National Core Indicators: A Growing Commitment

Five Years of Performance Measurement

Human Services Research Institute

National Association of State Directors of
Developmental Disabilities Services

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INTRODUCTION

In January 1997, the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI) launched the National Core Indicators (NCI). The number of states actively participating in the project has climbed steadily, reaching 21in the Spring of 2003. One sub-state agency is also a participant. The decision to initiate NCI grew out of the recognition by the members of NASDDDS that the increasing complexity of developmental disabilities services required vastly improved capabilities to evaluate overall system performance. State officials also recognized that quality improvement hinges on the capacity to conduct systematic and rigorous measurements of performance and outcomes.

Alabama
Arizona
Connecticut
Delaware
Hawaii
Illinois
Iowa
Indiana
Kentucky
Massachusetts
Maine
North Carolina
Nebraska
Oklahoma
Pennsylvania
Regional Center of Orange County
Rhode Island
South Carolina
South Dakota
Vermont
Washington
West Virginia
Wyoming

NCI began and continues as a voluntary collaboration among participating NASDDDS member agencies and sub-state entities committed to developing a coherent and comprehensive approach to performance and outcome measurement. Participating states pool their resources and knowledge to create performance monitoring systems, identify common performance indicators, work out sound data collection strategies, and share results. There are several important forces that formed the context for the initiation of a multi-state performance monitoring project, including the following:

- *Emphasis on person-centered approaches* ;
- *Emphasis on data driven decision-making;*
- *Pressure for accountability* from federal and state policy makers
- *Growth in cost constraints (e.g., managed care related approaches);*
- *Growth in the use of performance indicators;*
- *Growth of the Home and Community-Based Waiver* Services and pressure for improved quality assurance.

NCI does not address every possible element of system-wide performance. The indicators are intended to operate in tandem with other performance tracking and monitoring systems that states operate. One key criterion for the selection of NCI measures was and continues to be the extent to which the indicator makes benchmarking between and among states possible. Comparability is accomplished through the use of common data collection protocols (e.g., consumer and family surveys) as well as through common definitions of the particular phenomenon and data source addressed by the indicator.

PROJECT CHRONOLOGY

The development of performance and outcome measures began in 1997 with the formation of a project steering committee comprised of 7 state agencies that had agreed to be "field test states" (AZ, CT, MO, NE, PA, VT, and VA). An additional eight states (AL, CO, FL, MI, NY, OK, RI, and SC) volunteered to serve as advisors and to share their expertise. Their work involved three main steps:

1. *Identify mission critical areas* such as work, relationships, community participation, and cultural competency.
2. *Define how the outcomes will be tracked*
3. *Identify the ways in which the data that supports the indicator will be collected*.

The group began with a list of 130+ possible "candidate" performance indicators which were subsequently reduced to a set of approximately 61. In addition, the consumer survey/interview instrument was designed. Project personnel also prepared a family survey for those who had an adult family member living at home.

Field test state data collection got underway in earnest at the beginning of 1998. Each state collected approximately 400 consumer surveys, and at least 400 family surveys in addition to compiling information on the systems and health and safety indicators (e.g., numbers of serious incidents, use of psychotropic medication, etc.). Based on the results, additional modifications were made to the indicator set as well as to data collection protocols.

NCI Phase II started in January 1999 and included a total of 12 states. Since then, the project has expanded its scope to include services for children with developmental disabilities and their families, continued to develop and refine the indicators, and recruited additional states to participate in the project. The Phase II data are considered baseline project data. Phase III spanned 2000 to 2001 and included an additional 4 states; 7 states joined in 2002. Phase II and Phase III and IV technical reports and other selected documents are available online at www.hsri.org/NCI/core.html. The fact that nearly one-half of the states have elected to be part of NCI is compelling evidence of their commitment to a systematic examination of performance.

CONSUMER SURVEY: SELECTED RESULTS

Consumer Survey

The National Core Indicators Consumer Survey was initially developed by the project's technical advisory subcommittee with the purpose of collecting information directly from individuals with developmental disabilities and their families or advocates. The survey is designed to measure over half of the 60 core indicators. Many questions were drawn from survey instruments already in use in the field; other questions were developed specifically for this project. Project staff have tested and refined the instrument each year based on feedback from interviewers.

Organization of the Survey

The Consumer Survey is composed of a pre-survey form and three sections.

- THE PRE-SURVEY FORM collects information necessary to schedule face-to-face interviews, including contact information for consumers, and the names of guardians, advocates, or other individuals who might be asked to provide responses. The form also was used by surveyors to identify special communication needs that individuals might have prior to conducting the interview, define terms the individual would be most familiar with (such as "case manager" or acronyms), and document that informed consent was obtained. In most instances, information for the pre-survey form was obtained from the individual's case manager. [Note: Individual identifying information was excluded from data submitted to HSRI.]

- THE BACKGROUND INFORMATION SECTION requests data that would most likely be found in agency records or information systems. In some states, case managers complete this section at the same time the pre-survey form is completed. In other states, surveyors complete the section during the direct interview.
- SECTION I of the survey, which concerns questions aimed at obtaining expressions of satisfaction and opinions from each individual, may be completed only through a direct interview with the individual; proxy responses are not acceptable.
- SECTION II questions are to be answered by the individual if possible. If the person is unable to respond, an advocate is asked to answer.
- The last page of the survey is the SURVEYOR FEEDBACK SHEET. Surveyors are asked to record the length of the interview with the individual and describe any problematic questions.
- The DAY/VOCATIONAL/EDUCATIONAL SUPPLEMENT is an optional add-on to the survey instrument. These data are generally collected at the same time the background information section is completed.

