



 **The New Jersey Council
on Developmental Disabilities**
Advocate. Collaborate. Educate. **njcdd.org**

The New Jersey Council on Developmental Disabilities (NJCDD) is creating our State Plan for the next five years. This plan will outline the direction of our work for the 2022-2026. The Council does not provide direct services, but part of our work might include funding for innovative programs to assess the impact on the lives of people with intellectual and developmental disabilities (I/DD) and people that support them.

THE WORK OF THE NJCDD CENTERS AROUND THREE AREAS:



As we develop our 5-Year State Plan, we need the input of individuals with I/DD, family members, caregivers, direct support staff, advocates, providers, and others. We want to know about service gaps and priorities, and get YOUR ideas for how we can plan to address what the state needs.

This survey takes most people about 9-12 minutes, but if you have a lot of ideas to share with us (which we love) it could take longer. The survey is voluntary and confidential.

Thanks!

PART I – DEMOGRAPHICS

Please tell us about yourself. These 5 quick questions help us know more about whose input we are getting. It helps us decide if we need to do more work to get input from all communities and stakeholders.

1. I am a:

- Person with an intellectual/developmental disability
 - Family member/caregiver (paid or unpaid) of a person with I/DD
 - Paid direct support staff, provider, nonprofit leader
 - Paid government agency representative/employee/teacher
 - Other (please specify)
-

2. Which category best describes your age:

- I am under 18
- I am 18-22
- I am 23-35
- I am 36-54
- I am 55 or older
- I prefer not to say

3. Which best describes your Race and/or Ethnicity? (Check all that apply)

- White/Caucasian
 - Black/African American
 - Hispanic, Latino(a), or Latinx
 - Asian (Chinese, Filipino, Japanese, Korean, Vietnamese, or other)
 - Middle Eastern
 - Native American, First Nation, or Alaskan Native
 - Native Hawaiian or other Pacific Islander
 - Race Unknown
 - I prefer not to say
 - Other (please specify)
-

4. What is your gender identity?

- I identify as a woman
- I identify as a man
- I identify as nonbinary (for example: transgender, gender neutral, etc.)
- I am unsure of my gender identity
- I identify as: (please specify)
- I prefer not to say

5. Which of the following best describes the area where you live?

- Rural or small town
 - Urban or City
 - Suburban - I live outside a city
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PART II – THE SERVICE SYSTEM

These 4 questions help us understand how you use (or don't use) the developmental disability service system. When we look at all the answers together, it will help us better understand the needs of this community. "The service system" includes all types of government programs for people with I/DD: special education, healthcare, employment services, housing, and others across state agencies.

1. How well do you think you understand and connect with New Jersey's service system for people with I/DD?

- Great** - I know a lot about services for people with I/DD in New Jersey and know where to get information if I need it.
- Pretty well** - I know a good deal of information about various services for people with I/DD but a few areas are still confusing or unknown.
- Somewhat** - I know a little bit about some services for people with I/DD, but feel confused about most of the system.
- Not at all** - I understand very little about services for people with I/DD.
- Not sure**

2. In your community, how available are the developmental disability services you or your family need?

- Very available** – There are many agencies that serve people with I/DD and their families near me and that offer what I need.
- Pretty available** – There are several agencies in my community that serve people with I/DD and their families that offer what I need.
- Somewhat available** - I know of only a few agencies or services for people with I/DD and families that offer what I need.
- Not at all available** - I don't know of any services or agencies serving people with I/DD near me that offer what I need.
- Not sure**
- N/A** – I do not use I/DD services.

3. In your experience, do government agencies and providers coordinate services for people with I/DD, and make it easy to access services seamlessly?

- Yes** – Agencies make sure services wrap around my needs or my family's needs, are easy to access, and that transitions are seamless.
- Most of time** - Services are usually coordinated and easy to access.
- Not really** – Sometimes agencies coordinate, but mostly, it is up to me to figure it out.
- Not at all** – Often I get conflicting stories, and one agency does not even know what the other one does.
- N/A** – I don't have any experience with this, or I have never tried to access services from more than one government agency.

4. Is there anything else you would like to share about your experience with the New Jersey's developmental disability service system and access to those systems?

PART III – YOUR PRIORITIES

Here, we will ask you questions about developmental disability issues that affect your life. We want to know which areas are most important to you so we can identify ways to improve services and supports.

