

*A hypothetical case illustrating how states can use NCI data to address important issues*

## Predictors of Abuse and Neglect

### Emerging Issue

A recent series of newspaper articles has focused on incidents of abuse and neglect of adults with intellectual and developmental disabilities in community residential settings. The state Quality Council – composed of self-advocates, family members, providers, advocates, and other stakeholders – put the issue of abuse and neglect on its quarterly agenda. The Council asked the director of the state’s Protection and Advocacy organization to help members understand what factors are likely to be precursors to abuse and neglect. The P&A director, who has had broad experience in investigating allegations of abuse, told the Council members there were a number of circumstances that are potential risk factors. She listed several factors that she had observed in her experience and that are borne out by the literature. They include:

- Social isolation (lack of friendships and relationships beyond paid staff)
- Social stigma related to a lack of respect for people with disabilities
- Lack of privacy within the residence
- Ignorance of individual rights
- Staff stress and lack of training
- Significant dependence on others
- Lack of control/decision-making
- Lack of community participation

The members wondered whether any of these indices could be tracked using National Core Indicators. The Commissioner of Intellectual and Developmental Disabilities noted that the NCI Adult Consumer Survey included questions that lined up with many of the issues outlined by the P&A director. He also suggested that there were helpful questions in the NCI family surveys. He agreed to provide a review of the most recent data at the next quarterly meeting.

### Data Trends

At the next quarterly meeting of the Quality Council, the Commissioner presented data on selected indices from the most recent round of data collection from the Adult Consumer Survey, the Adult Guardian Survey, and the Staff Stability Survey. There were several relevant domains in these surveys and the Commissioner noted that on many of them, the state results were either above or in line with the national average. Those areas included:

- Community participation – individuals reported substantial levels of participation in a variety of community activities.

The 2014-15 NCI Adult Consumer Survey sample included 25,820 adults with IDD. Of these:

- 76% reported having friends who were not family or staff
- 91% reported having enough privacy at home
- 78% reported they could be alone with friends or visitors in their home
- 87% reported that their mail or email is not read without their permission
- 93% reported that their staff always treat them with respect
- 10% reported using a self-directed supports option

- Treated with respect – the proportion of individuals that reported that their staff treated them with respect was similar to the national norm.
- Knowledge of rights and rules regarding abuse and neglect – more than two-thirds of families surveyed reported that they knew how to report abuse and neglect.

However, the Commissioner explained that there were several areas where the results on selected indicators fell below the national norms and reflected a need for improvement:

- Has friendships and relationships (other than with staff), reflecting the potential for social isolation
- Has privacy (relevant survey questions included: Do you have a place to be alone in your home? Are there rules about having friends or visitors in your home? Do you have a key to your home? Can you lock your bedroom if you want to?)
- Makes decisions (where to live, whom to live with, staff, etc.)

The Commissioner also looked at the results of the latest staff stability survey and noted a significantly higher staff turnover rate for the state compared to the national average. He speculated that such turnover might reflect staff stress and lack of preparation.

## Quality Improvement Initiatives

After the Commissioner outlined the data trends, the Quality Council Chair appointed a subcommittee to review the implications of the data and to propose initiatives likely to improve performance. At the next quarterly meeting, the subcommittee made the following recommendations:

1. Work with the Developmental Disabilities Council to develop an initiative aimed at supporting individuals with IDD to develop and sustain relationships and friendships.
2. Review and revise provider certification and monitoring protocols to ensure that there are robust requirements regarding resident privacy.
3. Review and revise person-centered planning requirements to ensure that individuals are supported and encouraged to make important life decisions. Also design case management training regarding person-centered principles.
4. Work with the legislature to allocate additional funding to increase workforce stability including raising DSP salaries and enhancing training.

## Next Steps

Following the implementation of the initiative, the Quality Council continued to follow results of the NCI data collection over the next 2 years and noted improvements. Further, they decided that it was important to ensure that individuals with IDD received training regarding how to recognize abuse and how to report it since anecdotal information from self-advocates on the committee suggested that many people were unaware of the warning signs. Finally, based on results from the NCI family surveys indicating that many respondents didn't know how to report abuse and neglect, they recommended developing educational materials for family members regarding procedures for reporting.

## Questions? Comments? Contact Us

For additional information on the National Core Indicators (NCI), please visit [www.nationalcoreindicators.org](http://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](mailto:dhiersteiner@hsri.org)

