Administering the NCI-AD Adult Consumer Survey

NCI-AD
NATIONAL CORE INDICATORS-
Aging and Disabilities

NASUAD
National Association of States United for Aging and Disabilities

HSRI
Human Services Research Institute

Key Dates

- **Project Planning:** 6-12 months before interview start date
- **In-Person Interviewer Training:** 1-4 weeks before interview start date
- **In-Person Interview start date:** No earlier than June 1st (can be later if necessary)
- **Data Submission date to HSRI:** May 31st
- **Availability of state-by-state reports:** November
- **Availability of national report:** May of the following year

Survey Guidelines

Survey structure and general guidelines

NCI-AD Survey Tool

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- **Pre-survey Form**
  - Used to setup interviews, for use by the interviewers only
- **Background Information** (21 questions)
  - Demographics and personal characteristics: gathers data about the consumer from agency records and/or the individual
- **Consumer Survey** (90 questions)
  - Includes <u>subjective satisfaction-related</u> questions that can only be answered by the consumer, and <u>objective</u> questions that can be answered by the consumer or, if needed, their proxy
- **Proxy Survey** (51 questions)
  - Includes objective questions only; rephrased to ask about the consumer
- **Interviewer Feedback Sheet**
  - Asks interviewer to evaluate the survey experience and flag concerns

General Guidelines

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- Read questions as they are written first; rephrase only if needed
- For most questions, the interviewer will not read the response options aloud
  - Instead, the interviewer should listen to the individual's response and mark the answer option that best fits
  - If the response does not fit in the available options, the interviewer may clarify with the individual
- Response options are only read aloud when the directions specifically state to do so
  - Ex. Question #9 on page 6
- Certain responses will allow the interviewer to skip questions
  - Skip patterns are pre-programmed in ODESA

State-Specific Questions

- State are allowed to add up to 10 questions to the survey
  - Must be approved by the NASUAD-HSRI team
  - May decided to use the same question other states are using
    - See “State-Specific Survey Questions” document
  - These questions may eventually be incorporated into the survey
  - Can be placed throughout the in-person consumer and proxy surveys

Proxy assistance

Establishing the need for a Proxy

- Need for a proxy must be established in-person
  - Cannot be established during the scheduling call
- All surveys should be attempted with the individual first
- Use questions 1-8 (“home” and “relationships”) to determine if a proxy is needed
  - **If <u>able</u> to reliably respond to ALL questions, proceed with full version**
  - **If <u>unable</u> to reliably respond to ALL questions, switch to proxy version**
  - In ODESA, the appropriate survey will open based on the answer to Proxy1 question

Assistance from a Proxy

- The individual may request proxy assistance throughout the survey on questions that have the grey **PROXY** box
  - Individual must still provide valid responses to questions 1-8 when a proxy is assisting with the survey

- When a proxy is helping the individual with the survey, but is not serving as the primary respondent, use the full version of the survey
  - Still direct all questions to the individual
  - Ensure the proxy doesn't talk over the individual
  - If proxy gives the answer, code appropriately in the respondent box

Who Can Serve as a Proxy?

- Someone the individual:
  - Trusts and feels comfortable around
  - Knows and can speak to the individual's experiences with services
  - Is willing to respond on behalf of the individual
- A proxy can be the individual's:
  - Child
  - Spouse/Partner
  - Family member
  - Friend
  - Paid/Unpaid caregiver

3 Phases of the Project

1. Project Planning
   - Project team logistics
   - Sampling frame
   - Participant education and consent
   - Stakeholder Engagement
   - Interviewer Training
2. Data Collection and Survey Implementation
3. Data Analysis, Management, and Reporting

Project Planning

- States should begin planning for survey implementation 6-12 months before interviews begin
- Plan for regular phone check-ins with the NASUAD-HSRI team
- States are give the “Considerations for Planning and Implementation of NCI-AD” document to help them think through initial questions
- States are required to complete the following documents for the NASUAD-HSRI team:
  - “Project Abstract”: describing key state protocols and sampling strategy
  - “BI Crosswalk”: Describes which administrative records are used to complete the background information and the differences in administrative vs. survey data
- States are required to sign an MOA with NASUAD

Project Team Logistics

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- Identify funding sources (Medicaid, OAA, state-funds, etc.)
- Identify project lead at the state level
  - Determine which state offices will be involved (Aging, Disability, Medicaid)
- Decide who will conduct interviews (state QA staff, vendor, etc.)
- If using vendor, determine timelines for RFP and contracting process
- Determine if IRB is needed
- Follow applicable state background check processes for interviewers
- Suggest 8-10 interviewers for 400 surveys
- Ensure proper Data Use Agreements are in place between state offices and between state office and vendor, if necessary
- Plan for intended uses of data

Sampling Frame

- Must complete a minimum of 400 surveys
  - Can oversample to subpopulations
- Eligible participants include seniors and adults with physical disabilities, including TBI/ABI being served in/by the following:

Medicaid waivers	Nursing Homes/SNFs
Medicaid state plans	PACE programs
MLTSS populations	State-funded programs
Older Americans Act programs	

- Determine which programs to include/exclude and desired margins of error and confidence levels
- Be sure to involve appropriate state staff in sampling decisions and planning

Sampling Frame continued…

- Decide if sample pull will be random, stratified random, etc.
- If there is crossover between sample populations, determine how samples will be de-duplicated
- Plan to involve other agencies, provider, health plans, etc. in order to gain access to need participant contact and background survey information
- Determine timelines for when samples should be pulled (e.g. all at once or staggered throughout the survey year)
- Plan for inaccuracies in sample list due to participant mortality, incorrect contact information, etc.

