Adult Family Survey 2014-15

Opinions of Services and Supports
for Adults with Intellectual/Developmental Disabilities and their Families in [State]

Thank you for helping us by completing the attached questionnaire. The state of [State] is collecting this information to evaluate how well the services your family receives are meeting the needs of people with intellectual/developmental disabilities and their families. Your opinions will help improve these services and supports in your state. The results of this survey will also allow us to compare family outcomes and satisfaction with similar information collected in other states.

We are fully aware that you receive many surveys and questionnaires. This is not simply another opinion poll. Your responses will help your state to evaluate the quality of its services and will help it to focus its improvement efforts in areas most lacking.

If you'd like to see previous results using information from this survey, please go to http://www.NationalCoreIndicators.org and click on: "Resources"→"Reports"→"Family Survey Final Reports".

INSTRUCTIONS:

Note: If there is more than one person receiving services in your family, please answer the questions about the person who is named on the address label.

For most questions, all you need to do is check the box that applies to you. All responses will remain confidential (meaning the case manager, providers, support workers, etc. will NOT know how you responded to these questions). Your answers will not negatively affect the specific services and supports you and your family member are receiving. If you come to a question that you feel uncomfortable answering, skip it. However, for us to get complete information, it is very important that you try to answer each question as accurately as you can.

When you have completed the questionnaire:

Please return it to us in the enclosed pre-addressed and pre-stamped envelope. Please try to return the survey as soon as possible.

If you would like to receive help reading or understanding this survey, or if you need an interpreter, please call: [name & phone]

Again, Thank You!

Part 1: INFORMATION ABOUT YOUR FAMILY

Please answer the following questions about your family member with a disability.

a.) Does this person live at home with you?

❑ 1. Yes ❑ 2. No

Note: If you answered "no" to the question above, please stop here and return the survey.

b.) Is there more than one person with an intellectual/developmental disability in your household?

❑ 1. Yes ❑ 2. No

Reminder: Please answer the questions considering the person who is named on the address label.

c.) How old is your <u>family member</u> with a disability? _____ years

d.) What is the gender of this person?

❑ 1. Male ❑ 2. Female

e.) Has this person been diagnosed with any of the following disabilities listed below? (Check one column for each disability)

No	Yes	Don't Know	
__ 1	__ 2	__ 3	Intellectual disability
__ 1	__ 2	__ 3	Mental illness/Psychiatric diagnosis (e.g. Depression)
__ 1	__ 2	__ 3	Autism spectrum disorder (e.g., Autism, Asperger syndrome, Pervasive developmental disorder
__ 1	__ 2	__ 3	Cerebral Palsy
__ 1	__ 2	__ 3	Brain injury
__ 1	__ 2	__ 3	Seizure disorder/Neurological problem
__ 1	__ 2	__ 3	Chemical dependency
__ 1	__ 2	__ 3	Down syndrome
__ 1	__ 2	__ 3	Prader-Willi syndrome
__ 1	__ 2	__ 3	Other disabilities not listed_____

e2.) Has this person been diagnosed with any of the following health conditions listed below? (Check one column for each condition)

No	Yes	Don't Know	
__ 1	__ 2	__ 3	Cardiovascular Disease (e.g., Coronary Heart Disease, Angina)
__ 1	__ 2	__ 3	Diabetes (including Type I and Type II)
__ 1	__ 2	__ 3	Cancer (e.g., Breast, Prostate, Colon, Lung, etc.)
__ 1	__ 2	__ 3	High Blood Pressure
__ 1	__ 2	__ 3	High Cholesterol
__ 1	__ 2	__ 3	Dysphasia
__ 1	__ 2	__ 3	Pressure Ulcers
__ 1	__ 2	__ 3	Limited or No Vision- Legally Blind
__ 1	__ 2	__ 3	Hearing Loss- Severe or Profound
__ 1	__ 2	__ 3	Alzheimer's Disease or other Dementia
__ 1	__ 2	__ 3	Other conditions not listed _____

f.) What is this person's race? (check all that apply)

- ❑ 1. American Indian or Alaska Native
- ❑ 2. Asian
- ❑ 3. Black or African-American
- ❑ 4. Native Hawaiian or Other Pacific Islander
- ❑ 5. White
- ❑ 6. Other/Unknown
- ❑ 7. Mixed (Two or More Races)
- ❑ 8. Hispanic or Latino

g.) What is this person's primary means of expression? (check only one response)

- ❑ 1. Spoken
- ❑ 2. Gestures/Body Language
- ❑ 3. Sign Language/Finger Spelling
- ❑ 4. Communication Aid/Device
- ❑ 5. Other

h.) What is this person's primary language? (if 'other', please indicate which language)

❑ 1. English ❑ 2. Spanish ❑ 3. Other _____

i.) What is this person's highest education level?

