

# Expert Meeting on the Demography of the Older Residential Care Population: Research Questions and Data Gaps

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Committee on National Statistics and Committee on Population**

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## Acronyms List

ACS	American Community Survey
ADRD	Alzheimer’s disease and related dementias
BSR	Division of Behavioral and Social Research
CNSTAT	Committee on National Statistics
HCBS	home- and community-based services
HRS	Health and Retirement Study
HUD	U.S. Department of Housing and Urban Development
LTC	long-term care
MCBS	Medicare Current Beneficiary Survey
MSA	metropolitan statistical area
MDS-COGS	Minimum Data Set Cognition Scale
NCHS	National Center for Health Statistics
NHATS	National Health and Aging Trends Study
NIA	National Institute on Aging
NORC	National Opinion Research Center
NSLTCP	National Study of Long-Term Care Providers
NSOC	National Study of Caregiving
NSRCF	National Survey of Residential Care Facilities
OASIS	Outcome and Assessment Information Set
RCC	residential care community

## Meeting Summary

### Introduction

Residential care settings, broadly defined, include a variety of residential settings in which services are made available to residents to help with daily activities. Often included in this definition are nursing homes, assisted living, independent living, continuing care retirement communities, group homes, and personal care homes. In addition, age-restricted communities such as retirement communities and senior housing may offer services.

The size of this population is substantial—13 percent of individuals ages 65 and older live in a residential care setting, including nursing home, assisted and independent living, and retirement communities and senior housing. At very old ages (90 and older), the figure exceeds 40 percent.<sup>1</sup> Alzheimer’s disease and related dementias are also highly prevalent in these settings: national studies suggest that about 40 percent of older adults in assisted living settings have dementia.<sup>2</sup>

During the past decade, more data have become available to study the basic demography of the residential care population. The National Center for Health Statistics (NCHS) has collected data from residential care communities every other year since 2012 as part of its National Study of Long-Term Care Providers (NSLTCP). In addition, the National Health and Aging Trends Study (NHATS), an annual panel study of approximately 8,000 Medicare beneficiaries with periodic replenishment, collects information from facilities about the places in which older adults reside; this information complements a detailed sample person interview. NHATS offers snapshots of this population at the national level and opportunities to study movement by individuals in and out of these settings.

Other national data collection efforts, such as the Health and Retirement Study (HRS) and Medicare Current Beneficiary Survey (MCBS), have included information to identify residential care setting.<sup>3</sup> Although it does not attempt to identify residential care per se, the Census Bureau classifies individuals not living in housing units as living in institutional (including nursing homes) or non-institutional quarters (including group homes).

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<sup>1</sup> V.A. Freedman, “The demography of late-life disability,” Chapter 10 in M.D. Hayward and M.K. Majmundar (Eds), *Future Directions for the Demography of Aging: Proceedings of a Workshop* (Washington, DC: The National Academies Press, 2014).

<sup>2</sup> See V.A. Freedman and B.C. Spillman, “The residential continuum from home to nursing home: size, characteristics and unmet needs of older adults,” *J. Gerontol. B*, 69(Suppl 1):S42-S50 (2014); L. Harris-Kojetin, M. Sengupta, J.P. Lendon, V. Rome, R. Valverde, and C. Caffrey, “Long-term care providers and services users in the United States, 2015–2016 data from the National Study of Long-Term Care Providers” (Hyattsville, MD: U.S. Department of Health and Human Services, National Center for Health Statistics, 2019); S. Zimmerman, P.D. Sloane, and D. Reed, “Dementia prevalence and care in assisted living,” *Health Affairs*, 33(4):658-666 (2014).

<sup>3</sup> B.C. Spillman and K.J. Black, *The Size and Characteristics of the Residential Care Population: Evidence from Three National Surveys*, prepared for the Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging, and Long-Term Care Policy, U.S. Department of Health and Human Services (Washington, DC: Health Policy Center, The Urban Institute, 2006).

Despite the growing number of resources, the demography of residential care has not been comprehensively examined. Fundamental definitional differences across surveys have not been assessed nor have the implications of various sampling and measurement approaches been addressed. Moreover, many important national policy-related questions remain unexplored. Little research exists, for instance, on how well the care needs of older adults are being addressed in these settings, how these patterns are changing over time as the population ages, how changing family structure and support profiles will change the demand for residential care in the future, or how well these settings meet needs in different parts of the country.

The Division of Behavioral and Social Research (BSR) commissioned the National Academies of Sciences, Engineering, and Medicine's Committee on National Statistics (CNSTAT) and Committee on Population (CPOP) to convene an expert meeting on May 8, 2019, in Washington, D.C., to further explore research gaps and data needs related to the demography of the older residential care population. Conveners agreed that a better understanding of the demography of the older residential care population is needed given the aging of the U.S. population, impending changes in family structure, and projected caregiving workforce shortages. BSR—and the federal government more generally—expends substantial resources on data collection efforts that cover this population. Yet there are gaps in knowledge about the size and characteristics (including family context) of the residential care population, now and in the future, and how well needs, including care for older adults with dementia, are being met in these settings.

Presentations by invited experts provided an overview of the structure and methodology of ongoing federal efforts to survey the older population and residential care services. The workshop identified issues from research, policy, and industry perspectives. The discussions indicate that many important national policy-related questions remain unexplored. The meeting agenda and participants list are included as Appendices 1 and 2, respectively.

Several key themes emerged from the presentations and discussions:

1. Understanding and accurately predicting the need for residential care for the burgeoning and diversifying older population in America is an important public policy concern. Research is also needed to understand the family and social context of older individuals living in residential care settings and how this context affects care quality and costs and who pays. More research is also needed to understand dementia care needs in residential care settings and the challenges in meeting those needs in such settings.
2. The collection and interpretation of residential care data are complicated by variation in the terms and definitions used, the licensing and requirements imposed, the services provided, and the payment mechanisms used. Efforts to harmonize existing data sources might enhance the usefulness of BSR-supported data and might heighten the understanding of unanswered research questions and data needs.

