

NCHS Human Subject Research Determination Request Form

Protocol Identifiers

Protocol Title: **State Agency Interviews about Residential Care Facilities Licensed to Exclusively Serve Residents with Intellectual and Developmental Disabilities for the National Study of Long-Term Care Providers**

NCHS Primary Contact

| | Name and degrees (First name Last name, Degrees) | User ID | Telephone# | NCHS Division/Branch |
|-----------------|---|---------|--------------|----------------------|
| Primary Contact | Lauren Harris-Kojetin, Ph.D. | FTI3 | 301-458-4369 | DHCS/LTCSB |

NCHS' Role in the Project

Yes No NCHS Employees or agents will obtain data by intervening or interacting with participants.

Yes No NCHS Employees or agents will obtain or use identifiable (including coded) private data or biological specimens.

Protocol Description (Please attach copies of any relevant protocol materials.)

The National Study of Long-Term Care Providers (NSLTCP) currently includes regulated residential care facilities that mainly serve an older adult population or an adult population with physical disabilities. However, among its coverage gaps, NSLTCP excludes residential care facilities that exclusively serve residents with intellectual and developmental disabilities (IDD). NCHS seeks to add this sector in the 2018 NSLTCP survey wave. Residential care facilities are regulated at the state rather than the national level, so the previous waves (2012-2016) of the NSLTCP residential care facility sampling frame have been constructed by identifying relevant licensure categories each state's website, interviewing state government representatives to verify which licensure categories meet the NSLTCP definition of residential care, and collecting lists of residential care facilities for each of the relevant licensure categories. Often the state government agencies that regulate the IDD-exclusive residential care facilities differ from the agencies that regulate residential care facilities that serve older adults and adults with physical disabilities. To help meet the goal of adding the IDD-exclusive residential care facility sector in the 2018 NSLTCP—by including both IDD-exclusive and non-IDD-exclusive residential care facilities in the 2018 sampling frame construction—the purpose of this exploratory work is to better understand the state government information sources on IDD-exclusive residential facilities. **This exploratory project is to conduct interviews with up to 65 state government representatives (some states have more than 1 agency) in the 50 states and the District of Columbia from agencies that regulate IDD-exclusive residential care facilities (see attached protocol summary).** The contact information for each state regulatory agency and its director will be obtained based on internet searching of publicly available information. The purpose of these interviews is to confirm the IDD residential care facility licensure categories we have identified that may exclusively serve an IDD adult population, to estimate the number of licensed facilities in each of these state licensure categories, and to determine whether the listings of residential care facilities for adults with IDD are publicly available, to inform the future construction of the 2018 RCC sampling frame.

Assessment of Requirements for IRB Review

Please provide details as to how the protocol relates to Title 45 Code of Federal Regulations (CFR), Part 46 requirements for IRB review. (Go to <http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.html> to access 45 CFR part 46.) Is the activity a systematic investigation designed to develop or contribute to generalizable knowledge [45 CFR 46.102(d)]? Does the research

Date received by Human Subject Contact Office:

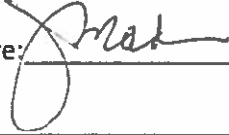
involve a living individual about whom the investigator conducting the research obtains either (1) data through intervention or interaction with the individual, or (2) identifiable private information [45 CFR 46.102(f)]?

The investigative team believes that this proposed activity does consist of a systematic investigation designed to develop generalizable knowledge and, therefore, meets the definition of research as stated by 45 CFR 46.102 (d). However, the investigative team believes that the research does not meet the criteria of involving human subjects. All collected information will be at the state level, and will be about the state's regulations and listings of regulated facilities. Although there will be interaction with individuals (state government representatives) through semi-structured interviews, this project will not collect private information about the state government representatives, other than their names and work contact information (through publicly available sources) for purposes of contacting them to conduct the interviews. According to 45 CFR 46.102 (f), a human subject is a living individual about whom an investigator conducting research obtains either (1) data through intervention or interaction with the individual, or (2) identifiable private information. The investigative team respectfully submits this human subject research determination request suggesting that this project does not meet the definition of Human Subjects Research and therefore would not be subject to IRB (NCHS ERB) review.

