

National Core Indicators™ AT-A-GLANCE Report

Selected Findings From the 2015-16 Surveys



www.nationalcoreindicators.org

National Core Indicators™ is a collaboration between:

NASDDDS

National Association of State Directors of Developmental Disabilities Services

&



Human Services
Research Institute

Where do these statistics come from?

This report includes selected findings from the National Core Indicators™ 2015-16 Surveys listed below. **The data shown here are NCI averages: They are calculated as averages of all state averages.**

The Adult Consumer Survey

This survey is completed with individuals age 18 and older who receive at least one paid service (in addition to case management) from the state DD agency. The survey instrument includes a Background Information Section, which gathers data about the consumer from agency records, and an in-person survey. The in-person survey is composed of two sections: Section I includes subjective questions that can only be answered by the person receiving services from the state. Section II includes objective, fact-based questions that can be answered by the person or, if needed, a proxy respondent who knows the person well.

The NCI Project Team interprets each state's data and produces reports that can support state efforts to strengthen LTSS policy, inform quality improvement activities, evaluate programs and policies and compare their performance with national norms.

Family Surveys

The **Adult Family Survey** is completed by families who have an adult family member (age 18 or older) with I/DD living **in the family home**. The family member receives at least one paid service (in addition to case management) from the state DD agency. This survey is mailed out to families.

The **Family/Guardian Survey** is completed by families or guardians who have an adult family member (age 18 or older) with I/DD living **outside the family home**. The family member receives at least one paid service (in addition to case management) from the state DD agency. This survey is mailed out to families or guardians.

The **Child Family Survey** is completed by families who have a child with I/DD living **in the family home**. The child receives at least one paid service (in addition to case management) from the state DD agency. This survey is mailed out to families.

For more information on the National Core Indicators project, please see www.nationalcoreindicators.org. For detailed information on samples, methodology and administration, please see the NCI Reports from 2015-16, available at <http://www.nationalcoreindicators.org/resources/reports/>.

Cover art:

MFA by Carmella Salvucci

Carmella Salvucci was born in Brighton, Massachusetts in 1951. She works at the Gateway Arts studios in Brookline, Massachusetts.

Using images she finds in books and photographs, Salvucci paints the urban landscape and interiors of well-known Boston landmarks. The photos she uses are often black and white, but she transforms the images into highly detailed colorful works which belie her quiet unassuming demeanor. Color, she says, is what she likes most about making art. She is the consummate observer and creates artwork from life as well as her imagination.

Salvucci has enjoyed considerable success and has completed many commissioned works. Images of her work have been reproduced on posters, cards and other objects. Her work has been exhibited and collected throughout the United States and abroad. In Massachusetts, Saalvucci's work has been exhibited at Gateway Gallery, Berenberg Gallery, Arnheim Gallery at Mass Art, Fuller Museum, Waterworks Museum, and Concord Center for Visual Art. In New York her work has been shown at Margaret Bodell Gallery, Cork Gallery at Lincoln Center, and the Outsider Art Fair. In 1995 she was the Massachusetts representative in the "Once Around America" traveling exhibition sponsored by Very Special Arts in Washington, DC. Her work was recently exhibited at the 21st Century Museum in Kanazawa, Japan.

See more of Salvucci's work at <http://www.gatewayarts.org>

LOOKING AT THE 2015-16 ADULT CONSUMER SURVEY (ACS)

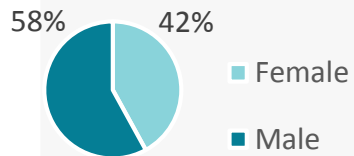
Respondents: Adults (aged 18 and over) with an intellectual/developmental disability receiving one service (in addition to case management) from the state DD agency.

36 states (including the District of Columbia)*: Total sample: 17,682

Demographics and personal characteristics of the sample

Average Age
43 years old

Gender

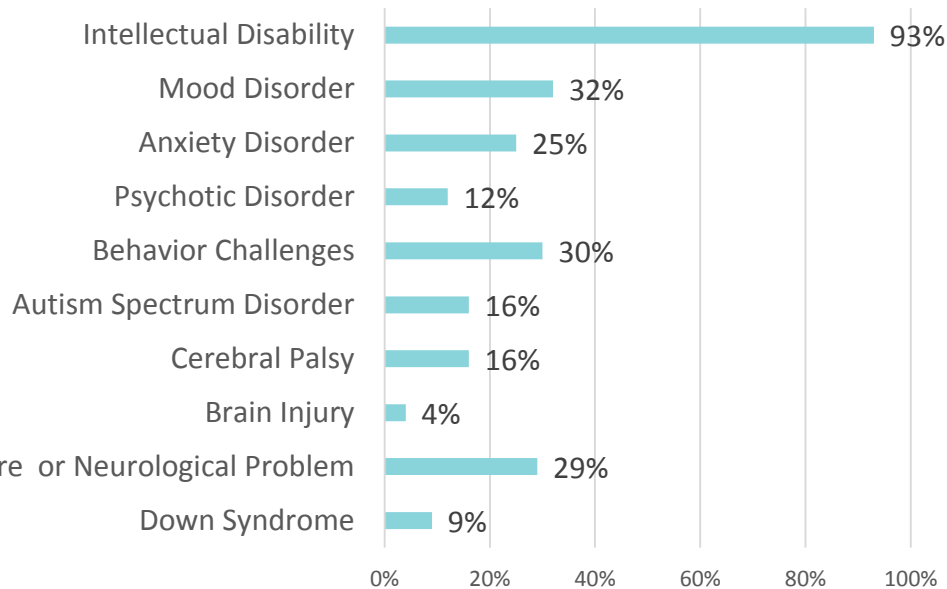


Race/Ethnicity:

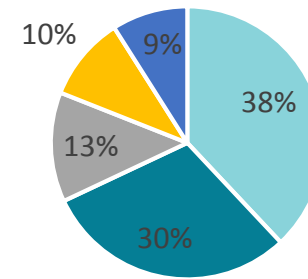
- 70% -- White
- 18% -- Black/African American
- 3% -- Hispanic
- 7% -- Other**
- 1% -- Don't know

Diagnoses of adults with disabilities

Not mutually exclusive; 'Don't know' responses included in denominator



Level of ID



■ Mild ■ Moderate ■ Severe ■ Profound ■ Unspecified

Residence Type

Parent/Relative's Home
35%

Group Residential Setting
(e.g., Group Home)
32%

Own Home or
Apartment
20%

Other (including
foster care and
those without a
home)
8%

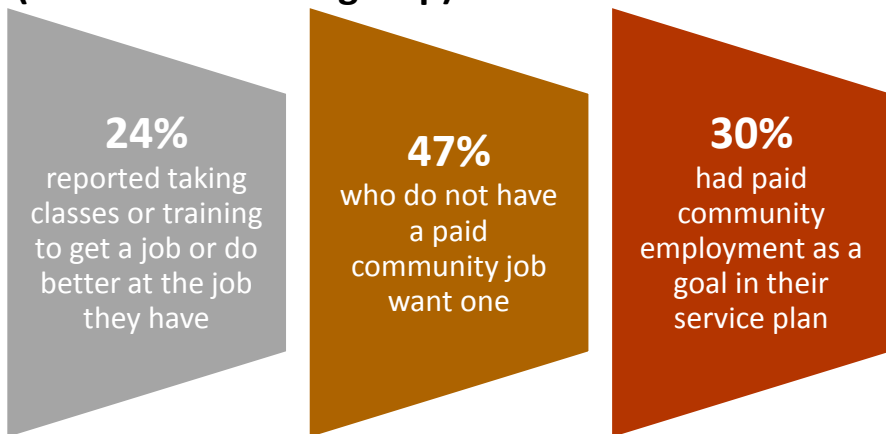
ICF/ID nursing facility
or other institutional
setting
5%

*ACS: AL, AR, AZ, CO, CT, DC, DE, FL, GA, HI, IL, IN, KS, KY, LA, MA, ME, MI, MN, MO, MS, NC, NV, NY, OH, OK, PA, RI, SD, TN, UT, VA, VT, WA, WI, WY

**Includes American Indian, Asian, Pacific Islander, two or more and other

Employment

19% of respondents were reported to have a **paid community job** (Individual and or group)



Access

YES

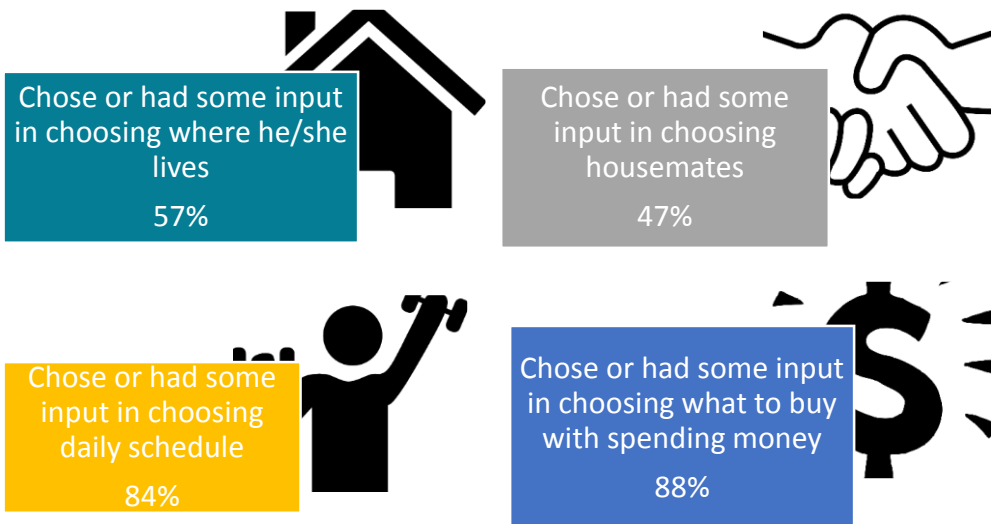
93% report having adequate transportation when they need to get somewhere

