



Using NCI-IDD and NCI-AD Data to Assess Progress with Person-Centered Requirements in the CMS Settings Rule

A Hypothetical Case Study

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In March 2014, the Centers for Medicare and Medicaid Services issued the Home and Community-Based Services (HCBS) Settings Final Rule (the “Settings Rule”)¹ which set out new expectations about the character of residential and day programs as well as the conduct of person-centered planning.

This case study provides a hypothetical example of how one state² in the US used National Core Indicator (NCI) data to monitor person-centered planning and practices and alignment with the Settings Rule.

In that state, a group representing waiver participants was formed to monitor the implementation of the Rule to ensure the aspirations in the Rule would continue to be honored even beyond the final compliance date. The group, the Settings Rule Stakeholder Committee, was composed of a range of stakeholders including people with disabilities, older adults, family members, providers, and representatives of advocacy organizations. In the first several years, the group concentrated on ensuring that the state agencies for intellectual and developmental disabilities (IDD) and aging and disability (AD) were systematically reviewing residential and day services, identifying isolating and segregated settings, singling out noncompliant settings for heightened scrutiny, and ensuring that noncompliant settings were replaced. The group also reviewed individual monitoring reports regarding whether service recipients were afforded the choices, privacy and other stipulations required in the Rule. By 2019, the goals in the state’s transition plan regarding HCBS settings were almost fully achieved.

However, members of the group noted that there had not been as much scrutiny of compliance with the Rule requirements regarding the individual planning process and other person-centered practices. The overarching concept in the Rule was that the supports planning process should be driven by the person. It further stipulated that employment and self-direction should be part of the planning conversation. Some of the major requirements to implement these goals stipulate that:

The support plan development process must...

- Include the people chosen by the person
- Take place in the location chosen by the person
- Provide information regarding the plan in language accessible to the person
- Offer choices to the person regarding the services and supports received and from whom
- Provide a method for the person to request updates to the plan
- Include individually identified goals and preferences related to relationships, community participation, employment, income and savings, healthcare and wellness, education and others
- Explore the possibility of self-direction

¹ [Home & Community Based Services Final Regulation | Medicaid](#)

² This case study uses an amalgam of state experiences to provide a narrative example.

Identifying a Data Source

These concerns were communicated to the state IDD and aging and disability agencies. In response, state staff suggested that one way to assess whether the CMS planning requirements were present in the lives of service recipients was to review the results of the National Core Indicators® Intellectual and Developmental Disabilities (NCI-IDD) In-Person Survey (IPS) and National Core Indicators® Aging and Disabilities (NCI-AD) Adult Consumer Survey (ACS), since these surveys include indicators of person-centered planning and practice. State staff noted the while NCI data cannot substitute for actual monitoring and follow-up on the individual level due to the anonymity of the survey, the data can provide a picture of what is occurring at the system level.

The group reviewed the [NCI-IDD indicators](#) and the [NCI-AD indicators](#) and selected those listed in the table below. The group determined that these indicators would demonstrate the level at which person-centered planning and practices were present statewide.

NCI-IDD	NCI-AD
The percentage of respondents who report that their case manager/service coordinator asks them what they want	The percentage of respondents whose case manager talked to them about services that might help with their unmet needs
The percentage of respondents who report that they can contact their case manager/service coordinator when wanted	The percentage of respondents who can reach their case manager when they need to
The percentage of respondents who report having understood what was being talked about at the last service planning meeting	The percentage of respondents who have access to information about services in their preferred language
The percentage of respondents who report that the service planning meeting included people they wanted to be there	The percentage of respondents whose service planning meeting included the people they wanted to be there
The percentage of respondents who report having been able to choose what services were included in their service plan	The percentage of respondents who can choose what services they receive
The percentage of respondents who report that their service plan includes things that are important to them	The percentage of respondents whose services meet their needs and goals
The percentage of respondents who report that they know who to talk to if they want to change services	The percentage of respondents who know whom to contact if they want to make changes to their services
The percentage of respondents who report that they want a job who are reported to have a related goal in their service plan	The percentage of respondents who would like a job
The percentage of respondents reported to be using a self-directed supports option	The percentage of respondents using a self-directed supports option

Results

State quality assurance staff compiled charts and graphs showing the results of the 2020-2021 data cycle for both NCI-IDD and NCI-AD. While most of the data demonstrated that a high percentage of respondents had experienced a person-centered supports planning process, there were two measures that posed substantial concern. One was the proportion of people **using a self-directed supports option**. Among people with IDD in the NCI-IDD IPS state sample, only 5% were self-directing—well below the NCI-IDD average of 12%. For older adults and people with physical disabilities, as demonstrated in the NCI-AD ACS data, the proportion was only 4% while the NCI-AD average was 21%.

