

REPORT

The Long-Term Care Ombudsman Program and the Changing Landscape of Long-Term Services and Supports

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PRESENTED TO:

Susan Jenkins, PhD
Director, Office of Performance and
Evaluation
Center for Policy and Evaluation
Administration for Community Living
US Dept. of Health & Human Services
Mary E. Switzer Building
330 C Street, SW, Rm 1243
Washington DC 20201
susan.jenkins@acl.hhs.gov

PRESENTED BY:

Kim Nguyen, PhD
Emily White, MA
Kristen Neishi, MA
NORC at the University of Chicago
4350 East-West Highway
Bethesda, MD 20814
(301) 634-9300

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Executive Summary

Since 1978, the Long-Term Care Ombudsman program (LTCOP or Ombudsman program) has promoted and protected the health, safety, welfare, and rights of residents living in long-term care (LTC) facilities. By responding to resident complaints and advocating for improvements in the long-term care system, the program plays a critical role in advancing residents' rights and supporting residents' quality of care and quality of life. Over the last few decades, however, changes in the policies, service delivery, and consumers of long-term services and supports (LTSS) have presented both challenges and opportunities to the long-term care delivery system. The populations in need of long-term care as well as the options for providing and financing their care have increased dramatically, and these trends are expected to continue as the U.S. population, and in particular the baby boom generation, ages.

In response to these developments, new or revised federal regulations for nursing facilities and home and community-based services (HCBS) have been implemented. These aim to modernize standards to reflect the growth in the older population and the evolving settings where LTSS are delivered, and to improve quality of care and safety for LTSS consumers. For the first time, regulations specific to the provision of managed LTSS have also been released. These respond to the significant expansion of this delivery system model during the interval since Medicaid managed-care rules were last revised. Meanwhile, the Ombudsman program itself has been undergoing important new legislative and regulatory changes that are designed to strengthen the program by clarifying the scope of its activities and better aligning its programs with provisions in the Older Americans Act (OAA).

Drawing on data collected as part of the *Process Evaluation and Special Studies Related to the Long-Term Care Ombudsman Program*, this report describes the changing landscape of LTSS in the U.S., and the implications of these interrelated developments for current Ombudsman program service delivery. Key findings from the study include the following:

1. **The growth and diversity of care settings, service delivery models, and LTSS consumers have placed increased demands on Ombudsman programs to assure residents' quality of care at a time when many programs are experiencing fiscal and other resource constraints.** The types of complaints that the program handles tend to be more complex and challenging than in the past. Grievances have moved away from requests for assistance with daily needs to more urgent concerns such as involuntary discharges and evictions. Ombudsmen described limitations in their ability to fully resolve certain types of complaints, particularly when solutions are ultimately outside the program's control, such as inadequate long-term care facility staffing or lack of available services to address residential or care needs. Programs have responded to changes in long-term care utilization, availability, and access by directing resources and advocacy efforts to areas of greatest need; and by prioritizing individual advocacy over systems advocacy, and visits to nursing homes over board and care homes. Against this backdrop, limited programmatic resources have compelled programs to increasingly cultivate partnerships with other agencies to support program implementation.

2. **The last five years have witnessed milestone regulatory reforms not only in the long-term care delivery system – with implementation of the revised Nursing Home Regulations, HCBS Settings Final Rule, and Medicaid Managed Care Final Rule – but also in the Ombudsman program itself, with the State Long-Term Care Ombudsman Programs Final Rule.** While each regulation is significant individually—each offering an additional tool for programs to advocate for residents—their concurrent release and implementation also have tremendous implications for Ombudsman program capacity. State Ombudsmen reported that understanding and responding to multiple requirements can strain program resources that are needed for ongoing efforts such as regular facility visits and resident complaint investigation. The additional responsibilities also mean that Ombudsmen must not only be trained on the complex new regulations, but they must then educate Ombudsman program stakeholders, including consumers, on these developments.
3. **While meeting the requirements of the LTCOP Final Rule, and to a lesser extent the 2016 OAA Reauthorization, has been a significant undertaking, there is general agreement that investment in these changes will strengthen Ombudsman programs in the long term and provide residents with more consistent services and protections.** Many federal staff and stakeholders reported that the Final Rule provided needed clarification around the role of the Ombudsman program and its relationship to other entities that serve older and vulnerable adults. Key stakeholders acknowledged that the Ombudsman program operates very differently across and within states and territories, and that these differences can lead to misunderstandings among partners and program staff at the state and local levels. The 2016 OAA reauthorization, and especially the Final Rule, served as useful tools to help educate the broader community about the role and uniqueness of the Ombudsman program and its need for independence to carry out mandated activities.

