

# Family Members



## Listen. Gather. Act.

This survey is for family members of individuals with intellectual and other developmental disabilities (I/DD). The NC Council on Developmental Disabilities wants to hear from you. Your ideas will make a difference as we plan for the next five years. Thank you for helping us by filling out this survey. Feel free to skip any questions you don't want to answer and use additional paper if needed.

### Demographic Questions:

Please check below to tell us who you are in relation to your family member(s) with I/DD. Check all that apply.

- Parent
- Grandparent
- Guardian (not biologically related)
- Child of
- Sibling
- Spouse
- Other family member

Does a family member with I/DD live with you?

- No
- Sometimes, but not all the time
- Yes, or most of the time
- Prefer not to answer

What is the age of your family member with I/DD?

If you have more than one family member with I/DD, you may check more than one box.

- Age 0-13 years
- Age 14-20 years
- Age 21-25 years
- Age 26-54 years
- Age 55 or over
- Prefer not to say

What is the gender of your family member(s) with I/DD?

If you have more than one family member with I/DD, you may check more than one box.

- Female
- Male
- Prefer not to say
- Prefer to self-describe: \_\_\_\_\_

What is your family member's race or ethnic background? Check all that apply.

- White
- Black or African American
- American Indian or Alaska Native
- Hispanic/Latin (o) (a) (x)
- Asian
- Native Hawaiian or Pacific Islander
- Unknown
- Prefer not to say

How would you describe the community of your family member(s) with I/DD? If you have more than one family member with I/DD, you may check more than one box.

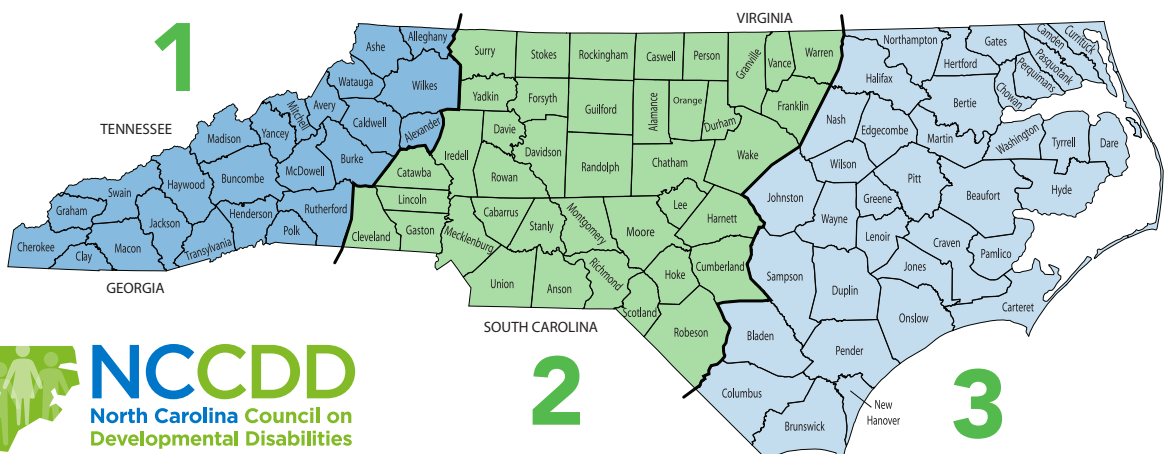
- Urban (medium or large city)
- Suburban (outside the city)
- Rural (fewer people and more open space than urban or suburban areas)
- Don't know
- Prefer not to say

Which region of North Carolina does your family member live in? (See map of NC regions below.)

If you have more than one family member with I/DD, you may check more than one box.

- Region 1
- Region 2
- Region 3
- Don't know
- Prefer not to say

### MAP of NC REGIONS



# Survey for Family Members

## 1) What do you think are the three (3) most important issues to people with I/DD in North Carolina right now?

Check up to 3.

