Using National Core Indicators (NCI) Data for Quality Improvement Initiatives

December 7, 2017

National Core Indicators (NCI) is a collaborative effort between the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI). The purpose of the program, which began in 1997, is to support NASDDDS member agencies to gather a standard set of performance and outcome measures that can be used to track their own performance over time, to compare results across states, and to establish national benchmarks.

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How to Use this Handbook

This handbook was created to enhance the use and application of information generated through the collection of data as part of National Core Indicators (NCI). The audience for this guide includes managers of public intellectual and developmental disabilities (ID/DD) systems, providers of services, board members, people with disabilities and their family members, and other interested advocates. Specifically, the handbook will inform the reader regarding:

- The fundamentals of NCI including how the data are collected and analyzed;
- The basic statistical standards needed to critique data and to understand the strengths and limitations for changing policy and practice;
- The ways in which NCI data can be used to improve the quality of services;
- The specific steps necessary to maximize the use of data at the state, regional and provider level; and
- The initiatives that states have already taken to address issues identified in the NCI data.

What is National Core Indicators (NCI)?

History of NCI

The development of indicators of system performance is an important first step in establishing a durable and robust method of tracking the progress toward change and improvement in systems of support for people with intellectual and developmental disabilities (ID/DD) and their families. The National Core Indicators (NCI) program is a collaborative effort between the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI) to do just that – establish indicators that measure the performance of ID/DD services and supports within and across states. Begun in 1997 as the "Core Indicators Project" (CIP), the aim was to explore ways of measuring whether the aspirations of the field in areas such as choice and relationships were in fact being realized.

NCI is a now a multi-state effort with more than a decade's worth of information about the experiences of people and families receiving services. This has been accomplished through the commitment of participating states to contribute resources and knowledge, identify common performance indicators, develop comparable data collection strategies, and share results.

Since the inception of NCI, yearly state and national reports have been circulated, and data briefs highlighting important issues have been published. Through presentations in the United States and internationally, results have been made available to wide ranging audiences including self-advocates and family members. The guiding principle of NCI has always been to enhance the transparency of information about system performance. Publications, data reports, a customizable "chart-making" tool, and other important resources can be found at: www.nationalcoreindicators.org.

Outcomes and Indicators

The core indicators are the foundation of NCI. The current set of performance indicators includes approximately 150 consumer, family, system, and health and safety outcomes. Taken together, these outcomes provide a comprehensive picture of the quality of public ID/DD services. Associated with each indicator is a source from which the data are collected. NCI uses four main data sources: an adult consumer survey (e.g., rights and choice issues), family surveys (e.g., satisfaction with supports), a provider survey (e.g., staff turnover), and system data from state administrative records (e.g., mortality rates). The indicators are intended to provide a system-level "snapshot" of how well each state is performing relative to other states and to the average across states.

- Indicators selected are:
- Reflective of the mission, vision and values of the field;
- Measurable;
- Practical to implement;
- Reliable and valid;
- Sensitive to changes in the system;
- Representative of issues the states had some ability to influence; and
- Reflective of outcomes that were important to all individuals regardless of level of disability or residential setting.

The core indicators provide a singular source of information for quality management and are intended to be used in conjunction with other state data sources, such as risk management information, regional level performance data, results of provider monitoring processes, and administrative information gathered at the individual service coordination level.

Description of NCI Indicator Domains and Sub-Domains

The table below briefly describes the core indicators associated with the Adult Consumer and Family Surveys. Indicators are divided into five Domains. Within these Domains are Sub-domains, each of which has a targeted outcome.

Domain	Sub-Domain	Description of Sub-Domain
Individual Outcomes	Work	People have support to find and maintain community integrated employment.
	Community	People have support to participate in everyday community activities.
	Choice and	People make choices about their lives and are actively engaged in planning their services and supports.
	Self Determination	People have authority and are supported to direct and manage their own services.
	Relationships	People have friends and relationships.
	Satisfaction	Families/family members with disabilities have the information and support necessary to plan for their services and supports.
Family Outcomes	Information and Planning	Families/family members with disabilities have the information and support necessary to plan for their services and supports.
	Choice and Control	Families/family members with disabilities determine the services and supports they receive, and the individuals or agencies who provide them.
	Access and	Families/family members with disabilities get the services and supports they need.
	Community Connections	Families/family members use integrated community services and participate in everyday community activities.
	Family Involvement	Families maintain connections with family members not living at home.
	Satisfaction	Families/family members with disabilities receive adequate and satisfactory supports.
	Family Outcomes	Individual and family supports make a positive difference in the lives of families.
Health, Welfare, and Rights	Safety	People are safe from abuse, neglect, and injury.
	Health	People secure needed health services.
	Medications	Medications are managed effectively and appropriately.
	Wellness	People are supported to maintain healthy habits.
	Restraints	The system makes limited use of restraints or other restrictive practices.
	Respect/Rights	People receive the same respect and protections as others in the community.
Staff Stability and Competence	Staff Stability	Direct contact staff turnover ratios are low enough to maintain continuity of supports and efficient use of resources.
	Staff Competence	Direct care staff are competent to provide services and support.
System Performance	Service	Service coordinators are accessible, responsive, and support the person's participation in service planning.
	Access	Publicly-funded services are readily available to individuals who need and qualify for them.

Consumer Survey and Other NCI Data Collection Tools

The primary sources of NCI data are the Adult Consumer Survey and Family Surveys. Additionally, some states collect staff stability and mortality data.

Adult Consumer Survey – This face-to-face survey collects data on approximately one-half of the outcome/performance indicators. The purpose of this survey is to acquire individual demographic, service and health information as well as information directly from adults with intellectual and developmental disabilities concerning the presence of valued outcomes in their lives.

