



Survey of People with Disabilities & Their Caregivers

This survey is being conducted by the Lehigh Valley Research Consortium (LVRC)—a group of researchers from colleges and universities in Lehigh and Northampton Counties, in conjunction with Good Shepherd Rehabilitation Network.

The purpose of the survey is to gather feedback from people with disabilities and their caregivers. Persons with disabilities of all kinds are encouraged to participate.

Your responses will be used to help build and empower a long-term Partnership for a Disability Friendly Community.

Please **DO NOT** put your name anywhere on this survey. We have provided a postage-paid return envelope for you to return the survey. **Your answers will remain completely anonymous and confidential.** There is no way for us to connect your responses and answers to you personally; your identity will remain unknown to the researchers. There are no risks or costs associated with completing a survey. This survey is intended to be completed by adults, ages 18 years and older. Your completion and submission of this survey indicates that you are at least 18 and voluntarily consent to participating. **Average time to complete this survey is 30 to 40 minutes.**

Copies of this survey are also available in Spanish, large print, and Braille. For copies or questions, please contact:

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You can also complete this survey on-line at: http://lehighvalleyresearch.org/disability_study

*Thank you for sharing your insight
and for helping us to make the Lehigh Valley more disability friendly!*



Part 1. Disability

1. Which of the following best describes you?

- I am a person with a disability completing this survey on my own behalf.
- I am a person with a disability completing this survey with the assistance of someone else.
- I am a parent or other family member of an adult person with a disability.
- I am a parent of a minor child under the age of 18 with a disability.
- I am a paid caregiver of an adult person with a disability.
- I am a paid caregiver of a child with a disability.

2. Please describe, in your own words, the health conditions, impairments, disabilities, and/or functional limitations that restrict or prevent you (or your child or the person you care for) from taking part in the normal life of your community on an equal level with others?

3. Which of the following categories best describes this health condition, impairment, disability or functional limitation? **Please check all that apply.**

- Mobility or physical disability or handicap limiting use of the legs, arms, or hands.
- Mental, psychological, psychiatric, or emotional disability (e.g., bipolar disorder, schizophrenia, depression)
- Neurological disability (e.g., epilepsy)
- Visual disability, blindness, severe vision impairment, color blind
- Auditory disability, deafness, or severe hearing impairment
- Speech disability, oral-motor disability, speech impairment, or muteness
- Learning or cognitive disability (e.g., dyslexia, learning disabled)
- Chronic illness or other health-related disability (e.g., diabetes, HIV/AIDS, respiratory disease, lupus)
- Traumatic brain injury
- Other: _____

4. Would you describe this disability (or disabilities) as:

- Mild Moderate Somewhat Severe Very Severe

5. Were you (or was your child or the person you care for) born with this disability?

- YES NO. If no, at what age was the disability diagnosed, or did the disability begin? _____ (write in age)

6. Which of the following major life activities are limited by this health condition, impairment, disability, or functional limitation? **Please check all that apply.**

- | | |
|---|---|
| <input type="checkbox"/> Self care, such as bathing, dressing, or feeding? | <input type="checkbox"/> Self-direction, such as making important decisions concerning health care, education, or career? |
| <input type="checkbox"/> Communicating, such as talking with or listening to other people? | <input type="checkbox"/> Living independently, such as preparing meals, shopping for groceries and personal items, and doing housework? |
| <input type="checkbox"/> Learning any new skills or activities? | <input type="checkbox"/> Going outside the home alone to shop or visit a doctor? |
| <input type="checkbox"/> Remembering and/or concentrating? | <input type="checkbox"/> Managing finances, such as keeping track of your money and paying bills? |
| <input type="checkbox"/> Interacting socially, such as developing friendships? | <input type="checkbox"/> Other, please explain: _____ |
| <input type="checkbox"/> Working at a job or business for employment? | |
| <input type="checkbox"/> Mobility, such as bending, walking, climbing stairs, or carrying something weighing approximately 10 pounds? | |

7. Do you (or does your child or the person you care for) ever require personal assistance, or get help from someone, with basic needs such as getting dressed, preparing meals, or bathing?

