NATIONAL CORE INDICATORS

Ten Years, Twenty Six States and Countless Achievements

This short report describes the evolution of the National Core Indicators over the past 10 years, the accomplishments of the initiative, and challenges and opportunities going forward

National Association of State Directors of Developmental Disabilities Services

Human Services Research Institute

November 7, 2007

National Core Indicators (NCI), a joint venture between the National Association of Directors of Developmental Disabilities Services and the Human Services Research Institute was launched 10 years ago in 1997. Since that time, the conduct of NCI has stimulated quality improvement initiatives around the country and has had a significant impact on how people in the field of developmental disabilities think about performance measurement. During these 10 years, data from NCI have been used to support state's 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 to form the basis of core reports on subjects ranging from health to family support to self-determination.

States participating in NCI have contributed to the largest cache of current information on people with intellectual and developmental disabilities in the country – a database that now exceeds 10,000 individuals. This rich source of information is increasingly being mined by leading researchers, such as Dr. Charlie Lakin. In collaboration with NASDDDS and HSRI staff, Dr. Lakin lead the recent CMS funded 6 state study that contrasted the lives of people in waiver funded services versus those living in ICF/MRs. Several articles that detail the findings of those analyses will soon be published in *Intellectual and Developmental Disabilities*.

As we go forward, it is our hope that participation in NCI will continue to grow, that the results from NCI will inform national policy, that collaborators from other DD stakeholder groups will increase, and that the indicators and measures that comprise NCI will emerge as national benchmarks.

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INTRODUCTION

The emergence of National Core Indicators coincided with a number of trends that coalesced nationally to focus attention on the measurement of performance. First, as public systems became increasingly complex, managers began to search for ways to assess the conduct of systems absent the ability to be constantly in the field observing services. Second, improvements in software and hardware opened up the possibility of aggregating information about the system and analyzing it in more efficient ways. Third, the clamor to view the performance of services and supports through the measurement of actual outcomes for people had grown into a roar. Finally, state intellectual and developmental disabilities systems had become large and visible budget items that required more than anecdotes to justify.

In 1997, 15 states convened to discuss the possibility of reaching consensus regarding the scope and content of a performance measurement scheme – a scheme that could be shared across states. Directors and staff from these 15 states worked hard to identify the major areas of performance (e.g., health, welfare and rights; system performance, etc.), the sub-domains of each, indicators and measures and data sources.

The materials that grew out of that deliberation are impressive and reflected a pioneering effort to standardize expectations and to subject individual state performance to comparisons with other states. While managers in other fields have attempted to develop similar guidelines, the products were limited and many fell into disrepair over time.

Another strength of NCI is that the content was not dictated at the federal level but was generated directly from the states. The funding for the effort came and continues to come primarily from the states. Federal funds have played a small role over the years including a grant from the Administration on Developmental Disabilities in the early years as well as CMS support more recently for an analysis of the consumer data in 6 states to ascertain any differences in outcomes among those living in Home and Community Based Waiver settings contrasted with outcomes of people living in Intermediate Care Facilities for People with Mental Retardation.

National Core Indicators began with the participation of 15 states as part of the original steering group. Representatives of those states reached consensus on7 critical domains, 61 indicators and data sources and protocols. Seven members of the steering group agreed to field test the consumer survey and other protocols. Those pioneering states were:

Alabama
Arizona (pilot state)
Colorado
Connecticut (pilot state)
Florida
Michigan
Missouri (pilot state)
Nebraska (pilot state)
New York
Oklahoma
Pennsylvania (pilot state)
Rhode Island
South Carolina
Vermont (pilot state)
Virginia (pilot state)

The fact that individual states as well as NASDDDS were present at the initiation of NCI and at each step along the way has meant that managers of public intellectual and developmental disabilities services have a sense of ownership of the process and a commitment to respond to the results.

NCI MILESTONES

The changes that have taken place in NCI over the past 10 years mirror those in the field of quality management generally. When NCI began, it was called “Core Indicators Project” and was not initially viewed by many states as an integral part of their quality management systems. Over time, the collection and analysis of the data moved to the center of state quality management systems and the effort moved out of the realm of “project” into a more fully integrated and ongoing process.

> The quality of our expectations determines the quality of our actions
>
> A. Godin

As the relevance of NCI to state quality management systems increased, so did the number of states. From a core of 7 states in 1997, the total reached 21 states and the Regional Center of Orange County by 2003. Today, in 2007, there are 25 states and 4 California Regional Centers participating. There are also additional states that have asked for more information about the implications of participation.