Family Surveys – Mail surveys are distributed to families who have a family member with a disability and are intended to assess system responsiveness to their needs, quality of services, and their overall satisfaction. There are three distinct surveys for families:

- a survey of families who have an adult family member with a developmental disability who lives with them (Adult Family Survey);
- a survey of families/guardians whose adult family member with a developmental disability is in residential placement (Family Guardian Survey); and
- a survey of families who have a child with a developmental disability who lives with them (Child Family Survey).

Staff Turnover/Vacancies – Participating states employ a common framework to collect information concerning direct support professional (DSP) turnover and vacancy rates along with information regarding employment longevity.

How NCI Data are Collected

How is the Adult Consumer Survey Administered?

Information for the Adult Consumer Survey is collected via a direct conversation with the person receiving services as well as the collection of background information from the individual's record. Section I of the Survey includes questions that can only be answered by the individual him or herself since it includes questions that require subjective judgments and personal experiences. Section II of the Survey allows for the use of "proxy" or other respondents who know the individual receiving services very well (such as a family member or friend), and consists of questions about objective facts regarding the individual's circumstances.

States employ a variety of individuals to conduct the face -to -face conversations. The major requirement is that they have no personal connection with the individual (such as a service provider, relative, personal case manager, etc.). Within this constraint, states have used university students, state staff, private contractors, advocacy organizations, and individuals with disabilities and their families to conduct the surveys. NCI provides standardized training to ensure uniform application of the survey.

Each state has to collect survey data from a random sample of at least 400 individuals – a number that makes it possible to generalize the results to individuals served statewide.

How are the Family Surveys Administered?

States, depending on their priorities, may use one, two or all three family surveys. The family survey is a mail survey. For each survey, the aim is receive at least 400 responses. Given an average response rate around 33% states are counseled to send out 1200 surveys. If the state serves few than 1200 individuals, then states are encouraged to send the surveys to 100% of families of individuals served.

Why You Can Rely on NCI Data

Why a Sample is Representative of People Served

Every state (or sub -state entity in some cases), draws a random sample of at least 400 individuals receiving services. Sample selection is randomized so that every person in the state or service area that meets the criteria has an equal opportunity to be selected. Samples are usually limited to individuals who are age 18 or older and who receive at least one service besides case management. A sample size of at least 400 is based on the minimum number needed to yield valid samples that meet the standard of a +/ -5% margin of error and a 95% confidence level. This strategy is consistent with agreed upon statistical methods.

National Norms and Statistical Significance

The NCI average or national norm is intended to serve as a point of comparison for framing a state's results. It does not represent a benchmark of acceptable or unacceptable performance – it merely indicates the average scores for all states that participated in the data collection period. In the NCI national report, states can determine whether their relationship to the cross state average on any given question is significantly higher or lower. Where there are scores that fall significantly below the norm, the results may point to the need for targeted system improvements. Of course the findings should be viewed in the context of the state's current array of supports and services, priorities, and goals.

Statistical significance means that the difference in magnitude between in two sets of responses to the same question is not likely to have happened by chance. This is an important concept to understand when looking at one state's data compared to other states. Simply scoring lower than another state or the national average does not necessarily mean that it is cause for concern unless the differences are statistically significant.

The Meaning of Validity and Reliability

Validity

There are many ways to measure the validity of a survey or a test. First, and most basic, is face validity. Do the questions appear to provide a good representation of what the survey is intended to measure? If the issue in question is whether people have relationships and friends, are the questions likely to elicit responses that would shed light on that issue? Another criterion is content validity – does the survey provide a comprehensive look at an issue or is it just a partial picture? During survey development, testing with focus groups and input from a Project Advisory Committee ensured the validity of the Adult Consumer Survey. Validity is maintained on an ongoing basis by gathering feedback from interviewers. A further test of validity is to see whether or not the responses are logically consistent given what is known about the respondent and whether, taken as a whole, the survey results produce logical discriminations among respondents.

Reliability

Reliability testing measures whether the survey yields consistent results. Reliability is important in order to ensure that regardless of who is asking the question the results are the same (inter -rater reliability). The Adult Consumer Survey has undergone numerous inter -rater reliability tests – most recently in 2011 – and all results have shown strong agreement. To maximize reliability it is important that those conducting NCI interviews receive standardized training so that the survey is administered in a consistent fashion. NCI provides standardized training protocols to all participating states.

Understanding Scales

Scales are used to combine similar responses from multiple questions into one outcome. Scales are used for two domains in the Adult Consumer Survey – Community Inclusion and Choice. By using scales, it is possible to create a measure of an overarching concept rather than specific elements of the concept. In order to create a scale, statistical tests are required to ensure that the multiple items share common properties.

The Community Inclusion composite measure was created by adding the following four items: the number of times a person went shopping, on errands, for entertainment, and out to eat. Two Choice composite scales were created by adding and averaging items from the Life Decisions scale and Everyday Choices scale. The Life Decisions scale consists of items about choosing place of residence, work, day activity, staff at both residence and day activity, and roommates. The Everyday Choices scale consists of items about choosing schedule, money, and free time activities.

Important Cautions about the Use of Data

Before jumping in to the world of using data for quality improvement, it is important to note some cautions about possible misinterpretations and misreading of the results of data collection. Dr. Steven Staugaitis (2005) laid out some of these caveats in a short manual on how to use data that he prepared for the Quality Council sponsored by the Massachusetts Department of Developmental Services (formerly Department of Mental Retardation). The following summarizes some rules of thumb[1]:

While the consistent use of objective data can be a valuable tool in understanding and managing the quality of services it is important to remember that it is not "perfect" and must be used in an intelligent and cautious fashion. It is important to seek balance between data and other sources of information and to approach the review of data with a "questioning" mind. Try to follow these general rules and you should become an effective and valuable member of the DMR quality team:

1. **ALWAYS** make sure you:
    a. Analyze the analysis.
    b. Identify BIG issues that may compromise the data
    c. Do NOT generalize the finding beyond their limits
    d. BALANCE your review. The data are one point of reference – take into consideration other sources of information

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[1] Steven Staugaitis, Ph.D., General Principles for Using Data as a Quality Improvement Tool: A User's Guide for the Massachusetts DMR Quality Councils, University of Massachusetts Medical School, E.K. Shriver Center, Center for Developmental Disabilities Evaluation and Research, 2005.