Administration

Most participating states used the basic survey tool developed by the project. Vermont and Pennsylvania include NCI items in their own statewide survey tools. States used a variety of types of surveyors, including: consumers and families, university students, and state personnel. Some independent interviewers were paid; others were unpaid volunteers. All of the above methods were acceptable and no major differences were noted in terms of using different types of interviewers. The only stipulation was that if case managers are used, they do not interview consumers on their own caseload.

Training

"Train-the-trainer" sessions were provided to the lead agencies from each state. These trainings were conducted by conference call. The first part of the training reviewed the survey tool in detail, question by question. The second part reviewed general interviewing techniques. The participants, or "trainers" from each state, then conducted training with the actual interviewers. The project provided a packet of standardized materials (including scripts for contacting respondents, frequently asked questions, general interviewing tips and skill exercises) to be used at these in-state training sessions.

Summary of Phase IV Results – Entire Sample

Sample Demographics. The most recent results presented here are based on NCI Phase IV data, which were collected during 2001-2002. Seventeen states participated in the 2001-2002 wave of data collection. Nearly every state fulfilled the minimum number of interviews specified by NCI. The final sample included 7917 respondents in all. The goal of each state was to conduct a minimum of 400 interviews. Each state drew a random sample of individuals over age 18 who were receiving at least one service, besides case management. Most states drew an over-sample to account for refusals.

After excluding incomplete and inconsistent responses, the number of valid respondents to Section I = 5372. Overall, 68% (5372/7917) of consumers in the total sample were able to respond to Section I of the direct interview. The number of valid responses to Section II = 7732. Overall, 63% (4836/7732) of consumers responded to Section II of the direct interview.

All states, with the exception of WV and WY, had a slightly higher percentage of males in their samples. Overall, the total sample was 55% male and 45% female. The average age of respondents was 41 years old, with a range from 18 to 103. Reported level of mental retardation among respondents varied by state. Overall, about 65% of the total sample had a diagnosis of “mild” or “moderate” MR, and 29% had a diagnosis of “severe” or “profound” MR (see Figure 1).

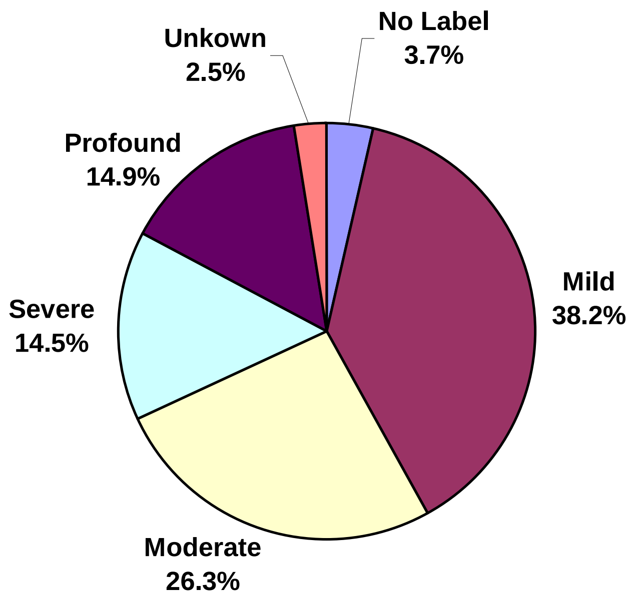

Figure 1 Level of MR (*N* = 7865)

Ten percent of respondents in the total sample used a nonverbal form of communication as their primary means of expression (e.g., gestures, sign language, communication device). The overall sample of respondents included small percentages of minority participation: 8% identified their race as Black or African American; 5% reported their race as Asian, Native Hawaiian, or Other Pacific Islander; and 5% reported their ethnicity as Hispanic. Another 5% reported their race as "Other" or "Mixed Race." Overall, 29% of the total respondents live with their families, although this figure varies by state. The percent of respondents living in other types of homes is shown in Figure 2.

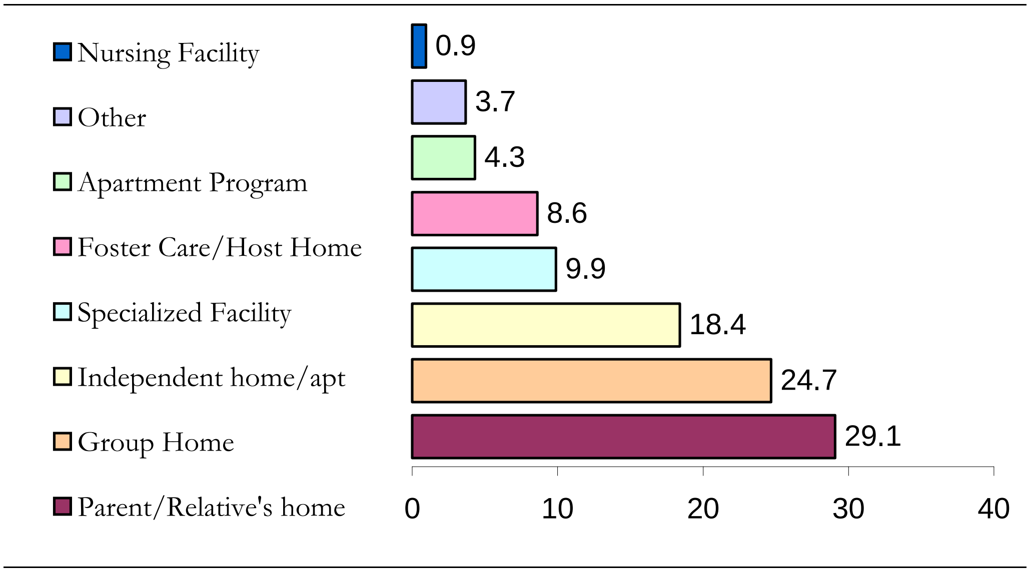

Figure 2 Type of Residence (*N* = 7904)

The type of day/employment services and supports received by respondents varies by state. Overall, about 20% receive supported employment services, 8% receive group employment services, 37% receive facility-based vocational services, and 34% receive non-vocational day services. About 53% of respondents in the overall sample receive Home and Community Based Waiver Services.

