NCI-AD Implementation Guide

The NCI-AD Implementation Guide, in tandem with the NCI-AD Project Abstract, is intended to assist Participating States with planning for the 2018-2019 NCI-AD survey year. The Guide identifies key aspects of the project that should be addressed to ensure successful implementation of the NCI-AD survey; however, it is not exhaustive, and Participating States should feel free to add additional information as needed for their purposes.

The collaborative nature of this program requires close communication between the Participating State and NASUAD and HSRI staff at all stages of project planning. Technical assistance provided by NASUAD and HSRI includes support and discussion of the topics below; however, the Participating State is encouraged to begin planning its implementation process as early as possible using this document as a guide. Addressing the questions below will also equip the State with all the information needed to complete the NCI-AD Project Abstract.

KEY DATES:

Project Abstract and Background Information Crosswalk due to NASUAD and HSRI: One month prior to surveyor training date

Surveyor training: No more than 4 weeks before interview start date

Interview start date: No earlier than June 1, 2018 (can be later if necessary)

Data submission date: No later than May 31, 2019

Availability of draft state reports: November-December 2019

I. Project Logistics

The state should identify a project team for NCI-AD, including designating the lead state office and project lead staff who will be NASUAD and HSRI's point of contact. The lead state office may need to collaborate with other offices (e.g. the Office on Disability and/or Medicaid Office) to design the sampling strategy and to gather the necessary contact info (Pre-Survey section) and items for the Background Information (BI) section available from administrative data sources. The following questions should help guide the state in preparing its project logistics:

1. Which state office will be the lead for the NCI-AD project? What other offices will be involved?
2. Who will be the state's project lead staff and serve as its primary NCI-AD contact?
   a. How much time will this person spend on this project (as a percentage)?
3. Are there others who will play key roles in implementing the project? (i.e., other state staff, vendor conducting interviews, etc.).
   a. What function will each contributor serve?
   b. How much time will each contributor spend on this project?
4. If vendors will be bidding on the project, what is the timeline for procurement?
5. If using an existing vendor, what is the timeframe for executing a modification to the existing contract?
6. How will the project be funded? (e.g., Claiming Medicaid Administrative Match, etc.)
7. Does the state or vendor require a formal Institutional Review Board (IRB) review to participate in data collection and analysis?
   a. If so, what are the timeframes associated with an IRB review and obtaining approval?
8. Will other state offices or vendors need to sign a Data Use Agreement to share background data and participant contact information?

II. Sampling Frame

The minimum number of completed NCI-AD surveys required in each Participating State is 400 (unless an exception has been discussed with and approved by NASUAD and HSRI). There is no maximum number of completed surveys. Participating States may choose to stratify and proportionally oversample one or more subpopulations. The state should thoughtfully consider what the intended use of the survey data will be (for example, within-state system comparisons) and design its sample with that intended use in mind.

Any senior or adult 18 years and older with a physical disability (including acquired or traumatic brain injury (ABI/TBI)) who receives publicly funded long-term services and supports (LTSS) at least 2-3 times a week — regardless of where they live or program funding source — is eligible to be included in the sample. The sample should not include individuals receiving LTSS through intellectual or developmental disability (ID/DD) or mental health (MH) waivers or programs. There should be no a priori exclusions based on geography, place of residence, level of disability, or other personal and demographic factors.

After the state decides on a target number of completed NCI-AD surveys, the state should begin planning how it will compile and provide, either to internal surveyors or to a vendor (if a vendor is used) the list/s of contact names and associated data. Selection of participants into the sample pool from among those eligible must be done *at random* and the *list/s should be compiled and provided in random order*.

The sample list of contact names compiled should be at least 2-3 times larger than the state's target number of completed surveys to account for refusals, inaccurate contact information, people who have moved or switched programs, passed away, etc. For example, for a target number of 400 completed NCI-AD surveys, NASUAD and HSRI recommend the state compiles a list of at least 800-1200 contacts for the sample pool (i.e. two-three times the target number of completed surveys).

If the state is employing a stratified sampling strategy in which each stratum has its own target number of completed surveys, then the sample pool also needs to be stratified, with the pool in each stratum being 2-3 times larger than the target number in that stratum. To the extent possible, participants should be contacted according to the order in the sample list/s, thus maintaining the randomness of selection. When the target number of completed surveys has been reached, the rest of the sample pool can be discarded.

