National Core Indicators | NASDDDS & HSRI

NCI ANNUAL SUMMARY REPORT 2011 - 2012

National Core Indicators (NCI), a joint venture between the National Association of State Directors of Developmental Disabilities Services and the Human Services Research Institute, 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 additionally have been used as the basis of data briefs on specific areas of interest such as employment, dual diagnosis, self-directed services, and autism spectrum disorders.

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.

As of June 2012, the NCI collaboration included 29 participating states and 23 sub-state entities. We are pleased to launch the fifth NCI Annual Summary Report, which highlights activities and key findings from 2011-2012.

Mary Lee Fay
Director of NCI
National Association of State Directors
of Developmental Disabilities Services

Valerie J. Bradley
President
Human Services Research Institute

Cover Art: “Rainbow Blocks’” by Jody St. Onge

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http://www.theriotrocks.org/spotlight-studios

INTRODUCTION

National Core Indicators (NCI) began in 1997 as a collaborative effort between the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI). The goal of the program was to encourage and support NASDDDS member agencies to develop a standard set of performance measures that could be used by states to manage quality and across states for making comparisons and setting benchmarks. Fifteen (15) states initially stepped forward to work on the Core Indicators Project, as it was originally known, and pooled their resources to develop valid and reliable data collection protocols. Over time, NCI has become an integral component of over half the states' quality management systems and aligns with basic requirements for assuring quality in HCBS Waivers. NCI states and project partners continue to work toward the vision of utilizing NCI data not only to improve practice at the state level but also to add knowledge to the field, to influence state and national policy, and to inform strategic planning initiatives for NASDDDS.

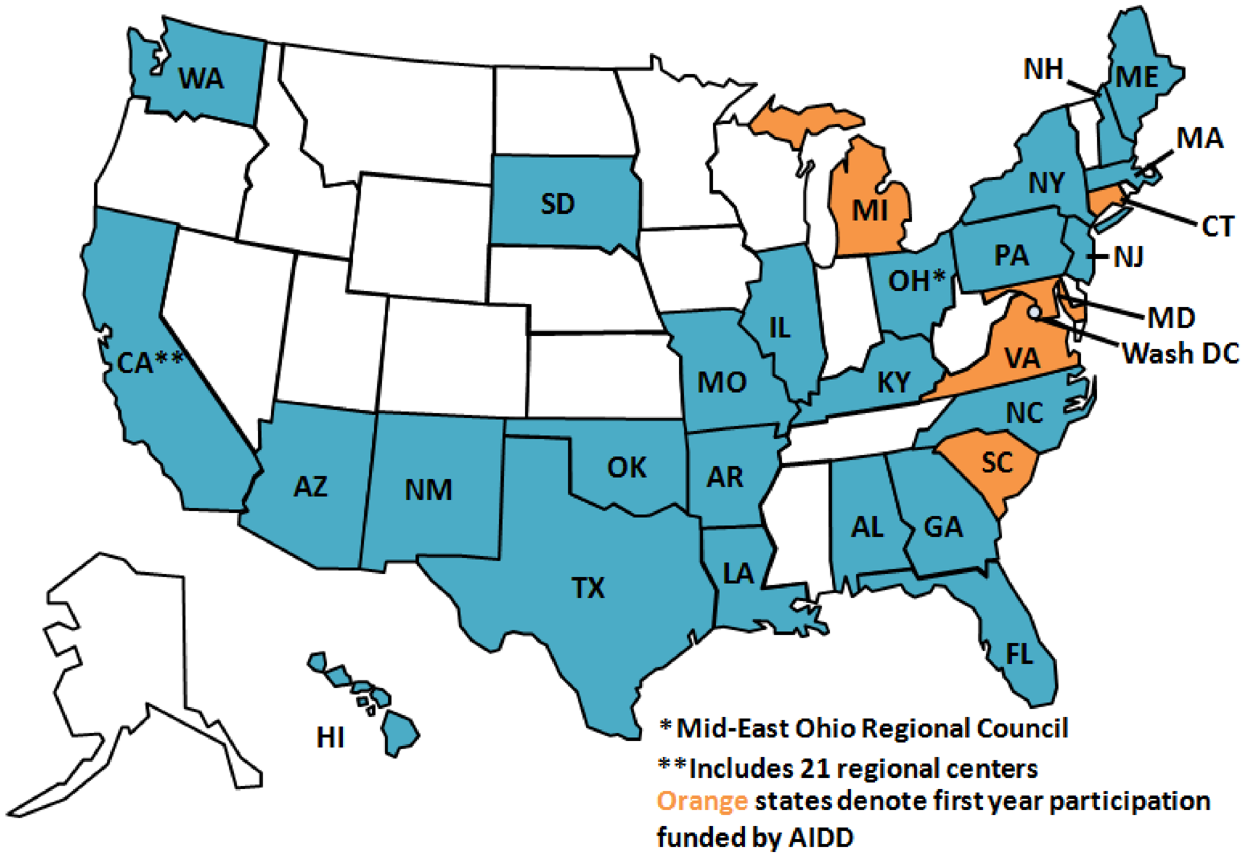
NCI Vision:

- Influence national and state policy
- Improve practice at the state level
- Add knowledge to the field
- Inform the Association's strategic planning and priority setting

PARTICIPATING STATES

In 2011-2012, the membership of NCI included 29 states, Washington D.C., and 22 sub-state entities (see Figure 1).

FIGURE 1. PARTICIPATING NCI STATES 2011-12



* Mid-East Ohio Regional Council

** Includes 21 regional centers

Orange states denote first year participation funded by AIDD

Core 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. These performance indicators were developed based upon 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 I/DD field.

Individual Outcomes
- Work
- Choice

Family Outcomes
- Access and Support Delivery

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

System Performance
- Access

Domains and Sub-domains addressed in this report

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 (e.g., mortality reports). Survey tools are regularly refined and tested for validity and reliability. The full list of core indicators may be viewed on the NCI website at: http://nationalcoreindicators.org/indicators/.

This report highlights selected aggregate results from the 2011-12 Adult Consumer and Family Surveys. Detailed summary reports of state by state results and national averages for all NCI measures are available on the website at: http://www.nationalcoreindicators.org. The full reports are organized by data source.

2011-12 Accomplishments, Activities, and On-Going Efforts

NCI continued its expansion with the support of the Administration on Intellectual and Developmental Disabilities (AIDD) which awarded NASDDDS a contract in 2010 to expand NCI. Through the contract, funding is being made available to up to five new states each year for the next five years with the goal of increasing NCI participation to all 50 states, Washington D.C., and all U.S. territories by 2016. This year NCI was made up of 29 states and 22 sub-state entities with over 20,000 individuals and families surveyed. Five new states joined NCI in 2011-12: Connecticut, Maryland, Michigan, Virginia, and South Carolina.

NCI welcomed Mary Lee Fay of NASDDDS as its new Director of NCI. Mary Lee has played an integral role in supporting states and helping them use NCI to measure quality. Prior to her work with NASDDDS and NCI, Mary Lee served as Oregon’s Director of Developmental Disabilities Services for 11 years. The NCI team wants to thank Chas Moseley, who served as the NASDDDS previous NCI director, for his work and continued commitment to the project.

NCI program staff developed a new implementation guide detailing how to use NCI data for quality improvement initiatives. The handbook is called the “Using NCI Data for Quality Improvement Initiatives.” The handbook was created to enhance the use and application of information generated through the collection of NCI data. The audience for this guide includes managers of state intellectual and developmental disabilities (I/DD) systems, service providers, board members, people with disabilities and their family members, and other interested advocates. The guidebook is available on the NCI website at: http://www.nationalcoreindicators.org/resources/guides/.

This year NCI produced state specific versions of the User-Friendly Adult Consumer Survey Report, "What We Have Learned from the NCI Adult Consumer Survey." California's Consumer Advisory Committee (CAC) was instrumental in developing this new resource for disseminating NCI data. The first national user-friendly report was released in 2010-11. The report features data from 20 questions with outcomes described in plain language and accompanying pie charts. National and state user-friendly reports are currently available on the NCI website at: http://nationalcoreindicatiors.org/reports. NCI program staff are working with the CAC to develop a user-friendly version of the Family Survey Reports as well as a user-friendly version of the "Using NCI Data for Quality Improvement Initiatives" guidebook.

