**SUBJECT MATTER EXPERT INTERVIEW:
RESEARCHERS AND REPRESENTATIVES OF DISABILITY ADVOCACY ORGANIZATIONS AND
PROVIDER ASSOCIATIONS**

COVERAGE GAPS IN THE NATIONAL STUDY OF LONG-TERM CARE PROVIDERS

Introduction

Thank you for taking time to meet with us. My name is [*interviewer*], and I am joined by [*colleague*]. We work for RTI International, a nonprofit research organization. As part of the National Study of Long Term Care Providers (NSLTCP), the National Center for Health Statistics (NCHS) currently collects information on nursing homes, home health agencies, some types of residential care communities, and hospices and adult day service providers. The NSLTCP does not collect information on residential care communities that have fewer than four beds or that are licensed to exclusively serve people with serious mental illness or intellectual or developmental disabilities. The NCHS has contracted with RTI to determine the advisability and feasibility of expanding the NSLTCP to include additional provider types.

To determine this, we are conducting interviews with experts who are knowledgeable about providers of long-term care services for individuals with a broad range of disabilities and about data sources for these providers.

With your permission, we would like to audio-record the conversation to most accurately and comprehensively capture the content of the discussion. RTI will summarize the information gathered from the interviews into a final report for internal NCHS use only. The information you provide will be held confidential. Information which would identify you or link you with your responses will only be used by NCHS staff and its contractors for the purposes of this project, and will not be disclosed to anyone else. All documentation generated as a result of the interviews, such as electronic notes and audio recordings, will be transferred securely to NCHS for storage and safekeeping.

Do you have any questions before we start the interview?

May we audio-record this conversation?

[*If audio-recording is permitted by interviewee*] We are now starting the audio-recording.

Questions

1. **To begin, please tell us briefly about the organization for which you work and your role in the organization.**

   a. **[If a provider organization] What types of providers does this organization represent?** What proportion of all these types of providers belong to this association?

   b. Nationally, how many providers of this type are there? How many providers are there in your state? [If the respondent does not know how many, ask for an estimate.]

   c. **Which populations with disabilities are you most involved with?**

   [*Optional probes*]
       i. People age 65 and older with cognitive and physical disabilities?

       ii. Adults age 18 to 64 with physical disabilities?

       iii. Adults age 18 to 64 with intellectual and other types of developmental disabilities?

       iv. Children with intellectual and other types of developmental disabilities?

       v. Adults age 18 to 64 with traumatic brain injury?

       vi. Adults age 18 to 64 with serious mental illness?

       vii. Children with serious emotional disturbances?

       viii. Adults of all ages with substance use disorders?

2. **For [*the population with whom the interviewee works; repeat for each*], what long-term care providers are important in meeting the needs of this population other than the ones already included in the NSLTCP? By most important, we mean those providers who serve the greatest number of people, represent the highest level of expenditures, or furnish the most critical services, or a combination of these characteristics.**

   Repeat questions below for each provider type identified.

   a. What services are offered by this type of provider (e.g., case management, transportation, housing, meals, and employment support)?

       i. [*For those services where the definition is not clear*] How would you describe this service?

   b. Are these providers licensed, certified, or otherwise regulated?

       i. [*If Yes*] What type of government agencies license or certify this type of provider?

ii. [*optional probe*] Is the regulation done at the state or local level?

    c. Does Medicaid have contract requirements or does Medicare have conditions of participation that providers must meet to receive reimbursement for services? What about other public programs?

    d. Nationally, how many people does this provider type serve on the average day? *[Provide estimate if number unknown.] [If subject matter expert does not have national estimate]* How many people does this provider type serve on the average day in this state?

    e. Nationally, what are the sources of payment for this provider type? Do you have an estimate of the level of funding, both by public programs or overall? *[Provide estimate if number unknown.] [If subject matter expert does not have national estimate]* What are the sources of payment for this provider type in this state? Do you have an estimate of the level of funding, both by public programs or overall in this state?

3. **For [*the providers identified above; repeat for each provider*], do you know of any data sources that include a list of providers with addresses, telephone numbers, or other contact information?**

    [*If YES, ask the following*]
    a. Who maintains this list? The federal, state, or local government? Does your organization maintain a list of providers?

    b. How complete is this list?

    c. How current or how frequently updated is this list?

    d. Is this list available in an electronic form? In what format is the list (e.g., Word, Excel, Access database, PDF, some other format)?

        i. [*If No*] In what form is this information available?

    e. Other than addresses and contact information, what other information is included on this list (e.g., data on number and characteristics of service users, ownership type, number of people served, services offered)?

    f. To develop a sample frame for a survey or to analyze the data list to learn about provider or user characteristics, NCHS would need access to a list of providers with contact information. Do you know if this list could be made available to NCHS or its contractors?

4. **If the National Center for Health Statistics were to include [*the providers identified above; repeat for each provider*] in its national study, what information about the providers and the services they provide would be most useful to providers, consumers and their advocates, researchers, and policymakers?**

[*Optional probes a-f*]

    a.   How would this information be useful for [repeat for each of the following groups: providers; consumers and their advocates; researchers; policymakers]?

    b.   What information about the providers would be important to collect (e.g., for-profit/nonprofit ownership, size/number of employees, types of services provided)?

    c.   What information about provider staff would be important to collect (e.g., types of staff, staffing levels, and training requirements)?

    d.   What information about the services they provide would be important to collect (e.g., duration and frequency of service delivery)?

    e.   What information about service users would be important to collect (e.g., age, race, ethnicity, type of disability, health conditions)?

    f.   What financial information would be important to collect (e.g., cost of services)?

    g.   What other types of information would be important to collect?

5. **For the population with disabilities with which you work, what three types of providers would you say are the most important to include in the National Study of Long-Term Care Providers (providers other than nursing homes, some residential care facilities, home health agencies, hospices, and adult day service centers)?**

    a.   **Why did you choose those provider types?**

    b.   Residential care communities that exclusively serve persons with intellectual or developmental disabilities and persons with serious mental illness are currently excluded from the NSLTCP. How important do you think it is to include these residential care communities in the NSLTCP?

6. **Finally, do you know of any additional sources of information or data about long-term care service providers for people with disabilities?**

THANK YOU FOR PARTICIPATING!