



NCI

ANNUAL SUMMARY REPORT 2008 - 2009



National Core Indicators Program | NASDDDS & HSRI

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 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 2009, the NCI collaboration included 25 participating states and 4 sub-state entities. We are pleased to launch the second NCI Annual Summary Report, which highlights activities and key findings from 2008-2009.

Nancy Thaler
Executive Director
National Association of State Directors
of Developmental Disabilities Services

Valerie J. Bradley
President
Human Services Research Institute

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 piece 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.

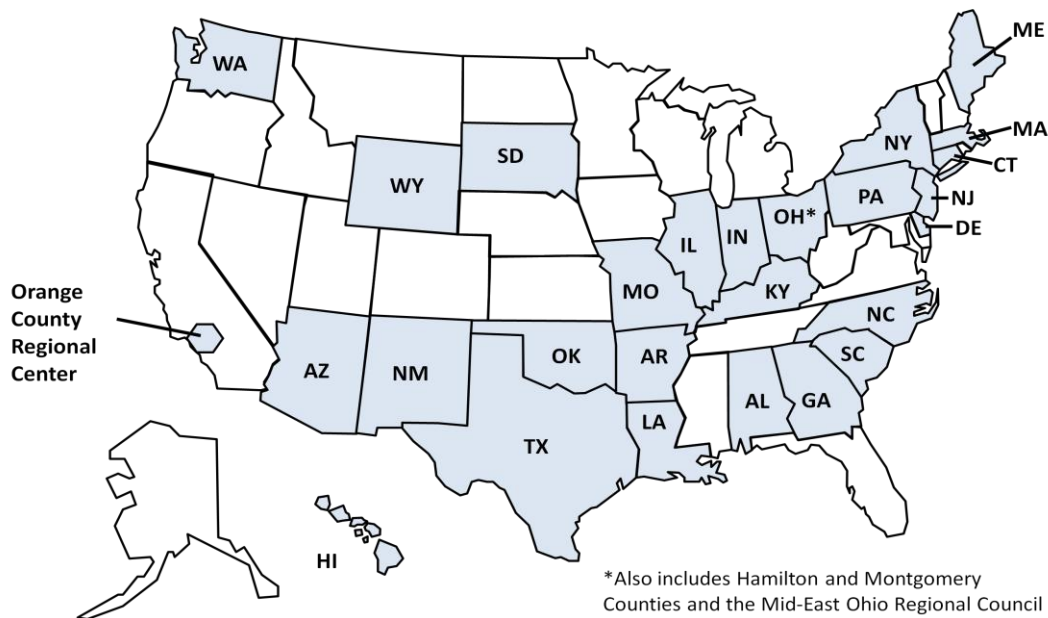
NCI Vision:

- » To influence national and state policy
- » To improve practice at the state level
- » To add knowledge to the field
- » To inform the Association's strategic planning and priority setting

PARTICIPATING STATES

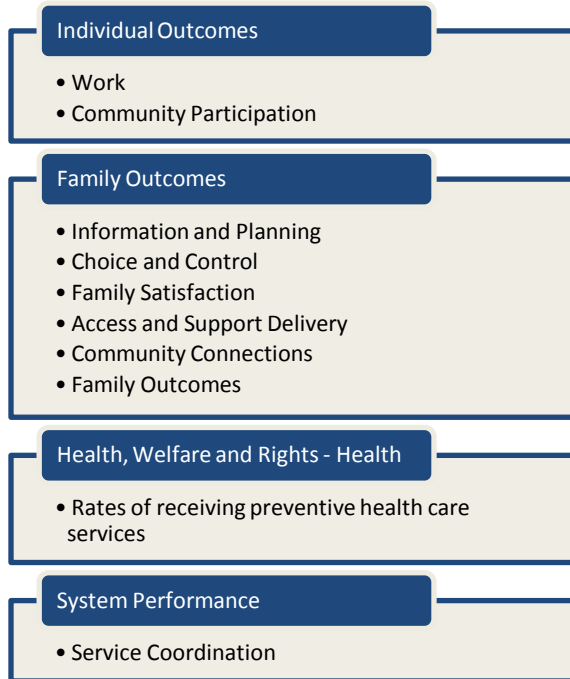
In 2008-2009, the membership of NCI included 25 states and four sub-state entities (see Figure 1).

FIGURE 1. PARTICIPATING NCI STATES 2008-2009



CORE INDICATORS

The NCI framework includes approximately 100 performance and outcome indicators organized across five broad domains: Individual Outcomes, Family Outcomes, Health Welfare & Rights, Staff



Stability & Competency, and System Performance. Each domain is further broken down into sub-domains representing specific expectations. For example, the expectation for the “Work” sub-domain is: *People have support to find and maintain community integrated employment.* The sub-domains are measured by one or more performance indicators selected by the steering committee of participating states based upon a set of criteria including face validity, usefulness as a benchmark, and feasibility to collect. Some indicators are measured using survey data gathered on a sample of individuals, while others are computed using population data available through state information management systems (e.g., incident reports). The full list of core indicators may be viewed and downloaded on the NCI website at www.nationalcoreindicators.org.

2008-2009 ACCOMPLISHMENTS AND ACTIVITIES

This report highlights selected aggregate results from 2008-09. Detailed summary reports of state by state results and national averages for all NCI measures are available on the website. The full reports are organized by data source. The graphic above summarizes the particular domains and sub-domains addressed in this annual report. This year we pay particular attention to 1) whether people living in different residential arrangements experienced different outcomes, and 2) whether people with a dual diagnosis of intellectual disabilities (ID) and mental illness had outcomes that differed from people with ID only.

State participation in NCI remains strong. New members in 2008-2009 included Illinois, Ohio, and three sub-state entities in Ohio: Hamilton County, Montgomery County, and the Mid East Ohio Regional Council (MEORC).

A major accomplishment of 2007-08 was the revision and testing of the Adult Consumer Survey, which includes expanded questions on health, self-direction, and community participation. In 2008-09, the first round of data from these new questions was collected, and highlights are presented in this report.

The Content Review and Field Test Committee (CRAFT), a group of state officials who work in conjunction with program staff to recommend changes and to assist with pilot testing of revised NCI protocols, began working on revising all three of the Family Surveys. All three revised surveys were completed and made available for implementation in the 2010-11 data cycle.

2008-09 was the first year that a new online data entry system application (ODESA) was used by states to enter Consumer Survey data. Reports from states that used ODESA were positive overall.

NCI conference calls were held during the year on a variety of topics, including: strategies for presenting NCI data, CMS Waiver requirements, the development of provider profiles, and sampling procedures.

On the research front, additional journal articles based on analyses of NCI data from six states were published in collaboration with researchers at the University of Minnesota. We continued the analyses of multistate data based on the acceptance in 2007-08 of two successful grant applications from the National Institute on Disability and Rehabilitation Research (NIDRR) and began to conduct case studies of NCI implementation.