The journal **Public Health Reports** published an article by NCI staff entitled "Place of Residence and Preventive Health Care for Developmental Disabilities Services Recipients in Twenty States." This publication was special in that it was a rare opportunity for NCI data to be presented in a journal that was not specific to I/DD issues. NCI also produced a Data Brief on employment. The findings from "What Work Means: What does NCI tell us about the quality of life of adults with intellectual and developmental disabilities who are employed in the community?" were presented at the University Centers on Disabilities (AUCD) conference and during the Supported Employment Leadership Network (SELN) meeting at the Alliance for Full Participation (AFP) conference in November. These and other Data Briefs can be found at: www.nationalcoreindicators.org/databriefs.

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. Additionally, 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. Figure 2 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 2011-12, and the total number of surveys collected overall.

FIGURE 2. SUMMARY OF SURVEYS BY STATE 2011-2012

NCI Survey	Target Population	Method of Administration	# States 2011-12	# Total Surveys
Adult Consumer Survey	Adults 18 and older receiving at least one service besides case management	In-person interview	19	12,236
Adult Family Survey	Families of adults 18 and older living at home	Mail	14	5,567
Family/Guardian Survey	Families or guardians of adults 18 and older living outside the home	Mail	10	3,530
Child Family Survey	Families of children under 18 (or under 23 if still in school system) living at home	Mail	5	1,481

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 are available on the NCI website: http://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 by going directly to: http://nationalcoreindicators.org/charts/.

ANALYSIS

NCI data management and analysis is coordinated by HSRI. For the 2011-2012 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 2011-2012 reports as well as analyses in this report.

SELECTED RESULTS 2011-2012

Family Outcomes

In 2011-2012, 14 states collected a total of 5,567 Adult Family Surveys (AFS), 10 states collected a total of 3,530 Family/Guardian Surveys (FGS), and five states collected a total of 1,481 Child Family Surveys (CFS). Responses to Family Survey outcomes are based on either a 5-point Likert scale (always, usually, sometimes, seldom, or never) or dichotomous yes or no responses. Families have the option to also write open-ended comments.

Selected Demographics

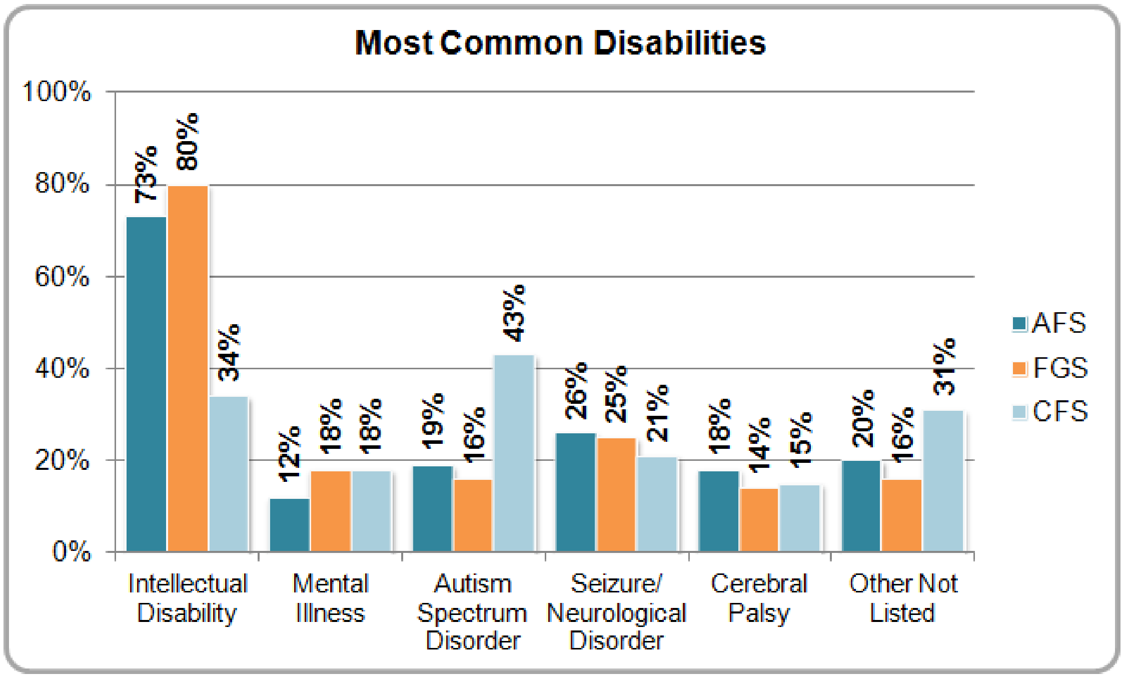
For all three Family Surveys, a higher percentage of respondents indicated their family member receiving services was male (56% AFS, 59% FGS, 66% CFS) compared to female. On average, individuals for whom the Family/Guardian Survey was completed were over a decade older than those for whom the Adult Family Survey was completed (45 years old compared to 34). The average age of children for whom the Child Family Survey was completed was 11.

For all surveys, respondents were most frequently a parent of the family member with a disability (86% AFS, 58% FGS, 95% CFS). Other respondents included a sibling or other family member. In some cases a staff person completed the Family/Guardian Survey – since this particular survey captures both family members and non-related respondents who are not family members, we expected fewer parents responding.

Other Disabilities

As illustrated in Figure 3, the most common disabilities from all three surveys were intellectual disability, mental disorder, Autism Spectrum Disorder (ASD), seizure or neurological disorder, cerebral palsy, or another disability not listed. A majority of family members from the Adult and Family/Guardian Surveys had an intellectual disability (73% and 80%, respectively) and just over one-third of children had this diagnosis (34%), as indicated in the Child Family Survey. However, more than twice as many respondents for the Child Family Survey reported the child was diagnosed with ASD (43%) than those adult family members diagnosed with ASD as indicated by the AFS (19%) and FGS (16%).

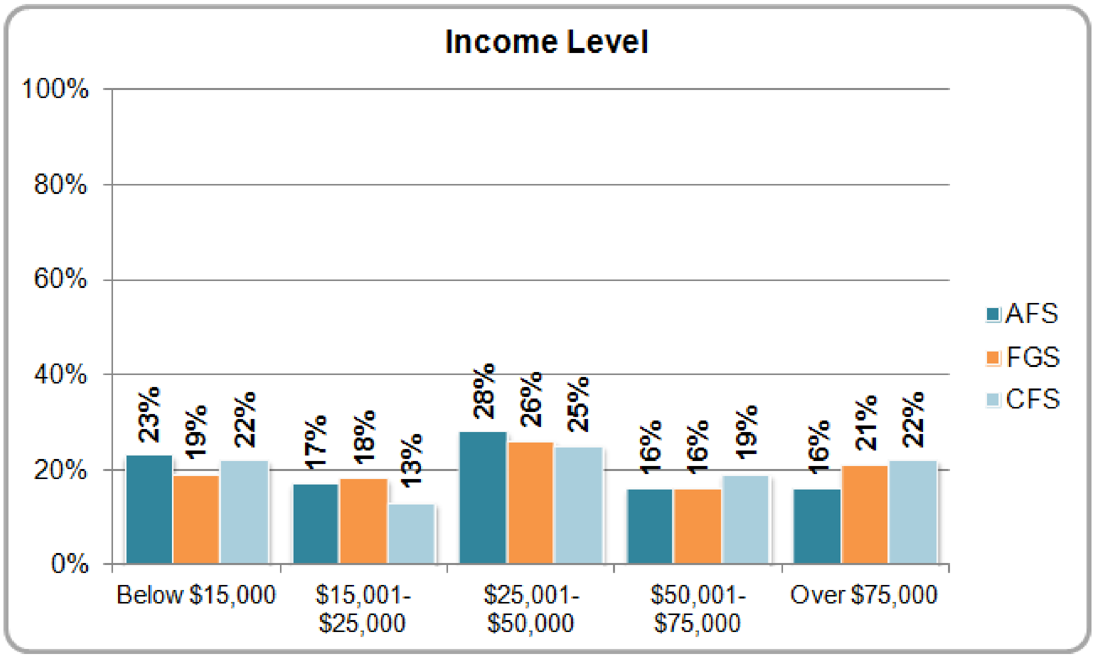
FIGURE 3. TYPE OF DISABILITY BY FAMILY SURVEY



Income Levels

Household income tended to be similar for respondents of all surveys with a majority of respondents falling within a range at or below $25,001-$50,000 per year (see Figure 4 below).