- ❑ 1. Does not have High School Diploma/GED
- ❑ 2. High School Diploma/GED
- ❑ 3. Vocational School
- ❑ 4. Some College
- ❑ 5. College Degree

j.) What does this person typically do during the day? CHECK ALL THAT APPLY

- ❑ 1. Out of Home Day Program- family member is unpaid
- ❑ 2. Out of Home Day Program- family member is paid
- ❑ 3. Vocational Training
- ❑ 4. Community Employment- family member is unpaid (e.g., volunteer work)
- ❑ 5. Community Employment- family member is paid
- ❑ 6. In-home day supports
- ❑ 7. At home- by choice
- ❑ 8. At home- no services
- ❑ 9. At home- other
- ❑ 10. Other

k.) How often does this person require medical care by a trained medical provider (e.g., nurse or physician)?

- ❑ 1. Less frequently than once/month
- ❑ 2. At least once/month, but not once/week
- ❑ 3. At least once/week, or more frequently

l.) Does this person need support to manage any of the following behaviors: self-injurious behavior, disruptive behavior, destructive behavior?

- ❑ 1. No support needed
- ❑ 2. Some support needed
- ❑ 3. Extensive support needed

m.) About how much help does this person need with daily activities (such as bathing, dressing, eating)? (check one)

❑ 1. None ❑ 2. Little ❑ 3. Moderate ❑ 4. Complete

Please answer the following questions about yourself.

n.) What is your age?

❑ 1. Under 35 ❑ 2. 35 – 54 ❑ 3. 55 – 74 ❑ 4. 75 or Older

o.) How would you describe <u>your</u> health? (check one)

❑ 1. Excellent ❑ 2. Good ❑ 3. Fair ❑ 4. Poor

p.) How are you related to this person?

- ❑ 1. Parent (biological, adoptive, or foster)
- ❑ 2. Sibling
- ❑ 3. Spouse
- ❑ 4. Other (please describe)_____

q.) Are you a primary caregiver for this person?

❑ 1. Yes ❑ 2. No

r.) Not including this person, how many adults live in your household?

❑ 1. One ❑ 2. Two ❑ 3. Three ❑ 4. Four or more

s.) Are you a legal guardian (e.g., you have been appointed by the court) or conservator for this person?

- ❑ 1. Yes, full guardianship/conservatorship
- ❑ 2. Yes, limited guardianship/conservatorship
- ❑ 3. No

t.) What is <u>your</u> highest education level?

- ❑ 1. Does not have High School Diploma/GED
- ❑ 2. High School Diploma/GED
- ❑ 3. Vocational School
- ❑ 4. Some College
- ❑ 5. College Degree

u.) What was the total taxable income last year of all the wage earner(s) in your household? (check one)

- ❑ 1. Below $15,000
- ❑ 2. $15,001- $25,000
- ❑ 3. $25,001- $50,000
- ❑ 4. $50,001- $75,000
- ❑ 5. Over $75,000

v.) Approximately how much out-of-pocket money did you spend last year on this person's medical services, equipment, supplies, therapies, and other supports/services?

- ❑ 1. Nothing
- ❑ 2. $1- $100
- ❑ 3. $101- $1,000
- ❑ 4. $1,001- $10,000
- ❑ 5. Over $10,000

w.) What County do you currently live in (do not write in Country- "USA")? _____

SERVICES AND SUPPORTS RECEIVED

Please check whether your family or your family member with an intellectual/ developmental disability is currently receiving any of the services or supports from the ID/DD agency described below.