Community Inclusion. For most types of community activities asked about in the survey, participation was high, ranging from 69% to 96%. Two activities had lower participation: 56% attended religious services, and 32% reported belonging to clubs or community organizations.

Respect and Rights. 92% of all respondents report that they have enough privacy. 28% of all respondents reported having attended a self-advocacy group meeting or event. Across the board, over 90% of respondents reported that support staff (at home, day program, and jobs) treat them with respect.

Service Coordination. 77% of all respondents report that service coordinators get them what they need

Access. 79% of respondents reported that they almost always have a way to get where they want to go.

Satisfaction. Satisfaction with home was 94% and satisfaction with work/day program was 96%

Relationships. The majority of respondents report having friends (other than family and staff), best friends, and being able to see their friends and family when they want. Just less than half of the respondents (48%) reported "sometimes" or "always" feeling lonely.

Safety. 80% of respondents reported feeling safe in their homes, and 81% reported feeling safe in their neighborhood.

Health. Across the board, women's access to yearly GYN exams was low (only 52% had an exam in the past year and 7% have never had one).

Trend Analysis

Each year, participating states receive reports that include their own data, aggregate figures for the total sample, and averages across all states that submitted data. The group of states that make up the "national" average fluctuates from year to year. Ideally, all states would administer the Consumer Survey every year. While this is a goal, the reality of state budgets dictates that some states may indeed skip a year of data collection. On the flip side, new states have joined NCI each year. Variation in the mix of states could present challenges when comparing data longitudinally.

Another factor to consider when looking at the data across years is that several of the questions went through significant changes in earlier iterations of the survey. For the past two years, the survey tool has remained basically the same.

With these challenges in mind, we have begun to look at trends for the past three years of data collection, where comparisons are possible. Five states – Connecticut, Kentucky, North Carolina, Pennsylvania, and Rhode Island – have consistently collected NCI Consumer Survey data over the past three years. For the first trend analysis, we are using these five states as a "core" group. We are also looking at trends using the "all-state" average, which includes a different mix of states each year. An example is shown in Figure 3, which displays results for one indicator, the proportion of people reporting that their case manager gets them what they need, over the past three years. While not statistically significant, the trend is clearly a downward in both the five-state average and the all-state average, suggesting that this is an issue that deserves further attention.

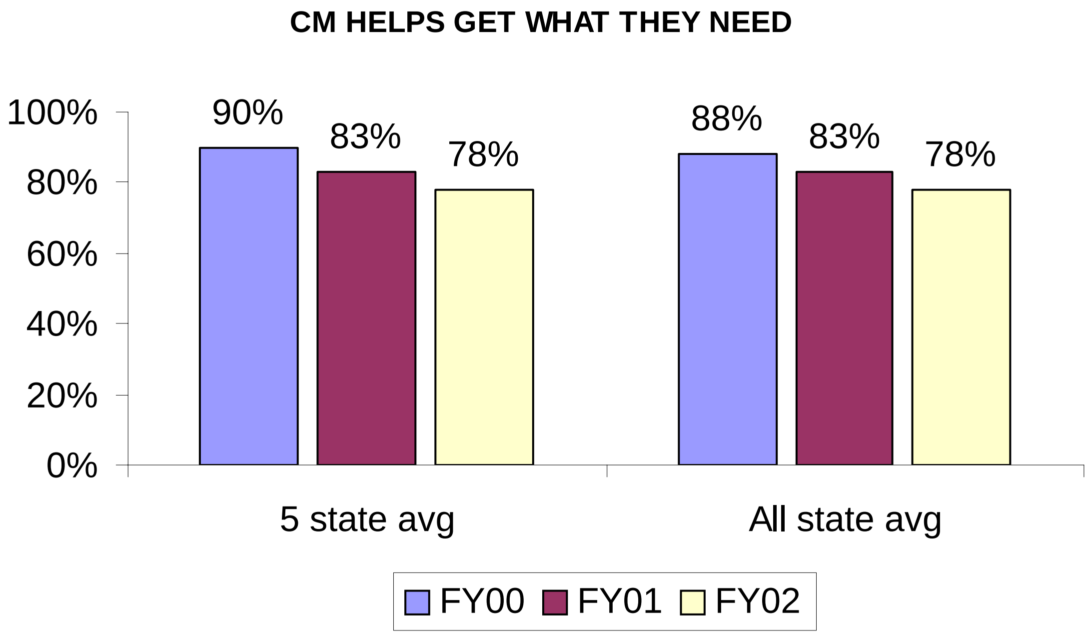

Figure 3 Trends in Case Management

Figure 4 below reflects the experience of five states with respect to the frequency of physical, gynecological and dental exams. States have noted that the latter two patterns indicate the need for improvement.

Figure 5 displays trends in five states over a three year period regarding the perceptions of participants insofar as safety in their homes and safety in their neighborhoods. Perceptions of safety appear to have worsened somewhat during this period.