3. Relevant survey and administrative data are collected by a variety of federal agencies and federally supported efforts, but these data sources are not coordinated and administrative and regulatory barriers limit data sharing.

A next step might be to further explore collaborations among federal agencies to share data and/or shape the data elements collected in ongoing surveys.

## Issues in Defining and Measuring the Residential Care Population

*Moderator: Anne C. Case, PhD, Princeton University and CNSTAT Member*

### Insights from the National Study of Long-Term Care Providers

*Lauren Harris-Kojetin, PhD, National Center for Health Statistics (NCHS) (via teleconference)*

NCHS initiated the National Study of Long-Term Care Providers (NSLTCP) in 2012 as an ongoing study to monitor trends in paid, regulated, long-term care (LTC) services. The study's vision is to provide reliable, accurate, relevant, and timely statistics to inform and support LTC services policy, research, education, and practice. Of the five sectors of LTC services included in the NSLTCP (residential care community [RCC], adult day, home health, nursing home, and hospice sectors), RCCs are most relevant to the focus of the current meeting. In the NSLTCP, most RCCs are assisted living communities, but some are as small as four beds but meet the study definition.

Because federal administrative data do not exist for the RCC sector, the NSLTCP collects nationally representative data via survey. The Total Survey Error framework<sup>4</sup> is useful for identifying sources of potential survey error, of which *coverage error* and *measurement error* pose particular challenges to the NSLTCP.

#### **Coverage error**

Coverage error refers to both the inclusion of cases that do not meet the sample criteria and the exclusion of those that do. For each NSLTCP wave, a sample is drawn from a frame intended to represent the entire RCC universe. However, no federal administrative source exists for RCC provider data. In addition, no standard federal definition of RCC exists. RCCs are primarily regulated at the state level, under a variety of definitions and terms (e.g., Assisted Living, Facility, Program, or Residence; Board and Care Home; Congregate Care; and Residential Care Home).

NCHS creates a new, nationally representative sampling frame for each wave of survey data collection. It uses a standardized definition to identify comparable facilities across time and among states. To be included in the NSLTCP, a facility must provide at least four beds to a primarily adult population. The facility must have at least one resident at the time of the interview, and it must be licensed, registered, listed, certified, or otherwise regulated by the state to provide room and board with at least two meals per day; around-the-clock on-site

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<sup>4</sup> R. Groves et al., *Survey Methodology* (New York: Wiley, 2004).

supervision; and help with personal care or health-related services.<sup>5</sup>

NCHS uses this RCC definition to develop the sampling frame and as a screening tool during data collection. Although the definition has remained constant since a 2010 predecessor survey to the NSLTCP, eligibility rates have varied between surveys, from 67.1 percent in 2012 to 81 percent in 2010. This variability, in turn, affects estimates from the survey of the numbers of RCCs: 31,100 in 2010 versus 22,200 in 2012. Because there is no evidence that this sector is shrinking, this range likely reflects a lack of precision due to coverage error.

Small RCCs introduce the most variability across the sample. Their numbers vary as eligibility characteristics change over time: for example, the population served may shift between surveys. NCHS is considering strategies to address the variability introduced by these facilities. Smaller RCCs might be addressed as a separate sector in the NSLTCP, or the survey could continue its current practice of producing multiple estimates, separated by size.

### ***Measurement error***

The NSLTCP is designed to provide a broad overview of relevant topics, rather than in-depth details. Topics measured to characterize RCCs include location, operating characteristics, services offered, staffing, and practices. Resident topics include socio-demographics, health and conditions, physical and cognitive functioning, health care use and adverse events, and length of stay and services used.

NCHS used a sequential mixed-mode protocol during 2012-16, starting with mailed surveys or web questionnaires and then telephone follow-up for non-respondents. RCC staff, rather than residents or family members, complete the questionnaires. Mailed questionnaires are 8-10 pages in length and require 30-45 minutes to complete. To prevent non-responses due to response burden, NCHS limits the survey length. A core set of items are repeated in each survey wave; two versions of the survey are used, each of which offers a different set of additional items. Data collection for each of the first three surveys required more than 6.5 months to complete. For the 2018 survey, NCHS introduced a telephone interview, which allowed for data collection about individually sampled residents. NCHS is assessing the impact of this approach on response rates.

NCHS develops samples for states with sufficient numbers of RCCs to enable state-level estimation. Among these states, the primary sampling strata are defined as state and number of beds. Specific RCCs are selected by systematic random sampling from a list of communities sorted by metropolitan statistical area (MSA), then randomly ordered within the MSA. Final weights reflect base weights/sampling weights for survey states, adjustments for unknown eligibility, and adjustments for non-response for survey and census states.

Ensuring that survey respondents focus on a single RCC when completing the survey poses another data collection challenge. Individual respondents can be responsible for more than

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<sup>5</sup> Nursing homes and providers serving exclusively adults with severe mental illness, intellectual disability, or developmental disability are excluded from the RCC sample.

one RCC or may work in facilities that include separately licensed units. Survey responses that include data from more than one RCC must be discarded.

***Brief overview of current data***

In 2016, RCCs represented 28,900 of the estimated 65,600 LTC providers in the United States among the five sectors included in the NSLTCP. RCC residents represented 811,500 of the 8.3 million LTC service users; of these, more than 757,000 were ages 65 or older, and more than half were older than 85 years. Seventy-one percent of RCC residents were female, and 81 percent were non-Hispanic whites. RCC residents were much less likely to use Medicaid than nursing home residents (17 percent versus 62 percent); the rate of Medicaid use is highest in the smallest RCCs, that is, those with 4-25 beds. The rate of Medicaid use also varied by state, from zero percent in Louisiana to 71 percent in Connecticut.