Looking ahead, long-term care stakeholders will continue to focus on implementing provisions that stem from this unusually intense period of federal reforms. Although consumers are expected to reap the benefits of these efforts, regulations and legislation alone cannot assure quality long-term care without sustained advocacy. Implementation of some standards outlined in the Nursing Home Regulations are already under threat as CMS has revised the rule around use of pre-dispute arbitration clauses, and has proposed revisions to these requirements.

Most State Ombudsmen reported that considerable work remains to advance resident rights and improve residents' quality of care and quality of life. While the program has historically struggled to meet its legislative mandates due to insufficient funding, the combination of demographic, industry, and regulatory changes has created additional strain on programs' capacity. As the long-term care delivery system evolves, Ombudsman programs will continue adapting to changing demands, yet they can only do so effectively with adequate resources to support full program implementation. To keep pace with changes in the long-term care landscape, increased funding is critical for the program to effectively serve a rapidly-growing population of older adults with more complex needs, who live in a diverse array of non-residential and residential care settings.

This report begins with an overview of the study's methodology and the Ombudsman program. Next, we summarize findings on the ongoing changes in long-term services and supports and the program's response to these developments. We then focus on recent legislative and regulatory changes affecting both the setting of care as well as Ombudsman programs, and how these changes have shaped program operations. A glossary of terms is provided at the end of the report to clarify terms and acronyms used.

Methodology

In September of 2015, the Administration for Community Living (ACL) contracted with NORC at the University of Chicago (NORC) and our partners to conduct a comprehensive process evaluation of the Ombudsman program. The NORC research team includes The National Consumer Voice for Quality Long-Term Care (Consumer Voice), Resnick, Chodorow & Associates, Associate Professor Brooke Hollister, Ph.D. of the University of California, San Francisco, Health Benefits ABCs, and the Human Services Research Institute (HSRI).

The overarching goal of the process evaluation is to support program planning and improvement by assessing the Ombudsman program's implementation at the federal, state, and local levels. As part of the study, data were collected from federal staff, national stakeholders, State Ombudsmen, local Ombudsmen, and volunteers. More detail on the methodology can be found in *Final Report: Process Evaluation and Special Studies Related to the Long-Term Care Ombudsman Program*. The following report draws on this data collection, particularly interview and survey data collected from State and local Ombudsmen, about trends in LTSS and the Ombudsman programs' responses to those changes, as well as federal staff and national stakeholders' perceptions of the OAA's Reauthorization and Long-Term Care Ombudsman Programs Final Rule. The report also draws on the Ombudsman program's administrative data, reported in the National Ombudsman Reporting System (NORS).

Overview of the Long-Term Care Ombudsman Program

In response to widely reported problems involving poor quality of care in nursing homes, the Long-Term Care Ombudsman program (LTCOP or Ombudsman program) was created in 1972 as a Public Health Service demonstration project in five states. Envisioned as an independent, person-centered consumer protection service, the Ombudsman program aims to provide a voice for long-term care residents. The Older Americans Act (OAA) established the Ombudsman program nationwide in 1978, and expanded the program’s scope to board and care homes and similar adult care facilities in 1981.¹ The 2006 amendments expanded the definition of board and care to include assisted living facilities.² To ensure the protection of residents’ rights, the OAA defined three key legislative mandates for the program.

1. The OAA charges the program with serving as an advocate for individual residents of nursing homes and board and care homes. In these settings, Ombudsmen identify, investigate, and resolve complaints about the care residents receive, focusing on their health, safety, welfare, and rights.
2. The Ombudsman program is required to advocate for systemic improvements in the long-term care system by representing residents’ interests before government agencies and analyzing, commenting on, and monitoring regulations, policies, and actions that potentially affect long-term care facilities.
3. The Ombudsman program is tasked with providing outreach and education to residents, their representatives, and facility staff, as well as coordinating with agencies that are relevant to the health, safety, well-being, and rights of residents.

These functions are performed by a State Long-Term Care Ombudsman who heads an Office of the State Long-Term Care Ombudsman (Office or Office of the SLTCO) in coordination with a state or territorial unit on aging (SUA) in all 50 states, the District of Columbia, Puerto Rico, and Guam. The State Ombudsman is responsible for statewide program administration, as well as oversight of designated representatives of the Office,³ including paid staff and volunteers, who help resolve residents’ complaints, address systemic issues, and provide information to consumers on long-term care services and supports. According to NORS, in federal fiscal year (FFY) 2017, 1,319 full-time-equivalent staff (FTEs) and 6,625 certified volunteer Ombudsman supported the program.

