



NCI

ANNUAL SUMMARY REPORT 2010 - 2011

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 2011, the NCI collaboration included 25 participating states and 4 sub-state entities. We are pleased to launch the third NCI Annual Summary Report, which highlights activities and key findings from 2010-2011.

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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 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.

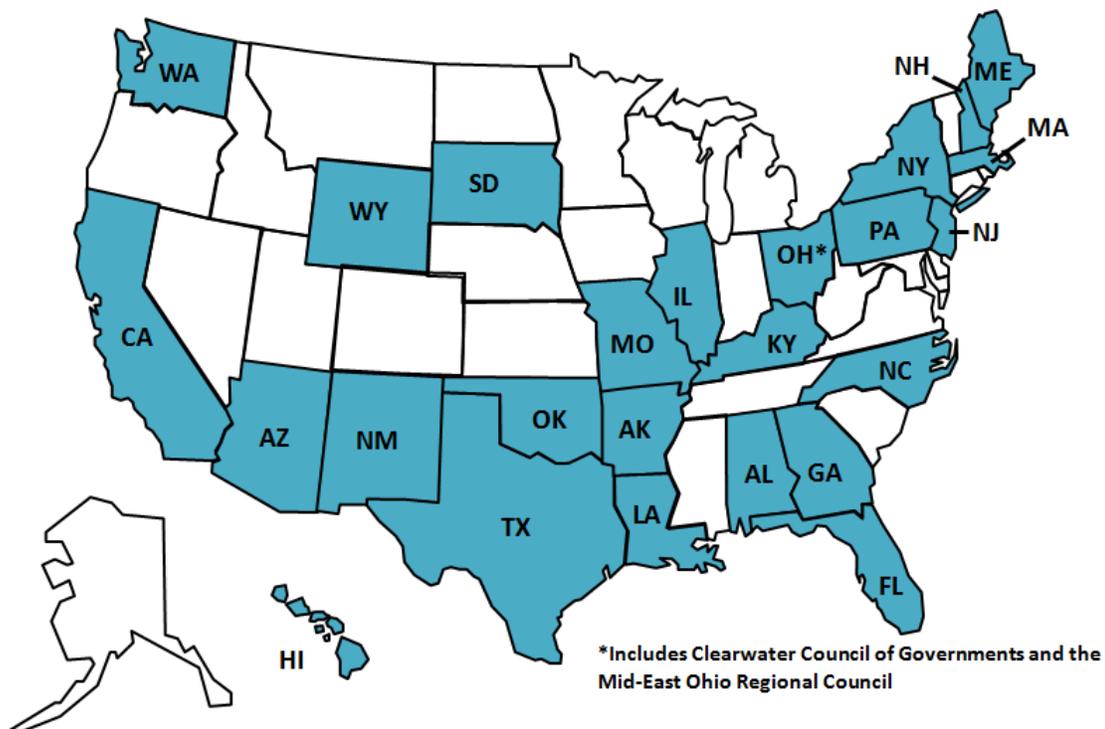
NCI Vision:

- 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 2010-2011, the membership of NCI included 25 states and two sub-state entities (see Figure 1).

FIGURE 1. PARTICIPATING NCI STATES 2010-11



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 were recently revised to include enhanced information about health, wellness and employment.

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 and downloaded on the NCI website at <http://www.nationalcoreindicators.org>.

This report highlights selected aggregate results from 2010-11. Detailed summary reports of state by state results and national averages for all NCI measures are available on the website [nationalcoreindicators.org](http://www.nationalcoreindicators.org). The full reports are organized by data source.

2010-11 ACCOMPLISHMENTS, ACTIVITIES, AND ON-GOING EFFORTS

Through the years, the prominence of NCI has increased at the national and international level. With several publications, international presentations, greater self-advocate involvement, and the new NCI website, NCI has continued to enhance its outreach in 2010-11. Further, in 2011, the Administration on Intellectual and Developmental Disabilities (AIDD) awarded NASDDDS a five year contract to expand NCI. Through the contract, funding is being made available to up to five new states each year with the goal of increasing NCI participation to all 50 states and the District of Columbia by 2016.

Two grants from the National Institute on Disability and Rehabilitation Research (NIDRR), which supported case studies on how NCI is implemented at the state level, wrapped up in 2011. Between 2009 and 2011, HSRI staff visited Missouri, New York, Orange County, California, Texas, and Washington to meet with state NCI project leads and state directors of developmental disabilities agencies and staff. HSRI also conducted focus groups with interviewers and shadowed NCI interviews. The site visits yielded information about the use of NCI data for HCBS waiver assurances, quality assurance and management, and to track performance over time. Results have been used to enhance NCI through increased technical assistance, provision of examples of states’ use of NCI data, and revisions of training and guidance materials. A recently published guidebook for using NCI data, [Using National Core Indicators \(NCI\) Data for Quality Improvement](#), can be found on the NCI website under the Resources tab.

During the past year, California, Florida, and Georgia conducted feedback surveys of respondents to the Adult Consumer Survey. These studies were designed to assess, among other things, whether the interviewers systematically provided necessary information to the individuals being interviewed. For example, the study evaluated whether the interviewer

informed the respondent that the survey was optional, and whether the respondent chose where and when the survey was conducted. The results of the surveys were largely positive. Nearly all respondents indicated that interviewers were respectful, that they were asked where and when they would like the meeting to be held, and the majority of respondents were told that their participation was optional. Additional questions from the Florida and Georgia feedback surveys found that most interviewers explained what the survey was about and let interviewees know that they didn't have to answer all the questions if they didn't want to. The results of these studies were also used to test survey validity.

In collaboration with research partners from the University of Minnesota and the University of Sydney Australia, NCI program staff produced a number of publications that were accepted by several leading journals including "Overweight and Obesity Among Adults with Intellectual Disabilities Who Use ID/DD Services in 20 U.S. States," published in the American Journal on Intellectual and Developmental Disabilities (November 2011). NCI data were also used as the foundation for data briefs produced by NCI project staff -- 2010-11 data briefs included: "Living at Home with Families," "Self-Direction," "Autism," and "Dual Diagnosis." Quarterly webinars are held for all participating states to provide NCI updates, give states a forum to discuss the ways in which they are using NCI data, and to address any questions or concerns they may have.

As part of NCI's commitment to improving the ease and validity of data collection, the online data entry system application (ODESA) was again enhanced for the 2010-11 data cycle to include more user-friendly and administrative functions. The ODESA now houses the Adult Consumer Survey along with all three Family Surveys within the same site and will be shifting to a new, larger platform in 2011-12 to accommodate to the increase in usage. Upgrades include: logic checks, ability to view past edits to data entries, and a report generator to view survey progress. A technical survey was sent to NCI state operational staff to determine how best to continue efforts to facilitate states in the data collection process. The survey found that several states are beginning to administer the Adult Consumer Survey using a laptop or other electronic device – interviewers enter data in the ODESA during the survey meeting. Based on the results, on-going efforts and discussion will include creating a more user-friendly look for ODESA and helping states to pre-populate background information.

NCI program staff met with members of California's Consumer Advisory Committee (CAC) in 2010 and again in 2011 to create a user-friendly version of the Consumer Outcome Report. The CAC was instrumental in helping to develop this new way of disseminating NCI data. The first national user-friendly report, "What We Have Learned from the NCI Adult Consumer Survey", is complete and is posted on the NCI website. It features 20 indicators with outcomes described in plain language and accompanying pie charts. In subsequent years each state will also receive a user-friendly report with their state data.

DATA SOURCES

Four primary data sources are referenced in this report. The Adult Consumer Survey gathers information face-to-face from service recipients and their families or other representatives. States are expected to interview a random sample of at least 400 individuals. Additionally, three Family Surveys are administered by mail. The Family Surveys collect data on family and guardian perspectives of 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 on the following page 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 2010-11, and the total number of surveys collected overall.