States are required to work closely with NASUAD and HSRI staff as they design their sample. The following questions should help guide the state in preparing its sampling frame:

9. How does the state envision using the survey data and reports?
10. Which service populations will be included in the sample? (i.e., seniors and/or adults with disabilities being served through: Medicaid programs, state-funded programs, Older Americans Act programs, those living in skilled nursing facilities, etc.)
11. Is there any overlap between these service populations? i.e. can the same person be receiving services through more than one program included in the sample?
    a. If so, how will the sample be de-duplicated? i.e. what will the procedure be to ensure that a person is only selected into the sample pool once?
12. What is the size of each service population included in the sample? i.e. how many people eligible to be surveyed are receiving services in each of the included programs (eligible population size of each service population included)?

13. Will the sample be simple random, stratified random, or other?
14. Is the state planning to proportionally oversample one or more of its populations served?
    a. Which population(s)?
    b. Why is an oversample desired?
15. What is the state's total target number of completed surveys? If stratifying, what is the target number of completed surveys in each stratum?
16. Will any of the eligible service populations or sub-populations be excluded from the sample? (e.g., MFP enrollees, Duals Demo participants, new service recipients, etc.)
17. How many contact names will the sample list/s contain?
18. When will names and contact information be compiled and provided to the vendor (if a vendor is used)? (e.g., all at once before surveying starts? In scheduled batches, for example, monthly? In non-scheduled batches as needed?)

III. Participant Education and Consent

States should determine education and consent procedures for potential participants. To increase survey participation and minimize refusal rate, potential survey participants should be informed they were selected for possible participation (i.e. the opportunity to provide input) and be educated about the NCI-AD survey and project. The following questions should help guide the state in preparing for participant education and consent:

19. How will potential survey participants and, when applicable, their guardians/legal representatives, be educated about the NCI-AD survey and their possible participation prior to being contacted by the surveyor?
20. How and when will consent be obtained from participants being surveyed?
21. In cases where the individual has a guardian/legal representative, does that guardian/legal representative need to give consent for the individual to be surveyed?
    a. If yes, how will the state identify and gather information to contact guardians/ legal representatives?
    b. How will the guardian's/legal representative's consent be obtained?
22. Will the state require written consent from individuals or their guardians/legal representatives?
23. Will there be a phone number or email address potential participants and/or others may contact if they have any questions about the project or their participation? Who will be responsible for the hotline and answering questions?

IV. Stakeholder Engagement

In order to create buy-in and support for the project and increase participation, states are encouraged to educate and engage their internal and external stakeholders about NCI-AD before surveying begins. These stakeholder groups may include other state agencies, area agencies on aging or county offices, service providers, advocacy organizations, individuals and their families, advisory groups, etc. The following questions should help guide the state in planning stakeholder engagement:

24. Which stakeholder groups in the state should be made aware of the NCI-AD project?
25. What kind of information about NCI-AD is pertinent to the various stakeholder groups and is important to share with them?
26. How will information about NCI-AD be shared with these groups (e.g. email campaigns, in-person meetings, presentations, printed materials, etc.)?
27. What is the timeline for stakeholder engagement?
28. Will survey results and final reports be shared with stakeholder groups, and if so, how (e.g. in-person meetings, presentations, workgroups, referring to the website, email, printed materials, etc.)?
29. Will any of the stakeholder groups have an advisory role?

V. Surveyors and Training

Data for NCI-AD are collected through in-person interviews that take, on average, between 45 and 60 minutes. States may decide who conducts surveys, whether using a private survey vendor/contractor, state staff, advocacy organization, university, or some other entity. Regardless of who is responsible for conducting the interviews, surveyors may not have a personal connection with the individual to be surveyed, which precludes service providers, friends, relatives, and case managers. Surveyors must go through an NCI-AD training, developed by NASUAD and HSRI, that uses standardized training materials and includes an in-depth discussion of survey questions' intent and response coding.