DATA SOURCES

Four primary data sources are referenced in this report. NCI utilizes an Adult Consumer Survey to gather information directly 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 to 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 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 2008-09, and the total number of surveys collected overall.

FIGURE 2. SUMMARY OF SURVEYS BY STATE 2008-2009

NCI Survey	Target Population	Method of Administration	# of States 2008-09	Total # of Surveys
Adult Consumer Survey	Adults 18 and older receiving at least one service besides case management	In-person interview	20	11,569
Adult Family Survey	Families of adults 18 and older living at home	Mail	11	4,986
Child Family Survey	Families of children under 18 (or under 23 if still in school system) living at home	Mail	6	2,407
Family Guardian Survey	Families or guardians of adults 18 and older living outside the home	Mail	12	5,629

ANALYSIS

NCI data management and analysis is coordinated by Human Services Research Institute (HSRI). Data were entered by each state and submitted to HSRI for analysis. All data files received were reviewed for completeness and compliance with standard NCI formats. The data files were cleaned and merged, and invalid responses were eliminated.

For the purposes of this report data were analyzed for the sample as a whole, with no weighting or risk-adjustment. The health care items include “don’t know” responses in the denominator.

SELECTED RESULTS 2008-2009

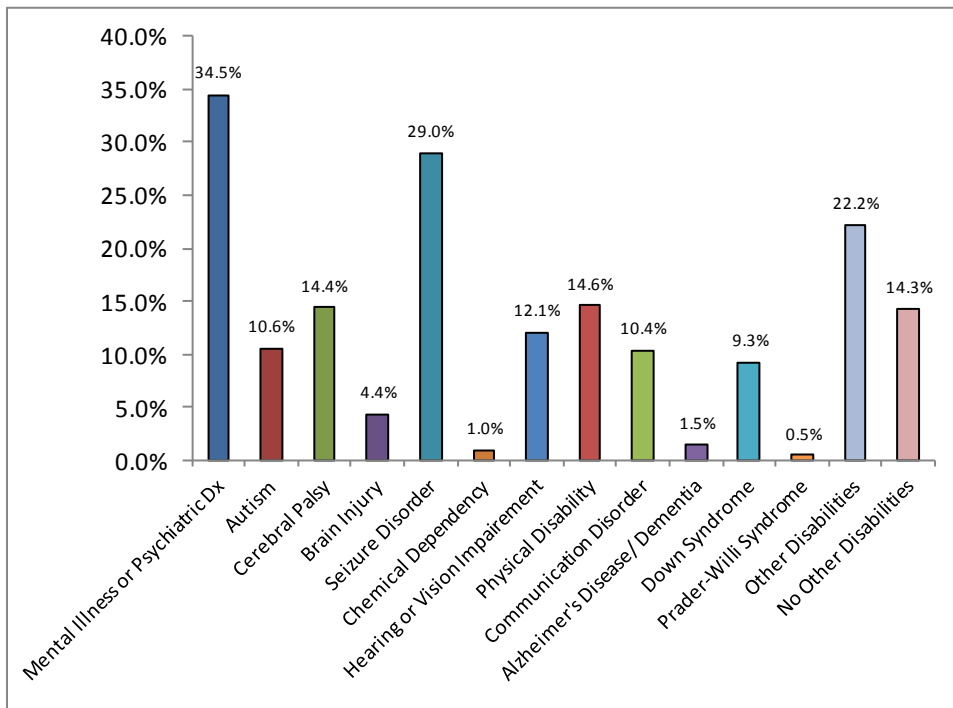
SAMPLE CHARACTERISTICS

In 2008-2009, a total of 11,569 consumer surveys were completed in 20 states.

Disabilities

Only 14.3% of all people surveyed had no disabilities reported other than ID (Figure 3). The most common other disabilities were mental illness or some kind of psychiatric diagnosis (34.5%), seizure disorder (29.0%), physical disability (14.6%), cerebral palsy (14.4%), and severe hearing or vision impairment (12.1%). Eleven percent (10.6%) of people surveyed had a diagnosis of autism. Less than 1% had a diagnosis of autism but no ID diagnosis.

FIGURE 3. PROPORTION OF PEOPLE WITH OTHER DISABILITIES



Residence

The Consumer Survey includes questions about where the person interviewed currently lives. Figure 4 shows the proportion of people living in each type of residence. The majority of people surveyed resided in a parent's or relative's home (30.7%), or in a group home (28.6%). Thirteen percent (12.9%) lived in an independent home or apartment, and 10.1% resided in a specialized institutional facility for persons with ID/DD, such as an ICF/MR.

To make comparisons between different types of residence more manageable, some categories were collapsed and four major types of living arrangements were considered: parent's/relative's home, community-based residence (which includes group home and agency-operated apartment-type setting), independent home/apartment, and specialized institutional facility. As is shown in Figure 5, 33.7% of people lived in a community-based residence.

