

*Using NCI data to identify, address,
and track important issues*

Forty-six states, the District of Columbia, and several regional agencies currently participate in the National Core Indicators, using a standardized suite of surveys to assess and monitor the quality of long-term services and supports and the satisfaction of those who receive them.

All told, the survey sample from the 2014-15 data collection period included:

- **25,820** adults with IDD
- **5,595** families of adults with IDD who live in the family home
- **4,423** families of adults with IDD who live outside the family home
- **3,319** families of children with IDD who live in the family home

Guardianship Reform

Emerging Issue

The case of a young woman with an intellectual disability who, after living in the community and working at an office job, was placed in an ICF/DD by her parents, created a statewide conversation on the issue of guardianship and individual rights. As a result of litigation on behalf of the young woman, a judge found that the guardianship was not justified, and allowed the plaintiff to return to the community. Following the decision, the young woman has been presenting at conferences in the state and has increased the awareness of the sometimes arbitrary nature of guardianship. The publicity surrounding these events prompted the state intellectual and developmental disabilities agency to convene a Guardianship Working Group to explore alternatives to guardianship. The group included self-advocates, families, case managers, legislators, legal advocates and other stakeholders. At the first meeting, the members decided that they needed to build a case for reform of guardianship and asked the state to provide some data to help them understand and describe the current context. They also asked for information about reform efforts mounted in other states.

Finally, the director of the University Center for Excellence in Developmental Disabilities (UCEDD) volunteered to organize focus groups with families, case managers, and self-advocates to explore particular experiences with guardianship.

Data Trends

State ID/DD staff reviewed the most recent NCI Adult Consumer Survey data to highlight factors relevant to the guardianship conversation. The most recent version of the Survey's background section includes a question about the individual's guardianship status (none, limited, or full) as well as an inquiry – if applicable – as to who that guardian is (family, friend, state guardian agency, other). State staff also explored whether there were any differences in outcomes between those with guardians and those without. At the next meeting of the Guardianship Working Group, state ID/DD staff presented the following findings:

- 40% of respondents had a full guardian and 7% had a limited guardian
- Of those with guardians, 50% had family members as guardians, 10% had friends as guardians, 25% had state guardians, and 15% had corporate guardians
- People with guardians were less likely to make choices about their lives, less likely to be employed, less likely to have friends, and less likely to have privacy in their homes.

The director of the UCEDD also presented results of the focus groups which indicated that families were pressured to seek guardianship during their family member's transition from school. He also noted that participants reported that guardianship was rarely terminated, even when individuals had shown they could be independent with support.

Further, the state guardianship agency noted that they had very high caseloads – as many as 30 wards per person – which made it very difficult to get to know those for whom they were responsible. Finally, corporate guardians had even higher caseloads.

Based on these findings, and an environmental scan of reforms in other states, the Guardianship Working Group identified subcommittees to work on legislative and other reforms of guardianship in the state.

Quality Improvement Initiatives

Based on reports from the sub-committees, the Guardianship Working Group, after conducting public forums on their preliminary findings, issued a report that made the following recommendations.

- Pass legislation that creates a Bill of Rights for individuals under guardianship or proposed guardianship, including the right to live, work and play in the most integrated setting; the right to visit with people of their choice; and the right to appear before the court to express their preferences or concerns.
- Explore less restrictive alternatives to guardianship, such as a power of attorney or representative payee, and require the court to review these alternatives.
- Revise the criteria for guardianship to narrow the circumstances under which it can be granted and include a requirement that individuals under guardianship should, if possible, be able to make decisions about where they reside.
- Develop more rigorous procedures regarding periodic review of guardianship.
- Expand the use of Supported Decision-Making and fund demonstrations.
- Work with case managers and school districts to eliminate the “automatic” recommendation for guardianship during transition.
- Develop rules regarding caseloads for state and corporate guardians.

Next Steps

The Working Group agreed to continue their work for the next two years to ensure continuity. Once the legislation passed, there was a need to develop training protocols and materials for individuals, families, case managers, judges, lawyers, and educators. The group also agreed to continue to use the NCI data to monitor progress and improvement in outcomes.

Questions? Comments? Contact Us

For additional information on the National Core Indicators (NCI), please visit www.nationalcoreindicators.org. If you'd like to discuss the use of NCI data or have questions about NCI in general, please contact: Dorothy Hiersteiner, NCI Project Coordinator, at dhiersteiner@hsri.org

According to the 2014-15 NCI Survey, 42% of adult consumers across all participating states had some form of guardianship arrangement:

