

NCI

ANNUAL SUMMARY REPORT 2007 - 2008

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. In 2008, the University of Minnesota, in partnership with NASDDDS and HSRI, was awarded five years of funding from the National Institute on Disability and Rehabilitation Research (NIDRR) to further investigate research questions using the NCI Consumer Survey multistate data set.

As of June 2008, the NCI collaboration included 26 participating states and 1 sub-state entity. We are pleased to launch the first NCI Annual Summary Report, which highlights activities and key findings from 2007-2008.

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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 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.

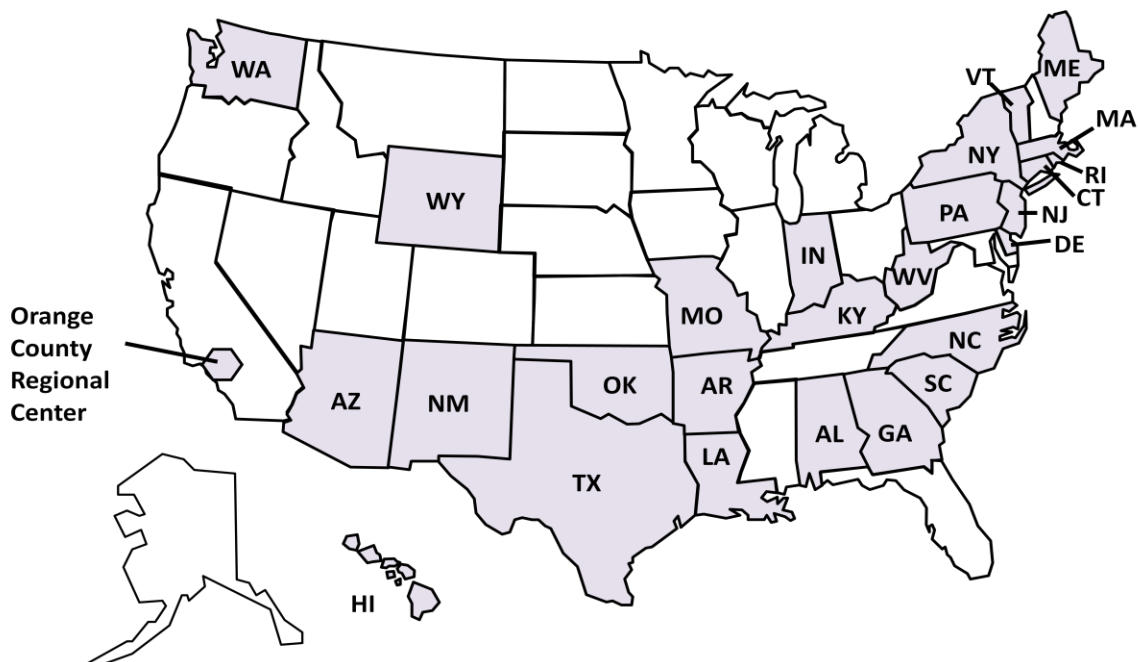
NCI Vision:

- » 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 2007-2008, the membership of NCI grew to 26 states and one sub-state entity (see Figure 1).

FIGURE 1. PARTICIPATING NCI STATES 2007-2008



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 further broken down into

Individual Outcomes

- Work
- Community Participation
- Consumer Satisfaction
- Choice and Decision-Making
- Relationships

Health, Welfare, and Rights

- Respect and Rights
- Health
- Medications
- Safety

Staff Stability and Competency

- Staff Stability

Family Outcomes

- Information and Planning
- Choice and Control
- Family Satisfaction
- Access and Support Delivery
- Community Connections
- Family Outcomes

System Performance

- Service Coordination

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 data systems (e.g., incident reports). The full list of core indicators may be viewed and downloaded on the NCI website at www.nationalcoreindicators.org.

This report highlights selected aggregate results from 2007-08. For some measures, trends noted over the past five years are included. 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 to the left summarizes the particular domains and sub-domains addressed in this annual report.