- NO
- YES. If yes, who generally provides this care? **Please check all that apply.**
- | | |
|--|--|
| <input type="checkbox"/> Family members or friends | <input type="checkbox"/> Others paid for providing this help |
| <input type="checkbox"/> Home health aides (paid) | <input type="checkbox"/> Someone else; please explain: _____ |

8. Has there been a time in the past 6 months when you (or your child or the person you care for) have needed help from someone with basic needs such as getting dressed, preparing meals, or bathing, but have not been able to get it?

- NO
- YES. If yes, *how many times in the past 6 months* were you unable to get the help you needed? _____

Part 2. Health & Health Care. *If you are a parent or caregiver, please answer questions from the point of view of the person for whom you provide care.*

9. In general, would you say your health overall (including physical and mental health) is

- | | | |
|------------------------------------|-------------------------------|-------------------------------------|
| <input type="checkbox"/> Excellent | <input type="checkbox"/> Good | <input type="checkbox"/> Don't Know |
| <input type="checkbox"/> Very Good | <input type="checkbox"/> Fair | |

10. Please indicate which of the following sources of health insurance you are covered by. **Please check all that apply.**

- | | |
|--|--|
| <input type="checkbox"/> Health insurance through my work or union | <input type="checkbox"/> Medicaid, Medical Assistance, or a Pennsylvania state program that pays health care for people with low incomes |
| <input type="checkbox"/> Health insurance through somebody else's work or union | <input type="checkbox"/> Health insurance from some other source |
| <input type="checkbox"/> Health insurance bought directly by me or another member of my family | <input type="checkbox"/> No health insurance |
| <input type="checkbox"/> Medicare (the government plan that pays health-care bills for people ages 65 and older and for some young people with disabilities) | <input type="checkbox"/> Don't know |
| | <input type="checkbox"/> Other; <i>please explain</i> :
_____ |

11. If you *do not* have health insurance, what is the primary reason why?

- | | |
|--|---|
| <input type="checkbox"/> It's too expensive. | <input type="checkbox"/> My employer does not offer it. |
| <input type="checkbox"/> I was refused coverage due to poor health, illness, age, or some other reason | <input type="checkbox"/> I am not eligible for employer coverage. |
| <input type="checkbox"/> I don't need it. | <input type="checkbox"/> Don't know |
| <input type="checkbox"/> I don't know how to get it. | <input type="checkbox"/> Other reason; <i>please explain</i> :
_____ |

12. In the past year, was there a time when you needed medical care but did not get it?

- YES; If yes, please explain the medical care you needed, but did not get:

- NO

13. If there was a time in the past year when you needed medical care but did not get it, what was the **main** reason? **Please check one.**

- | | | |
|---|---|--|
| <input type="checkbox"/> Couldn't get an appointment. | <input type="checkbox"/> It cost too much. | <input type="checkbox"/> My health problem went away. |
| <input type="checkbox"/> Couldn't find a doctor who speaks my language. | <input type="checkbox"/> Too difficult to get to the doctor's office. | <input type="checkbox"/> Couldn't find a doctor who understands my condition and is willing to treat it. |
| <input type="checkbox"/> Didn't know a good doctor/clinic to go to. | <input type="checkbox"/> Not covered by insurance. | <input type="checkbox"/> Couldn't find a doctor who is willing to work with a sign-language interpreter. |
| <input type="checkbox"/> Couldn't find a doctor that would accept my insurance. | <input type="checkbox"/> Too much paperwork. | <input type="checkbox"/> Didn't want to go. |
| | <input type="checkbox"/> Too nervous or afraid. | <input type="checkbox"/> Other: _____ |
| | <input type="checkbox"/> Difficulties/disagreements with my doctor. | |

For each of the following, please indicate how satisfied you are (if you are a parent or caregiver, please answer questions **from the point of view of the person for whom you provide care**):

