FAMILY/GUARDIAN SURVEY 2019-20

Survey on Services & Supports for Adults with Intellectual/Developmental Disabilities Living Outside of the Family Home in New Hampshire

Thank you for taking the time to complete this survey. Your opinions will help the state of New Hampshire improve services and supports for people with intellectual/developmental disabilities and their families. And your responses will allow us to compare family outcomes and satisfaction across states.

To see results from past years’ surveys, please visit www.NationalCoreIndicators.org and go to Resources → Reports → National Family Survey Final Reports.

This survey takes about 15 minutes to complete.

Your responses are confidential. No one will know your answers—not case managers, providers, support workers, or any others. Your answers will not affect you, your family member, or the services your family receives.

NOTE: If more than one person is receiving services, please answer these questions about the person named on the address label.

This survey is for family members or non-family guardians. To simplify, we use the term ‘your family member’ to refer to the person named on the address label. If you come to a question that you feel uncomfortable answering, skip it. For us to get complete information, however, it’s very important that you try to answer each question as accurately as you can.

When you’ve completed the survey, please return it in the enclosed pre-addressed, pre-stamped envelope. Please try to return it as soon as possible.

If you would like to receive help reading or understanding this survey, or if you need an interpreter, please call: Ellen Barry at 603-459-1796.

THANK YOU
Part 1: Information about your family

Please answer the following questions about your family member with a disability who is receiving services.

A. Does your family member with a disability live at home with you?
   - 1. No
   - 2. Yes

   **Note: If your answer is “yes,” please stop here and return the survey.**

B. Where does your family member live?
   - 1. Specialized facility for people with intellectual disabilities (ICF, state-run or other institutional setting)
   - 2. Group home or agency-operated apartment
   - 3. Independent home or apartment (not operated by an agency; family member may be living with roommates)
   - 4. Adult foster care/host family home (round-the-clock services provided in a single-family residence where only one person with a disability lives with a person or family who furnishes services—sometimes called shared living)
   - 5. Nursing home
   - 6. Homeless
   - 7. Other: ________________________________

C. Does your family member live in an urban or rural area?
   - 1. Urban or suburban (in or near a city or large town)
   - 2. Rural (outside of a city or town)
   - 99. Don’t know

D. How old is your family member with a disability?
   _____ years

E. What is the gender of your family member?
   - 1. Male
   - 2. Female
DOES NOT LIVE AT HOME WITH A FAMILY MEMBER

F. Has your family member been diagnosed with any of the conditions listed below? (Check all that apply.)
   - 1. Intellectual disability
   - 2. Mood illness/psychiatric diagnosis (for example, depression, anxiety, psychotic disorder)
   - 3. Autism spectrum disorder (for example, autism, Asperger syndrome, pervasive developmental disorder)
   - 4. Cerebral palsy
   - 5. Limited or no vision – legally blind
   - 6. Hearing loss – severe or profound
   - 7. Brain injury
   - 8. Seizure disorder and/or neurological problem
   - 9. Chemical dependency
   - 10. Down syndrome
   - 11. Prader-Willi syndrome
   - 12. Fetal alcohol spectrum disorder (FASD)
   - 13. Other disabilities not listed: ______________________________________________________

G. Has your family member been diagnosed with any of the health conditions listed below? (Check all that apply.)
   - 1. Cardiovascular disease (for example, coronary heart disease, angina)
   - 2. Diabetes (including Type 1 and Type 2)
   - 3. Cancer (for example, breast, prostate, colon, lung)
   - 4. High blood pressure
   - 5. High cholesterol
   - 6. Dysphagia (difficulty swallowing)
   - 7. Pressure ulcers (bed sores)
   - 8. Alzheimer’s disease or other dementia
   - 9. Oral health or dental problems that cause ongoing pain or difficulty eating
   - 10. Sleep apnea
   - 11. Other: ______________________________________________________

H. What is your family member’s race and ethnicity? (Check all that apply.)
   - 1. American Indian or Alaska Native
   - 2. Asian (Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, Other Asian)
   - 3. Black or African-American
   - 4. Pacific Islander (Native Hawaiian, Guamanian or Chamorro, Samoan, Other Pacific Islander)
   - 5. White
   - 6. Hispanic/Latino (Mexican, Mexican-American, Chicano, Puerto Rican, Cuban, Other Spanish/Hispanic/Latino)
   - 7. Other: ______________________________________________________
I. What is your family member’s preferred means of communication? (Check ONE – the most frequently used.)

