



# 2022-2023 NCI<sup>®</sup>-IDD Family Surveys

Overview of New Jersey Results

# What is the National Core Indicators (NCI)?

The National Core Indicators (NCI) is a collaborative effort between the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI).

- NCI offers valid, reliable, person-centered measures that states use to demonstrate how publicly funded supports are impacting people's lives and to determine where they can improve the quality of those supports. These measures are obtained through a series of voluntary surveys.
- In 2022-2023, New Jersey administered the In-Person Survey (IPS), Family/Guardian Survey (FGS), Adult Family Survey (AFS) and the State of the Workforce Survey (SoTW).

# Adult Family Survey

The **Adult Family Survey** (AFS) is administered to families who have an adult family member (18 years or older) with an intellectual or developmental disability who lives in the family home and receiving at least one paid service, in addition to support coordination, from the Division of Developmental Disabilities (DDD).

2022-2023 participating states:

- Delaware
- District of Columbia
- Georgia
- Louisiana
- Maryland
- Missouri
- New Jersey
- North Dakota
- Pennsylvania
- Oklahoma

# Family/Guardian Survey

The **Family/Guardian Survey** (FGS) is administered to families who have an adult family member (18 years or older) with an intellectual or developmental disability who does not live in the family home and receiving at least one paid service, in addition to support coordination, from the Division of Developmental Disabilities (DDD).

2022-2023 participating states:

- Arizona
- Georgia
- Maryland
- New Jersey
- Pennsylvania

# What does the NCI-IDD Family Surveys Measure?

## Individual Outcomes

- Information and Planning
- Community Connections
- Choice, Decision-Making and Control
- Family Satisfaction

## System Performance

- Access and Delivery of Services & Supports
- Services & Supports Received
- Workforce

## Health, Welfare & Safety

- Health
- Welfare
- Safety

# Survey Methodology

- May 2024, DDD mailed letters to primary contacts for all individuals receiving at least **one** Division service, in addition to, Support Coordination.
- Survey is voluntary and confidential
- Survey is conducted online with a unique access code
- Hard copies in English or other languages available upon request
- Surveys were open through June 30, 2024

# Family Surveys: Response Data

Response Data	NCI Family/Guardian Survey	NCI Adult Family Survey
Surveys Sent	7834	14,340
Surveys Received	598	761
Margin of Error	3.7%	3.3%

\*Total number of all states participating including NJ, PA, DE, DC, GA, LA, MD, MO, ND and OK

# Presentation of Today's Data

- NCI Question
- NCI Average
- NJ Average
  - Adult Family Survey (AFS)
  - Family/Guardian Survey (FGS)



# Falling above, within, or below the NCI-IDD Weighted Average?

Falls significantly above NCI Average

- Significantly above the NCI-IDD weighted average, where the difference between the state's percentage and the weighted NCI-IDD average a) was in favor of the state, b) was statistically significant\*

Falls within NCI Average

- Within the NCI-IDD weighted average range, where the difference between the state's percentage and the weighted NCI-IDD average was a) not statistically significant (i.e.,  $p \geq .01$ ), or b) did not meet the effect size criterion (i.e., Cohen's  $d \leq 0.2$ );

Falls Significantly below NCI Average

- Significantly below the NCI-IDD weighted average, where the difference between the state's percentage and the weighted NCI-IDD average a) was in favor of the NCI-IDD average, b) was statistically significant (i.e.,  $p \leq 0.01$ ).

\*Statistical significance is taken to be at or below the .01 level.

# Individual Outcomes

- ✓ Information and Planning
- ✓ Community Connections
- ✓ Choice, Decision-Making, and Control
- ✓ Family Satisfaction

# Information and Planning

NCI QUESTION	Adult Family Survey		Family/ Guardian Survey	
	NCI-IDD Average	New Jersey Average	NCI-IDD Average	New Jersey Average
Has your family learned about alternatives to guardianship?	50%	45%	50%	50%
Does your family member have a service plan?	88%	90%	92%	91%
Does the plan include all the services and supports your family member needs?	88%	84%	90%	86%
Did you or someone else in your family (besides your family member with a disability) help make the plan?	85%	87%	83%	86%
Did your family member help make the plan?	64%	61%	61%	58%
Do you get enough information to take part in planning services for your family member?	34%	29%	35%	33%
Is the information you get about services and supports easy to understand?	25%	20%	36%	32%
Do you get information about services and supports in your preferred language?	88%	87%	90%	93%

\*FGS-State data were not tested for significance due to the small number of participating states.