	Very Satisfied	Satisfied	Dissatisfied	Very Dissatisfied	Not applicable
14. The availability of care management services when I need them.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. My access to medical services and health care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. My access to dental services.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. My access to mental health services.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. My access to reproductive and sexual health services.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. My access to rehabilitative services.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. My access to alternative health practices.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. My access to affordable and adequate health insurance.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. The affordability of my prescriptions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. The quality of health care that I receive.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. The quality of care that I receive from my caregiver.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. The quality of my communication with my doctor.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. My access to information about fitness and exercise relevant to my health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. My knowledge and awareness of health services and resources that are available to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

28. How frequently do you participate in exercise or fitness activities?

- Daily
 Once a week
 Never
 Two to four times a week
 Rarely

29. How often do you smoke or use other tobacco products?

- Daily
 Once a week
 Never
 Two to four times a week
 Rarely

30. How frequently do you consume more than two drinks of alcohol?

- Daily
 Once a week
 Never
 Two to four times a week
 Rarely

Part 3. Transportation. *If you are a parent or caregiver, please answer questions from the point of view of the person for whom you provide care.*

31. How often do you need transportation but are unable to obtain it?

- A few times per day
 Never
 Daily
 A few times per week
 Once a week
 Several times per month

32. Is inadequate transportation a major problem, minor problem, or not a problem for you?

- Major problem
 Not a problem
 Minor problem
 Don't know

33. Is the availability of handicap parking a major problem, minor problem, or not a problem for you?

- Major problem
 Not a problem
 Minor problem
 Don't know

For the following, please indicate how much you agree or disagree with each statement:

	Strongly Agree	Agree	Disagree	Strongly Disagree	N/A
34. When I use public transportation (such as a bus) I feel as if there are convenient schedules to easily make a round trip to the doctor, the store, or to some social function.					
35. I feel as though a taxi cab may not stop to pick me up because I have a disability.					
36. It is difficult for me to use our public transportation system due to my disability.					
37. I have a variety of public transportation options available to make traveling convenient.					

Part 4. Employment. *If you are a parent or caregiver, please answer questions from the point of view of the person for whom you provide care.*

38. What is your current employment status? **Check more than one if applicable.**

- | | |
|--|--|
| <input type="checkbox"/> Working fulltime | <input type="checkbox"/> Looking for work |
| <input type="checkbox"/> Working part time | <input type="checkbox"/> Full time student |
| <input type="checkbox"/> Retired and not working | <input type="checkbox"/> Full time homemaker |
| <input type="checkbox"/> Unemployed | <input type="checkbox"/> Other; _____ |

39. If you are unemployed, what is the **primary** reason why?

- | | |
|---|--|
| <input type="checkbox"/> Unable to work due to health problem or disability | <input type="checkbox"/> Might lose income assistance or health benefits if I work |
| <input type="checkbox"/> Cannot find a job that accommodates my disability | <input type="checkbox"/> Cannot find a job based on my skills |
| <input type="checkbox"/> I prefer not to work | <input type="checkbox"/> Other reason; <i>please explain:</i>
_____ |

40. If you are currently working, or volunteering, is your workplace easily accessible to you?

- YES
- NO. If no, please explain how your work place is NOT accessible: _____
- _____

41. What kind of work (or volunteering) do you do? _____

42. In what municipality/town do you work and/or volunteer? _____

For each of the following, please indicated how much you agree or disagree with the statement (if you are a parent or caregiver, please answer questions from the point of view of the person for whom you provide care):

	Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
43. I can set and pursue goals related to my employment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
44. I know how to find job training when I want it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
45. I am engaged in meaningful work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
46. I am satisfied with my salary.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
47. I am satisfied with my work hours.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
48. I am satisfied with my work benefits.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
49. I am able to obtain assistance in finding and keeping employment when I need it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Part 4. Housing. *If you are a parent or caregiver, please answer questions from the point of view of the person for whom you provide care.*

50. What type of housing do you have?

- Private housing that I own or partially own
- Private apartment or home that I rent
- Group home
- Residential or long term care
- Other: _____

51. Does your current housing meet your needs?

- YES
- NO. If no, please explain how your current housing does not meet your needs

52. If your current housing does not meet your needs, what is preventing you from obtaining more adequate housing? **Please check all that apply.**