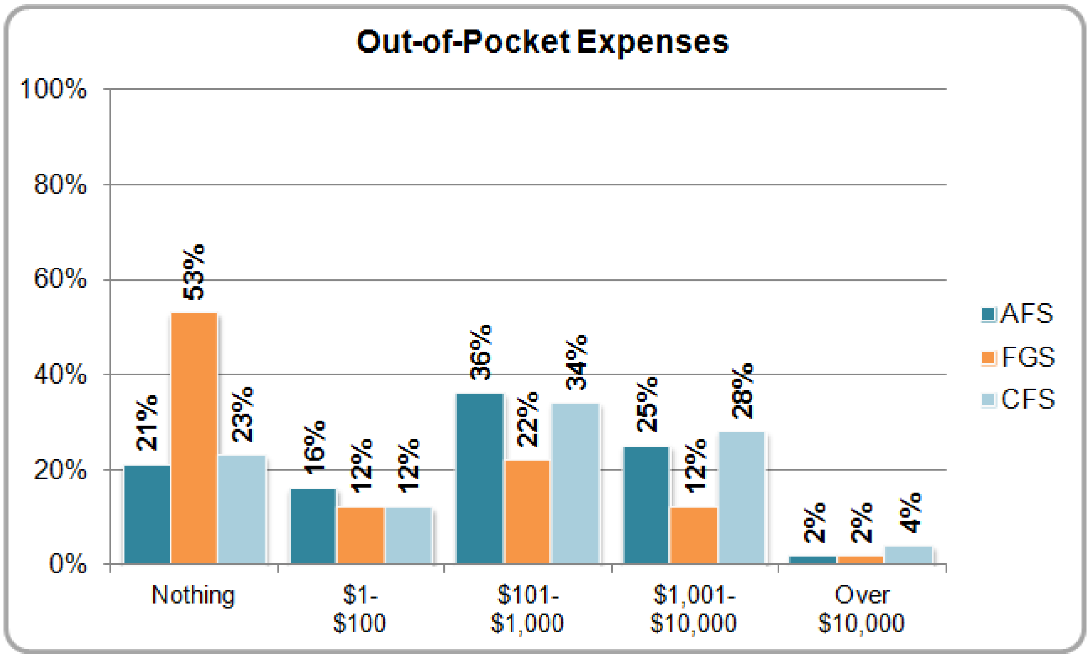
FIGURE 4. HOUSEHOLD INCOME BY FAMILY SURVEY



Out-of-Pocket Expenses

As illustrated in Figure 5 below, over half of Family/Guardian Survey respondents reported they did not spend out-of-pocket money on services or supports for their family member in the past year (53%), while 21% Adult Family Survey and 23% Child Family Survey respondents did not use out-of-pocket expenses in the past year. The highest percentage of respondents from the Adult and Child Family Surveys spent between $101 and $1,000 (36% and 34% respectively).

FIGURE 5. OUT-OF-POCKET EXPENSES IN THE PAST YEAR BY FAMILY SURVEY



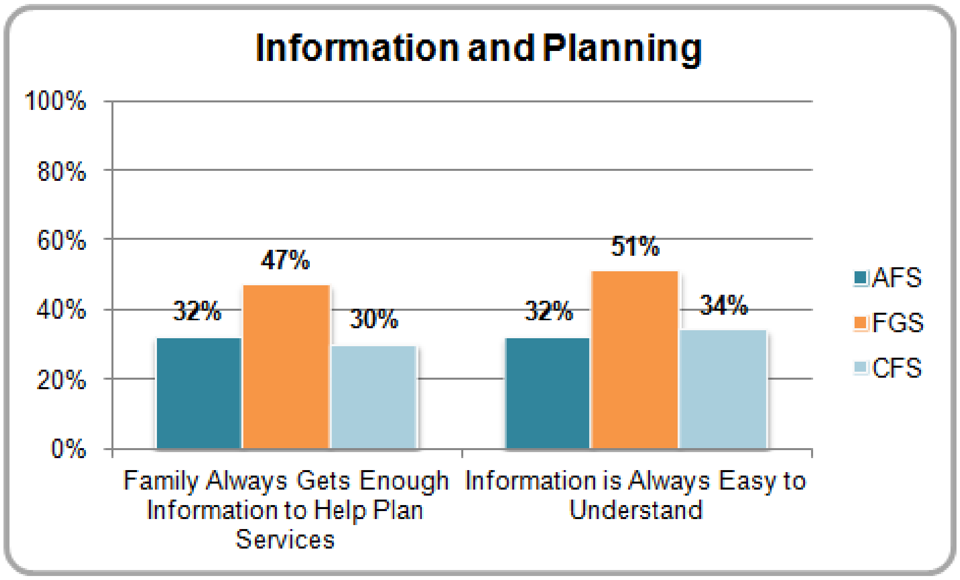
Information and Planning

Family member's case manager/service coordinator is always knowledgeable:

- 51% AFS
- 60% FGS
- 47% CFS

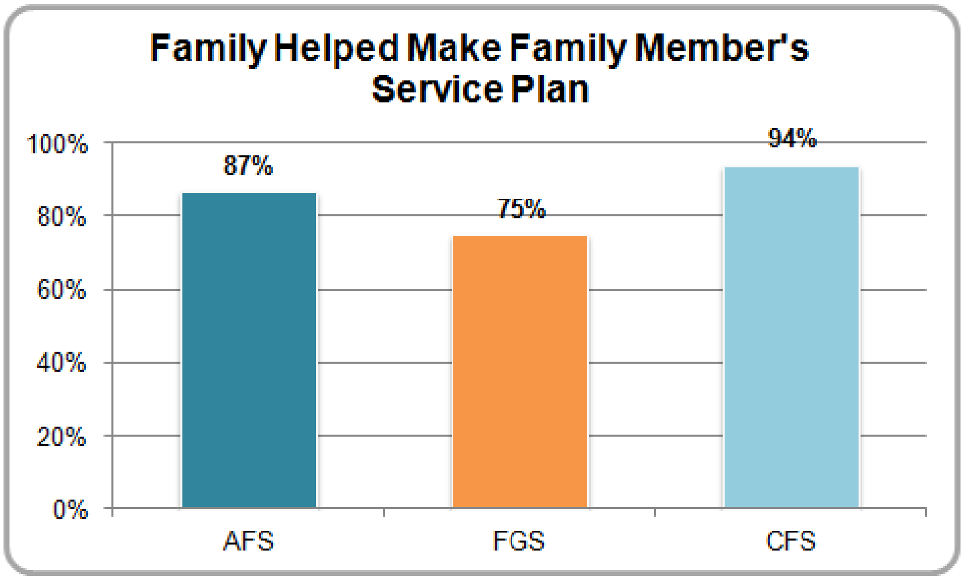
Around half of the respondents for the Family/Guardian Survey reported they always get enough information to help plan their family member's services (47%) and information about services and supports was always easy to understand (51%). Around one-third of Adult and Child Family respondents reported they always received enough information to help plan (32% and 30%) and information about services and supports was always easy to understand (32% and 34%). These results are shown in Figure 6 below. The vast majority of respondents reported they received information about their family member's rights (94% AFS, 93% FGS, and 91% CFS).

FIGURE 6. INFORMATION ABOUT SUPPORTS AND SERVICES



As illustrated in Figure 7 below, anywhere from three-quarters to over 90% of respondents, depending on which survey, reported they or another family member helped create their family member's service plan. Just over half of the Adult Family and Family/Guardian Survey respondents indicated their family member helped make their own service plan (58% and 57%). The vast majority of respondents indicated the service plan includes things that are important to the family (93% AFS, 96% FGS, and 94% CFS).

FIGURE 7. FAMILY HELPS MAKE SERVICE PLAN BY FAMILY SURVEY



Access and Support Delivery

As illustrated in Figure 8 below, more than half of respondents from all Family Surveys reported they were always able to get in contact with their support workers and case manager/service coordinator when needed (54% and 53% AFS, 63% and 58% FGS, 52% and 53% CFS). Over half of the respondents for all surveys indicated support workers always had the proper training to meet the needs of their family member (52% AFS, 51% FGS and 51% CFS).