Given that NCI now numbers more than half of the states as participants, the possibilities and opportunities to use the data for national policy analyses and conversations are increasing. In recognition of the power of the information, HSRI and NASDDDS staff recently met to broaden the vision of NCI going forward.

- NCI will influence national and state policy – federal and state legislation and rule making are informed by NCI findings
- NCI will be used to improve practice at state level – all states participate and use NCI in Quality Management Programs
- NCI will add knowledge to the field – conduct research; collaborate with other researchers; publish findings
- NCI will be used for the Association’s strategic planning and priority setting

WHAT DOES NCI MEASURE?

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 each 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.

The indicators are divided into domains (such as Health, Welfare, and Rights). You can download the full list of indicators at www.hsri.org/nci. In order to reflect the outcome anticipated by the domain, a concern statement was developed (e.g., “people have support to find and maintain community integrated employment”). In working with the original steering group, HSRI and NASDDDS staff facilitated workgroups and asked state representatives to think of concrete ways in which they would know that an outcome has been achieved in their systems. If integrated work is an end goal, then the indicators for that area should include the numbers of people earning a competitive wage, a comparison between those in sheltered versus supportive work, and so forth.

For each indicator, it was necessary to identify a data source or protocol that could be used across states. Because of the numbers of indicators associated with outcomes for people, the first product that needed to be designed was a consumer survey. With the help of a technical advisory group drawn from the states, a survey was developed, tested and launched. That survey, which continues to be updated as new priorities emerge, now generates critical information on over 10,000 people with intellectual and developmental disabilities receiving publicly supported services. To view the most recent consumer survey results, go to: http://www.hsri.org/nci/index.asp?id=reports.

Other surveys include 3 mail surveys for families with adults as well as children, a provider survey that captures staff turnover, and other guidelines and definitions for collecting a range of systems level data. There are also supplements developed by participating state that are available to probe additional health issues and case manager concerns.

SELECTED FINDINGS

In addition to the regular reports generated by NCI describing findings from the consumer and family surveys, staff turnover, mortality, and other issues, HSRI/NASDDDS have also circulated periodic data briefs on a range of topics including attitudes and experiences of families with members living at home versus the community, access to health care, and people with dual diagnoses.

> **Quality is never an accident; it is always the result of high intention, sincere effort, intelligent direction and skillful execution.**
>
> **William A. Foster**

NCI DOMAINS

Consumer Outcomes

- Work
- Community Inclusion
- Choice and Decision-Making
- Self Determination
- Relationships
- Satisfaction

System Performance

- Service Coordination
- Family and Individual Participation
- Service Utilization
- Financial Level of Effort
- Cultural Competency
- Access

