

[NCHS Letterhead]

Date

Name of Director
Name of Community
Community Address
Community city, state, zip code

Dear <NAME OF DIRECTOR >,

We contacted you recently about participating in the **2016 National Study of Long-Term Care Providers (NSLTCP)**. We need your help with this important research to further our nation's understanding of the long-term care needs of seniors and younger adults with disabilities.

To participate, please complete the questionnaire by web over a safe and secure network by going to this URL address and typing in your unique User ID and password:

URL:

User ID:

Password:

Benefits to completing by web include getting only the questions that apply to your community based on your responses—so it takes less time—and having the option to print a copy of your completed questionnaire for your records. However, if you prefer to use hardcopy, please complete the enclosed questionnaire and return it in the pre-addressed, postage-paid envelope provided.

Please submit the questionnaire by web or hardcopy by August 19, 2016. Otherwise, you may receive a call to complete the questionnaire by telephone. If you are the director for more than one community selected for this study, you will receive and be asked to complete a separate questionnaire for each selected community. If you have already completed and returned your questionnaire, this letter and your package may have crossed in the mail; you do not have to complete the questionnaire a second time.

Completing the questionnaire will take 30 minutes on average. Before starting, please consult or have your records available to be prepared to answer questions on the number of residents (see question x), numbers of select types of staff (see question x), and the demographic distribution, activities of daily living, health conditions, and health care use of the residents (see questions x-x).

The information you provide will be used only for statistical purposes and held in the strictest confidence. See http://www.cdc.gov/nchs/nsltcp/nsltcp_products.htm for examples of products using NSLTCP data.

These organizations join me in urging you to participate in this important study: the Center for Excellence in Assisted Living (CEAL), American Seniors Housing Association (ASHA), Assisted Living Federation of America (ALFA), LeadingAge, and the National Center for Assisted Living/American Health Care Association (NCAL/AHCA).

On the back of this letter are NSLTCP Frequently Asked Questions. If you need technical support or have further questions about this survey, visit <http://www.cdc.gov/nchs/nsltcp.htm> or call (XXX) XXX-XXXX.

Sincerely,

Charles Rothwell

Director, National Center for Health Statistics

National Study of Long-Term Care Providers (NSLTCP)
Frequently Asked Questions

Why should I participate in this survey?

CDC's National Center for Health Statistics (NCHS) recognizes that residential care communities are an important part of the long-term care spectrum in the United States. NCHS' National Study of Long-Term Care Providers (NSLTCP) tracks trends, every two years, in the supply and use of five major types of long-term care providers—assisted living and similar residential care communities, adult day services centers, home health agencies, nursing homes, and hospices. When you participate in NSLTCP, you help ensure that the survey data for residential care communities are up-to-date and accurately portray your industry to health care planners and policymakers.

Should I complete a questionnaire if I participated in NSLTCP in 2012 or 2014?

Yes. Your participation in this 2016 survey is important. NSLTCP is conducted every two years to obtain accurate, up-to-date data about residential care communities, other long-term care providers, and the people they serve to detect changes in the long-term care services industry over time.

What other residential care communities are being contacted to participate in this survey?

The 2016 survey includes approximately [insert number] residential care communities operating in the United States. This is a random nationally representative sample. To protect the privacy of individual communities, their staff, and the residents they serve, we do not release the names of sampled communities to anyone.

Will the results be made public?

An overview report that will include survey data from the 2016 NSLTCP is anticipated for release in 2017 and will be made available online at <http://www.cdc.gov/nchs/nsltcp.htm>. If you would like to be informed of when it is available, you may join the Long-Term Care ListServ at http://www.cdc.gov/nchs/dhcs/longterm_listserv.htm. Identifying information about participants will not be contained in the summary report. At http://www.cdc.gov/nchs/nsltcp/nsltcp_products.htm you can see examples of products that include NSLTCP data.

Why can't some other community take our place?

You represent other communities like yours. If you do not participate in NSLTCP, there is no guarantee that residential care communities like yours will be represented adequately and the representation of your community's unique qualities may be lost. NCHS produces state estimates where possible, and your participation may allow us to produce estimates for your state.

Where did you get my name?