Human Subject Contact Office Use Only

Does not meet the definition of Human Subjects Research: Does not require IRB (NCHS ERB) Review

Date: 10/25/16

Signature: 

Remarks: _____

Does meet the definition of Human Subjects Research: Requires IRB (NCHS ERB) Review

Date: _____ Signature: _____

Remarks: _____

State Agency Interviews about Residential Care Facilities Licensed to Exclusively Serve Residents with Intellectual and Developmental Disabilities for the National Study of Long-Term Care Providers

October 21, 2016

Background

The biennial National Study of Long-Term Care Providers (NSLTCP) produces national and state statistical information about the supply, use, and key characteristics of providers and services users in the major sectors of paid, regulated long-term care services in the United States. NSLTCP is intended to enable efficient monitoring of the diverse field of long-term care services and to help support and inform long-term care policy, research, and practice.

The first three NSLTCP waves conducted between 2012 and 2016 included five sectors. NCHS uses nationally representative administrative data (regulatory, assessment, and claims) obtained from the Centers for Medicare & Medicaid Services on nursing homes and residents, home health agencies and patients, and hospices and patients; and collects primary data through surveys on residential care facilities and residents and adult day services centers and enrolled participants, because national administrative data are not available on these two sectors.

Although NSLTCP includes five sectors, coverage gaps remain. One of these coverage gaps is residential care facilities that, although they meet other elements of the NSLTCP residential care facility definition, are excluded because they exclusively serve adults with intellectual and developmental disabilities (IDD). The current NSLTCP study definition of a residential care facility is one that is licensed, registered, listed, certified, or otherwise regulated by the state to provide room and board with at least two meals a day, provide around-the-clock on-site supervision, and offer help with activities of daily living (e.g., bathing, eating, or dressing) or health-related services (e.g., medication supervision); serves primarily an adult population; and has at least four licensed, certified, or regulated beds. Residential care facilities licensed to serve the mentally ill or IDD populations exclusively have to date been excluded from NSLTCP. As with residential care facilities more generally, IDD-exclusive residential care facilities are regulated at the state rather than the federal level, so the national sampling frame of residential care facilities used for each NSLTCP survey wave has been created from lists of regulated facilities in each state. NCHS intends to add IDD-exclusive residential care facilities and their residents to the 2018 NSLTCP wave, by including state-regulated IDD-exclusive residential care facilities into the process of creating the 2018 residential care frame.

Objectives

To help meet the goal of adding the IDD-exclusive residential care facility sector in 2018, the purpose of this exploratory work is to better understand the residential facilities that exclusively serve adults with IDD and the state regulatory environment in which they operate. This exploratory work includes several components: (1) review the residential care facility state regulatory licensure categories already reviewed for the 2016 NSLTCP wave and add any categories that were excluded from the 2016 wave because they exclusively served adult residents with IDD; (2) identify other potentially eligible residential care facility state licensure categories, some of which fall under state agencies not previously included in earlier waves of NSLTCP frame development; and (3) describe the extent to which comprehensive listings of regulated IDD-exclusive residential care facilities are available and from what agencies, to inform the 2018 residential care facility frame activities. Three methods will be used to complete this exploratory work: (1) internet searches of publicly accessible state web sites; (2) review and summarizing of relevant state regulations for licensure categories not previously included in NSLTCP; and, (3) interviews with state government representatives that oversee licensure categories for IDD-exclusive residential care facilities. This protocol summary is for the third method, conducting interviews.