2. **NEVER**:

    a. Make assumptions about the data – ask questions.

    b. Expand the findings to the whole served population – unless it's appropriate.

    c. Treat the data as "significant" unless it says it is.

    d. Jump to conclusions without checking other sources.

Ways that NCI Data Should Not be Used

While NCI data provide a valuable tool for understanding programmatic, policy and practice issues at the systems level, it is not meant to understand the circumstances of a particular person or family. NCI is not an individual monitoring tool (except in cases where the interviewee suspects abuse or neglect – in which case reports are mandated). There are several reasons why this is the case. First, the NCI Adult Consumer Survey and families surveyed were designed to elicit information about general performance domains not to understand the particular situation of a person with ID/DD and/or their family. Secondly, the surveys are meant to be confidential in the case of the individual and anonymous in the case of the family.

To use the data to respond to a particular situation would mean that the individual's or family's identity would have to be disclosed. Some states, such as Pennsylvania, have adopted a "considerations" policy in which an individual can request follow -up – but this is not the norm. Finally, NCI was not intended to be a monitoring or quality assurance tool – it was meant to be a tool for identifying areas for quality improvement.

The data should also not be used to gauge the performance of a particular provider or region of the state unless the sample size is sufficient to guarantee a relatively small margin error and high confidence level. The required sample size of 400 per state is enough to make it possible to say that the results are an approximation of the circumstances of the total number of individuals being served statewide. To be able to have the same confidence at the sub - state or provider level, you would need to collect samples in the magnitude of 400 for every sub state unit.

With respect to the use of data as part of evidence packages submitted to CMS as part the reporting requirements for Home and Community Based Waivers (1915(c)), NCI data cannot be used if it is the single data source for a particular assurance or sub -assurance. It can be used in tandem with at least one other data source.

Ways to Use NCI Data for Quality Improvement

Overview of the NCI Reports

Every state (and participating sub -state entity) that participates in NCI receives a yearly state report on Adult Consumer Survey results (assuming that they have been collecting data during the past year). Each state report shows responses by survey question and a comparison with the NCI average across states for that same question. Below is an example of a state's results regarding whether the person chose with whom they live compared to the national norm.

Consumer Chose the People He/She Lives With
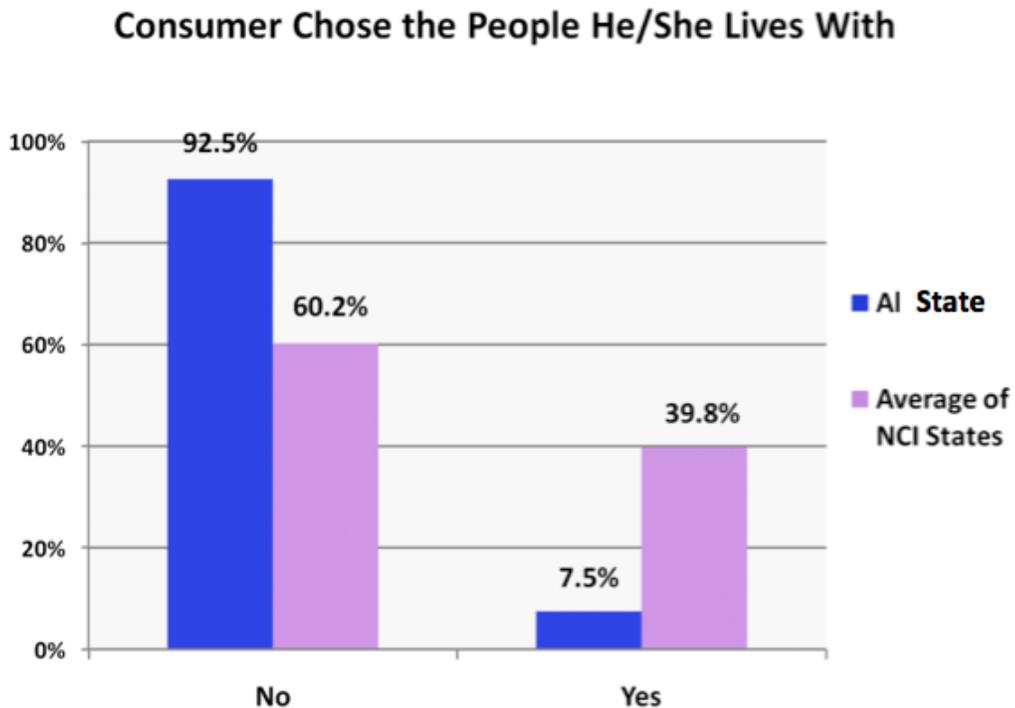
Beginning in 2011 -2012, each state report will be formatted so that individuals with visual impairments will be able to read it using a screen reader. This means that the reports will be compliant with federal accessibility regulations (Section 508). They can be posted on websites that require such formatting.

The national NCI Adult Consumer Survey report includes results for each state by question and by living arrangement. Individual state scores are also ranked "significantly above the national average," "at the average," or "significantly below the national average." The chart below shows – for choice of case manager – the way data are displayed. The total row includes figures for the "average of averages" across states.

