

Attachment D-1

Advance Package

RCC ADVANCE LETTER

Date

Director Name

Facility Name

Street Address

City, state, zip

Dear [Director Name]:

We greatly appreciate that your residential community participated in the National Study of Long-Term Care Providers (NSLTCP) survey in 2014. The enclosed Data Brief is an example of the information you helped make possible. We invite you to participate in an important project to assess how feasible it is to sample and collect resident-level data and how to improve the materials used to make it easier for providers like you to give this information in future NSLTCP surveys. There will be indirect benefits if you participate. By participating you will help to improve the value of long-term care data which will be used to inform providers like you, researchers, and policymakers. There are no anticipated risks other than your time. We ask for approximately one hour of your time to participate.

Participating in this study will involve completing a brief screening questionnaire, selecting three residents using random sampling procedures with the help of a telephone interviewer, and completing questionnaires for these three residents over the telephone. Your participation is voluntary and you do not have to answer any questions that you do not want to. Refusal to participate will involve no loss of benefits and participation can be discontinued at any time. We will not share your information or any information about the residents you report on with anyone outside the project, and your name will never be connected to your answers. Your answers will only be used to help us assess how easy or difficult it is to sample the residents, complete the resident questionnaires over the telephone, and how to improve the materials for national implementation. All information collected will be held in the strictest confidence according to section 308(d) of the Public Health Service Act (42, U.S. Code, 242m(d) and the Confidential Information Protection and Statistical Efficiency Act (Title 5 of PL 107-347). No resident names or social security numbers will be collected. This study also conforms to the Privacy Rule as mandated by HIPAA, where disclosure of resident data is permitted for public health purposes. If you have any questions about your rights as a participant in this research study, call the Research Ethics Review Board at the National Center for Health Statistics toll-free at 1-800-223-8118.

One of our interviewers will call you within the next few weeks with additional information about participating in this important feasibility project. If you have any questions about this study, please call (XXX) XXX-XXXX.

If you are eligible and choose to participate after you complete the interview, we will send you or your residential care community a \$50 gift card as a token of appreciation.

We look forward to talking with you soon.

Sincerely,

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

ADSC ADVANCE LETTER

Date

Director Name

Facility Name

Street Address

City, state, zip

Dear [Director Name]:

We greatly appreciate that your adult day services center participated in the National Study of Long-Term Care Providers (NSLTCP) survey in 2014. The enclosed Data Brief is an example of the information you helped make possible. We invite you to participate in an important project to assess how feasible it is to sample and collect participant-level data and how to improve the materials used to make it easier for providers like you to give this information in future NSLTCP surveys. There will be indirect benefits if you participate. By participating you will help to improve the value of long-term care data which will be used to inform providers like you, researchers, and policymakers. There are no anticipated risks other than your time. We ask for approximately one hour of your time to participate.

Participating in this study will involve completing a brief screening questionnaire, selecting three center participants using random sampling procedures, and completing questionnaires for these three participants over the telephone. Your participation is voluntary and you do not have to answer any questions that you do not want to. Refusal to participate will involve no loss of benefits and participation can be discontinued at any time. We will not share your information or any information about the participants you report on with anyone outside the project, and your name will never be connected to your answers. Your answers will only be used to help us assess how easy or difficult it is to sample the participants, complete the participant questionnaires over the telephone, and how to improve the materials for national implementation. All information collected will be held in the strictest confidence according to section 308(d) of the Public Health Service Act (42, U.S. Code, 242m(d) and the Confidential Information Protection and Statistical Efficiency Act (Title 5 of PL 107-347). No participant names or social security numbers will be collected. This study also conforms to the Privacy Rule as mandated by HIPAA, where disclosure of participant data is permitted for public health purposes. If you have any questions about your rights as a participant in this research study, call the Research Ethics Review Board at the National Center for Health Statistics toll-free at 1-800-223-8118.

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Sincerely,

Charles J. Rothwell, MS, MBA

Acting Director, National Center for Health Statistics

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.

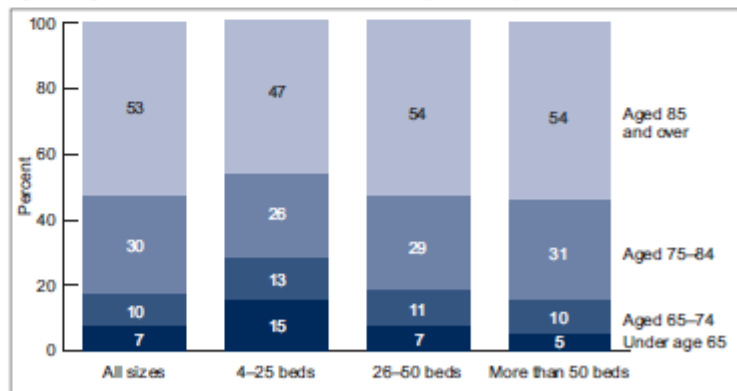
Residents of residential care communities are persons who cannot live independently but generally do not require the skilled care provided by nursing homes. There were 835,200 current residents in residential care communities in 2014 (1,2). “Current residents” refers to those who were living in the community 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



NOTE: 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.



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

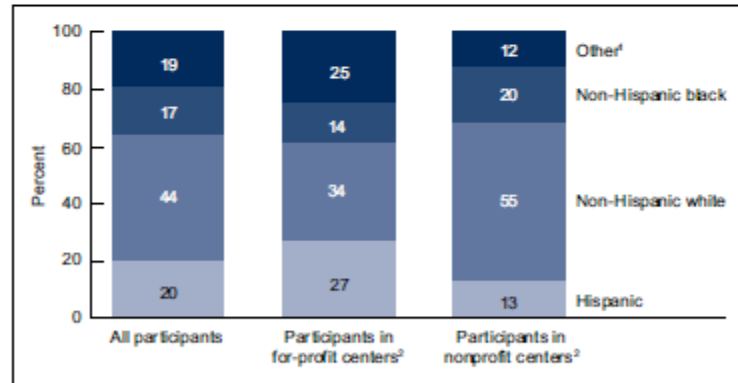
- The racial and ethnic composition of participants in for-profit adult day services centers was more diverse than in nonprofit centers.
- About 61% of participants in for-profit centers received Medicaid, compared with 46% of those in nonprofit centers.
- The percentage of participants living with Alzheimer's 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.



**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



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