		YES	NO	DON'T KNOW
i.	**Financial Support** – your family receives money (cash, stipends, vouchers, or reimbursement) to purchase items, equipment, or needed services for your family member with an intellectual/ developmental disability. This money does NOT include SSI payments.	❑ 1	❑ 2	❑ 3
ii.	**In-Home Support** – people are paid to come to your home to provide assistance to your family member with an intellectual/ developmental disability. Examples include: in-home respite care, Activities for Daily Living support (ADL), etc.	❑ 1	❑ 2	❑ 3
iii.	**Out-of-Home Respite Care** -- someone takes care of your family member with an intellectual/developmental disability outside of your home to give your family a break. Includes recreational respite care.	❑ 1	❑ 2	❑ 3
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.	❑ 1	❑ 2	❑ 3
v.	**Transportation** – someone arranges or provides for transportation for your family member with an intellectual/developmental disability to go to a day program, work, medical appointments, etc.	❑ 1	❑ 2	❑ 3
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, or recreational therapy).	❑ 1	❑ 2	❑ 3

Additional Services Question (non-ID/DD Agency Services):

Social Security Benefits -- your family/family member receives SSI payments, survivor benefits, etc.	❑ 1	❑ 2	❑ 3

Part 2: QUESTIONS ABOUT SERVICES AND SUPPORTS

Please answer the following questions about services and supports provided by the ID/DD Agency. Check one response for each question unless otherwise indicated. If a question does not apply to you or your family member, please check the last column (Does Not Apply).

INFORMATION & PLANNING		Always	Usually	Sometimes	Seldom	Never	Don't Know	Does Not Apply
1.	Do you get enough information to help you participate in planning services for your family?	❑1	❑2	❑3	❑4	❑5	❑6	❑7
2.	Is the information you receive easy to understand?	❑1	❑2	❑3	❑4	❑5	❑6	❑7
3.	Does the information you receive come from your case manager/service coordinator?	❑1	❑2	❑3	❑4	❑5	❑6	❑7
4.	Does the case manager/service coordinator respect your family's choices and opinions?	❑1	❑2	❑3	❑4	❑5	❑6	❑7
5.	Does the case manager/service coordinator tell you about other public services that your family is eligible for (e.g., food stamps, Supplemental Security Income [SSI], housing subsidies, etc.)?	❑1	❑2	❑3	❑4	❑5	❑6	❑7

INFORMATION & PLANNING		Yes	No	Don't Know	Does Not Apply
6.	Does your family member have a service plan?	❑1	❑5	❑6	❑7
***If "No" to Question 6,* skip to Question 13.**					
7.	Does the plan include all the services and supports your family member wants?	❑1	❑5	❑6	❑7
8.	Does your family member receive all of the services listed in the plan?	❑1	❑5	❑6	❑7
9.	Did **your family member** help develop the plan?	❑1	❑5	❑6	❑7
10.	Did **you or another family member** help develop the plan?	❑1	❑5	❑6	❑7
11.	Does the plan include all the services and supports your family member needs?"	❑1	❑5	❑6	❑7
12.	Did you discuss how to handle emergencies related to your family member at the last service planning meeting?	❑1	❑5	❑6	❑7
13.	Have you or your family member received information about his/her rights?	❑1	❑5	❑6	❑7

ACCESS & DELIVERY OF SUPPORTS		Always	Usually	Sometimes	Seldom	Never	Don't Know	Does Not Apply
14.	Are you or your family member able to contact his/her support workers when you need to?	❑1	❑2	❑3	❑4	❑5	❑6	❑7

ACCESS & DELIVERY OF SUPPORTS		Always	Usually	Sometimes	Seldom	Never	Don't Know		Does Not Apply
15.	Are you or your family member able to contact his/her case manager/service coordinator when you need to?	❑1	❑2	❑3	❑4	❑5	❑6		❑7
16.	Are services and supports available when your family member needs them?	❑1	❑2	❑3	❑4	❑5	❑6		❑7
17.	Are services and supports available within a reasonable distance from your home?	❑1	❑2	❑3	❑4	❑5	❑6		❑7
18.	Do the services and supports change when your family member's needs change?	❑1	❑2	❑3	❑4	❑5	❑6		❑7
19.	If English is not your primary language, are there support workers or translators who can speak to you in your language?	❑1	❑2	❑3	❑4	❑5	❑6		❑7
20.	If English is your primary language, do the support workers speak to you effectively?	❑1	❑2	❑3	❑4	❑5	❑6		❑7
21.	If your family member does not communicate verbally (for example, uses gestures or sign language), are there support workers who can communicate with him/her?	❑1	❑2	❑3	❑4	❑5	❑6		❑7
22.	Are services delivered in a way that is respectful to your family's culture?	❑1	❑2	❑3	❑4	❑5	❑6		❑7