FIGURE 4. PROPORTION OF PEOPLE LIVING IN ALL DIFFERENT TYPES OF RESIDENCE

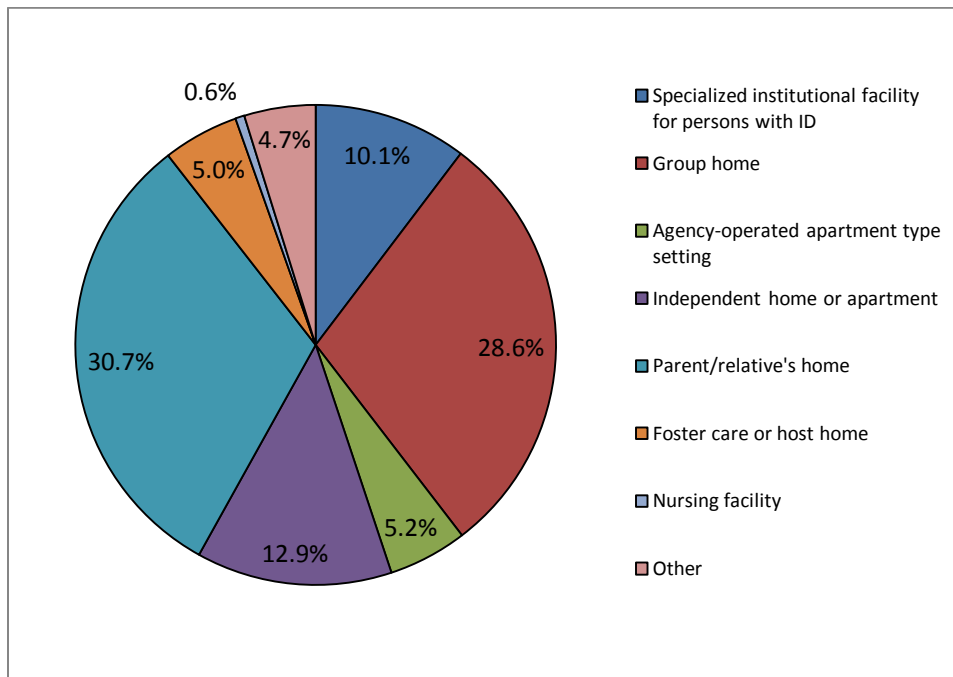
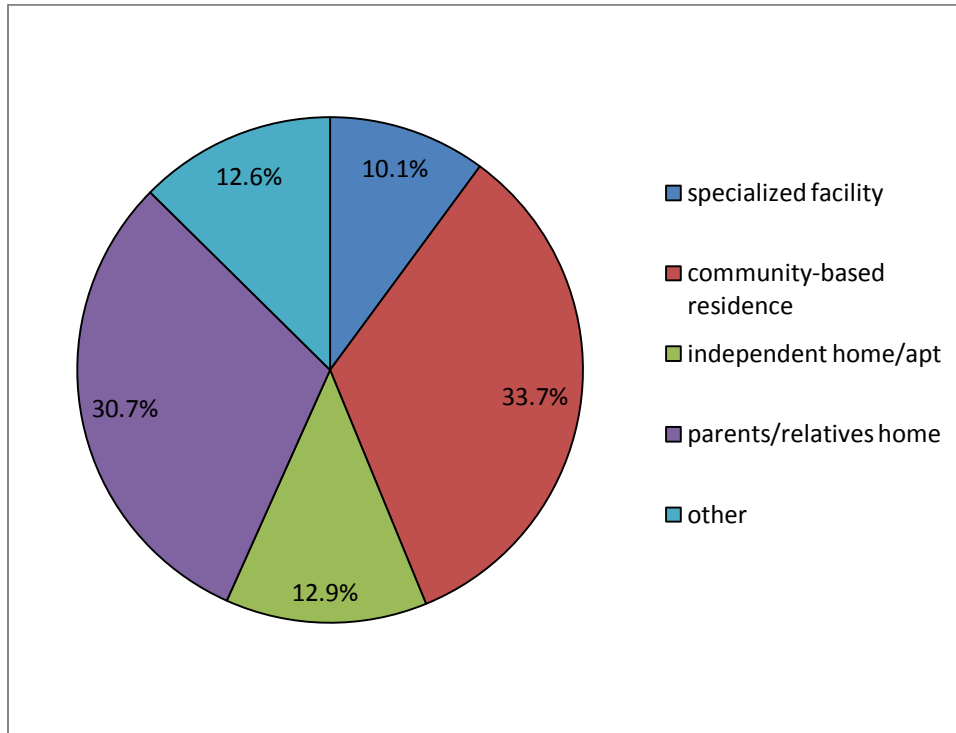


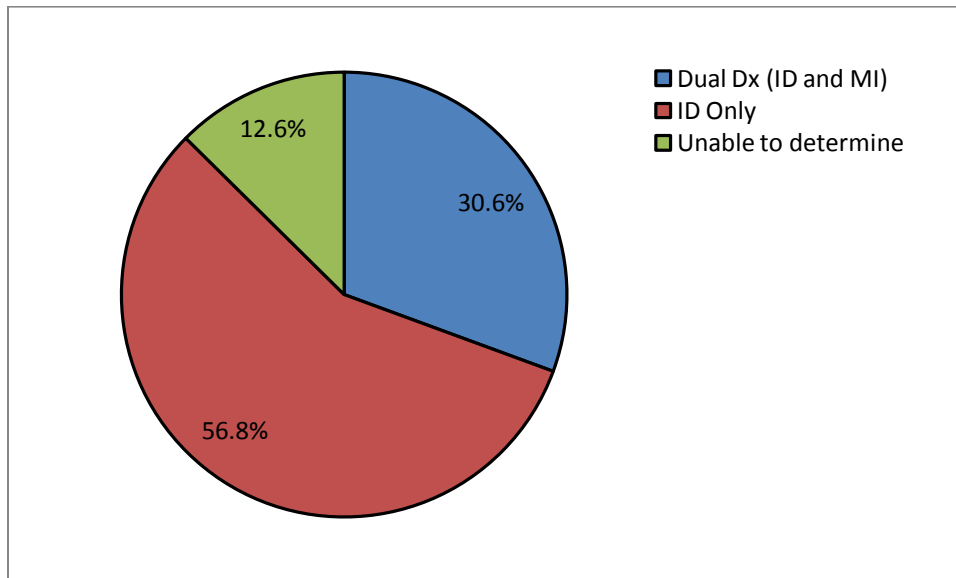
FIGURE 5. PROPORTION OF PEOPLE LIVING IN FOUR MAJOR TYPES OF RESIDENCE



Dual Diagnosis

Thirty-one percent (30.6%) of people interviewed were identified as having co-occurring ID and a mental illness or psychiatric diagnosis; 56.8% had ID only.

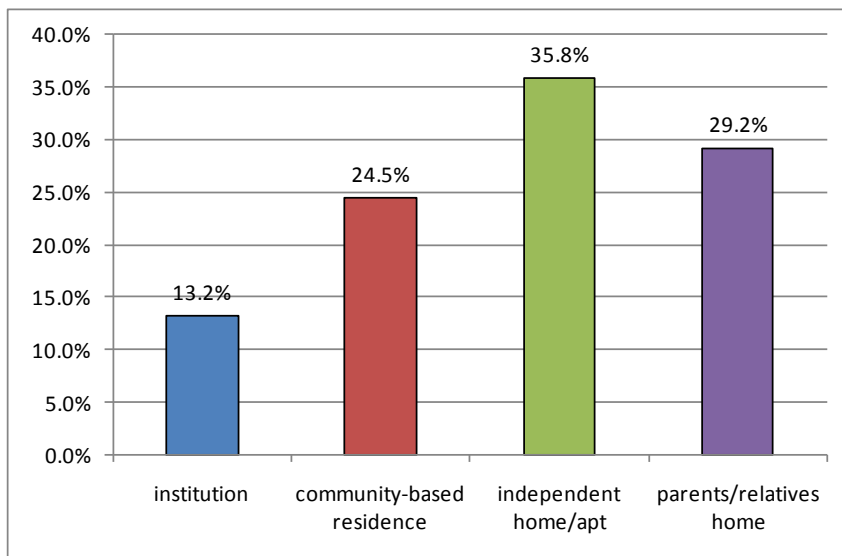
FIGURE 6. PROPORTION OF PEOPLE WITH DUAL DIAGNOSIS



EMPLOYMENT

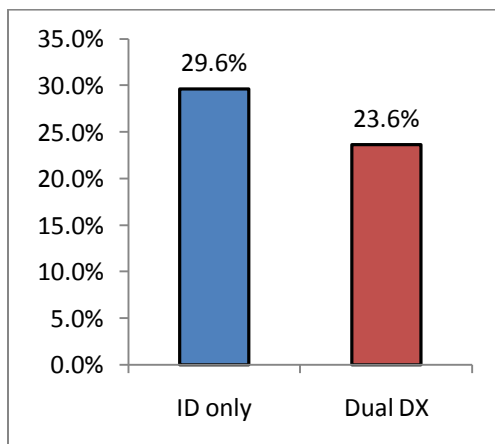
In 2008-2009, a total of 7,718 respondents answered the question about whether or not the individual held a job in the community. Twenty-seven percent (26.8%) of respondents stated “yes.” However, the proportion of people with a job in the community varied depending on where people lived. Thirty-six percent (35.8%) of people living in independent homes/apartments reported having a job in the community, followed by 29.2% of those living in a parent’s/relative’s home, and 24.5% of those living in a community-based residence (see Figure 7). Of those living in an institutional setting, 13.2% were reported to have some type of community employment.