FIGURE 2. SUMMARY OF SURVEYS BY STATE 2010-2011

NCI Survey	Target Population	Method of Administration	# of States 2010-11	Total # of Surveys
Adult Consumer Survey	Adults 18 and older receiving at least one service besides case management	In-person interview	15	8,796
Adult Family Survey	Families of adults 18 and older living at home	Mail	9	3,654
Family Guardian Survey	Families or guardians of adults 18 and older living outside the home	Mail	11	3,482
Child Family Survey	Families of children under 18 (or under 23 if still in school system) living at home	Mail	7	1,886

LINKS TO FULL REPORTS

Detailed reports on Adult Consumer and Family Survey outcomes by state with national average comparisons are available on the NCI website: <http://www.nationalcoreindicators.org>. These reports are organized by data source and by year. Additional Data Briefs and other special reports focusing on special topics are also posted on the Reports page: <http://www.nationalcoreindicators.org/resources/reports/>.

ANALYSIS

NCI data management and analysis is coordinated by Human Services Research Institute (HSRI). Most states entered data in ODESA which HSRI in turn downloaded for analysis. Data files were reviewed for completeness and compliance with standard NCI formats, and then cleaned and merged with invalid responses eliminated. For the purposes of this report, data were analyzed with no risk-adjustment. This is the first year significance testing was conducted on Family Surveys.

SELECTED RESULTS 2010-2011

FAMILY OUTCOMES

In 2010-2011, nine states collected a total of 3,654 Adult Family Surveys (AFS), 11 states collected a total of 3,482 Family/Guardian Surveys (FGS), and seven states collected a total of 1,886 Child Family Surveys (CFS). Responses to all three Family Surveys are based on either a 5-point Likert scale (always, usually, sometimes, seldom, or never) or dichotomous yes or no responses.

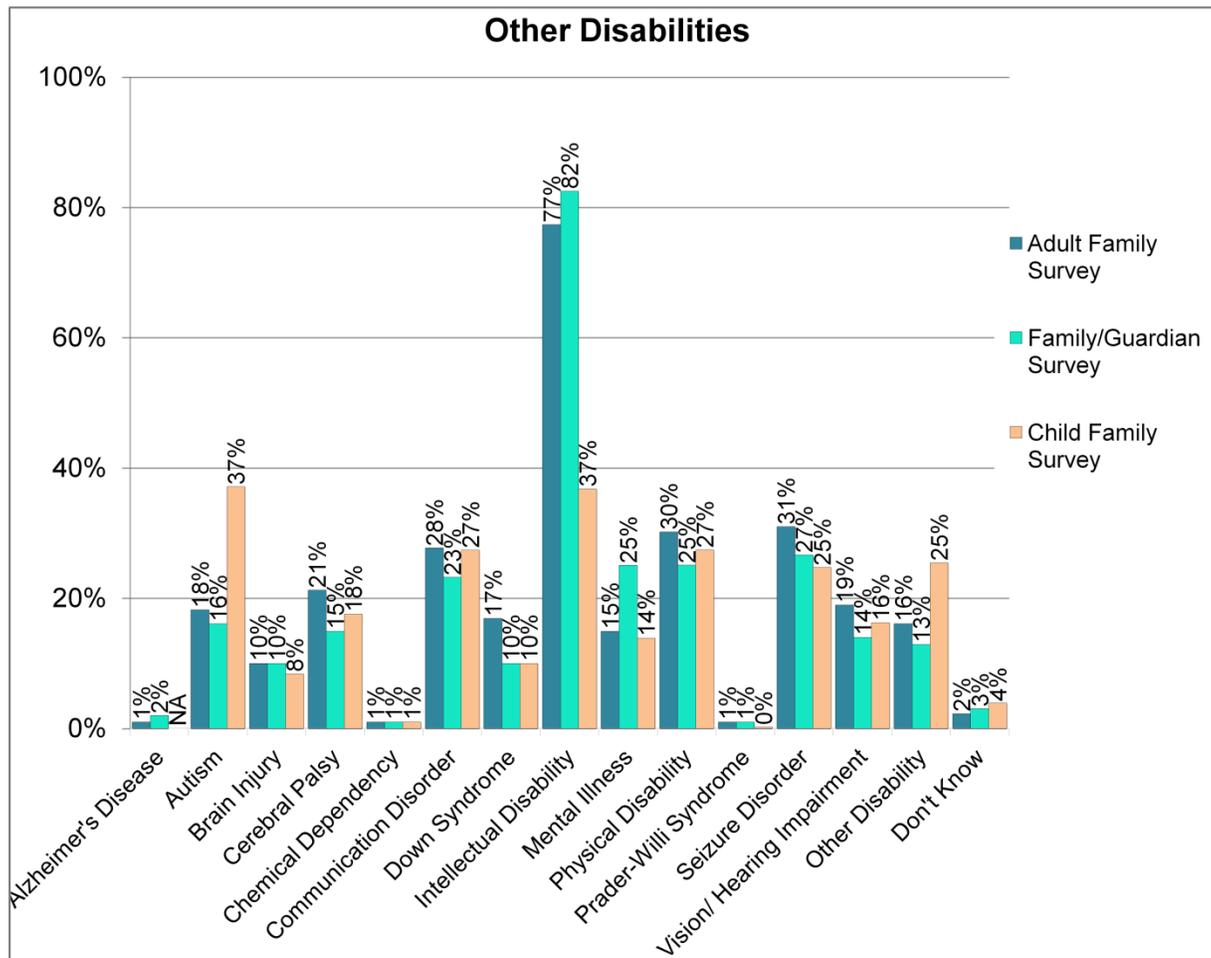
Selected characteristics

For all three Family Surveys, a higher percentage of respondents indicated their family member receiving services was male – 57% AFS and FGS and 64% CFS. On average, individuals for whom the FGS was completed were a decade older than those for the AFS (45 years old compared to 34). The average age of family members from the CFS was 10. For all three Family Surveys, the majority of family members receiving services were white (68% AFS, 80% FGS, and 65% CFS) or black (18% AFS, 12% FGS, and 15% CFS).

Other Disabilities

For all surveys, the most common type of disability was an intellectual disability. However this was true at far higher rates for AFS (77%) and FGS (82%) compared to 37% of CFS respondents. **Conversely, nearly twice as many respondents from the CFS reported the child was on the Autism Spectrum (37%) as compared to those from the AFS (18%) and FGS (16%).**

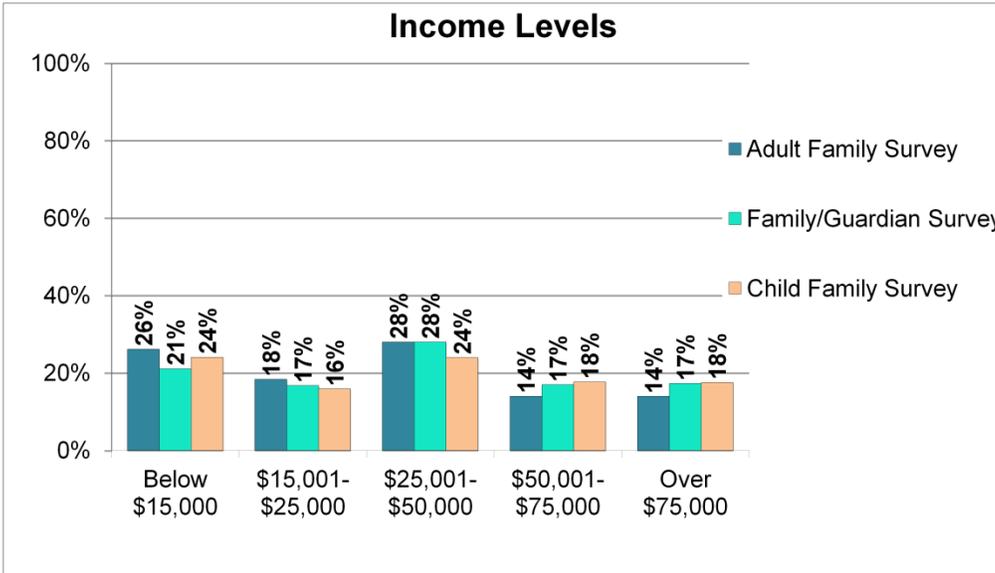
FIGURE 3. TYPE OF DISABILITY BY FAMILY SURVEY



Income Levels

Household income tended to be similar among surveys with most respondents falling within a range at or below \$25,001-\$50,000 per year.

