Considerations for NCI-AD Planning and Implementation

This document, in tandem with the NCI-AD Work Plan, is intended to identify the key aspects of the NCI-AD project that need to be addressed to ensure successful implementation of the NCI-AD survey. States should feel free to add additional elements as needed for their purposes. The collaborative nature of this program necessarily requires the state to communicate with NASUAD and HSRI staff at all stages of the project planning. Questions found in this document will help states to fill out the Project Abstract.

KEY DATES:

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

In-Person Interviewer Training: 1-4 weeks before interviewer start date

In-Person Interview start date: No earlier than June 1, 2017 (can be later if necessary)

Data Submission date to HSRI: May 31, 2018

Availability of state-by-state reports: December 2018

I. Project Logistics

The state should identify a project team for NCI-AD, including a project lead who will be NASUAD and HSRI's point of contact. The lead state office may also need to collaborate with the Office on Aging, Disability, and/or Medicaid to build the survey sample. The state should also thoughtfully consider the end-use of the survey data, including system comparisons and waiver assurances compliance, among other issues. The following questions should help guide the state in preparing its project logistics:

1. Who will serve as the state's lead project contact?
    a. How much time will this person spend on this project (as percentage)?

2. Are there others who will play key roles? (i.e., other state staff, vendor conducting interviews, etc.).
    a. What function will each participant carry out?
    b. How much time will each participant spend on this project?
3. If bidding for a vendor, what is the timeline for that procurement?
4. If using an existing vendor, what is the timeframe for executing a modification to the existing contract?
5. Which state offices will be involved in the project?
6. How will the project be funded? (e.g., Claiming Medicaid Administrative Match, etc.)
7. How will the state use the survey outcome data and reports?
8. Does the state or vendor require a formal Institutional Review Board (IRB) review to participate in data collection and analysis?
9. Will other states offices or vendors need to sign a Data Use Agreement to share background data items and participant contact information?

II. Sampling Frame

Minimum Number of Completed Surveys: 400

Any senior or adult with a physical disability who receives services provided by the state—regardless of where they live or what their funding source is—should be eligible to be included in the sample. This includes adults with acquired or traumatic brain injury (ABI/TBI). In addition, there should be no *a priori* exclusions based on geography or level of disability. The state may choose to oversample one or more subpopulations in order to look more closely at that population's outcomes. Because it is expected that there will be some refusals and/or inaccurate/outdated contact information, the sample pool should be larger than 400. NASUAD recommends that the state draw at least 800 contacts for the sample pool. When 400 surveys have been completed, 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:

10. Which populations will be included in the sample? (i.e., seniors and/or adults with disabilities being served through: Medicaid, state-funded programs, Older Americans Act programs, and/or those living in skilled nursing facilities)
11. Will there be crossover in the sample between the populations?
    a. If so, how will the sample be de-duplicated?
12. Will the sample be random, stratified random, or other?

13. Is the state planning to oversample a portion of the population served?
    a. Which population(s)?
    b. Why is an oversample desired?
14. Will any group be excluded from the sample? (e.g., MFP enrollees, Duals Demo participants, etc.)
15. What data sources will be used to gather the pre-survey and background information?
    a. Who controls access to that data (other state agencies, providers, health plans)?
    b. Who will complete the Background Information Crosswalk?
16. When will names and contact information be pulled for the sample (e.g., all at once or staggered throughout the survey year)?
17. How will the state/vendor handle inaccuracies in the sample list due to mortality, incorrect participant contact information, etc.?

III. Participant Education and Consent

The following questions should help guide the state in preparing for its participants' education and consent:

18. How and when will consent be obtained from the individuals, or their guardians/legal representatives, being surveyed?
19. How will potential participants, or their guardians/legal representatives, be educated about the survey (prior to contact with interviewer)?

IV. Stakeholder Engagement

In order to create buy-in and support for the project, states are encouraged to educate their internal and external stakeholders about NCI-AD before they begin the interviewing process. These groups include other state agencies, AAAs or county offices, providers, advocacy organizations, clients and families served by the programs, etc. The following questions should help guide the state in preparing for stakeholder engagement:

20. What groups in the state need to be aware of the NCI-AD project?
21. How will these groups be educated (i.e. email campaign, in-person meeting, etc.)?
22. What kind of communications will be important to share with stakeholders?
23. What is the timeline for stakeholder engagement?
24. How will final data and reports be shared with stakeholder groups?