FIGURE 7. PROPORTION OF PEOPLE HAVING A JOB IN THE COMMUNITY BY RESIDENCE TYPE



The proportion of people with ID only who reported having a job in the community was slightly higher than the proportion of people with a dual diagnosis of both ID and a mental illness diagnosis (see Figure 8).

FIGURE 8. PROPORTION OF PEOPLE HAVING A JOB IN THE COMMUNITY BY DUAL DIAGNOSIS VS. ID ONLY



Of those who reported having a job in the community, 92.6% stated that they liked their job. The percentage was very similar across all residence types, and there was no difference in percentage between people with dual diagnosis and people with ID only.

The four most common types of community jobs that people held were: cleaning and maintenance (29.7%), food preparation (20.0%), retail (14.5%), and assembly and manufacturing (11.0%). The proportions did not vary significantly for people with or without a dual diagnosis, with the exception that those with co-occurring ID and MIs were slightly less likely to work in food preparation and slightly more likely to be employed in cleaning and maintenance. People living in institutions were somewhat more likely to work in assembly and manufacturing.

For people with jobs in the community, only 42.5% of their hourly earnings were at or above their state’s minimum wage level. The average hourly wage in community jobs was \$6.25. However, both hourly wage (Figure 9) and number of people earning at least the minimum wage (Figure 10) varied by the locations where they lived. People living in independent homes/apartments made highest hourly wage (\$6.68) and larger proportion of them made at least minimum wage (50.0%). People living in institutions, on the other hand, made the lowest hourly wage (\$4.14) in community jobs and had the lowest proportion of people making minimum wage (7.1%).

States with the highest proportion of...

People reporting having a job in the community:
CT, OK, WY, MA

People reporting liking their job: AR

People earning at or above state minimum wage:
AR, OH

People receiving employment benefits: OH, CT, MA, NY

FIGURE 9. AVERAGE HOURLY WAGE BY RESIDENCE TYPE

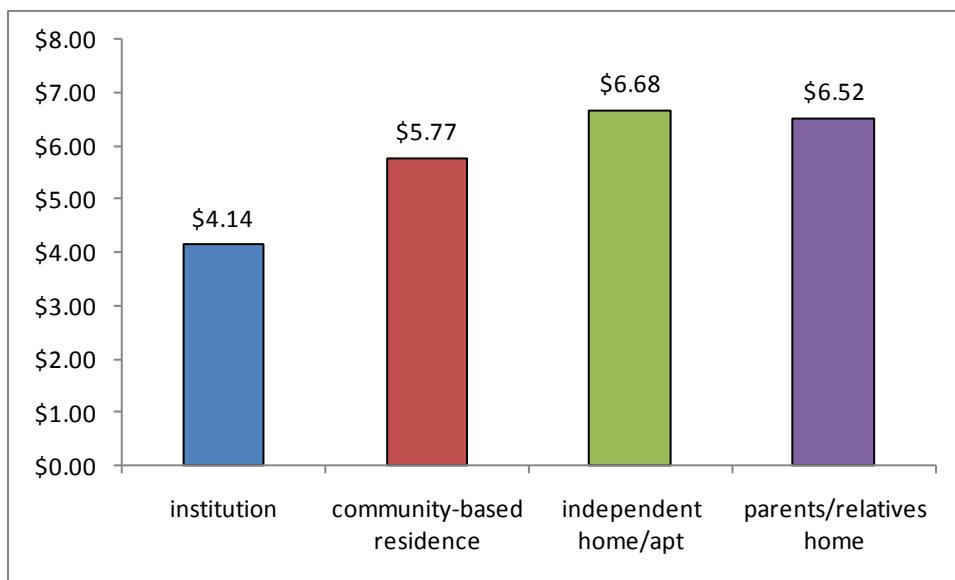
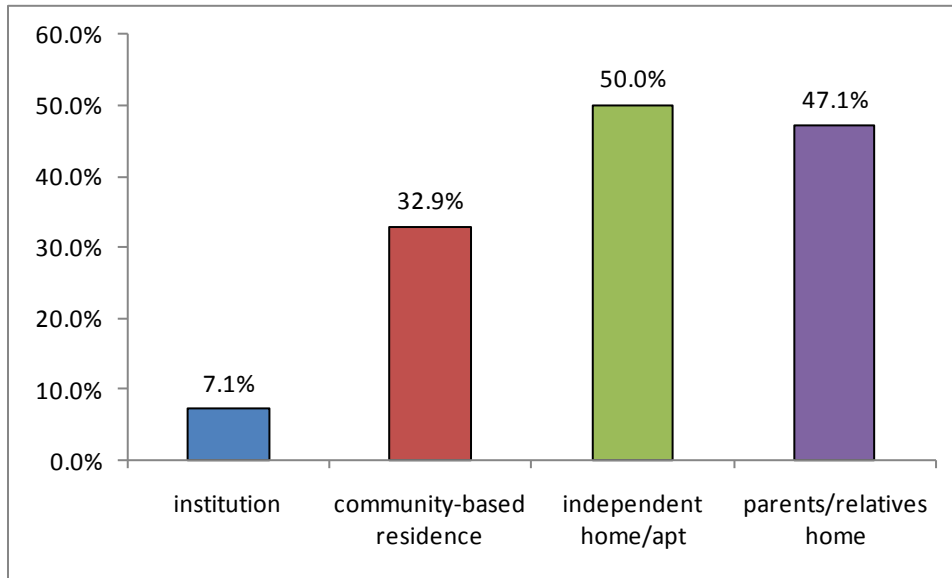