There are MANY issues that affect people with I/DD and families, but we will ask you to pick three that matter most to you. For each of the areas you choose, we will ask you a few questions:

1. **EMPLOYMENT JOBS and related training**
2. **HEALTH and WELLNESS**
3. **TRANSPORTATION**
4. **RECREATION**
5. **EARLY INTERVENTION, CHILDCARE, and SPECIAL EDUCATION**
6. **TRANSITION to ADULTHOOD and COLLEGE/ JOB TRAINING after HIGH SCHOOL**
7. **HOUSING/INDEPENDENT LIVING**
(Formal and Informal Supports)
8. **IN-HOME FAMILY SUPPORT**
(Formal and Informal Supports)

1. Is EMPLOYMENT and JOBS a priority for you or your family member with I/DD?

- No - **Go to #2**
- Yes - **Answer questions 1.1, 1.2, and 1.3**

1.1 Getting accurate information about employment services for people with I/DD has been...

- Very easy
- Fairly easy
- Kind of hard
- Very hard
- Not sure
- N/A – I have not tried to get information about these services.

1.2 Accessing employment services for people with I/DD has been...

- Very easy
- Fairly easy
- Kind of hard
- Very hard
- Not sure
- N/A – I have not tried to access these services.

You can tell us more, if you want:

1.3 What is most important for the NJCDD to focus on related to employment? (pick up to two)

- Finding and keeping good jobs
- Managing benefits and employment
- Career advancement
- Interagency collaboration and coordination
- Meaningful day services (*non-employment*)
- Alternatives to workshops
- Internship opportunities
- Learning skills needed to get and keep a job (*resume writing, job interviews, interacting with coworkers, etc.*)
- Other (*please specify*)

2. Is **HEALTHCARE (behavioral health, dentistry, and wellness) a priority for you or your family member with I/DD?**

- No - *Go to question #3*
- Yes - *Answer question 2.1, 2.2, and 2.3*

2.1 Learning about healthcare, behavioral health, dentistry and wellness services for people with I/DD has been...

- Very easy
- Fairly easy
- Kind of hard
- Very hard
- Not sure
- N/A - I have not tried to get information about these services

2.2 Accessing healthcare services, behavioral health, dentistry and wellness services has been...

- Very easy
- Fairly easy
- Kind of hard
- Very hard
- Not sure
- N/A - I have not tried access these services

You can tell us more, if you want:

2.3 What is most important for the NJCDD to focus on related to health and wellness? (pick up to two)

- Trainings on managing emergency situations and crises
- Increasing the pool of qualified medical professionals who take Medicaid
- Abuse prevention education and activities
- Creating inclusive community-based health and wellness programs
- Accessing quality specialty care (*OB/gyn, dental, orthopedic*) Behavioral health
- Interagency collaboration and coordination
- Other (*please specify*)

3. Is **TRANSPORTATION a priority for you or your family member with I/DD?**

- No - *Go to question #4*
- Yes - *Answer question 3.1, 3.2, and 3.3*

3.1 Getting information about transportation services for people with I/DD has been...

- Very easy
- Fairly easy
- Kind of hard
- Very hard
- Not sure
- N/A - I have not tried to get information about these services

3.2 Using transportation services has been ...

- Very easy
- Fairly easy
- Kind of hard
- Very hard
- Not sure
- N/A - I have not tried to access these services

You can tell us more, if you want:

You can tell us more, if you want:

3.3 Which is most important for the NJCDD to focus on related to transportation? (pick two)

- Learning how to navigate transportation options
- Paying for transportation
- Accessing transportation door-to-door
- Accessing transportation when I need it
- Accessibility
- Interagency collaboration and coordination
- Other *(please specify)*

4.3 Which is most important for the NJCDD to focus on related to recreation? (pick two)

- Access to appropriate arts and recreation activities
- Limited range and options offered
- Accessibility barrier for those with mobility challenges
- Lack of behavioral support
- Costs/Fees to participate in arts and recreation activities
- Transportation to arts and recreation activities
- Afterschool sports/Access to organized community-based sports
- Other *(please specify)*

4. Is participating in RECREATIONAL activities a priority for you, your family member with I/DD or those you support?

- No - *Go to question #5*
- Yes - *Answer questions 4.1, 4.2, and 4.3*

4.1 Getting information about community recreational activities has been...

- Very easy
- Fairly easy
- Kind of hard
- Very hard
- Not sure
- N/A - I have not tried to get information about these services

4.2 Participating in arts and recreation activities has been ...

- Very easy
- Fairly easy
- Kind of hard
- Very hard
- Not sure
- N/A - I have not tried to participate in these services

5. Is EARLY INTERVENTION, CHILDCARE, or SPECIAL EDUCATION a priority for you or your child with I/DD or those you support?