Design

The information will be collected from state government representatives in the 50 states and the District of Columbia via telephone interviews, resulting in up to 65 interviews since some states have more than one agency that regulates IDD-exclusive residential care facilities. The procedure to identify the state government representatives to interview includes: (1) based on searching state agency websites and a targeted regulatory review, states agencies will be identified as overseeing licensure categories of residential care facilities that potentially exclusively serve an IDD adult population; (2) based on searching state agency websites, the state government representatives (typically the director, manager, or leader of the state regulatory program) will be identified along with the person's work contact information (email, telephone, address).

The first step in the data collection process is a telephone call to state agencies to verify the preliminary contact information (e.g., work telephone and email) for the state government representatives that we obtained from searching state agency websites (Attachment A). Using the verified contact information, we will email an advance package to each state government representative that includes a cover letter from NCHS stating the purpose and importance of the interview, and noting that they will be called shortly (Attachment B-1). Each email will be tracked to ensure that it was delivered to the intended contact. For those that are returned, we will call the agency and get clarification on the email address and resend. If we receive a

response that directs us to another representative in the state, we will send a new package to that person via email and restart the process of contacting them using the previously described steps. Within a week of emailing the advance package, we will begin to contact these state government representatives by telephone using a scheduling script (Attachment C) to set up the interviews. We will use a semi-structured protocol (Attachment D) for the interviews. The data to be collected from these state government representatives, which constitute the agenda for the calls with them, include (1) confirming that we have identified the appropriate licensure categories of residential care facilities within each state that serve adults with IDD and meet the NSLTCP definition and (2) for each relevant licensure category, obtain information about the availability of a listing of licensed facilities, what data are included on the listing, how current the listing is, and how to obtain the listing. A thank you letter will be emailed after we have completed the interview with each state government representative (Attachment E).

Sensitivity

We will not collect identifiable private information about the state government representatives. The names and work contact information of the state government representatives are publicly available on the state agency websites. The information that state government representatives provide during the interviews will be used exclusively for statistical purposes and will be kept confidential. NCHS will not publicly release the names of the state government representatives who participate in the interviews nor their responses.

Data

The interview questions are designed to collect information on how a state defines IDD; what residential care settings the state regulates; the state's definition of each licensure category and how it relates to the NSLTCP eligibility criteria for a residential care facility; and for each licensure category, what is the responsible state agency, the approximate number of facilities, and how to obtain listings of these facilities. No personal information will be collected.

Users and Reporting

During each interview the NCHS contractor will take notes; these electronic notes, will be transferred securely to NCHS for storage/safekeeping. The electronic notes will be analyzed to create a summary. The summary will note patterns, and similarities and differences among states in response to the interview questions regarding regulating residential care communities that exclusively serve adults with IDD. The summary will also list the licensure categories used by each state, and include a listing of all state agencies and work contact information for the state government representatives interviewed. **Confidentiality for the state government representative respondents is being promised; no information about specific states will be**

released publicly, because doing so could make it possible to identify the name of the respondent. The summary document is for internal use by NCHS only; the summary document will not be published or otherwise be made publicly available. No publicly available publications are planned at this time. However, if NCHS were to share results publicly from this project in the future, only statistical results would be provided (e.g., xx% of states use this approach to regulation, while xx% use that approach); no information about individual or specific states or individual or specific state agency representatives will be shared publicly.

Expected users of the information gained from this project include staff of NCHS' Long-Term Care Statistics Branch and project staff for its contractor, RTI International.

Findings from these interviews will be used to inform construction of the 2018 residential care facility sampling frame which will be used to draw a sample of residential care facilities for the 2018 NSLTCP survey. Adding IDD-exclusive residential care facilities to NSLTCP will enable NCHS to fill a gap in coverage, which will make NSLTCP findings useful to data users interested in this sector and population. Expected users of this potential, future new data include, but are not limited to NCHS and its contractors; other Department of Health and Human Services (DHHS) agencies, such as the Office of the Assistant Secretary for Planning and Evaluation and the Administration for Community Living; state government agencies, such as State departments of developmental disabilities; associations, such as National Association of States United for Aging and Disabilities and the National Association of State Directors of Developmental Disabilities Services; universities; foundations; and other private sector organizations.