The survey will continue under a new name beginning in 2020: National Post-Acute and Long-Term Care Study.

**Lessons from the National Health and Aging Trends Study**

*Judith D. Kasper, PhD, Johns Hopkins University Bloomberg School of Public Health*

*Vicki A. Freedman, PhD, University of Michigan*

NIA initiated NHATS to facilitate research on causes and consequences of disability and disability trends, and on disability dynamics and individual pathways to disability. The NHATS sample is nationally representative of the Medicare population ages 65 and older. The sampling frame is Medicare enrollment files, age-stratified into 5-year groups, beginning with 65- to 69-year-olds and extending to persons 90 or older. There is an oversampling of Black individuals. Data are collected through annual in-person interviews, conducted in May-October of each year since 2011. The sample was approximately 8,500 in 2011, was replenished to address attrition in 2015, and will be replenished again in 2020.

The NHATS conceptual framework includes factors at the person level as well as environmental factors that influence disablement. NHATS has made the measurement of residential environments and settings that provide care a priority. This decision was driven by the fact that: (1) trends are difficult to describe when nursing homes/institutional settings are omitted from surveys and (2) trajectories of assistance are difficult to characterize when the types of residential care and services are unclear or measured differently across residential settings. NHATS includes persons in all residential settings and seeks to use the same measures of care whenever possible, regardless of the setting in which they are received.

NHATS defines residential care as the place where an older person lives, rather than short-term settings in which they might receive care. This differs from the NSLTCP, which begins with providers and settings and characterizes the individuals and care provided in those settings.

The data collected by NHATS allows for characterization of the residential continuum by type of place, level of care, and services offered.<sup>6</sup> Type of place includes, for example, senior housing, continuing care retirement community, an assisted living community with a special care unit, or a freestanding nursing home. Level of care refers to, for example, independent living, assisted living, or nursing home care. Groupings of services may include, for example, no residential-based services, transportation and social services only, household services such as meals, personal care services such as bathing and dressing, or medication management.

Several issues arise when measuring residential care. The terms and definitions used to describe places where care is delivered are inconsistent. The terms may not be meaningful to the lay person, which may introduce reporting error. It can be difficult to discern whether an older adult lives in a location or is temporarily receiving care there. Finally, some facilities offer different levels of service at different sites within the facility.

NHATS seeks to mitigate these challenges by including all settings and following a standardized approach to defining residential care settings by both name and type of services offered. In addition, NHATS obtains information about the part of the place in which the older adult lives and about the entire location/facility. It also collects data on the types of assistance received by older adults and who provided that assistance for persons who live in traditional community settings and in places that provide residential care.

NHATS asks about services offered and used through a sample person interview and a facility staff person interview. The sample person interview asks (1) respondents who live in a free-standing or attached house to describe the place they live by general category and (2) respondents who live in multi-unit building are asked about availability of meals or help with personal care and whether there are areas at the place that offer different levels of care. Responses that indicate the availability of services in the place where the sample person lives trigger the facility interview.

Facility staff interviews provide information to characterize the broader facility and its levels of care as well as services available in the area where the sample person lives. Facility interviews may be conducted without a sample person interview (in cases where the sample person is unable to complete the interview and a proxy respondent is not available). Analytic weights are adjusted to account for these cases, thus minimizing bias in estimates of the residential care population.

### ***Brief overview of current data***

NHATS estimates that 5.7 million adults ages 65 and older (~13 percent) lived in retirement communities, residential care places, and nursing homes in 2015. The number has been relatively stable since 2011, while the proportion in these settings has declined slightly (from 15 percent to 13 percent). In 2015, about 1.9 million older adults were living in residential care settings (assisted living, independent living) and another 1 million lived in nursing home

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<sup>6</sup> See V.A. Freedman and B.C. Spillman, "The residential continuum from home to nursing home: size, characteristics and unmet needs of older adults," *J. Gerontol. B*, 69(Suppl 1):S42-S50 (2014).

settings. Services varied with type of setting. Personal care and medication assistance were available to virtually all residents of nursing home and assisted living settings. About one-third (34 percent) of individuals in independent living settings had personal care and medication assistance available, but 46.3 percent had household help (meals, laundry, housekeeping) and no personal care services, and 18 percent were in settings that offered only amenities (transportation, social activities, health and wellness programs). Of those living in retirement communities and senior housing, three-quarters had only amenities available and 17.3 percent had no services available if they lived in these places.

By drawing on other information collected in the NHATS interview, NHATS can characterize and nationally profile persons living in residential care of various types to a degree not previously possible and compare persons in these settings with other older adults in the community. Examples include the ability to characterize residents' demographic and family composition, physical, cognitive, and sensory capacity, assistance received, unmet needs, services used, participation in activities, end-of-life experiences, family caregiver involvement, and transitions in and out of settings.

### **Discussion**

Discussion focused on the NSLTCP design. The variability in case mix in that study appears to be due primarily to shifts in the eligibility of smaller RCCs. For example, changes in a few residents in a 10-bed facility may result in the facility serving a majority of individuals with intellectual disability. The researchers have reformatted and tested the survey questions related to services to assure respondent understanding. In some cases, facility identification measures are available in multiple survey waves, which allows for some longitudinal analysis of changes in classification. The researchers develop the survey frame using a list of facilities from each state and interviews with state officials. A central challenge is understanding the criteria used by the state and how those criteria relate to the NSLTCP survey criteria.