- No - *Go to question #6*
- Yes - *Answer questions 5.1, 5.2, and 5.3*

5.1 Learning about early intervention, education and resources for students with I/DD, and/or childcare options has been...

- Very easy
- Fairly easy
- Kind of hard
- Very hard
- Not sure
- N/A - I have not tried to get information about these services

5.2 For my family and child, participating in early intervention, school, and/or childcare programs has been ...

- Very easy
- Fairly easy
- Kind of hard
- Very hard
- Not sure
- N/A- I have not tried to access these services

You can tell us more, if you want:

5.3 Which is most important for the NJCDD to focus on related to special education, early intervention or childcare?

(pick two)

- Parental rights
- Peer Parental Support
- Eligibility
- IEP/Rights
- Placement
- Discipline, expulsion, suspension
- Inclusive education
- Bullying
- Access to challenging curriculum
- Afterschool care
- Parent engagement in schools
- School to prison pipeline
- Interagency collaboration and coordination
- Other (please specify)

6. Is TRANSITION FROM SCHOOL TO ADULTHOOD and POSTSECONDARY EDUCATION (like college or job training programs) a priority for you, your family member with I/DD, or those you support?

- No - **Go to question #7**
- Yes - **Answer questions 6.1, 6.2, and 6.3**

6.1 Learning about transition from high school to adulthood has been...

- Very easy
- Fairly easy
- Kind of hard
- Very hard
- Not sure
- N/A- I have not tried to get information about these services

6.2 For myself, family member or those I support, the experiences with preparing for the transition from high school to adulthood has been ...

- Very easy
- Fairly easy
- Kind of hard
- Very hard
- Not sure
- N/A- I have not tried to access these services

You can tell us more, if you want:

6.3 Which is most important for the NJCDD to focus on related to transition? (pick two)

- Community-based learning and job experiences
- Preparation for college and higher education
- Linkages to adult service providers (DDD, Voc Rehab, other)
- Life skills
- Lack of IEP goals related to transition
- Interagency collaboration and coordination
- Mobility training (driving, using public transportation)
- Self-advocacy
- Self-direction
- Sexuality, friendships and relationships
- Health Care transition

Other (please specify)

7. Is HOUSING, INDEPENDENT LIVING and SUPPORTS a priority for you or your family member with I/DD or those you support? For an adult over the age of 21 with I/DD, this means having the help (paid and unpaid), resources (money, benefits, programs, supplies, technology, etc.) and skills to live in their own home or place of their choosing, as opposed to with their parents/family, in a group home, a nursing home or in an institution.

- No - **Go to question #8**
- Yes - **Answer questions 7.1, 7.2, and 7.3**

7.1 Learning about getting help with independent living has been ...

- Very easy
- Fairly easy
- Kind of hard
- Very hard
- Not sure
- N/A- I have not tried to learn about these services

7.2 How hard has it been for you, your family member or those you support to get the help you need with housing, independent living, and/or the supports you need to live independently?

- Very Easy
- Fairly easy
- Kind of hard
- Very hard
- Not sure
- N/A- I have not tried to access these services

You can tell us more, if you want:

7.3 Which is most important for the NJCDD to focus on related to independent living? (pick two)

- Affordable housing
- Accessible housing
- Budget to access needed services
- Spending flexibility within the DDD budget
- Hiring and keeping quality direct support staff
- Understanding of the service system and living options
- Options for medically complex/ behaviorally-complex individuals
- Interagency collaboration and coordinationHow to access services
- Who to ask for help

You can tell us more, if you want:

- Other (please specify)

8. Is FAMILY SUPPORT a priority for you, your family member with I/ DD or those you support? This means services designed to help families - respite care, camp programs, home modifications, etc.