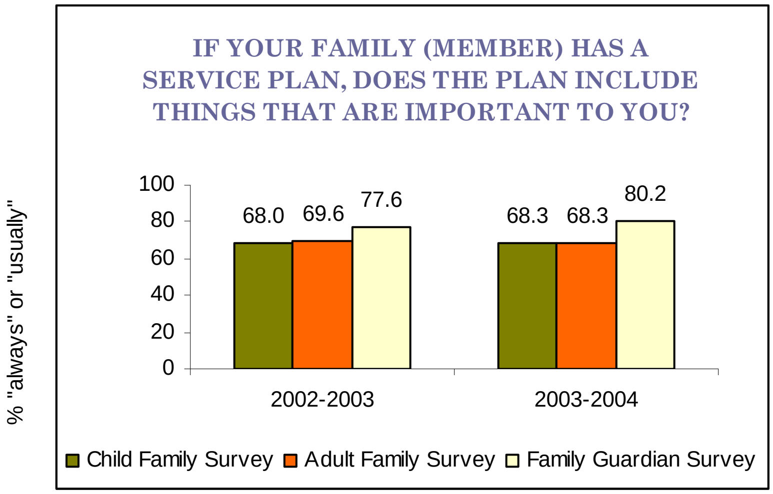
Health, Welfare and Rights

- Safety
- Health
- Medications
- Wellness
- Restraints
- Respect/Rights

Staff Stability/Competency

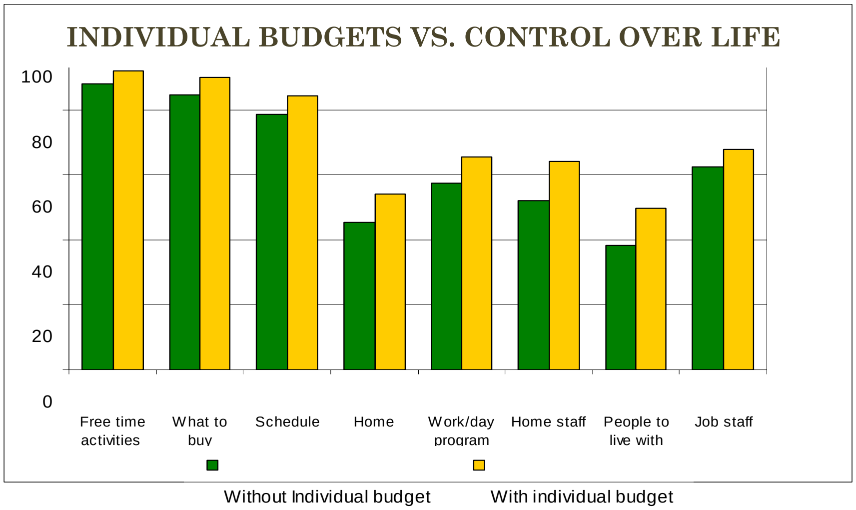
Family Support

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

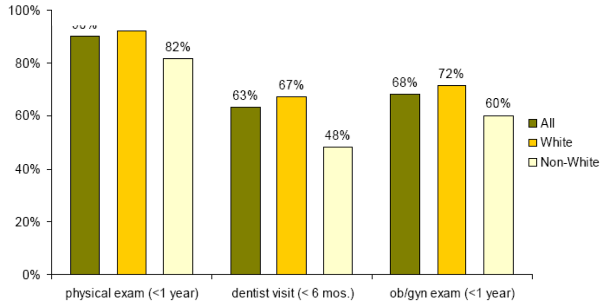


The figure on the left provides information from surveys conducted during 2002/3 and 2003/4, contrasting the levels of satisfaction of families of people living at home with those of families whose family member was living outside the home. The chart above and others in the NCI Data Brief: Family Support issued in August 2007, suggested that families with members living out of the home were generally happier with various aspects of the services and supports they were receiving. One of the brief's concluding observations was: “Overall, why do families of adults in out-of-home placements (who have <u>less choice and control</u>), feel <u>more informed</u> and satisfied with the planning process, <u>more connected</u> to their communities, and <u>more satisfied</u> with their services and supports?”

The chart below, which appeared in the NCI Data Brief Self-Determination and Consumer Outcomes, published on March 10, 2004, suggests the strong connection between individuals who had an individual budget and their feelings of control over a range of critical areas of their lives. People's ability to make choices was even more prominent among those individuals who had individual budgets *and* the services of a fiscal intermediary.



