

Supporting Statement Part B

State of the States in Services and Supports for Autism Spectrum Disorders (ASD) Data Collection Tool

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B. METHODS

B.1. Respondent Universe and Sampling Methods

The Centers for Medicare & Medicaid Services (CMS) has contracted with L&M Policy Research (L&M) and its partners, Thomson Reuters, and the National Association of State Directors of Developmental Disabilities Services (NASDDDS) to address the need among policymakers, key stakeholders as well as families and individuals with Autism Spectrum Disorder (ASD) for information regarding services and supports for people with ASD. The purpose of this tool is to assist the research team in capturing federal and State level information about available supports and services and to communicate through the research team's structured interviews with key stakeholders additional information about services available to people with ASD and the public policy issues that affect people with ASD.

We propose interviewing multiple staff at each state, because several state agencies have an impact on supports for people with ASD. These include State departments of developmental disabilities, early intervention, education, Medicaid, mental health, corrections, insurance, public health, and vocational rehabilitation.

B.2. Procedures for the Collection of Information

The L&M team's partners, Thomson Reuters and NASDDDS, have established contacts within each state for this project. The initial approach to the data collection will be to reach out to the key contacts identified, in consultation with the CMS Contracting Officer's Technical Representative (COTR), by Thomson Reuters and NASDDDS within each agency. We may also consult with the research team technical advisory panel (TAP) of ASD experts established early in this project to provide us with key contacts. To schedule the interviews, the research team plans to make phone calls using a script (see below) to set-up a time for the discussions and will offer to send a project description and letter from the CMS Project Officer about the project.

"Hello my name is _____ and I'm calling from a healthcare research firm located in Washington, D.C., that is conducting a study on behalf of the Centers for Medicare & Medicaid Services (CMS). CMS has contracted with L&M Policy Research (L&M) and its partners, Thomson Reuters, and the National Association of State Directors of Developmental Disabilities Services (NASDDDS) to address the need among policymakers, key stakeholders as well as families and individuals with Autism Spectrum Disorder (ASD) for information regarding services and supports for people with ASD. Although we have obtained and reviewed data about various services and supports by State, we would like to better understand about how your agency [or office] is helping people with ASD and also have some questions about some of the information we've collected. Would you be able to set-up an interview time today? We will send you a letter and project description for your reference. Thank you for your time."

A two-person team will conduct the interviews. All interviews will be audio taped to assist with note taking. The team estimates that based on the multiplicity of State agencies, a total of about 400 respondents may be reached.

A qualitative data collection tool that includes questions for individuals about knowledge of

National and Federal Data Sources (quantitative methodology) will be used to capture the information about services and supports for people with ASD (see Data Collection Tool).

We propose conducting these interviews commencing in July, 2011 in order to meet project deadlines and report to the National Institute of Mental Health and the Interagency Autism Coordinating Committee (IACC), whose 2010 and 2011 Strategic Plans have given priority to understanding services and supports for people with ASD (see 2010 and 2011 IACC Strategic Plans).

The information that is collected in the interviews will be used to communicate additional information about services available to people with ASD and the public policy issues that affect people with ASD to key stakeholder audiences. The format of the report will include data tables from various state programs and narrative about the data being presented based on the interviews with state agency staff. We propose interviewing multiple staff in each state because several state agencies have an impact on services and supports for people with ASD.

Each participant will take part in one interview session. Once the interview data are collected, they will be analyzed. A process of qualitative analysis will be used to identify common themes across multiple topic areas. Notes and audio recordings will be reviewed to insure that no biases were introduced (e.g., from leading questions) and that alternate interpretations of the data are considered. There are no details of recruitment methods for the study, as the interviews involved are related to typical State administrative structure.

B.3. Tests of Procedures or Methods to be Undertaken

This submission is in itself a request for authorization to conduct tests of procedures and methods. The purpose of this request is not to obtain survey data, but rather to obtain information about the type of services and supports public-funded programs provide to people with ASD across the life span which will help guide a state of the states profile for policymakers, researchers, and families and persons with ASD. The procedures and methodologies to be used by CMS and its contractors are consistent with those of other Federal agencies in similar contexts.

B.4. Individuals Consulted on Individuals Analyzing Data

The person with overall responsibility for the technical aspects of the described activities is:

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