Healthcare Access

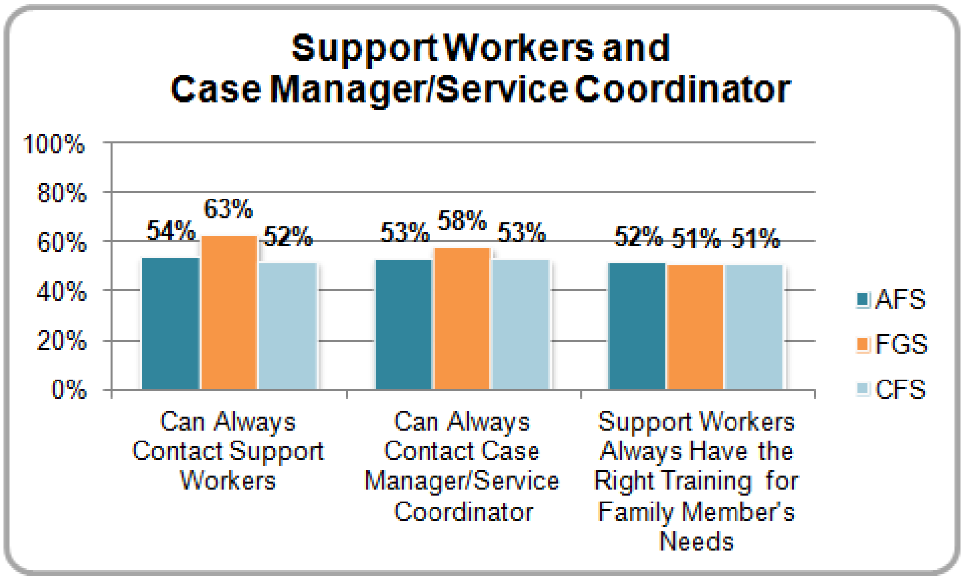
Health services:
98% AFS and 97% CFS

Dental services:
80% AFS and 91% CFS

Needed medication:
97% AFS and 97% CFS

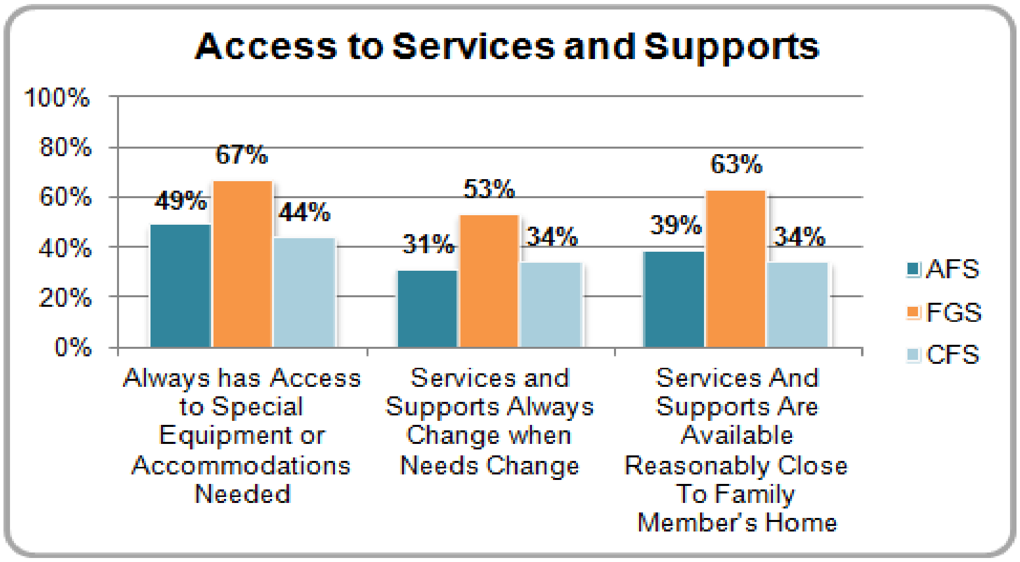
Mental health services:
84% AFS and 81% CFS

FIGURE 8.SUPPORT WORKERS AND CASE MANAGER/SERVICE COORDINATOR BY FAMILY SURVEY



A majority of respondents reported their family member received all services listed in their service plan (54% AFS, 60% FGS, and 60% CFS). However, just 43% of respondents for both the Adult Family and Child Family Surveys indicated their family member always got all services needed. A lower percentage reported the family always got all services they needed (39% AFS and 37% CFS). Shown in Figure 9 below, just over half of the Family/Guardian Survey respondents reported services and supports changed to meet their family member's changing needs (53%). This was true for only about one-third of Adult Family and Child Family Survey respondents (31% and 34%).

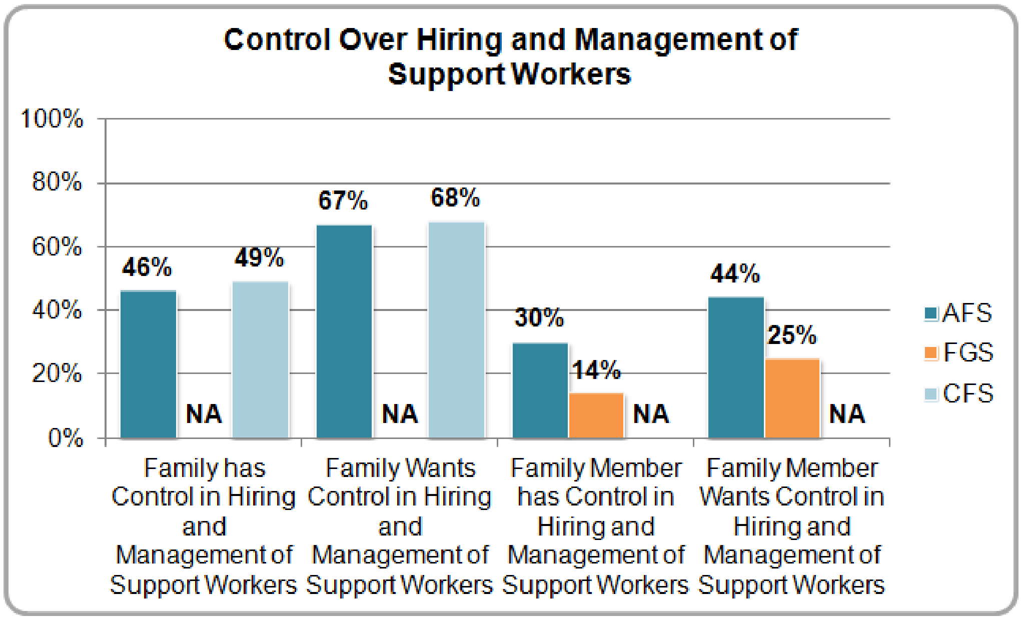
FIGURE 9. ACCESS TO SERVICES AND SUPPORTS BY FAMILY SURVEY



Choice and Control

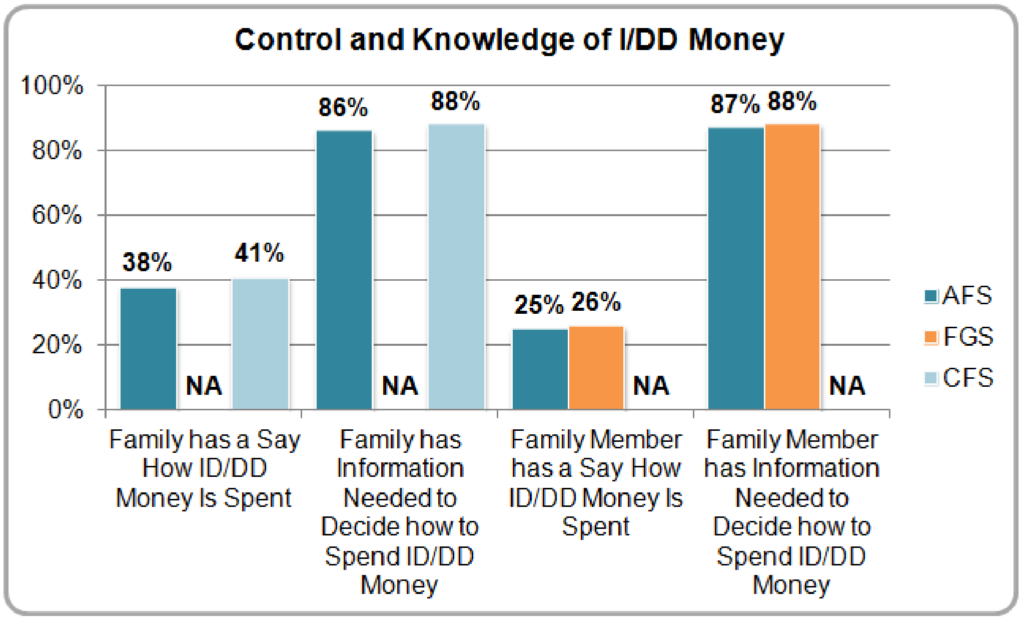
As illustrated in Figure 10 below, just under half of the Adult Family and Child Family Survey respondents reported they or another family member had at least some control or input in hiring and managing their family member's support workers (46% and 49%). Approximately two-thirds indicated they wanted to have this control (67% and 68%). Similarly, lower percentages of Adult Family and Family/Guardian Survey respondents reported their family member had control or input in managing their support workers (30% and 14%) than those that indicated their family member wanted this control (44% and 25%).