- 1. Spoken
- 2. Gestures/body language
- 3. Sign language or finger spelling
- 4. Communication aid/device
- 5. Other: ________________________________

J. Does your family member have a legal/court-appointed guardian or conservator? (A guardian/conservator is a person who is legally granted authority to make decisions on behalf of an individual.) (Check ONE.)

- 1. No, does not have a guardian/conservator (legally competent or presumed competent)
- 2. Yes, limited guardianship (a person has authority over certain decisions, such as entering into contracts, medical procedures, etc.)
- 3. Yes, full guardianship
- 4. Yes, has a guardian but not sure whether it’s full or limited
- 99. Don’t know

K. If your family member has a legal/court-appointed guardian/conservator, what’s the guardian/conservator’s relationship to your family member? (Check ONE.)

- 98. Does not apply – Person does not have a legal/court-appointed guardian/conservator
- 2. Family
- 3. Friend
- 4. Employee of state or guardianship agency
- 5. Other: ________________________________

L. What is your family member’s highest completed level of education?

- 1. Did not complete high school – Not currently in school
- 2. Currently enrolled in high school
- 3. High school certificate (NOT a high school diploma/GED)
- 4. High school diploma/GED
- 5. Vocational school or certificate program
- 6. Some college
- 7. College degree or higher
M. In the past two weeks, has your family member participated in any of the following activities? Select ONE response for EACH item.

M.1. Paid individual job in the community – Works at an individual job in a local business alongside peers who do not have disabilities. Job is part of the typical labor market (for example, competitive employment).
   - 1. No
   - 2. Yes
   - 99. Don’t know

M.2. Paid small group job in a community-based setting – Works in an integrated setting, as part of a group of not more than 8 people with disabilities (for example, enclave, work crew).
   - 1. No
   - 2. Yes
   - 99. Don’t know

M.3. Unpaid activity in the community – For example, volunteering, skills training, and staff-supported community connections
   - 1. No
   - 2. Yes
   - 99. Don’t know

M.4. Paid work in a community business that primarily hires people with disabilities – Works in a setting where s/he interacts with the non-disabled population; this is NOT in a traditional sheltered workshop and NOT enclave. Some examples include bakeries, car washes, thrift stores, etc.
   - 1. No
   - 2. Yes
   - 99. Don’t know

M.5 Paid work performed in a facility-based setting – Works at a location developed specifically to provide work activity exclusively for people with disabilities; may be paid sub-minimum wage. Examples include traditional sheltered workshops or work activity centers.
   - 1. No
   - 2. Yes
   - 99. Don’t know
M.6. Unpaid activity in a facility-based setting – Examples include day habilitation, senior programs, or drop-in centers
- 1. No
- 2. Yes
- 99. Don’t know

M.7. School
- 1. No
- 2. Yes
- 99. Don’t know

M.8. Stays at home
- 1. No
- 2. Yes
- 99. Don’t know

M.9. Other (Please describe):
- 1. No
- 2. Yes
- 99. Don’t know

N. If your family member needs support to manage self-injurious, disruptive, or destructive behavior, how much support is needed? (Check ONE.)
- 1. No support needed (no issues with managing behavior)
- 2. Some support needed; requires only occasional assistance or monitoring
- 3. Extensive support needed; frequent or severe enough to require regular assistance

O. If your family member needs help (support) with personal care activities (for example, bathing, dressing, eating), please indicate how much. (Check ONE.)
- 1. No support needed (no help needed with personal care activities)
- 2. Some support needed; requires only occasional assistance or monitoring
- 3. Extensive support needed

P. If your family member needs help (support) with other daily activities (for example, scheduling, managing money, or shopping), please indicate how much. (Check ONE.)
- 1. No support needed (no help needed with other daily activities)
- 2. Some support needed; requires only occasional assistance or monitoring
- 3. Extensive support needed
Please answer the following questions about yourself.

