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 2010, 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 2009-2010.

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Executive Director  
National Association of State Directors of Developmental Disabilities Services

Valerie J. Bradley  
President  
Human Services Research Institute

Cover Art: “The Woodcutter’s Cottage” by Daniel May  
http://www.prospectnow.ca/Services/Studio%20C.aspx  
www.theriotrocks.org/spotlight-studios
INTRODUCTION

National Core Indicators (NCI) began in 1997 as a collaborative effort between the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI). The goal of the program was to encourage and support NASDDDS member agencies to develop a standard set of performance measures that could be used by states to manage quality and across states for making comparisons and setting benchmarks. Fifteen 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.

PARTICIPATING STATES

In 2009-2010, the membership of NCI included 25 states, four sub-state entities, and the District of Columbia (see Figure 1).

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
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 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., mortality 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 2009-10. 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.

2009-10 ACCOMPLISHMENTS AND ACTIVITIES

Even as state governments across the country have had to practice unprecedented levels of austerity, state participation in NCI remains strong. New members in 2009-2010 included California, Florida, and the District of Columbia.

In 2009-10, a few indicators were added and others revised in order to better align with the CMS Waiver Assurances. Most of these new and revised indicators are found in the Access and Service Coordination sub-domains. The data results from these indicators are indicated by an asterisk (*) and are located in the “Selected Results” section.

Program staff began conducting case studies of NCI implementation based on the acceptance in 2007-08 of two successful grant applications from the National Institute on Disability and Rehabilitation Research (NIDRR). HSRI staff visited Orange County, CA, Texas and New York, and activities included observing surveys out in the field, conducting focus groups of interviewers, and
meeting with state staff. On the research front, several articles based on analysis from NCI data were accepted for publication in collaboration with researchers from the University of Minnesota, including “Adults with intellectual disability: Uptake of aided AAC, effective communication, and loneliness,” which was accepted for publication to the Journal of Augmentative and Alternative Communication (AAC).

In 2009-10, we debuted a new reporting format for NCI data. The “NCI State Report” takes a state’s consumer survey data and compares it to the average of all the other NCI states that collected data for that year. The data are presented in simple, easy to read graphs. The reports have received a very favorable review and can be found on the website.

The Content Review and Field Test (CRAFT) Committee, a group of states who work in conjunction with program staff to recommend changes and to assist with pilot testing of revised NCI protocols, completed work on revising all three of the Family Surveys. All three revised surveys have been finalized and are being used during the current 2010-11 data cycle.

2009-10 was the second year the new online data entry system application (ODESA) was used by states to enter Consumer Survey data. All NCI states bar one or two are now using the ODESA. In 2010-11, the ODESA will be adapted to allow for Family Survey data entry.

NCI began a blog in 2009-10 where state staff, interviewers, and self-advocates among others can share ideas with one another and talk about NCI successes, challenges, and improvements. “The NCI Blog” can be found at www.nciblog.org.

**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 2009-10, and the total number of surveys collected overall.
**Figure 2. Summary of Surveys by State 2009-2010**

<table>
<thead>
<tr>
<th>NCI Survey</th>
<th>Target Population</th>
<th>Method of Administration</th>
<th># of States 2008-09</th>
<th>Total # of Surveys</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult Consumer</td>
<td>Adults 18 and older receiving at least one service besides case management</td>
<td>In-person interview</td>
<td>18</td>
<td>11,599</td>
</tr>
<tr>
<td>Survey</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adult Family</td>
<td>Families of adults 18 and older living at home</td>
<td>Mail</td>
<td>10</td>
<td>4,421</td>
</tr>
<tr>
<td>Survey</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child Family</td>
<td>Families of children under 18 (or under 23 if still in school system) living at home</td>
<td>Mail</td>
<td>6</td>
<td>2,628</td>
</tr>
<tr>
<td>Survey</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family Guardian</td>
<td>Families or guardians of adults 18 and older living outside the home</td>
<td>Mail</td>
<td>6</td>
<td>3,372</td>
</tr>
<tr>
<td>Survey</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Ongoing Methods Testing and Improvement**

The NCI Program conducts regular reviews and tests of data collection and analysis protocols. In 2010, inter-rater reliability studies were conducted on the Adult Consumer Survey in two NCI states. The goal of an inter-reliability study is typically to determine the degree to which different raters (or interviewers) agree when hearing or looking at the same information (e.g., survey responses) and using the same tools (e.g., surveys, checklists) to describe it. These computations provide tool developers feedback regarding survey questions and, if needed, revisions to the tool. To do this, NCI staff observed 19 and 30 surveys in each state respectively. After getting permission from the individual, the observer would follow along as the interviewer asked questions and would code his/her own copy of the survey. The interviewer and observer answers were later compared and analyzed. In both states, the overall level of agreement between raters was high and considered acceptable by rigorous statistical methods.