FIGURE 10.CONTROL OVER HIRING AND MANAGEMENT OF SUPPORT WORKERS BY FAMILY SURVEY



Similar proportions of Adult Family and Child Family Survey respondents knew how much money was spent by ID/DD agencies for the care of their family member (27% and 30%). Just 12% of Adult Family and 11% of Family/Guardian Survey respondents reported their family member knew how much money was spent by the ID/DD agency on their behalf. Shown in Figure 11 below, of those who reported they or their family member helped decide how I/DD money was spent on their family member, most reported they had all the information needed to make this decision.

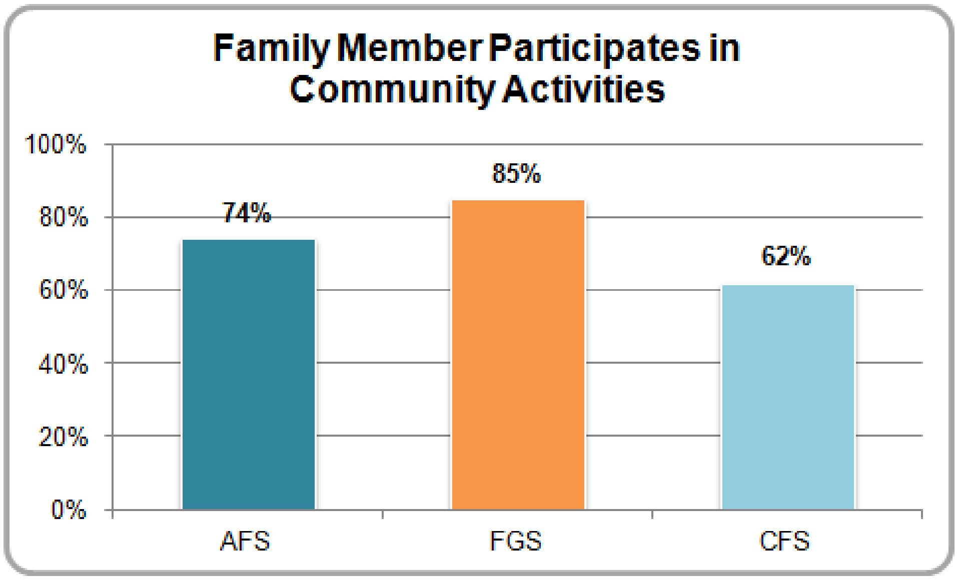
FIGURE 11.CONTROL AND KNOWLEDGE OF I/DD MONEY BY FAMILY SURVEY



Community Connections

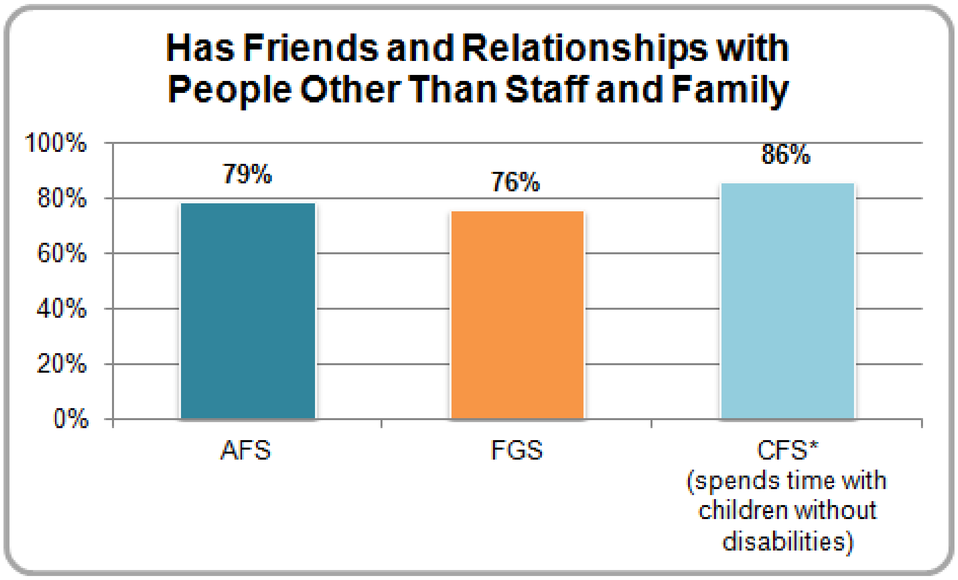
As seen in Figure 12 below, the majority of respondents reported their family member participated in community activities (74% AFS, 85% FGS, and 62% CFS). The majority of Adult Family and Family/Guardian Survey respondents also reported their family member has the support needed to work or volunteer in the community (63% AFS and 69% FGS).

FIGURE 12. FAMILY MEMBER PARTICIPATES IN COMMUNITY ACTIVITIES BY FAMILY SURVEY



As illustrated in Figure 13 below, over three-quarters of respondents reported their family member has meaningful relationships with people other than support workers and family (79% AFS and 76% FGS). Eighty-six percent (86%) of Child Family Survey respondents indicated the child spends time with children without disabilities.

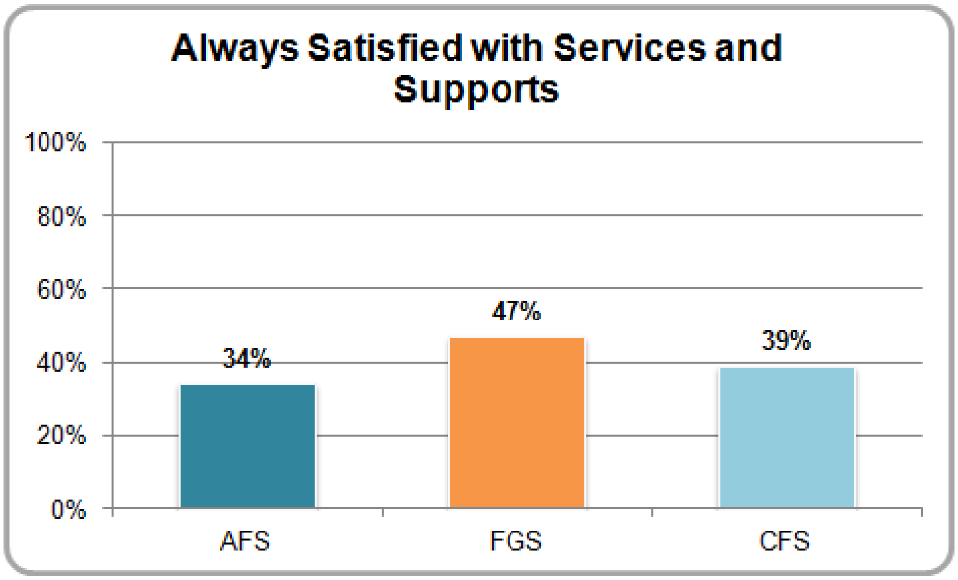
FIGURE 13.FRIENDS AND RELATIONSHIPS BY FAMILY SURVEY



Satisfaction

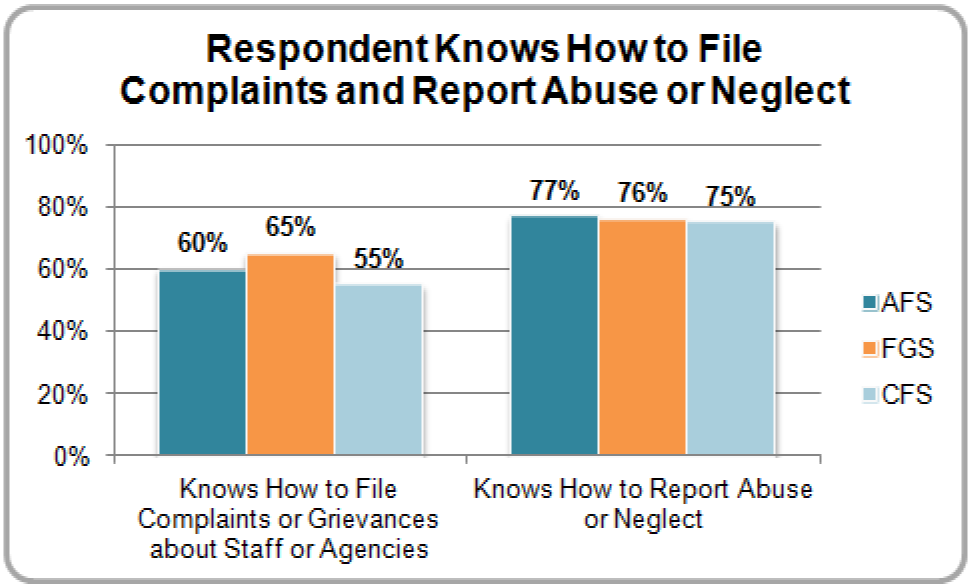
As demonstrated by Figure 14 below, less than half of the respondents from each survey indicated they were always satisfied with their family member's services and supports (34% AFS, 47% FGS, and 39% CFS).