FIGURE 4. HOUSEHOLD BY FAMILY SURVEY



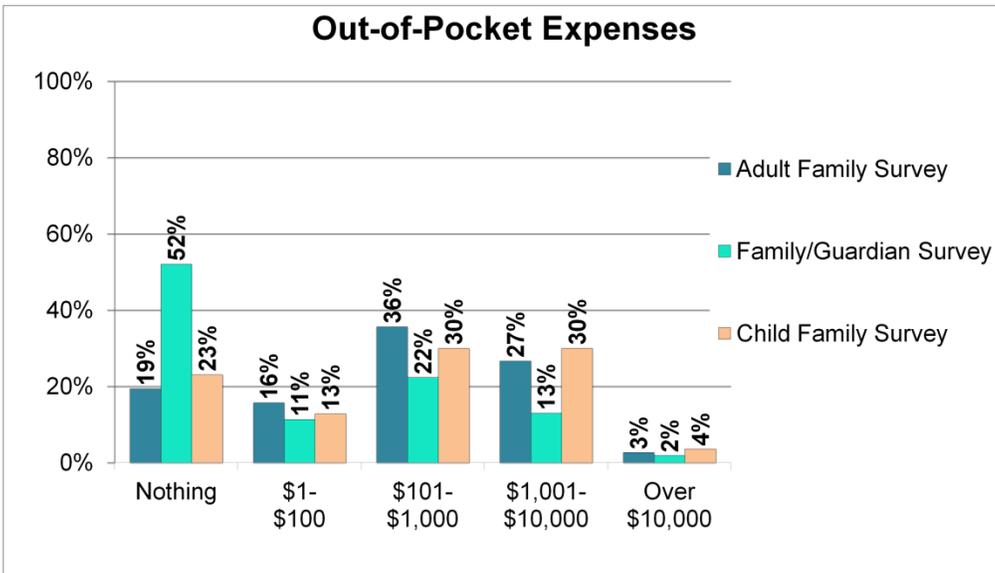
Family member's case manager/service coordinator who helps plan services and support is always knowledgeable:
58% AFS, 66% FGS, and 57% CFS

Family member's case manager/service coordinator who helps plan services and support is always courteous:
79% AFS, 80% FGS, and 77% CFS

Out-of-Pocket Expenses

Just over half of FGS respondents did not spend any out-of-pocket money on services or supports for their family in the past year (52%), while over half the respondents from the AFS and CFS spent between \$101-\$1000 or \$1001-\$10,000.

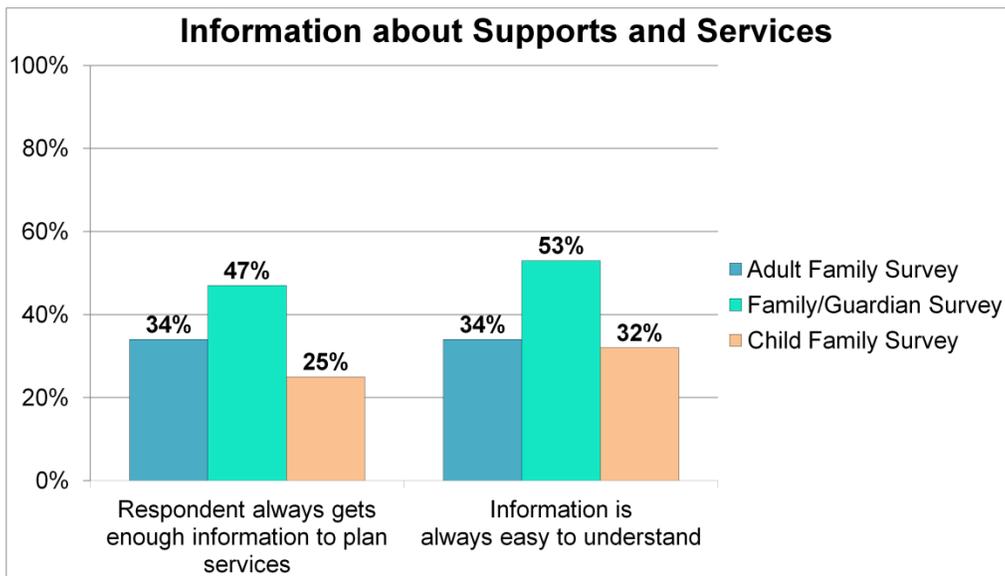
FIGURE 5. OUT-OF-POCKET EXPENSE IN THE PAST YEAR BY FAMILY SURVEY



Information and Planning

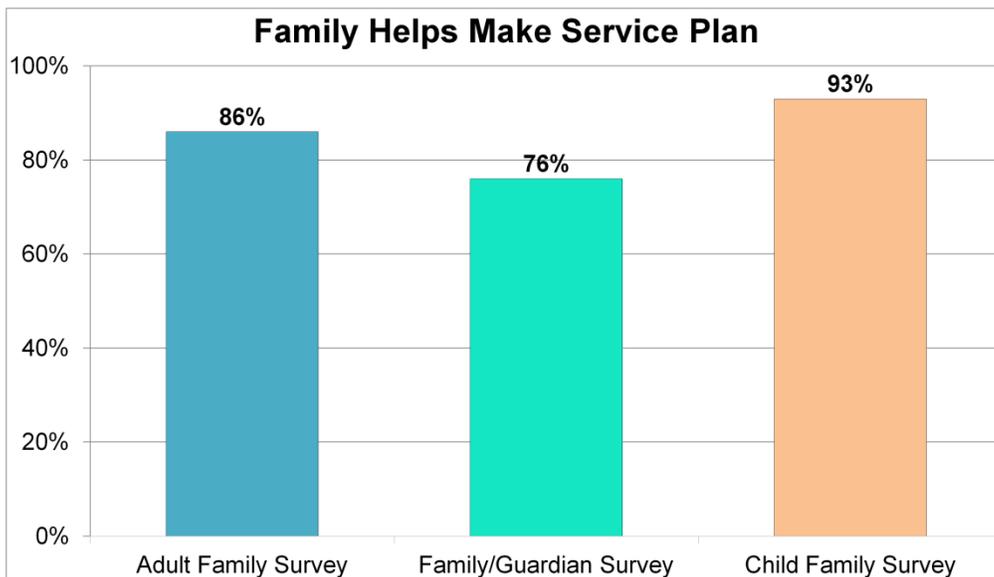
As shown in Figure 6, below, a higher percentage of respondents from the FGS *always* received enough information to help plan their family member’s supports and services, and the information is always easy to understand.

FIGURE 6. FAMILY RECEIVES INFORMATION ABOUT SUPPORTS AND SERVICES



The majority of respondents from all surveys reported that they assisted in creating their family member’s service plan. This occurred with slightly more frequency for respondents from the CFS (93%) than those from the AFS (86%) and FGS (76%) (see Figure 7). Results show more than half the family members for both the AFS and FGS helped make their own service plan (58% and 62%).