These studies can also provide feedback to states on how the survey process is being conducted. More specifically, the testing can help determine whether interviewers have been trained appropriately and are applying that training in a consistent manner. Overall the studies found that the process was being implemented according to specified protocols. In one state, the observer noted that while there was variation in terms of the content and the duration of the introduction process, the interviewers all did an exceptional job introducing themselves, explaining the survey process, and the NCI project.

In the coming year, NCI staff plan to explore differences by type of respondent. Specifically, testing will focus on whether who responds - a proxy respondent or the individual him/herself – significantly impacts the results.
**ANALYSIS**

NCI data management and analysis is coordinated by Human Services Research Institute (HSRI). Data was entered by each state, and files were 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. It should also be noted that several states used slightly different sampling frames for conducting their adult consumer surveys.

**SELECTED RESULTS 2009-2010**

**Sample Characteristics**

In 2009-2010, a total of 11,599 consumer surveys were completed in 16 states, the District of Columbia, and 1 sub-state entity (Regional Center of Orange County, CA).

**Disabilities**

Only 16% of all people surveyed did not have some type of disability in addition to ID/DD (Figure 3). The most common were mental illness or psychiatric diagnosis (36%), seizure disorder (31%), physical disability (15%), cerebral palsy (15%), communication disorder (12%) and severe hearing or vision impairment (12%). Eleven percent (11%) of people surveyed had a diagnosis of autism.

![Figure 3. Proportion of people with other disabilities](image-url)
Residence

The Consumer Survey includes information on where the person interviewed currently lives. Figure 4 shows the proportion of people living in each type of residence reported on the survey. The majority of people surveyed resided in a group home (28%) or in a parent’s or relative’s home (27%). Twenty percent (20%) resided in a specialized institutional facility for persons with ID/DD, and eleven percent (11%) lived in an independent home or apartment.

To make comparisons between different types of residence more manageable, two 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, 34% 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-two percent (32%) of people interviewed were identified as having both ID and a mental illness or psychiatric diagnosis; 55% had ID and no mental illness or psychiatric diagnosis.

**FIGURE 6. PROPORTION OF PEOPLE WITH DUAL DIAGNOSIS**

![Dual Diagnosis Pie Chart]

Self-Direction

Only 3% of people were identified as using a self-directed supports option.

Employment

In 2009-2010, a total of 6,950 valid responses were given to the question about having a job in the community. Twenty-seven percent (27%) of respondents stated “yes”. However, the rate of responding “yes” varied by residence. Thirty-eight percent (38%) of people living in independent home/apt reported having a job in the community – this was the highest proportion, followed by those living in a parent’s/relative’s home (Figure 7). The proportions of people with and without autism who reported having a job did not differ. Interestingly, the same proportion (27%) of people self-directing reported having a job in the community as the proportion of people not self-directing.

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

![Employment Bar Chart]
Of those who reported having a job in the community, 91% stated that they like it. The percentage was very similar across all residence types.

Of people surveyed, the four most common types of community jobs that people were employed in were: cleaning and maintenance (30%), retail (18%), food preparation (16%), and assembly and manufacturing (6%). Nineteen percent of people had an “other” response. The proportions didn’t vary much by whether the person had a dual diagnosis or not, with the exception that dually diagnosed respondents were slightly less likely to work in food preparation.

Only 52% of people’s hourly earnings were at or above their state’s minimum wage. The average hourly wage in community jobs was $7.10. However, both hourly wage (Figure 8) and number of people earning at least the minimum wage (Figure 9) varied somewhat by where they lived. People living with families made highest hourly wage ($7.71) and larger proportion of them made at least minimum wage (57%). People living in institutions, on the other hand, made the lowest hourly wage ($4.71) and lowest proportion making minimum wage (30%).

**Figure 8. Average Hourly Wage by Residence Type**
Only 25% of people surveyed received benefits (vacation and sick leave) 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 10).

**FIGURE 10. PROPORTION OF PEOPLE RECEIVING BENEFITS AT THEIR JOB BY RESIDENCE TYPE**

Less than a fifth (18%) of people who had a community job worked on average 30 hours a week or more (60 hours in the last two weeks). In fact, the average number of hours worked in a community job over the last two week period was only 31.4 hours, or 15.7 hours per week.
**Choice and Decision-Making**

As illustrated in Figure 11, many people had no input into major life decisions such as where they live, work, and go during the day. Only 41% chose their home, and 37% chose their roommates. Though 64% had input into where they work or go during the day, only 59% had input into choosing their work or day staff; 63% chose their home staff. Forty-five percent of persons surveyed had no input into selecting his/her case manager.