DATA SOURCES

Five 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. Finally, the Provider Survey on Staff

Stability is a brief two-page survey used to collect information from provider agencies on direct support staff turnover rates, average length of employment, and vacancy rates. This survey is sent to all providers or a representative sample of at least 50 agencies in larger states. Depending on resources and other factors, some states alternate which surveys they administer from year to year. 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 2007-08, and the total number of surveys collected overall.

FIGURE 2. SUMMARY OF SURVEYS BY STATE 2007-2008

NCI Survey	Target Population	Method of Administration	# of States 2007-08	Total # of Surveys
Adult Consumer Survey	Adults 18+ receiving at least one service besides case management	In-person interview	24	12,058
Adult Family Survey	Families of adults 18+ living at home	Mail	15	6,321
Child Family Survey	Families of children under 18 living at home	Mail	8	2,711
Family Guardian Survey	Families or guardians of adults 18+ living outside the home	Mail	11	4,828
Provider Survey on Staff Stability	All provider agencies	Mail/E-mail	10	606

2007-2008 ACCOMPLISHMENTS AND ACTIVITIES

State participation in NCI continues to grow. New members in 2007-2008 included Louisiana, New Jersey, New York, and the renewed membership of a founding NCI state, Missouri. With the increasing number of participants, the program underwent some restructuring aimed at maintaining the active involvement of all members while providing additional oversight and direction to the overall effort. These changes included engaging the NASDDDS Research Committee in an oversight role, changing the name of the Steering Committee to the Operations Committee to reflect its focus on implementation of NCI, and formation of the Content Review and Field Test (CRAFT) Committee, a group of states that will work in conjunction with program staff to recommend changes and to assist with pilot testing of revised NCI protocols.

A major accomplishment of the last year was the revision and testing of the Adult Consumer Survey, which includes expanded questions on health, self-direction, and community participation. In addition, a new online data entry system application (ODESA) was developed to facilitate data entry.

On the research front, several journal articles based on analyses of NCI data from six states were published, in collaboration with researchers at the University of Minnesota. A related achievement was the acceptance of two NIDRR grant applications, which will provide five years of funding to continue the analyses of multistate data and to conduct case studies of NCI implementation.

SELECTED RESULTS 2007-2008

INDIVIDUAL OUTCOMES

WORK

In 2007-2008, a total of 6,538 responses were received from the supplemental employment section of the consumer survey, of which 4,298 (66%) indicated that the individual was participating in some form of employment for some portion of the past month. Categories included competitive employment, individual supported employment, group supported employment and facility-based employment. As shown in Figure 3 below, individuals who worked in group supported employment settings and facility-based work programs worked more hours and earned less money per month on average than those who worked in competitive or individual supported employment settings.

FIGURE 3. AVERAGE HOURS AND WAGES PER MONTH BY EMPLOYMENT SETTING IN 2007-08

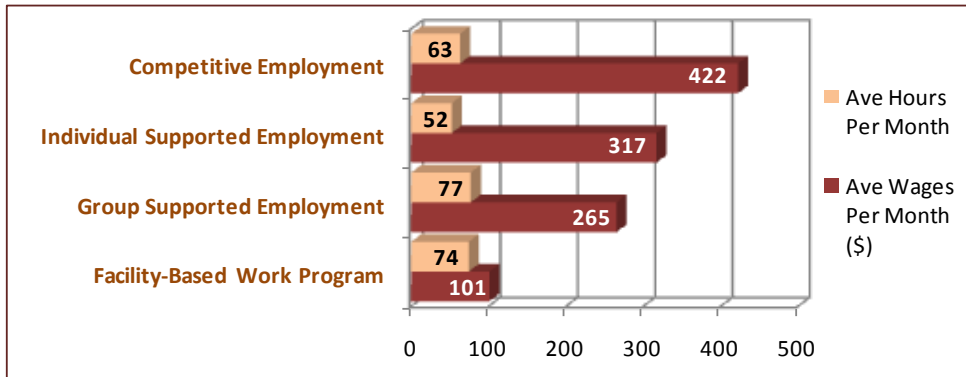
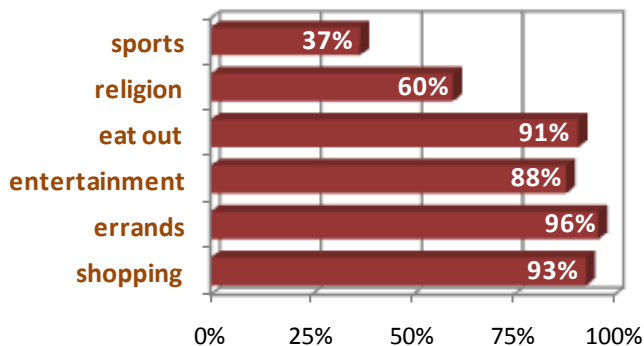