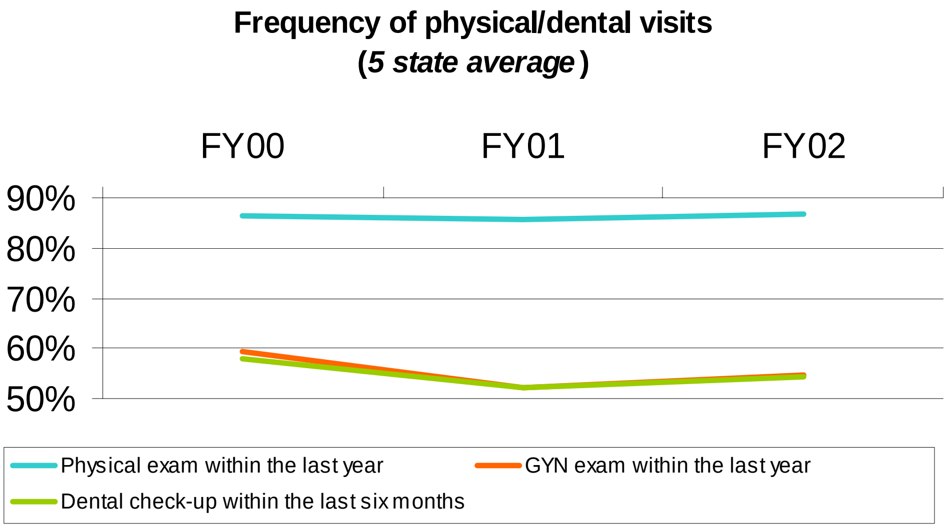

Figure 4: Trends in Health Care Exams

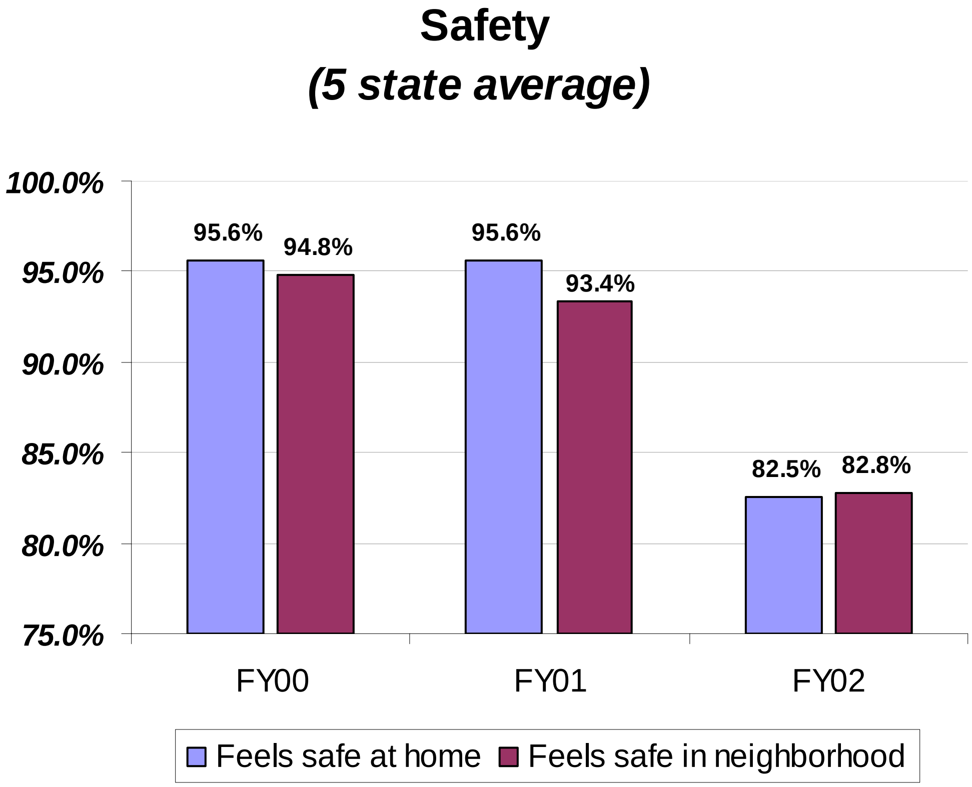

Figure 5 Trends in Perceptions of Safety

Figure 6 below shows the trends in 5 states regarding the individual's satisfaction with where they live. The results show a steady increase in positive perceptions.

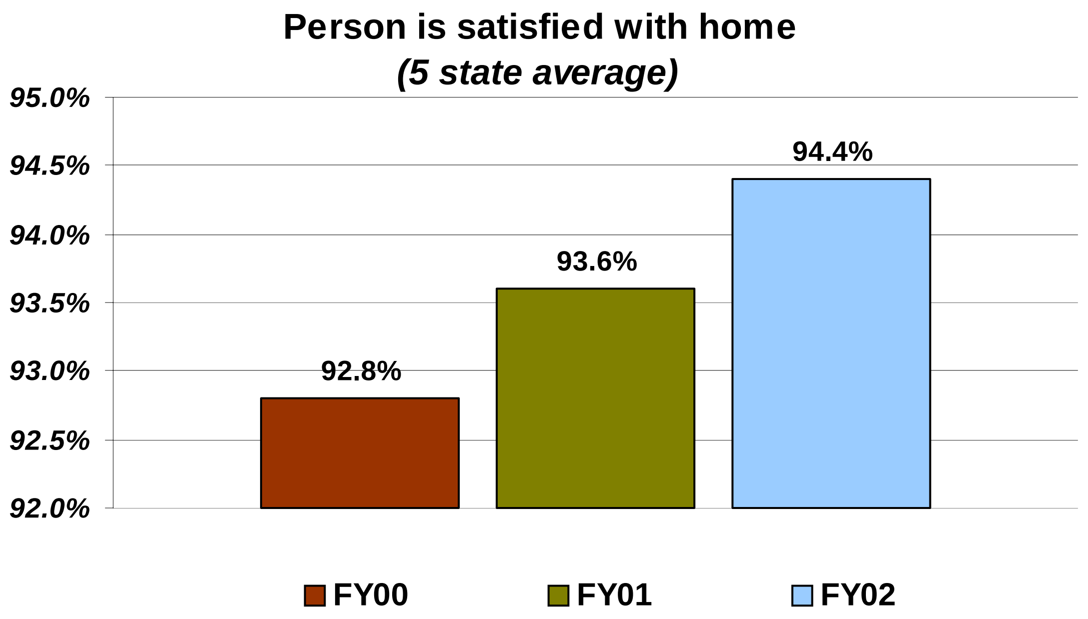

Figure 6 Trends in Satisfaction with Home

Figure 7 below reflects trends in states regarding the perceptions among individuals regarding their ability to make choices and to influence their lives. The trend line is clearly in a positive direction.