**Figure 11. Proportion of people who had input into major life decisions**

<table>
<thead>
<tr>
<th>Decision</th>
<th>Proportion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chose case manager</td>
<td>55%</td>
</tr>
<tr>
<td>Chose job or day activity staff</td>
<td>59%</td>
</tr>
<tr>
<td>Chose job or day activity</td>
<td>64%</td>
</tr>
<tr>
<td>Chose home staff</td>
<td>63%</td>
</tr>
<tr>
<td>Chose roommates</td>
<td>37%</td>
</tr>
<tr>
<td>Chose home</td>
<td>41%</td>
</tr>
</tbody>
</table>

A higher proportion of people report having input into every day decisions such as choosing their own schedule (81%), choosing how to spend their free time (89%), and choosing what to do with their own money (87%) (Figure 12).

**Figure 12. Proportion of people who have input into everyday decisions**

<table>
<thead>
<tr>
<th>Decision</th>
<th>Proportion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chooses what to buy with own money</td>
<td>87%</td>
</tr>
<tr>
<td>Chooses what to do with free time</td>
<td>89%</td>
</tr>
<tr>
<td>Chooses schedule</td>
<td>81%</td>
</tr>
</tbody>
</table>

Figures 13 and 14 show the proportion of people who had input into major life and everyday decisions broken down by the type of living arrangement. Not surprisingly, 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.
Figure 13. Proportion of people who had input into major life decisions by residence type

<table>
<thead>
<tr>
<th>Decision</th>
<th>Parents/relatives</th>
<th>Independent home/apt</th>
<th>Community-based residence</th>
<th>Institution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chose case manager</td>
<td>64%</td>
<td>57%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chose job/day activity staff</td>
<td>62%</td>
<td>59%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chose job/day activity</td>
<td>62%</td>
<td>50%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chose home staff</td>
<td>63%</td>
<td>79%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chose roommates</td>
<td>13%</td>
<td>31%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chose home</td>
<td>8%</td>
<td>49%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Figure 14. Proportion of people who had input into everyday decisions by residence type

<table>
<thead>
<tr>
<th>Decision</th>
<th>Parents/relatives</th>
<th>Independent home/apt</th>
<th>Community-based residence</th>
<th>Institution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chooses what to buy with own money</td>
<td>87%</td>
<td>92%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chooses what to do with free time</td>
<td>89%</td>
<td>96%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chooses schedule</td>
<td>83%</td>
<td>93%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
HEALTH CARE AND HEALTH

Only 5% of people surveyed were in poor health and only 7% used tobacco products. Ninety-nine percent had a primary care doctor and 91% had had a physical exam in the past year. The proportion of people who received other routine preventive health care was lower (Figure 15). Eighty-four percent had a dental visit in the past year, 75% had a hearing exam in the past five years, and 65% received an eye exam in the past year. Seventy-eight percent received a flu vaccination in the past year and only 43% had ever had a pneumonia vaccine. Eighty-four percent of women over 40 had a mammogram in the last two years, and 76% of all women had a Pap test in the past three years. Fifty-nine percent of men over 50 had a PSA test in the past year, and only 23% of people over 50 had had a colorectal cancer screening in the past year.

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

Rates of receiving preventive health care services varied by where people resided (see Figure 16). 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, over 90% of people in institutions and community-based residences had a dental visit in the last year, as compared to about 70% of people in independent homes and family homes. Only 47% of people living in family and 59% in...
independent homes have had a vision exam in the last year, compared to over 70% of those living in an institutions and community-based residences. Seventy-seven percent of people living in institutional settings had received a pneumonia vaccine; the number was 27% for those living in an independent home or apartment and only 24% for those living with parent or relative. 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 and over 80% received an annual physical exam.

**Figure 16. Proportion of people who received preventive health care services by residence type**
System Performance

Service Coordination

Almost all people interviewed reported meeting their case manager or service coordinator (93%). A vast majority said that their case manager asks what’s important to them and helps them get what they need. A somewhat smaller proportion (75%) reported that their case manager gets back to them right away after they leave a message (see Figure 17). Eighty-four percent of people said that they helped make their own service plan. Additionally, another 84% always had transportation when it was needed.