## **The Demography of the Older Residential Care Population and Meeting Dementia Care Needs in Residential Settings: What Do We Know and What Would We Like to Know?**

*Moderator: Vicki Freedman, PhD, Research Professor, University of Michigan*

### **The Older Residential Population: Policy Challenges**

*Ruth Katz, MEd, LeadingAge*

LeadingAge is a membership-based advocacy organization. Its members include affordable housing organizations, nursing homes, life plan communities, and providers of home- and community-based services (HCBS). LeadingAge conducts "Town Hall" sessions, in which members are invited to comment upon ongoing concerns and policy issues that impede their work with older residential populations. The "demographic imperative" (i.e., demographic changes put pressure on the public sector and public health) and limited options to finance care are central issues. New residential models are being created and tested in an effort to address middle market challenges and other concerns. LeadingAge seeks to capture the insights from

these sessions and to facilitate communication between researchers and policymakers.

The tendency to use the current senior population to plan for future needs is problematic. A recent LeadingAge-National Opinion Research Center (NORC) survey of adults ages 60-72 challenged the widespread assumption that older Americans prefer to receive care at home. The survey asked respondents to consider where they would like to receive LTC if it were required due to physical or cognitive disability. When help with daily activities is needed, people care most about safety, followed by being around family and having access to the outdoors. Even with physical disability and a need for help with daily activities, 60 percent of respondents said they would prefer remaining in their current home. That percentage drops to 29 percent if they had dementia and needed help with daily activities. The LeadingAge-NORC survey also found large variations in preferences for internet access, with internet access registering greater importance for higher-income groups.

To prepare for the future, LTC providers must be able to predict and plan for the functional characteristics and family status of the individuals they will serve. They must prepare for dramatic changes to care due to technological advances, and they must identify ways to ensure quality in diverse, dispersed settings, without over-regulation. Person-centered care must be better understood and defined, and ways to assure its effective delivery identified. Payment for services—and the ways in which payment will drive and shape service infrastructure and delivery—is another critical area that requires attention, as are transitions between post-acute and LTC settings.

LTC providers report a number of challenges that vary based on the type of sector:

- **Nursing home providers** are concerned about the differentiation between the post-acute and long-stay populations and to understand patients' movement through post-acute care and transition into long-term care. They view the regulatory framework as costly and not evidence-based. Medicaid rates are inadequate and inconsistent from state to state. Some states have raised rates over time, while other states have allowed their reimbursements to stagnate. The primary payers for LTC services have shifted over time—from Medicaid to Medicare to Medicare Advantage—and this migration will shape the population that receives care and will impact the structure of nursing home financing. Nursing homes image problem exacerbates workforce challenges.
- **Assisted living providers** are concerned about the potential for over-building; although currently high, there are signs that occupancy may be declining. The baby boomers will likely reverse this trend as they age, but providers must survive in the meantime. Assisted living providers also struggle to define and deliver person-centered care and to cope with inadequate Medicaid rates. Abuse scandals have impacted assisted living facilities, and providers are fearful of federal regulation.
- **Life plan community providers**, which offer more than one level of care typically on one campus, are concerned about maintaining the independence of their independent-living residents, managing vacancies, and addressing the movement of residents between different levels of care. Some life plan communities offer memory care units, but these

are currently unregulated. Some life plan communities are exploring a model of continuing care at home, which would enable individuals to join the community without moving into the facility. Fair housing requirements are also a concern for these providers.

- **Affordable housing providers** face severely reduced public financing to develop and preserve senior housing. Waiting lists are years long and not static, and their associated data are insufficient. Affordable housing residents are increasingly frail, and there is a growing need for service coordinators. Co-location of HCBS may prove to be a useful model.

Across the board, LTC providers note concerns about paying for LTC and substantial workforce shortages. By 2030, 2.5 million new LTC service and support providers will be needed to meet the needs of the growing senior population. Other concerns impacting the entire industry include defining and meeting the needs for middle-income individuals, addressing increasing numbers of people with dementia, and measuring and addressing the impact of social isolation and loneliness.

Industry and policymakers must address several factors as they consider the future of residential care. Although the reasons are not entirely clear, the movement out of residential settings is slowing, increasing waiting lists for some facilities. Because HCBS will become increasingly important, the types of communities and the mechanisms to deliver community-based services require additional study. Implications of different payment models for health care will shape care for older residents. The need for mental health services is expected to increase over time and must be better understood. Housing for older Americans in every setting may be challenging. Regulation and technology will shape this industry; the better these impacts are understood, the more effectively providers can respond and adapt.

### **Data Gaps Related to Care for Residents with Dementia**

*Sheryl Zimmerman, PhD, University of North Carolina at Chapel Hill (via teleconference)*

New data in five areas will be especially helpful in informing the care needs of individuals with dementia: the prevalence of dementia; the severity of behavioral expressions; comorbidities requiring preventive care, especially in assisted living; family information; and cultural background. Data on comorbidities, family, and cultural characteristics are useful for all residents of LTC settings and are especially important when individuals with dementia cannot communicate.

Nursing homes and assisted living both play an important role in dementia care, but they do not constitute a planned “continuum” of care. Variability of dementia ascertainment exists within both federally regulated nursing homes and state-regulated assisted living; current estimates are that approximately 65 percent of nursing home residents and approximately 40 percent of assisted living residents have dementia.