FIGURE 4. PERCENT OF INDIVIDUALS PARTICIPATING IN EACH COMMUNITY ACTIVITY IN 2007-08



COMMUNITY PARTICIPATION

The majority of individuals surveyed participated in at least one activity in the community in 2007-08. As illustrated in Figure 4, roughly 90% of individuals went shopping, on errands or appointments, out for entertainment, or ate in a restaurant. A smaller percentage went to religious services (60%) or took part in integrated sports activities (37%). It is important to note that while 37% of individuals reported participating in community-integrated

sports, an additional 33% reported participating in non-integrated sports, and another 30% were not active in any sports activities. Participation rates have changed only minimally since 2003-04. In addition, in 2007-08 there were minimal state differences in community activity participation rates.

CHOICE AND DECISION-MAKING

Analysis of individual data over the past five years from states that provided data for at least four of those years indicated that people surveyed were more likely to choose the staff who support them in their homes than to choose where they lived. Further, they were more likely to choose their home and home staff than with whom they lived. As illustrated in Figure 5, these differences were consistent over this five year period despite small fluctuations in each type of choice over time.

Another interesting trend was the increase in the percentage of individuals who were able to choose their case manager, from roughly 47% during 2003-2006 to roughly 52% during 2006-2008.

RELATIONSHIPS

Between 2003-04 and 2007-08, roughly 90% of individuals surveyed stated that they had friends. Of these, the majority had friends who were not staff or family. In 2007-08 AR, DE, ME, MO, NM, OK, and RI had a significantly higher proportion of people with friends who were not staff or family than the other NCI states.

Roughly 35% of individuals stated that they were sometimes lonely during this five year period and only a minority stated that they often felt lonely. As presented in Figure 6,

the proportion of people who were often lonely was highest in 2005-06, and conversely the proportion of individuals who were not lonely was lowest during this last cycle.¹

A 2007 study of NCI data found a link between loneliness, relationships with friends and family, and feelings of safety. Specifically, according to Stancliffe, Lakin, Doljanac, Byun, Taub, and Chiri (2007)², significantly greater feelings of loneliness were reported by NCI participants who were afraid at

FIGURE 5. FIVE YEAR TRENDS IN HOME-RELATED CHOICE

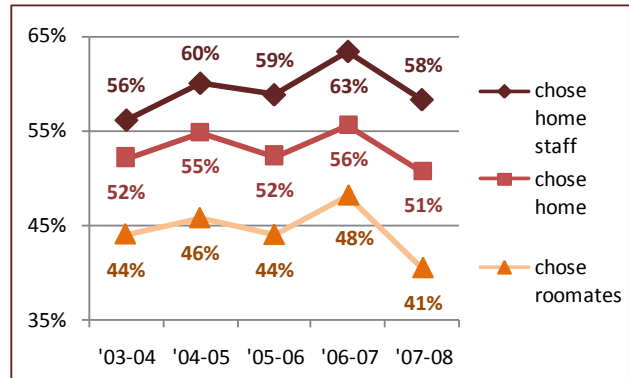
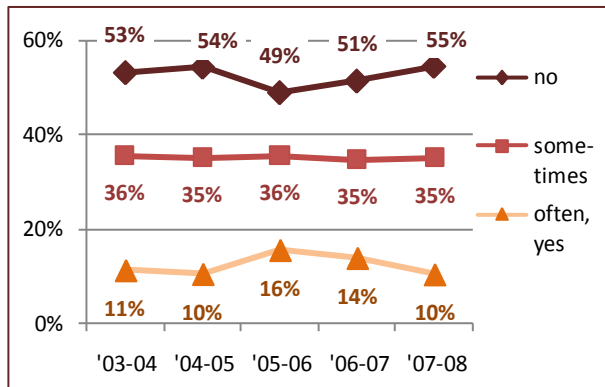