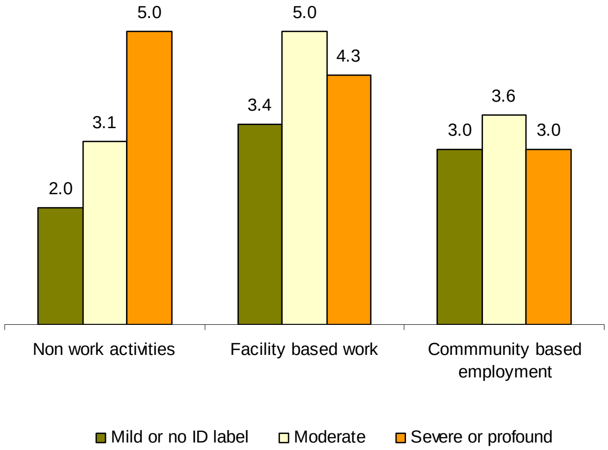
HEALTH CARE ACCESS BY RACE



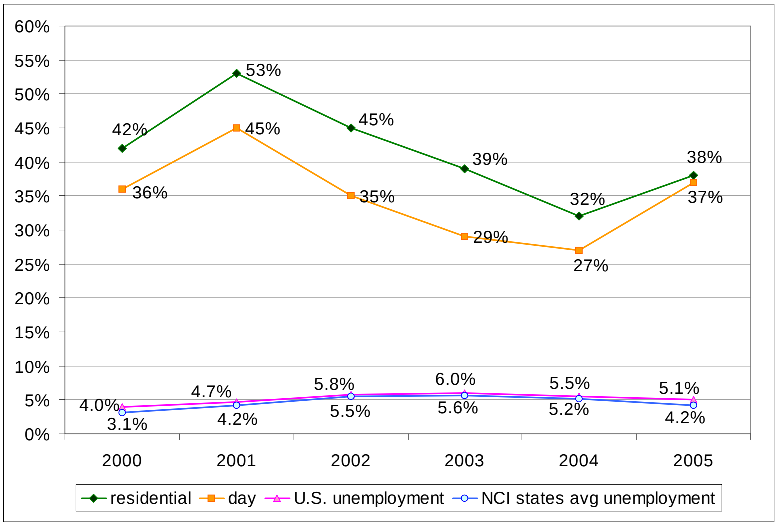
The chart on the left on Health Care Access was drawn from the NCI Data Brief: *Factors Influencing Access to Health Care, February 2005.* It shows the disparities in access to health care between white and non white individuals with intellectual and developmental disabilities receiving services.

The chart on the right, Median Length of Employment, is provocative on many levels. First it underscores the fact that people with more severe disabilities are disproportionately involved in non-work activities. Further, there are a significant number of individuals with moderate disabilities who have spent a median of 5 years in facility based work.

MEDIAN LENGTH OF EMPLOYMENT (BY YEARS)



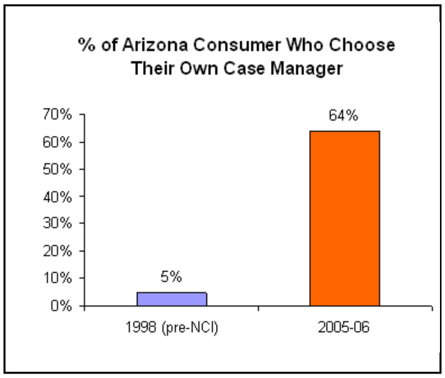
TURNOVER VERSUS UMEMPLOYMENT RATES



The chart, at left, Turnover Versus Unemployment Rates, is drawn from NCI staff turnover data and indicates the clear inverse relationship between U.S. and NCI state unemployment rates and turnover rates among residential and day program staff.

HOW DO STATES USE THE INFORMATION THAT NCI GENERATES?

NCI states have used their state and national data to bring about a range of changes in training, technical assistance, and policy. Over the past 10 years, NCI data has been used to reform incident management systems, improve family support, and influence the design of information systems.



In Arizona, for example, the state used the consumer survey data to track changes in people's ability to choose their case manager. In 1998, when the DDD discovered that only 5% of survey respondents chose their own case manager, the division focused their efforts on developing more flexible case management models. By 2005-06, 64% of participants reported that they chose their case manager.

Alabama used the NCI consumer data as part of the data collection requirements in the *Wyatt v. Sawyer* settlement. The court received data on pre and post levels of satisfaction among Partlow Developmental Center residents who moved to community settings. Using findings from the NCI consumer survey, the state Division of Mental Retardation identified the need for improvement in choice and decision-making. In response, the division developed a five year plan to increase the numbers of person centered planning facilitators and launched an initiative to provide *Social Role Valorization* training.

Several states have used the data to improve the responsiveness of the public system to consumers of services. In Vermont, the state moved to improve accessibility of information on grievances when a significant number of consumers reported that they were unfamiliar with the process. At the Regional Center of Orange County (RCOC), young families reported much less involvement in their communities and more dissatisfaction with the information available to them regarding their service and support options. The center's staff took the following steps:

- Created Early Start Survey to develop a deeper understanding of the needs of young families;
- Conducted staff training for typical childhood development for children 0-3 and over 3 in order to influence staff expectations;
- Provided more support/counseling to families of children under 18
- Continually developing relationships with city recreation departments, etc. to facilitate more opportunities for community activities
- Developed RCOC Newsletter - "Dialogue" to provide a vehicle for the dissemination of information

The Massachusetts Department of Mental Retardation (2004) used performance data from NCI and state data sources as the cornerstone of their annual quality assurance report.

Finally, an increasing number of states – including Massachusetts, Washington and Wyoming, are using NCI data to craft their evidence reports to the Centers for Medicare and Medicaid Services as well as to complete Part H of the new Home and Community Based waiver application.

INCREASING PUBLIC SECTOR EXPECTATIONS FOR OUTCOME DATA

The nature, scope and extent of publicly financed services for individuals with developmental disabilities have changed significantly over the past ten years. Indeed, the pattern of developmental disability service delivery has been one of constant expansion since the late 1970s. Between 1977 and 2005, for example, the number of residential settings for persons with ID/DD increased by more than thirteen fold as the total number of residents grew by sixty-six percent.