Proportion of people who chose their case manager/service coordinator

State	N	Overall In State	In Institution	In Community-Based	In Ind. Home	In Parent's Home
Significantly Above Average						
WY	373	89%	n/a	87%	88%	88%
RCOC	558	82%	70%	86%	95%	80%
OH	456	80%	58%	74%	89%	81%
AR	384	79%	51%	88%	86%	91%
NY	1,071	74%	40%	70%	85%	81%
LA	196	74%	n/a	30%	75%	89%
NC	818	69%	11%	79%	80%	82%
IL	343	67%	71%	62%	70%	68%
Within Average Range						
GA	418	63%	n/a	59%	62%	68%
ME	384	52%	n/a	53%	53%	n/a
Significantly Below Average						
OK	396	49%	15%	69%	53%	n/a
DC	336	47%	n/a	49%	51%	40%
KY	428	45%	19%	53%	n/a	25%
TX	1,925	42%	30%	n/a	n/a	72%
MO	396	42%	36%	37%	49%	n/a
NJ	393	33%	n/a	34%	n/a	n/a
PA	1,225	32%	18%	29%	36%	30%
AL	433	22%	4%	23%	n/a	23%
Total	**10,533**	**58%**	**36%**	**58%**	**69%**	**65%**

Likewise, NCI participating states also receive yearly national reports on family survey results that – beginning in the 2010 -2011 data cycle – will also include state scores ranked according to the national norm. All of these reports can be found on the NCI website – www.nationalcoreindicators.org

User Friendly Reports

The User-Friendly Reports were developed together with self-advocates who wanted to make NCI data more accessible to policy-makers and other stakeholders. The User-Friendly report takes approximately 20 items from the Adult Consumer Survey and describes the outcomes in plain language and accompanying pie charts. NCI staff produce a National User Friendly Report that demonstrates national averages. In addition, a User Friendly Report is produced for each participating state's data. Here is an example of a page from a User-Friendly Report:
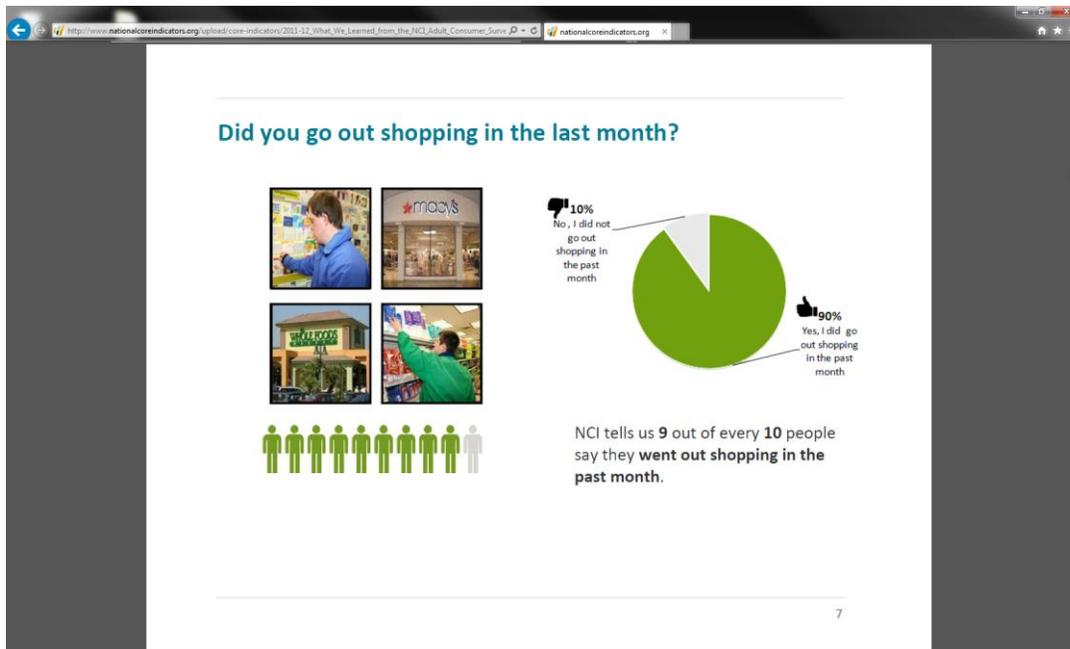
Generate State Specific Charts

Each state has the ability to generate charts displaying specific scores on items in the Adult Consumer Survey (e.g., feels safe at home, chose their job, etc.). Generating these charts can be done through the website noted above. In addition to the state reports that list scores on particular items, the chart generator allows individuals to do cross tabulations (e.g.,

psychotropic medication use by diagnosis). Individuals can filter results for up to two chosen indicators and compare multiple years of data. The charts page looks like this:
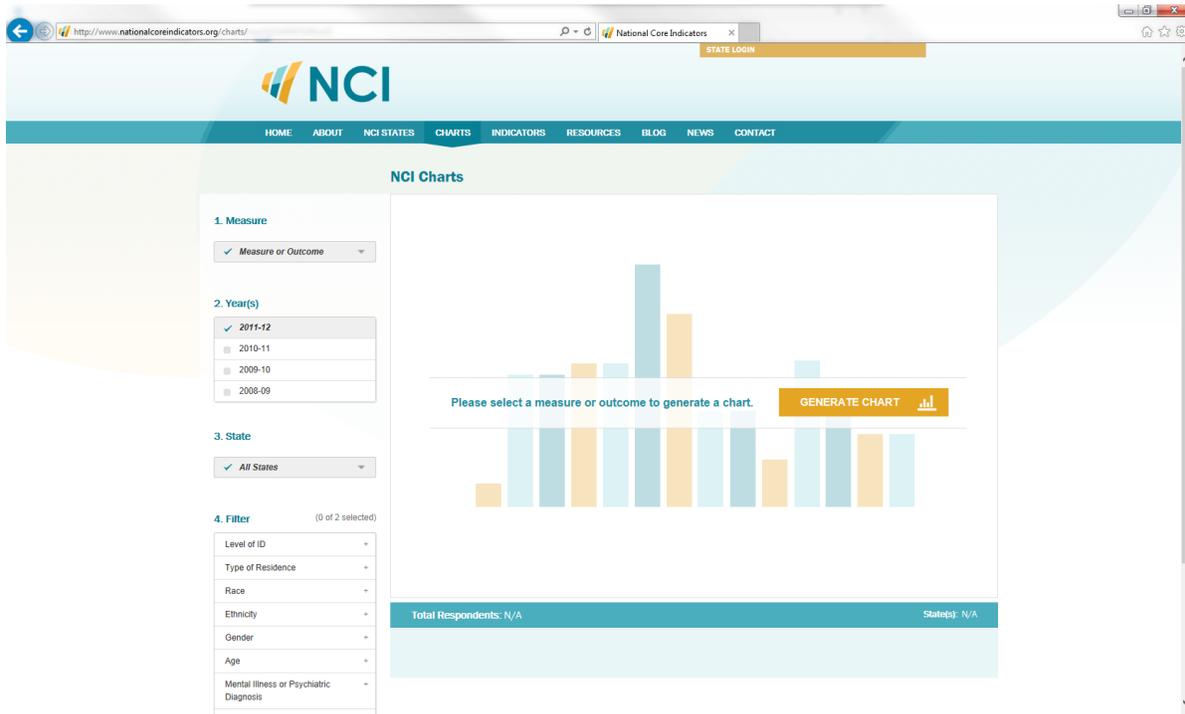
Create Groups to Review the Data