FIGURE 6. FIVE YEAR TRENDS IN LONELINESS



¹ These findings refer to the 15 states that provided data for at least four years during this five year period.

² Stancliffe, R.J., Lakin, K.C., Doljanac, R., Byun, S., Taub, S., & Chiri, G. (2007). Loneliness and living arrangements. *Intellectual and Developmental Disabilities, 45*, 380-390.

home or in their neighborhood, who did not like where they lived, or who had less contact with their family and friends.

CONSUMER SATISFACTION

There were very high levels of individual satisfaction with work and home life in 2007-08. Specifically, most people said they were satisfied with where they lived (95%) and worked (95%), and felt that home (90%) and work staff (94%) were respectful. There were minimal state differences in home and work satisfaction. However, a few states differed on whether individuals felt their home and work staff were respectful. Significantly more individuals in RI, AR, IN, LA, NM, ME, and PA felt their home or day support staff treated them with respect than those in other states.

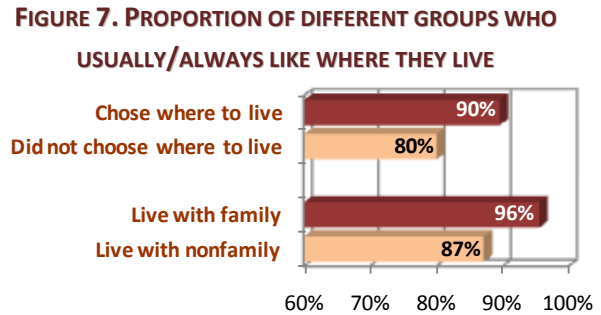


Figure 7 above illustrates findings from a 2009 article by Stancliffe, Lakin, Taub, Chiri, & Byun examining satisfaction and well-being among NCI participants³. According to this study, individuals who were given more choice about their living situation reported significantly higher home satisfaction. In addition, those who lived with their families liked where they lived more than those who did not live with their families.

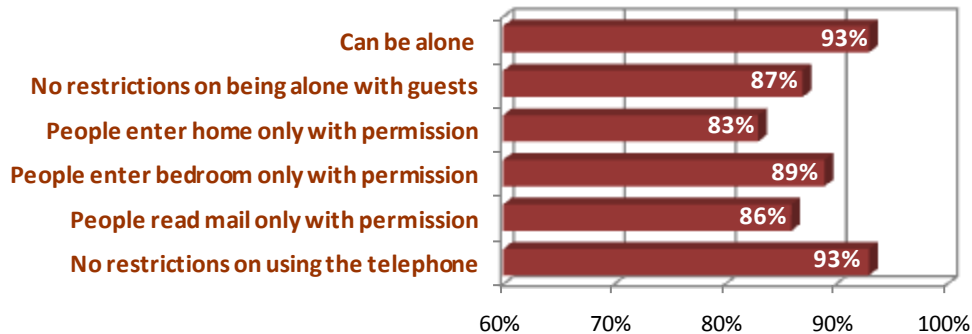
³ Stancliffe, R.J., Lakin, K.C., Taub, S., Chiri, G., & Byun, S. (2009). Satisfaction and sense of well being among Medicaid ICF/MR and HCBS recipients in six states. *Intellectual and Developmental Disabilities*, 47, 63-83.

HEALTH, WELFARE, AND RIGHTS

RESPECT AND RIGHTS

Between 2003-04 and 2007-08, individual survey results have indicated high rates of consumer privacy and other rights, as shown in Figure 8. For instance, over 80% of people surveyed reported having privacy at home and control over who opens their mail, and over 90% of individuals said they had no telephone-related restrictions. In addition, the percentage of individuals who said their mail was only read with permission increased from 82% in 2003-04 to 88% in 2007-08.