83% report having adequate transportation when they want to do something for fun



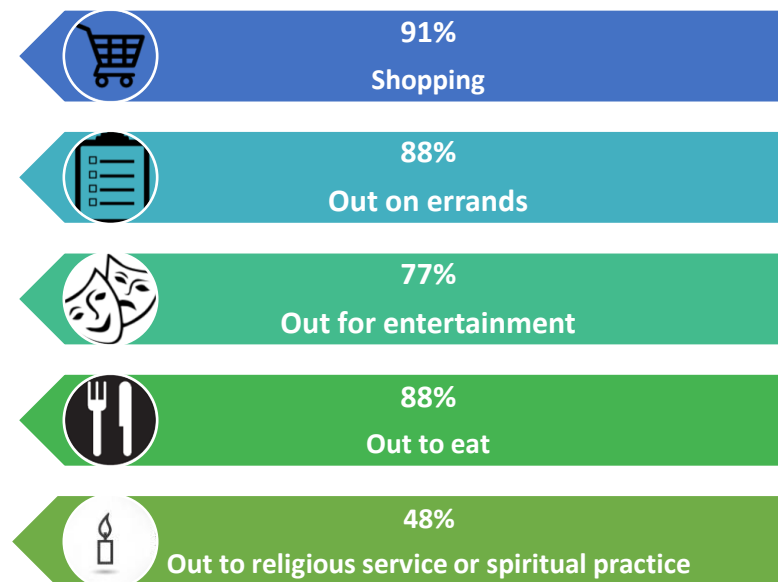
Choice, Decision-making and control

Adjusted variables

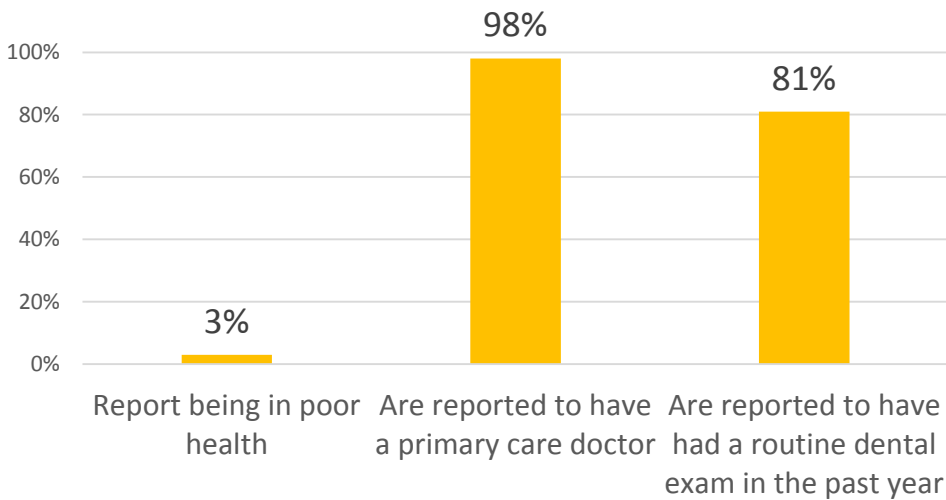


Community Inclusion, Participation and Leisure:

Percentage of respondents that report having done the following activities in the community at least once in the past month

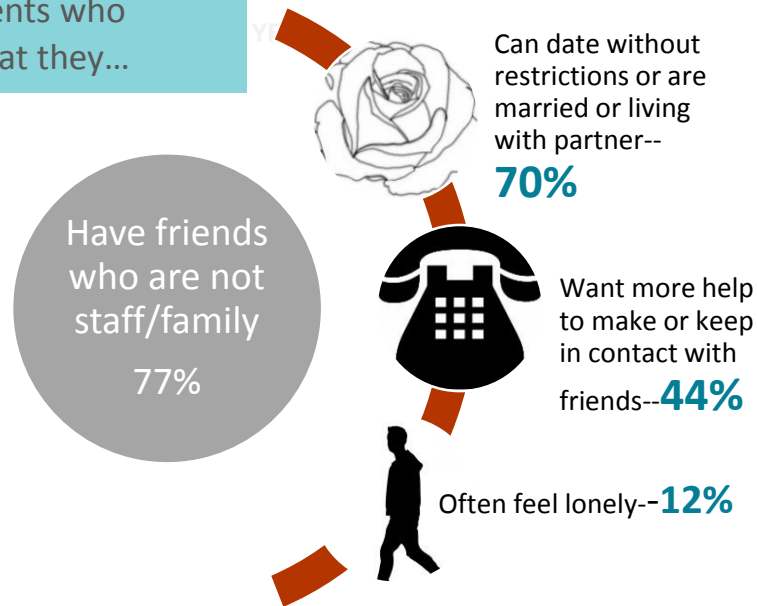


Health:
Percentage of respondents who



Relationships:

Percentage of respondents who report that they...