¹ To reflect expanded Ombudsman coverage, the program’s name was also changed from the Nursing Home Ombudsman program to the Long-Term Care Ombudsman program (LTCOP).

² The terms “board and care” (including assisted living) and “residential care communities” are being used interchangeably throughout the report.

³ In the OAA, “Ombudsman” refers to the State Ombudsman. All other staff that perform the duties of the Office are “representatives of the Office.” In practice, however, local staff and volunteers are typically referred to as Ombudsmen (and not representatives of the Office). For the purposes of this research, we refer to both the Ombudsman and representatives of the Office as Ombudsmen, unless otherwise noted.

Growth in Populations in Need of Long-Term Services and Supports and Specialized Care

The past several decades have witnessed considerable growth in both the population in need of long-term services and supports (LTSS) and the options for care that are available. In the following two sections, we discuss the implications of these complex, interrelated trends for the capacity and implementation of Ombudsman programs.

Growth in Population in Need of Long-Term Services and Supports (LTSS)

The ongoing transformation of the long-term care landscape has been driven in part by consumers themselves. Since at least the middle of the last century, the U.S. has experienced unprecedented growth in its older adult population. Between 1950 and 2000, the number of individuals age 65 and older nearly tripled, from 12.3 million to 35.1 million (Shrestha and Heisler 2011). In 2016, the number of people age 65 and older living in the U.S. grew to an estimated 50 million (U.S. Census Bureau, 2016).

In addition to their large numbers, today's older adults have longer life expectancies than in prior generations, but higher survival rates mean that they are also expected to have higher rates of chronic illness (King et al., 2013). This combination of factors—large numbers of older adults with more chronic illness—has, and will continue to lead to increased demand for long-term care services. According to the National Center for Health Statistics (NCHS), there were 1,347,600 residents in nursing homes, 811,500 residents in residential care communities, and 4,455,700 individuals receiving home health services in 2016. By comparison, there were about 1,287,400 residents in nursing homes in 1977 (at that time the report did not provide counts for community-based care or home-health services).

Although the population in need of LTSS has increased dramatically, the number of people who are trained to care for them in long-term care facilities has not kept pace. This ongoing workforce challenge is driven by several factors. In nursing homes, there has long been a lack of federal standards related to staffing levels, despite evidence that these standards are needed to ensure quality care is provided (Harrington et al., 2016). The Omnibus Reconciliation Act of 1987 (OBRA 87) required nursing homes to have “sufficient” staff, but it failed to define the staffing level needed to meet this definition. Some studies show that although the number of licensed practical nurses (LPNs) and nursing assistants (NAs) have increased in some facilities, the number of registered nurses (RNs) has decreased. In addition, there is considerable variation in staffing across large and small nursing homes, as well as those with for-profit and nonprofit ownership (Seblega et al., 2010).

Furthermore, staff training requirements vary greatly from state to state. For example, 36 states allow unlicensed staff to administer medications to residents in residential care settings, and only 24 states require residential care staff to complete a course in medication administration (ASPE, 2015). For residential care communities, staffing standards are often less well defined, and vary widely by state and facility size. Most states choose a “flexible, or as-needed” staffing approach over minimum resident to staff ratios (ASPE, 2015).