FIGURE 8. AVERAGE RATES OF PRIVACY AND RIGHTS BETWEEN 2003-04 AND 2007-08



SELF-ADVOCACY

On average, one-quarter of individuals attended self-advocacy meetings during this five year period, and an additional 6% had the opportunity to attend such meetings but chose not to. The remaining nearly 70% of individuals reported that they had never attended a self-advocacy meeting.

HEALTH

The proportion of individuals who had basic health examinations remained high between 2003-04 and 2007-08. Over 90% of individuals had a health exam in the past year, almost 70% of women had a gynecological exam in the past year, and over 60% of individuals had a dental exam in the past six months.

Highest rates of health exams in 2007-08:

AR, KY, LA, ME, NJ, NY, OK, TX, WV

Highest rates of OB/GYN exams in 2007-08:

CT, DE, MO, NC, OK, NY, TX

Highest rates of dental exams in 2007-08:

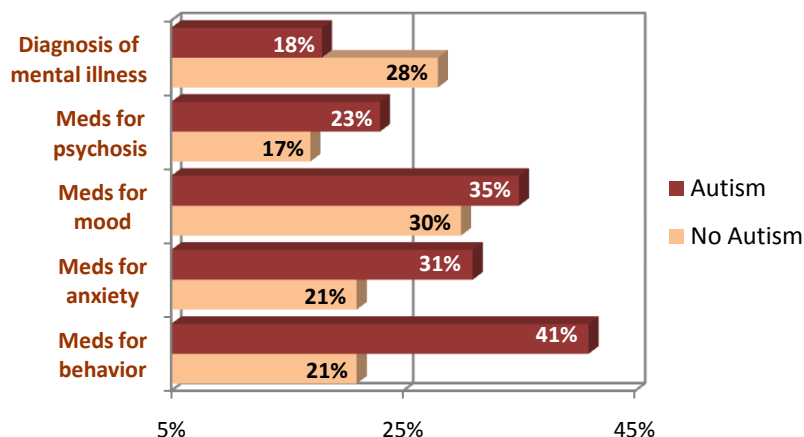
CT, DE, ME, NJ, NM, NY, OK, RI, TX, WV

MEDICATIONS

Overall, more individuals took psychotropic medications than were diagnosed with a mental illness or psychiatric disorder. Between 2003-04 and 2007-08, almost one-third (30%) of individuals on average were diagnosed with a psychiatric illness, and almost one-half (46%) on average took at least one psychotropic medication. The rate at which individuals receive psychotropic medications has remained constant since the inception of NCI.

Of particular concern is the subgroup of individuals in the sample who have a diagnosis of autism. Figure 9 below shows that consumer survey respondents with autism are less likely to have a co-existing diagnosis of mental illness and more likely to be taking medications for psychotic, mood, anxiety, and behavioral disorders than those without a diagnosis of autism. For a more detailed comparison of outcomes for those respondents with and without a diagnosis of autism, see the NCI Data Brief at: <http://www.hsri.org/docs/DATA%20BRIEF-%20Autism.pdf>

FIGURE 9. MENTAL ILLNESS DIAGNOSIS AND TYPE OF MEDICATION RECEIVED, BY AUTISM DIAGNOSIS



SAFETY

Over 80% of individuals felt safe in their home and neighborhood between 2003-04 and 2007-08. In addition, in 2007-08 slightly over ten percent of individuals reported feeling afraid sometimes in their home (13%) or neighborhood (11%), and roughly 5% felt afraid in their home or neighborhood most of the time.