- Adequate housing is too expensive.
- I don't know where to look for adequate housing.
- I've looked but been unable to find adequate housing.
- Adequate housing would force me to move; I don't want to move.
- There is a waiting list for the housing that I want.
- Other reason; *please explain:* _____

For the following, please indicate how much you agree or disagree with each statement:

	Strongly Agree	Agree	Disagree	Strongly Disagree
53. I am able to choose where I want to live.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
54. I am able to choose with whom I want to live.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
55. My home is safe.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
56. My housing arrangements are affordable.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
57. I am happy with the location of my home.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
58. My home allows me to live independently.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
59. My neighbors treat me with respect and include me in neighborhood activities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

For the following, please indicate how worried you are about each situation:

	Not at all worried	Somewhat worried	Very Worried	Extremely worried
60. Having to go into a nursing home.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
61. Not having long-term housing plans.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
62. Being able to afford long-term housing.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
63. Not being able to care for myself.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
64. Being a burden on my family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
65. Needing to get help with basic needs, like getting dressed, preparing meals, or bathing.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
66. Becoming disconnected from my friends and family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
67. Losing my health insurance.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
68. Losing my disability benefits.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Part 5. Technology & Assistive Devices. If you are a parent or caregiver, please answer questions *from the point of view of the person for whom you provide care.*

69. Is there any special equipment or type of assistive devices that you currently *need but do not have*?

- NO
- YES; if Yes, what type of special equipment or assistive device is that? _____
- Don't Know

70. What kind of special equipment or assistive devices *do you need but do not have*? **Please check all that apply.**

- | | | |
|--|--|---|
| <input type="checkbox"/> Motorized wheel chair/cart/scooter | <input type="checkbox"/> Lifts/chairs/other mechanized assists | <input type="checkbox"/> Hearing aid |
| <input type="checkbox"/> Walker/cane | <input type="checkbox"/> Railing/bar/other non-mechanized assist | <input type="checkbox"/> Computer/software |
| <input type="checkbox"/> Wheelchair | <input type="checkbox"/> Knee/ankle braces | <input type="checkbox"/> Communication device |
| <input type="checkbox"/> Lift/carrier to handle wheelchairs/scooters in cars | <input type="checkbox"/> Prosthetic | <input type="checkbox"/> Vision assistance |
| <input type="checkbox"/> Vehicle big enough to handle wheelchair/scooter | <input type="checkbox"/> Adaptive driving technology | <input type="checkbox"/> Oxygen/other breathing assist device |
| <input type="checkbox"/> Ramp | <input type="checkbox"/> Orthotics | <input type="checkbox"/> Exercise equipment |
| | <input type="checkbox"/> Hearing assistance | <input type="checkbox"/> Adjustable bed/hospital bed |
| | | <input type="checkbox"/> Don't know |
| | | <input type="checkbox"/> Other; please explain _____ |

71. Thinking about the equipment and devices you need but do not have, what explains your lack of access or ownership of them? **Please check all that apply.**

- | | |
|--|---|
| <input type="checkbox"/> I don't know where to get it. | <input type="checkbox"/> I don't know how to use it. |
| <input type="checkbox"/> I can't afford it. | <input type="checkbox"/> I am not comfortable using it. |
| <input type="checkbox"/> I have it, but it's broken/doesn't work. | <input type="checkbox"/> I used it for a while, but it didn't really help me. |
| <input type="checkbox"/> Insurance declined it. | <input type="checkbox"/> I never tried to get it. |
| <input type="checkbox"/> I have one on order, but it hasn't arrived yet. | <input type="checkbox"/> My doctor says I don't need it. |
| <input type="checkbox"/> I am on a waiting list for it. | <input type="checkbox"/> Don't know. |
| | <input type="checkbox"/> Other; please explain _____ |

Part 6. Community and Political Participation. *If you are a parent or caregiver, please answer questions from the point of view of the person for whom you provide care..*

For the following, please indicate how frequently you participate in each activity in an AVERAGE MONTH:

	More than 4 times a month	2 to 4 times a month	Once a month	Less than once a month	Never
72. Socialized with close friends, relatives, or neighbors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
73. Gone to restaurants, out to eat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
74. Gone to church, synagogue, or another place of worship	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
75. Gone to a show, movie, sports event, club meeting, class or other group event	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