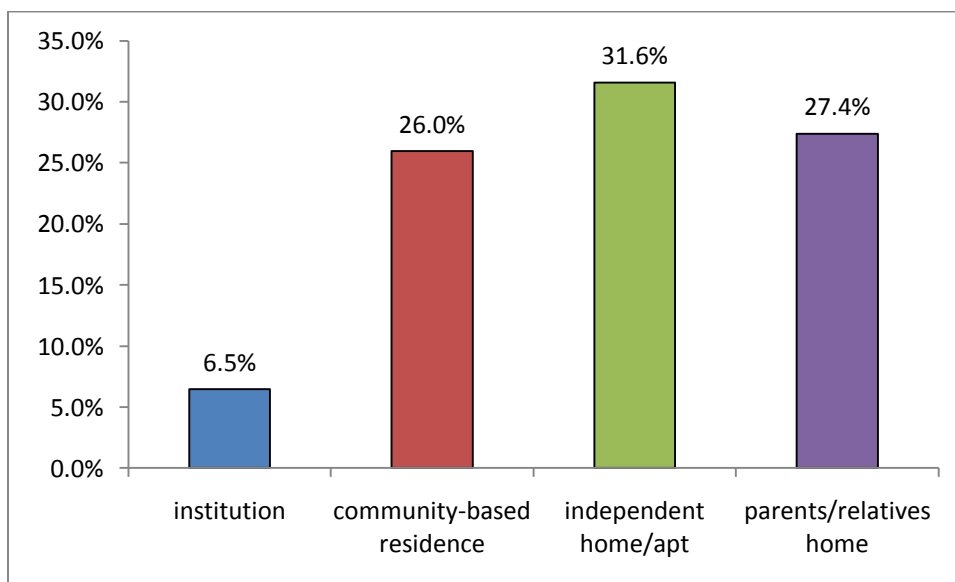
FIGURE 10. PROPORTION OF PEOPLE EARNING AT OR ABOVE STATE MINIMUM WAGE BY RESIDENCE TYPE



There were also differences depending on whether people had a diagnosis of mental illness. Thirty-five percent (34.8%) of people with dual diagnosis earned at or above minimum wage and their average hourly wage was \$5.70; people with diagnosis of ID only made on average \$6.31 per hour and 42.9% of them earned at least minimum wage.

Only 27.8% of people surveyed received benefits at their community jobs. This also varied by type of residence. The proportion receiving benefits was highest for people living in independent homes and lowest for people living in institutions (Figure 11). There was no substantive difference in the proportion receiving benefits between those with dual diagnosis vs. diagnosis of ID only.

FIGURE 11. PROPORTION OF PEOPLE RECEIVING BENEFITS AT THEIR JOB BY RESIDENCE TYPE



COMMUNITY PARTICIPATION

The majority of individuals surveyed participated in at least one activity in the community in 2008-09. As illustrated in Figure 12, almost 90% of individuals went shopping, on errands or appointments, or out to eat. A somewhat smaller proportion (71%) went out for entertainment; yet fewer people went to religious services, out for exercise or on a vacation (around 50%).

FIGURE 12. PROPORTION OF PEOPLE WHO PARTICIPATED IN COMMUNITY-BASED ACTIVITIES

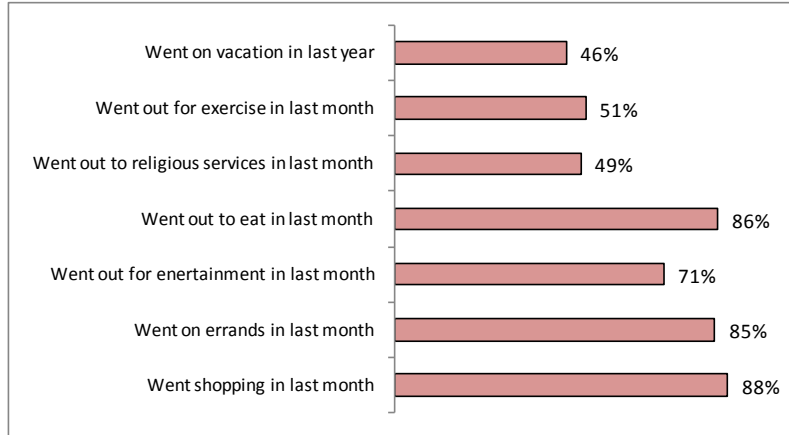
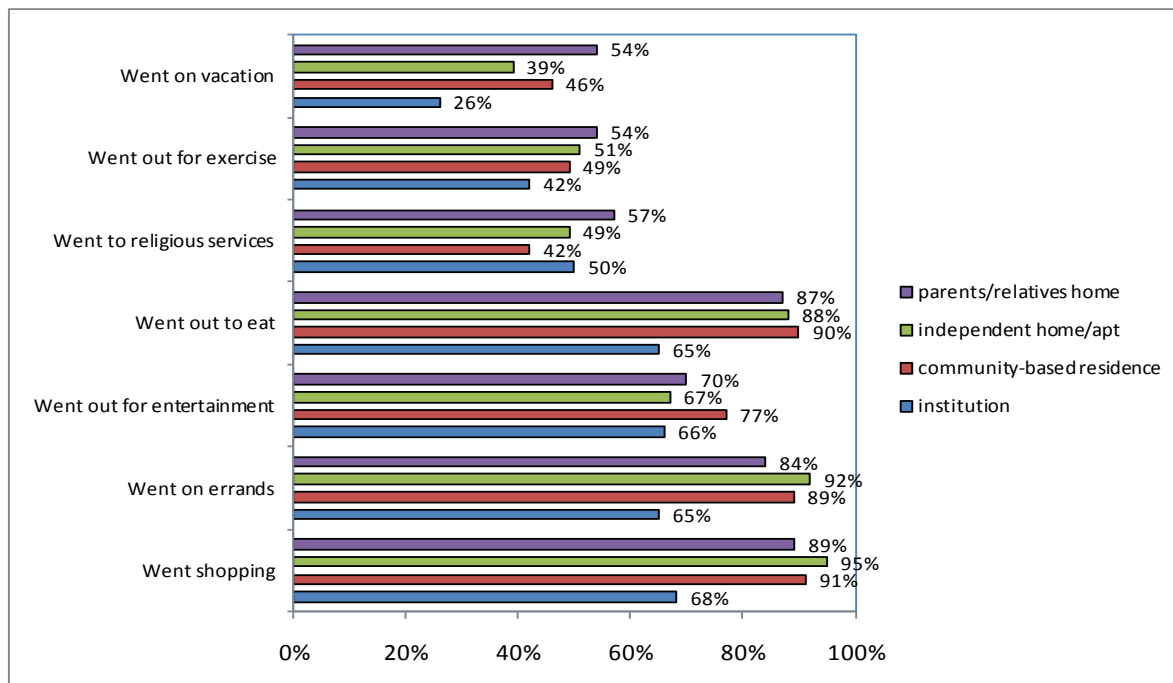


Figure 13 shows the proportion of people who participated in community-based activities broken down by the type of living arrangement. People living in institutions were the least likely to have participated in any community activity.

FIGURE 13. PROPORTION OF PEOPLE WHO PARTICIPATED IN COMMUNITY-BASED ACTIVITIES BY RESIDENCE TYPE



There were no substantive differences in the proportion of people with and without dual diagnosis who participated in the community-based activities. The only exception was that those with dual diagnoses were slightly less likely to have gone on vacation and to have attended religious services.