FIGURE 7. FAMILY HELPS MAKE SERVICE PLAN BY FAMILY SURVEY

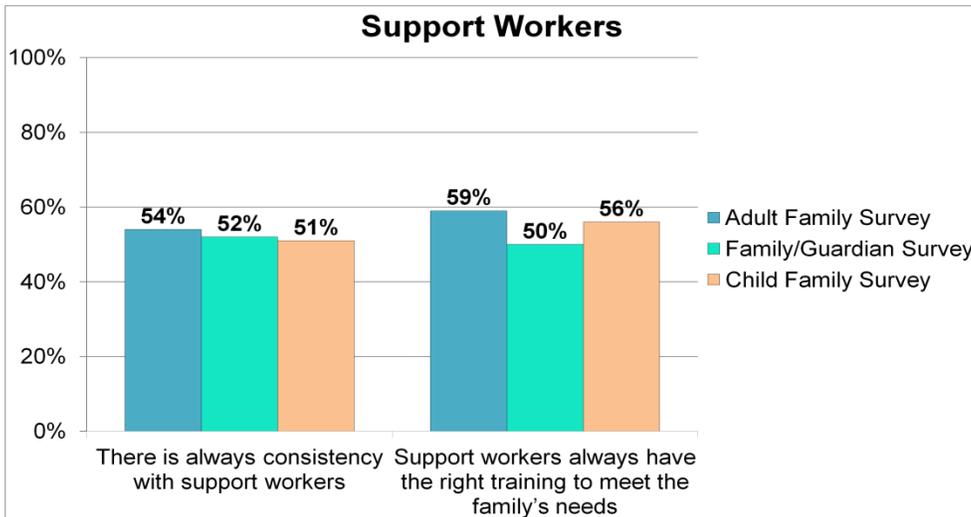


Nearly all respondents indicated the service plan includes things that are important to the family – 93% AFS, 94% FGS, and 92% CFS.

Access and Support Delivery

The majority 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 (58% and 56% AFS, 54% and 59% CFS). As illustrated in Figure 8, below, about half of the respondents for all surveys indicated there was consistency in support worker staffing. Likewise, around half the respondents for each survey felt that support workers had the proper training to meet the needs of their family member.

FIGURE 8. CONSISTENCY AND TRAINING OF SUPPORT WORKERS BY FAMILY SURVEY



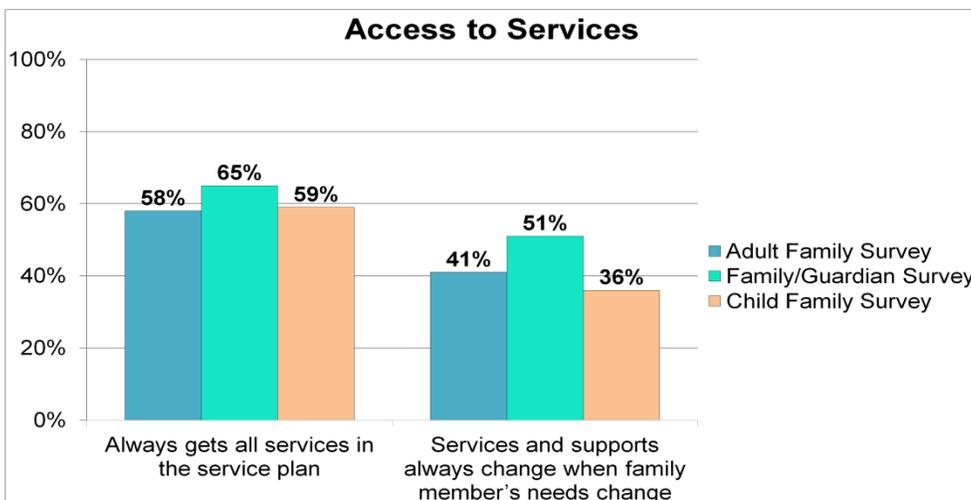
Family member always has access to needed equipment:
53% AFS, 69% FGS, and 41% CFS

Family member has access to health services:
97% AFS and CFS

Services with the lowest rates of access:
respite services – 75% AFS and 79% CFS
mental health services – 84% AFS and 83% CFS
dental services – 80% AFS and 93%

Of those whose adult family member transitioned from school to state DD funded services in the past year, 64% of respondents from the AFS reported that they were happy with this transition. 84% of FGS respondents answered similarly. Though over half the respondents indicated their family member gets all the services listed in the service plan, **less than half reported that services and supports change when their family member's needs change** (shown in Figure 9). The data show that 47% of AFS and 45% of CFS respondents reported their family member always got the services and supports needed. However, 41% of AFS respondents and 44% of CFS respondents indicated that their family member needs other services that are not currently offered. This is a particular concern since being responsive to changed needs is one of the sub-assurances that CMS looks for as part of waiver compliance.

FIGURE 9. ACCESS TO NEEDED SERVICES BY FAMILY SURVEY

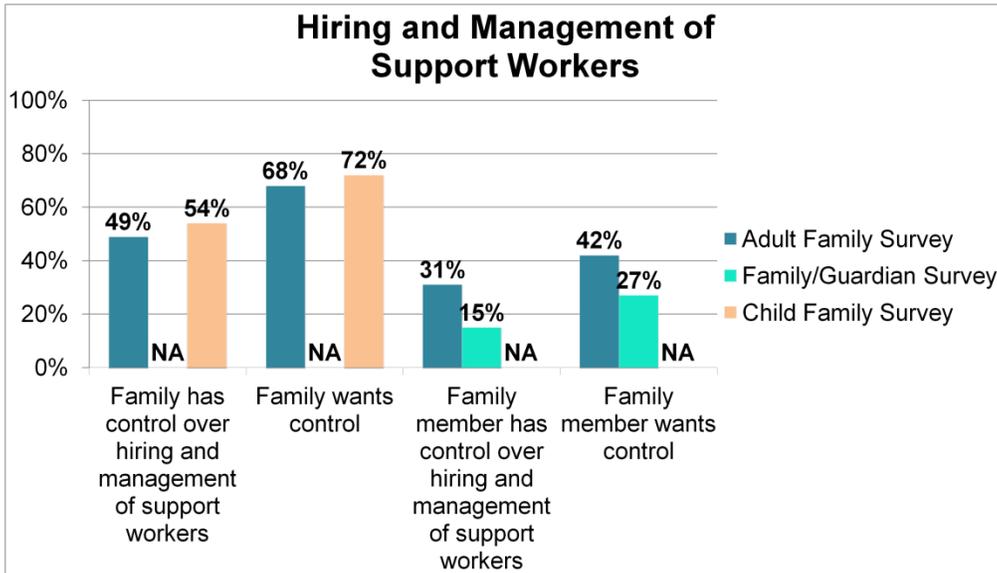


Choice and Control

Results from the Choice and Control section show that, compared with past years, a greater proportion of respondents have control over who works with family members. Furthermore, an even greater percentage desire that control.

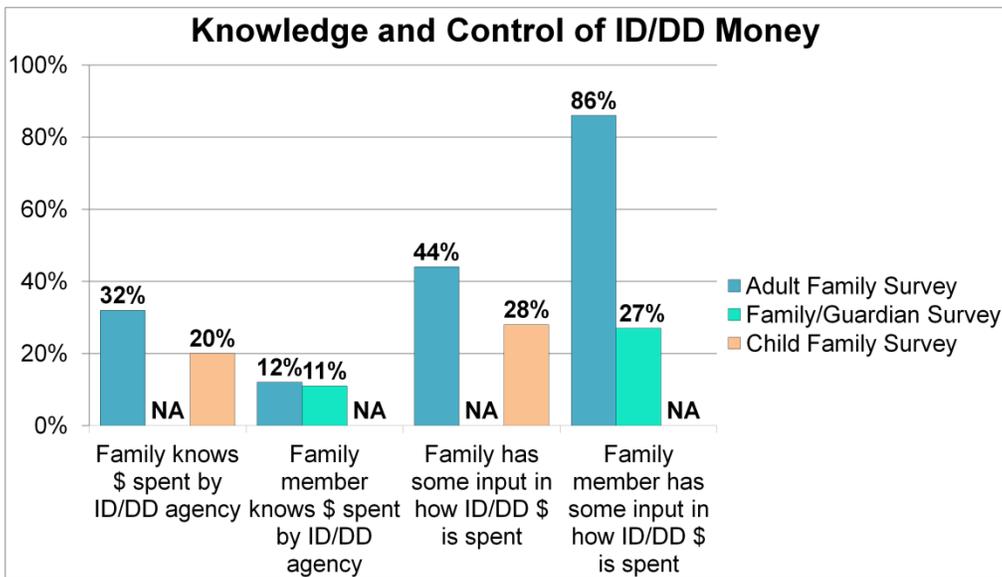
Shown in Figure 10, about half of AFS and CFS respondents had control over the management and hiring support workers. Additionally, most family respondents wanted to assert such control.