NCI data – and all performance data for that matter, should be reviewed on some systematic schedule to mark trends, progress and potential backsliding. Review groups can be internal to the state ID/DD agency or external and comprised of key stakeholders. To understand the implications of the data, it is helpful to bring together individuals from varying perspectives who may have different reflections on the meaning of what the data appear to suggest. Where there are other data sources that may provide a further explanation of findings, they should also be reviewed by the group. For instance, if the numbers of individuals who say that don't feel safe in their homes is going up or is significantly higher than the national norm, then the group may also want to look at patterns in incident management data.

Identify Areas for Improvement

Since quality improvement efforts cannot be effectively engaged on all fronts simultaneously, those working with data need to determine which areas should be targeted

for improvement over the next measurement period. Decisions about priorities should be informed by the following criteria:

- The priority reflects strong consensus among those most affected (people with disabilities and their families);
- The priority area is susceptible to change within the measurement period;
- Change or reform within the priority area can be accomplished within available resources.

Priorities should be reassessed each year. Some priorities may result in multi - year efforts and others may be successfully addressed within the year. Selecting priorities does not mean that other aspects of the data are not important – they merely reflect the major targets of change over the next period of time.

Develop Change Strategies

Once priorities have been set, the group and others in the ID/DD system can begin to concentrate on those strategies that are most likely to bring about improvement. For each priority, there may be different strategies. For instance, if individuals are not clear about their rights, then collaboration with a self - advocacy agency may yield increased knowledge among system consumers. If the goal is to enhance the numbers of people with ID/DD who have friends and important relationships, then strategies may be more complex (e.g., changes may be required in case manager and direct support professional trainings, expansion of social opportunities, emphasizing strategies that create social capital, etc.). Change strategies can be employed at each level of the system including at the state agency, the sub -state agency, private provider organizations, service brokers and case coordinators, and advocacy organizations.

Develop Benchmarks

The adoption of change strategies necessitates the development of benchmarks or targets to map how well the change strategies are working. If the goal is to increase the number of individuals who are aware of their rights, the benchmark will reflect by how much this outcome will increase the next time that the survey is administered. With respect to

enhancing the ability of people to develop relationships, then the hope would be that the percent of people who have friendships increases annually.

The creation of benchmarks is important to gauge whether the particular strategies are successful and – if benchmarks are not reached – whether to explore new or modified quality improvement strategies.

Share the Data in an Accessible Format

To enhance transparency, data generated from NCI should be made available to interested stakeholders and to the public at large. Many states put the results on their websites (see Washington State's announcement of the availability of state results), incorporate them into strategic plans, and share them with stakeholder groups. The challenge is to display the information in ways accessible to a range of audiences including self -advocates.

Some states, like Pennsylvania, have developed consumer -friendly reports that help to explain the findings in an engaging and intuitive fashion. The use of icons to portray domains is an effective tool. Also, using photographs of individuals others may know in the state is also a positive way of enhancing understanding. The following report from Pennsylvania on their NCI results shows the use of icons to facilitate understanding.

Independent Monitoring for Quality
A Statewide Summary for 2010

- Independent Monitoring for Quality (IM4Q) visits with adults and children age three and over who are supported by the Pennsylvania Office of Developmental Programs (ODP).

- IM4Q sends interviewers to talk to people who live in licensed community homes at least once every 3 years. Interviews are also conducted with people who live with their family, life-sharing families, independently, in intermediate care facilities (ICFs/MR), nursing facilities and personal care homes.

- Reports created from Independent Monitoring for Quality interviews are shared with provider agencies, administrative entities/counties, and the Planning Advisory Committee for the Office of Developmental Programs for purposes of improving peoples' quality of life.

- This information presents some of the findings from the 2009-10 statewide report. For a full report please contact your administrative entity/county or go to the Department of Public Welfare (DPW)'s website at www.state.pa.us.