The following are questions about you, the person responding to this survey. This information is used to better understand the experiences of families who have a family member with a disability. Like the rest of this survey, your answers are confidential, and this information will be kept private. Your responses will not affect you, your family member, or the services your family receives.

Q. What language do you usually speak at home?
   - 1. English
   - 2. Spanish
   - 3. Other

R. What is your age?
   - 1. Under 35
   - 2. 35 – 54
   - 3. 55 – 74
   - 4. 75 or older

S. How would you describe your health? (Check ONE.)
   - 1. Excellent
   - 2. Very good
   - 3. Fairly good
   - 4. Poor

T. How are you related to this person? (Check ONE.)
   - 1. Parent (biological, adoptive, or foster)
   - 2. Sibling
   - 3. Spouse
   - 4. Grandparent
   - 5. Public guardian (for example, state, county)
   - 6. Private guardian
   - 7. Other (please describe): ________________________________

U. Typically, how often do you see this person each year (Check ONE.)
   - 1. Less than once
   - 2. 1 to 3 times
   - 3. 4 to 6 times
   - 4. 7 to 12 times
   - 5. More than 12 times
V. What is your highest education level?
   ○ 1. No high school diploma/GED
   ○ 2. High school diploma/GED
   ○ 3. Vocational school or certificate program
   ○ 4. Some college
   ○ 5. College degree or higher

W. What was the total income last year of all wage earners in your household? Do not include state/federal benefits such as SSI, SSDI, etc.
   Do not reply if you are a public guardian/administrator, or if you represent a financial institution or guardianship agency (Check ONE.)
   ○ 1. Up to $15,000
   ○ 2. $15,001–$25,000
   ○ 3. $25,001–$50,000
   ○ 4. $50,001–$75,000
   ○ 5. Over $75,000
   ○ 6. No earned income
   ○ 7. Prefer not to say
   ○ 98. Does not apply – respondent is a public guardian/public administrator, or represents a financial institution or guardianship agency

Services & Supports Received
Is your family member with an intellectual/developmental disability currently receiving any of the services and supports listed below from the area agency? (Check ONE response for each item.)

i. Financial support – Your family member receives money (cash, stipends, vouchers, or reimbursement) to purchase items, equipment, or needed services for him/herself. This does NOT include SSI payments.
   ○ 2. Yes
   ○ 1. No
   ○ 99. Don’t know

ii. In-home support – People are paid to go to your family member’s house to provide assistance. Examples include Activities of Daily Living support (ADL), etc.
   ○ 2. Yes
   ○ 1. No
   ○ 99. Don’t know
Does not live at home with a family member

iii. **Residential supports** – Your family member with an intellectual/developmental disability receives care and support in a residence outside your home.
   - 2. Yes
   - 1. No
   - 99. Don’t know

iv. **Day/employment supports** – Your family member with an intellectual/developmental disability attends a day program, workshop, or receives vocational supports such as job training or job coaching at a job in the community.
   - 2. Yes
   - 1. No
   - 99. Don’t know

v. **Transportation** – Someone arranges or provides transportation for your family member with an intellectual/developmental disability to go to a day program, work, medical appointments, etc.
   - 2. Yes
   - 1. No
   - 99. Don’t know

vi. **Other services/supports** – Your family member with a disability receives mental/behavioral health care and/or other treatments or therapies (such as physical therapy, occupational therapy, speech therapy, or recreational therapy).
   - 2. Yes
   - 1. No
   - 99. Don’t know

vii. **Self-direction/fiscal intermediary services** – “Self-directed” or “participant-directed” support options offer individuals (and their representatives, including family members) the opportunity to manage some or all of their services. You/your family member may hire and fire your own support workers and/or control how budget is spent.
   - 2. Yes
   - 1. No
   - 99. Don’t know

Supports from other agencies

viii. Does your family member with a disability receive Social Security benefits (SSI or SSDI, survivor benefits, etc.)?
   - 2. Yes
   - 1. No
   - 99. Don’t know
ix. Does your family member with a disability receive services or supports from other agencies or 
organizations (school services, vocational rehab, etc.)?