ACCESS & DELIVERY OF SUPPORTS		Always	Usually	Sometimes	Seldom	Never	Don't Know	Does Not Apply
23.	Does your family member have access to the special equipment or accommodations that s/he needs (for example, wheelchair, ramp, communication board)?	❑1	❑2	❑3	❑4	❑5	❑6	❑7
24.	Do you feel that your family member's day/employment setting is a healthy and safe environment?	❑1	❑2	❑3	❑4	❑5	❑6	❑7
25.	Do the support workers have the right training to meet your family's needs?	❑1	❑2	❑3	❑4	❑5	❑6	❑7
26.	Do the support workers who come to your home arrive on time and when scheduled?	❑1	❑2	❑3	❑4	❑5	❑6	❑7

ACCESS & DELIVERY OF SUPPORTS		Yes	No	Don't Know	Does Not Apply
27.	If your family member transitioned from school services to State funded services during the past year, were you happy with the transition process?	❑1	❑5	❑6	❑7
28.	If you asked for crisis or emergency services during the past year, were services provided when needed?	❑1	❑5	❑6	❑7
29.	Do you have access to health services for your family member?	❑1	❑5	❑6	❑7
29a.	**If Yes to Q29,** are you satisfied with the quality of these providers?	❑1	❑5	❑6	❑7
30.	Do you have access to dental services for your family member?	❑1	❑5	❑6	❑7

ACCESS & DELIVERY OF SUPPORTS		Yes	No	Don't Know	Does Not Apply
30a.	**If Yes to Q30,** are you satisfied with the quality of these providers?	❑1	❑5	❑6	❑7
31.	Are you able to get medications needed for your family member?	❑1	❑5	❑6	❑7
31a.	**If Yes to Q31**, are you satisfied with how your family member's medication needs are monitored?	❑1	❑5	❑6	❑7
32.	If needed, do you have access to mental health services for your family member?	❑1	❑5	❑6	❑7
32a.	**If Yes to Q32,** are you satisfied with the quality of these providers?	❑1	❑5	❑6	❑7
33.	If you need respite services, do you have access to them?	❑1	❑5	❑6	❑7
33a.	**If Yes to Q33**, are you satisfied with the quality of these providers?	❑1	❑5	❑6	❑7
34.	Are there other services that your family member needs that are not currently offered or available?	❑1	❑5	❑6	❑7
34a.	**If Yes to Q34,** what services are needed (list here):				

CHOICE & CONTROL		Always	Usually	Sometimes	Seldom	Never	Don't Know	Does Not Apply
35.	Did **you** choose the provider agencies who work with your family?	❑1	❑2	❑3	❑4	❑5	❑6	❑7
36.	Did **your family member** choose the provider agencies who work with your family?	❑1	❑2	❑3	❑4	❑5	❑6	❑7

CHOICE & CONTROL		Always	Usually	Sometimes	Seldom	Never	Don't Know	Does Not Apply
37.	Can **you** choose a different provider agency if you want to?	❑1	❑2	❑3	❑4	❑5	❑6	❑7
38.	Did **you** choose the individual support workers who work directly with your family?	❑1	❑2	❑3	❑4	❑5	❑6	❑7
39.	Did **your family member** choose the individual support workers who work directly with your family?	❑1	❑2	❑3	❑4	❑5	❑6	❑7
40.	Can **you** choose different support workers if you want to?	❑1	❑2	❑3	❑4	❑5	❑6	❑7

CHOICE & CONTROL		Yes	No	Don't Know	Does Not Apply
41.	Did **you** choose your family member's case manager/service coordinator?	❑1	❑5	❑6	❑7
42.	Did **your family member** choose his/her case manager/service coordinator?	❑1	❑5	❑6	❑7
43.	Do **you** have control and/or input over the hiring and management of your family member's support workers?	❑1	❑5	❑6	❑7
44.	Does **your family member** have control and/or input over the hiring and management of his/her support workers?	❑1	❑5	❑6	❑7
45.	Do **you** know how much money is spent by the ID/DD agency on behalf of your family member?	❑1	❑5	❑6	❑7
46.	Does **your family member** know how much money is spent by the ID/DD agency on his/her behalf?	❑1	❑5	❑6	❑7

