2013-14 NCI AT-A-GLANCE

OVERVIEW

of National Core Indicators activities from the past year and selected findings from the 2013-14 surveys

NATIONAL
CORE
INDICATORS™

National Core Indicators (NCI), a joint venture between the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and Human Services Research Institute (HSRI), has been in operation since 1997. Participating states utilize a common set of data collection protocols to gather information about the performance of service delivery systems for people with intellectual and developmental disabilities. Data from NCI are aggregated and used to support state efforts to strengthen long term care policy, inform the conduct of quality assurance activities and compare performance with national norms. NCI data have also been used as the basis of data briefs on specific areas of interest such as employment, behavior support, respondents who communicate nonverbally, and more.

On the national level, NCI data provide a rich source of information for researchers seeking answers to important policy questions. Increasingly, these data sets are being requested for research purposes, and several articles have been published in peer-reviewed journals in recent years.

We are pleased to launch the NCI At-A-Glance Report, which highlights activities and key findings from 2013-14.

Cover Art: John Kelting, *Aslan.* See more of John Kelting's art at
http://www.theriotrocks.org/spotlight-studios/about-john

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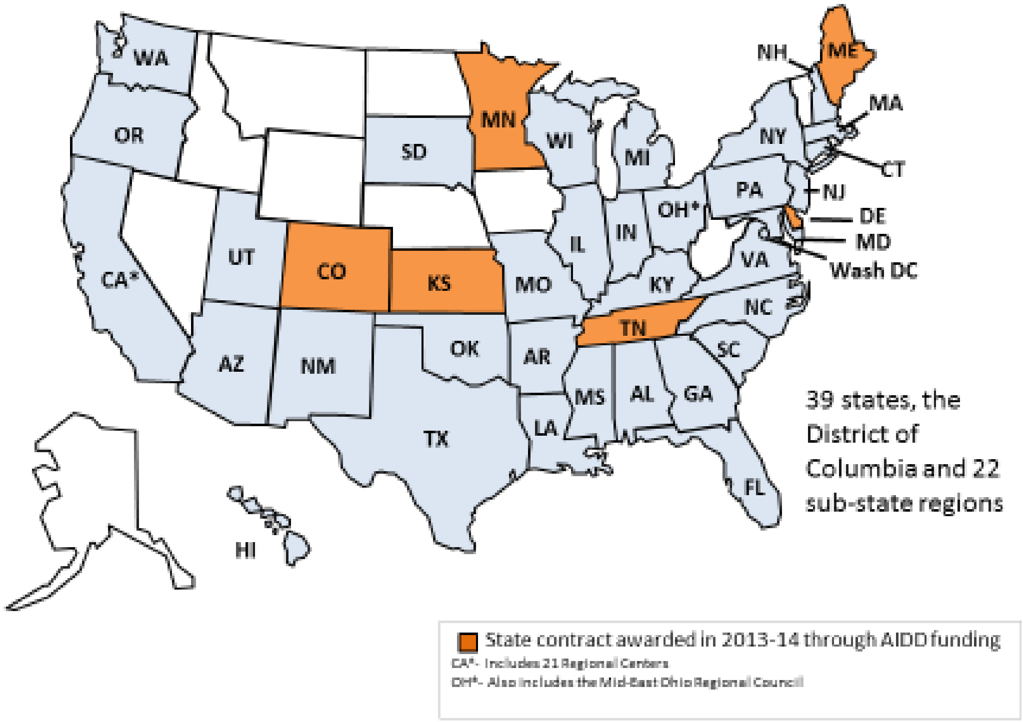
2013-14 ACHIEVEMENTS, ACTIVITIES AND ONGOING EFFORTS

Expansion

NCI continued to expand its membership during 2013-14 thanks in part to funding from the Administration on Intellectual and Developmental Disabilities (AIDD). In 2010, AIDD awarded NASDDDS a contract to increase NCI participation, making funds available for several new states to join each year for five years with the goal of increasing participation to all 50 states, Washington D.C., and all U.S. territories by 2016. Six states joined in 2013-14: Minnesota, Colorado, Kansas, Tennessee, Delaware, and Maine. With these additions, NCI membership grew to encompass 39 states, Washington D.C., and 22 sub-state entities. It's important to note, however, that not every participating state administers each NCI survey every year. Therefore, annual survey samples do not span the full membership.

Not familiar with the Indicators measured by NCI? Visit [nationalcoreindicators.org/indicators.](nationalcoreindicators.org/indicators)

NCI State Participation 2013-14



39 states, the District of Columbia and 22 sub-state regions

🟧 State contract awarded in 2013-14 through AIDD funding

CA*- Includes 21 Regional Centers

OH*- Also includes the Mid-East Ohio Regional Council

2013-14 ACHIEVEMENTS, ACTIVITIES AND ONGOING EFFORTS

Improving the Tools

In 2013-14, NCI staff revised the **NCI Staff Stability Survey to provide more comprehensive and relevant information about staff turnover, the rate at which staff positions are vacant, wages, and benefits.** The new survey will be piloted and rolled out during the 2014-15 data collection cycle.

In collaboration with the National Association of States United on Aging and Disabilities (NASUAD), NCI continued to develop and pilot the **National Core Indicators for Aging and Disabilities (NCI-AD) project**. NCI-AD was conceived in response to growing concern about the limited information available to help states assess the quality of long-term services and supports (LTSS) for seniors, adults with physical disabilities, and caregivers. In 2013-14, the tool was piloted in three states. The full rollout began in June 2015.