For following, please indicate how often you have had these feelings in the PAST MONTH:

	Very Often	Often	Somewhat Often	Not Often	Never
76. Felt there were people you were close to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
77. Felt your daily life has been full of things that were interesting to you	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
78. Felt loved and wanted	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
79. Felt isolated from others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
80. Experienced your physical health or emotional problems interfering with your social activities (like visiting with friends, relatives, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

81. What are the PRIMARY ways that you participate in your community? Please explain in your own words.

82. In what ways would you like to be MORE involved in your community? Please explain in your own words.

83. . Did you vote in the 2008 Presidential Election?

YES

NO

Not Sure

84. If you did not vote in the 2008 Presidential Election, what is the reason why?

Just didn't vote

I was ineligible to vote.

I was not registered to vote.

I need an absentee ballot and didn't get one.

I got an absentee ballot but didn't send it in.

My polling place was inaccessible.

The candidates did not address issues that I care about.

I did not like the candidates.

I was unable to understand the issues.

Other: _____

Part 7. Perceptions & Attitudes. *If you are a parent or caregiver, please answer questions from the point of view of the person for whom you provide care.*

For the following statements please indicate how much you agree or disagree with each statement:

	Strongly Agree	Agree	Disagree	Strongly Disagree
85. Most people would willingly accept a person with a disability as a close friend.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
86. Most people believe that a person who has a disability is just as intelligent as the average person.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
87. Most people believe that a person with a disability is just as trustworthy as the average citizen.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
88. Most people think less of a person who has a disability.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
89. Most people in my community would treat someone with a disability just as they would treat an average person.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Part 8. Information & Referral. *If you are a parent or caregiver, please answer questions from the point of view of the person for whom you provide care.*

For the following, please indicate how strongly you agree or disagree with each statement:

	Strongly Agree	Agree	Disagree	Strongly Disagree
90. I have enough information to make good choices about my housing.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
91. I get enough support in planning for the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
92. I know where to get information about disability services.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
93. I know how to obtain transportation when I need it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
94. I know how to contact my medical professional when I need him/her.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
95. I know whether or not I am eligible for disability benefits.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
96. I know how to find out if I am eligible for disability benefits.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
97. I know how to get involved in my community when I want to.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Part 9. Emergency Preparedness. *If you are a parent or caregiver, please answer questions from the point of view of the person for whom you provide care.*

98. Are you able to evacuate your residence independently if an evacuation order is issued by the health department or government?

YES

NO

Not Sure

For the following, please indicate whether you have each of the following preparations:

	YES	NO	Not Sure
99. An emergency contact list.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
100. An emergency supply kit containing information about my medical history and medications I am taking.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
101. A system of updating my emergency contact list and emergency supply kit every 6 months.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
102. A plan with family members/friends/neighbors so that we can contact each other in the event of an emergency.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
103. A spare key to my house/room at my neighbor's/family's/friend's house for use in the event of an emergency.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Part 10. Opportunity & Discrimination. If you are a parent or caregiver, please answer questions *from the point of view of the person for whom you provide care.*

For each of the following, please indicate how often you have

	Very Often	Somewhat Often	Often	Not Often	Never
104. Been refused a job promotion because of my disability.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
105. Been denied a workplace accommodation because of my disability.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
106. Been paid less than other workers in similar jobs with similar skills because of my disability.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
107. Been denied work-related benefits (other than a workplace accommodation) because of my disability.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
108. Been denied entrance into an educational program because of my disability.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
109. Had trouble with access to educational buildings.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
110. Encountered difficulty trying to get an accommodated schedule at school or work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Part 11. Education. If you are a parent or caregiver, please answer questions *from the point of view of the person for whom you provide care.*

111. What is the highest level of education that you have completed?

- | | |
|---|---|
| <input type="checkbox"/> Some high school | <input type="checkbox"/> 2 year college degree (Associate's degree) |
| <input type="checkbox"/> High school degree | <input type="checkbox"/> 4 year college degree (Bachelor's degree) |
| <input type="checkbox"/> Some college | <input type="checkbox"/> Post-college or graduate degree |

112. Are you currently in school or pursuing education?

- NO YES. If yes, what kind of schooling or education are you pursuing (e.g., college credit, technical training)?