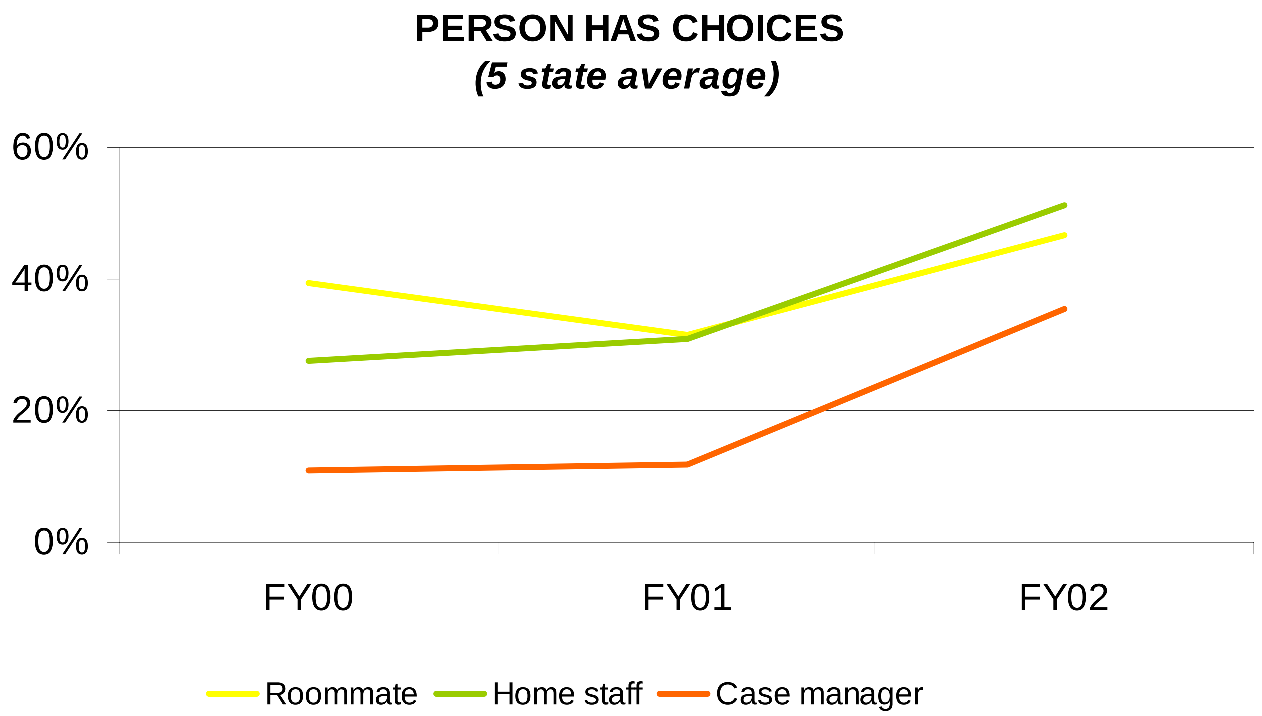

Figure 7 Trends in Making Choices

FAMILY SURVEY: SELECTED RESULTS

Obtaining direct feedback from families is an important means for states to gauge satisfaction with services and supports as well as to pinpoint potential areas for quality improvement. The results garnered from family surveys enable a state to establish a baseline against which to gauge changes in performance over time. In addition, these results permit a state to compare its own performance against other states. NCI includes three family surveys — a survey of families with participants living at home (Adult Family); families with a participant living outside the house (Adult Family Guardian), a families with children. The selected results reflect the first two surveys.

Figure 8 includes multiple indices of family/guardian satisfaction with the types of information and planning support available to them. Figure 9 displays family satisfaction with the degree of choice and control that they experience.

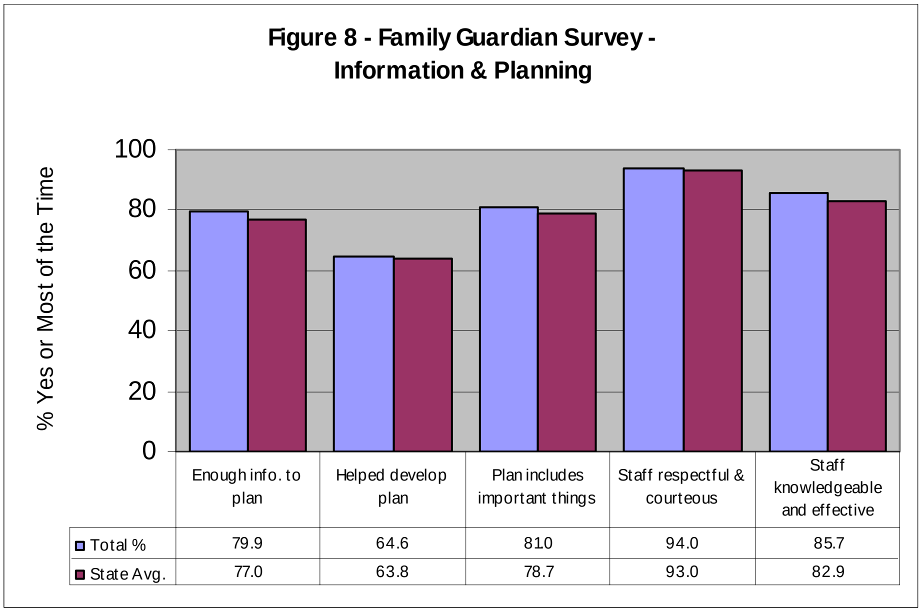
Figure 8 - Family Guardian Survey - Information & Planning