Choice:

41% vote

64% choose what they do during the day

46% choose where they live

36% have a key to get into the house

61% always carry ID

Community:

84% go out for fun

33% go to worship weekly

41% go to the mall weekly to shop

41% go to a restaurant weekly
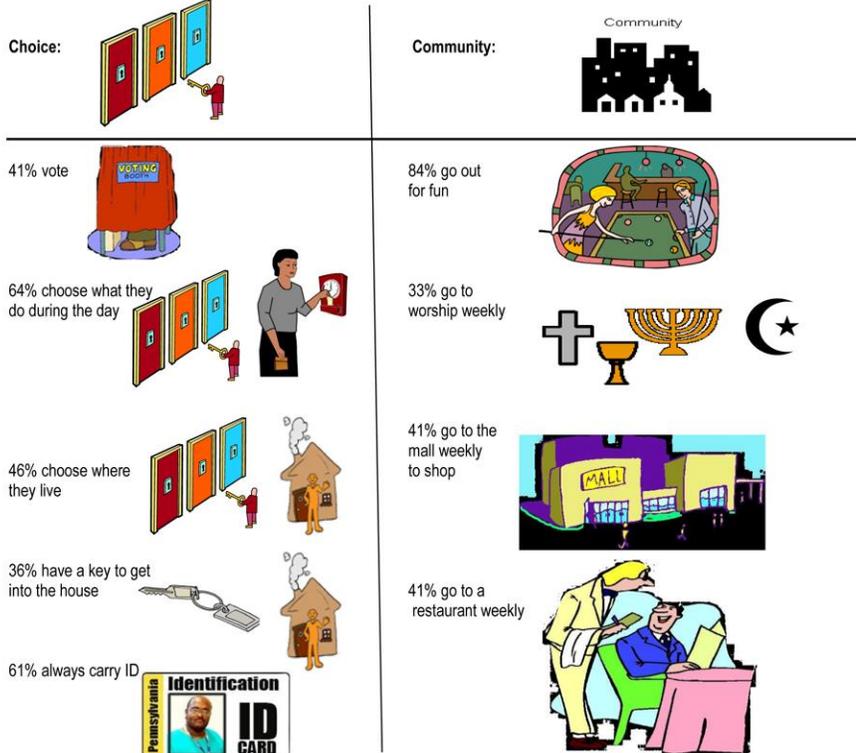
Case Example

The following is an example of how you can use NCI data for quality improvement initiatives. We'll assume that the state director wants a group of stakeholders to review performance data and make recommendations for quality improvement initiatives. You are

the Director of Quality Management and charged with managing this project. How might you begin? Below are seven suggested steps to conducting a quality improvement initiative:

1. Convene a group to examine information and propose quality improvement priorities;
2. Identify important issue(s) in the data findings;
3. Select a Quality Improvement Project with a high likelihood of making a difference;
4. Select intervention strategies and how data will be collected;
5. Apply intervention(s);
6. Measure and analyze any change; and
7. Disseminate findings widely, even if interventions were not as successful as desired.

Step 1. Convene a Group to Examine Information and Propose Quality Improvement Priorities

The stakeholder group may be an advisory body, a quality council, a team of managers, or even a legislative committee. Whatever the group's composition and numbers, good practice suggests making a commitment to having as much transparency as possible and involving those who are directly affected by the conduct of the ID/DD system.

Be clear about what the group's purpose is and how long they can expect to be engaged in this activity. Are they a short -term or a standing committee? Are members required to join due to their work positions, invited to participate by virtue of their viewpoint or experience, or is membership open to anyone? For this case example, let's assume that the group is a Quality Improvement Council that will have representation by ID/DD agency regional managers, service providers, individuals receiving services and family members of people receiving services. Member guidelines have been considered and adopted that establish criteria for membership, rotation on and off the council, voting privileges, and the authority of the council. (See Appendix A for an example of Quality Council guidelines from Georgia's Division of Developmental Disabilities.)

The workgroup has been charged with reviewing NCI data and making recommendations to the state department of ID/DD. The Director of Quality Management is the workgroup's Chair, responsible for facilitating the workgroup, taking minutes and disseminating

information to members. The NCI report for the state was distributed to workgroup members in advance of the meeting along with a document explaining how to use data for quality improvement in community -based service systems. (See Chapter 8: Resources, for a full description of this resource, Work Book: Improving the Quality of Home and Community Based Services and Supports, and a link to download.)

Workgroup members are meeting for the first time to discuss the NCI report and findings regarding the state's performance. After introductions and discussion of the group's purpose, and going over the agenda for this meeting, the Chair leads a discussion of the NCI findings.

Members reflect on what stands out to them. Some members note significant changes in improved outcomes, a few are drawn to areas where performance is not improving, and others focus on performance that is on par with the state and national levels but is still below what should be.

Consumer Quality Council, Fitzmaurice Community Services, Stroudsburg, PA

Step 2: Identify Important Issue(s) in the Data Findings

The Chair asks each member to suggest two target areas for a quality improvement (QI) project. There is clear agreement on what stands out as nearly all suggested areas for improvement receive multiple votes. Below is the initial vote tally among the 11 member group:

Enhance employment in integrated settings:	6
Reduce psychotropic medication use:	6
Expand choice of where to live:	5
Increase choice of where to live:	3
Increase self advocacy for those living with family:	3

Step 3: Determine a QI Project with a High Likelihood of Making a Difference

Three performance areas (integrated employment, choosing who you live with, and psychotropic medications) receive the most votes. To begin moving toward consensus on a target area for a quality improvement initiative, the Chair facilitates a discussion of each proposed area requesting that members use the criteria below to narrow the list to one priority[2]:

- A large number of people are affected by the issue;
- There is a strong likelihood, or evidence exists, that the issue is amenable to improvement;
- Resolving the issue is important for compliance with federal or state requirements;
- Not addressing the issue entails high cost(s) to the system (financial, people's time, etc.) and/or a human toll on individuals receiving services and their families;
- The problem is growing and/or worsening;

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[2] These criteria were excerpted from Louisiana's System Transformation Grant for cross waiver program quality management including development of cross waiver QI stakeholder groups that determined cross program QI projects. See the Appendix for QI project guidelines.

- Improvement is likely in a reasonable amount of time and with a reasonable amount of expense;
- Aligns with other agency priorities.

During discussion, compelling points were made for all the suggested areas for improvement. Increasing the number of people who have real jobs and real wages was seen as optimal, but since the state ID/DD agency has adopted an Employment First policy and progress is noticeable in this domain, members turned to considering the presumed over -use of psychotropic medications. The state is currently performing below the national NCI average on this measure; 58 percent of people were taking at least one psychotropic medication compared to 48 percent across the NCI member states.