Individual state licensing agencies provided the names of all licensed, certified, or otherwise regulated residential care communities in their respective states.

Will my name and information be held confidential?

Yes. NSLTCP is authorized by Congress in Section 306 of the Public Health Service Act (42 USC 242K). All information collected in this survey will be held in the strictest confidence according to law [Section 308 (d) of the Public Health Service Act (42 United States Code 242m (d) and the Confidential Information Protection and Statistical Efficiency Act (PL 107-347)]. Information collected in this survey may be used only for statistical purposes. Any government staff, contractor, or agent who willfully discloses confidential information may be subject to a jail term or a \$250,000 fine.

Who supports this study?

This survey is supported by the Center for Excellence in Assisted Living (CEAL), American Seniors Housing Association (ASHA), Assisted Living Federation of America (ALFA), LeadingAge, and the National Center for Assisted Living/American Health Care Association (NCAL/AHCA). The enclosed letter of support provides this specific information.

Where should I mail my completed hardcopy questionnaire?

Please return your completed questionnaire in the enclosed pre-addressed, postage-paid envelope. The address is: NSLTCP, RTI International, One North Commerce Center, 5265 Capital Blvd., Raleigh, NC 27616.

If I choose to complete the web questionnaire, can I stop partway through and start again, at a later time, where I left off?

Yes. The answers you entered will be saved, and you can pick up, at a later time, where you left off. You will not need to start the web questionnaire from the beginning again.

[NCHS Letterhead]

Date

Name of Director
Name of Center
Center Address
Center city, state, zip code

Dear <NAME OF DIRECTOR >,

We contacted you recently about participating in the **2016 National Study of Long-Term Care Providers (NSLTCP)**. We need your help with this important research to further our nation's understanding of the long-term care needs of older adults and people with disabilities.

To participate, please complete the questionnaire by web over a safe and secure network by going to this URL address and typing in your unique User ID and password:

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Please submit the questionnaire by August 19, 2016. Otherwise, you may receive a call to complete the questionnaire by telephone. If you are the director for more than one center, you will receive and be asked to complete a separate questionnaire for each of your centers. If you have already completed and returned your questionnaire, this letter and your package may have crossed in the mail; you do not have to complete the questionnaire a second time.

Completing the questionnaire will take 30 minutes on average. Before starting, please consult or have your records available to be prepared to answer questions on the number of participants (see questions x-x), numbers of select types of staff (see question x), and the demographic distribution, activities of daily living, health conditions, and health care use of the participants (see questions x-x).

The information you provide will be used only for statistical purposes and held in the strictest confidence. See http://www.cdc.gov/nchs/nsltcp/nsltcp_products.htm for examples of products using NSLTCP data.

The National Adult Day Services Association (NADSA), LeadingAge, and the National Association of States United for Aging and Disabilities (NASUAD) join me in urging you to participate in this important study.

On the back of this letter are NSLTCP Frequently Asked Questions. If you need technical support or have further questions about this survey, visit <http://www.cdc.gov/nchs/nsltcp.htm> or call (XXX) XXX-XXXX.

Sincerely,

Charles Rothwell

Director, National Center for Health Statistics

National Study of Long-Term Care Providers (NSLTCP)
Frequently Asked Questions

Why should I participate in this survey?

CDC's National Center for Health Statistics (NCHS) recognizes that adult day services centers are an important component of the long-term care spectrum in the United States. NCHS' National Study of Long-Term Care Providers (NSLTCP) tracks trends, every two years, in the supply and use of five major types of long-term care providers—adult day services centers, assisted living and similar residential care communities, home health agencies, nursing homes, and hospices. When you participate in NSLTCP, you help ensure that the survey data for adult day services centers are up-to-date and accurately portray your industry to health care planners and policymakers.

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Yes. Your participation in this 2016 survey is important. NSLTCP is conducted every two years to obtain accurate, up-to-date data about adult day services centers, other long-term care providers, and the people they serve to detect changes in the long-term industry over time.

What other adult day services centers are being contacted to participate in this survey?

The survey includes approximately [insert number] adult day services centers operating in the United States. To protect the privacy of individual centers, their staff, and the participants they serve, we do not release the names of these centers to anyone.