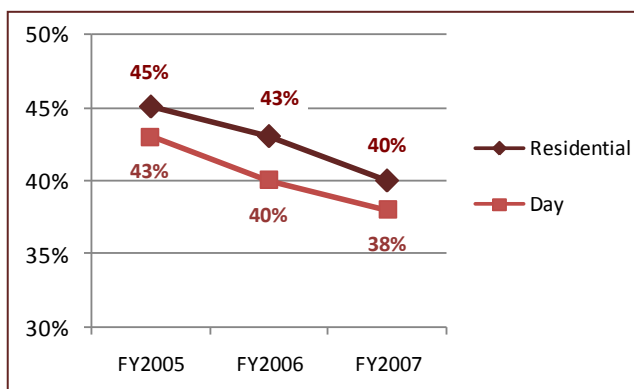
STAFF STABILITY AND COMPETENCY

STAFF STABILITY

From FY2005 to FY2007, there has been a steady decrease in staff turnover in residential and in day service settings, as Figure 10 shows.

In FY2007, residential and day service providers had a 7% vacancy rate for their full-time positions, and a 13% vacancy rate for part-time positions.

FIGURE 10. DIRECT CONTACT STAFF TURNOVER: FY2005-FY2007



Among all staff that left their jobs in FY2007, 40% had worked in the agency for over one year. Slightly fewer (39% residential staff and 38% day staff) had worked six months or less.

FAMILY OUTCOMES

INFORMATION AND PLANNING

In 2007-08, roughly 40% of adult family and child family survey respondents reported that they usually or always received information about services and supports available to their family (42% and 39%, respectively). Roughly 40% of both respondent groups said they sometimes received this information (38% and 40%, respectively), and approximately 20% responded that they seldom or never received information.

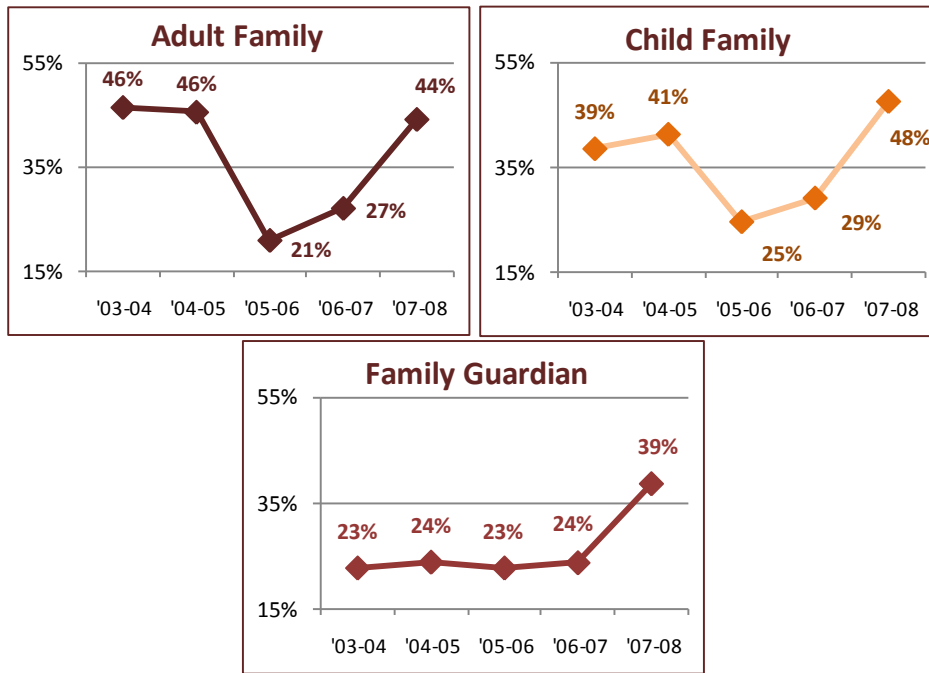
Of those who received this information, 55% of both adult family and child family survey respondents reported that this information was usually or always easy to understand, 38% of both groups rated the information as sometimes easy to understand, and 7% responded that the material was seldom or never easy to understand. Thus, although the majority of respondents receive and understand this information about available services and supports, it should be noted that this outcome is met only some of the time for a substantial number of adult and child family survey respondents, and 20% almost never receive information.