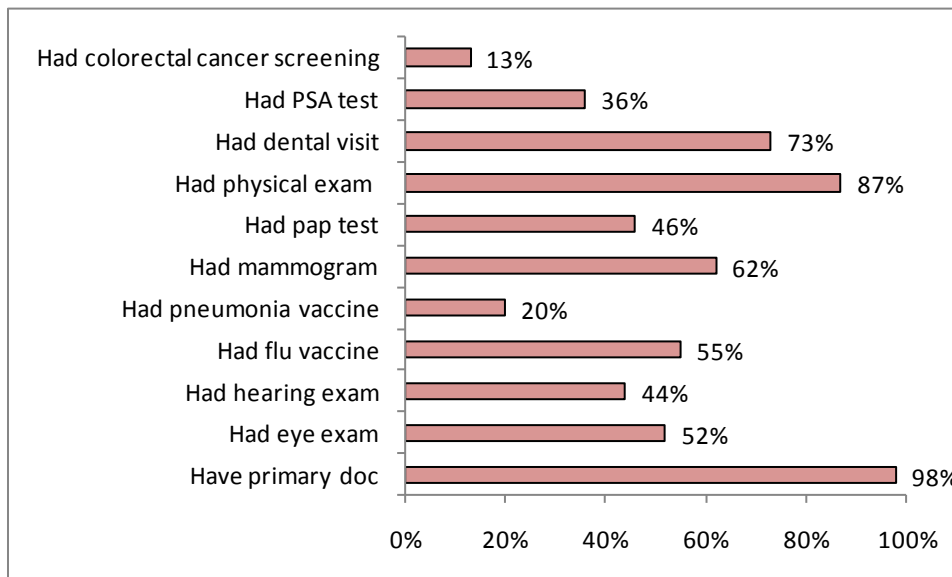
States with highest frequency of...

- People went shopping:** AR, NC, OK, WY
- People went out on errands:** DE, OK, PA, CT, MA
- People went out for entertainment:** OK, WY, AR
- People went out to eat:** AR, MA, NC, WY
- People went out to religious services:** LA, SC, GA, AR
- People went out to exercise:** WY, AR, TX
- People went out on vacation:** TX, AR, MA

HEALTH CARE AND HEALTH

Only 4% of people surveyed were reported to be in poor health, and only 8% used tobacco products. Ninety-eight percent (98%) had a primary care doctor and 87% had had a physical exam in the past year. However, the proportion of people who received other routine preventive health care was lower (Figure 14). Seventy-three percent (73%) had a dental visit within the past year, 52% had received a vision exam in the past year, and only 44% had received a hearing test within the past five years. Fifty-five percent (55%) received a flu vaccination during the past year and only 20% had ever had a pneumonia vaccine. Sixty-two percent (62%) of women over 40 had a mammogram in the last two years, but only 46% of all women had a Pap test in the past three years. Thirty-six percent (36%) of men over 50 years of age had a PSA test in the past year, and only 13% of people over age 50 had had a colorectal cancer screening in the past year.

FIGURE 14. PROPORTION OF PEOPLE WHO RECEIVED PREVENTIVE HEALTH CARE SERVICES



Rates of receiving preventive health care services varied by where people resided (see Figure 15). For almost all services, people living with parents/relatives and people living in independent homes/apartments were less likely to have received the procedure or exam than people living in community-based residences and in institutions. For example, approximately 90% of people in institutions and community-based residences had received a dental visit in the last year, as compared to about 60% of people in independent homes and family homes. Only 30% of people living in family and independent homes had received a hearing exam in the last five years, compared to 80% of those living in an institution and 60% of those living in community-based residences. A reported 43% of people living in institutional settings had ever received a pneumonia vaccine; the number was only 11% for those living with parent or relative and only 16% for those living in an independent home or apartment. Colorectal cancer screening rates were low regardless of where people lived. On the other hand, almost 100% of people in all types of living situations had a primary doctor.

States with highest proportion of...

People who had a primary doctor: AR, OK, KY, NY, MA

People who had a physical exam: OK, NJ, AR, KY, LA, MO, NY, IL

People who had a dental exam: NJ, MO, IL, OK, KY, MA, TX, NY

People who had a vision exam: IL, MO, KY, OK, NY, TX

People who had a hearing exam: IL, NJ, NY, TX, PA

People who had a flu vaccine: MO, IL, OK, WY, NY

People who have had a pneumonia vaccine: DE, IL, MO, OK

Women over 40 who had a mammogram: IL, MO, NY

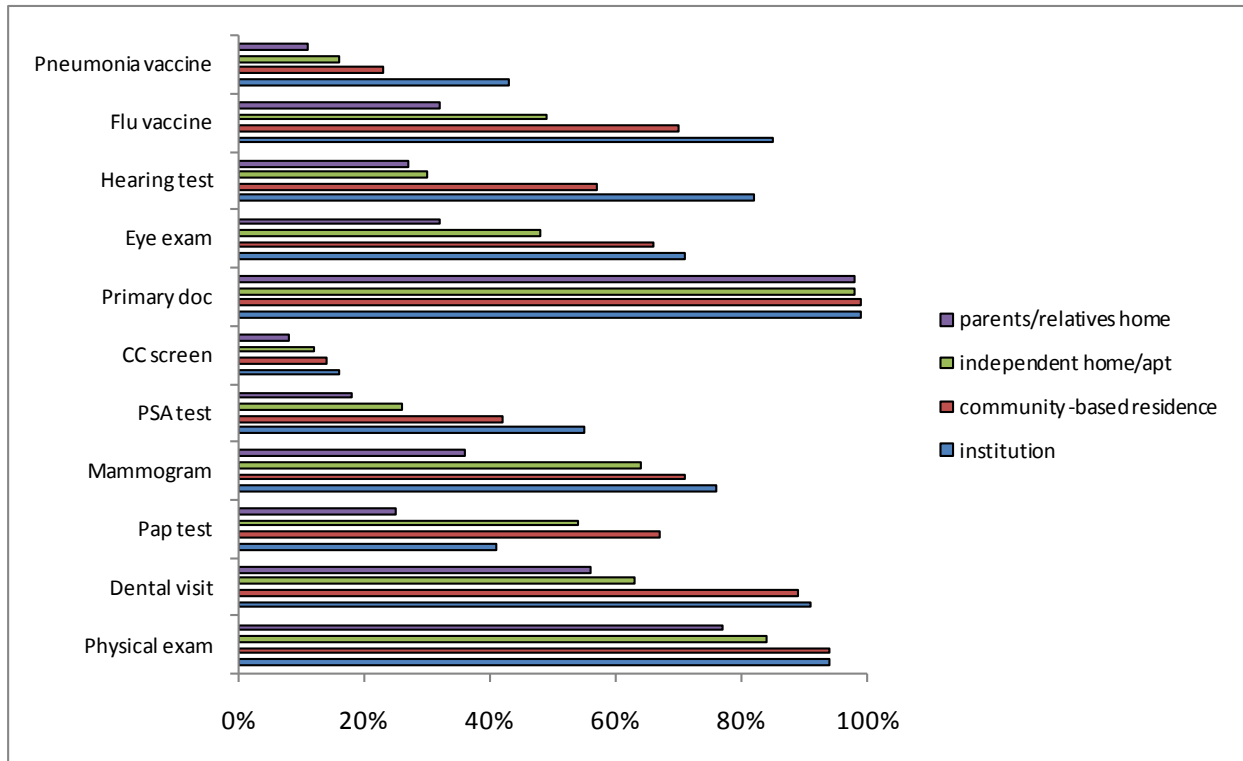
Women who had a Pap exam: IL, MO, NY

Men over 50 who had a PSA test: IL, MO, NY

People over 50 who had colorectal cancer screening: NY

There were also some differences in rates of receiving preventive health services for individuals who had a dual diagnosis. People with dual diagnoses were slightly more likely to have had hearing and vision exams, to have received a flu vaccine, and to have visited a dentist. Women with dual diagnosis were slightly more likely to have had a Pap test and a mammogram. On the other hand, people with dual diagnoses were also more likely to smoke or use tobacco products.