Will the results be made public?

An overview report that will include survey data from the 2016 NSLTCP is anticipated for release in 2017 and will be made available online at <http://www.cdc.gov/nchs/nsltcp.htm>. If you would like to be informed of when it is available, you may join the Long-Term Care ListServ at http://www.cdc.gov/nchs/dhcs/longterm_listserv.htm. Identifying information about participants will not be contained in the summary report. At http://www.cdc.gov/nchs/nsltcp/nsltcp_products.htm you can see examples of products that include NSLTCP data.

Why can't some other center take our place?

You represent other centers like yours. If you do not participate in NSLTCP, there is no guarantee that adult day services centers like yours will be represented adequately and the representation of your center's unique qualities will be lost. NCHS aims to produce state estimates where possible, and your participation may help allow us to produce estimates for your state.

Where did you get my name?

A nonprofit association of adult day services centers, under contract to NCHS, compiled a list of all adult day services centers in the U.S.

Will my name and information be held confidential?

Yes. NSLTCP is authorized by Congress in Section 306 of the Public Health Service Act (42 USC 242K). All information collected in this survey will be held in the strictest confidence according to law [Section 308 (d) of the Public Health Service Act (42 United States Code 242m (d) and the Confidential Information Protection and Statistical Efficiency Act (PL 107-347)]. Information collected in this survey may be used only for statistical purposes. Any government staff, contractor, or agent who willfully discloses confidential information may be subject to a jail term or a \$250,000 fine.

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Yes. The answers you entered will be saved, and you can pick up, at a later time, where you left off. You will not need to start the web questionnaire from the beginning again.

2016 NSLTCP Card Insert for Questionnaire Packets

2016 National Study of Long-Term Care Providers



User ID:

Password:

Please complete the questionnaire using the most convenient method for you: by web or by mailing in the hardcopy in the enclosed business reply envelope.

To complete by web:

- Go to the secure study website at **<https://nsltcp2016.rti.org>**
- Enter your unique User ID and Password printed on the left side of this card.

Need assistance? For technical problems or general questions call toll-free 1-XXX-XXX-XXXX

Variation in Residential Care Community Resident Characteristics, by Size of Community: United States, 2014

Manisha Sengupta, Ph.D.; Lauren D. Harris-Kojetin, Ph.D.; and Christine Caffrey, Ph.D.

Key findings

Data from the 2014 National Study of Long-Term Care Providers

- Residents in residential care communities with more than 25 beds were older than those in smaller communities.
- A higher percentage of residents in communities with 4–25 beds were receiving Medicaid compared with residents in larger communities.
- The prevalence of Alzheimer’s disease and depression was higher among residents of communities with 4–25 beds than in larger communities, but the prevalence of cardiovascular disease was lower.
- The percentage of residents needing assistance in bathing, dressing, toileting, transferring, walking, and eating was highest in communities with 4–25 beds.
- The percentage of residents who had fallen in the previous 90 days increased with increasing community bed size.

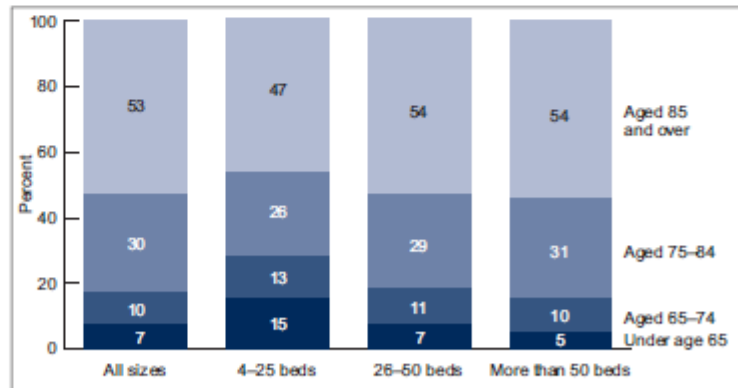
Residents of residential care communities are persons who cannot live independently but generally do not require the skilled care provided by nursing homes. There were 835,200 current residents in residential care communities in 2014 (1,2). “Current residents” refers to those who were living in the community on the day of data collection (as opposed to the total number of residents who lived in the community at some time during the calendar year). This report presents national estimates of selected characteristics of current residents in 2014 and compares these characteristics by community bed size. State-level estimates for these characteristics are available online at: http://www.cdc.gov/nchs/nsltcp/nsltcp_products.htm.