FIGURE 14.SATISFACTION WITH SERVICES AND SUPPORTS BY FAMILY SURVEY



As shown in Figure 15 below, the majority of respondents know how to file complaints or grievances about provider agencies or staff. A large majority also reported they were satisfied with the way complaints and grievances are handled (81% AFS, 85% FGS, and 77% CFS). Also shown in Figure 15, at least three-quarters of respondents in each survey know how to report abuse or neglect (77% AFS, 76% FGS, and 75% CFS). Of those who filed a report of abuse or neglect in the past year, approximately three-quarters found the appropriate parties responsive to their report[1] (78% AFS and 74% FGS).

FIGURE 15.KNOWS HOW TO FILE COMPLAINT AND ABUSE AND NEGLECT REPORTS



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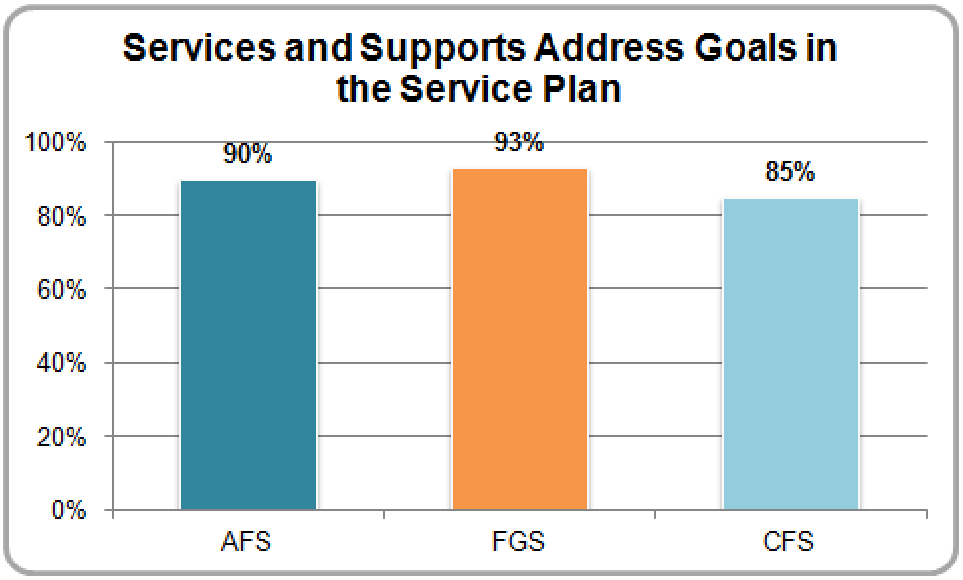
[1] For this question, there were too few cases to report results from the Child Family Survey.

Outcomes

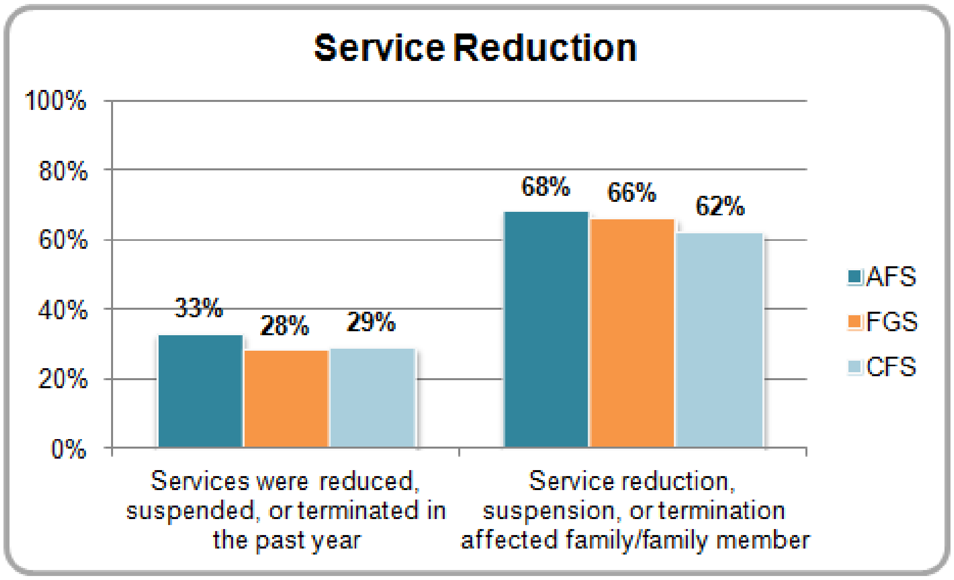
The vast majority of respondents felt services and supports made a positive difference for their family member (94% AFS, 97% FGS, and 90% CFS). Shown in Figure 16 below, most indicated their family member's services and supports address the goals in their service plan.

FIGURE 16.SERVICES AND SUPPORTS ADDRESS GOALS IN THE SERVICE PLAN



As illustrated in Figure 17 below, one-third or less of respondents from each survey reported their family member's services or supports had been reduced, suspended, or terminated in the past year (33% AFS, 28% FGS, and 29% CFS). Of the respondents whose family member had a reduction in services or supports in the past year, the approximately two-thirds from each survey indicated the reduction affected their family member (68% AFS, 66% FGS, and 62% CFS).

FIGURE 17. SERVICE REDUCTION



INDIVIDUAL OUTCOMES

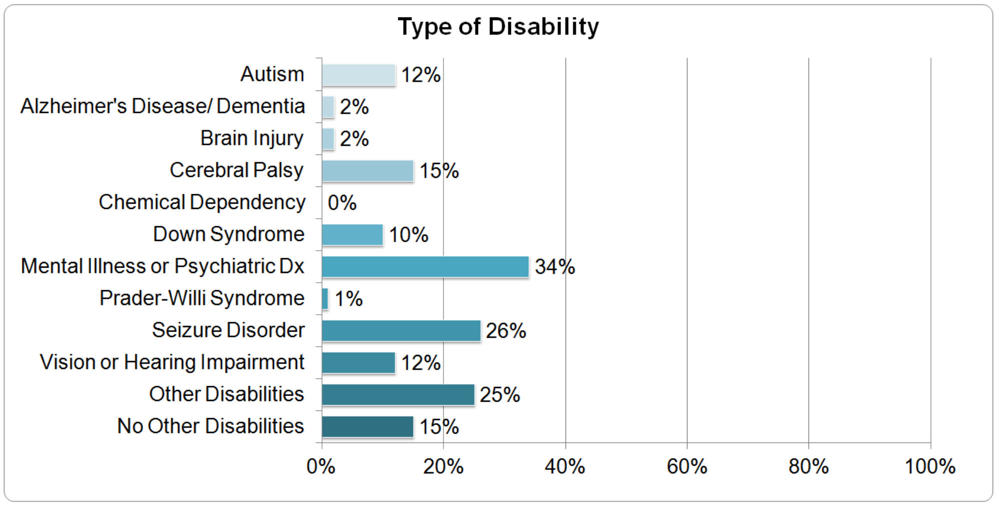
Sample Characteristics

For 2011-2012, a total of 12,236 Adult Consumer Surveys in 19 states and one sub-state entity are represented in this report.

Disabilities

Only 15% of all people surveyed did not have some type of disability in addition to ID/DD (Figure 18). The most common disabilities were mental illness or psychiatric diagnosis (34%), seizure disorder (26%), and cerebral palsy (15%).