CHOICE AND CONTROL

Over half of adult family and child family survey respondents usually or always chose the agencies or providers who worked with their family member in 2007-08 (65% and 59%, respectively). In addition, roughly 20% of adult family and child family survey respondents sometimes made these choices (17% and 22%, respectively). These figures did not change substantially over the five years.

Regarding control over and knowledge of funding amounts for services and supports, all family survey respondents have reported an increasing awareness of how much money was spent on their family member's services over the past few years. According to Figure 11 on the next page, the proportion of adult and child family survey respondents who reported knowing this information decreased between 2004-05 and 2005-06, but increased each year between 2005-06 and 2007-08. For child family survey respondents, the overall increase was 9% over the five year period. Between 2006-07 and 2007-08, the percentage of family guardian survey respondents who reported having this knowledge jumped from a relatively stable 24% to 39%. This trend may be the result of the increased use of supports waivers with financial caps as well as an increased emphasis on individual allocations and budgets.

FIGURE 11. FIVE YEAR TRENDS IN KNOWING HOW MUCH MONEY IS SPENT ON SERVICES



FAMILY SATISFACTION

Trends in all family survey respondents’ familiarity with grievance procedures over the past five years followed the same pattern as trends in knowing how much money was spent on services (as shown in Figure 11). Namely, the proportion of adult family and child family survey respondents who were usually or always familiar with these procedures decreased by about 20% from 2004-05 to 2005-06, and then increased by this amount from 2005-06 to 2007-08. These findings may be the result of the increased expectations from the Centers for Medicare and Medicaid Services regarding quality management in HCBS waivers generally and a renewed emphasis on complaint data in particular.

ACCESS AND SUPPORT DELIVERY

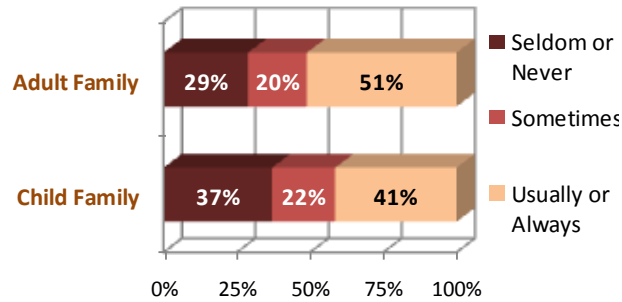
In 2007-08 roughly 90% of adult family and child family survey respondents reported that their family member had access to health services and medications. However, while 87% of child family survey respondents reported that their family member had access to dental services, only 74% of adult family survey respondents said their family member had access to these services. Lack of access to dental care was a common concern expressed in open-ended comments as well.

*“Persons with severe disabilities have a right and should receive dental health care. Oral healthcare is just as important as general medical care and treatment and preventative. Oral healthcare could prevent future medical complications...”
(2007-08 Adult Family Survey Comment)*

EMERGENCY SUPPORT

One area of concern regarding the delivery of supports and services is the extent to which adult and child family respondents felt supports were available in a crisis or emergency. In 2007-08, roughly one-third of respondents said they felt these supports were seldom or never available. In addition, as presented in Figure 12, roughly 20% felt these supports were sometimes available, and only 40 to 50% reported they were usually or always available in a crisis or emergency.

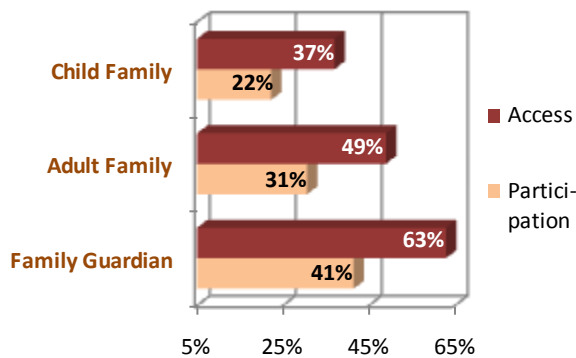
FIGURE 12. SUPPORTS ARE AVAILABLE IN CRISIS OR EMERGENCY IN 2007-08



COMMUNITY CONNECTIONS

Over the past five years, family guardian survey respondents (who have a family member living outside the home) were much more likely than adult and child family survey respondents (whose family members live at home with them) to report that their family members have access to and