Keywords: assisted living • long-term care services and supports • National Study of Long-Term Care Providers

In 2014, residents in larger communities were older than those in smaller communities.

- Overall, the majority of residents of residential care communities (53%) were aged 85 and over (Figure 1).

Figure 1. Age distribution of residential care residents, by community size: United States, 2014



NOTES: For all age groups, there was a significant difference between communities with 4–25 beds and other community sizes ($p < 0.05$). Percentages are based on unrounded numbers; estimates may not add up to totals because of rounding. SOURCE: CDC/NCHS, National Study of Long-Term Care Providers, 2014.



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Centers for Disease Control and Prevention
National Center for Health Statistics



Variation in Adult Day Services Center Participant Characteristics, by Center Ownership: United States, 2014

Eunice Park-Lee, Ph.D.; Lauren D. Harris-Kojetin, Ph.D.;
Vincent Rome, M.P.H.; and Jessica P. Lendon, Ph.D.

Key Findings

Data from the 2014 National Study of Long-Term Care Providers

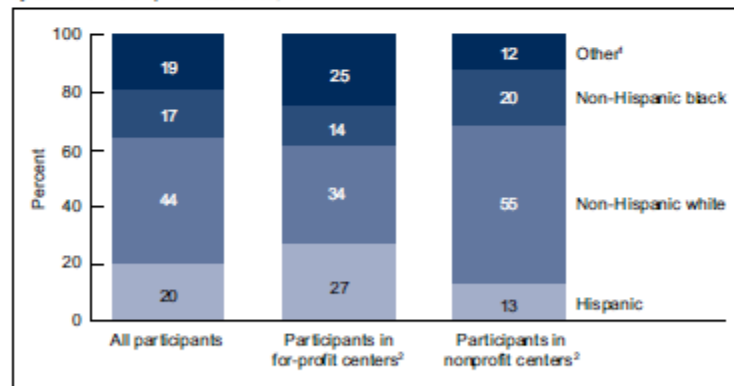
- The racial and ethnic composition of participants in for-profit adult day services centers was more diverse than in nonprofit centers.
- About 61% of participants in for-profit centers received Medicaid, compared with 46% of those in nonprofit centers.
- The percentage of participants living with Alzheimer's disease or with intellectual or developmental disability was higher in nonprofit adult day services centers than in for-profit centers.
- The percentage of participants needing assistance with dressing, toileting, and eating was higher in nonprofit centers than in for-profit centers.
- A higher percentage of participants in nonprofit centers (9%) than in for-profit centers (7%) had fallen in the last 90 days.

More than one-quarter million participants were enrolled in adult day services centers in the United States on the day of data collection in 2014 (1). The number of for-profit adult day services centers has grown in recent years (2). In 2012, 40% of adult day services centers were for-profit, serving more than one-half of all participants (3–5). This report presents the most current national estimates of selected characteristics of participants in adult day services centers and compares these characteristics by center ownership type. State-level estimates for the characteristics presented in this report are available online at http://www.cdc.gov/nchs/nsltcp/nsltcp_products.htm.

Keywords: medical conditions • activities of daily living (ADLs) • home and community-based services • National Study of Long-Term Care Providers

The racial and ethnic composition of participants in for-profit adult day services centers was more diverse than in nonprofit centers.

Figure 1. Percent distribution of race and ethnicity among adult day services center participants, by center ownership: United States, 2014



¹Includes participants of the following racial and ethnic backgrounds: non-Hispanic American Indian or Alaska Native, non-Hispanic Asian, non-Hispanic Native Hawaiian or other Pacific Islander, non-Hispanic of two or more races, other race or ethnicity category not reported in the center's system, and unknown race and ethnicity.
²Significant difference between participants in for-profit and nonprofit centers ($p < 0.05$).
NOTES: Cases with missing data are excluded; see "Data source and methods" for details. Percentages are based on unrounded numbers; estimates may not sum to totals because of rounding.
SOURCE: CDC/NCHS, National Study of Long-Term Care Providers, 2014.