### **Prevalence of dementia**

Data from the 2010 National Survey of Residential Care Facilities (NSRCF) conducted by NCHS

can be used to ascertain the prevalence of dementia in residential care settings using staff reports of two types of data: reports of dementia prevalence itself and responses to items constituting the Minimum Data Set Cognition Scale (MDS-COGS). The MDS-COGS is a nine-item instrument measuring memory, orientation, decision-making, understanding, and dressing. Both NSRCF methods indicate a 42 percent prevalence of moderate or severe cognitive impairment among residents at the communities surveyed. However, disparities exist between the two sources: while staff reports of dementia agreed with 90 percent of MDS-COGS findings of severe dementia, they agreed only 26 percent of the time with MDS-COGS findings of mild dementia, and 61 percent of the time with MDS-COGS findings of moderate dementia. Because prevalence rates can be used to identify care needs and to evaluate the quality of care, more accurate understanding of dementia prevalence in these settings is needed. Obtaining data from more than one measure helps to increase accuracy. Then, analysis of the correlates of differences might be used to refine current estimates.

### ***Behavioral expressions of dementia***

National data suggest a similar prevalence of behavioral expressions of dementia—such as anxiety, agitation, and wandering—in both nursing homes and assisted living (37-38 percent).<sup>7</sup> Responsive to the Centers for Medicare and Medicaid Service efforts, antipsychotic prescribing appears to be falling in nursing homes such that the rate (15 percent) may now be lower than in assisted living.<sup>8</sup> The NSRCF measured the prevalence of the top six behavioral expressions by level of cognitive impairment; many of these behaviors do not appear to require medication. Data also reveal that the majority of assisted living communities report using evidence-based nonpharmaceutical interventions at least some of the time.

Better data on the more serious behavioral expressions may provide a better sense of the level of behavioral severity faced by staff in these settings, which may help to predict care needs and monitor the quality of care provided. Obtaining organizational and person-level data regarding treatment by mental health professionals and inpatient psychiatric hospitalization as well as prescribing of behavioral/psychoactive medications, and differentiating these data by dementia diagnosis, may provide insight into the level of behavioral severity, which may be the most accurate predictor of care needs.

### ***Comorbidities***

Comorbidities are common for people with dementia living in both nursing homes and assisted living. The medical care needs of people with dementia in the latter is an emerging concern. Although the rates for new or worsening morbidities and mortality among residents with dementia are similar in nursing homes and assisted living, the rates of hospitalization are higher in assisted living (14.2 per 100 residents/quarter, versus 10 per 100 residents/quarter in nursing

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<sup>7</sup> D. Seitz, N. Purandare, and D. Conn, "Prevalence of psychiatric disorders among older adults in long-term care homes: a systematic review," *Int. Psychogeriatr.* 22(7), 1025-1039 (2010); S. Zimmerman, P.D. Sloane, and D. Reed, "Dementia prevalence and care in assisted living," *Health Affairs*, 33(4):658-666 (2014).

<sup>8</sup> Prescribing from the National Partnership to Improve Dementia Care in Nursing Homes: Antipsychotic Medication Use Data Report (January 2019). <https://www.nhqualitycampaign.org/dementiaCare.aspx#modal>

homes).<sup>9</sup> To the extent that these hospitalizations are linked to ambulatory care (or primary care) sensitive conditions, additional preventive care may prove effective in reducing hospitalization. More comprehensive understanding of ambulatory care sensitive conditions, obtained through expert input, may reveal the potential benefits of integrated care or other emerging models of care.

### **Family**

Family involvement for nursing home and assisted living residents changes with dementia severity but does not vary significantly by type of setting (nursing home versus assisted living). Family involvement is related to resident life satisfaction and psychosocial well-being, the likelihood of discharge from a nursing home, lowered risk of infection, and more timely detection of changes in health. Lack of involvement of family members affects the person-centered nature of care. Also related to lack of involvement, emerging data indicate that 16 percent of family members did not know their relative was taking an antipsychotic medication.<sup>10</sup>

Staff and family reports of family engagement for residents with dementia showed statistically significant differences on many items. In every case, family engagement was under-reported by staff. Family members may be an important source of information on resident needs and may be the only source of some data. Family members might be asked, for example, about the availability of supportive care and about the resident's culture. They also play an important role in monitoring care, especially in assisted living.

### **Cultural background**

The national population of nursing homes and assisted living is currently majority non-Hispanic white, although there is significant state-level variation in the diversity of this population. By 2060, the older adult population in the United States will be minority white; more comprehensive understanding of cultural issues that relate to care needs and outcomes and to person-centered care will inform preparation for the cultural demographic shift. Data on spoken dialect, food and activity preferences, advanced directives, decision-making patterns, family involvement, and sex/gender preferences, as well as items related to quality of life, will be necessary to understand and meet the needs of an increasingly diverse residential population.

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<sup>9</sup> P.D. Sloane, S. Zimmerman, A.L. Gruber-Baldini, J.R. Hebel, J. Magaziner, T.R. Konrad, "Health and functional outcomes and health care utilization of persons with dementia in residential care and assisted living facilities: comparison with nursing homes," *Gerontologist* 45 Spec No 1(1):124-132 (2005).

<sup>10</sup> Preliminary data from R01 AG050602. National Institute on Aging. Sheryl Zimmerman, Principal Investigator. Addressing Behavior and Mood in Assisted Living: Organizational Characteristics Related to the Use of Antipsychotic and Psychotropic Medications and Alternative Practices

## Discussion

### ***Increasing understanding of antipsychotic prescribing***

Antipsychotic prescribing may be a strategy employed in under-resourced settings. Linking data on reimbursement (e.g., percent private pay, on Medicaid) to prescribing patterns may provide insight into relationships between resources and quality of care. The 2018 NSLTCP collected data on antipsychotic drug use, behavioral symptoms, chronic conditions, hospitalizations, and whether hospitalizations are related to ambulatory-sensitive conditions. These data should be available in the near future.