Participant Education and Consent

- Decide if participant consent to participate in the survey should be verbal, written, or both
- If the participant has a guardian, determine if the guardian will need to provide consent
- If the guardian must provide consent, ensure that guardian contact information can be obtained from state records
- Plan to communicate with potential participants about the survey via mailed letter, case managers, etc.

Stakeholder Engagement

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- Prepare a list of stakeholders, including service recipients, family members, advocacy groups, providers, and program administrators
- Create a timeline for stakeholder engagement and communications
- Determine the best avenues for communications (e.g. conference calls, email reminders, in-person meetings, newsletter updates, website pages, etc.)
- Plan to share final state reports with interested stakeholders
- NASUAD and HSRI are available to assist with stakeholder engagement as requested by the State

Interviewer Training

- Interviewers are provided with the “Interviewer Survey Guide” providing details about the intent, guidelines, and rephrasing for each question
- Prepare for 1-2 day in-person training of interviewers (if new) or yearly refresher webinar for returning interviewers, topics include:
  - Overview of the project
  - Abuse, neglect, and exploitation guidance and procedures follow-up on unmet needs
  - General survey instructions and procedures for identifying and interviewer proxy respondents
  - Discussion each survey question’s wording, intent, and potential rephrasing
  - General surveying skills and procedures
  - Population-specific interviewing techniques and etiquette
  - Data entry procedures

Data Collection Process

- State must prepare to collect Pre-Survey and Background Information via state, country, and/or health plan administrative records
- Data must be entered in the Online Data Entry System Application (ODESA) unless otherwise specified
- When possible, interviewers should enter survey responses directly into ODESA during the interview using a wi-fi enabled laptop or tablet
  - Paper copies of the survey are provided, if needed
- States should ensure that PS and BI data are collected and transferred to ODESA or to the interviewer prior to the interview

Background Information

- At a minimum, States must collect the following data from agency records/administrative data – i.e. they should never be collected during the interview:
  - **BI-12.** Is this person currently participating in a self-directed supports option?
  - **BI-16.** What is the person's primary source of funding for long-term care services?
  - **BI-17.** What type of paid long-term care supports is the person receiving?
  - **BI-19.** How long has the person been receiving long-term care supports through his or her primary current program? (The latest episode of receiving long-term care supports through the current program.)
  - **BI-20.** Does the person have a legal guardian?

Survey Administration

- Surveys must be complete and entered into ODESA no later than May 31st
- The State and vendor, if applicable, should decide:
  - How to track refusals, incompletes, bad contacts, etc.
  - How to follow relevant data privacy and HIPPA protocols
  - How to keep pre-survey information secure
  - The best strategy for coordinating interview schedules
  - What to do in situations where the interviewer is struggling to gain access to a participant due to their living situation (e.g. resident in nursing home who doesn't have direct access to the phone)
- Interviewers should plan to wear a badge and/or bring official documentation to show their role in the project

Data Analysis and Management

- The NCI-AD team provides the following services:
  - Preparing the ODESA and codebooks for survey data
  - Tracking and reviewing state data for completeness
  - Merging individual state data files into aggregate files
  - Cleaning and formatting aggregate data files to ensure comparability
  - Computing scales/indicators
  - Creating tables and graphs of indicator and descriptive data
  - Conducting state by state and national benchmark comparisons
  - Testing for significant differences (including state-by-state results on survey items)
  - Developing and disseminating analytical and interpretative guidelines
  - Maintaining a data archive for all project data
  - Furnishing project data files to the State when requested

Reporting

- Each year, participating state are provided with their state-specific report
  - States are expected to provide the following written sections for the report:
    - An overview of the project in the state
    - A description of each population/program included in the sample
    - A description of the survey process and vendor, if applicable
    - An overview stakeholder and participant engagement and education
    - States may also include a Preface letter
- States must designate a staff person (could be vendor staff) to answer any questions pertaining to data and verify information in the state report
- States should determine who in the state will need to sign off on the report before it is published
- State reports are published on www.nci-ad.org

Reporting continued…

- Each State's data are also included in a national report
- State programs are categorized into the following program buckets:
  - Nursing Home/SNF
  - PACE
  - MLTSS
  - Aging Medicaid
  - PD Medicaid
  - Combined Medicaid
  - BI Medicaid
  - OAA
  - Other (state-specific programs)
- The national report is published on www.nci-ad.org

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Data powered by HSRI

Project managed by NASUAD