Attachment A: Contact Information Verification

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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".

VERIFY CONTACT INFORMATION

- Hello, my name is _____. I am calling regarding the National Study of Long-Term Care Providers that RTI International is conducting for CDC's National Center for Health Statistics.
- I have some information that I would like to email to the following state government representative [name]. May I please verify this person's name and title?
- I have the name of this state government representative as _____. SPELL IF NECESSARY. Is this correct?
- I have the address of the state government representative as _____. Is this correct? Is there a separate mailing address you would like to give me?
- The number I called is [xxx-xxx-xxxx]. Is this the correct number to reach _____? REPEAT TO VERIFY
- What is [state government representative's] email address? SPELL ALOUD TO VERIFY.
- Thank you. We will email this information in the near future. Have a good day. Good bye.

Attachment B-1: Advance Package NCHS Cover Email

Date

Name of State Representative

Name of Agency

Agency Address

Agency City, State, Zip

Dear <Name of State Representative>,

The CDC's National Center for Health Statistics (NCHS) is exploring adding state-regulated assisted living and similar residential care communities in the United States that serve adults with intellectual/developmental disabilities (IDD) to the **National Study of Long-Term Care Providers (NSLTCP)**.

We are asking for your help to identify the licensure categories of residential care facilities (or communities) in your state along with the availability of listings of such licensed facilities that could be used to create a listing of IDD facilities for future NSLTCP surveys. A representative of RTI International will contact you soon to arrange an appointment for a short telephone call. During the scheduled call we will verify your state's current regulatory categories for residential care facilities that serve adults with IDD and ask for some further details about each licensure category. We expect the discussion to take on average 30 minutes or less. Your participation is voluntary, but will assist greatly in helping further our nation's understanding of residential care communities for adults with IDD.

For NSLTCP, the definition of a residential care community is one that is regulated by the state to provide room and board with at least two meals a day, provide around-the-clock on-site supervision, and help with activities of daily living (e.g., bathing, eating, or dressing) or health related services, such as medication supervision; serves primarily an adult population; and has at least four licensed, certified, or regulated beds. Facilities licensed to serve a mentally ill population exclusively are excluded. Nursing homes, skilled nursing facilities, and intermediate care facilities are also excluded, unless they have a unit or wing meeting the above definition and residents can be separately enumerated.

Please know that nothing you tell us will be shared. All information collected will be used only for statistical purposes. Strict federal laws protect your information. Questions on the back of this letter describe these laws and who may see your personal information. If you have any questions about confidentiality, call NCHS' Confidentiality Officer Eve Powell-Griner at (888) 642-1459.

Thank you in advance for your help with this important endeavor.

Sincerely,

Charles J. Rothwell, MS , MBA
Acting Director, National Center for Health Statistics

If you would like to learn more about this study, please visit <http://www.cdc.gov/nchs/nsltcp.htm>.

Frequently Asked Questions

1. WHO WILL SEE MY ANSWERS?

We take your privacy very seriously. The answers you give us are used for statistical research only. This means that your answers will be combined with other people's answers in a way that protects everyone's identity. As required by federal law, only those NCHS employees, and our specially designated agents (such as RTI International), who must use your personal information for a specific reason can see your answers. Anyone else is allowed to use your data only after all information that could identify you and/or your agency has been removed.

Strict laws prevent us from releasing information that could identify you or your agency to anyone else without your consent. A number of federal laws require that all information we collect be held in strict confidence: Section 308(d) of the Public Health Service Act (42 United States Code 242m), the Confidential Information Protection and Statistical Efficiency Act (CIPSEA, Title 5 of Public Law 107-347), and the Privacy Act of 1974, 5 U.S.C. § 552a. Every NCHS employee, contractor, and agent has taken an oath to keep your information private. Any NCHS employee, agent or contractor who willfully discloses ANY identifiable information could get a jail term of up to five years, a fine of up to \$250,000, or both. In addition, NCHS complies with the Federal Cybersecurity Enhancement Act of 2015. This law requires the federal government to protect federal computer networks by using computer security programs to identify cybersecurity risks like hacking, internet attacks, and other security weaknesses.