- School
- Housing
- Money and finances
- Knowing their rights
- Knowing what services and supports are available
- Getting good medical care
- Living more independently
- Doing more activities they like
- Being more a part of the community
- Employment
- Transportation
- Planning for the future
- Self-Advocacy
- Getting the services and supports they need
- Technology to help them do the activities they want
- Helping people with disabilities move out of institutions
- Having friends and meaningful relationships
- Other (please describe): \_\_\_\_\_

### Community Services and Supports

## 2) What type of services and supports does your family member with I/DD currently receive? Check all that apply.

- Medicaid Waiver-funded services (Innovations, CAP-C, CAP-DA, TBI)
- State-funded services (non-Medicaid Waiver)
- Help from a family member or friend who isn't paid
- Technology
- Public school
- Institution (ICF, Nursing Facility)
- Group home
- Help in family home
- Help in own home
- Vocational Rehabilitation
- Employment supports not through Vocational Rehabilitation
- Day program
- LME MCO
- Don't know
- None
- Other help (please describe): \_\_\_\_\_

## 3) If your family receives more than one paid service or support, do they work well together?

- No
- Somewhat
- Yes
- I only receive one paid service
- I do not receive paid services
- Don't know

## 4) Who most helps your family member(s) with I/DD with daily activities? Pick the box that most applies to their situation.

- A family member or friend
- A paid service provider
- A school or day program
- No one helps, because they do not need help
- No one helps, but help is needed
- I don't know
- Other (please describe): \_\_\_\_\_

## 5) Does your family member with I/DD currently receive enough support to do what they need and want to do?

- Yes, my family member has what is needed
- No, my family member needs a little more help
- No, my family member needs a lot more help
- No, my family member needs more help almost all the time
- Don't know/doesn't apply to me

### Technology

Some people are able to participate more in their communities with technology. Examples are iPad, voice-activated e-mail, screen readers, eye-gaze sensors, apps.

## 6) Does your family member with I/DD have the technology they need to participate in community?

- No
- Somewhat
- Yes
- I don't know enough about what technology might be helpful
- Don't know/doesn't apply to me

## 7) If you said no to the question above, what other technology is needed?:

\_\_\_\_\_

### Education and Learning

## 8) Please tell us about your family member's school activities.

Check all that apply in each row.

	High School Certificate	High School Diploma	Some College Classes	College Degree	Job Training	Day Program	Recreation Classes
Which did they finish?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Which do they take now?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Which would they like to take?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## 9) Does/Did your family member's school do a good job of preparing them for adulthood?

- No, a big change is needed
- Some change is needed
- Yes, it's about right – no change is needed
- Don't know/doesn't apply to me

# Survey for Family Members

10) How can schools prepare students better for adulthood?

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11) Does/Did your family member's school do a good job of preparing them to have a job or go to college?

- No, a big change is needed
- Some change is needed
- Yes, it's about right – no change is needed
- Don't know/doesn't apply to me

## Jobs and Money

12) How important is it to you that your family member with I/DD be paid at least minimum wage (\$7.25 an hour) for employment?

- It is very important
- It is somewhat important
- It is not important to me
- Don't know/doesn't apply to me

13) Does your family member with I/DD work at a paid job?

- No
- Yes
- Don't know/doesn't apply to my family member

14) How important is it to your family member with I/DD to have a paid job? Why is it important or not important?

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15) If your family member with I/DD does NOT have a job, do they have help to find a job?

- No
- Yes
- Don't know/doesn't apply to my family member

16) If your family member with I/DD DOES have a job, is this a job he/she/they want?

- No
- Yes
- Don't know/doesn't apply to my family member

17) If your family member with I/DD DOES have a job, do they earn minimum wage (\$7.25 per hour) or more, and work with people with and without disabilities?

- No
- Yes
- Don't know/doesn't apply to my family member

## Health and Wellbeing

18) Does your family member with I/DD have friends and caring relationships with people other than support staff and family members?

- No, my family member only has relationships with staff and family
- My family member has one friend/relationship other than staff and family
- Yes, my family member has several friends/relationships other than staff and family
- Don't know/doesn't apply to my family member

19) Is your family member with I/DD able to see a doctor when they need to? Check all that apply.

- No, they do not have insurance.
- No, they cannot afford a doctor
- No, they do not have a doctor to go to
- No, they cannot get to the doctor because of a lack of transportation
- Sometimes
- Yes
- Don't know/ doesn't apply to my family member

20) Do you think most people who help in emergencies (police officers, fire fighters, E.R. staff) know enough about individuals with disabilities?