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



Slightly higher proportions of respondents from the AFS knew the amount of money spent by ID/DD agencies for the care of their family members, as compared to CFS respondents (32% and 20%). Just 12% of AFS and 11% of FGS respondents reported that their family member knew how much money was spent by the ID/DD agency on their behalf. However, AFS respondents reported at a much higher rate that their family member has *some* input on how the money is spent (86% AFS) than FGS respondents (27% FGS) (Figure 11, below).

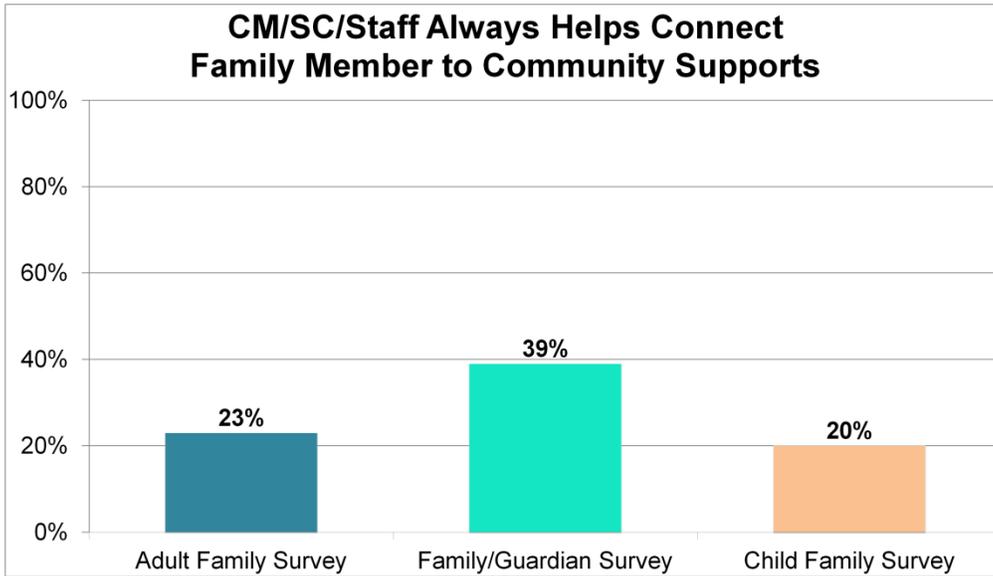
FIGURE 11. KNOWLEDGE AND CONTROL OF ID/DD MONEY BY FAMILY SURVEY



Community Connections

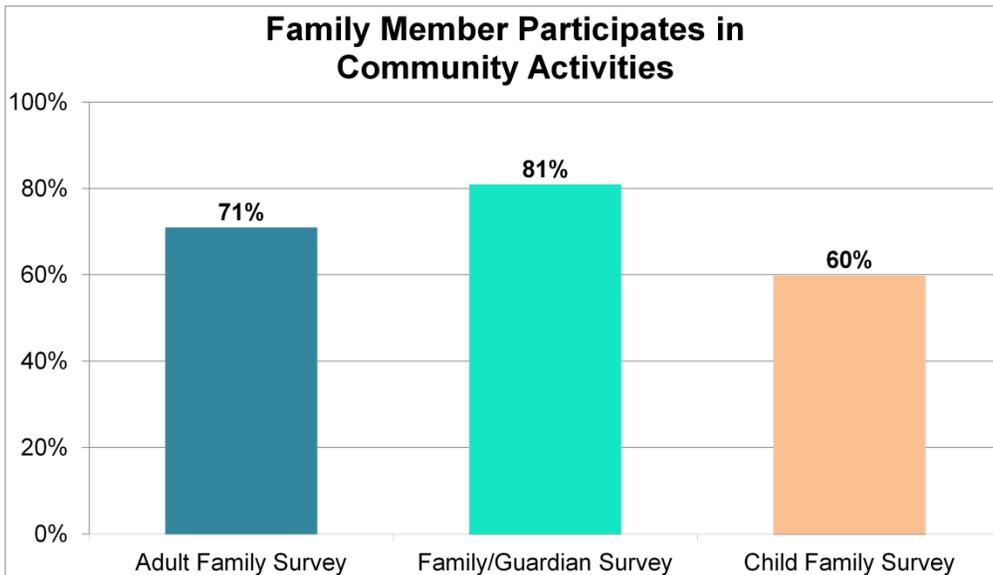
A low percentage of respondents reported that they *always* receive adequate support to keep their family member connected to the community. Only 23% AFS, 39% FGS, and 20% CFS respondents reported that case managers/service coordinators or staff *always* help family member use typical community supports (e.g., church or recreational centers) (Figure 12). Similarly, a minority indicated family and friends are *always* helped by case managers/service coordinators and staff to assist with providing support to their family member (26% AFS, 42% FGS, and 27% CFS).

FIGURE 12. CASE MANAGER/SERVICE COORDINATOR OR STAFF CONNECT FAMILY TO COMMUNITY SUPPORTS BY FAMILY SURVEY



As indicated in Figure 13, the majority of respondents for all surveys reported their family member participates in community activities – 71% AFS, 81% FGS, and 60% CFS.