2. WHAT DO MY ANSWERS HAVE TO DO WITH CYBERSECURITY?

The purpose of the Federal Cybersecurity Enhancement Act of 2015 is NOT to read your personal information. The act allows software programs to scan information that is sent, stored on, or processed by government networks in order to protect the networks from hacking, denial of service attacks, and other security threats. If any information is suspicious, it may be reviewed for specific threats by computer network experts working for the government (or contractors or agents who have governmental authority to do so). Only information directly related to government network security is monitored. The Act requires any personal information that identifies you, your agency, or your answers to questions to be removed from suspicious files before they are shared.

Attachment C: Telephone Scheduling Script

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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.

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SCHEDULER WILL CALL STATE AGENCY REPRESENTATIVE. IF THE STATE AGENCY REPRESENTATIVE IS NOT AVAILABLE OR IF ROUTED TO VOICEMAIL, THE SCHEDULER WILL OFFER TO CALL BACK.

IF STATE AGENCY REPRESENTATIVE IS AVAILABLE:

Hello, my name is _____. I am calling regarding the National Study of Long-Term Care Providers that RTI International is conducting for CDC's National Center for Health Statistics. Recently you received an email from Kristie Porter at RTI International that contained a letter from the director of the National Center for Health Statistics, Charlie Rothwell. The National Center for Health Statistics is currently exploring adding residential care facilities that exclusively serve an IDD population to the National Study of Long-Term Care Providers. I am calling to schedule a 30-minute interview to be conducted over the phone. Would it be possible for you to schedule this interview now?

IF NO → Ok, when would be a better time to call you to schedule the interview? OBTAIN AND RECORD DATE AND TIME TO CALL BACK.

DATE: ____/____/2016
MONTH DAY

TIME: __:__ AM/PM

We will call you back at this time to schedule the interview. If you have any questions before then, please e-mail me at XXXXX@rti.org or call me at [SCHEDULER TELEPHONE NUMBER]. Thank

you.

IF YES → SCHEDULE AN APPOINTMENT WITH THE SUBJECT MATTER EXPERT AND CONFIRM THE PHONE NUMBER.

DATE: ____/____/2016
MONTH DAY

TIME: __:__ AM/PM

PHONE NUMBER TO CALL FOR INTERVIEW: (____) - ____ - _____, EXT: _____

I have scheduled an appointment for you with [INSERT NAME of RTI Interviewer] on [RESTATE DATE AND TIME OF APPOINTMENT]. [INSERT NAME of RTI Interviewer] will call you. If you have any questions before the appointment or need to reschedule, please e-mail me at XXXXXX@rti.org or call me at [SCHEDULER TELEPHONE NUMBER].

Thank you.

Attachment D: Semi Structured Telephone Protocol – IDD Exploratory Work

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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.**

Attachment E: Thank You Letter



DEPARTMENT OF HEALTH & HUMAN SERVICES
Centers for Disease Control and Prevention
National Center for Health Statistics
3311 Toledo Road
Hyattsville, Maryland 20782

Thank You

I want to personally thank you for helping us to learn about licensed residential care facilities in your state that serve adults with intellectual and developmental disabilities. It is only through the cooperation of state officials like you that we are able to make an informed decision as to whether to include these facilities in future surveys for the National Study of Long-Term Care Providers (NSLTCP). The NSLTCP's findings are an invaluable source of information for health care professionals, long-term care providers, policymakers, researchers, and the general public.

Again, I appreciate the time and effort you have given in support of this study.

Sincerely,

A handwritten signature in black ink, appearing to read "Charles J. Rothwell".

Charles J. Rothwell, MS, MBA
Director, National Center for Health Statistics

If you would like to learn more about this study, please visit <http://www.cdc.gov/nchs/nsltcp.htm>.