Figure 17. Case Management*

There were no major differences in quality of case management by type of residence, with two exceptions: 1) people residing in institutions were somewhat less likely to report having met their case manager and that their case manager asks what’s important to them, 2) people living in community-based residences and independent apartments were less likely to say that their case managers get back to them right away. People in institutions were also less likely to have a way to get places whenever they wanted.

States with the highest proportion of people who...

Have met their case manager: KY, NY, OK, AR
Reported that case manager asks what they want: ME, AR, WY, NY, AL, OH
Reported that case manager helps them get what they need: WY, AR, IL, NY
Reported that case manager calls them back right away: AL, KY, AR, TX
Reported that they helped make their own service plan: AL, OH
Reported that they always have a way to get where they want to go: WY, LA, KY, OK, AR, PA
**Access**

In general, people report that their staff have adequate training (93%). A large majority also report getting needed services (86%). For those reporting not getting needed services, the most common unmet needs were: transportation (30%), finding or changing jobs (30%), social and/or relationship areas (29%), and education or training (24%) (Figure 18).

**Figure 18. Services needed**

![Bar chart showing percentages of unmet needs](image)

Whether people received needed services did vary by where people lived, with those living in a parent’s or a relative’s home having the lowest rates of receiving needed services (Figure 19).

**Figure 19. Proportion of people getting needed services by residence type**

![Bar chart showing percentage by residence type](image)
For those living in family homes the most commonly reported needed services were (in descending order): social/relationships, transportation, education and training, finding or changing jobs, and dental care. For those living in independent apartments or homes they were: transportation, finding or changing jobs, education and training, social/relationships, and finding or changing housing. Those living in community-based residence most often needed services in the areas of: finding or changing jobs, social/relationships, finding or changing housing, and transportation. For those living in institutions, most commonly reported needed services were: social/relationships, transportation, finding or changing housing, and finding or changing jobs.

**Family Outcomes**

**Access and Support Delivery**

In 2009-10, 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 78% of Adult Family Survey respondents said their family member had access to these services. Ninety-four percent (94%) of respondents from both surveys reported that their family member had access to necessary medications.

Eighty-six percent (86%) of Family Guardian respondents reported their family member always or usually receives all the services listed in his/her service plan. This compares with 76% of Adult Family respondents and 69% of Child Family respondents. When asked if these services change when the family member’s needs changed, the respondents stating “always or usually” varied (81% of Family Guardian respondents; 55% of Child Family respondents) (see Figure 20).

When asked if frequent changes in support staff were a problem for their family, roughly 20% of respondents across surveys reported that this was always or usually the case. An additional 38% of Adult Family and Family Guardian respondents indicated that this was sometimes the case.

Approximately 79% of Adult Family and Family Guardian respondents reported that their family member’s support staff have the right training to meet their needs. However, only 68% of Child Family respondents indicated that their family member’s staff were appropriately trained (see Figure 21).
**Information and Planning**

In 2009-10, 48% of Adult Family and 42% of Child Family Survey respondents reported that they always or usually received information about services and supports available to their family. Roughly 37% of both respondent groups said they sometimes received this information, and approximately 18% responded that they seldom or never received information (16% and 20%, respectfully).

Of those who received this information, around 58% of both Adult Family and Child Family Survey respondents reported that this information was always or usually easy to understand, 36% of both groups rated the information as sometimes easy to understand, and 6% 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 18% almost never receive information.

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

When asked if their family member was involved in developing their plan, only 49% of Adult Family respondents and 59% of Family Guardian respondents indicated “always or usually.” However, when asked if they themselves were involved in developing their family member’s plan, 78% of Adult Family respondents reported they always or usually were involved while, interestingly, the same amount of Family Guardian Survey respondents (59%) indicated they always or usually helped develop their family member’s plan (see Figure 22).

**Figure 22. Who Helps Develop Service Plan?**

<table>
<thead>
<tr>
<th></th>
<th>Family Guardian</th>
<th>Adult Family</th>
</tr>
</thead>
<tbody>
<tr>
<td>Always/Usually Help Develop Service Plan - Survey Respondent</td>
<td>59%</td>
<td>49%</td>
</tr>
<tr>
<td>Always/Usually Help Develop Service Plan - Family Member Receiving Services</td>
<td>59%</td>
<td>78%</td>
</tr>
</tbody>
</table>

**Choice and Control**

Approximately three-fifths of Adult Family and Child Family Survey respondents always or usually chose the agencies or providers who worked with their family member in 2009-2010. However, only 44% of Adult Family respondents and 51% of Child Family respondents said they always or usually chose the specific support workers who work with their family.