FIGURE 15. PROPORTION OF PEOPLE WHO RECEIVED PREVENTIVE HEALTH CARE SERVICES BY RESIDENCE TYPE



FAMILY OUTCOMES
INFORMATION AND PLANNING

In 2008-2009, 47% of Adult Family and 38% of Child Family Survey respondents reported that they usually or always received information about the services and supports that were available for their families. Roughly 40% of both respondent groups said they sometimes received this information, and approximately 20% responded that they seldom or never received information (16% and 23%, respectively).

Of those who received this information, around 55% of both Adult Family and Child Family Survey respondents reported that this information was usually or always easy to understand, roughly 38% of both groups rated the information as sometimes easy to understand, and approximately 7% responded that the material was seldom or never easy to understand. Thus, although the majority of respondents received and understood information about available services and supports, a substantial percentage of Adult and Child Family Survey respondents found the information sometimes, seldom or never easy to understand. In addition, 20% reported that they almost never receive information.

When asked if their plan included things that that were important to the respondents and the family member, approximately 75% of Adult Family, Child Family, and Family Guardian respondents indicated that the plan usually or always included things that were important to them. In addition,

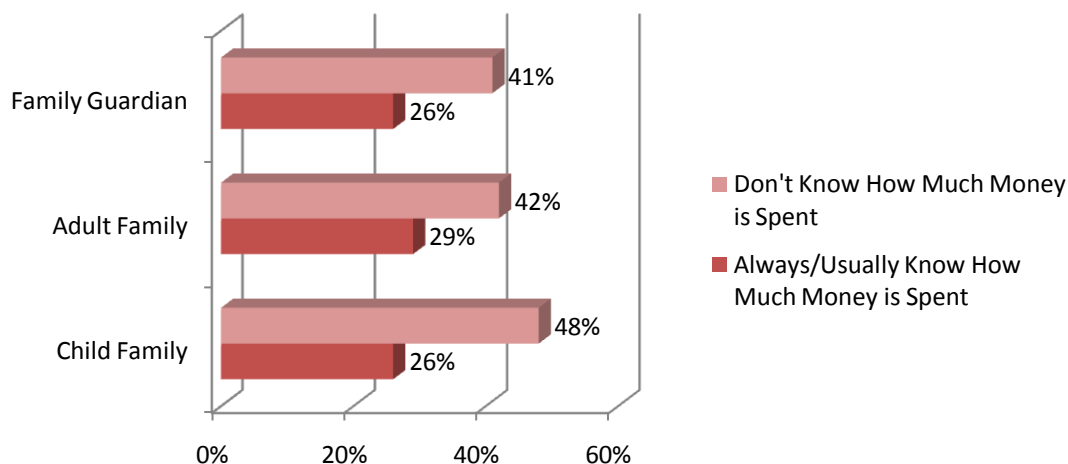
only around 5% indicated that their plan seldom or never included things that were important to the respondents or their family members.

CHOICE AND CONTROL

Just over two-thirds of Adult Family and Child Family Survey respondents usually or always chose the agencies or providers who worked with their family member in 2008-2009. In addition, almost 20% of Adult Family and Child Family Survey respondents reported that they sometimes made these choices. While roughly half of Adult Family and Child Family Survey respondents indicated that they usually or always had control or input over the hiring and management of support workers, approximately 65% of respondents indicated that they usually or always *wanted* to have control or input of hiring and management of support workers.

In 2008-2009, across all family survey respondents, while between 26-29% responded that they usually or always knew how much money was spent on services, between 41-48% said they did not know (see Figure 16). An additional 15% to 20% of respondents indicated that they seldom or never had knowledge of how much money was being spent on their family member's services.

FIGURE 16. KNOWING HOW MUCH MONEY IS SPENT ON SERVICES



FAMILY SATISFACTION

As in previous years, families stated in broad terms that they were usually or always satisfied with the overall services and supports that they and their family member received. However, this level of satisfaction varied between surveys. Eighty-three percent (83%) of Family Guardian Survey respondents were always or usually satisfied, while in comparison, 61% of Child Family Survey respondents were always or usually satisfied.

In more specific terms, families were less satisfied with certain aspects of services and supports. Between 57-71% of family respondents across all services were satisfied with the way complaints or

grievances regarding services or staff are handled and resolved. Even fewer respondents were familiar with the process for filing a complaint or grievance (ranging from 45-61% across all surveys).

ACCESS AND SUPPORT DELIVERY

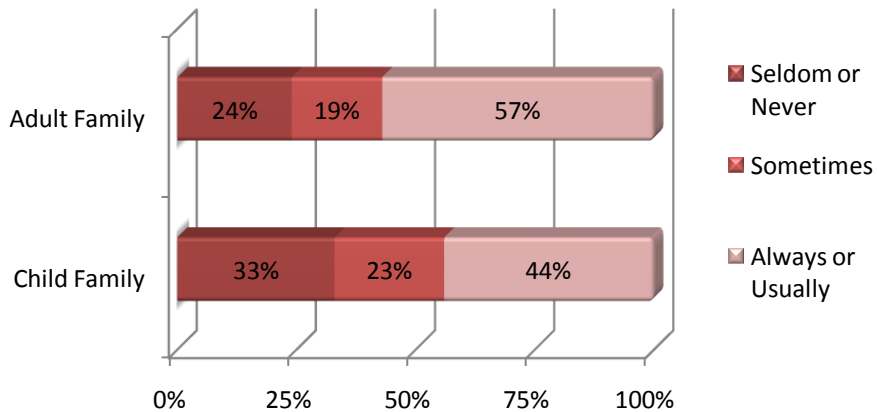
In 2008-2009 over 90% of Adult Family and Child Family Survey respondents reported that their family member had access to health services and medications. However, while 87% of Child Family Survey respondents reported that their family member had access to dental services, only 77% of Adult Family Survey respondents said their family member had access to these services.

For Adult Family Survey respondents, of those families who reported that they requested different types of supports, 42% indicated that the state agency always or usually responded to these requests. For Child Family Survey respondents, however, only 34% reported that the state agency was always or usually responsive.

