

AIDD National Data Measurement Project Purpose and Description

Introduction

The Administration for Children and Families, U.S. Department of Health and Human Services Administration on Intellectual and Developmental Disabilities (AIDD) recognizes the critical role that performance and outcome data play in the management, operation and funding of state developmental disabilities systems. AIDD is taking an unprecedented step in building the capacity of state developmental disabilities (DD) agencies to gather vital information on service outcomes through the National Data Measurement Project and the adoption of the National Core Indicators (NCI) as the uniform dataset to use for this purpose. Through this project, funding is being made available to assist state DD agencies in covering the costs of the first year of data collection with the expectation that the state will continue to participate in NCI in subsequent years.

Background

The decision expand the availability of system performance data across all 50 states and the District of Columbia not only will strengthen the ability of states to administer key long term support programs for people with developmental disabilities (DD), but also will facilitate collaboration between state DD agencies and the ADD funded Developmental Disability Network on the identification of service delivery trends, policy planning and development of mutual strategies to improve the well-being of those receiving services across the country.

Many factors underscore the importance of gathering valid and reliable information on state developmental disabilities system performance, service quality and individual outcomes at this time.

- Documenting Service Strengths and Needs. The stagnating economy and high unemployment nationwide have depressed state revenues while increasing demands for public supports and individual assistance. State developmental

disabilities agencies are under growing pressure to serve greater numbers of people at less cost, to identify the outcomes of the supports that are delivered and to demonstrate the impact that a potential diminution of services and supports may have on participants.

- Meeting Federal Medicaid Requirements. During the past five years, the Centers for Medicare and Medicaid Services (CMS) have sharpened requirements regarding the generation of evidence by states on the performance of their waiver programs. Version 3.5 of the 1915(c) Medicaid Waiver Application and Technical Guide requires states to develop Quality Improvement Strategies that include performance measures for all waiver assurances. CMS currently is updating the evidence requirements in the Interim Procedural Guidance which will further delineate requirements regarding performance measurement, remediation and quality improvement.
- Planning Public Policy. Individual and systems level data on service performance and outcomes plays a critical role in the planning, development and implementation of sound public policy and practice.
- Managing State DD Agency Programs. The expansion of home and community based supports for people with developmental disabilities makes it increasingly difficult to monitor the quality of services at the state and sub-state level, particularly in rural areas. Public managers must lean increasingly on valid and reliable data that measure and assess all aspects of individual and system performance.
- Aligning System Priorities with Desired Outcomes. Performance data on service outcomes, particularly those that are meaningful to people with disabilities such as choice, relationships, community participation and employment, make it possible to determine the extent to which the values that underpin the Developmental Disabilities Act, and state laws are manifest in the lives of those served.

Purpose

The purpose of this funding opportunity is to assist states in managing and improving the quality of services furnished to individuals with intellectual and developmental disabilities (ID/DD) and their families through the use of valid and reliable data on performance and outcomes. Currently, 39 states and 22 counties or state regions gather and utilize NCI data to assist in service management and policy planning, meet CMS

waiver program assurances, and track key individual and system outcomes (See *NCI Program Description*). The goal of this project is to extend participation in the NCI program to all 50 states, the District of Columbia and the U.S. Territories by supporting their ability to gather NCI data during the most costly first year of implementation and operation.

Availability of Funds

The National Data Measurement Project (Project) provides funding to state DD agencies to cover set-up and operation costs related to NCI activities during the first year of participation. Up to five new states will receive awards during each of the next five years, resulting in a total of 25 new states joining the program over the five year period. Funds will be awarded to states with the expectation that the state DD agency intends to continue participation in subsequent years. The grant cycle is October 2011 – September 2016.

Funding. Funds provided under the Project are targeted to cover the NCI annual participation fee (\$13,380), and to defray all or a portion of the costs that a state incurs in conducting the NCI individual interviews and family surveys (up to \$29,820). Funding will be furnished through a contract between the state and NASDDDS. Payments will be made based on the submission of data, consistent with a work plan developed by the state and approved by the NASDDDS/HSRI Project Team. A description of the NCI system, the surveys used and the costs of participation is included in the accompanying *National Core Indicators Description*.

Project Timelines. NCI data typically is gathered by states beginning in the late fall and early winter and submitted by the end of June of each year. Because this Project is being launched in October, new states will have less time to collect their data for the current fiscal year. The following is an approximate timeline for all Project application and implementation activities starting in March each year and extending to the following June (14 Months):

March	Letter of Interest/Application deadline
April	Notification of funding
May-August	Introductory calls with states
Oct-Dec	Site visits and interviewer training in states completed Program documents completed:

Participation Agreement. The NCI program operates as a collaborative agreement between NASDDDS, HSRI and the participating state. The Participation Agreement is signed by all parties and outlines the roles and expectations of each partner.

Data Workplan. The Data Workplan is completed by each participating state to identify the surveys and methods that it intends to use to gather the data during the upcoming year. The Adult Consumer Survey constitutes the “heart” of the NCI program and is required for states to administer under this offering. States use the Data Workplan to describe the survey process that they intend to use for the Adult Consumer Survey, the three Family Surveys and the other information they intend to collect during the upcoming year.

Implementation Plan. The implementation plan outlines the approach that the state plans to use to gather interview data for the face-to-face Adult Consumer Survey and the three mail-in Family Surveys. The approach includes a description of entities or individuals who will be conducting the interviews, plans for gathering, aggregating and entering the data, timelines and other operational information. A format will be provided so that each participating state can complete the implementation plan before the site visit.

Site Visit. A site visit will be made to each state participating in the Project to review the Implementation Plan, provide orientation to staff, provide interviewer training (if possible; otherwise interviewer training will be provided via webinar), describe the operation of the ODESA web-based data entry system and offer additional information on the project.

Ongoing Support and Assistance. All members of the NASDDDS/HSRI Project Team will be available by phone or email to provide technical assistance, answer questions, review materials or offer other supports throughout the project and as long as the state continues to participate in the NCI program.

Additional Information

For additional information about this initiative, the application process or the NCI program please contact Mary Lee Fay, mlfay@nasddds.org, (703) 683-4202.