- No - **Go to Part IV**
- Yes - **Answer questions 8.1, 8.2, and 8.3**

8.1 Learning about getting family support has been ...

- Very easy
- Fairly easy
- Kind of hard
- Very hard
- Not sure
- N/A- I have not tried to get information about these services

8.2 How hard has it been for you or your family member with I/DD to get the help you need with family support?

- Very easy
- Fairly easy
- Kind of hard
- Very hard
- Not sure
- N/A – I have not tried to access these services

You can tell us more, if you want:

8.3 Which is most important for the NJCDD to focus on related to family support? (pick two)

- DDD/DCF Application process
- Accessing services
- Quality and trained caregivers
- Limited budget for support services
- Crisis Support
- Lack of camp programs
- Lack of In Home Services
- Behavioral Supports
- Therapy Services (OT/PT/Speech and Hearing)
- Enough hours of care each week/month
- Range and type of support services available
- Afterschool care
- Physical Accessibility
- Transportation
- Other (please specify)

PART IV – CROSS-CUTTING ISSUES

Some issues cut across areas. Please tell us which of the following Cross-Cutting Issues are important to you.

Access to technology

- Not Important at all
 Not very Important
 Moderately Important
 Important
 Very Important

Access to the internet

- Not Important at all
 Not very Important
 Moderately Important
 Important
 Very Important

Poverty among people with I/DD and their families

- Not Important at all
 Not very Important
 Moderately Important
 Important
 Very Important

Accessing and coordinating services across agencies and systems

- Not Important at all
 Not very Important
 Moderately Important
 Important
 Very Important

Access to mental health resources, behavioral support and crisis services

- Not Important at all
 Not very Important
 Moderately Important
 Important
 Very Important

Abuse and neglect

Not Important at all Not very Important Moderately Important Important Very Important

Emergency planning for people with I/DD

Not Important at all Not very Important Moderately Important Important Very Important

Racial disparity in service delivery and access

Not Important at all Not very Important Moderately Important Important Very Important

Language barriers

Not Important at all Not very Important Moderately Important Important Very Important

Culturally competent services and supports
(inclusion of people with different cultures, LGBTQ, etc.)

Not Important at all Not very Important Moderately Important Important Very Important

Planning for the future *(Trusts, Wills, Supported decision-making)*

Not Important at all Not very Important Moderately Important Important Very Important

Issues affecting aging caregivers, siblings and other family members

Not Important at all Not very Important Moderately Important Important Very Important

Public awareness efforts that affect all people with I/DD *(Cross disability awareness)*

Not Important at all Not very Important Moderately Important Important Very Important

Criminal justice and re-entry issues affecting those with I/DD

Not Important at all Not very Important Moderately Important Important Very Important

Children with I/DD in foster care

Not Important at all Not very Important Moderately Important Important Very Important

Money and Finance *(SSI, SSDI, ABLE accounts and other benefits)*

Not Important at all Not very Important Moderately Important Important Very Important

Other – please specify

PART V- HOW WE WORK TO MAKE CHANGE

Across the country, State Councils on Disability use different tools to address our priority areas. How important do you think each of these tools are?

Training and support in self-advocacy skills

Not Important at all Not very Important Moderately Important Important Very Important

Developing local self-advocacy groups

Not Important at all Not very Important Moderately Important Important Very Important

Increasing public awareness of disability issues

Not Important at all Not very Important Moderately Important Important Very Important

Information on disability policy

Not Important at all Not very Important Moderately Important Important Very Important

Training on disability issues, trends and best practices

Not Important at all Not very Important Moderately Important Important Very Important

Training parents and self-advocates for leadership development

Not Important at all Not very Important Moderately Important Important Very Important

Funding for pilot or demonstration projects for new approaches

Not Important at all Not very Important Moderately Important Important Very Important

Policy Research to set a new direction for services

Not Important at all Not very Important Moderately Important Important Very Important

Coalition-building and community organization

Not Important at all Not very Important Moderately Important Important Very Important

Educating and Informing lawmakers and policy makers

Not Important at all Not very Important Moderately Important Important Very Important

Interagency Collaboration and Coordination

Not Important at all Not very Important Moderately Important Important Very Important

Elimination of Barriers in the System/System Re-Design

Not Important at all Not very Important Moderately Important Important Very Important

This last question gives you an opportunity to share anything else we might not have asked you that you think would be helpful to us.

Q. Is there anything else that you think the New Jersey Council on Developmental Disabilities Council needs to know as we develop our plan for the next five-years?



Thank you

*for taking the time to fill out our survey.
Your input is extremely important and valuable to us.*

PLEASE MAIL YOUR HARDCOPY TO:
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