States will need to decide which entity will be managing the interview process and be responsible for conducting NCI-AD surveys. A one- to two-day onsite in-person surveyor training conducted by NASUAD and HSRI staff is required for new Participating States and for states who contract with a new surveying entity or have all new surveyors. State staff and their contractor, if applicable, should be present during the training and are responsible for providing the meeting space, a projector and speakers and may also be asked to provide a Wi-Fi connection and a microphone. All surveyors who will be conducting NCI-AD interviews must attend the training. For Participating States who are not new to NCI-AD and who have mostly returning surveyors, a refresher training via webinar or train-the-trainer model may suffice; additional onsite in-person training may be requested. The following questions should help guide the state in preparing for surveyor preparation and training:

30. Who will be conducting the surveys and managing the interview process (i.e. survey vendor/contractor, state staff, etc.)?
31. Does this entity have prior experience conducting and managing NCI-AD interviews? If no, does this entity have prior experience conducting other face-to-face surveys with similar populations?
32. How many surveyors will conduct NCI-AD interviews?
33. Will surveyors need to be vetted through a background check process? If so, what is the process and how long will it take?
34. Will the state need bilingual surveyors?
35. If the vendor/surveyors are to be reimbursed per survey conducted, what will count as a "completed" interview for the purposes of payment?
36. If an in-person training is needed, when and where will the training be held? How will the surveyors get to the training? Will they need sleeping accommodations? Will breakfast and/or lunch be provided?
37. For either onsite training or refresher training, who will be responsible for coordinating the state's training logistics?

VI. Data Collection: Pre-Survey and Contact Information

After the state compiles its sample list/s and associated contact info, this information needs to be provided to the entity managing the interview process. The Participating State decides procedures by which contact info and sample list/s are transmitted. In addition to basic contact information (names, addresses, phone numbers), it is recommended surveyors are provided supplementary information about the participant that may be helpful in arranging and preparing for the interview, when possible. This information could include the individual's living circumstances, guardianship status, communication needs, etc.

The Pre-Survey section of NCI-AD is a form intended to provide surveyors information that may be helpful to schedule interviews with individuals. There is no requirement for states to use the Pre-Survey form; instead, it is meant to be an example of how contact and supplementary information can be provided to surveyors. Pre-Survey and contact information is not submitted and *should not* be shared with HSRI and NASUAD staff. The following questions should help guide the state in preparing its contact and Pre-Survey information:

38. What contact and supplementary Pre-Survey data are available in state databases and should be provided to the surveyors (e.g. participant's name, phone number, communication needs, living situation, guardianship status, etc.)?
39. What databases will be used?
40. Who will be responsible for extracting and compiling the available contact and Pre-Survey information for the sample pool?
41. How will this information be extracted, compiled and transmitted to the vendor and/or surveyors? Are there any data-sharing agreements (e.g. state staff, client databases, etc.) that are necessary?
42. When will the information be extracted, compiled and transmitted to the vendor and/or surveyors?
43. What procedures, if any, should be followed in the event of inaccurate contact information? Will the state attempt to update inaccurate or outdated contact info?

VII. Data Collection: Background Information Section

The NCI-AD Survey includes a section titled Background Information (BI), which collects demographic, personal and service-related information on the survey participant. The BI section contains critical information integral to the validity of NCI-AD data and data analysis and it must be completed and submitted in its entirety. To the extent possible, information in this section should come from the state's existing administrative records. States vary with respect to both the availability and accuracy of BI items in administrative data sources. It is unlikely all BI items will be available for all survey participants solely from administrative records.

To track which BI items are available from administrative records, each state is asked to complete the "BI Crosswalk", which not only tracks the source of data for each item, but also identifies any recoding necessary to align admin-derived data with the associated BI items. BI items that could not be reliably obtained for the participant from administrative sources should be identified before the in-person interview takes place and collected by the surveyor at the end of the interview (either by asking the participant or, when appropriate, by direct observation). This expectation should be included in any RFP the state issues for survey vendors.

Surveyors may collect any missing BI data *except* for BI items that must be completed using administrative data sources/agency records only – these items are indicated clearly on the BI Crosswalk. Data for these items should never be provided by the participant or be based on surveyor observations.

The following questions should help guide the state in preparing its Background Information data:

44. Who will be responsible for completing the BI Crosswalk?
45. What BI data are available in state administrative databases?
46. What databases will be used?
47. Are there BI items that cannot be reliably derived from administrative databases?
48. Who will be responsible for extracting and compiling BI data available from administrative records?
49. How will the available BI data be extracted, compiled and transmitted to the vendor and/or surveyors?
50. When will the available BI data be extracted from administrative data sources?
51. When will the available BI data be compiled and transmitted to the vendor and/or surveyors?
52. Will the surveyors be responsible for collecting missing or unavailable BI data? If yes, will the surveyors know which BI items are missing for a survey participant before the interview takes place?
53. Who will be responsible for entering BI data? When will this data entry take place?