### ***Identifying and prioritizing data sources***

Although challenging, data collection from family members of older adults living in residential care settings is feasible. The National Study of Caregiving (NSOC) is a national source of data on family members and other unpaid caregivers of older adults who participate in NHATS. The study has plans to follow family caregivers over time. Because it begins with the older adult, the NSOC design provides a frame that allows for weighting to minimize bias.

### ***Measuring dementia care needs***

When considering data collection for the purposes of understanding dementia-related care or care needs, it may be useful to focus on characteristics and behaviors, rather than diagnosis. The MDS-COGS is useful in characterizing residents, regardless of their diagnosis.

### ***Defining residential care: Place names vs. services offered***

The identification of care settings is challenging given the complex and changing names for places that are in use. For example, “life plan communities” is a new term for continuing care or retirement communities. “Independent living” is a commonly used term, but these settings vary considerably with respect to whether they offer only amenities, household-related assistance, and/or personal care services. Nursing home settings also pose a challenge, because they offer services to both post-acute patients who are short term (who stay but do not live in these settings) and long-term residents who live in these settings. Asking about services rather than focusing on the place name offers useful complementary information for classifying the type of residential care setting in which older adults live.

## **Data Gaps for Studying the Demography of the Older Residential Care Population**

*Moderator: Judith Seltzer, PhD, Professor, Department of Sociology, UCLA*

### **Data Gaps for Studying the Demography of the Older Residential Care Population**

*Kali Thomas, PhD, Associate Professor of Health Services, Policy and Practice, Brown University School of Public Health*

In the United States, more than 31,000 residential care/assisted living communities serve more than 800,000 older adults.<sup>11</sup> This industry developed without the influence of federal financing

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<sup>11</sup> From National Survey of Long-Term Care Providers.

or regulation, so significant variation exists among states in the level of care supported and the services allowed. Assisted living communities face less monitoring and fewer reporting requirements than other health care settings; these characteristics limit the ability to use administrative data to understand the demographics, health outcomes, and service variations in assisted living communities as is possible in other long-term care settings. However, it is feasible to combine administrative data from multiple sources to describe Medicare beneficiaries in assisted living communities in the United States.

### ***Identifying residents through 9-digit ZIP codes***

With funding from NIA, Thomas and colleagues have developed and validated a methodology to identify Medicare beneficiaries residing in assisted living, using the 9-digit ZIP code reported in Medicare enrollment records. The last four digits of the 9-digit ZIP code are assigned to “high volume mail receivers,” such as a block side, building, or even a floor within a building. A large residential setting is likely to have its own 9-digit ZIP code, if not its own set of 9-digit ZIP codes. Mail is the primary means of Medicare contact to beneficiaries, and the 9-digit ZIP codes reported in the Medicare enrollment record are based on beneficiaries’ mailing addresses.

The researchers reviewed summaries from the National Center for Assisted Living (NCAL), the Office of Assistant Secretary for Planning and Evaluation (ASPE), and the NCHS sampling frame to identify relevant license terms. They also searched a legal database for known state license terms and reviewed state agency websites. In the end, they identified 121 different state license categories for assistance living communities.

The researchers then combined 2016 Home Health Outcome and Assessment Information Set (OASIS) data and the 2016 Medicare Part B Claims data with assisted living place of service or CPT codes to identify 560,484 unique Medicare beneficiaries receiving services in assisted living in 407,275 unique 9-digit ZIP codes. The researchers matched those codes to the 9-digit ZIP codes of 13,187 identified assisted living communities with 25 beds or more. They used the resulting 47,603 9-digit ZIP codes to search the 2016 Medicare denominator file, resulting in the identification of 563,064 unique Medicare beneficiaries residing in assisted living communities with 25 or more beds.

### ***Characterizations available through use of 9-digit ZIP codes***

This approach to identify Medicare beneficiaries in assisted living enables close examination that would not be practical otherwise. These data, can, for example, show state-level variation in the prevalence and outcomes of dementia patients, or in end-of-life care for residents of assisted living facilities.

The national prevalence of Alzheimer’s disease and related dementias (ADRD) among residents of assisted living is 36.2 percent. However, there is significant geographic variability—from 25.4 percent in Minnesota to 48.3 percent in West Virginia. The rates for hospitalization and emergency department visits of Medicare beneficiaries with ADRD in assisted living and in community settings also demonstrates geographic variability. For example, in Idaho, California, and Nevada, the rate of hospitalizations for beneficiaries in assisted living was 5 percentage points higher than that for beneficiaries in community settings. Further, while residents of

assisted living with ADRD are less likely than their community peers to be admitted to an emergency department in New Hampshire, Connecticut, Delaware, Pennsylvania, Ohio, and Maryland, the reverse is true in New York, Oregon, and North Carolina.

Nationally, the share of assisted living residents who received hospice care in the last 30 days of life rose, from 20 percent 30 days prior to 45 percent on the day of death. The number of days receiving hospice care in assisted living varies by state, from more than 12 days in Utah to fewer than 5 in North Dakota, New York, and Kentucky.

### ***Limitations***

This data collection methodology only captures data from assisted living communities with at least 25 beds, covering 83 percent of the assisted living beds in the United States but only 37 percent of assisted living communities. In addition, this methodology does not capture beneficiaries who do not change their mailing address to that of the facility and does not account for state variability in definitions or requirements of assisted living facilities. Other types of senior housing and unlicensed care homes are not included in this data set; these facilities could be included, to the extent that lists are available or are developed.