Sharing the Data

In addition to formal reports, NCI staff used a variety of means to disseminate results, including **presentations, posters, webinars, and data briefs**. Staff wrote about and presented on a number of findings: racial and ethnic disparities, disparities based on communication style (verbal versus nonverbal), the use of psychotropic medication, and differences in outcomes for individuals who require behavior supports.

- **October 2013:** At the annual National Association for the Dually Diagnosed conference in Baltimore, NCI staff presented "**Who Are Adults With IDD Requiring Behavioral Supports?**" http://www.nationalcoreindicators.org/upload/presentation/behavioral_supports_and_psych_meds.pdf
- **November 2013**: At the annual Association of University Centers on Disabilities conference, NCI staff presented "**Race/Ethnicity, Preventive Care, and Employment Among Adults with Intellectual and Developmental Disabilities.**" http://www.nationalcoreindicators.org/upload/presentation/RE_Health___employ.pdf
- **February 2014:** At a webinar sponsored by ANCOR, NCI staff presented on **psychotropic medication use** among the population with IDD. Representatives from Massachusetts and Georgia presented on state efforts to address overuse of psychotropic medication. http://www.nationalcoreindicators.org/upload/presentation/ANCOR_Webinar_powerpoint_2_18_14.pdf

2013-14 ACHIEVEMENTS, ACTIVITIES AND ONGOING EFFORTS

- **May 2014**: Staff released “**What Do NCI Data Reveal About Individuals with Intellectual and Developmental Disabilities Who Need Behavior Support?**,” a data brief comparing Adult Consumer Survey respondents who require behavior support to those who do not. The brief showcases demographics and outcomes related to health, home, employment, choice, rights and respect, safety, and wellness. It also includes a section describing how some states address the needs of individuals requiring behavior supports. http://www.nationalcoreindicators.org/upload/core-indicators/NCI_DataBrief_MAY2014_ADDENDUM_090314.pdf
- **June 2014**: At the American Association on Intellectual and Developmental Disabilities (AAIDD) Annual Meeting in Orlando, Florida, NCI staff presented on **differences in outcomes for individuals who need behavior supports and for individuals who communicate nonverbally**. http://www.nationalcoreindicators.org/upload/presentation/AAIDD_Verbal_and_behavior_FINAL_2.pdf
- **July 2014**: At the Association of People Supporting EmploymentFirst (APSE) conference in Long Beach, California, NCI staff presented on **employment trends for individuals with IDD** and suggestions for policy development. NCI staff presented with John Butterworth from the Institute on Community Inclusion at the University of Massachusetts, Boston. http://www.nationalcoreindicators.org/upload/presentation/ASPE_Presentation_060914FINAL_1.pdf
- **October 2014:** Staff published an article entitled “**Race/Ethnicity and the Use of Preventive Health Care Among Adults with Intellectual and Developmental Disabilities**” in the journal *Medical Care*. The abstract is available at http://www.ncbi.nlm.nih.gov/pubmed/25215916.

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SELECTED FINDINGS

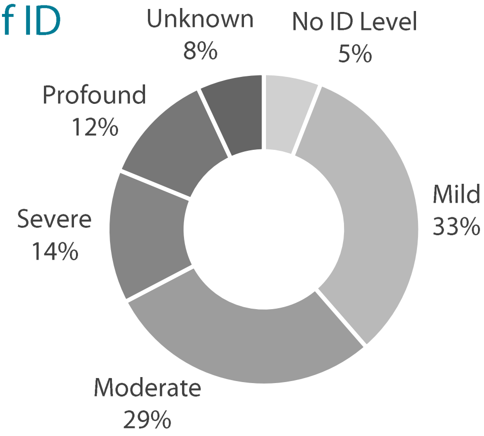
Selected Findings From the 2013-14 Adult Consumer Survey

To view full versions of the ACS report, visit [nationalcoreindicators.org/resources/reports.](nationalcoreindicators.org/resources/reports)

RESPONDENT DEMOGRAPHICS

These data are from the 15,525 individuals interviewed as part of the 2013-14 NCI Adult Consumer Survey (ACS)—from 30 states and one sub-state entity.

Level of ID



Average Age:

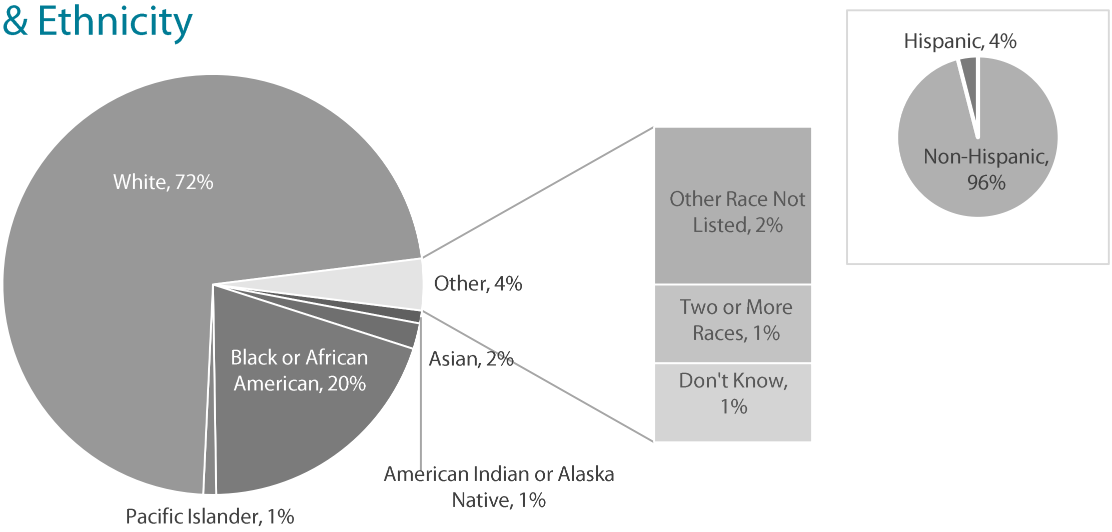
43

Gender:

Male: 58%

Female: 42%

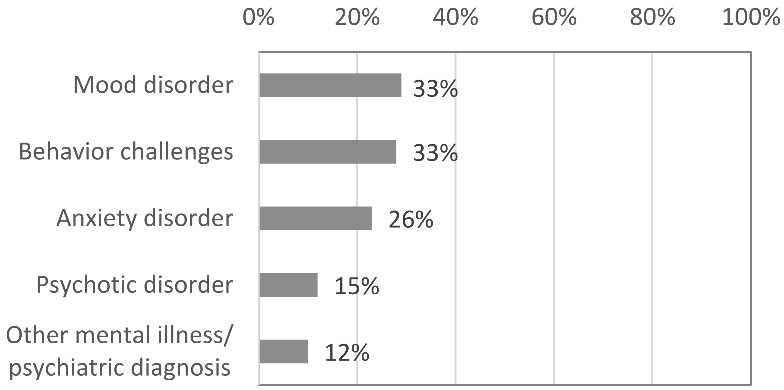
Race & Ethnicity



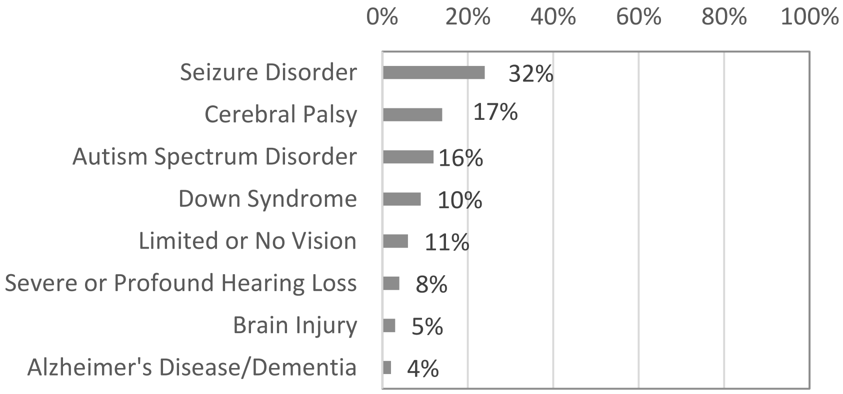
SELECTED FINDINGS

A high percentage of adult consumers (90%) had been diagnosed with a co-occurring condition. The most common were mood disorder (33%), behavior challenges (33%), seizure disorder (32%), and/or anxiety disorder (26%).

Respondents With Co-Occurring Mental Illness Diagnosis

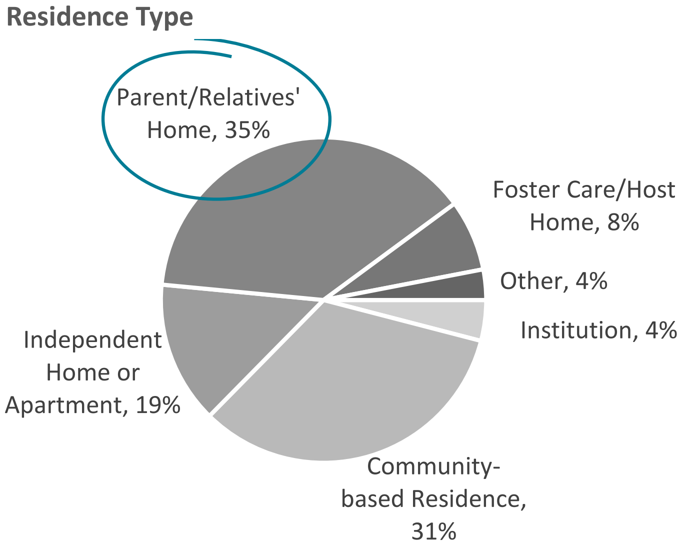


Other Co-Occurring Diagnoses



SELECTED FINDINGS

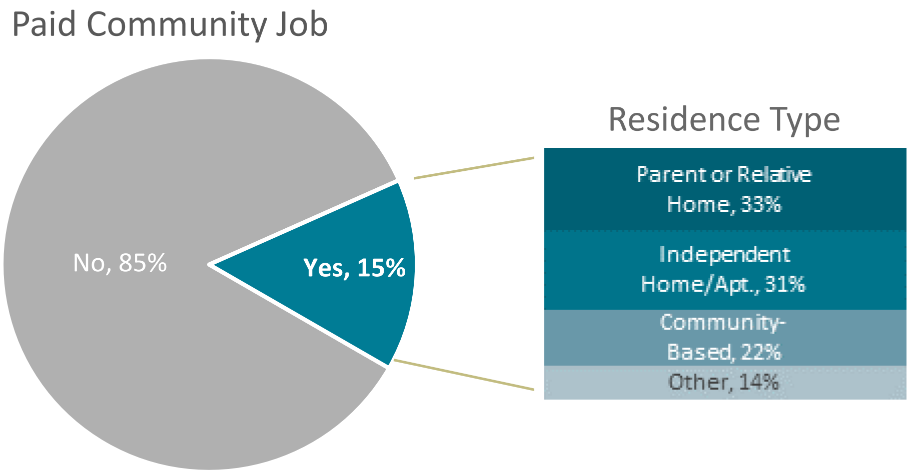
The majority of respondents for whom a residence type was reported were living either with a parent or relative (35%) or in a community-based residence (group home or agency-operated apartment setting; 31%).



