligible.

✓ **Will my name be used?**

We value confidentiality and data privacy. The interviewer will ask for your contact information solely for the purpose of sending you a gift card and inviting you to participate in the next survey in 2020. This information is kept separate from your responses and will not be used in any reports. Your responses will be combined with the responses of other families and youth in your area.

✓ **Who will see my data?**

Only the researchers at Wilder Research will be able to see your confidential responses. We will ask for your contact information solely for the purpose of sending you a gift card and inviting you to participate in the next survey in 2020. This information is kept separate from your responses. Combined data will be shared in a report with the Tower Foundation, organizations providing services, and participants.

✓ **Who should I contact if I have questions about the survey?**

If you have any further questions, you can contact Don Matteson, Chief Program Officer at the Tower Foundation, at [dwm@thetowerfoundation.org](mailto:dwm@thetowerfoundation.org) or **716-689-0370 x207**. If you are having technical difficulties with the online registration, please call **1-888-328-2972** and ask for **Terry Franklin**.

**THANK YOU!!**

Finally, thank you so much for participating in this effort!  
A summary of the survey results will be shared with all respondents.  
We truly could not do this study without you!



# If you have a family member with **INTELLECTUAL DISABILITIES** or **LEARNING DISABILITIES,** we want to hear from you!

We invite you to participate in a brief survey to help improve support for families and youth (up to age 26) with intellectual disabilities or learning disabilities.

The survey is being funded by The Peter and Elizabeth C. Tower Foundation. The Tower family, like so many others, has members who have intellectual disabilities or learning disabilities. Because of this, the Tower Foundation funds organizations in Barnstable, Dukes, or Niagara Counties working to better meet the needs of young people and their families affected by these issues.

Results of the survey will be used by the Foundation and organizations in your area that serve youth and families with intellectual disabilities or learning disabilities and to identify priorities and improve services. The results will also be shared with participants.

If you sign up to participate in the survey, you may be contacted later this spring to complete a 20-minute phone interview. The information you share will be kept confidential. You will receive a \$20 gift card as a thank you for your time and information. You will also be invited to participate in a follow-up interview conducted approximately every two years.

To sign up to be considered for the study, please go to <http://towerfdn.link/surveysignup>

 20 minutes  
 \$20 gift card

**Help families like yours!**



For this survey, we are using the following definitions:

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