	Enough info. to plan	Helped develop plan	Plan includes important things	Staff respectful & courteous	Staff knowledgeable and effective
■ Total %	79.9	64.6	81.0	94.0	85.7
■ State Avg.	77.0	63.8	78.7	93.0	82.9

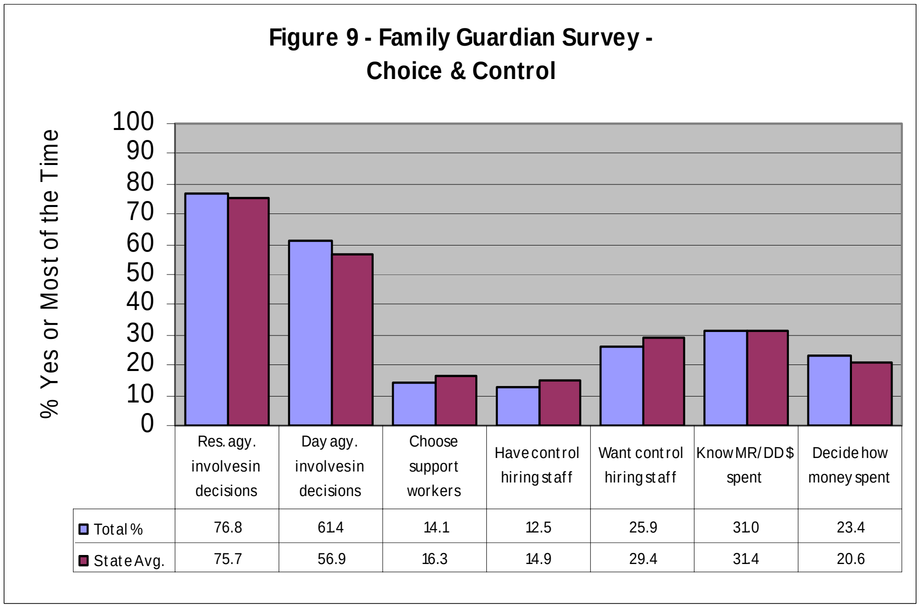
Figure 9 - Family Guardian Survey - Choice & Control

	Res. agy. involves in decisions	Day agy. involves in decisions	Choose support workers	Have control hiring staff	Want control hiring staff	Know MR/DD $ spent	Decide how money spent
■ Total %	76.8	61.4	14.1	12.5	25.9	31.0	23.4
■ State Avg.	75.7	56.9	16.3	14.9	29.4	31.4	20.6

Figure 10 includes multiple indices of satisfaction among families with a participant at home with the types of information and planning support available to them. Figure 11 displays family satisfaction with the degree of choice and control that they experience.

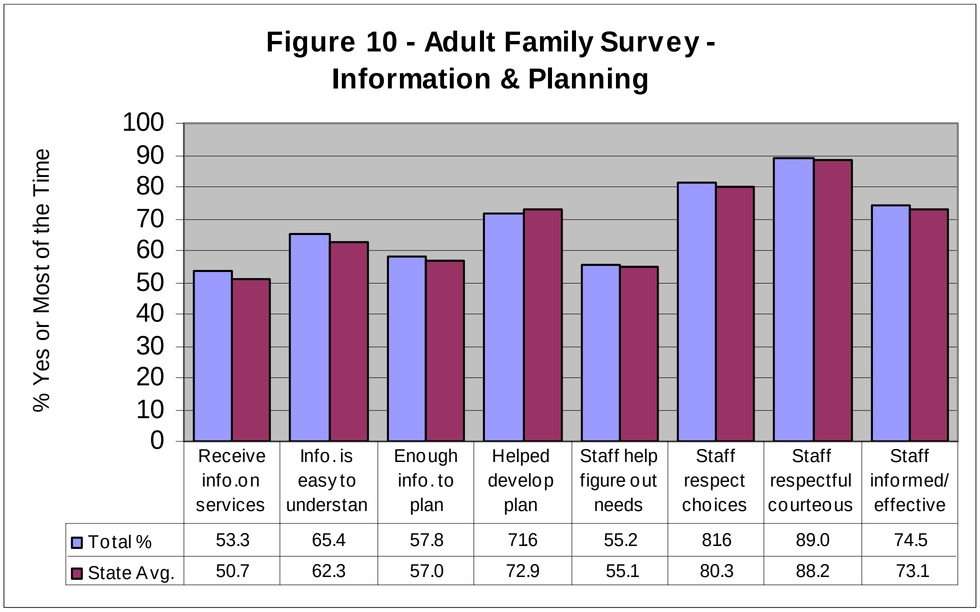

Figure 10 - Adult Family Survey - Information & Planning

	Receive info.on services	Info. is easy to understan	Enough info. to plan	Helped develop plan	Staff help figure out needs	Staff respect choices	Staff respectful courteous	Staff informed/ effective
■ Total %	53.3	65.4	57.8	716	55.2	816	89.0	74.5
■ State Avg.	50.7	62.3	57.0	72.9	55.1	80.3	88.2	73.1