Interestingly, although the number of people receiving residential supports increased during this period, the size of the residential settings in which they live decreased significantly. The average number of individuals per residential setting dropped precipitously from 22.5 in 1977 to 2.7 in 2005. Not only are fewer people living together in congregate settings, but increasing numbers are being supported in their own homes or in those of family members. In 2005, for example, over 56% of all individuals with developmental disabilities receiving residential supports received them "in or out of" their family homes (Prouty, R.W., Smith, G., & Lakin, K.C., 2006; Coucouvanis, K., Prouty, R.W., & Lakin, K.C., 2006). One could argue that at a national level, the traditional bricks and mortar service delivery system has changed to one of individual and family support.

The shift toward small community residential settings, integrated employment and dispersed systems of home-based support has required significant changes in service design, oversight, funding and management. These changes have exerted considerable pressure on state developmental disabilities agencies struggling to respond to increased needs and demands for program flexibility, personalized supports, self-directed services and individualized budgets. The move toward smaller, more dispersed settings and individually tailored supports challenged the capacities of traditional management information systems and brought increased calls from state and federal policymakers for timely and accurate data documenting the performance and outcomes of community supports. As noted above, this need prompted NASDDDS and HSRI to develop the National Core Indicators to assist member state agencies measure and track key performance variables in the mid-1990s.

Over the past ten years, federal initiatives have increased states' needs for accurate, valid and reliable system performance data In 2001, for example, the Department of Health and Human Services Centers for Medicare and Medicaid Services (CMS) implemented a new waiver review protocol designed to assess, among other things, states efforts to assure and improve service quality. That same year CMS, in collaboration with NASDDDS and HSRI, performed a national inventory of the quality assurance practices of state DD programs and, in 2002, launched the Quality Framework to provide guidance to states on the four components of an effective quality assurance process: design, discovery, remediation and improvement.

> With these multi-state data sets we can look at levels of disability, ethnic minorities, age groups and other sub-populations in ways we just can't do with data sets that don't have such a large sample.
>
> Charlie Lakin

During the following year, a GAO report on waiver quality recommended that CMS increase its oversight of home and community based services furnished by state Medicaid waiver programs, and provide increased direction to states on program quality. In 2006, CMS issued a new draft Medicaid waiver application template that clarified its expectations regarding waiver program design and operation. The new application format included a key provision requiring states to implement comprehensive quality management strategies to demonstrate compliance with all mandated waiver assurances. These new federal requirements represented a significant departure from previous practice. Now, CMS intended to draw conclusions regarding the effectiveness of a state's quality management strategy based on evidence. Specifically, the presence or absence of objective, measurable data demonstrating that the state is strengthening the quality of Medicaid waiver services and supports through a continuous process of discovery, remediation and improvement. To respond to the new evidence-based evaluation protocol, CMS recommended that states consider the use of standardized tools and protocols, such as the National Core Indicators, to gather and analyze information on waiver participants' outcomes and satisfaction with the services they receive.

FUTURE NEEDS AND TRENDS

CMS' interest in evidence-based quality management strategies for waiver programs reflects a broader trend at both the federal and state levels to quantify system performance outcomes and accomplishments. The Deficit Reduction Act of 2005, for example, included provisions requiring the federal Agency for Health Care Research and Quality (AHRQ) to identify existing measures that could be used or modified for the purpose of assessing Medicaid Home and Community Services. In response, AHRQ launched the Measure Scan Project to perform a comprehensive review of existing measures which could be used as a baseline for the future development of additional performance indicators of HCB services. The overall intent of the DRA directive is to develop program performance and individual functioning and satisfaction measures that can be used to assess HCBS service quality and outcomes across states and beneficiary populations.

CMS expressed similar interest in identifying common measures for assessing individual satisfaction and service related outcomes for persons transitioning from institutional settings to home and community based services under its Money Follows the Person (MFP) state demonstration initiatives. This past fall, the federal agency contracted with NASDDDS to perform a survey of state developmental disabilities agencies involved in the MFP demonstrations to determine the nature and type of assessment instruments used to evaluate and track individual and system performance. The information was used to inform the development of instruments and procedures for assessing the impact of community placement under state MFP initiatives.

These and other federal initiatives reflect the need for effective, empirically based valid and reliable system performance measures.