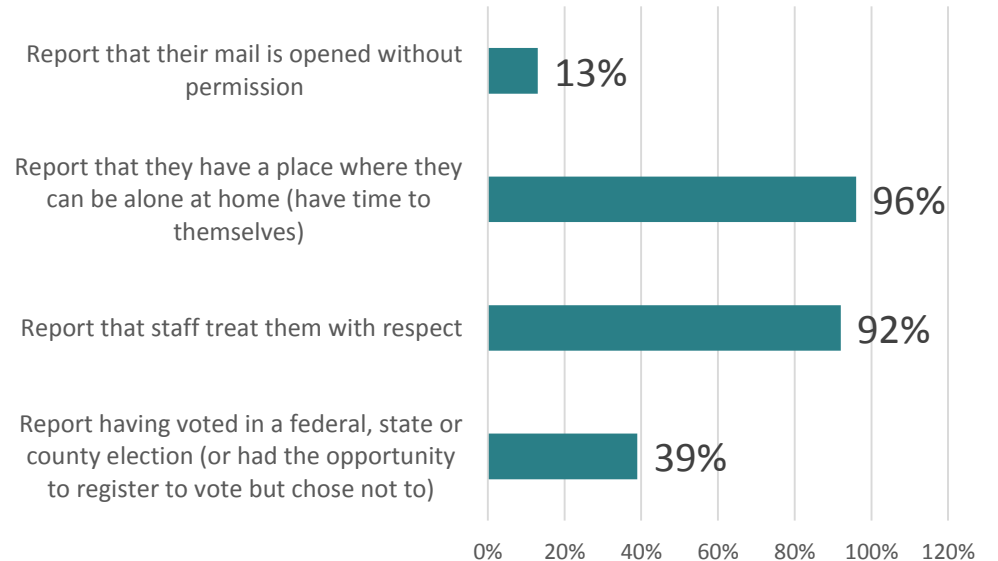
Satisfaction:
Percentage of respondents who report that...

They like where they live -- 89%

They like where they work in a paid community job -- 92%

Services are helping them to live a good life -- 91%

Rights and Respect:
Percentage of respondents who...



LOOKING AT THE 2015-16 ADULT FAMILY SURVEY (AFS)

Respondents: families or guardians of an adult (aged 18 and over) with an intellectual/developmental disability. The adult with the disability lives in the family home (with the respondent) and receives at least one service funded by the state developmental disability agency in addition to case management.
15 states*: Total sample: 5,716

Demographics of sample of family members with disabilities receiving supports from the state

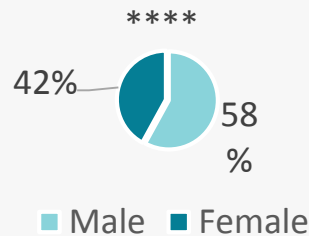
Average Age

of the sample of family members with disabilities receiving supports from the state

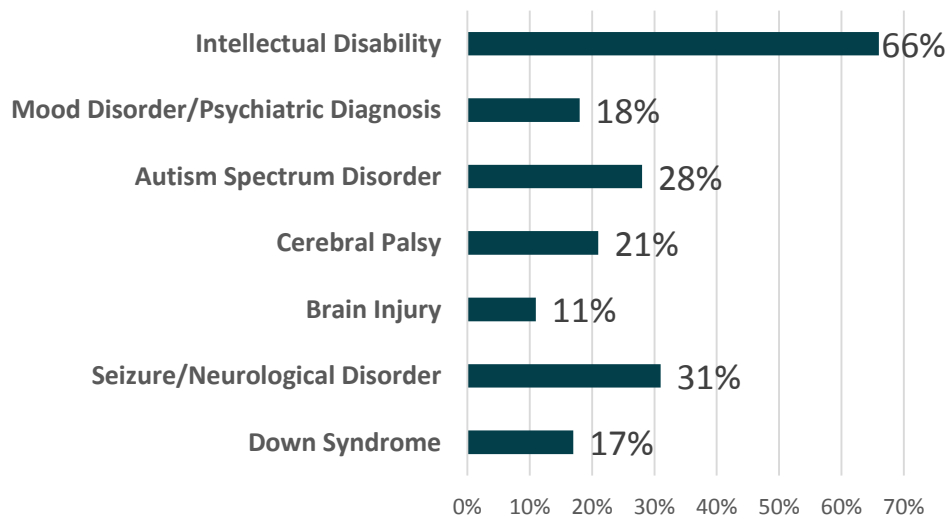
34 years old

Gender Breakdown

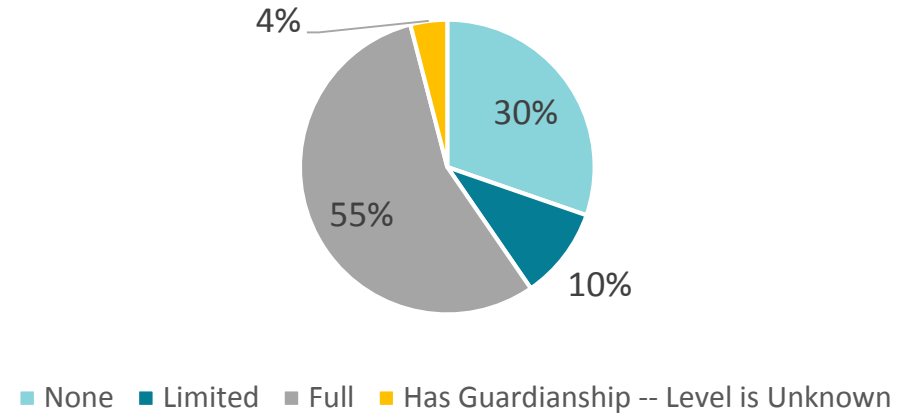
of the sample of family members with disabilities receiving supports from the state