### ***Other potential sources of administrative data***

Other administrative datasets might characterize assisted living residents, but each has limitations. There is variation, for example, in how providers code outpatient claims for services delivered in assisted living communities. The researchers used the place of service code 13, corresponding to assisted living and reported on the Part B claim. However, there are additional codes that providers may use for services delivered in assisted living, including 12 (home), 14 (group home), and 33 (custodial care facility). The definition of assisted living reported in the Home Health assessment, OASIS, is imprecise; while it notes if a patient “lives in congregate situation,” no definitions are based on the services available in the setting. Medicare Provider Enrollment, Chain, and Ownership System (PECOS) data are another source that would allow for identification of group practices that serve assisted living residents, but claims from these providers only cover enrollees in traditional Medicare only and will not capture care if residents travel to see their own doctor. State variations in Medicaid claims limit the usefulness of these data to identify assisted living residents. Veterans Health Administration data reporting residence in a U.S. Department of Veterans Affairs–approved community residential care facility is specific to Veterans; Medicare Advantage Plans owned and operated by assisted living providers are new and exhibit slow uptake. State-specific data are beset by large variations and are not available for all states.

### ***Data priorities***

An important first step to any effort to improve our understanding of the characteristics of residential care is to develop consensus on terminology, typologies, and definitions. Typologies are important for developing sampling frames derived from the population, and definitions are important for frames derived from providers. Services provided may prove to be the most useful method for achieving consensus. For approaches that use primarily administrative data, other important areas of extension (i.e. through linkages) include clinical data, resident outcomes, and community characteristics.

## Discussion

### ***Research gaps vs. data gaps***

The meeting demonstrated that valuable new resources exist to study the demography of the older residential care population. Nevertheless, there are gaps in the existing literature with respect to comprehensively describing the size and characteristics of this population and systematically comparing findings from different data sources. In addition, several important research questions likely remain to be identified and explored that existing data may not be able to adequately address.

### ***Limits on data sharing***

Regulations related to confidentiality and concerns with potential re-identification of respondents limit the ability to share data. The frame created for the NSLTCP, for example, is not available for researchers who want to identify the national census of licensed residential care communities. Census data are also unavailable for these efforts.

### ***Studying unmet need***

Discussion focused on two distinct concepts referred to as “unmet need”: (1) living in an area where the number of service providers is insufficient to meet existing needs and (2) the consequences of a care need going unmet. Current efforts contribute to understanding both types of unmet need. For instance, with respect to the first approach, the mapping of assisted living facilities by 9-digit ZIP code showed a very uneven geographic distribution of such facilities. To address the second approach, each round of NHATS has included questions about unmet needs for assistance with specific activities. If an individual reports receiving help or having difficulty performing an activity by themselves, they are asked whether there was a time in the last month when a consequence occurred (e.g., In the last month did you ever go without a hot meal because no one was there to help or make one for you?). Research with NHATS suggests that unmet need for care among those reporting difficulty or requiring help with performing daily activities is substantial both in community and residential care settings.<sup>12</sup>

Community resources and demographics may also shape the extent to which the needs of older adults can be met. In rural areas, for example, adult children may move away, while older parents remain in place. Communities may lack the resources to fully meet the needs of these residents. These resources include family, community organizations, and a workforce for providing care as well as transportation to services. The NSLTCP includes data on where individuals moved when they left LTC and whether the move was due to a lack of resources.

### ***Other resources for studying the older residential care population***

Participants also briefly reviewed other potential resources for studying the older residential care population. Four possible sources were discussed: The HRS, Census Bureau studies (e.g., American Community Survey [ACS] and the Census); studies run by the U.S. Department of Housing and Urban Development (HUD); and data from the Internal Revenue Service.

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<sup>12</sup> V.A. Freedman and B.C. Spillman, “The residential continuum from home to nursing home: size, characteristics and unmet needs of older adults,” *J. Gerontol. B*, 69(Suppl 1):S42-S50 (2014).

***The Health and Retirement Study.*** The HRS excludes individuals living in facilities at study enrollment, but it follows respondents who move into these facilities over time. Facilities are identified each wave by asking participants questions about where they live. Address information has been geocoded, but does not always reflect where the participant lives, so additional refinement would be required to identify residential care facilities. Modifications are planned for the 2020 survey to refine facility name and address information to increase identification accuracy. The HRS also defines residential care facilities by services offered (as reported by participants). The HRS includes information on economic resources, adult children, and other characteristics of individuals who move into residential care communities, as well as those who do not, thus providing opportunities to examine characteristics related to moves into facilities. HRS data are linked to Medicare claims data, so information on service use and costs are available for participants who consented and are enrolled in fee-for-service Medicare; assessment data (e.g., the Minimum Data Set collected in nursing homes) are also available for individuals who consented.

***Census Bureau studies.*** The Census Bureau makes some effort to identify and describe group quarters. The Census Bureau begins with address lists from state sources and uses several methods—including advance canvassing—to define the living situation at any “group quarter.” Enumerator scripts are specific for assisted living facilities, nursing homes, and other designations. For the purposes of the decennial census, assisted living facilities are designated as housing, while nursing homes are designated as group quarters. While it would prove difficult to isolate assisted living facilities from the census database, it might be possible to flag addresses provided to the Census Bureau. With the ACS, which is conducted more frequently than the census and is more flexible, it may be possible to identify assisted living and other residential care, either by adding items or employing the address methodology.

***Housing and Urban Development studies.*** HUD shares lists of HUD-assisted (i.e., rent is subsidized, but personal assistance is not provided) units with the Census Bureau each year. Through address-matching, data on these units can be pulled from the ACS and Census. NIA and HUD could enter into a data-sharing agreement to identify additional addresses of interest. Currently, HUD’s lists excludes group quarters and does not identify residential care settings.

***Internal Revenue Service data.*** The Internal Revenue Service might be able to provide data on LTC facilities, based upon business tax records. However, these records may not provide exact addresses for facilities because a single entity may have multiple facilities.