EMPLOYMENT

In 2013-14, **15% of adult consumers surveyed had a paid job in the community. The average hourly wage in community jobs was $7.36—close to the 2013 federal minimum of $7.25**.

Of those with a paid job in the community, 33% were living with a parent or relative, 31% were living in an independent home or apartment, and 22% were living in a community-based residence.



24% receive benefits (vacation/sick leave)

The four most common types of paid community jobs were:

- Building and grounds cleaning and maintenance, 32%
- Food preparation and food service, 17%
- Retail, 16%
- Assembly and manufacturing, 8%

SELECTED FINDINGS

RELATIONSHIPS

Respondents reported having relationships and being able to spend time with loved ones. Large majorities of adult consumers reported having friends who were not family or staff (76%), having a best friend (79%), being able to see family whenever they want (79%), being able to see friends whenever they want (78%), and being able to go on dates without restrictions (or being married) (67%). Close to three-fifths of respondents (61%) reported never feeling lonely.

CHOICE

Many respondents reported that they have input in major life decisions such as where and with whom they lived and where they went during the day. Fifty-one percent (51%) had at least some input in choosing their home, and 45% had at least some input in choosing their roommates. And while 82% of those with paid community jobs had input into where they work, only 60% had input into choosing their non-work day activity. Sixty-five percent (65%) chose their staff, while 83% said they had input in choosing their daily schedule.

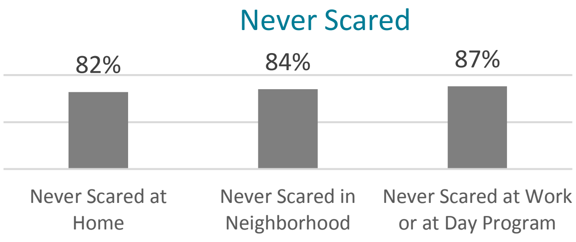
Higher percentages of respondents reported that they had at least some input in choosing what to do in their free time (91%) and choosing what to buy with their own money (87%).

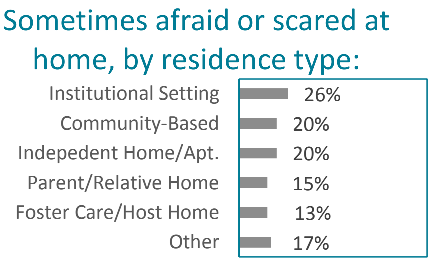
SERVICE COORDINATION

A majority of adult consumers surveyed (87%) reported that they helped make their own service plan. Large majorities also reported positive opinions of their case managers: 78% say their case manager **gets back to them in a timely manner;** 88% say their case manager **asks what they want;** 88% say their case manager **helps them get what they need.**

SAFETY

High proportions of adult consumers reported feeling safe in their day-to-day surroundings. However, the proportions who feel scared at home varied significantly by residence type. Those in institutional settings were significantly more likely to report they sometimes or often feel scared at home (26%).





Selected Findings From the 2013-14 Family Surveys

To view full versions of the reports visit nationalcoreindicators.org/resources/reports.

There are three NCI Family Surveys that are administered by mail. The Family Surveys collect family and guardian perspectives on the quality of services and supports received by adults living at home, adults living outside the home, and children living at home. In 2013-14, 14 states collected a total of 8,123 Adult Family Surveys (AFS), 12 states collected a total of 6,835 Family/Guardian Surveys (FGS), and 8 states collected a total of 2,199 Children/Family Surveys (CFS). For each survey type, states typically mail surveys to 1,000 to 1,200 service recipients in the hopes of generating at least 400 responses. Across the three survey types, respondents were most frequently a parent of the family member with a disability (survey recipient). Other respondents included siblings or other family members.

The table below provides a brief description of the target population for each survey, the method of administration, the total number of states that used each tool in 2013-14, and the total number of surveys collected overall.

Responses to Family Survey outcomes are based on either a 5-point Likert scale (always, usually, sometimes, seldom, or never) or yes or no responses. Families have the option to also write open-ended comments.

NCI SURVEY	TARGET POPULATION	METHOD OF ADMINISTRATION	# STATES 2013-14	# TOTAL SURVEYS
ADULT FAMILY SURVEY (AFS) (***Adult in the Family Home***)	Respondents are families of adults 18 and older living at home	Mail	14	8,123
FAMILY/GUARDIAN SURVEY (FGS) (***Adult Outside the Family Home***)	Respondents are families or guardians of adults 18 and older living outside the home	Mail	12	6,835
CHILDREN/FAMILY SURVEY (CFS) (***Child in the Family Home***)	Respondents are families of children under 18 (or under 23 if still in school system) living at home	Mail	8	2,199