Diagnoses of the sample of family members with disabilities receiving supports from the state

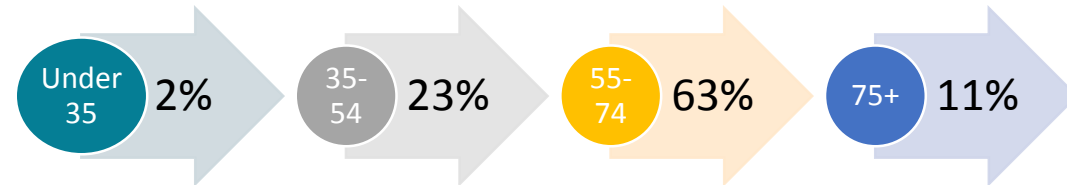


Legal guardianship arrangement for adult with disabilities



Characteristics of respondents (family or guardian of the adult with disability)

Age of respondents



Total taxable income of wage earners in the household over past year

44% of respondents report a total taxable income of **\$25,000** per year or less

*AFS: AK, AZ, DC, FL, GA, HI, LA, MD, MS, NC, NH, OK, PA, VA, WA

Information and Planning

Respondents reported...

42%

- Always receive enough information to help plan services for family member with disability

35%

- Information received to help plan services is always easy to understand

Access and Delivery of Supports and Services

Respondents reported...

78%

Services and supports are delivered in a way that is respectful of family's culture

49%

Services and supports always change when family's needs change

64%

Always able to contact adult with disability's case manager/service coordinator when wanted

Choice, Decision-making and Control

Respondents reported...

Family can always choose or change the agency that provides supports to the adult with disability

66%

Involvement in the Community

Respondents reported...

89%

Adult with disability takes part in community activities

73%

Adult with disability has friends other than paid support workers and family

Satisfaction with Services and Supports

Respondent is always satisfied with services and supports family receives

41%

LOOKING AT THE 2015-16 FAMILY/GUARDIAN SURVEY (FGS)

Respondents: families or guardians of an adult (18 years or older) with an intellectual/developmental disability. The adult with the disability should not live in the family home (with the respondent) and should receive at least one service funded by the state developmental disability agency in addition to case management.
14 states*: Total sample: 6,173

Demographics of sample of family members with disabilities receiving supports from the state

Average Age

of the sample of family members with disabilities receiving supports from the state

46 years old

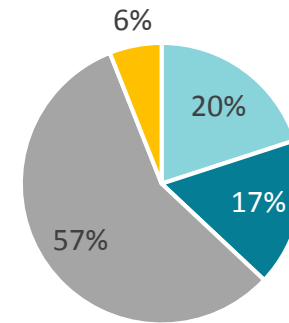
Gender Breakdown

of the sample of family members with disabilities receiving supports from the state



■ Male ■ Female

Legal guardianship arrangement for family member with disability



■ None ■ Limited ■ Full ■ Has Guardianship - Level Is Unknown

Where do family members with disabilities live?

Group Home Setting
51%

Specialized Institutional Setting

13%

Adult Foster Care or Host Home

9%

Independent Home or Apartment

19%

Agency Owned/Operated Apartment

4%

Other

4%

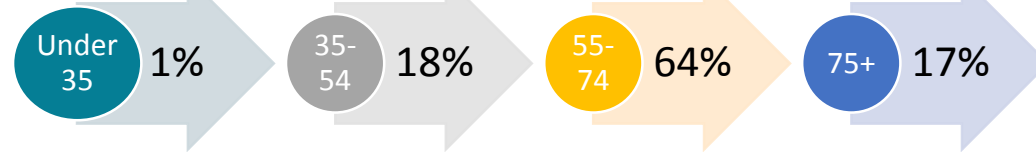
Nursing Home

1%

Characteristics of respondents (family or guardian of the adult with disability)



Age of respondents



Number of times per year respondent sees family member with disability

64% of respondents report seeing their family member 12+ times per year

*FGS: AK, FL, GA, LA, MD, MI, MN, NC, NH, PA, SD, UT, VA, WA

Information and Planning



Respondents reported...

48%

- Always receive enough information to help plan services for family member with disability

45%

- Information received to help plan services is always easy to understand

Access and Delivery of Supports and Services

Respondents reported...

77%

Services and supports are delivered in a way that is respectful of family's culture

52%

Services and supports always change when family's needs change

66%

Always able to contact family member's case manager when wanted

64%

Always able to contact family member's support workers when wanted

Choice, Decision-making and Control

Respondents reported...

Family can always choose or change the agency that provides family member with disability's supports

66%

Involvement in the Community

Respondents reported...