Step 4: Select Intervention Strategies & How Data Will Be Collected

Members considered the criteria, and the discussion led to more questions being raised. Among those individuals receiving at least one psychotropic medication, what was the total number of medications prescribed? Two medications? Five medications? Were these medications being used to chemically restrain people? Why are people living with family or relatives taking fewer medications than those in group homes? How was the general health of people affected by taking multiple psychotropic medications? Was this a human rights issue? It seemed that this was an area where the data findings pointed to a performance issue, but it was not clear what led to the problem or what to do about it.

The more questions that came up, the more complex the issue or the "problem" became. The group agreed on the need to address the issue but needed additional time to think through an intervention strategy. As a wrap -up to the meeting, the Chair recapped the main issues that were raised, congratulated members on assessing what the most important findings were and their selection of a QI focus area. She then advised that the next step was to devise a strategy or strategies to improve performance in this area, and this would require another meeting. Once the group agreed upon a recommended strategy to address over use of psychotropic medications, the Chair would then take their recommendation to the state ID/DD Director. As homework, members were asked to review articles or reports on this subject to inform their strategy brainstorming at the next meeting.

Members came to the next meeting excited about making a difference and with information on ways to dig deeper into psychotropic medication use in their state. To prepare for the meeting, the Chair drafted a QI project work -plan using the Work Book: Improving the Quality of Home and Community Based Services and Supports funded by the Centers for Medicare and Medicaid Services (CMS)3 and discussions from the initial meeting. By isolating a problem statement and a goal, the group was able to focus on brainstorming possible interventions, potential barriers and methods to minimize the barriers. The project overview follows:

Title: Appropriate Use of Psychotropic Medications

Problem Statement: People receiving services in this state report taking psychotropic medications more frequently than in other states. The data suggest that a high percentage of people may be taking more than one psychotropic medication, and that some people may be prescribed these medications without having a mental health diagnosis.

Goal: Every person taking psychotropic medication must be significantly benefiting from the medication. Risks, particularly medication interactive effects, are considered when prescribing, and the person or legally identified decision maker provides informed consent at least annually and when changes in medication are recommended.

Benchmark:

The numbers of individuals taking more than one psychotropic medication decreases 5% each year for the next 3 years.

Intervention Strategy:

1. Request additional data from the state on the numbers of people who are taking more than one psychotropic medication.
2. Recommend that the state conduct a medication review at least annually for every person taking more than one psychotropic medication to determine if each medication is

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3 Maureen Booth and Julie Fralich, *Workbook: Improving the Quality of Home and Community Based Services and Supports*, Edmund M. Muskie School of Public Service, University of Southern Maine. Centers for Medicare and Medicaid Services, 2003.

the least restrictive option and is not causing additional harm through interactive effects with other medications or diet.

3. Create a form for individuals to give informed consent that clearly notes benefits and any risk(s) of taking the recommended psychotropic medication(s).

4. Recommend that the state identify individuals on psychotropic medications for whom there is no mental health diagnosis and assess whether medications are being appropriately prescribed.

Step 5: Apply Intervention(s)

Step 6: Measure and Analyze Any Change

In order to assess the success of the QI intervention, the group identified the benchmark listed above. Next, discussion turned to tracking implementation of the strategies and periodically reviewing data to determine if strategies were having an impact. Over the period of implementation, the group agreed to:

- Review the benchmark on at least an annual basis and assess whether additional information and reporting was necessary to assess the success of the strategies;
- Determine if midcourse corrections are required and whether parts of the intervention strategies should be modified;
- Decide if the intervention(s) should be continued or not. If yes, the members would suggest the adoption of specific monitoring and review policies.

Step 7: Disseminate Findings

The members agreed that a yearly report would be made on the results of the intervention regardless of whether or not the results were positive. Members agreed that public reporting was important in order to raise awareness, to promote the use of safeguards, and to invite suggestions regarding other possible solutions to the problem.

How Have NCI States Used the NCI Dataset?

In April 2011, the National Association of State Directors of Developmental Disabilities Services conducted a short survey of how participating states were using NCI data for quality improvement in both practice and policy[4]. State DD agency directors and key program managers from nine (38%) of the 24 participating states responded to the survey[5].

All respondents indicated that NCI data from the various reports and publications were being used for a variety of policy development, quality assurance and strategic planning activities. When asked to identify the various NCI survey reports6[6] that are most helpful for policy development, planning and system change, the majority of the states identified the Adult Consumer Survey, followed by the Adult Family Survey, the Family Guardian Survey and the Child Family Survey reports in equal numbers.

The survey reports identified by state leaders as being the most helpful for quality assurance, remediation and improvement were the Adult Consumer Survey followed by the Child Family Survey, and the Adult Family Survey. About a third of the respondents ranked the Family Guardian Survey and the State/County Survey reports as being most helpful.

One director noted that the state's program goals and objectives are set based on NCI data. Others reported that they are working to develop stronger connections between the NCI data and their state's quality management system.. Other states reported that:

- "We have included NCI as a component of our quality improvement strategy in Appendix H of our newest HCBS waiver applications, but we haven't used the data

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[4] Excerpted from Moseley C. (May 2011). Using National Core Indicators Data to Improve Service Quality and System Performance, Benchmark Progress and Document Change Over Time. Report to the California Department of Developmental Services. NASDDDS: Alexandria, VA.

[5] Responding states: Louisiana, Oklahoma, Maine, Kentucky, Missouri, Washington, Texas, and Arkansas.

[6] NCI Reports: Adult Consumer Survey, Adult Family Survey, Family Guardian Survey, Child Family survey.

for development of performance measures or as evidence for the quality assurances."

- "We've included the NCI data along with other internal monitoring data for reporting health, medication and other issues and this assists us in developing areas for system improvement."

- "We used information from the NCI reports to guide us in further analysis of data we were collecting through our internal systems; for example, additional reports around medication usage were developed based on the results of the NCI data."

