

Attachment E: Semi Structured Telephone Protocol – IDD Exploratory Work

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Assurance of Confidentiality – We take your privacy very seriously. All information that relates to or describes identifiable characteristics of individuals, a practice, or an establishment will be used only for statistical purposes. NCHS staff, contractors and agents will not disclose or release information in identifiable form without the consent of the individual or establishment in accordance with section 308(d) of the Public Health Service Act (42 USC 242m) and the Confidential Information Protection and Statistical Efficiency Act of 2002 (CIPSEA, Title 5 of Public Law 107-347). In accordance with CIPSEA every NCHS employee, contractor, and agent has taken an oath and is subject to a jail term of up to five years, a fine of up to \$250,000, or both if he or she willfully discloses ANY identifiable information about you. In addition, NCHS complies with the Cybersecurity Enhancement Act of 2015. This law requires the Federal government to protect its information by using computer security programs to identify cybersecurity risks against federal computer networks.

The Cybersecurity Act of 2015 permits monitoring information systems for the purpose of protecting a network from hacking, denial of service attacks and other security vulnerabilities.¹ The software used for monitoring may scan information that is transiting, stored on, or processed by the system. If the information triggers a cyber threat indicator, the information may be intercepted and reviewed for cyber threats. The Cybersecurity Act specifies that the cyber threat indicator or defensive measure taken to remove the threat may be shared with others only after any information not directly related to a cybersecurity threat has been removed, including removal of personal information of a specific individual or other information that identifies a specific individual. Monitoring under the Cybersecurity Act may be done by a system owner or another entity the system owner allows to monitor its network and operate defensive measures on its behalf.

¹ “Monitor” means “to acquire, identify, or scan, or to possess, information that is stored on, processed by, or transiting an information system”; “information system” means “a discrete set of information resources organized for the collection, processing, maintenance, use, sharing, dissemination or disposition of information”; “cyber threat indicator” means “information that is necessary to describe or identify security vulnerabilities of an information system, enable the exploitation of a security vulnerability, or unauthorized remote access or use of an information system”.

Introduction

Thank you for taking time to meet with me today. My name is [Interviewer]. I work with RTI International, a nonprofit research institute. We are conducting this exploratory research on behalf of the CDC’s National Center for Health Statistics (NCHS). NCHS conducts the biennial National Study of Long-term Care Providers (NSTLCP) to monitor trends in supply, provision and use of the major sectors of paid, and regulated long-term care services for adults. As part of this study, state-regulated assisted living and similar residential care communities (RCCs) are included. In previous years, RCCs that have exclusively served an intellectually and developmentally disabled (IDD) population have been excluded from the study; we are now conducting an exploratory project to assess the feasibility of including them in future years of the NSTLCP. We are asking for your help to confirm the licensed IDD RCC categories we have identified that may exclusively serve an IDD adult population. This phone call will take on average 30 minutes to complete. For this interview, we are focused on state licensed, certified or registered residential care facilities that provide care -- not licensed IDD services.

All information collected will be used only for statistical purposes. NCHS staff, contractors and agents will not disclose or release responses in identifiable form without your consent. If you have any questions about confidentiality or your rights as a participant in this research study, call NCHS’ Confidentiality Officer Eve Powell-Griner at (888) 642-1459.

Participation is voluntary, but will assist greatly in helping further our nation’s understanding of residential care communities.

Do you have any questions before we begin?

Are you already to start the interview?

- 1. First, how does your state define IDD?**
- 2. What category of residential care facilities for adults with IDD are regulated (licensed, registered, or certified) at the State level? (list all)**

[NOTE FOR INTERVIEWER: Do not include categories that are ICF level or are for services brought into the IDD adult's personal home]:

- 3. Are these residential care facility categories required to provide or offer:**
 - at least 2 *prepared* meals per day?
 - personal care and/or assistance with medications?
 - 24-hour direct care supervision for scheduled and unscheduled care needs?
- 4. Do any of these licensure categories:**
 - Serve three or fewer adults with IDD?
 - Exclusively serve an IDD population?
 - Serve a mixed population? (*define the allowed mix*)
 - Serve anyone under the age of 18?
- 5. What agency is responsible for licensure for each licensure category?**
 - Is the category licensed at the state or local level?
 - If local, probe as to how many local/regional offices there are and confirm whether the state oversees all of the local offices
 - Is a listing of all licensed facilities maintained at the state or local level?
 - Probe for contact information for each licensed category, if different from current contact.
 - Can you estimate the number of licensed facilities in each licensure category?
 - Are listings of residential care facilities for adults with IDD publicly available?
 - If yes, how can we access them?
 - Are they pdf or excel?
 - Do they include: facility name, address, phone number, administrator, licensed bed capacity, [owner, license number, types of residents?
 - If not, how should we request a copy of it?
 - Would someone at the state be able to create a listing for us that includes, at a minimum: facility name, address, phone number, administrator, licensed bed capacity, license number (or facility ID).
 - How current are these lists? How frequently are these lists updated?
- 6. If we have additional questions, can I follow-up with you by email/phone?**

7. Thank you and closure.