VIII. Data Collection: In-Person Survey

All NCI-AD survey data, including the BI section and in-person interview data, must be entered into the Online Data Entry System Application (ODESA), the project's preferred method for data entry and submission. ODESA's programming ensures that all data entered are compliant with standard project data formats and conventions; it also minimizes surveyor error due to pre-programmed skip patterns and logic checks.

Using ODESA requires an internet connection; it can be accessed at no charge through the web using any computer, laptop, or tablet. While not required, some states provide surveyors with mobile Wi-Fi hotspots and/or Wi-Fi enabled devices such as laptops or tablets. This enables surveyors to use ODESA directly in the field and enter data while conducting the interview. If a Wi-Fi enabled device and/or internet connection is not available, surveyors can conduct the interview using a paper copy of the survey and subsequently transfer data into ODESA manually.

Any exemptions from entering and submitting data through ODESA must be previously discussed with and approved by NASUAD and HSRI; non-compliant data will not be accepted. No information considered to be confidential or violating HIPAA should be entered into ODESA (e.g. names, addresses, phone numbers, etc.) or otherwise transmitted to NASUAD and HSRI. The following questions should help guide the state in preparing for data collection:

54. Will the surveyors be using Wi-Fi connected devices to conduct interviews and enter data into ODESA while in the field?
    a. If not, how will surveyors record data from the interview (e.g. a pre-programmed offline device, paper surveys)?
    b. Who will be responsible for manually entering survey data into ODESA, if needed?
    c. When will data entry take place?
    c. What sort of impact will manual data entry have on project timelines?
55. What, if any, accommodations will be provided for non-English speaking participants, so they are able to participate in the survey (e.g. translation services, dual-speaking surveyors, etc.)? Which languages will be accommodated? (A Spanish-language translation of the NCI-AD survey is available to Participating States upon request.)

IX. Survey Implementation

The following additional questions should help guide the state in preparing for NCI-AD survey implementation:

56. Does the state want to add any state-specific questions to the standard NCI-AD Survey?
    a. If yes, how many state-specific questions would the state like to add?
    b. How were these state-specific questions developed and/or selected?
    c. Should these questions allow for proxy responses?
57. Who will be responsible for assigning interviews to the surveyors and managing the interviewing process, including tracking survey completion progress, rates of refusals, etc.?
58. How will refusals, incompletes, bad contacts, etc. be tracked?

59. Who will be responsible for scheduling in-person interviews (e.g. the surveyor him/herself, a supervisor, designated state staff, etc.)?
60. What administrative procedures, if any, must be followed when scheduling the interviews?
61. If applicable, what is the strategy for contacting individuals living in settings where they may not have direct access to a phone?
62. Will the surveyors wear a badge/ID or carry any other kind of official document?
63. Will the surveyors be provided with any materials containing information or resources that can be left behind with the survey participant if requested?
64. When will in-person interviews begin?
65. When should all in-person interviews be completed?
66. What, if any, quality assurance protocols will be implemented either by the state or by the survey vendor (e.g. procedures to verify/ensure that data collected are valid and reliable and that the data entered into ODESA are accurate and do not contain any identifying personal information)? Will there be ongoing quality oversight and monitoring?
67. What, if any, processes will be implemented to ensure that confidential data about survey participants (e.g. contact information) are kept secure and that relevant data privacy and HIPAA protocols are being followed?

X. Reporting

Once NCI-AD surveys are completed and the state submits all its data, HSRI staff will examine the state's raw data for completion and validity. If questionable or problematic data elements are discovered, the state will be asked to review, verify and, to the extent possible, help diagnose and correct the problems identified before data analysis can begin.

After analysis is completed, the state will also be asked to review a draft of its state-specific report and provide any edits, corrections, comments and feedback within the next 30 days. After the state's review and input on the draft, the report will be finalized and posted on the NCI-AD website. A similar review process will be followed for the national NCI-AD report. The following questions should help guide the state in preparing for the data verification and reporting process:

68. If the submitted data contain potentially problematic values or elements, who will be responsible for reviewing, verifying and, if needed and to the extent possible, correcting the problems identified?

69. Who will be responsible for reviewing draft reports and providing edits and feedback?
70. Who else at the state will need to review and approve the reports before they are made publicly available through the project website?
    a. When does that review and approval need to take place (e.g. only when the report has otherwise been finalized, when a near-final version of the report is ready, when all tables and charts have been created, etc.)?
    b. What are the timeframes associated with additional reviews?