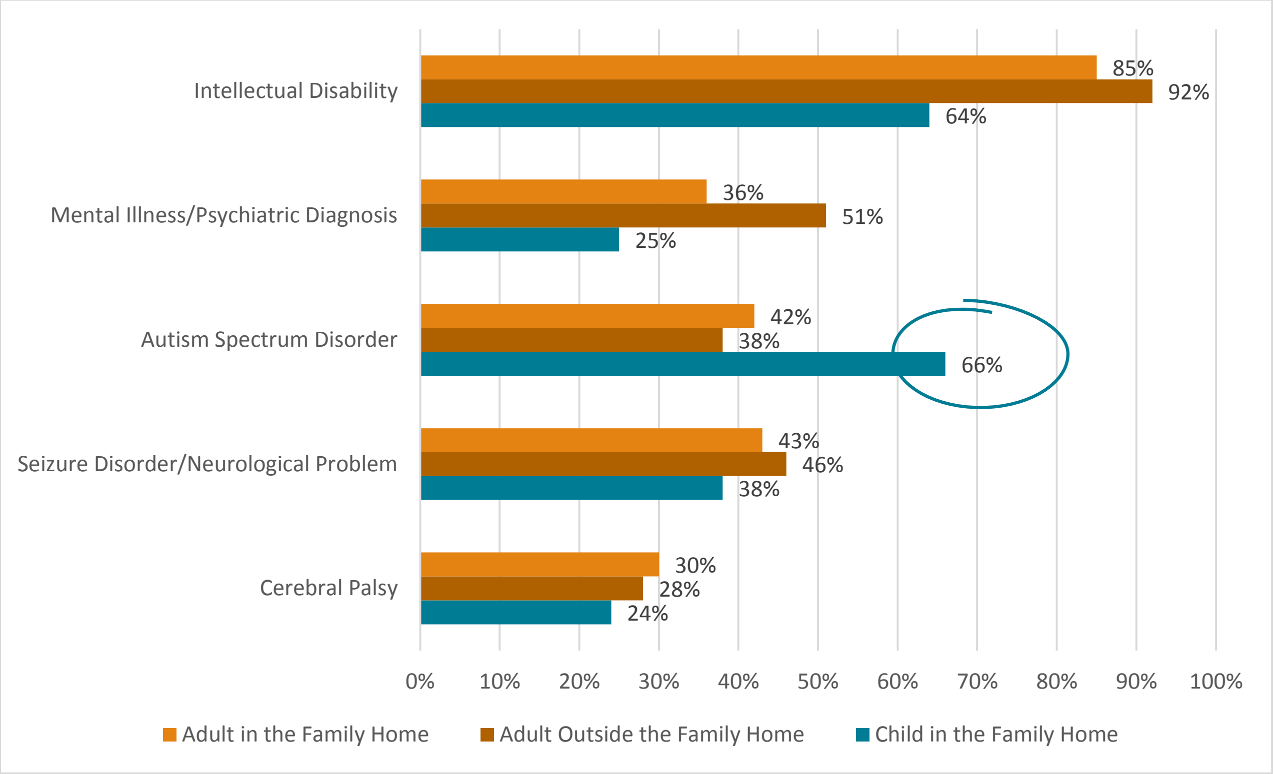
SELECTED FINDINGS

DEMOGRAPHICS

NCI SURVEY	Average Age OF SURVEY RECIPIENTS	Gender OF SURVEY RECIPIENTS
AFS (*Adult in the Family Home*)	33	59% Male 41% Female
FGS (*Adult Outside the Family Home*)	46	58% Male 42% Female
CFS (*Child in the Family Home*)	12	69% Male 31% Female

Survey recipient's type of disability

(As reported by respondents)

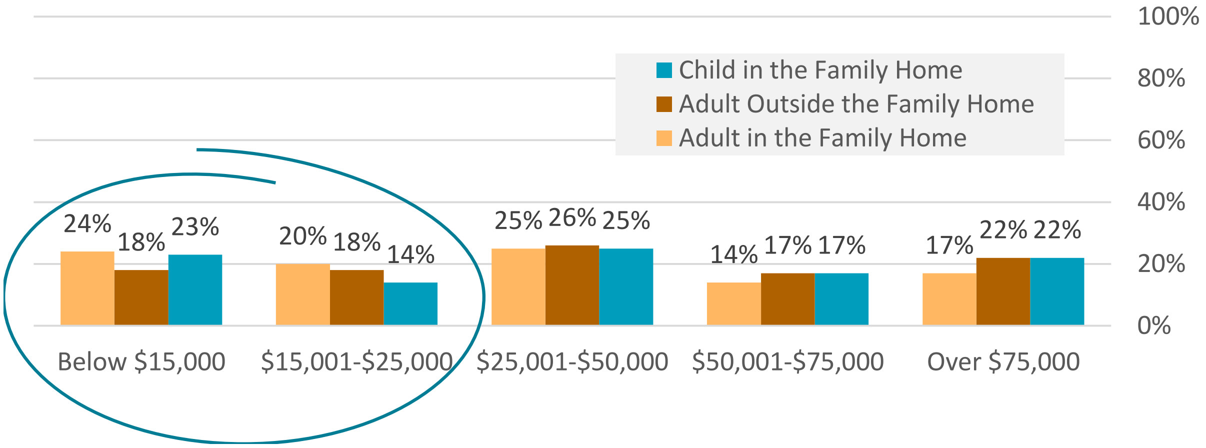


Notably, many more child survey recipients than adult survey recipients had been diagnosed with Autism Spectrum Disorder (66%).

SELECTED FINDINGS

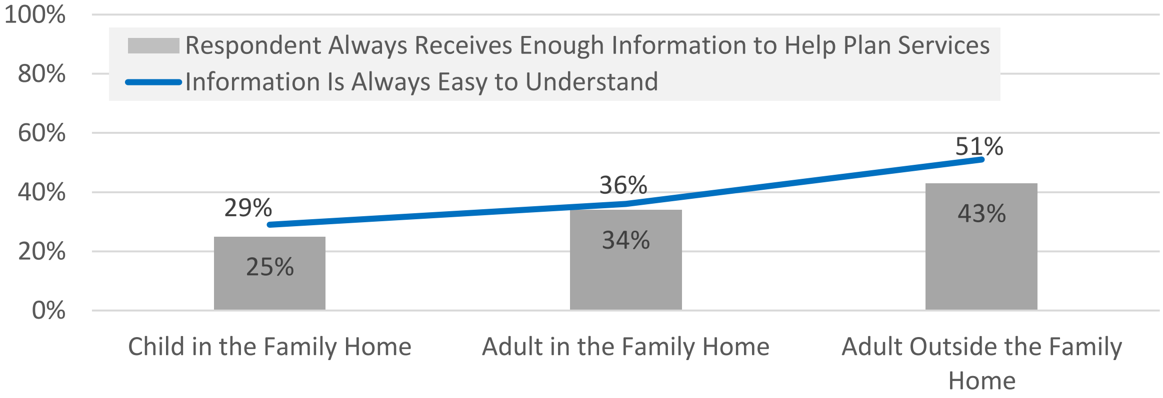
A large proportion of respondents to all surveys reported that their household income in the past year was $25,000 or less, including:

- 44%, *adult in family home*
- 36%, *adult outside family home*
- 37%, *child in family home*



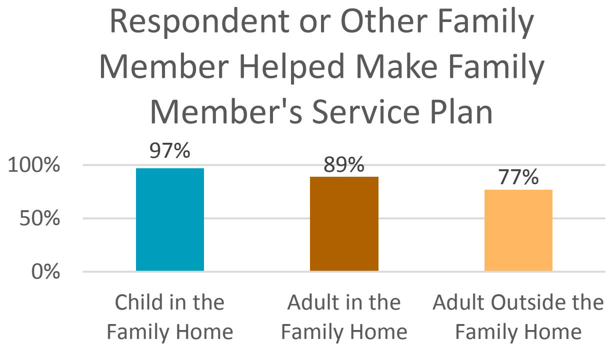
SERVICES & SUPPORTS

For each of the three survey types, high proportions of respondents (91% to 92%) reported that they receive information about the survey recipient's rights. In contrast, opinions varied by survey with regard to the information they receive about services and supports:



SELECTED FINDINGS

More than half of respondents to the adult surveys (adult in the family home and adult outside the family home) indicated that the survey recipient themselves helped make their own service plan (70% and 67%, respectively). Across the three surveys, the proportions of respondents who helped make their family member's service plan varied:



In terms of respondents' opinions on support workers and case managers:

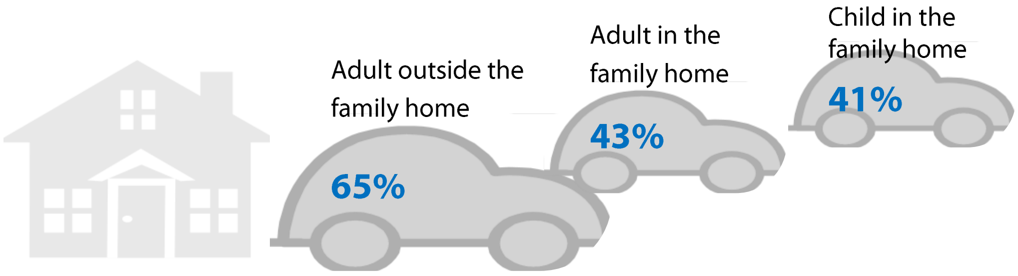
- More than half reported that they were always able to get in contact with their support workers and case manager/service coordinators, respectively, when needed:
  - 55% and 53%, *adult in family home*
  - 61% and 56%, *adult outside family home*
  - 57% and 56%, *child in family home*
- More than half indicated that support workers always had the proper training to meet the needs of their family member:
  - 55%, *adult in family home*
  - 53%, *adult outside family home*
  - 50%, *child in family home*

Access to Services

Most respondents reported that their family member **received all the services listed in their service plan** (88%, *adult in family home*; 93%, *adult outside family home*; and 84%, *child in family home*). When asked if **services and supports change to meet survey recipients' changing needs**, only slightly more than half (54%) said yes among those with an adult outside the family home, and only about two-fifths said yes among those with an adult in family home (40%) and among those with a child in the family home (38%).

SELECTED FINDINGS

Services and supports are always available reasonably close to where the family-member lives"



Among those respondents with a survey recipient in the home receiving services, nearly all report having access to physical health care services and needed medication for their family member:

Health services:

- 96%, *adult in family home*
- 98%, *child in family home*

Needed medication

- 97%, *adult in family home*
- 97%, *child in family home*

However, smaller proportions report consistent access to dental and mental health services:

Dental services:

- 79%, *adult in family home*
- 95%, *child in family home*

Mental health services

- 84%, *adult in family home*
- 90%, *child in family home*

CHOICE, CONTROL, AND SELF-DIRECTION

While results varied by survey type, the survey responses point to possible gaps in the areas of choice, control, and self-direction. Fewer respondents report positive outcomes for these questions than for many of the other survey categories.

RESPONDENT

Knows how much money is spent by the DD agency on behalf of survey recipient:

- 29%, *adult in family home*
- 33%, *child in family home*

Has a say in how money from DD agency is spent on family member's behalf:

- 44%, *adult in family home*
- 46%, *child in family home*

If has a say in how money from DD agency is spent, also has info to decide how agency money is spent:

- 89%, *adult in family home*
- 87%, *child in family home*

Has control over hiring and management of support workers:

- 48%, *adult in family home*
- 64%, *child in family home*

SELECTED FINDINGS

FAMILY MEMBER WITH A DISABILITY

Knows how much money is spent by the DD agency on their behalf:

- 14%, *adult in family home*
- 13%, *adult outside family home*

Has a say in how money from DD agency is spent on their behalf

- 30%, *adult in family home*
- 31%, *adult outside family home*

If has a say in how money from DD is spent, also has info to decide how agency money is spent:

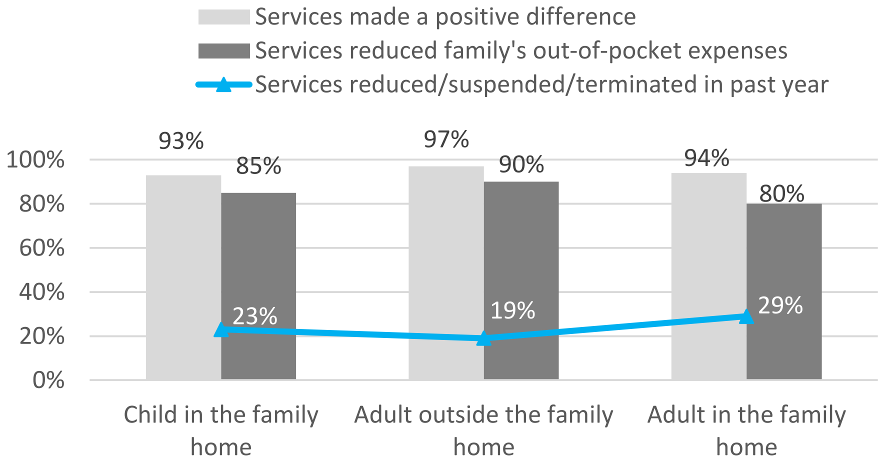
- 90%, *adult in family home*
- 89%, *adult outside family home*

Has control over hiring & management of support workers:

- 34%, *adult in family home*
- 21%, *adult outside family home*

IMPACT OF SERVICES

Nearly all respondents felt that **services and supports made a positive difference for their family member** (94%, *adult in family home*; 97%, *adult outside family home*; and 93%, *child in family home*). Additionally, the majority of respondents across all Family Surveys state that **services and supports have reduced the family's out-of-pocket expenses for care** (80%, 90%, and 85%, respectively). Less than one-third of respondents for each survey reported that services had been reduced, suspended or terminated in the past year:



Among the respondents whose family member had a reduction in services or supports in the past year, close to three-quarters indicated that **the change had affected their family member negatively** (77%, *adult in family home*; 72%, *adult outside family home*; 81%, *child in family home*).

USE OF THE DATA

How States Are Using NCI Data

NCI states use data in a number of ways to inform their quality management processes and to improve the delivery of services and supports to people with intellectual and other developmental disabilities. Many states use their NCI data to:

- Complete CMS waiver requirements
- Increase quality assurance/improvement
- Make state-by-state comparisons
- Assist with community transition
- Provide information for planning to Developmental Disabilities Councils and Quality Councils

The following are examples provided by specific states. For additional examples, visit http://www.nationalcoreindicators.org.

Arizona uses NCI data to identify areas of low performance. These data are then presented to the Statewide Management Team, which works to develop priorities and strategies to improve performance. NCI data have contributed to the Developmental Disabilities Division's decision to increase provider rates to incentivize Community and Supported Employment initiatives. In addition, NCI data have contributed to the creation and allocation of District Employment Specialist positions.

Georgia has also used NCI data to identify areas for improvement. Specifically, public managers in the state noted a troubling yearly increase in the rate of use of psychotropic medications. Using NCI data, state quality management staff found there was an increase in psychotropic medication use over time for all individuals with ID/DD receiving services through the Medicaid Home and Community-Based Services program, and they noted that the rate of psychotropic drug use was increasing even faster for individuals who were transitioning out of institutional settings. They also noticed that the use of psychotropic medications varied by certain demographic characteristics. Based on these findings, the state agency implemented a series of trainings for providers and support coordinators on what informed consent means, the importance of obtaining informed consent for prescription of psychotropic medications, and who can be designated to provide informed consent if the individual is unable to do so.

In addition, the Georgia Human Rights Council began reviewing the case records of all individuals who are prescribed five or more psychotropic medications. Based on these reviews, the Council made recommendations concerning the ongoing medication regimen.

Data following the implementation of these reforms eventually showed a decrease in psychotropic medication use.

USE OF THE DATA

The Kentucky NCI Quality Improvement Committee presented a series of recommendations to the Kentucky Division of Developmental and Intellectual Disabilities (DDID) in 2010. Based around NCI data, the recommendations included goals regarding employment, health and exercise, medications and loneliness. The DDID endeavored to implement several changes to its service delivery systems as a result, including:

- Changes to the Supports for Community Living (SCL) Waiver to increase rates of individuals receiving supported employment and to decrease the use of non-work day activity/day habilitation services.
- Amendment to the SCL Waiver menu of services to include a service called “Community Access” to support people with disabilities to engage in community life.
- Initiation of partnerships with the Human Development Institute at the University of Kentucky and the University of Illinois-Chicago. This collaboration led to pilot projects such as an evidence-based wellness and health curriculum.
- Development of various health risk screening tools and scales, as well as new services to increase health and wellness.

Missouri uses NCI data to assist with performance improvement and benchmarking efforts. Upon examining NCI data, Missouri decided to collect further data on the use of psychotropic drugs among individuals in the state using services. This led to the implementation of quality improvement strategies to address the over-prescription of drugs.

In addition, Missouri is in the process of developing an improved Quality Enhancement (QE) Review that integrates the NCI survey, the HCBS new rule, and Missouri Quality Outcomes. The new QE review process will support the assessment of current services and individual outcomes related to quality of life. The review process will help MO provide immediate feedback to Support Coordinators and other members of an interdisciplinary team. System-wide adjustments and quality improvement can be made based on the information and recommendations gathered from this Quality Enhancement review. Missouri hopes to pilot the new review process in 2015-16.