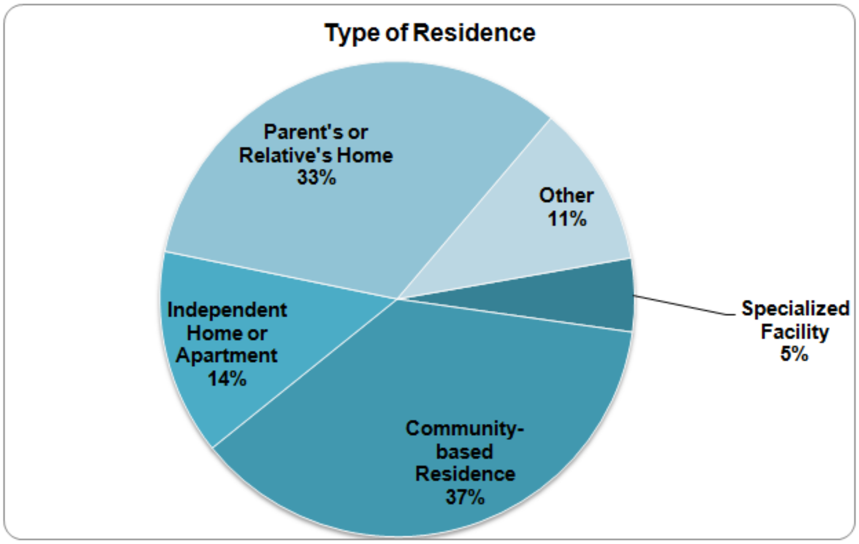
FIGURE 18. PROPORTION OF PEOPLE WITH OTHER DISABILITIES



Residence

As is shown in Figure 19, the majority of people surveyed were living either in a community-based residence (which includes group home and agency-operated apartment-type setting) (38%) or with a parent or relative (34%).

FIGURE 19. PROPORTION OF PEOPLE- IN TYPES OF RESIDENCE



Self-Direction

Only 7% of people were identified as using a self-directed supports option. That proportion varied from 0% in one state to 18% in the highest performing state. The type of residence also mattered – people living in a parent's home were most likely to self-direct (12%), followed by people living in independent home (8%).

Employment

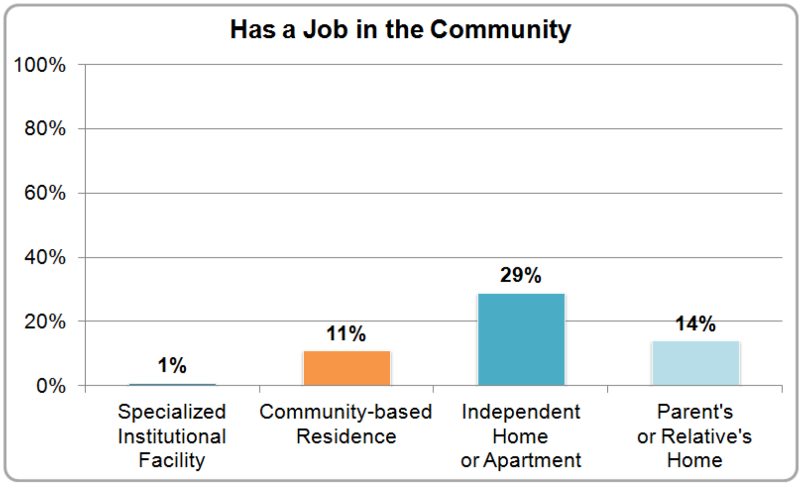
In 2011-2012, 14% of people had a paid job in the community; the average hourly wage in community jobs was $7.89 – the federal minimum wage in 2012 was $7.25. Twenty-nine percent (29%) of people living in their own home or apartment, 11% living in community-based residences and 14% living with a parent or relative had a paid community job (Figure 20). Only 29% of people with a paid community job who were surveyed received benefits (vacation and/or sick leave). Of people surveyed, the four most common types of paid community jobs were: cleaning and maintenance (32%), food preparation (22%), retail (12%), and assembly and manufacturing (6%).

Hourly Wage by Residence*

- Parent or Relatives Home: $7.98
- Community-based Residence: $7.97
- Independent Home or Apartment: $7.24

*Too few cases to report hourly wage information by institution

FIGURE 20. EMPLOYMENT STATUS BY TYPE OF RESIDENCE

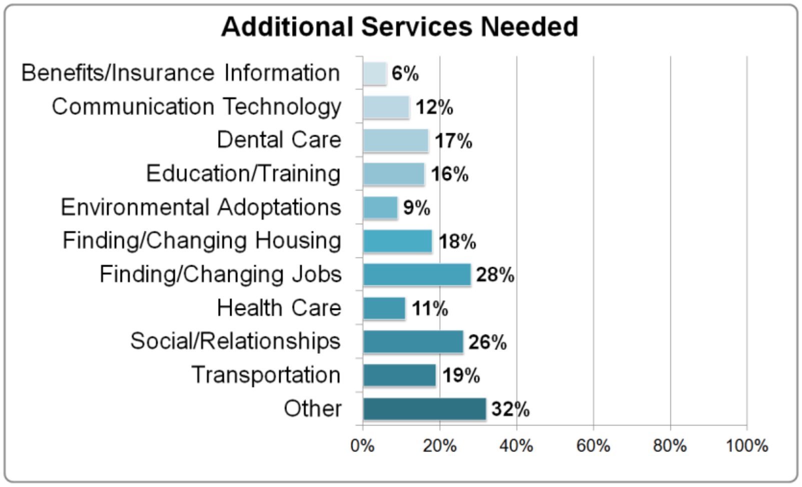


System Performance

Access

A large majority of people reported that their staff had adequate training (92%) and that they got needed services (83%). Of those who reported they did not get needed services, the most common needs were: finding or changing jobs (28%), social and/or relationship areas (26%) and transportation (19%) (Figure 21).

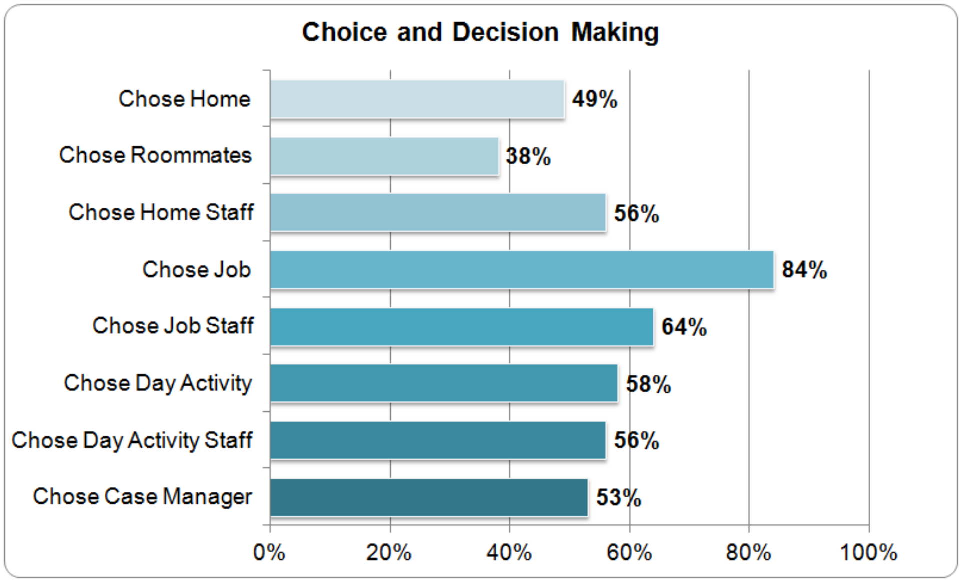
FIGURE 21. SERVICES NEEDED



Choice and Decision-Making

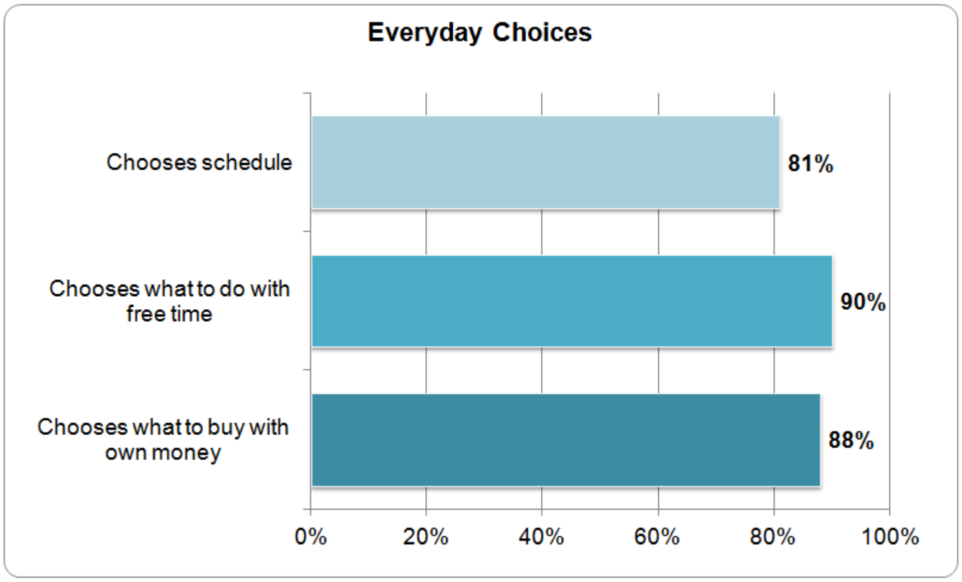
Many respondents reported that they did not have input in major life decisions such as where and with whom they live and where they go during the day. As illustrated in Figure 22, 49% chose their home, and 38% chose their roommates. Though 84% had input into where they work, only 58% had input into where they go during the day (their non-work day activity). Furthermore, 64% had input into choosing their work staff and 56% their day activity staff. Fifty-six percent (56%) chose their home staff, and 53% percent of persons surveyed chose his/her case manager.