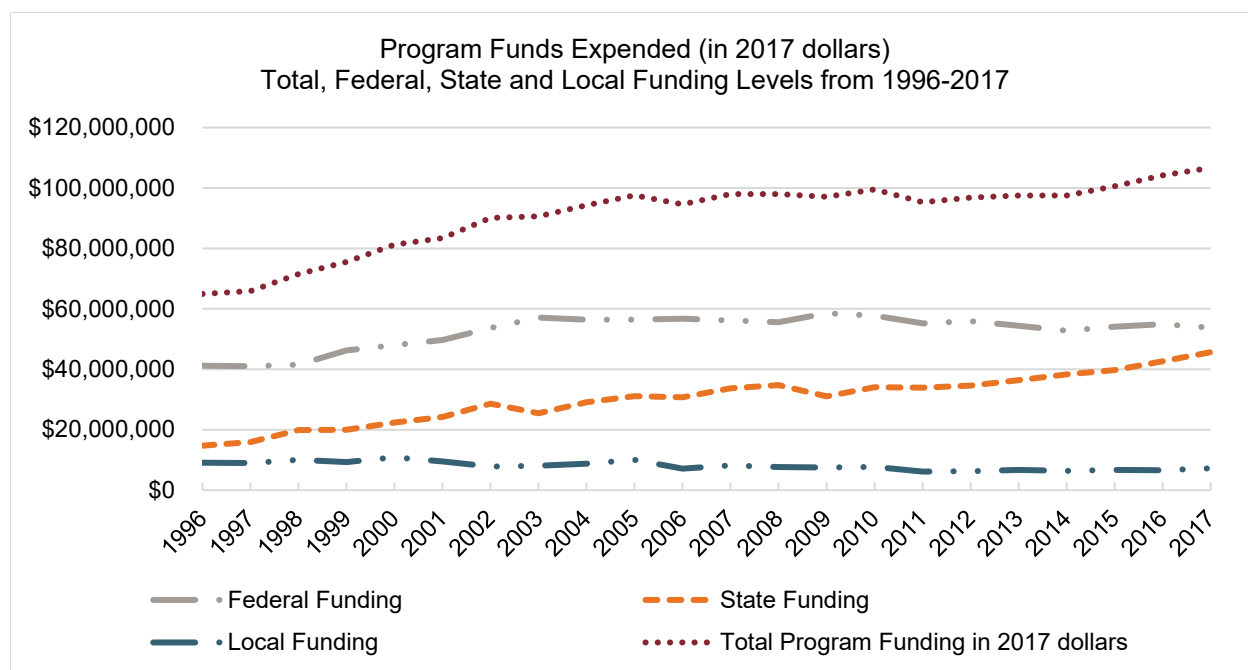
The shortage of adequately trained workers has important implications for the quality of care that residents receive. Research has consistently shown a positive relationship between nurse staffing levels and quality of care (Harrington et al., 2012; Harrington et al., 2016; Armijo-Olivo et al., 2019; Spilsbury et al., 2011; Backhaus et al., 2014), including better clinical outcomes (such as reductions in pressure sores

and use of chemical restraints), resident safety (such as reduction in falls), and fewer nursing deficiencies overall. In addition, the Office of the Inspector General (OIG) found that in 2011, 33% of skilled nursing facility residents experienced either an adverse event or temporary harm during their stay, 59% of these events were either clearly or likely preventable, and 62% of preventable events were due to inadequate monitoring or failure to provide necessary treatments (OIG, 2014).

Against the backdrop of staffing and training challenges in long-term care facilities, Ombudsman program resources to support consumer protections in these settings have also lagged behind growth in the older adult population. Programs reported that insufficient resources were a major challenge. Seventy-five percent of State Ombudsmen and 73% of local Ombudsmen cited challenges related to insufficient funding, and the impact was broad. Funds were perceived to be insufficient with respect to staffing, salaries, travel, and data systems. Only 23% of State Ombudsmen and 26% of local Ombudsmen reported that their state program’s fiscal resources were sufficient to enable their program to meet federal mandates.

Exhibit 1 shows that overall program funding has steadily increased since 1996. However, funding from federal sources remained relatively stagnant or declined between 2003 and 2017. Notably, multiple new federal regulations were passed that introduced complex new responsibilities for the Ombudsman program (described later in this report). Whereas federal funds represented 63% of all program expenditures in 1996, the share of federal dollars dropped to 50% in 2017. Programs must increasingly seek other sources of funding at the state and local levels to support program operations. However, some programs rely on federal sources for the majority of their funding. In 2017, state contributions to overall program funding ranged from zero percent to 83%.