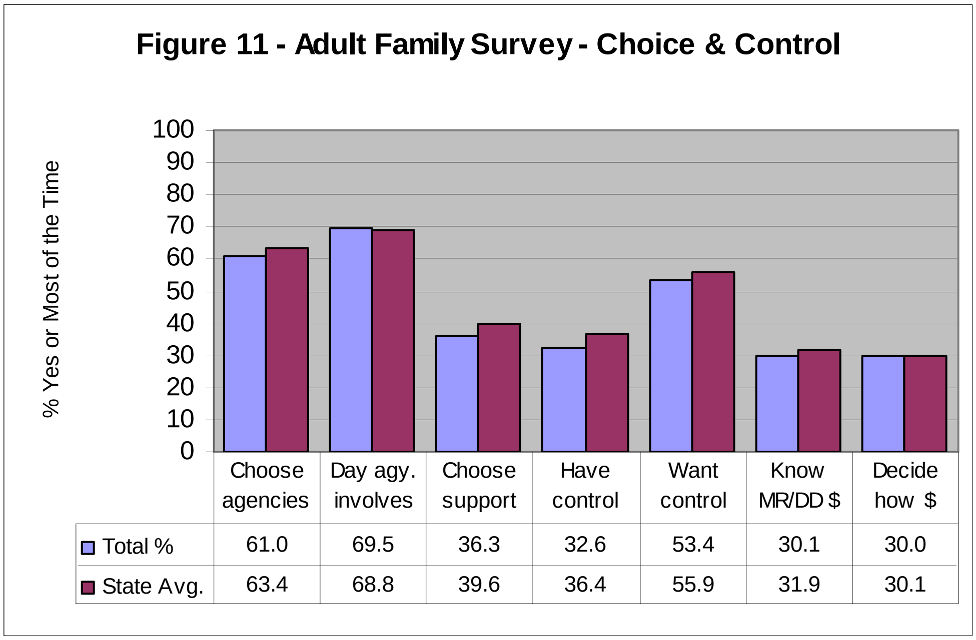

Figure 11 - Adult Family Survey - Choice & Control

	Choose agencies	Day agy. involves	Choose support	Have control	Want control	Know MR/DD $	Decide how $
■ Total %	61.0	69.5	36.3	32.6	53.4	30.1	30.0
■ State Avg.	63.4	68.8	39.6	36.4	55.9	31.9	30.1

SELECTED SYSTEMS LEVEL RESULTS

Provider Survey

Provider survey data is primary data collected directly from service agencies. In general, this data is not collected by states on a regular basis. Participating NCI states may elect to administer the NCI Provider Survey, which currently has two data collection modules: direct care staff stability (e.g. turnover rates) and representation of consumers and families on boards of directors.

Note: system data, which is secondary data that is already reported and available to state system managers, is also analyzed by NCI. Project staff and participating states recognize the sensitivity of these data, as well as the challenges that compilation of the data presents. Given the importance of the information, the steering committee agreed to continue the pursuit of the information, while maintaining the results internal to the project.

Staff Stability

With respect to direct contact staff stability, state developmental disabilities authorities have expressed that the most critical area of concern lies in the arena of residential services and supports. Thus, NCI states are asked to collect staff stability data from agencies that provide such services. Optionally, states may decide to furnish information on day supports as well. Although the residential and day results are reported separately, it is important to note that there is some overlap in the results since many agencies submitted both types of data.

Agencies derived this information from payroll data. For the purposes of this survey, direct contact staff were defined as employees whose primary duties include hands-on, face-to-face contact with consumers. This may exclude psychologists, nurses, and managers whose responsibilities are primarily supervisory in nature.

Figure 12 below displays direct contact staff turnover rates over a period of three years. Although only a small number of states submitted data each year (4-5 states per year), and the combination of states differed from year to year, the results show a clearly increasing trend in direct contact staff turnover. Also, residential services consistently report higher turnover rates than day services.

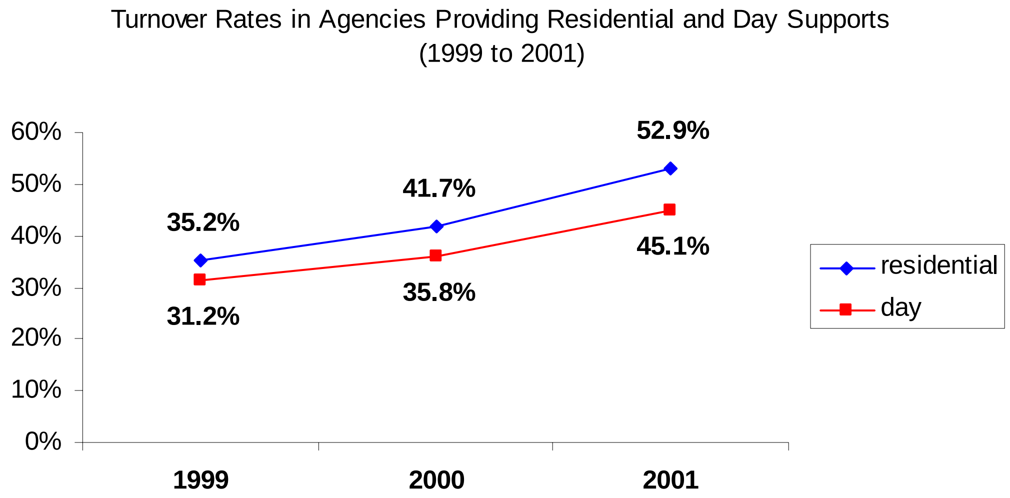

Figure 12 Staff Turnover Rates -- All State Average (FY1999 to FY2001)

In FY2001, turnover rates in residential agencies ranged from 33% (Hawaii) to 54% (Indiana).