CHOICE & CONTROL		Yes	No	Don't Know	Does Not Apply
47.	Do **you** have a say in how this money is spent?	❑1	❑5	❑6	❑7
47a.	**If Yes to Q47,** do **you** have all the information you need to make decisions about how to spend this money?	❑1	❑5	❑6	❑7
48.	Does **your family member** have a say in how this money is spent?	❑1	❑5	❑6	❑7
48a.	**If Yes to Q48,** does **your family member** have all the information s/he needs to make decisions about how to spend this money?	❑1	❑5	❑6	❑7

COMMUNITY CONNECTIONS		Yes	No	Don't Know	Does Not Apply
49.	Does your family member participate in community activities (such as going out to a restaurant, movie, or sporting event)?	❑1	❑5	❑6	❑7
49a.	**If No to Q49,** why? (check and/ or write all reasons that apply) ❑ lack of transportation ❑ cost ❑ lack of support staff ❑ negative attitudes from community members ❑ other_____				
50.	Does your family member have friends or relationships with persons other than paid support workers or family?	❑1	❑5	❑6	❑7
51.	Does your family member have enough supports (e.g., support workers, community resources) to work or volunteer in the community?	❑1	❑5	❑6	❑7

SATISFACTION		Always	Usually	Sometimes	Seldom	Never	Don't Know	Does Not Apply
52.	Overall, are you satisfied with the services and supports your family currently receives?	❑1	❑2	❑3	❑4	❑5	❑6	❑7

SATISFACTION		Yes	No	Don't Know	Does Not Apply
53.	Do you know the process for filing a complaint or grievance against provider agencies or staff?	❑1	❑5	❑6	❑7
54.	Are you satisfied with the way complaints or grievances against provider agencies or staff are handled and resolved?	❑1	❑5	❑6	❑7
55.	Do you know how to report abuse or neglect?	❑1	❑5	❑6	❑7
56.	Within the past year, if abuse or neglect occurred, did you report it?	❑1	❑5	❑6	❑7
56a.	**If Yes (to Q56),** were the appropriate people responsive to your report?	❑1	❑5	❑6	❑7

OUTCOMES		Yes	No	Don't Know	Does Not Apply
57.	Do you feel that services and supports have made a positive difference in the life of your family?	❑1	❑5	❑6	❑7
58.	Do you feel that services and supports have reduced your family's out-of-pocket expenses for your family member's care?	❑1	❑5	❑6	❑7
59.	Have the services or supports that you or your family member received during the past year been reduced, suspended, or terminated?	❑1	❑5	❑6	❑7

OUTCOMES		Yes	No	Don't Know	Does Not Apply
59a.	**If Yes to Q59,** did the reduction, suspension, or termination of these services or supports affect your family or your family member negatively?	❑1	❑5	❑6	❑7

COMMENTS

Additional Comments on Information and Planning

What are you most satisfied with regarding information and planning? (Please write your answer below)

What do you feel needs the most improvement regarding information and planning? (Please write your answer below)

Additional Comments on Access and Delivery of Supports

What are you most satisfied with regarding access and delivery of supports? (Please write your answer below)

What do you feel needs the most improvement regarding access and delivery of supports? (Please write your answer below)

Additional Comments on Choice and Control

What are you most satisfied with regarding choice and control? (Please write your answer below)

What do you feel needs the most improvement regarding choice and control? (Please write your answer below)

Additional Comments on Community Connections

What are you most satisfied with regarding community connections? (Please write your answer below)

What do you feel needs the most improvement regarding community connections? (Please write your answer below)

Additional Comments on Satisfaction

What are you most satisfied with regarding service and supports? (Please write your answer below)

What do you feel needs the most improvement regarding services and supports? (Please write your answer below)

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

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?**

Question#	Reason
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

3. **Any other comments pertaining to this survey:**

_____
_____
_____
_____
_____
_____

COMMUNITY RESOURCE LINKS (for State Agency use if desired)

[STATES MAY CHOOSE TO PUT A STATEMENT HERE THAT TELLS RESPONDENTS WHAT