91%

- Family member with disability takes part in community activities

72%

- Family member with disability has friends other than paid support workers or family

Satisfaction with Services and Supports

Respondent is always satisfied with services and supports family receives

49%

LOOKING AT THE 2015-16 CHILD FAMILY SURVEY (CFS)

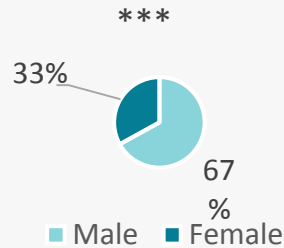
Respondents: families or guardians of a child with an intellectual/developmental disability. The child with the disability lives in the family home (with the respondent) and receives at least one service funded by the state developmental disability agency in addition to case management.
8 states*: Total sample: 16,999

Demographics of sample of children with disabilities receiving supports from the state

Average Age

Of the sample of children with disabilities receiving supports from the state

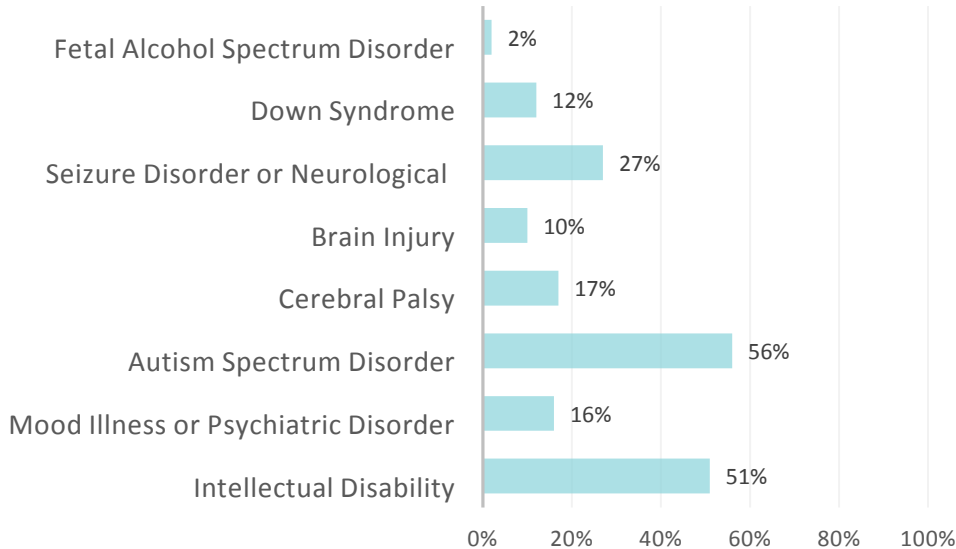
12 years old



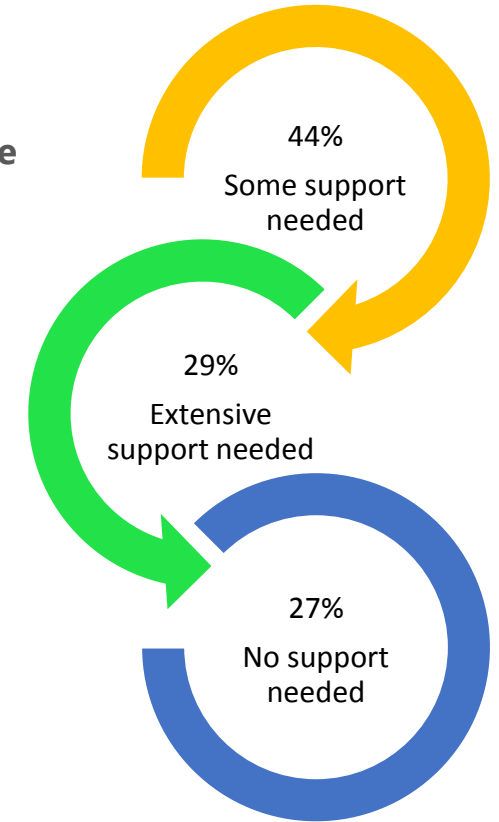
Gender Breakdown

Of the sample of children with disabilities receiving supports from the state

Diagnoses of children with disabilities

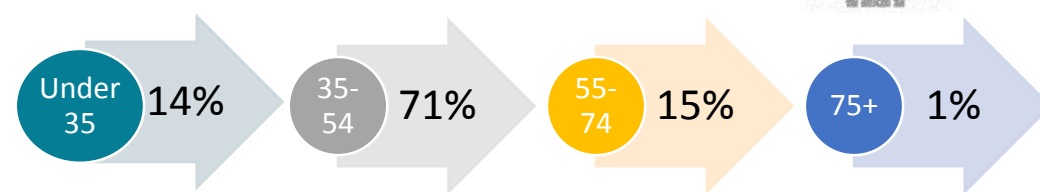


Child's support needs for self-injurious, disruptive and/or destructive behaviors



Characteristics of respondents (family or guardian of the child with disability)

Respondent's Age



*CFS: CA, ID, NC, OR, SD, TX, UT, VA

Information and Planning



Respondents reported...