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Centers for Disease Control and Prevention
National Center for Health Statistics



**How the
National
Health Care
Surveys
Keep Your
Information
Strictly
Confidential**

National Ambulatory Medical Care Survey

National Hospital Ambulatory Medical
Care Survey

National Hospital Care Survey

National Study of Long-Term Care Providers



Centers for Disease
Control and Prevention
National Center for
Health Statistics

Protecting the public's privacy...no idle pledge

There is safety in numbers, especially our numbers!

The law . . .

Information collected in the National Health Care Survey (NHCS) is used for research and statistical purposes only. No information that could identify a person or establishment can be released to anyone—including the President, Congress, or any court—without the consent of the provider.

The affidavit . . .

Anyone working for the National Center for Health Statistics (NCHS) must sign an affidavit—a legal document making them subject to the Privacy Act, the Public Health Service Act, and other laws.

The penalties . . .

Unauthorized disclosure of confidential statistical information is considered a class E felony that is punishable by imprisonment for up to 5 years, a fine of \$250,000, or both.

The record . . .

For more than 50 years, NCHS has protected confidential information collected in its surveys.

NCHS is well known for the high quality statistical information it provides. Maintaining that level of quality is not possible unless those who provide us with this information can be guaranteed confidentiality.

The confidentiality of records is of primary concern to NCHS. This principle is firmly grounded in federal laws, including the Privacy Act, the Public Health Service Act, the E-Government Act of 2002, 18 USC section 1001. NCHS staff must sign a pledge to obey these laws and associated regulations to prevent disclosure of information, and they must follow strict procedures concerning data access, physical protection of records, avoidance of disclosure, and maintenance of confidentiality.

A strong record for maintaining privacy during data collection and processing

NCHS collaborates with other organizations, for example, the U.S. Census Bureau and private research companies, to collect and process data for NHCS. These groups have an impeccable record of protecting the privacy of survey respondents.

HIPAA Privacy Rule on individual patient information and survey participation

The Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule permits you to make disclosures of protected health information without patient authorization for public health purposes and for research that has been approved by an institutional review board (IRB) with a waiver of patient authorization. The NHCS meets both of these criteria.

As part of the IRB approval process, all component surveys of the NHCS that collect information on individual patients have had a review of the survey's procedures for handling protected health

information. Based on the review, practices were determined to be appropriate for safeguarding respondent confidentiality. Additionally, disclosures may be made under a data-use agreement with NCHS for some surveys that do not collect directly identifiable data.

Copies of IRB approval letters and other related materials, such as data-use agreements, are available upon request for each component survey of the NHCS. There are several things that you must do to assure compliance with the Privacy Rule when participating in the survey. First, the privacy notice that you generally provide to your patients must indicate that patient information may be disclosed for either research or public health purposes. Second, you may need to keep a record of the disclosure that shows that some data from the patient's medical record were disclosed to CDC for NHCS (we will provide forms to assist you in record keeping). If you do not transmit health information electronically (such as claims data), you are not subject to the Privacy Rule or the requirements described above.

For additional information on the HIPAA Privacy Rule, see:

<http://www.hhs.gov/ocr/hipaa>

The National Study of Long-Term Care Providers is not subject to the privacy rule or IRB review because it collects aggregate level information.

Other safeguards for your privacy

- Items that could be used, either directly or indirectly, to identify health care providers or their patients are removed from public-use data files. Names, addresses, dates of birth, dates of service, and location of the health care establishment are never released to the public.
- NCHS withholds statistical totals if they represent a location so small that the numbers might identify someone.
- Information security procedures, including use of coded passwords and physical security of computers, prevent unauthorized access to the data.
- The restriction on who sees personal information extends from the highest levels of our government (we can deny the President and any member of Congress access to confidential information as well as Immigration, Justice, and IRS officials) to the kinds of inquiries we are all increasingly worried about (market research firms, insurance companies, employers). Your survey responses are also protected from the Freedom of information Act as well as court subpoenas.
- All published summaries are presented in such a way that no respondent can be identified.