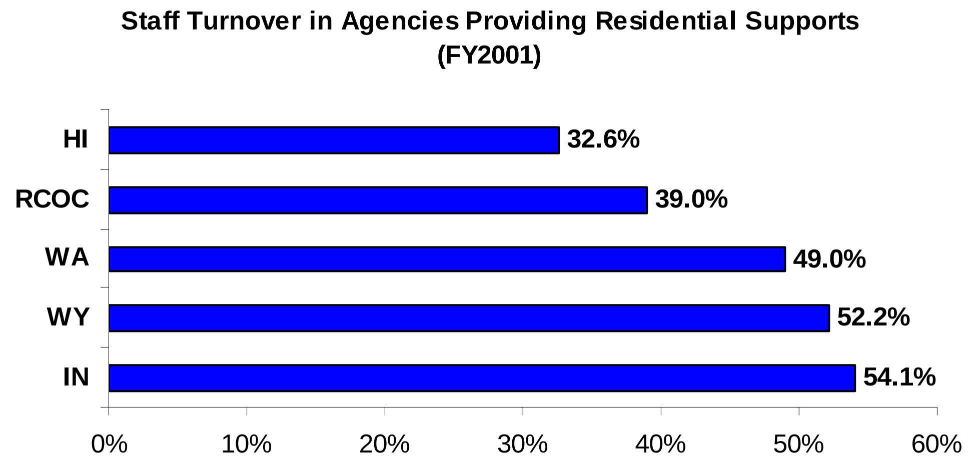

Figure 9 Staff Turnover in Residential Agencies, by State (FY2001)

MAJOR ACCOMPLISHMENTS

At the National Level

The collaboration of state developmental disabilities authorities from around the country during the early stages of NCI resulted in a set of wide-ranging performance indicators. The indicators and corresponding measures have been fine-tuned but remain basically intact. It is expected that the indicator set will continue to evolve to reflect changes in systems of support and that the reliability and validity of the measures will be improved as more information is gleaned from the data.

NCI has also produced a companion set of valid and reliable data collection protocols. These tools include: a direct interview protocol (Consumer Survey) for collecting information from individuals who receive services and supports, three distinct family surveys, and separate protocols for the collection of data concerning employment, staff turnover and stability, board representation, serious injuries, restraints, and deaths. NCI surveys are widely used, even beyond the participating states. The Consumer Survey has undergone psychometric testing to ensure its reliability and validity. Definitions and data specifications developed for cross-state compatibility of system data have been used by states to establish routine methods of collecting critical information from providers. As NCI grows, the power of this national data base will increase. The most recent wave of consumer surveys yielded data on more than 8,000 individuals with cognitive and other developmental disabilities.

At the State Level

National Core Indicators has already had both long-range and immediate influences on the ways in which states monitor performance and use performance data to influence system change. In Massachusetts, the NCI data is being used as the cornerstone for the state's strategic plan for the enhancement of services to people with mental retardation. Additionally, both Massachusetts and Wyoming are using the NCI data as part of their Home and Community Based Waiver reviews. In Pennsylvania, the NCI data requirements helped to shape the design of new and comprehensive management information system for the mental retardation service system. Additionally:

- Pennsylvania uses NCI information in conjunction with independent monitoring at the local level, and it is an integral part of their overall Quality Management framework.
- Arizona also uses NCI for Medicaid Agency requirements; advertises reports in their newsletter; sends reports to all families who participated; and shares their information with the Legislature and Governor.
- Alabama will use the consumer survey as part of *Wyatt* settlement

requirements.

- Rhode Island is in the process of putting together a statewide consortium of advocacy groups that will look at issues, trends and best practices. This group will also review NCI data. They are also working on creative ways to get the results out in accessible formats.
- Kentucky included NCI in its ten-year plan. Also they are expanding their focus on team interviewing techniques to enhance consumer and family participation.
- Washington used the NCI data collection protocols to revise their incident reporting and mortality data system
- In Indiana, the information from the surveys has been posted on the web site of the Bureau of Quality Improvement Services and notice has gone out to all providers notifying them of the availability of this information.

Provider Level

At the provider level, the NCI data reinforce the importance of using consumer-generated information as the foundation of any quality assurance system. Second, the data also helps providers – many of whom are in the process of revamping their internal management information systems, to anticipate the types of information that the state is committed to collect. Finally, especially in those states that have made an effort to disseminate NCI data, it gives an indication of statewide norms and provides comparisons to the aggregate performance of providers in other states.

TECHNICAL CHALLENGES

There have been many technical challenges in conducting NCI. By far the most challenging task is ensuring that measures are comparable across states. Creating "standard" measures general enough to meet a common definition but sufficiently specific to yield meaningful data was a major focus of Phase I and continues to be a challenge. Through much discussion, testing, and further refinement, feasible measures have been developed for most of the indicators.

Another data collection challenge is the varying level of sophistication among states with respect to their information systems. Some states have mature, comprehensive, and automated management information systems. Others keep critical records by hand. As a result, the reliability, availability, and completeness of information vary across and sometimes within state systems.

NCI GOING FORWARD

NCI is now in a position to give states more robust information concerning performance. The project's databases have grown quite large and increasingly reliable. There is every prospect that exploiting this data will result in improved understanding of where states individually and collectively stand in achieving person-centered outcomes. Just as important is the role that this information can play in discussions in the state about quality improvement systems. It is also anticipated that the present indicator set will change to include better measures to describe how effective state systems are in supporting individuals and families to direct and manage their own supports.

NCI's arguably greatest significance has been and will continue to be its emphasis on outcomes and particularly those that directly affect people with disabilities and their families. It is to the credit of the states that helped launch NCI and the states that have joined the project since that they have willingly taken the very courageous step of measuring their own performance – good or bad – so that they can engage in meaningful quality improvement.