While less than half of Adult Family (44%) and Child Family (49%) Survey respondents indicated that they always or usually had control or input over the hiring and management of support workers, 60% of Adult Family and 67% of Child Family respondents indicated that they always or usually wanted to have control or input of hiring and management of support workers (see Figure 23).

In 2009-2010, across all three family surveys, between 19-44% respondents reported that they always or usually knew how much money was spent on services. There was also great variation
across surveys in the percentage of respondents who indicated they seldom knew or did not know how much was spent (37-70%). The Adult Family Survey (37%) had a much lower percentage of seldom or don’t know responses compared to the Family Guardian and Child Family Surveys.

**FIGURE 23. CONTROL OVER HIRING AND MANAGEMENT OF SUPPORT WORKERS**

![Graph showing control over hiring and management of support workers]

**FAMILY SATISFACTION**

As usual, families stated in broad terms that they were always or usually satisfied with the overall services and supports that they and their family and family member received. However, this level of satisfaction varied between surveys. Eighty-four percent (84%) of Family Guardian Survey respondents were always or usually satisfied, while in comparison, 60% of Child Family Survey respondents were always or usually satisfied. Seventy percent (70%) of Adult Family Survey respondents indicated they were always or usually satisfied with the services and supports their family and family member received.

In more specific terms, families overall were only slightly less satisfied with specific services and supports. Between 63-76% of family respondents across all services were satisfied with the way complaints or grievances regarding services or staff are handled and resolved. Child Survey respondents were far less familiar with the process for filing a complaint or grievance (42%) compared to Family Guardian and Adult Family respondents (68% to 74% respectively).

*“For my child, your department does a good job considering the extreme budget constraints you are facing (Family Comment from 2009-10 Child Family)*
**Community Connections**

As in previous years, 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 2009-10 are presented in Figure 24.

**Figure 24. Community Access and Participation**

<table>
<thead>
<tr>
<th>Survey Type</th>
<th>Access (%)</th>
<th>Participation (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Guardian</td>
<td>46%</td>
<td>22%</td>
</tr>
<tr>
<td>Child Family</td>
<td>39%</td>
<td>22%</td>
</tr>
<tr>
<td>Adult Family</td>
<td>53%</td>
<td>36%</td>
</tr>
</tbody>
</table>

**Family Outcomes**

A range from 68-85% of Adult Family, Family Guardian, and Child Family Survey respondents said that services and supports have always or usually made a positive difference in their family member’s life in 2009-10. There was also a range of respondents who indicated that overall they were satisfied with their supports and services (60% from Child Family; 84% from Family Guardian).

In addition, approximately 75% (range of 72% to 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.

**Links to Full Reports**

Detailed reports by state and with national averages are available on the NCI website: [www.nationalcoreindicators.org](http://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 Alabama, they are continuing to use NCI data to look at the outcomes of people who live in institutions and then again following their transition to a community-based residence.

- In Georgia, the Division of Developmental Disabilities created regional and statewide Quality Improvement Councils to review NCI and other data on the quality of services. Councils use data to determine quality improvement initiatives. A number of initiatives to improve care within the regions have been adopted by the Division for statewide implementation. Councils have representation by self-advocates, family members, providers, and state staff.

- In Washington State, volunteers recruited by the Developmental Disabilities Council review NCI reports and make recommendations to the state DD agency based upon them. A couple of the recommendations included: 1) Continue to focus on providing easy-to-understand information to families about the services and supports that are available to them, and 2) Increase the use of technology to more effectively serve people with disabilities and their families.

- Massachusetts presented NCI data to a Quality Council made up of self-advocates, providers, state staff, family members and guardians. Focus areas identified included: Health, Employment, and Safety.

- New York used data from the Consumer Survey for some of their statewide performance measures in an interim report for their Statewide Comprehensive Plan. The report is available through this link: [http://www.opwdd.ny.gov/507plan/images/Interim_5_07_Rpt_Final_2_15.pdf](http://www.opwdd.ny.gov/507plan/images/Interim_5_07_Rpt_Final_2_15.pdf)

- Several states are using NCI data as part of their HCBS waiver quality improvement strategies, including Arkansas, Georgia, 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

<table>
<thead>
<tr>
<th>NASDDDS Members</th>
<th>Non-NASDDDS Members</th>
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<tbody>
<tr>
<td>Linda Rolfe (WA)</td>
<td>Charlie Lakin (RTC/ICI/UMN)</td>
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<td>Rick Hemp (CICG/UC)</td>
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<td>Kevin Casey (PA)</td>
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