- 2. Yes
- 1. No
- 99. Don’t know

Part 2: Questions about services and supports

Please answer the following questions about services and supports provided by the area agency. Select
one response for each question unless otherwise indicated. If a question does not apply to you or your 
family member, please select the last option – “Does not apply.”

Information and Planning

1. Do you get enough information to take part in planning services for your family member?

- 1. Always
- 2. Usually
- 3. Sometimes
- 4. Seldom/Never
- 99. Don’t know
- 98. Does not apply – I don’t take part in planning

2. Is the information you get about services and supports easy to understand?

- 1. Always
- 2. Usually
- 3. Sometimes
- 4. Seldom/Never
- 99. Don’t know
- 98. Does not apply – I don’t get information about services and supports

3. Do staff or the residential agency keep you informed about how your family member is doing?

- 1. Always
- 2. Usually
- 3. Sometimes
- 4. Seldom/Never
- 99. Don’t know
- 98. Does not apply – Family member lives alone
4. Does the service coordinator respect your family’s choices and opinions?
   - 1. Always
   - 2. Usually
   - 3. Sometimes
   - 4. Seldom/Never
   - 99. Don’t know
   - 98. Does not apply – No case manager/service coordinator

5. Do you need help planning for your family member’s future with respect to any of the following? (Check all that apply.)
   - 1. Employment
   - 2. Financial
   - 3. Housing
   - 4. Legal
   - 5. Medical
   - 6. Social/Relationships
   - 7. Transition from school
   - 8. Recreation/Having fun
   - 9. Other: __________________________

6. In the past year, did your family member move out of the family home for the first time?
   - 2. Yes
   - 1. No → Go to Q9
   - 99. Don’t know → Go to Q9

7. If yes to Q6, did your family member receive enough information about services available to support him/her?
   - 2. Yes
   - 1. No
   - 99. Don’t know
   - 98. Does not apply – Did not move out of family home in past year

8. If yes to Q6, did you have enough choices of service providers to support your family member living outside the family home?
   - 2. Yes
   - 1. No
   - 99. Don’t know
   - 98. Does not apply – Did not move out of family home in past year
DOES NOT LIVE AT HOME WITH A FAMILY MEMBER

9. Does your family member have a service plan? (Does your family member have a list of services his/her service coordinator will help get?)
   - 2. Yes
   - 1. No → Go to Q15
   - 99. Don’t know → Go to Q15

If your family member has a service plan, please answer Questions 10-14. If not, skip to Question 15.

10. Does the plan include all the services and supports your family member needs?
   - 98. Does not apply — person does not have a service plan
   - 2. Yes
   - 1. No
   - 99. Don’t know

11. Does your family member get all the services listed in the plan?
   - 98. Does not apply — person does not have a service plan
   - 2. Yes
   - 1. No
   - 99. Don’t know

12. Did you or someone else in your family (besides your family member with a disability) help make the plan?
   - 98. Does not apply — person does not have a service plan
   - 2. Yes
   - 1. No
   - 99. Don’t know

NH-1. At the last service planning meeting, were you given the choice to take part in setting goals for your family member?
   - 2. Yes
   - 1. No
   - 99. Don’t know
   - 98. Does not apply – Did not take part in meeting

13. Did your family member help make the plan?
   - 98. Does not apply — person does not have a service plan
   - 2. Yes
   - 1. No
   - 99. Don’t know
14. Did you discuss how to handle emergencies (such as a medical emergency or natural disaster) at your family member's last service planning meeting?
   - 2. Yes
   - 1. No
   - 99. Don’t know
   - 98. Does not apply – Did not take part in meeting

15. If your family member left school services during the past year, did s/he have a transition plan? Your family member may have left school because s/he graduated or s/he was no longer enrolled due to age. (A transition plan is part of an IEP or Section 504 plan through a high school. The transition planning process usually starts around age 14.)
   - 2. Yes
   - 1. No → Go to Q17
   - 99. Don’t know → Go to Q17
   - 98. Does not apply – Did not transition out of school → Go to Q17

16. If yes to Q15, did the transition plan include getting or continuing work in a community job?
   - 2. Yes
   - 1. No
   - 99. Don’t know
   - 98. Does not apply – Did not transition out of school or did not have transition plan

17. Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community?
   - 2. Yes
   - 1. No
   - 99. Don’t know
   - 98. Does not apply – Chooses not to work/volunteer in community

18. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or natural disaster?
   - 2. Yes
   - 1. No
   - 99. Don’t know
DOES NOT LIVE AT HOME WITH A FAMILY MEMBER

Access and Delivery of Supports

19. Are you or your family member able to contact his/her support workers when you want?
   ○ 1. Always
   ○ 2. Usually
   ○ 3. Sometimes
   ○ 4. Seldom/Never
   ○ 99. Don’t know
   ○ 98. Does not apply – No support workers

20. Are you or your family member able to contact his/her service coordinator when you want? (If you call or email, do they get back to you?)
   ○ 1. Always
   ○ 2. Usually
   ○ 3. Sometimes
   ○ 4. Seldom/Never
   ○ 99. Don’t know
   ○ 98. Does not apply – No service coordinator

21. Do support workers come and go when they are supposed to? (Do they show up and leave on time? Do they show up and leave when they say they will?)
   ○ 1. Always
   ○ 2. Usually
   ○ 3. Sometimes
   ○ 4. Seldom/Never
   ○ 99. Don’t know
   ○ 98. Does not apply – No support workers

22. Do services and supports change when your family’s needs change?
   ○ 1. Always
   ○ 2. Usually
   ○ 3. Sometimes
   ○ 4. Seldom/Never
   ○ 99. Don’t know
   ○ 98. Does not apply – Needs haven’t changed
23. Do support workers speak to you in a way you understand? *(Do they use words you understand? Do they speak to you in the language you prefer?)*
   - 1. Always
   - 2. Usually
   - 3. Sometimes
   - 4. Seldom/Never
   - 99. Don’t know
   - 98. Does not apply – No support workers

24. Are services delivered in a way that is respectful of your family’s culture?
   - 1. Always
   - 2. Usually
   - 3. Sometimes
   - 4. Seldom/Never
   - 99. Don’t know

25. If your family member does not communicate verbally (for example, uses gestures, sign language, or a communication aid), are there support workers who can communicate with him/her?
   - 1. Always
   - 2. Usually
   - 3. Sometimes
   - 4. Seldom/Never
   - 99. Don’t know
   - 98. Does not apply – Communicates verbally

26. Do support workers have the right information and skills to meet your family’s needs?
   - 1. Always
   - 2. Usually
   - 3. Sometimes
   - 4. Seldom/Never
   - 99. Don’t know
   - 98. Does not apply – No support workers
27. Does your family member have the special equipment or accommodations that s/he needs? *(For example, wheelchair, ramp, communication board)*
   - 1. Always
   - 2. Usually
   - 3. Sometimes
   - 4. Seldom/Never
   - 99. Don’t know
   - 98. Does not apply – No equipment or accommodations needed

28. Can your family member see health professionals when needed? *(For example, doctor, dentist, psychologist)*
   - 1. Always
   - 2. Usually
   - 3. Sometimes
   - 4. Seldom/Never
   - 99. Don’t know

29. Does your family member’s primary care doctor understand your family member’s needs related to his/her disability?
   - 1. Always
   - 2. Usually
   - 3. Sometimes
   - 4. Seldom/Never
   - 99. Don’t know
   - 98. Does not apply – No primary care doctor

30. Can your family member go to the dentist when needed?
   - 1. Always
   - 2. Usually
   - 3. Sometimes
   - 4. Seldom/Never
   - 99. Don’t know
31. Does your family member’s dentist understand your family member’s needs related to his/her disability?
   - 1. Always
   - 2. Usually
   - 3. Sometimes
   - 4. Seldom/Never
   - 99. Don’t know
   - 98. Does not apply – No dentist

32. If your family member takes medications, do you know what they’re for?
   - 1. Always
   - 2. Usually
   - 3. Sometimes
   - 4. Seldom/Never
   - 99. Don’t know
   - 98. Does not apply – Does not take medication

33. Do you, your family member, or someone else in your family know what is needed to safely take the medications (when it should be taken, how much to take, and the potential side effects)?
   - 1. Always
   - 2. Usually
   - 3. Sometimes
   - 4. Seldom/Never
   - 99. Don’t know
   - 98. Does not apply – Does not take medication