The second measure that stood out was that few people **knew whom to contact if they wanted to request changes in their services**. Only 50% of respondents to the NCI-IDD survey knew whom to ask if they wanted to change something in their services (compared to an NCI-IDD average of 83%), and 53% of older respondents to the NCI-AD knew whom to contact for changes (compared to an NCI-AD average of 80%).

These two areas were identified as priorities, and the Stakeholder Committee agreed to pursue quality improvement strategies to address these concerns.

Understanding the Findings

Before meeting to decide on policy recommendations, the Stakeholder Committee made sure they were interpreting the findings correctly and that the data were representative of the state. They asked the state whether there were any events during the survey period that might have skewed the results (e.g., regulatory changes). Were the respondents representative of service recipients statewide? Were the results significantly different statistically than the NCI-IDD and NCI-AD averages? Do the findings square with other statewide data and sources of information? The results of this review satisfied the members of the group that the data were being understood and interpreted accurately and could be used as a basis to proceed with an improvement plan.

The group adopted the [“Plan, Do, Study, Act”](#) model to guide their quality improvement initiative.

Quality Improvement Strategy (Plan)

The Stakeholder Committee convened two task groups to explore ways to expand the use of self-direction and to increase service recipient awareness of how to change their services if desired.

The two task groups made the following recommendations to the state’s IDD and aging and disabilities agencies.

On Self-Direction:

1. Strengthen self-direction by sponsoring state legislation emphasizing that every participant should be offered the ability to self-direct
2. Develop training materials in plain language for older adults, people with disabilities, and families regarding the self-direction option
3. Create videos highlighting the experiences of people who are self-directing
4. Present on self-direction at state aging and disability conferences providing examples of the benefits of self-direction
5. Work with educators to introduce the possibility of self-direction during the transition from school to adulthood, or even earlier
6. Simplify the self-direction paperwork burden for case managers and for people who are self-directing

On Increasing Knowledge Regarding How to Make Service Changes:

7. Provide user-friendly material during annual planning sessions regarding how to request a change in services given changing needs
8. Ensure that the materials developed regarding service changes are accessible to people with limited English proficiency and can be easily understood by families and people receiving services
9. Require case managers to share contacts and contact information for service changes with people receiving services during routine check-ins and service planning meetings, such as annual and quarterly meetings
10. Circulate material on the process of securing service changes to self-advocacy groups, family caregiver organizations, and other aging and disability advocacy groups
11. Review the waiver performance measure data source to ensure data is showing the most accurate extent of compliance or noncompliance

Implementing the Strategy (Do)

Self-Direction

Based on a review of self-direction legislation from other states, consultation with public managers in charge of self-direction in other states, and focus groups of families and people who were self-directing, the Stakeholder Committee developed the provisions of a bill to be introduced in the state legislature. To mobilize support, the group used the [Toolkit for Stakeholder Asset Mapping](#) and identified potential allies for the legislation across the state. The proposed bill required the development of individual supports budgets for people self-directing, annual reports from the state IDD and aging agencies regarding the numbers of

people self-directing, and a mandate that all service recipients should be introduced to self-direction.

The state IDD and aging and disability representatives agreed to work together to develop videos and other related materials showcasing the experiences of individuals who are self-directing. They also agreed to share these materials with staff at the state Department of Education for use by special education teachers and counselors working with people transitioning out of school. They shared these materials with focus groups to get suggestions from service recipients and family members. Working with the Medicaid agency, the state collaborators reviewed the self-direction provisions in the waiver to see whether there was a need to amend the waiver to make the self-direction option more accessible. They also convened a group of case managers/care coordinators to review the paperwork requirements for self-direction and developed a new simplified manual for both programs.

Further, with the help of statisticians at the University School of Public Policy, the Stakeholder Committee reviewed data on the characteristics of people who were self-directing and found that service recipients who were non-white, had more complex health or disabilities, or came from low-income families were less likely to be self-directing. They shared the analysis with state representatives who agreed to develop guidelines for case managers/care coordinators that spelled out the importance of introducing the self-direction option to all service recipients and described how to develop culturally sensitive outreach to ethnic and racial minorities.