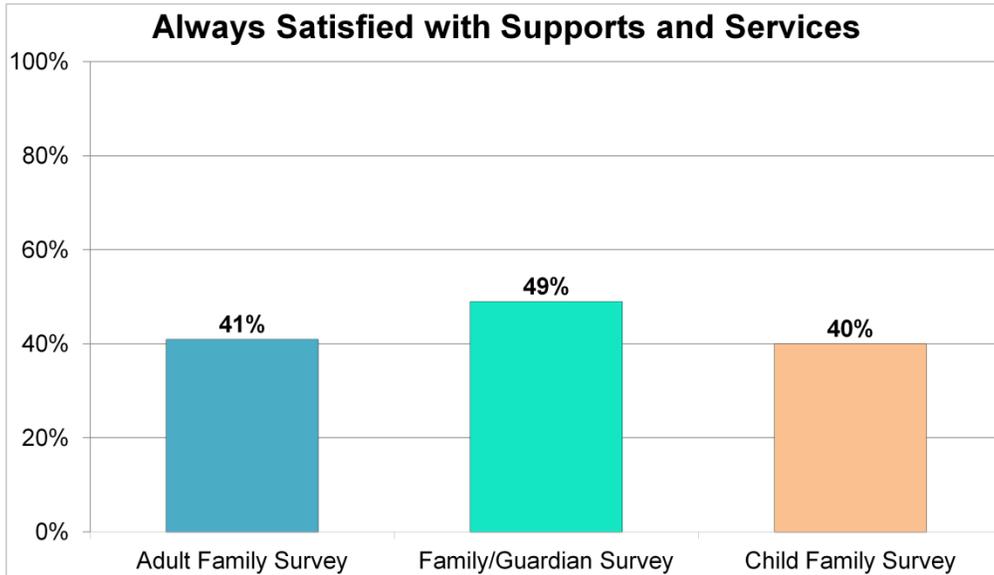
FIGURE 13. FAMILY MEMBER PARTICIPATES IN COMMUNITY ACTIVITIES BY FAMILY SURVEY



Satisfaction

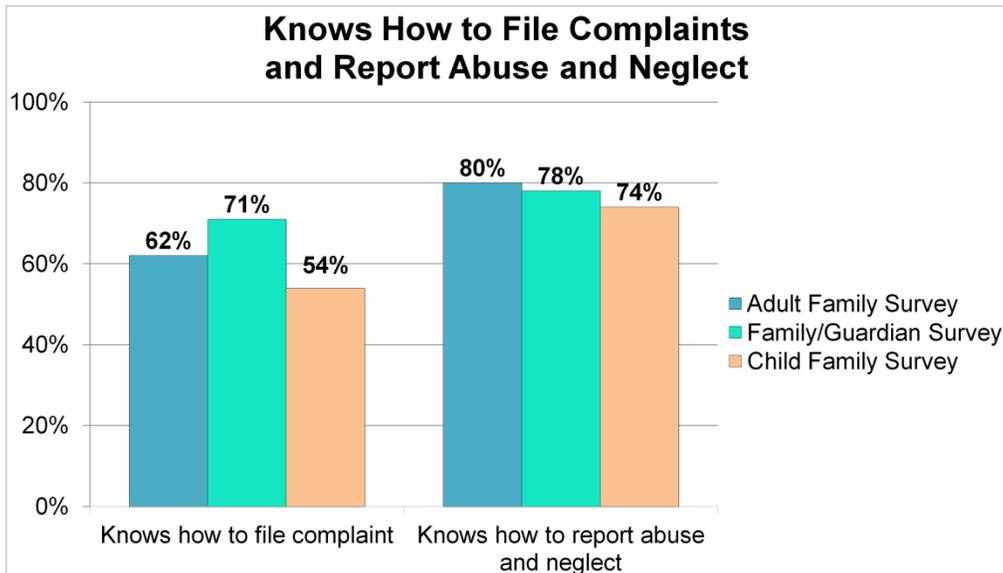
Less than half the respondents from each survey were *always* satisfied with their family member's services and supports – 41% AFS, 49% FGS, and 40% CFS (Figure 14, below).

FIGURE 14. SATISFACTION BY FAMILY SURVEY



As shown in Figure 15 below, most respondents knew how to file complaints or grievances about provider agencies or staff (62% AFS, 71% FGS, and 54% CFS), and the majority of respondents were satisfied with the way complaints and grievances are handled (82% AFS, 79% FGS, and 76% CFS). Nearly all respondents also knew how to report abuse or neglect (80% AFS, 78% FGS, and 74% CFS). Of those who filed a report of abuse or neglect in the past year, the majority found the appropriate parties responsive to their report (71% AFS, 81% FGS, and 79% CFS).

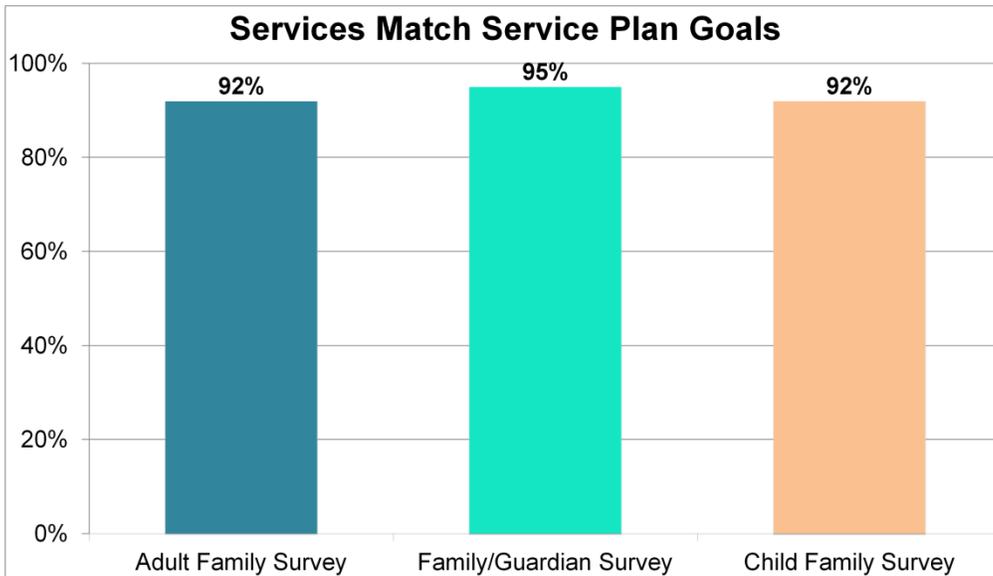
FIGURE 15. KNOWS HOW TO FILE COMPLAINT AND ABUSE AND NEGLECT REPORTS



Outcomes

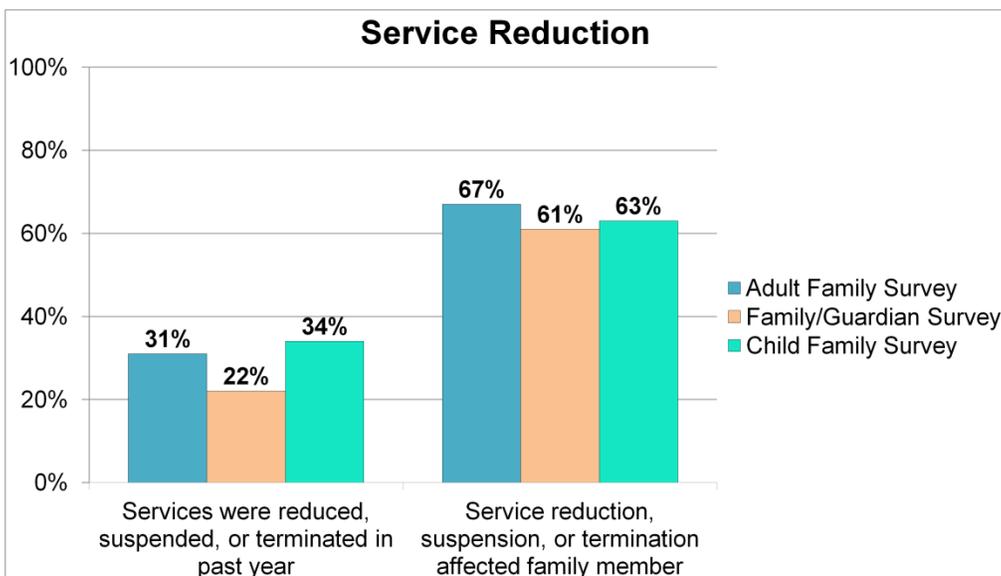
Nearly all respondents felt services and supports made a positive difference for their family member – 96% AFS, 97% FGS, and 94% CFS. Most also indicated their family member’s supports and services match those in their service plan (92% AFS, 95% FGS, and 92% CFS, Figure 16).

FIGURE 16. SERVICES MATCH GOALS IN SERVICE PLAN



Illustrated in Figure 17 below, less than a third of respondents from each survey reported that their family member’s services or supports were reduced, suspended, or terminated in the past year (31% AFS, 22% FGS, and 34% CFS). **Of the respondents whose family member had a reduction in services or supports in the past year, nearly two-thirds of respondents from each survey indicated the reduction affected their family member (67% AFS, 61% FGS, and 63% CFS).**

FIGURE 17. SERVICE OR SUPPORT REDUCTION



SELECTED RESULTS 2010-2011

INDIVIDUAL OUTCOMES

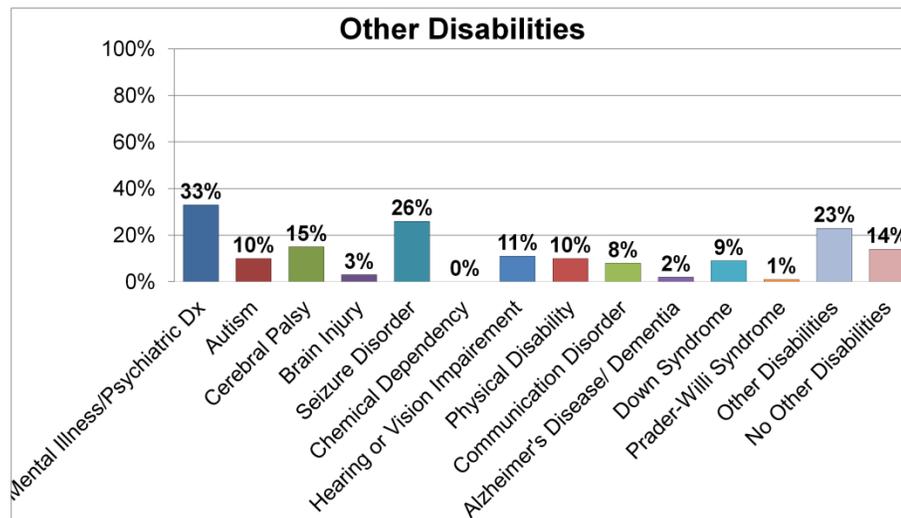
Sample characteristics

In 2010-2011, a total of 8,796 Consumer Surveys were completed in 15 states.