NCI MAKES SENSE

The National Core Indicators provide a sound foundation for documenting and tracking the impact of HCB waiver services. Consisting of approximately 100 consumer, family, system, cost, and health and safety indicators, each measure tracks the effectiveness, utilization and outcomes of services provided to individuals with developmental disabilities. The NCI indicators are closely aligned with the CMS Quality Framework. Many of the states currently participating in the NCI program find that the data gathered through the Consumer, Family and Case Manager Surveys, as well as other NCI instruments, can play a significant role in documenting the quality and appropriateness of HCBS waiver services and in pinpointing areas in need of improvement. States are using NCI data in combination with other sources of information to assist in strategic planning and program development, respond to CMS requirements for effective quality management strategies, set quality improvement and management priorities, build budget requests, and gather key individual and systems data on staffing, incidents, and mortality. The purpose of the NCI program is to:

- Establish a nationally recognized set of performance and outcome indicators for developmental disabilities service systems
- Develop reliable data collection methods and tools.
- Report state comparisons and national system level performance benchmarks.

Managed in collaboration with participating state developmental disabilities, NCI is well positioned to continue to grow and refine its set of valid and reliable outcome indicators to meet state's needs for empirically sound data on system performance. Future activities will further analyze and explore the information included in the extensive National Core Indicators database. In the months and years ahead, the program will support states' efforts to develop and embed effective performance measurement tools into their quality management systems; improve the capacity of public managers to use, display, and disseminate system performance information; expand the participation of self-advocates and families in peer-interviewer training and the development of accessible report formats; and strengthen the ability of the NCI to indicators to identify and track self-directed service outcomes.

NATIONAL CORE INDICATORS RECENT PUBLICATIONS

Becker, H., Roberts, G., Morrison, J., Silver, J., and Taub, S. (2004). Recruiting People with Disabilities as Research Participants: Challenges and Strategies to Address Them. Mental Retardation, 42, 471-475.

Bradley, V.J. & Moseley, C. (2007). Perspectives: National Core Indicators: Ten Years of Collaborative Performance Measurement. Intellectual and Developmental Disabilities, 45, 5: 354-358.

Freedman, R.I. & Chassler, D. (2004). Physical and Behavioral Health of Adults With Mental Retardation Across Residential Settings. Public Health Reports, 119, 401-408.

Havercamp, S.M., Scandlin, D., & Roth, M. (2004). Health Disparities Among Adults with Developmental Disabilities, Adults with Other Disabilities, and Adults Not Reporting Disability in North Carolina. Public Health Reports, 119, 418-426.

Lakin, K.C., Doljanac, R., Byun, S., Stancliffe, R.J., Taub, S., & Chiri, G. (in press). Choice-making Among Medicaid Home and Community-Based Services (HCBS) and ICF/MR Recipients in Six States. American Journal on Mental Retardation.

Lakin, K.C., Doljanic, R., Byun, S., Stancliffe, R.J., Taub, S., & Chiri, G. (in press). Factors Associated with Expenditures for Medicaid Home and Community Based Services and ICF/MR Services for Persons with Intellectual/Developmental Disabilities. Intellectual and Developmental Disabilities.

Lakin, K.C., Doljanac, R., Taub, S., Chiri, G., & Byun, S. (in press). Adults with Dual Diagnoses of Intellectual and Psychiatric Disability Receiving Medicaid Home and Community-Based Services (HCBS) and ICF/MR Recipients in Six States. MentalHealth Aspects of Developmental Disabilities.

Neely-Barnes, S.L., Graff, J.C., Marcenko, M.O. & Weber, L.A. (in press). Family decision-making: Benefits to persons with DD and their family members. Intellectual and Developmental Disabilities.

OTHER PUBLICATIONS

Coucouvanis, K., Prowty, R.W., & Lakin, K.C. (2006). Services provided by state and nonstate agencies in 2005. In Prouty, R.W., Smith, G., & Lakin, K.C. (Eds). Residential services for persons with developmental disabilities: Status and trends through 2005. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

Prouty, R.W., Smith, G., & Lakin, K.C. (Eds). (2006). Residential services for persons with developmental disabilities: Status and trends through 2005. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

NATIONAL CORE INDICATORS

PARTICIPATING STATES

Alabama

Arkansas

Arizona

Connecticut

Delaware

Georgia

Hawaii

Indiana

Kentucky

Maine

Massachusetts

Missouri

New Jersey

New Mexico

North Carolina

Oklahoma

Pennsylvania

Regional Center of Orange County, California

Rhode Island

South Carolina

South Dakota

Texas

Vermont

Washington

West Virginia

Wyoming