34. If your family member uses mental health services, does the mental health professional understand your family member’s needs related to his/her disability? (For example, psychologist, psychiatrist, counselor)
   - 1. Always
   - 2. Usually
   - 3. Sometimes
   - 4. Seldom/Never
   - 99. Don’t know
   - 98. Does not apply – Does not get mental health services

35. Does your family get the supports and services it needs?
   - 2. Yes  → Go to Q37
   - 1. No
   - 99. Don’t know  → Go to Q37
DOES NOT LIVE AT HOME WITH A FAMILY MEMBER

36. If no to Q35, what additional services does your family need? (Check and/or write all that apply.)
   ○ 1. Regularly scheduled support for family member
   ○ 2. Homemaker services
   ○ 3. Home and/or vehicle modifications
   ○ 4. Counseling
   ○ 5. Family-to-family networks
   ○ 6. Other: ________________________________

Choice, Decision-making, and Control

37. Does the agency providing residential services to your family member involve him/her in important decisions?
   ○ 1. Always
   ○ 2. Usually
   ○ 3. Sometimes
   ○ 4. Seldom/Never
   ○ 99. Don’t know
   ○ 98. Does not apply – Do not receive residential supports

38. Can your family choose or change the agency that provides your family member’s services?
   ○ 1. Always
   ○ 2. Usually
   ○ 3. Sometimes
   ○ 4. Seldom/Never
   ○ 99. Don’t know
   ○ 98. Does not apply – Do not use agency services

NH-2. Do you feel there are enough choices in service providers in New Hampshire?
   ○ 1. There are enough that meet my family’s needs
   ○ 2. There are not enough in my area
   ○ 3. There are not enough that can meet needs of my family
   ○ 4. Other: ________________
   ○ 98. Does not apply – Do not use agency services
39. Can your family choose or change the individual staff that provide the services for your family member?
   - 1. Always
   - 2. Usually
   - 3. Sometimes
   - 4. Seldom/Never
   - 99. Don’t know
   - 98. Does not apply – Services do not include support workers

NH-3. Do your family member’s support workers understand your family member’s needs related to his/her disability?
   - 1. Always
   - 2. Usually
   - 3. Sometimes
   - 4. Seldom/Never
   - 99. Don’t know
   - 98. Does not apply – Services do not include support workers

40. Does your family directly manage support staff? (For example, hiring and deciding schedule)
   - 1. Always
   - 2. Usually
   - 3. Sometimes
   - 4. Seldom/Never
   - 99. Don’t know
   - 98. Does not apply – Services do not include support workers

41. Do service providers for your family member work together to provide support? (For example, does the agency providing transportation work together with the agency providing in-home support if necessary?)
   - 2. Yes
   - 1. No
   - 99. Don’t know
   - 98. Does not apply – Only one service provider
42. Did you, your family member, or someone else in your family choose your family member’s service coordinator?
   - 2. Yes
   - 1. No, didn’t choose but can change service coordinator if wanted
   - 3. No, didn’t choose and cannot change service coordinator if wanted
   - 99. Don’t know
   - 98. Does not apply – No service coordinator

NH-4. Did the service coordinator give you or your family member the choice to take part in Self-Directed Service (Participant Managed and Directed Services)?
   - 2. Yes
   - 1. No
   - 99. Don’t know

Involvement in the Community

43. Does your family member take part in activities in the community? (For example, going out to a restaurant, movie, or sporting event)
   - 2. Yes
   - 1. No
   - 99. Don’t know

44. For your family member, what makes it hard to take part in activities in the community? (Check and/or write all reasons that apply.)
   - 1. Lack of transportation
   - 2. Cost
   - 3. Lack of support staff
   - 4. Stigma (negative attitude or reaction in the community)
   - 5. Other: ________________________________
   - 98. Does not apply-- Nothing makes it hard to participate in activities in the community

45. Does your family member have friends other than paid support workers or family?
   - 2. Yes
   - 1. No
   - 99. Don’t know
DOES NOT LIVE AT HOME WITH A FAMILY MEMBER

46. In your community, are there resources that your family can use that are not provided by the area agency (for example, recreational programs, community housing, library programs, religious groups, etc.)?
   - 2. Yes
   - 1. No
   - 99. Don’t know