V. Interviewers and Training

Data for NCI-AD is collected through in-person interviews of service participants. On average, it takes between 45 and 60 minutes to conduct each interview. States may use state staff, private contractors, advocacy organizations, college/university students, or peers to conduct NCI-AD interviews. However, interviewers may not have a personal connection with the individual, which precludes service providers, relatives, and case managers from conducting the interviews. States will need to decide who will be conducting the interviews and plan for a one to two day in-person training of their interviewers, conducted by NASUAD and HSRI staff. State staff and their contractor, if applicable, must be present during the training and must provide a projector and speakers and may also be asked to provide a Wi-Fi connection and a microphone. The following questions should help guide the state in preparing for interviewing and training:

25. Who will be conducting the interviews (i.e. vendor, peer interviewers, etc.)?
    a. What will count as a "completed" interview, for the purposes of paying the vendor?
26. Will interviewers need to be vetted through a background check process? If so, how long will this process take?
27. How many interviewers will be used?
28. Who will coordinate training logistics and cover any associated costs?
29. When will the training be held?
30. Where will the training be held?
31. How will the interviewers get to the training and will they need sleeping accommodations?
32. Will breakfast and/or lunch be provided?

VI. Data Collection

Interviewers will enter survey responses into the online data entry system application (ODESA), which can be accessed through the web using any computer, laptop, or tablet. If states (or their contractors) use non-NCI-AD survey tools or data entry formats, it is their responsibility to ensure that all data is formatted according to NCI-AD standard protocols. Some states (or their contractors) may choose to provide Wi-Fi ready laptops or tablets to interviewers for use during the interview to simplify the data entry process. Note: Laptops and tablets must be connected to the internet in order to access the ODESA. The following questions should help guide the state in preparing for data collection:

33. Will interviewers be provided a Wi-Fi connected laptop or tablet for use during the interview?
    a. If not, how will data be collected and then entered into ODESA?

VII. Pre-Survey Information

The pre-survey is intended to provide interviewers with the information they will need to schedule and conduct interviews. The state should review this form and decide a) what information will be provided to interviewers in advance (e.g. client name, phone number, communication needs, etc.); b) how the information will be gathered, including any necessary data-sharing agreements (e.g. state staff, client databases, etc.); and c) what administrative procedures must be followed when arranging interviews.

Pre-survey information **should not** be shared with HSRI or NASUAD staff.

The following questions should help guide the state in preparing its pre-survey information:

34. Who will collect the pre-survey information?
35. Which databases will be used?
36. How will the available background data be transmitted to the contractor/interviewers?
37. When will collection of pre-survey information begin?
38. How will this information be transmitted to the vendor/interviewers?
39. Will incorrect contact information be updated?
40. If necessary, how will the state identify if an individual has a legal guardian that must give consent for the individual being surveyed?
    a. How will the state gather information to contact legal guardians?

VIII. Background Data

The completion of this section is critical for the validity of the project. It is likely that staff will not be able to collect all of the requested background data solely by referencing agency records or program databases; however, this section must be filled out in its entirety. With regards to background questions that cannot be completed from administrative databases, those questions should be identified before the interview and asked at the end of the interview. In this case, states should be sure to include this expectation in any RFP for interviewer contractors.

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?[1]

BI-16. What is the person's primary source of funding for long-term care services?[2]

BI-17. What type of paid long-term care supports is the person receiving?[3]

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?

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

41. Who will collect the available background data (recommend using the same staff person that collects the pre-survey information)?
42. Which databases will be used?
43. How will the available background data be transmitted to the contractor/interviewers?
44. Who will enter background data into ODESA and when will this happen?
45. Based on a review of the information available in administrative records, which background questions **cannot** be answered?
    a. How will interviewers know which background questions to include at the end of the interview?
46. When will background data collection from administrative records begin?

IX. Survey Administration

The following questions should help guide the state in preparing for survey administration:

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[1] "Self-directed" or "participant-directed" supports options offer individuals (and their representatives, including family members) the opportunity to manage some or all of their services. They may hire & fire their own support workers and/or control how their budget is spent. [Note: We are referring to a formal self-direction program.]
[2] Answer options to question BI-16 will be specific to each State's programs and sample populations. These options will be programmed into ODESA and ready for use when the State begins conducting interviews.
[3] Types of paid long-term care supports in question BI-19 must be crosswalked to the available administrative data at the State.

47. What is the strategy for coordinating interview schedules, including assigning interviews to interviewers?
48. When will in-person interviews begin?
49. When will all in-person interviews be completed?
50. When/who will enter all data into ODESA?
51. How will refusals, incompletes, bad contacts, etc. be tracked?
52. How will interviewers contact and gain access to individuals living in settings where they do not have direct access to a phone?
53. Will interviewers wear a badge or bring any other kind of official document?
54. Will interviewers be provided with any leave behind documents?
55. How will the state or vendor provide quality oversight and monitoring of survey administration?
56. How will data be kept secure?
57. What are relevant data privacy and HIPPA protocols and what procedures will interviewers/vendors need to follow?

X. Reporting

HSRI will review the data for completion and validity (i.e. "clean" the data). If, during the cleaning process, questionable items are found, HSRI staff will need to contact state staff to verify the information. HSRI will produce draft reports before public release, and look to states for feedback. The following questions should help guide the state in preparing for reporting:

58. Who will verify information as needed (state staff, contractor staff, etc.)?
59. Who will review the draft reports and providing feedback?