FIGURE 13. COMMUNITY ACCESS AND PARTICIPATION IN 2007-08



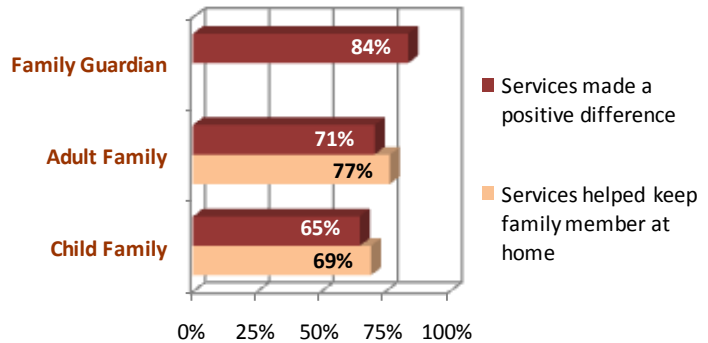
participate in community activities. There was a significant gap between the number of families that said their family members *had* community access and those who said they *used* this access (participation) for all three surveys. Community access and participation levels for family members of these three respondent groups in 2007-08 are presented in Figure 13.

These levels have stayed roughly the same for the adult family and family guardian survey groups since 2003-04. However, access and participation increased between 2004-05 and 2007-08 for families that had a child at home by roughly 9%.

FAMILY OUTCOMES

The majority of family respondents have reported positive family outcomes over the past five years. For instance, as illustrated in Figure 14, over 65% 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 2007-08. And roughly 70% 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. These responses are characteristic of responses since 2003-04.

FIGURE 14. FAMILY OUTCOMES IN 2007-08

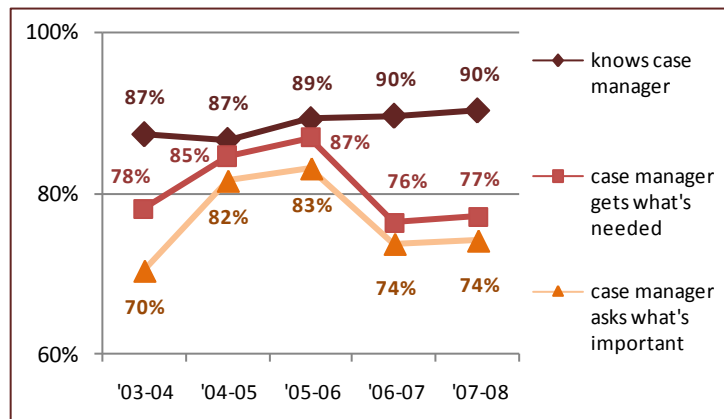


SYSTEM PERFORMANCE

SERVICE COORDINATION

There have been several interesting trends in service coordination outcomes in the past five years. As illustrated in Figure 15, the majority of individuals (roughly 90%) have consistently reported knowing who their service coordinator is. However, people surveyed were more likely to report that their service coordinator got them the supports and services they needed and that their service coordinators asked what was important in 2004-05 rather than in 2005-06 than in other years. The reason for these trends is unclear.

FIGURE 15. SERVICE COORDINATION BETWEEN 2003-04 AND 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 Arizona and Washington, the statewide People First organizations are both working on addressing the findings related to high numbers of people reporting feelings of loneliness.
- The Texas Department of Aging and Disability Services publishes reports annually using NCI data to benchmark the quality of its programs for long term services and supports. Over time, the data are used to identify opportunities for program improvements and to measure the impact of those improvements. The reports are posted online at: http://www.dads.state.tx.us/news_info/publications/legislative/
- Several states are using NCI data as part of their HCBS waiver quality improvement strategies, including Alabama, Oklahoma, Washington State, and Wyoming.

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.

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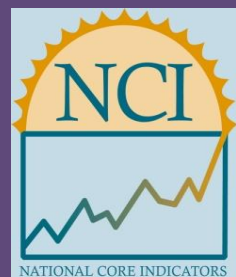
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