47. Does your family take part in any family-to-family networks in your community (for example, Parent to Parent, sibling networks, etc.)?
   - 2. Yes
   - 1. No
   - 99. Don’t know
   - 98. Does not apply – None in my community

**Satisfaction**

48. Overall, are you satisfied with the services and supports your family member currently receives?
   - 1. Always
   - 2. Usually
   - 3. Sometimes
   - 4. Seldom/Never
   - 99. Don’t know

49. Do you know how to file a complaint or grievance about provider agencies or staff?
   - 2. Yes
   - 1. No
   - 99. Don’t know

50. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled?
   - 2. Yes
   - 1. No
   - 99. Don’t know
   - 98. Does not apply – No complaint or grievance filed or resolved in the past year

51. Do you know how to report abuse or neglect related to your family member?
   - 2. Yes
   - 1. No
   - 99. Don’t know
52. Within the past year, was a report of abuse or neglect filed on behalf of your family member?
   ○ 2. Yes
   ○ 1. No → Go to Q55
   ○ 99. Don’t know → Go to Q55

53. If yes to Q52, did the appropriate people respond to the report?
   ○ 2. Yes
   ○ 1. No
   ○ 99. Don’t know
   ○ 98. Does not apply – No abuse or neglect reported in the past year

54. If yes to Q52, if someone outside of your family reported abuse or neglect, were you notified of the report in a timely manner?
   ○ 2. Yes
   ○ 1. No
   ○ 99. Don’t know
   ○ 98. Does not apply – No abuse or neglect reported in the past year by someone else

55. Do you feel that services and supports have made a positive difference in the life of your family member?
   ○ 2. Yes
   ○ 1. No
   ○ 99. Don’t know

56. Have the services or supports that your family member received during the past year been reduced, suspended, or terminated?
   ○ 2. Yes
   ○ 1. No → Go to Q58
   ○ 99. Don’t know → Go to Q58

57. If yes to Q56, did the reduction, suspension, or termination of these services or supports affect your family member negatively?
   ○ 2. Yes
   ○ 1. No
   ○ 99. Don’t know
   ○ 98. Does not apply – Services/supports not reduced, suspended, or terminated in past year
58. Have the services or supports that your family member received been increased in the past year?
   ○ 2. Yes
   ○ 1. No
   ○ 99. Don’t know

59. Are services and supports helping your family member to live a good life?
   ○ 2. Yes
   ○ 1. No
   ○ 99. Don’t know
COMMENTS

The following section is for adding optional comments. **Please do not enter any personal information (names, addresses, etc.), names of providers, service coordinators, agencies, or contact information of any sort.**

Please add any additional comments about things you are satisfied with and things that need improvement in the following areas:

**Information and Planning**

Please do not enter any personal information (names, addresses, etc.), names of providers, service coordinators, agencies, or contact information of any sort.

________________________________________________________________________

________________________________________________________________________

**Access and Delivery of Supports**

Please do not enter any personal information (names, addresses, etc.), names of providers, service coordinators, agencies, or contact information of any sort.

________________________________________________________________________

________________________________________________________________________

**Choice and Control**

Please do not enter any personal information (names, addresses, etc.), names of providers, service coordinators, agencies, or contact information of any sort.

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
Involvement in the Community

Please do not enter any personal information (names, addresses, etc.), names of providers, service coordinators, agencies, or contact information of any sort.

Satisfaction with Services

Please do not enter any personal information (names, addresses, etc.), names of providers, service coordinators, agencies, or contact information of any sort.

Is there anything else you’d like to discuss? (Please write your answer below.)

Please remember that these surveys are confidential. Do not enter any personal information (names, addresses, etc.), names of providers, service coordinators, agencies, or contact information of any sort.
Family Survey Feedback Sheet

Please help us improve this survey by answering the questions below:

1. **How long did it take you to complete this survey?**
   
   _______ hour(s) _______ minutes

2. **Were there any questions that were difficult to understand?**

<table>
<thead>
<tr>
<th>Question #</th>
<th>Reason</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3. **Any other comments about this survey?**

   __________________________________________
   __________________________________________
   __________________________________________
   __________________________________________