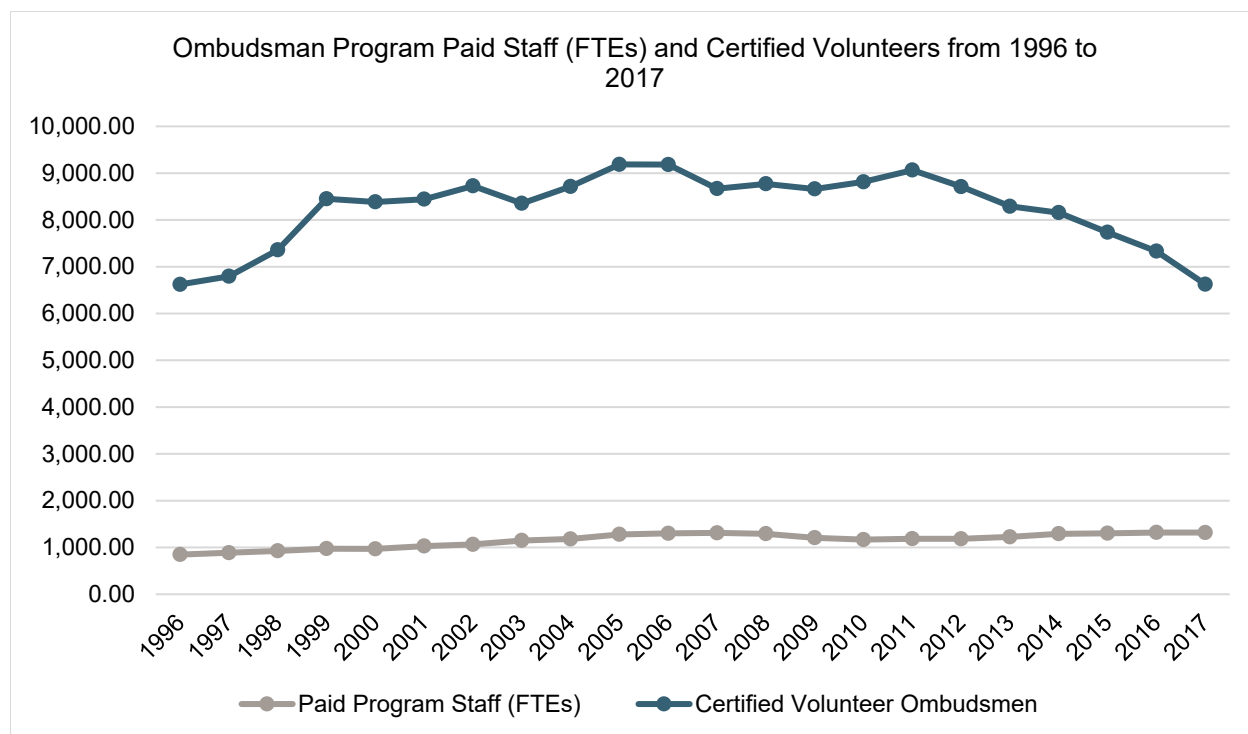
Exhibit 1: Program Funds Expended (NORS)⁴



⁴ Converted to 2017 dollars Using Bureau of Labor Statistics: <https://data.bls.gov/cgi-bin/cpicalc.pl>.

According to the National Ombudsman Reporting System (NORS; the program’s administrative reporting system), staffing for the Ombudsman program fluctuated between 1996 and 2017. In 1996, 847 staff and 6,622 certified volunteers supported the program. In 2000, the number of staff and volunteers had risen to 970 and 8,394, respectively. Since that time, the number of staff have continued to grow (1,319) while the number of volunteers has decreased by 21% to 6,625 in 2017. The decline in volunteers is especially noteworthy because some programs rely heavily on them to maintain an ongoing presence in facilities.

Exhibit 2: Number of Long-Term Care Ombudsman Program Paid Staff and Certified Volunteers from 1996-2017 (NORS)



In the current study, State Ombudsmen reported challenges in recruiting and retaining both staff and volunteers. Twenty-seven percent reported difficulties hiring qualified paid staff, and another 17% reported that high turnover of paid staff was a challenge. Challenges with respect to volunteers included turnover (30%) and difficulty recruiting and supporting volunteers (73%). While limited funds and staffing have characterized the program since its inception, increases in the size of the older population exacerbate ongoing challenges in program operations.

Growth in Diversity of Populations in Need of Specialized Care

Trends in population aging have been accompanied by key shifts in sub-populations that the long-term care provider community serves. These groups include older adults who have specialized or complex care needs. In 2014, 50% of nursing home residents and 42% of residential care community residents had Alzheimer’s disease or other dementias (Alzheimer’s Association, 2019). Individuals with behavioral health concerns encompass those with a wide range of mental health conditions, such as schizophrenia, bipolar disorder, and depression, as well as substance use disorders, including alcohol and illicit substance use. According to a 2017 report from the National Coalition on Mental Health and Aging, nearly 50% of long-term care recipients have a mental disorder other than dementia. A report by the Substance

Abuse and Mental Health Services Administration (SAMHSA) found that the share of people aged 50-59 who used illicit drugs nearly doubled from 2002 to 2007, increasing from 5.1% to 9.4% (Han et al., 2009). As the baby boom generation continues to age, the number of older adults with dementia, mental illness and who use illicit drugs is also expected to rise.