Disabilities

Only 14% of all people surveyed did not have some type of disability in addition to ID/DD (Figure 18). The most common co-occurring disabilities were mental illness or psychiatric diagnosis (33%), seizure disorder (26%), or another disability not listed (23%).

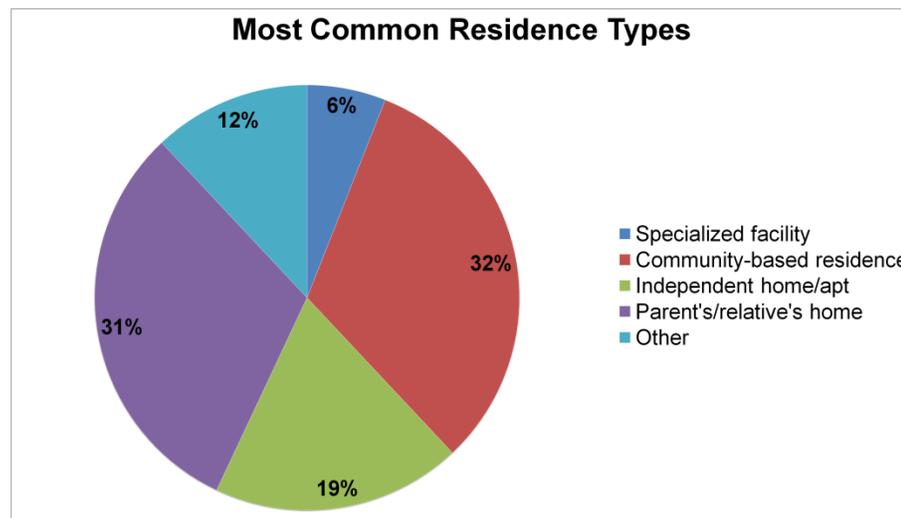
FIGURE 18. PROPORTION OF PEOPLE WITH OTHER DISABILITIES



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, (32%) or with parent or relatives (31%).

FIGURE 19. PROPORTION OF PEOPLE LIVING IN FOUR MAJOR TYPES OF RESIDENCE



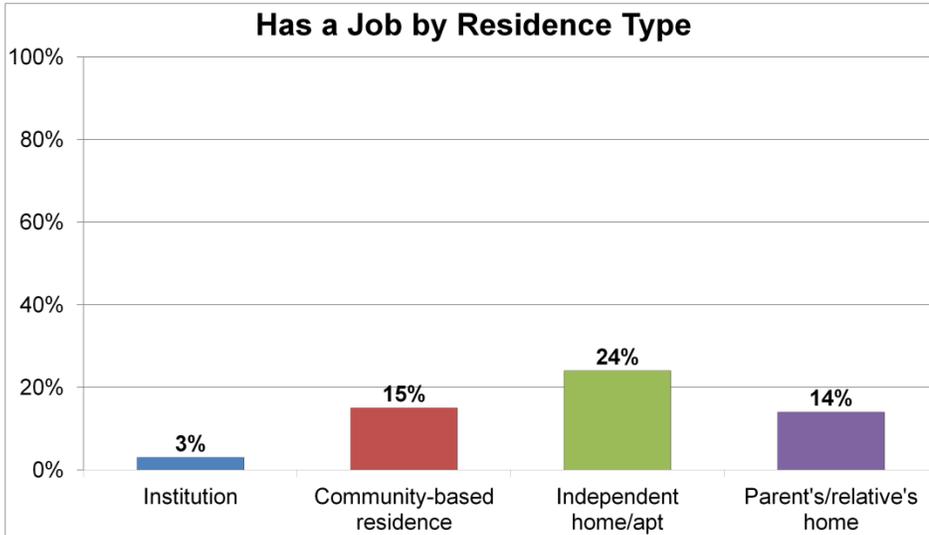
Self-Direction

Only 6% of people were identified as using a self-directed supports option.

Employment

In 2010-2011, 16% of people had a job in the community; the average hourly wage in community jobs was \$7.11. Twenty-four percent (24%) of people living in their own home or apartment, 15% living in community-based residences and 14% living with a parent or relative had a job (Figure 20). Only 21% of people with a job who were surveyed received benefits (vacation and/or sick leave) at their community jobs.

FIGURE 20. EMPLOYMENT STATUS BY LIVING ARRANGEMENT



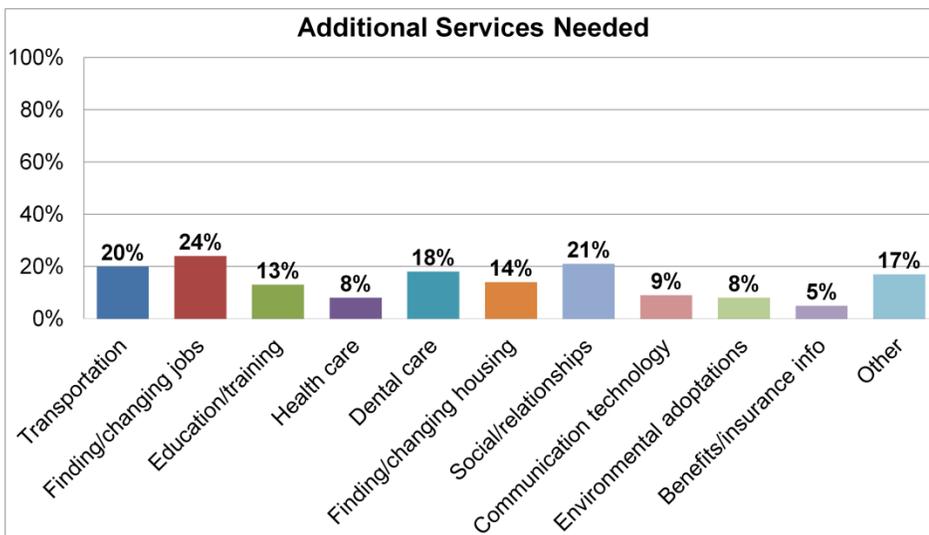
Of people surveyed, the four most common types of community jobs in which people were employed were: cleaning and maintenance (29%), food preparation (20%), retail (17%), and assembly and manufacturing (5%).

System Performance

Access

A large majority of people reported that their staff have adequate training (92%) and get them needed services (83%). Of those who reported they did not get needed services, the most common needs were: finding or changing jobs (24%), social and/or relationship areas (21%), and transportation (20%) (Figure 21).