Current data provide a range of estimates of the size of the residential care population in the United States. The NSLTC estimates that approximately 800,000 people live in regulated residential care facilities of four or more beds that provide at least two meals per day, around the clock on-site supervision, and help with personal or health-related care needs. NHATS reports approximately 1 million older adults live in assisted living settings (with no size, regulatory, or service restrictions). The Brown University ZIP code methodology identified approximately 600,000 people in places of 25 beds or more. Despite these differences, estimates of the proportion of older adults in assisted living who have dementia are similar

across studies—just over 40 percent for NHATS and NSLCTP—and the ZIP code methodology produces a reasonably similar estimate of 36 percent. NHATS also provides an estimate of retirement communities and senior housing of approximately 2.5 million.

## **General Discussion and Wrap-up**

*Moderator: Judith Seltzer, Professor, Department of Sociology, UCLA*

The first step in understanding the demography of the residential care population is defining the population in terms of its size and characteristics. This effort is complicated by the fact that the population size and characteristics, as well as the characteristics of the places where this population resides, are changing over time.

Estimates of the available stock of facilities and services offered, as well as the resources of the people who will need these services and the available workforce to provide these services are needed. NHATS and HRS provide the data necessary for estimates of service needs and individuals' family and economic resources. NHATS can also describe the care trajectory for individuals in residential care settings and moves between settings. Finally, if it were possible to either add items or to adopt the 9-digit ZIP code method or to identify places with four or more unrelated individuals, the ACS could contribute to characterization of the older residential care population for fine-grained geographic areas. There is also potential for data from the Bureau of Labor Statistics to inform estimates of the workforce available to provide services in these settings.

### ***Small facilities***

Very small facilities are currently omitted from the NSLCTP and ZIP code methodology estimates, and they are included but cannot be identified separately in NHATS. It is possible that very small assisted living facilities may proliferate as suburban areas age and as zoning increasingly permits the development of mother-in-law suites and other housing options. The ACS and HUD surveys could serve as a preliminary means of identifying the smallest facilities. The ACS could, for example, identify households in which four or more unrelated adults reside. Questions regarding services received at a residence could be added to upcoming HUD surveys. Requests for additions to the 2021 American Housing Survey are being accepted; questions that have been used in other federal surveys are preferred and suggestions for added content are needed as soon as possible.

### ***Other potential sources of data on costs of care***

The Assisted Living Disclosure Collaborative, convened by the Agency for Healthcare Research and Quality, developed a questionnaire on services, costs, and environment in assisted living. The questionnaire was not implemented, but the questionnaire and the Collaborative's experience could be helpful if developing new questions on the costs of care was of interest. Participants noted several other existing sources of data that may be relevant to understanding the costs of residential care. For instance, the MCBS offers data on service charges and payments; NHATS asks about monthly costs, and the NSLCTP also offers data on costs. Other ongoing longitudinal surveys, such as the Panel Study of Income Dynamics and the National Longitudinal Survey of Youth 1979, may begin to generate increasingly relevant data as their

cohorts age. Potential private data sources include LTC insurance companies, such as Genworth, and senior care referral services, such as A Place for Mom.

***Independent living***

Fewer studies identify residents of independent living communities. NHATS collects identical information on residents of independent and assisted living communities, including their health and functioning, family and economic resources, the assistance they receive (from the place and from others), the services available at their level of care, and payments for care by source. NHATS also collects data on whether these individuals have LTC insurance, types of services covered, and cost of premiums

## Appendix 1.

### Meeting Agenda

- 1:00 pm      Introductions and Welcome  
Judith Seltzer and John Phillips
- 1:10 pm      Issues in Defining and Measuring the Residential Care Population  
Anne Case, Moderator
- Insights from the National Study of Long-Term Care Providers  
Lauren Harris-Kojetin, CNSTAT
  - Lessons from NHATS  
Judith D. Kasper, Johns Hopkins University  
Vicki A. Freedman, University of Michigan
- 2:00 pm      The Demography of the Older Residential Care Population and Meeting  
Dementia Care Needs in Residential Settings: What Do We Know and  
What Would We Like to Know?  
Vicki Freedman, Moderator
- The Older Residential Population: Policy Challenges  
Ruth Katz, LeadingAge
  - Data Gaps Related to Care for Residents with Dementia  
Sheryl Zimmerman, University of North Carolina at Chapel Hill
- 3:10 pm      Coffee break
- 3:20 pm      Data Gaps for Studying the Demography of the Older Residential Care  
Population  
Judith Seltzer, Moderator
- Data Gaps for Studying the Demography of the Older  
Residential Care Population  
Kali Thomas, Brown School of Public Health
- 4:15 pm      General Discussion and Wrap-Up  
Judith Seltzer, Moderator
- 5:00 pm      Adjourn

## **Appendix 2.**

### **List of Participants**

#### **Presenters**

Anne Case, Princeton University, and CNSTAT Member  
Jessica Faul, University of Michigan  
Vicki Freedman, University of Michigan, and CPOP Member  
Lauren Harris-Kojetin, National Center for Health Statistics  
Judith Kasper, Johns Hopkins University  
Ruth Katz, LeadingAge  
Judith Seltzer, University of California-Los Angeles, and CNSTAT Member  
Kali Thomas, Brown University  
Sheryl Zimmerman, University of North Carolina at Chapel Hill

#### **Census Bureau**

Victoria Velkoff  
Steve Wilson

#### **Department of Housing and Urban Development**

Shawn Bucholtz

#### **Division of Behavioral and Social Research, National Institute on Aging**

Elena Fazio  
John Phillips  
Georgeanne Patmios  
Melissa Capers, Rose Li and Associates, Inc. (Contractor)

#### **Committee on National Statistics, National Academies**

Constance Citro  
Brian Harris-Kojetin