North Carolina produces reports for each Local Management Entity (LME)/Managed Care Organization (MCO). In 2011, the state used NCI data in a report that compared outcomes for managed care LMEs and non-managed care LMEs. North Carolina also looks closely at the text comments provided by respondents to the NCI Family Surveys. All comments are sent for review to the Advocacy and Customer Support section and the Department of Mental Health, and they conduct content analysis to address common themes. North Carolina also uses its data as part of the C waiver measures reported to CMS; in

Division/Department legislative reports; in reports published for public consumption; and in reports distributed to LME/MCOs and in discussions with them regarding their QI processes and initiatives.

Yearly, the state of Washington convenes a group of volunteers recruited by the Developmental Disabilities Council. This committee reviews and makes systems change recommendations to the Division on Developmental Disabilities based on the NCI data reports. Some examples of policy and programmatic changes resulting from these recommendations are:

- The development of a website and a podcast from which information for families and caregivers is easily accessible.
- The development of a project to help schools prepare people leaving school for a more inclusive life.
- The development of an information template to go annually to each person/family receiving services informing them of the costs of the services they received in the past fiscal year.
- Revised case manager training that emphasizes the need to encourage service recipients to ask for what they want.
- The development of trainings for individuals with disabilities on general safety.
- A collaboration between DDD and staff from the University of Washington that is working to find ways to impart information to primary care doctors on the unique care needs of individuals with developmental disabilities.

Many states, such as Tennessee and Michigan, convene committees and quality improvement councils to assess the data annually and develop priorities that are presented to stakeholders and lawmakers. In addition, some states use the NCI data for regulatory reporting to CMS.

Information on the National Core Indicators

THE INDICATORS

The NCI framework includes approximately 100 performance and outcome indicators organized across five broad domains: Individual Outcomes, Health Welfare & Rights, Staff Stability & Competency, Family Outcomes, and System Performance. Each domain is broken down into sub-domains representing specific expectations. For example, “Work” is a sub-domain of Individual Outcomes. Performance indicators for the Work sub-domain assume that individuals receiving services have support to find and maintain community-integrated employment. The sub-domains are measured by one or more performance indicators developed by the steering committee of participating states.

Domains and sub-domains addressed by NCI surveys

Individual Outcomes
- Work
- Choice

Family Outcomes
- Access and Support Delivery

Health, Welfare and Rights
- Rates of receiving preventive health care services

System Performance
- Access

These performance indicators were developed based on a set of criteria including face validity, usefulness as a benchmark, and feasibility to collect. Indicators have remained largely consistent over the years. However, the indicators are reviewed annually and revisions are made from time to time to keep up with the current trends and thinking in the ID/DD field.

Some indicators are measured using survey data gathered on a sample of individuals, while others are computed using population data available through state data systems. Survey tools are regularly refined and tested for validity and reliability. You can view the full list of core indicators at www.nationalcoreindicators.org/indicators.

This report highlights selected aggregate results from the 2013-14 Adult Consumer and Family Surveys. Detailed summary reports of state-by-state results and national averages for all NCI measures are available at www.nationalcoreindicators.org. The full reports are organized by data source.

NCI INFORMATION

DATA SOURCES

Four primary data sources are referenced in this report. The Adult Consumer Survey gathers information from service recipients in a face-to-face meeting. Participating states interview a random sample of at least 400 individuals. The three Family Surveys are administered by mail. The Family Surveys collect family and guardian perspectives on the quality of services and supports received by adults living at home, adults living outside the home, and children living at home. For each Family Survey, states typically send out 1,000 to 1,200 surveys in order to obtain a target return of 400 responses per survey. The table below provides a brief description of the target population for each survey, the method of administration, the total number of states that used each tool in 2013-14, and the total number of surveys collected overall.

SUMMARY OF SURVEYS 2013-14

NCI SURVEY	TARGET POPULATION	METHOD OF ADMINISTRATION	# STATES 2013-14	# TOTAL SURVEYS
Adult Consumer Survey (ACS)	Adults 18 and older receiving at least one service besides case management	In-person interview	30	16,370
Adult Family Survey (AFS)	Families of adults 18 and older living at home	Mail	14	8,123
Family/Guardian Survey (FGS)	Families or guardians of adults 18 and older living outside the home	Mail	12	6,835
Children/Family Survey (CFS)	Families of children under 18 (or under 23 if still in school system) living at home	Mail	8	2,199

LINKS TO FULL REPORTS AND CHART GENERATOR

Detailed reports on Adult Consumer and Family Survey outcomes by state with national average comparisons, as well as Data Briefs and other special reports, can be found at nationalcoreindicators.org/resources/reports. The Chart Generator, a special feature of the NCI website, allows users to create custom charts using state or national Adult Consumer Survey data. The Chart Generator can be accessed via the homepage or directly via nationalcoreindicators.org/charts.

ANALYSIS

NCI data management and analysis is coordinated by HSRI. For the 2013-14 survey cycle, states entered data into the Online Data Entry Survey Application (ODESA) system, which HSRI staff subsequently downloaded into an SPSS data file. A few states entered data into their own data files and submitted those files to HSRI for analysis. Separate data files were kept for each survey.

All data files were reviewed for completeness and compliance with standard NCI formats. Invalid responses were eliminated. All state files were then merged into one SPSS file for each survey type. Data from those four merged files were used for the 2013-14 reports as well as analyses in this report. Please note that Mississippi and New Mexico completed Adult Consumer Survey data collection for the 2013-14 cycle, but are not included in this report because survey administration processes did not align with administration protocol.

Please also note that the averages shown in this report are aggregate averages—that is, the averages of all cases, and *not* the averages of the state averages shown in the 2013-14 survey reports**. Therefore, the data shown in this Annual Report may not match those shown in the 2013-14 survey reports.**

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