- No, they need a lot more training
- They need some more training
- Yes, it's about right
- Don't know/doesn't apply to me

## Self-Advocacy and Leadership

*Self-advocacy means that individuals can speak up for themselves, know their rights, and advocate.*

21) How does your family member with I/DD learn about personal rights? My family member with I/DD learns about rights ... Check all that apply

- From our family
- At school
- From other self-advocates
- At meetings and conferences
- From the North Carolina Council on Developmental Disabilities (NCCDD) and/or other advocacy organizations
- He/she doesn't know about rights
- Don't know/doesn't apply to my family member

22) What would help your family member with I/DD to be a better self-advocate? Check all that apply

- Training about self-advocacy
- Knowing other self-advocates
- Meetings and conferences about self-advocacy
- Self-advocacy practice at school
- More information and training on the issues important to people with I/DD
- Transportation to events and meetings with leaders
- More opportunities to advocate at the state, local, and federal level
- Don't know/doesn't apply to me

23) What would help you be a better advocate on I/DD issues? Check all that apply

- Training on advocacy
- Knowing other advocates and self-advocates
- Meetings and conferences about advocacy
- More information and training on disability issues
- Transportation to events and meetings with leaders
- More advocacy events
- Don't know/doesn't apply to my family member

(continued on the back page)

Home

24) Does your family member with I/DD have the kind of housing they need?

- No
 Yes
 Don't know/doesn't apply to my family member

25) How would you describe where your family member with I/DD lives? Check all that apply.

- In own home or apartment
 With one or more family member(s)
 With one or more roommates(s)
 On own (without roommates)
 In a non-family member's home
 With one or two other people with disabilities
 With 4 to 15 people with disabilities (including my family member)
 With 16 or more people with disabilities (including my family member)
 Doesn't have a regular place to stay
 Don't know/doesn't apply

26) Did your family member with I/DD choose where they currently live?

- No, they didn't have a choice
 They had some input but someone helped them choose
 Yes, they chose on their own
 Don't know/doesn't apply to my family member

27) Did your family member with I/DD choose who they live with?

- No, they didn't have a choice
 They had some input but someone helped them choose
 Yes, they chose on their own
 Don't know/doesn't apply to my family member

28) How could housing for people with disabilities be better in your community?

\_\_\_\_\_
\_\_\_\_\_

Transportation

29) How often does your family member with I/DD have the transportation to get where he or she wants and needs to go?

- Never
 Hardly ever
 Sometimes
 Most of the time
 Always
 Don't know/doesn't apply to my family member

30) How could transportation for people with disabilities be better in your community?

\_\_\_\_\_
\_\_\_\_\_

Family Support Services and Advocacy

Many individuals with I/DD live with their families. These families may need services and supports (e.g. respite, family peer services, case management, natural supports) to meet the needs

Thank you again for your participation in our survey. We value and appreciate your input.

If you would like to request a different survey format or if you have questions about the 5 Year State Plan development process, please contact David Ingram at 1-800-357-6916 or David.Ingram@dhhs.nc.gov. This effort is supported by NCCDD and funds it receives through P.L. 106-402, the Developmental Disabilities Assistance and Bill of Rights Act of October 2000.

of their family member with I/DD. Families should also have the opportunity to be meaningfully involved in policy and decision making at all levels.

31) Does your family have services and supports?

- Limited or no services or supports
 Some services or supports
 Yes, we have all the services or supports we need
 Don't know/doesn't apply to me and my family

32) Does your family have the support you need to plan for the future?

- No, we need support to plan
 We have some support
 Yes, we have about the right support
 Don't know/doesn't apply to me and my family

33) Does your family have enough opportunity to be involved in advocating on public policy issues and decisions related to people with I/DD?

- No opportunity to be involved
 Some opportunity to be involved
 Yes, enough opportunity to be involved
 Don't know/doesn't apply to my family member

Follow-Up to This Survey:

What are three (3) things you would most like to change or improve for people with disabilities in North Carolina? Type one or two words on each line.

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

Did these questions let us know what is important to you?

- No, they did not
 Some questions did
 Yes, they did
 Don't know/doesn't apply to me

Additional Comments – What Do We Need to Know

\_\_\_\_\_
\_\_\_\_\_

COVID-19 Emergency

As we developed this survey, the COVID-19 (coronavirus) emergency was beginning in North Carolina. Please tell us anything we need to know about your experiences and the experience of your family member with I/DD. For example, have you had all the help and information you needed? If not, what else has been needed?

\_\_\_\_\_
\_\_\_\_\_

Please email the completed form to: NCFYP@nccdd.org

or mail to:

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ATTN: Five Year Plan
2010 Mail Service Center
Raleigh, NC 27699