EMERGENCY SUPPORT

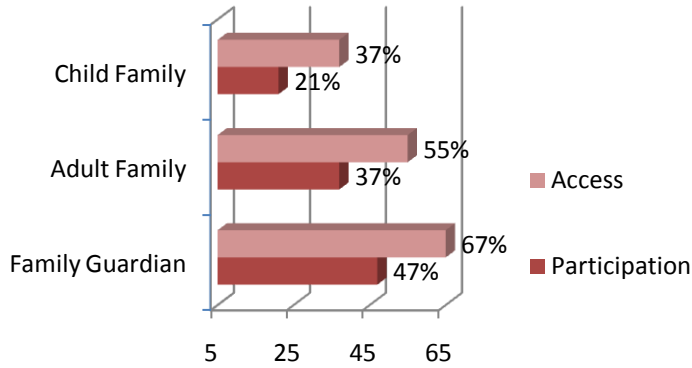
One area of concern regarding the delivery of supports and services is the extent to which Adult Family and Child Family Survey respondents felt supports were available during a crisis or emergency. In 2008-09, roughly one-quarter (AFS- 24%) to one-third (CFS- 33%) of respondents said they felt these supports were seldom or never available. Only 44% to 57% reported they were usually or always available in a crisis or emergency.

FIGURE 17. SUPPORTS AVAILABLE IN A CRISIS OR EMERGENCY



COMMUNITY CONNECTIONS

FIGURE 18. COMMUNITY ACCESS AND PARTICIPATION

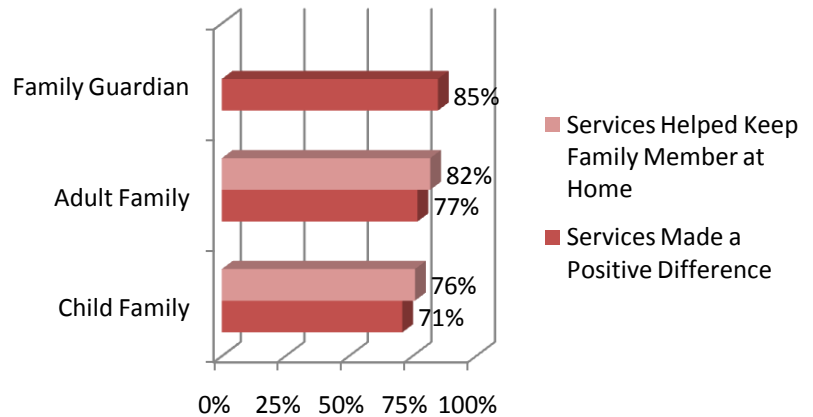


As in previous years, a significant gap existed across all three surveys between the number of families reporting their family members *had* access to community activities and those who indicated that they *used* this access (participated in activities). Perceptions of community access and participation levels for family members of these three respondent groups in 2008-09 are presented in Figure 18.

FAMILY OUTCOMES

As illustrated in Figure 19, over 70% of Adult Family, Family Guardian, and Child Family Survey respondents said that services and supports have usually or always made a positive difference in their family member’s life in 2008-2009. More than two-thirds of all respondents indicated that overall they were satisfied with their supports and services. In addition, roughly 80% of Adult Family and Child Family Survey respondents said that services have usually or always made a difference in helping to keep their family member living at home. Finally, over 80% of Family Guardian, Adult Family, and Child Family Survey respondents reported that that their family member was happy (82%, 84%, and 86%, respectively).

FIGURE 19. FAMILY OUTCOMES IN 2007-08



LINKS TO FULL REPORTS

Detailed reports by state and with national averages are available on the NCI website: www.nationalcoreindicators.org. These reports are organized by data source and by year. Additional “Data Briefs” focusing on special topics are also posted on the Reports page.

HOW STATES ARE USING NCI

NCI participating states are using data in a variety 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. Some specific examples of states’ use of NCI data include:

- In Washington State, volunteers recruited by the Developmental Disabilities Council review NCI reports and make recommendations based upon them. A couple of the recommendations included: 1) Create a website that includes information and resources in local communities; and 2) Employers should make workplaces more accessible to increase choice in employment for people with developmental disabilities.
- Missouri presented the NCI data to a Quality Council made up of self-advocates, family members and guardians. Three focus areas were identified: Satisfaction, Health, and Employment.
- Several states are using NCI data as part of their HCBS waiver quality improvement strategies, including Arkansas, Georgia, New Mexico, and Washington State.

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 2008-09

NASDDDS Members

Linda Rolfe (WA)
Kathryn duPree (CT)
Kevin Casey (PA)
Ric Zaharia (AZ)
Gary Lind (NY)
Bernie Simons (MO)
Kathy Kliebert (LA)

Non-NASDDDS Members

Charlie Lakin (RTC/ICI/UMN)
Rick Hemp (CICG/UC)
Bill Kiernan (ICI/UMass)
Val Bradley (HSRI)

NASDDDS Staff

Chas Moseley
Nancy Thaler

NCI PROGRAM STAFF:

Charles R. Moseley, Ed.D.
Co-Project Director
NASDDDS
cmoseley@nasddds.org

Valerie J. Bradley, M.A.
Co-Project Director
HSRI
vbradley@hsri.org

Sarah Taub, M.M.H.S.
Project Manager
staub@hsri.org

Josh Engler, M.Ed., MSc, CRC
Project Coordinator
jengler@hsri.org

Julie Bershadsky, Ph.D.
Project Statistician
jbbershadsky@hsri.org

Cheryl Sartori
Project Assistant
csartori@hsri.org

Bridgid Conn, Ph.D. Candidate
Project Assistant



www.nationalcoreindicators.org

2008-2009 State Coordinators

ALABAMA
Jeff Williams

ARIZONA
Brian Lensch

ARKANSAS
Shelley Lee
Cindy Young

CALIFORNIA - Orange County
LeeAnn Christian

CONNECTICUT
Deborah Duval

DELAWARE
Karen Smith
Katie Hoffman

GEORGIA
Eddie Towson

HAWAII
Aaron Arakaki

ILLINOIS
Michael Hurt

INDIANA
Barbara Stachowiak

KENTUCKY
Betsy Dunnigan

LOUISIANA
Dena Vogel

MAINE
Bridget Bagley

MASSACHUSETTS
Janet George

MISSOURI
Margy Mangini

NEW JERSEY
Virginia Carlson

NEW MEXICO
Elizabeth C. Kennedy
Bobbi Britt

NEW YORK
Ray Pierce

NORTH CAROLINA
Maria Fernandez
Terrie Qadura

OHIO
Tina Evans

OHIO - Hamilton County
Alice Pavey

OHIO - MEORC
Tara Nicodemus

OHIO - Montgomery County
Mark Vonderbrink

OKLAHOMA
Genny Gordon

PENNSYLVANIA
Lee Stephens

SOUTH CAROLINA
Ann Dalton

TEXAS
Terri Richard

WASHINGTON STATE
Lisa Weber

WYOMING
Chris Newman

NASDDDS

www.nasddds.org



www.hsri.org