35%

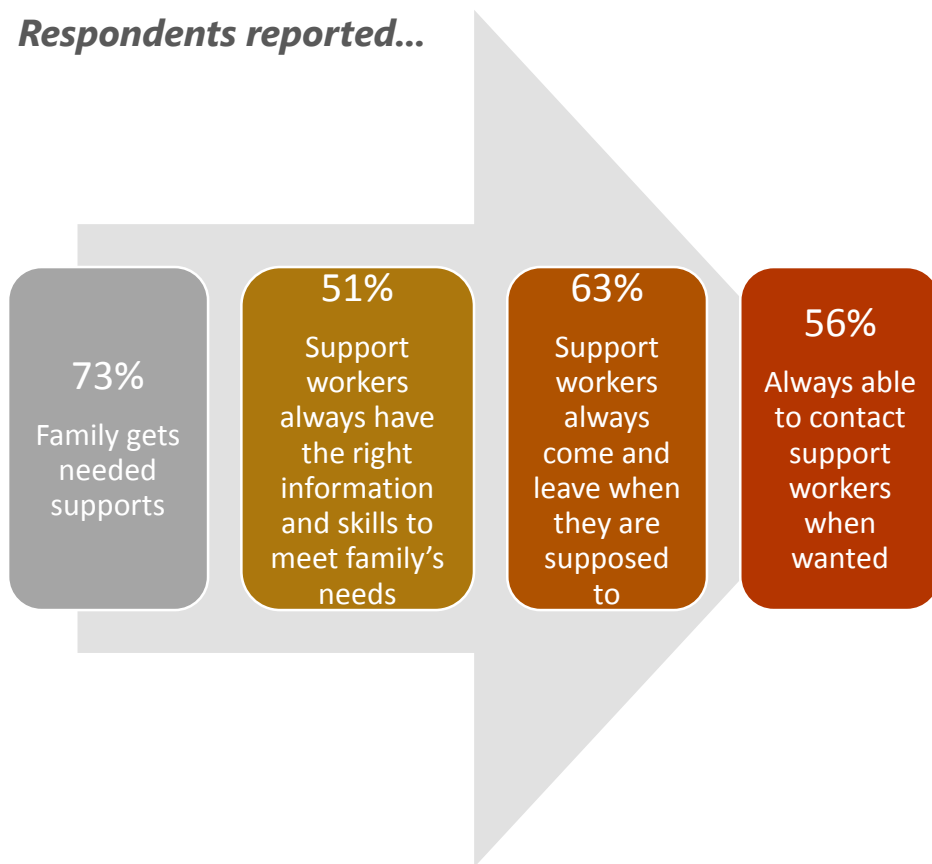
- Always receive enough information to help plan services for child with disability

27%

- Information received to help plan services is always easy to understand

Access and Delivery of Supports and Services

Respondents reported...



Choice, Decision-making and Control



Respondents reported...

Family can always choose or change the agency that provides supports

66%

Involvement in the Community

Respondents reported...



Satisfaction with Services and Supports

Respondent is always satisfied with services and supports family receives

36%

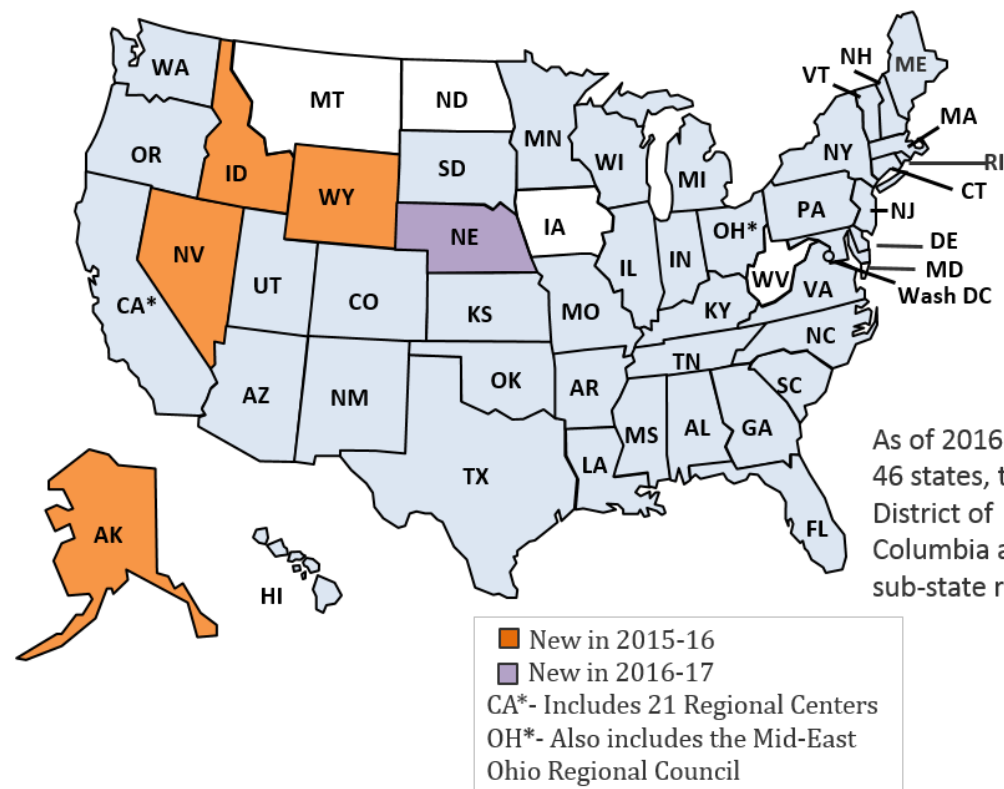
EXPANDING NCI PARTICIPATION

In 2015-16, NCI membership included 45 states, Washington D.C., and 22 sub-state entities. One additional state joined for the 2016-17 survey cycle. Not every participating NCI state administers each survey every year, so survey samples may not include all states.