# Information and Planning

NCI QUESTION	Adult Family Survey		Family/ Guardian Survey	
	NCI-IDD Average	New Jersey Average	NCI-IDD Average	New Jersey Average
Does the case manager or service coordinator listen to your family's choices and opinions?	68%	74%	56%	59%
Do you have enough information about other public services for which your family is eligible (i.e., food stamps, SSI, housing subsidies, etc.)?	25%	21%	N/A	N/A
Do you feel like your family had enough say or input in making the plan?	94%	93%	89%	89%
Did your family member leave school services and begin adult services during the past 12 months?	5%	6%	1%	1%
If your family member left school services during the past 12 months, did your family member have a transition plan?	83%	76%	94%	N/A*
If your family member had a transition plan, did the plan include getting or continuing work in a community job?	58%	40%	N/A*	N/A*

\*States had a low count of responses (N<20) and were not shown: AZ, GA, MD, NJ, PA

# Additional Assistance Needed

NCI QUESTION	Adult Family Survey		Family/ Guardian Survey	
Do you need help planning for your family member's future in any of these areas?	NCI-IDD Average	New Jersey Average	NCI-IDD Average	New Jersey Average
Employment	26%	31%	28%	28%
Financial	35%	41%	38%	39%
Housing	55%	69%	38%	39%
Legal	34%	35%	32%	31%
Medical	31%	36%	45%	47%
Social or Relationships	33%	38%	38%	42%
Transition from school	6%	5%	3%	3%
Recreation or having fun	39%	45%	45%	48%
Other	16%	11%	18%	20%

# Community Connections

NCI QUESTION	Adult Family Survey		Family/ Guardian Survey	
	NCI-IDD Average	New Jersey Average	NCI-IDD Average	New Jersey Average
Does your family member do things in the community?	86%	84%	89%	82%
Does your family member have friends other than paid support workers or family?	64%	58%	57%	54%
In your community, are there resources or support that your family member can use that are not provided by the I/DD agency?	72%	70%	75%	68%
Does your family take part in any family-to-family networks in your community?	18%	19%	14%	15%
<b>For your family member, what makes it hard to do things in the community?</b>				
Lack of Transportation	21%	30%	16%	24%
Cost	16%	17%	12%	15%
Lack of Support Staff	21%	26%	31%	33%
Stigma	10%	11%	8%	9%
Other	26%	30%	30%	27%

# Choice, Decision-Making and Control

NCI QUESTION	Adult Family Survey		Family/ Guardian Survey	
	NCI-IDD Average	New Jersey Average	NCI-IDD Average	New Jersey Average
Can someone in your family choose or change the provider agency that provides your family member's services?	69%	69%	61%	57%
Can someone in your family choose or change your family member's support workers?	62%	61%	25%	27%
Can someone in your family directly manage support staff?	61%	65%	9%	16%
Did you, your family member, or someone else in your family choose your family member's case manager or service coordinator?	38%	57%	24%	47%

# Family Satisfaction

NCI QUESTION	Adult Family Survey		Family/ Guardian Survey	
	NCI-IDD Average	New Jersey Average	NCI-IDD Average	New Jersey Average
Overall, are you satisfied with the services and supports your family member currently receives?	42%	38%	39%	36%
Do you feel that services and supports have made a positive difference in the life of your family member?	94%	95%	92%	92%
Have services and supports reduced your family's out-of-pocket expenses for your family member's care?	65%	78%	N/A	N/A
Does the agency providing residential services to your family member involve them in important decisions?	N/A	N/A	42%	42%

\* Indicates that while data falls significantly below the NCI average, it is a positive to have fewer people losing services.



# Family Satisfaction

NCI QUESTION	Adult Family Survey		Family/ Guardian Survey	
	NCI-IDD Average	New Jersey Average	NCI-IDD Average	New Jersey Average
Have the services or supports that your family member received during the past 12 months been reduced, suspended, or terminated?	12%	8% *	12%	14%
If services or supports received by the family were reduced, suspended or terminated during the past 12 months, did the change in services affect your family member negatively?	80%	82%	80%	88%
Have the services or supports that your family member received been increased in the past 12 months?	23%	25%	21%	23%
Are services and supports helping your family member to live a good life?	94%	94%	93%	92%

\* Indicates that while data falls significantly below the NCI average, it is a positive to have fewer people losing services.