113. What school district do you live in? _____

If you are a CURRENT STUDENT, or a caregiver or parent of a current student, please complete the following section. If not, please skip to next section.

School Resources: *Please indicate how strongly you agree or disagree with the statement. In thinking about each question, consider the school that you/your dependent currently attend and check the appropriate box.*

<i>In my school...</i>	Strongly Agree	Agree	Disagree	Strongly Disagree
114. There are enough tutors for students with special needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
115. There are enough counselors for students with special needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
116. The administration makes every effort to understand the needs of those with disabilities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
117. There is a strong effort to implement programs that foster awareness of disabilities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
118. There is a strong effort to obtain assistive technology devices for students who need them.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
119. The administration and teachers are knowledgeable about referral services or community programs for the disabled.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
120. The administration and teachers are helpful in providing alternative assignments and access materials.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
121. There are enough opportunities for students with disabilities to be involved in extracurricular activities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
122. There are enough programs that focus on job placement.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
123. There is enough support from the school towards planning for the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Experiences of Discrimination: <i>Please indicate how often you/your dependent, has dealt with these experiences because of being disabled.</i>				
124. Received a lower grade.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
125. Received less support from teachers.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
126. Been denied acceptance into an educational program.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
127. Been denied access to an accommodation program.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
128. Been bothered by teachers or peers for having an accommodation plan.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Part 12. Individual Information. *If you are a parent or caregiver, please answer questions from the point of view of the person for whom you provide care.*

129. In what year were you born? _____

130. Are you

MALE

FEMALE

131. Which of the following **best** describes your race/ethnicity?

White/Caucasian (non-Hispanic)

Asian American

Black/African American

Other, *please specify:* _____

Latino/Hispanic

132. What is your first, or native, language (e.g., English, Spanish, Vietnamese)? _____

133. What is your home zip code? _____

134. What municipality/town do you live in? _____

135. Please indicate whether you are

Married

Widowed

Single/never been married

Partnered/Long-term relationship

Divorced/separated

136. How many children do you have? _____ (write in the number of children)

137. What was your FAMILY income before taxes in 2007? Please include income from all sources, including yourself and all other persons living in your household.

Less than \$14,999

Between \$60,000 and \$99,999

Between \$15,000 and \$24,999

More than \$100,000

Between \$25,000 and \$39,999

Don't know

Between \$40,000 and \$59,999

138. What was your PERSONAL income before taxes in 2007, excluding anyone but yourself?

Less than \$14,999

Between \$60,000 and \$99,999

Between \$15,000 and \$24,999

More than \$100,000

Between \$25,000 and \$39,999

Don't know

Between \$40,000 and \$59,999

139. Which of the following sources of income support your personal total income? **Please check all that apply.**

- | | |
|--|--|
| <input type="checkbox"/> Employment income (wages and earnings from paid employment) | <input type="checkbox"/> Workers' Compensation |
| <input type="checkbox"/> Social Security Disability Insurance (SSDI) | <input type="checkbox"/> Pension Program |
| <input type="checkbox"/> Private disability insurance | <input type="checkbox"/> Social Security Income |
| <input type="checkbox"/> Supplemental Security Income (SSI) | <input type="checkbox"/> Other. Please describe: _____ |
| | <input type="checkbox"/> Don't know |

Part 13. Living Fully & Independently. *If you are a parent or caregiver, please answer questions from the point of view of the person for whom you provide care.*

140. Are there other things (not covered in this survey) that you would like to do in your life but are prevented from doing or are unable to do?

141. What are the primary obstacles preventing you from doing what you would like to do in your life?

142. What would be necessary to enable you to do more fully the things you would like to do in your life?

If you are a CAREGIVER or PARENT of a person with a disability please complete the following section from your OWN POINT OF VIEW.

