National Core Indicators - Aging and Disabilities: A Person-Centered Approach to Understanding Quality of Long-Term Services and Supports

Authors: Stephanie Giordano, Rosa Plasencia

Abstract: In the USA, in 2013, public service systems such as Medicaid, aging, and disability systems undertook an effort to measure the quality of service delivery by examining the experiences and outcomes of those receiving public services. The goal of this effort was to develop a survey to measure the experiences and outcomes of those receiving public services, with the goal of measuring system performance for quality improvement. The performance indicators were developed through with input from directors of state aging and disability service systems, along with experts and stakeholders in the field across the United States. This effort, National Core Indicators -Aging and Disabilities (NCI-AD), grew out of National Core Indicators -Intellectual and Developmental Disabilities, an effort to measure developmental disability (DD) systems across the States. The survey tool and administration protocol underwent multiple rounds of testing and revision between 2013 and 2015. The measures in the final tool - called the Adult Consumer Survey (ACS) - emphasize not just important indicators of healthcare access and personal safety but also includes indicators of system quality based on person-centered outcomes. These measures indicate whether service systems support older adults and people with disabilities to live where they want, maintain relationships and engage in their communities and have choice and control in their everyday lives. Launched in 2015, the NCI-AD Adult Consumer Survey is now used in 23 states in the US. Surveys are conducted by NCI-AD trained surveyors via direct conversation with a person receiving public long-term services and supports (LTSS). Until 2020, surveys were only conducted in person. However, after a pilot to test the reliability of videoconference and telephone survey modes, these modes were adopted as an acceptable practice. The nature of the survey is that of a "quided conversation" survey administration allows for surveyor to use wording and terminology that is best understand by the person surveyed. The survey includes a subset of questions that may be answered by a proxy respondent who knows the person well if the person is receiving services in unable to provide valid responses on their own. Surveyors undergo a standardized training on survey administration to ensure the fidelity of survey administration. In addition to the main survey section, a Background Information section collects data on personal and service-related characteristics of the person receiving services; these data are typically collected through state administrative record. This information is helps provide greater context around the characteristics of people receiving services. It has also been used in conjunction with outcomes measures to look at disparity (including by race and ethnicity, gender, disability, and living arrangements). These measures of quality are critical for public service delivery systems to understand the unique needs of the population of older adults and improving the lives of older adults as well as people with disabilities. Participating states may use these data to identify areas for quality improvement within their service delivery systems, to advocate for specific policy change, and to better understand the experiences of specific populations of people served.

Keywords: quality of life, long term services and supports, person-centered practices, aging and disability research, survey methodology

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