NCI staff revised the **NCI Staff Stability Survey** to provide more comprehensive and relevant information on staff turnover, vacancy rates, wages, and benefits. The 2015 report is available at <http://www.nationalcoreindicators.org/resources/staff-stability-survey/>

HSRI and the National Association of States United on Aging and Disabilities (NASUAD) continued the implementation of the **National Core Indicators for Aging and Disabilities (NCI-AD) Survey**. The NCI-AD project was conceived in response to growing concern about the limited information currently available to help states assess the quality of long-term services and supports (LTSS) for seniors, adults with physical disabilities, and caregivers.

NCI State Participation



USING THE DATA

This year we asked the Regional Center of Orange County (RCOC) and Virginia to tell us about how they've used the NCI data.

A tool for policy and program development

The Regional Center of Orange County (RCOC)

by LeAnn Christian, PhD.

Chief Clinical Officer

Regional Center of Orange County

The Regional Center of Orange County (RCOC) in Santa Ana, California, joined National Core Indicators as a sub-state region in 2000. Since that time, RCOC has relied on NCI as a critical source of objective information about the individuals we serve and their families regarding the outcomes of the services and supports they receive. To further assist the RCOC Board of Directors and management team in analyzing survey results and in prioritizing areas for improvement, RCOC established a NCI Advisory Council in 2012, which is comprised of self-advocates, Board members, staff, providers, parents and other community stakeholders.

Throughout the years, NCI results have motivated RCOC's Board to revise and add guiding principles/value statements regarding employment, healthcare and community integration. Our attention to integrated competitive employment based on NCI results predates the current national and California statewide focus on Employment First.

Additionally, the ongoing work of our NCI Advisory Council led us to target health and wellness as a priority area. Specifically, our focus is on adults who are supported by independent and supported living agencies because nearly two-thirds of those individuals have a Body Mass Index in the overweight or obese range and a higher percentage of them have diabetes. In response to identifying this priority area, the Board of Directors adopted a strategic goal to foster healthier lifestyles that reduce health risk factors and improve the overall well-being of the individuals we serve. A Health and Wellness Advisory Council was also recently created and is in the process of researching, developing and implementing a health and wellness program.

For more information, please contact Dorothy at dhiersteiner@hsri.org



Examining the Links Between Support Needs, Cost and Outcomes in Virginia

by Parthy Dinora, PhD.

Associate Director-Research, Evaluation, and Policy

Partnership for People with Disabilities—UCEDD at Virginia Commonwealth University

Services for people with intellectual and developmental disabilities (I/DD) in Virginia are in a time of major transition. With a United States Department of Justice Settlement Agreement requiring greater community integration and significant Medicaid home and community-based services waiver reform, the state is in the process of transforming its systems of services and supports for people with I/DD.

Because of these system changes, the Partnership for People with Disabilities at Virginia Commonwealth University (Virginia's University Center for Excellence in Developmental Disabilities) saw the importance of examining relationships among **support needs, costs, and outcomes** as these changes are implemented. We worked with partners at the Association of University Centers on Disabilities (AUCD), the Administration on Intellectual and Developmental Disabilities (AIDD), and the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) to develop a research protocol called the *Virginia Costs and Outcomes Project*.

For this project, we are using Virginia-based linked, individual-level datasets from three sources: (1) the American Association on Intellectual and Developmental Disabilities (AAIDD)'s Supports Intensity Scale (SIS)[®], which provides data on an individual's support needs; (2) I/DD Medicaid expenditures data, which specify service types and costs; and (3) the National Core Indicators (NCI) Adult Survey. The purposes of the research are (a) to determine the individual and service characteristics, including service types and costs, that are associated with enhanced outcomes for people with I/DD, and (b) to examine how outcomes change over time as Medicaid systems change policies and practices are implemented at the state level.

For the past two years, the research team has been conducting a pilot study to both test the feasibility of linking the three databases and to analyze the resulting linked dataset to identify factors that are predictive of enhanced outcomes. To this end, we have used data from Virginia's 2014 NCI Adult Consumer Survey as the core dataset and retrieved the associated data for the same individuals' SIS results and Medicaid expenditures and services during the relevant time period.

Through the conduct of this pilot study, we have gained invaluable insight into how to successfully accomplish the linkage of complex databases from three different state sources. This includes establishing procedures and processes to enhance data security and guarantee privacy protections, developing protocols for efficient data cleaning and standardization, using both deterministic and manual linkage methods, and evaluating and validating linkage results.

We are now in the process of conducting multiple regression analysis to identify variables that made statistically significant contributions to the explanation of variance in individuals' outcomes. Data for the outcome variables originated from individuals' scores on seven scales constructed from items on the NCI Adult Consumer Survey, measuring constructs such as community inclusion, social participation and determination, choice and control, and rights. The predictor/explanatory variables included demographic characteristics, indicators of support needs, type of residence, service costs, and expenditure type. Without data from NCI, we would have been unable to link functioning and cost data to quality of life outcomes.

For more information, please contact Dorothy at dhiersteiner@hsri.org



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