# System Performance

- ✓ Access and Delivery of Services & Supports
- ✓ Services & Supports Received
- ✓ Workforce

# Access and Delivery of Services & Supports

NCI QUESTION	Adult Family Survey		Family/ Guardian Survey	
	NCI-IDD Average	New Jersey Average	NCI-IDD Average	New Jersey Average
Does your family member get all the services listed in the plan?	86%	90%	84%	80%
Does your family get the supports and services it needs?	71%	66%	87%	83%
Do service providers for your family member work together to provide support?	82%	79%	92%	87%
Does your family member use technology in their everyday life to help them do things on their own?	27%	38%	22%	30%
Is there a computer, tablet (iPad or similar), or smartphone that you can use in your home?	88%	95%	92%	94%
Do services and supports change when your family's needs change?	40%	42%	34%	34%
Does your family member have the special equipment or accommodations that they need?	50%	51%	60%	58%

# Access and Delivery of Services & Supports

NCI QUESTION	Adult Family Survey		Family/ Guardian Survey	
	NCI-IDD Average	New Jersey Average	NCI-IDD Average	New Jersey Average
Does your family member have enough supports to work or volunteer in the community? (These types of supports might include support workers, community resources, transportation)	58%	49%	64%	58%
Are you or your family member able to contact support workers when you want?	54%	53%	50%	51%
Are you or your family member able to contact the case manager or service coordinator when you want?	62%	67%	55%	62%
Are services delivered in a way that is respectful of your family's culture?	81%	84%	73%	77%
If you need respite services, how often are you able to get them when needed?	22%	16%	N/A	N/A
If you have used respite services in the past 12 months, were you satisfied with the quality of the respite services?	55%	42%	N/A	N/A

# Additional Services & Supports Needed

NCI QUESTION	Adult Family Survey		Family/ Guardian Survey	
If your family does not get the support and services needed, what additional services does your family need?	NCI-IDD Average	New Jersey Average	NCI-IDD Average	New Jersey Average
Respite	61%	*70%	13%	15%
Regularly scheduled support for family member	38%	37%	29%	32%
Homemaker services	19%	22%	13%	27%
Home and/or vehicle modifications	14%	14%	9%	10%
Counseling	15%	18%	25%	30%
Family-to-family networks	15%	24%	16%	24%
Assistive technology training and support	12%	12%	14%	13%
Other	34%	34%	56%	53%

\*This data is consistent with what is reported on the previous page noting the need for improved respite services for families.

# Internet Access

NCI QUESTION	Adult Family Survey		Family/ Guardian Survey	
	NCI-IDD Average	New Jersey Average	NCI-IDD Average	New Jersey Average
The internet...	Always works and the connection is good			
How well does the internet work in your home?	77%	85%	85%	91%

# Services & Supports Received from I/DD Agency

NCI QUESTION	Adult Family Survey		Family/ Guardian Survey	
Services & Supports Received from I/DD Agency	NCI-IDD Average	New Jersey Average	NCI-IDD Average	New Jersey Average
Financial Support	16%	22%	29%	34%
In-Home Support	40%	34%	36%	34%
Out-of-home respite care	20%	17%	90%	81%
Day or Employment Supports	51%	62%	65%	74%
Transportation	58%	62%	93%	90%
Mental or behavioral health care or other treatments or therapies	29%	35%	63%	59%
Self-Direction or fiscal intermediary services	47%	64%	18%	26%

# Other Services & Supports Received

NCI QUESTION	Adult Family Survey		Family/ Guardian Survey	
Other Services & Supports Received	NCI-IDD Average	New Jersey Average	NCI-IDD Average	New Jersey Average
Social Security (SSI or SSB)	94%	94%	97%	95%
Services or Supports from other agencies or organizations	32%	28%	25%	26%



# Workforce

NCI QUESTION	Adult Family Survey		Family/ Guardian Survey	
	NCI-IDD Average	New Jersey Average	NCI-IDD Average	New Jersey Average
Do support workers come and go when they are supposed to?	61%	63%	49%	52%
Do support workers speak to you in a way you understand?	79%	81%	70%	73%
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 them?	47%	49%	50%	51%
Do support workers have the right information and skills to meet your family's needs?	51%	47%	35%	36%
Do your family member's support workers change too often? Is there too much "turnover" of support workers?	34%	30%	51%	49%
Is there always a staff person available to support your family member when support is needed?	76%	76%	88%	84%

\*Family Member refers to the person receiving services whom the respondent is answering questions about in this survey.