*If you are not a caregiver or parent, you have finished the survey. THANK YOU!!!
Please return survey in pre-paid envelope provided.*

	Major Problem	Minor Problem	Not a Problem	N/A
150. Having enough money to pay for care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
151. Understanding government programs such as Medicare or SSI.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
152. Finding out about legal options.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
153. Getting cooperation and assistance from other family members.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
154. Dealing with break downs in care arrangements.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
155. Getting information about the illness/disability of the person I care for.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
156. Ensuring the safety of the person I care for.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
157. Identifying available transportation options.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
158. Finding culturally-sensitive resources.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
159. Communicating with professional resource providers.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
160. Doing end-of-life planning.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
161. Balancing other family responsibilities—e.g., children, marriage, housework.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
162. Dealing with dangerous, unwanted, or difficult behaviors of the person that I care for.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
163. Involvement in decisions about the medical treatment of the person I care for.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
164. Modifying my home to meet care requirements.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
165. Adjusting my work schedule, meeting my work responsibilities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
166. Meeting my personal needs such as personal time, exercise, etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

For each of the following, please indicate how often you experience these feelings as a CAREGIVER or PARENT of a person with a disability.

	Not at All	Some	Quite a Bit	A Great Deal
167. Physical strain/fatigue.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
168. Financial strain.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
169. Emotional upset, guilt.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
170. Interference with work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
171. Reluctance to ask for help.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
172. Feelings of being underappreciated.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

To what extent do you agree/disagree with the following statements:

	Strongly Agree	Agree	Disagree	Strongly Disagree
173. I have more care giving responsibilities than I can handle comfortably.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
174. I don't have enough time for myself due to my caregiving responsibilities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
175. I cannot get a restful night's sleep.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
176. I have a good balance between work, family, and personal relationships.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
177. I am doing a good job of meeting work, family, and personal responsibilities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
178. I feel in control of the important things in my life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

179. What other issues, not addressed above, concern you when it comes to your role in providing care or a person with a disability?

180. Are you

Female

Male

181. What year were you born? _____

182. What is your home zip code? _____

183. What municipality/town do you live in? _____

184. Which of the following **best** describes your race/ethnicity?

White/Caucasian (non-Hispanic)

Asian American

Black/African American

Other; *please specify:*

Latino/Hispanic

185. Please indicate whether you are

Married

Widowed

Single/never been married

Partnered/Long-term relationship

Divorced/separated

186. What was your FAMILY income before taxes in 2007? Please include income from all sources, including yourself and all other persons living in your household.

- | | |
|--|--|
| <input type="checkbox"/> Less than \$14,999 | <input type="checkbox"/> Between \$60,000 and \$99,999 |
| <input type="checkbox"/> Between \$15,000 and \$24,999 | <input type="checkbox"/> More than \$100,000 |
| <input type="checkbox"/> Between \$25,000 and \$39,999 | <input type="checkbox"/> Don't know |
| <input type="checkbox"/> Between \$40,000 and \$59,999 | |

187. What was your PERSONAL income before taxes in 2007, excluding anyone but yourself?

- | | |
|--|--|
| <input type="checkbox"/> Less than \$14,999 | <input type="checkbox"/> Between \$60,000 and \$99,999 |
| <input type="checkbox"/> Between \$15,000 and \$24,999 | <input type="checkbox"/> More than \$100,000 |
| <input type="checkbox"/> Between \$25,000 and \$39,999 | <input type="checkbox"/> Don't know |
| <input type="checkbox"/> Between \$40,000 and \$59,999 | |

188. What is the highest level of education that you have completed?

- | | |
|--|---|
| <input type="checkbox"/> Some high school | <input type="checkbox"/> 4 year college degree
(Bachelor's degree) |
| <input type="checkbox"/> High school degree | <input type="checkbox"/> Post-college or graduate degree |
| <input type="checkbox"/> Some college | |
| <input type="checkbox"/> 2 year college degree
(Associate's degree) | |

RETURN SURVEY IN PRE-PAID ENVELOPE PROVIDED

*Thank you for completing this survey!
If you are interested in participating in a focus group,
please fill out and return the enclosed postcard separately.*