FIGURE 22. PROPORTION OF PEOPLE WHO HAD INPUT INTO MAJOR LIFE CHOICES



A higher proportion of people reported having input into every day decisions such as choosing their own schedule (81%), how to spend free time (90%), and how to spend their money (88%) (Figure 23).

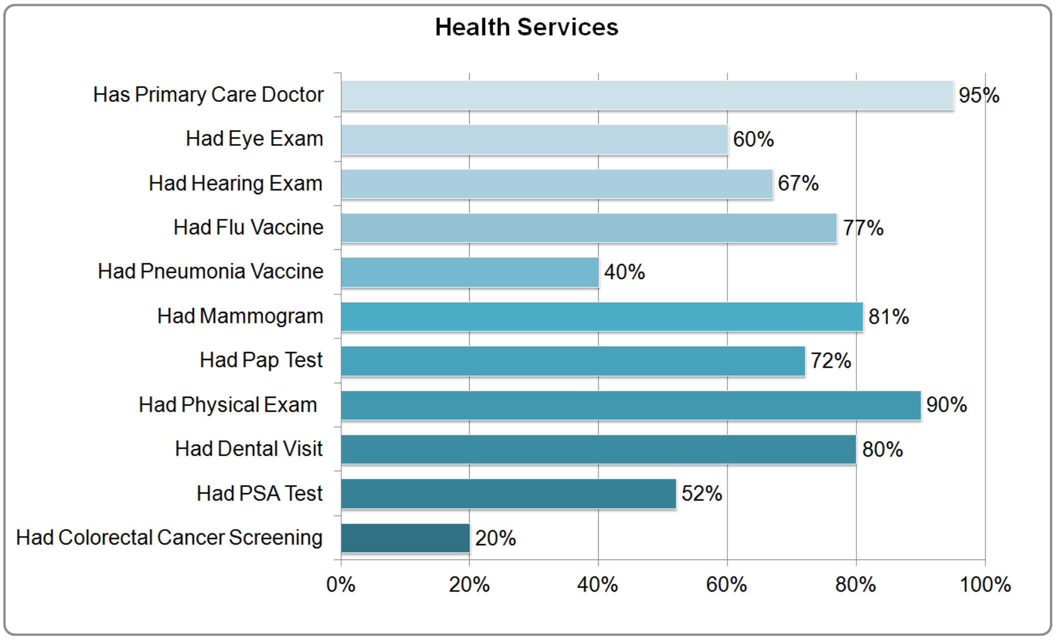
FIGURE 23. PROPORTION OF PEOPLE WHO HAVE INPUT INTO EVERYDAY DECISIONS



Health Care and Health

Only 5% of people surveyed were in poor health and just 6% used tobacco products. Most people surveyed had routine care – 95% had a primary care doctor and 90% had had a physical exam in the past year. However, the proportion of people who received more specialized preventive health care was lower (Figure 24). Eighty percent (80%) had a dental visit in the past year, 67% had a hearing exam in the past five years, and 60% received an eye exam in the past year. Seventy-seven percent (77%) received a flu vaccination in the past year and only 40% had ever had a pneumonia vaccine. Eighty-one percent (81%) of women over 40 had a mammogram in the last two years, and 72% of all women had a Pap test in the past three years. Fifty-two percent (52%) of men over 50 had a PSA test in the past year, and 20% of people over 50 had had a colorectal cancer screening in the past year.

FIGURE 24. PROPORTION OF PEOPLE WHO RECEIVED PREVENTIVE HEALTH CARE SERVICES



Rates of preventive health care tests and exams varied by where people resided. For almost all services, people living with parents or relatives and those living in independent homes or apartments were less likely to have received exams and tests than people living in community-based residences and in institutions.

Rates of receiving preventive health care services varied by residence

Dental exam: 75% in independent homes and 70% in family homes compared to over 94% of people in institutions and 88% in community-based residences

Vision exam: 56% in independent homes and 47% of those living with family compared to 72% of those in institutions and 67% in community-based residences

HOW STATES ARE USING NCI

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

Specific examples of states' use of NCI data include:

- Georgia's Department of Developmental Disabilities Division established State and Regional Quality Councils. These councils are charged with reviewing NCI and other state data and will make recommendations on Quality Improvement activities.

- The Kentucky National Core Indicators Quality Improvement Committee (QIC) was convened in 2010 at the request of the KY Division of Developmental and Intellectual Disabilities to review and make recommendations regarding the quality assurance and improvement elements and activities within the Supports for Community Living Waiver. The QIC identified strategic areas for policy change regarding Employment, Health and Exercise, Medications, and Loneliness and Friendships. As a result KY :
    - revised Medicaid waivers
    - made employment a priority in all spoken and written communications
    - the rate of hourly payment for supported employment was nearly doubled

For more examples of how states are using NCI data, visit the NCI website (http://www.nationalcoreindicators.org).

NCI PROGRAM STAFF:

Mary Lee Fay
NASDDDS Director of NCI
mlfay@nasddds.org

Val Bradley
President
HSRI
vbradley@hsri.org

Josh Engler
HSRI Director of NCI
jengler@hsri.org

Julie Bershadsky
Senior Research Associate
jbershadsky@hsri.org

Stephanie Giordano
Policy Analyst
sgiordano@hsri.org

Cheryl Sartori
Project Assistant
csartori@hsri.org

Dorothy Hiersteiner
Research Analyst
dhiersteiner@hsri.org

NATIONAL CORE INDICATORS

http://www.nationalcoreindicators.org

NCI DIRECTORS AND STATE CONTACTS

The members of the NASDDDS Research Committee provide oversight and direction to NCI, and the liaisons in each state coordinate project activities and implementation at the state level.

NASDDDS Research Committee

NASDDDS Members
Bernard Simons (MO)
John Martin (OH)
Lee Price (VA)
Linda Rolfe (WA)
Alex Bartolic (MN)
Stephen R. Hall, Ph.D (KY)

Non-NASDDDS Members
Amy Hewitt (RTC/ICI/UMN)
Rick Hemp (CICG/UC)
Bill Kiernan (ICI/UMass)
Val Bradley (HSRI)

NASDDDS Staff
Chas Moseley
Nancy Thaler

2011-12 State Coordinators

Alabama
Jeff Williams
Arizona
Sherri Wince
Arkansas
Regina Davenport
California
Renee Kurjiaka
Connecticut
Tim Deschenes-Diamond
Florida
Edwin B. DeBardeleben
Georgia
Eddie Towson
Hawaii
Aaron Arakaki
Illinois
Michael Hurt
Kentucky
Kathy Sheppard-Jones
Louisiana
Dena Vogel
Maine
Jodi Ingraham
Maryland
Nancy Hatch
Massachusetts
Janet George
Michigan
Nora Barkey
Missouri
Shelly Brown
New Hampshire
Denise Sleeper
New Jersey
Catherine Yankitis
New Mexico
Marc Kolman
New York
Ray Pierce
North Carolina
Karen Feasel
Ohio
Tina Evans
Ohio- MEORC
Stacey Hurlow
Oklahoma
Genny Gordon
Pennsylvania
Lee Stephens
South Carolina
Ann Dalton
South Dakota
Kelli Anderson
Texas
Janie Eubanks
Virginia
Cheri Stierer
Washington State
Lisa Weber

NASDDDS
http://www.nasddds.org

HSRI Human Services Research Institute
http://www.hsri.org