# Health, Welfare and Safety

- ✓ Health
- ✓ Welfare
- ✓ Safety

# Health

NCI QUESTION	Adult Family Survey		Family/ Guardian Survey	
	NCI-IDD Average	New Jersey Average	NCI-IDD Average	New Jersey Average
Can your family member see a primary care provider (doctor, registered nurse, etc.) when needed?	80%	81%	77%	72%
Does your family member's primary care doctor understand your family member's needs related to their disability?	63%	61%	58%	62%
Can your family member go to the dentist when needed?	67%	72%	70%	66%
Does your family member's dentist understand your family member's needs related to their disability?	63%	64%	68%	68%
If your family member takes prescription medications, do you know what they're for?	92%	93%	71%	76%
Do you, your family member, or someone else in your family know what is needed to safely take the prescription medications (when it should be taken, how much to take, and the potential side effects)?	93%	94%	74%	75%
Can your family member get mental or behavioral health supports when needed? (Like see a therapist, go to group counseling.)	49%	43%	58%	52%
If your family member uses mental health services, does the mental health professional understand your family member's needs related to their disability?	57%	56%	59%	60%

# Safety

NCI QUESTION	Adult Family Survey		Family/ Guardian Survey	
	NCI-IDD Average	New Jersey Average	NCI-IDD Average	New Jersey Average
If you asked for crisis or emergency services during the past 12 months, were services provided when needed?	60%	57%	79%	71%
Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or natural disaster?	95%	93%	79%	77%
Have you talked about how to handle emergencies (such as a medical emergency, pandemic, or natural disaster) with your family member's case manager or service coordinator?	59%	57%	47%	47%

# Welfare

NCI QUESTION	Adult Family Survey		Family/ Guardian Survey	
	NCI-IDD Average	New Jersey Average	NCI-IDD Average	New Jersey Average
Do you know how to file a complaint or grievance about provider agencies or staff?	57%	43%	57%	50%
If a complaint or grievance was filed or resolved in the past 12 months, are you satisfied with the way it was handled?	45%	28%	44%	40%
Do you know how to report abuse or neglect related to your family member?	79%	70%	71%	66%
Within the past 12 months, was a report of abuse or neglect filed on behalf of your family member?	2%	0% *	10%	9%
If a report of abuse or neglect was filed on behalf of family member, if someone other than you or another family member reported abuse or neglect in the past 12 months, were you notified of the report in a timely manner?	84%	N/A	67%	58%

- Indicates that while data falls significantly below the NCI average it is a positive to fewer reports of abuse or neglect.
- N/A- Represents states that had a low count of responses (N<20) and were not shown: DC, DE, GA, MO, OK, PA, MD, ND, LA, NJ

# What do the Family Surveys tell us about the service system?

## Strengths

- Access and Delivery of Services and Supports
  - People receive the services identified in their plans
  - People have access to and use technology in their everyday life
  - Contact their Support Coordinator when they want

## Challenges

- Information and Planning
  - More information about guardianship
  - More and easier to understand information about service planning
  - Information about additional public services available
- Welfare
  - Knowledge of how to file a grievance
  - Knowledge of how to report abuse

# How are we using the NCI data?

## NCI Data

- Prioritize quality improvement initiatives
- Measure the impact of the FFS transition
- Measure the impact of the HCBS Settings Rule
- Inform HCBS Quality Measures Set Report
- Inform Strategic Planning

# Improvement Initiatives in Action

## DDD/Boggs Training and Resource Materials

- My Right to a Community Life
- Supporting the Right to a Community Life
- Exploring Possibilities & Supports: An Information Gathering Tool
- Developing Effective Person-Center Planning Tools & NJ Individualized Service Plans
- Council on Quality Leadership
  - Personal Outcome Measures Workshops
- Charting the Life Course Initiatives and Tools
  - Life Trajectory Tool
  - Integrated Supports Star

## HCBS Statewide Transition Plan Resources

- HCBS Settings Rules Webinars
- HCBS Settings Rule Provider Guidebook

## Revisions to internal Division monitoring process

- Revised PPMU Audits
- Revised Support Coordination Monthly and Quarterly Contact Tools

## Money Follows the Person Grant

- DSP Competency and Capacity Building Steering Committee
- Supports Coordination Training Committee



# Thank you for Viewing!

- For more information, visit [NCI-IDD State of the Workforce](#)
- If you have any questions, please email us at [DDD-WQU@dhs.nj.gov](mailto:DDD-WQU@dhs.nj.gov)