We believe that our procedures for safeguarding information and our record of protecting the privacy of respondents are reasons why so many providers readily participate and provide reliable, high quality information. As a result, ample representative and accurate statistical information on health care utilization is made available every year to the American public, health care providers, the U.S. government, and the research community.

For further information

NCHS data are released in printed reports, CD-ROMs, and on the NCHS website,
<http://www.cdc.gov/nchs/>

For more information about how NCHS protects the information you provide, see:

<http://www.cdc.gov/nchs/about/policy/confidentiality.htm>

or contact:

Information Dissemination Staff
3311 Toledo Road, Room 5412
Hyattsville, MD 20782

For specific questions about how NCHS protects the information you provide, contact:

Confidentiality Officer
Eve Powell-Griner, Ph.D.
3311 Toledo Road, Room 7116
Hyattsville, MD 20782

Telephone: (888) 642-4159
E-mail: EPowell-Griner@cdc.gov



CS246861A

Draft PROVIDER ASSOCIATION LETTERS OF SUPPORT

RCC letter of support



In 2016, CDC's National Center for Health Statistics will conduct the third wave of the National Study of Long-Term Care Providers (NSLTCP), a biennial national study of the major sectors of paid, regulated providers of long-term care services. This data collection effort will include a representative sample of assisted living and similar residential care communities across the country.

National data collection will start in May 2016 and end in November 2016. The Center for Excellence in Assisted Living (CEAL), an organization representing providers, advocates, and other stakeholders in assisted living (see theceal.org) strongly encourages your participation as do the following organizations:

- American Seniors Housing Association (ASHA)
- Argentum
- LeadingAge
- National Center for Assisted Living/American Health Care Association (NCAL/AHCA)

Residential care directors/executive directors will be asked to complete a questionnaire about their community. The questionnaire will take approximately 30 minutes to complete. NSLTCP will collect information about the characteristics of residential care providers, services offered, staffing; and the demographics, functional status and health of the residents they serve.

The information collected will help policymakers, health care planners, and providers better understand, plan for, and serve the future long-term care needs of the older population and disabled adults.

While results from this survey will be made publicly available, all data will be kept strictly confidential and aggregated, so that the names of the communities, staff, residents and respondents will not be identifiable.

ADSC letter of support

The National Study of Long-Term Care Providers (NSLTCP), designed by the Centers for Disease Control and Prevention's National Center for Health Statistics (NCHS), is conducting its third survey of U.S. adult day services centers. We thank everyone who completed the 2014 survey and contributed to its final response rate of 58.0%. We need your help to further increase the number of adult day providers that complete the 2014 survey.

All centers are invited to participate in the 2016 NSLTCP, which begins in May and ends in November. We strongly encourage you to participate in the survey, whose benefits include (1) advancing adult day services in our long-term services and supports system; (2) allowing state estimates, where possible, to compare centers across states and nationally; and (3) contributing to NCHS' 2017 long-term care overview report.

Data from the 2014 survey allowed CDC to compare our services, participants, and funding to other providers like home health agencies and residential care communities. The overwhelming positive feedback on that report (http://www.cdc.gov/nchs/data/nsltcp/long_term_care_services_2015.pdf) demonstrates the usefulness of this information to adult day services providers, policymakers, and health care planners in helping them better understand, plan for, and serve the future long-term care needs of older persons and younger adults with disabilities.

Center directors can submit their survey questionnaires by mail, using the pre-addressed, postage-paid envelope, or online over a safe and secure network. All individual data from the survey will be kept confidential. The names of the adult day services centers, staff, participants, and respondents will not be identifiable.

NADSA, LeadingAge, and NASUAD appreciate your participation in this important national initiative. Please encourage all your fellow adult day providers in your state and region to complete the survey and improve the research on adult day services. If you have any questions or concerns, please contact us at our national office.

Many thanks,

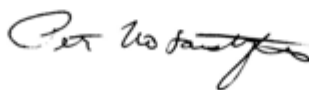
Teresa Johnson



Managing Director
(877-745-1440)



Peter Notarstefano



Director, Home and Community-based
Services (202-508-9406)



Martha Roherty



Executive Director
(202-898-2578)