FIGURE 21. SERVICES NEEDED



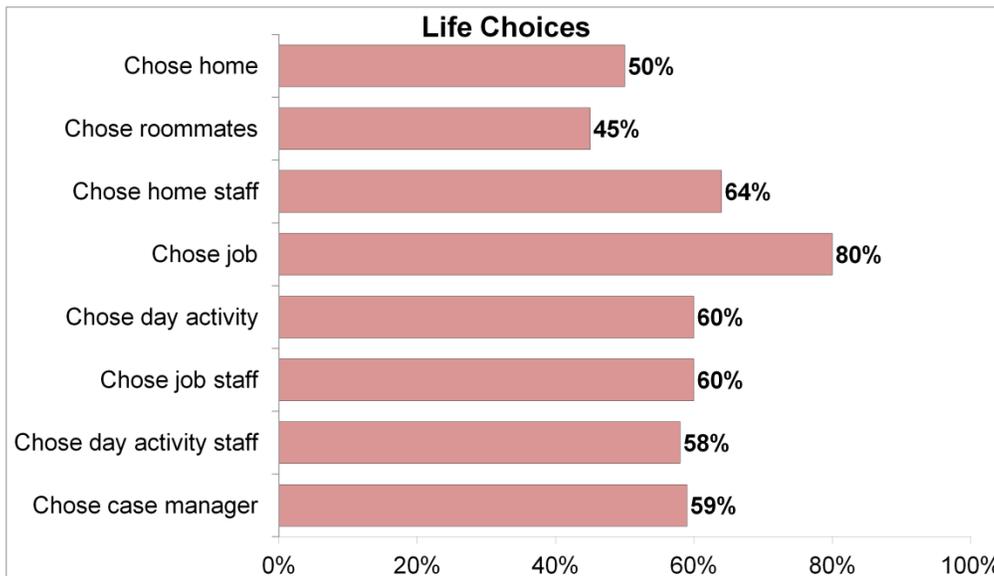
Hourly Wage by Residence:
 Parent/Relatives Home: \$8.21
 Independent Home/Apt: \$6.71
 Community-Based Residence: \$6.54
 Institution: \$6.31

Gets Needed Services by Residence:
 Parent/Relatives Home: 74%
 Independent Home/Apt: 82%
 Community-Based Residence: 87%
 Institution: 92%

Choice and Decision-Making

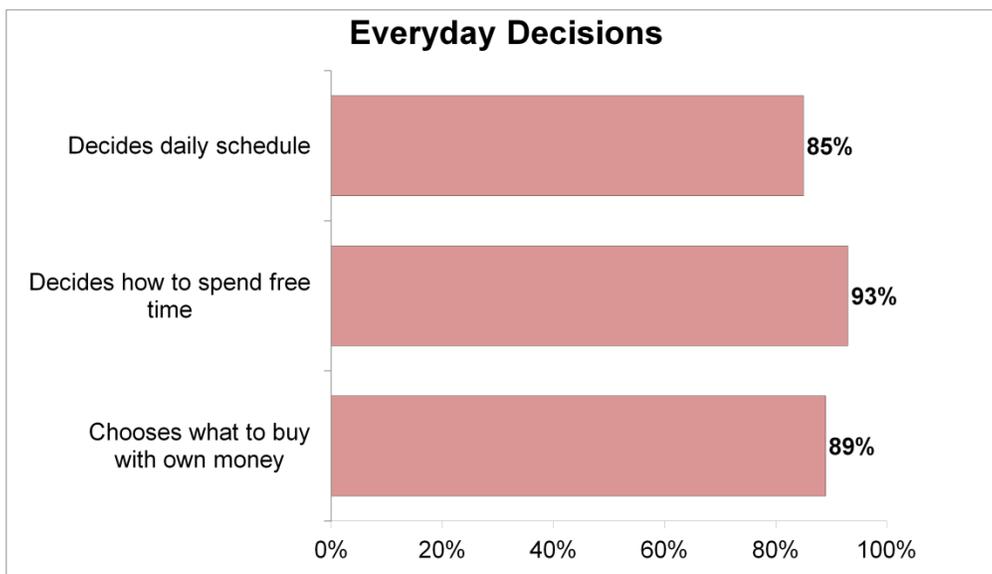
Many respondents reported that they did not have input in major life decisions such as where and with whom they live and where they go during the day. As illustrated in Figure 22, only 50% chose their home, and 45% chose their roommates. Though 80% had input into where they work, only 60% had input into where they go during the day (their non-work day activity). Furthermore, just 60% had input into choosing their work staff and 58% their day activity staff. Sixty-four percent (64%) chose their home staff, and 41% percent of persons surveyed did not choose 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 (85%), how to spend free time (93%), and how to spend their money (89%) (Figure 23).

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

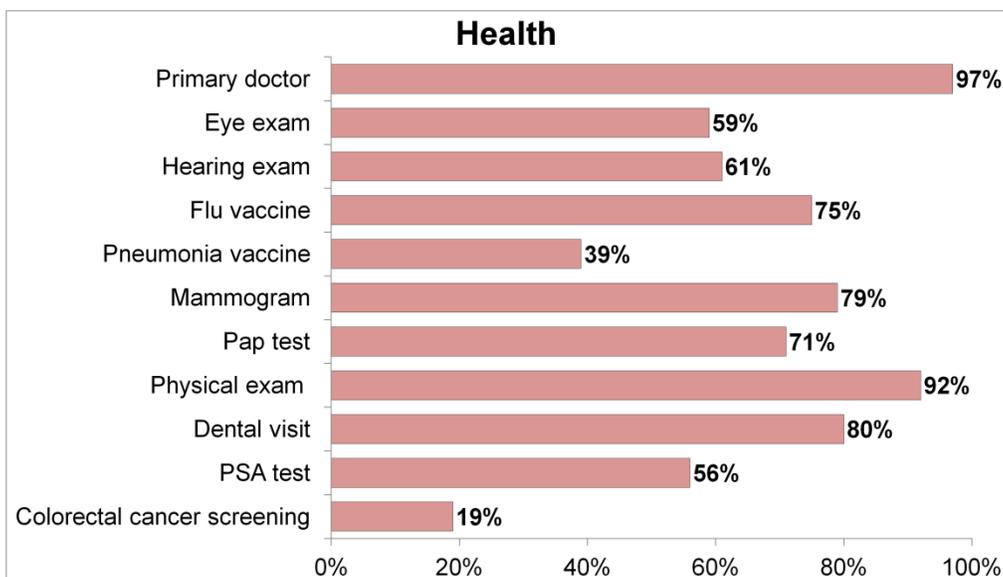


Results by residence type show that people living in institutions were least likely to have input, particularly in life decisions areas. Those living in their own apartments or homes were most likely to exercise choice. These findings are consistent with results from previous years and discussed in the 2010 NCI Data Brief, *People Who Live at Home*, which can be found on the NCI website under the Resources tab (<http://www.nationalcoreindicators.org/resources/>).

Health Care and Health

Only 5% of people surveyed were in poor health and just 8% used tobacco products. Most people surveyed had routine care -- 97% had a primary care doctor and 92% had had a physical exam in the past year. However, the proportion of people who received other routine preventive health care was lower (Figure 24). Eighty percent (80%) had a dental visit in the past year, 61% had a hearing exam in the past five years, and 59% received an eye exam in the past year. Seventy-five percent (75%) received a flu vaccination in the past year and only 39% had ever had a pneumonia vaccine. Seventy-nine percent (79%) of women over 40 had a mammogram in the last two years, and 71% of all women had a Pap test in the past three years. Fifty-six percent (56%) of men over 50 had a PSA test in the past year, and only 19% 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 receiving preventive health care services varied by residence

Dental exam: 70% in independent homes and family homes compared to over 95% of people in institutions and 88% in community-based residences

Vision exam: with family and 58% in independent homes compared to 70% of those in institutions and community-based residences

Rates of preventive health care services 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 services than people living in community-based residences and in institutions.**

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:

- Alabama's Division of Developmental Disabilities uses the overall satisfaction number and employment numbers in their SMART Plan which is a budgeting and planning process through the Governor's office to gauge their success in meeting national benchmarks. The State is conducting a pre/post survey analysis of people leaving Alabama's last developmental center. An Alabama Summary is forwarded to providers and they are encouraged to use findings to include in their own agency Quality Plans.
- Washington's Developmental Disabilities Council convened a review panel of self-advocates, family members, community providers and other professionals to review the results of the NCI survey data. As a result of their work, the review panel made recommendations to the Division.

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

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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.

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