Finally, the Stakeholder Committee convened a statewide conference on self-direction with resources contributed by the state IDD, aging, disability, and education agencies as well as the Developmental Disabilities Council and Aging and Disability Resource Centers. The conference included panels of people self-directing, case managers/care coordinators, direct support professionals, families, advocates, and others interested in self-direction. The conference also provided an opportunity to rally support for the self-direction legislation.

They kicked off the rollout of the effort with “Self-Direction Awareness Week.” A recognizable logo was designed for the self-direction program in the state. State agencies, DD councils, and other relevant groups posted messages to their social media accounts discussing self-direction. The media was involved to document and publicize the effort. Items with relevant information and phone numbers were given out to interested people and groups (refrigerator magnets with important telephone numbers, etc.).

Increasing Knowledge on How to Make Service Changes

The state IDD agency and aging and disability agency worked with the Medicaid agency to review data on service changes collected as part of the HCBS waiver

assurance evidence. Data were collected through a sample plan review to determine whether significant status changes (such as residence change, getting a job, etc.) resulted in service changes. Though these data did not relate specifically to whether service recipients knew how to request changes, it indicated where changes in services should have been made regardless of the reason. The data showed there was variation within regions in the state regarding compliance with the waiver requirement that services in the plan should change when recipient needs change. State staff used that information to prioritize case management training about informing service recipients on how to secure service changes as well as other person-centered planning requirements to specific regions. That training was eventually rolled out statewide.

In conjunction with advocacy organizations and self-advocates, state staff developed user-friendly materials regarding the process for making service changes. They also took the opportunity to include other expectations that the service recipient should have regarding the planning process as outlined in the Rule—including materials in plain language, arranging the meeting at a convenient location, being able to choose who is present, and other guidelines.

Finally, based on their collaboration with the Stakeholder Committee and the focus on person-centered approaches, state staff from the two operating agencies were interested in reviewing their overall policy framework to determine where they could enhance person-centered practices. They chose the [NCAPPS Person-Centered Practices Self-Assessment](#) to conduct the review. As a result of the assessment, a number of regulatory and policy changes were instituted.

Monitoring the Quality Improvement Strategy (Study)

To track whether the strategies proposed resulted in system change, state officials agreed to continue to track changes by reviewing the NCI-IDD and NCI-AD data. They also agreed to add state-specific questions to the surveys to measure the effectiveness of the specific initiatives and to continue to monitor the other indices of person-centered planning and to report back every year regarding the sustainability of the change. To help them to identify additional indicators, the Stakeholder Committee recommended [NCAPPS Person-Centered Thinking, Planning and Practice: A National Environmental Scan of Indicators](#).

Revisiting the Quality Improvement Initiatives (Act)

Over the next two years, the Stakeholder Committee continued to monitor whether the reforms put in place had the intended effect. They also followed the implementation of the new self-direction law that passed one year earlier by examining outcomes and scrutinizing implementation. With respect to knowledge among service recipients regarding how to change their plans, the NCI-IDD and NCI-AD data over two data cycles showed that each year the state percentages moved closer to the national averages. With respect to self-direction,

the numbers of participants grew very slowly. The Committee created a workgroup to explore what could be done to increase the uptake in self-direction. The workgroup created a survey of case managers/care coordinators to identify potential issues in the implementation of self-direction. The workgroup also reviewed answers to some of the state-specific supplemental questions added to NCI-IDD and NCI-AD regarding self-direction. Both the survey of case managers/care coordinators and respondents to the case manager/care coordinator survey and two NCI surveys emphasized the continuing complexity of the process as a barrier to self-direction. As a result, state staff revised the self-direction manual and identified additional procedures that could be eliminated or made more user-friendly.

The Stakeholder Committee also congratulated the state on increases across the person-centered indicators in the two NCI surveys that they credited to the policy review carried out as part of the NCAPPS self-assessment.

Conclusion

The state continued to monitor outcomes of these initiatives, understanding that the outcomes of policy change can take time to be evident. In the meantime, the state continued to make small changes to the initiatives and to use various methods to study the results. In this way, the state agencies made strides in transforming into systems that support people to reach their individual goals and live the lives that they desire.

This document is publicly available for use in the administration and improvement of supports for older adults and people with long-term service and support needs. All uses should acknowledge the developers of this content.

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