As Evidence of the Need for Improvement in State Planning and Implementation

With respect to enhancements in state policy planning, development and implementation, state leaders reported using the NCI data in the following ways:

- Reviewing and setting priorities for quality improvement in areas 5% or more below the national average;
- Sharing system performance data and information with waiver program administrators, providers and stakeholders;
- Targeting areas for remediation and improvement at the state and system levels and sharing the information with stakeholder groups;
- Strengthening service delivery and quality system -wide by providing NCI survey findings to statewide and regional quality councils for review and analysis leading to the identification of quality concerns and the prioritization of service improvement activities;
- Using results from the Adult Consumer Survey Report to provide direction for an intervention to increase the awareness of the Consumer Directed Services option in Texas;
- Using information from the Adult Consumer Survey Report and the Child Family Survey to identify areas for future program interventions and improvements;
- Using the NCI data to support self -directed service initiatives, develop employment opportunities and improve health and medication usage;

- As a platform to identify additional data needs;

- Assisting in the formulation of policy positions;

- Providing information to document compliance with waiver quality assurance requirements, reviewing progress and identifying areas of improvement each year;

- Improving system quality and responsiveness by sharing NCI performance data with the state Developmental Disabilities Council for their review and evaluation. This initiative has been used in the State of Washington for many years and resulted in important policy changes (e.g., with respect to crisis services).

- As Evidence to Guide Program Operation and Practice State DD Agency Directors and managers use NCI data to:
  - Establish annual program goals and objectives.
  - Evaluate the state's performance scores on NCI domains compared to scores in other states. This has been helpful in securing resources, for changing policies and to suggest implementation strategies.
  - Improve program and policy planning.

- Assist state leaders in formulating policy positions and direct staff activities in key areas.

- Facilitate productive discussions and activities with the state's quality advisory council's work on outcomes valued by consumers.

- Address "actionable" items in conjunction with other quality assurance data. For example, comparing employment related NCI questions with actual outcomes has led to continued focus on improving employment outcomes.

- Improve program management by encouraging managers to include findings from the NCI data reports when making decisions about program operation and practice.

To Track Progress on Meeting the CMS Settings and Person-Centered Planning Requirements

The NCI survey tools are designed to assess system performance and track service quality across a wide range of individual outcome; family outcome; health, welfare and rights; and system outcome measures. Because the measures are risk adjusted, states can benchmark performance from one year to the next and compare outcome data with that of other states.

NCI data provide a valuable addition to provider level quality and outcome information gathered by the state ID/DD agency from other sources, such as ongoing state quality assurance monitoring, risk assessment and review and other quality management activities.

Specifically, since January 2014 – when the Centers for Medicare and Medicaid promulgated the HCBS settings and person-centered planning rule -- state DD agency directors have been able to use NCI data from the Adult Consumer, Family Guardian, Adult Family and Child Family Surveys to monitor progress toward realigning services and supports to more closely adhere to the HCBS provisions.

Other Resources

1. *Work Book: Improving the Quality of Home and Community Based Services and Supports* (2003). The HCBS Work Book is a technical assistance guide to assist state agencies with their HCBS quality improvement efforts. It provides step -by -step guidance on how to conduct quality improvement projects within the HCBS waiver program, and illustrates the principles of quality improvement in an easy to use format. The Work Book was developed for the Centers for Medicare & Medicaid Services, Center for Medicaid and State Operations by the Muskie School of Public Service at the University of Southern Maine. Download from The Clearinghouse for HCBS : http://www.hcbs.org/moreInfo.php/doc/653

2. Steven Staugaitis, Ph.D., *General Principles for Using Data as a Quality Improvement Tool: A User's Guide for the Massachusetts DMR Quality Councils*, University of Massachusetts Medical School, E.K. Shriver Center, Center for Developmental Disabilities Evaluation and Research, 2005.

3. Jackson, Beth (2010). *Medicaid HCBS Quality*, National Quality Enterprise. The National Quality Enterprise (NQE) is a technical assistance collaboration providing free consultation to states on quality management in home and community based services. The NQE is funded by the Centers for Medicare and Medicaid Services. This monograph depicts continuous quality improvement as applied to home and community based waiver services. See page 12 for an example quality improvement project. http://www.nationalqualityenterprise.net/nqe

4. *Home and Community Based Services: Quality Management Roles and Responsibilities* (2005). This Discussion Paper was prepared for the Community Living Exchange Collaborative by Maureen Booth, Julie Fralich, and Taryn Bowe of the Muskie School of Public Service at the University of Southern Maine. The Community Living Exchange Collaborative was funded by the Centers for Medicare and Medicaid Services (CMS) to assist states awarded grants from CMS to improve their quality management strategies for home and community based services. This paper focused on 4 questions:

    1) How is quality defined for HCBS?
    2) What is meant by quality management?
    3) How do states develop quality management expertise? and

4) How do states organize their quality management strategies? Link to paper: http://muskie.usm.maine.edu/Publications/DA/HCBS_QMroles.pdf

Link to paper appendices:

http://muskie.usm.maine.edu/Publications/DA/HCBS_QMrolesAppendices.pdf

5. *Discovery Methods for Remediation and Quality Improvement in HCBS* (2005). This Discussion Paper was prepared for the Community Living Exchange Collaborative by Julie Fralich, Maureen Booth, Carolyn Gray, Taryn Bowe and Stuart Bratesman of the Muskie School of Public Service at the University of Southern Maine. The Community Living Exchange Collaborative was funded by the Centers for Medicare and Medicaid Services (CMS) to assist states awarded grants from CMS to improve their quality management strategies for home and community based services. This paper focused on describing what a discovery method is and how discovery translates to evidence reporting, as well as how states move from discovery to action.

http://muskie.usm.maine.edu/Publications/DA/HCBS_DiscoveryMethods.pdf