The specialized and complex care that these adults require can be challenging for facilities that lack the resources and/or staff knowledge to serve these individuals. For example, the unique characteristics of dementia, such as impaired communication, disorientation, confusion, and behavioral challenges, can frustrate staff who have not been properly trained to work with these residents (Glister et al., 2018; Hazelhof et al., 2016). In some cases, this frustration leads to use of inappropriate methods to manage behavior. These methods include physical and chemical restraints, which can increase residents' risk for Parkinsonism, stroke, and even death (Molloy, 2016). Further exacerbating this challenge is the absence of federal nursing home regulations addressing staffing requirements for cognitively impaired residents (Alzheimer's Association, 2019). Most states also lack minimum staffing requirements for dementia care in residential care settings (Glister et al., 2018; Harrington, 2010; Carder, 2017).

State Ombudsmen described the challenges that they experience in serving individuals with complex care needs or special vulnerabilities. These include individuals with Alzheimer's disease or other dementias; mental and behavioral health issues; intellectual, developmental, or physical disabilities; and complex medical conditions (e.g., tracheostomy or feeding tube). Common challenges that were reported to complicate advocacy and complaint resolution for these groups included the following:

- State Ombudsmen reported that some facilities may refuse to admit/re-admit individuals with special needs due to liability concerns (e.g., alleged violent behavior is perceived to place the safety of staff and other residents at risk) or insufficient resources (e.g., lack of training and staff) to meet their needs.
- Some Ombudsmen indicated that they now serve larger numbers of younger adults with disabilities in long-term care facilities. Ombudsmen added that many of these younger adults have mental health conditions and/or a history of substance abuse, particularly opioid addictions, and that younger adults in long-term care facilities tend to have different psychosocial needs than their older counterparts.
- Given the shortage of beds in facilities that specialize in residents with challenging behaviors, Ombudsmen are limited in their ability to resolve access issues. Identifying facility placement for these residents is often difficult because few options are available. State Ombudsmen reported that some individuals who were denied placement were either transported to a facility in another state, remained hospitalized until a facility would take them in, or lived with family members who were ill-equipped to care for them. In some cases, a mental illness or behavioral health problem may have been undiagnosed. Assisting these individuals requires staff who have been educated to identify and support residents who may be experiencing mental health issues, even if they lack a recognized clinical diagnosis.
- Of the broad complaint categories, State Ombudsmen reported “admission, transfer, discharge, and eviction” to be the most challenging and most time-consuming to resolve in nursing homes (37% and 54%, respectively) (see Exhibit 13). State Ombudsmen also reported that individuals whose behaviors are difficult for staff to handle have high rates of involuntary discharges. For example, several noted if a facility does not have sufficient or adequately trained staff capable of meeting the service and support needs of cognitively impaired residents, their response may be to involuntary discharge or transfer them, stating that they can no longer care for the resident. Similarly, individuals with behavioral health disorders are often characterized by emotional distress and functional disability, two characteristics that long-term care staff often find challenging. As a result, State

Ombudsmen reported that these residents often face difficulty finding a long-term care facility that can provide needed care, and once a facility is identified and the resident is admitted, they are more likely to face involuntary discharge or transfer.

- State Ombudsmen reported that the types of complaints and issues raised by individuals with mental health or behavioral issues tend to be more complicated, and time consuming for Ombudsmen to resolve. In some cases, particularly when residents' complaints are caused by a general deficit in needed services, such as access to mental health supports, Ombudsmen are unable to effectively resolve the issue.

State Ombudsmen described efforts to better serve individuals with special needs, including:

- Providing more targeted education and training for Ombudsmen and long-term care facility staff to better inform them on how to assist and advocate for special populations.
 - ▶ State Ombudsmen reported reaching out to and coordinating with professionals from national, state, and local entities that specialize in working with special populations. Some of these entities include: behavioral health units/agencies, public health departments, universities, police departments, corrections and rehabilitation departments, legal services, and disability rights organizations. For example, Ombudsmen in one state participate in a national program called Mental Health First Aid, an eight-hour course that provides training on how to identify and assist people who may be experiencing mental health issues. Another program worked with partners to develop a curriculum explaining residents' rights concerning discharges. In another state, some Ombudsmen are certified trainers for a program designed to educate the community about caring for people who exhibit signs and symptoms of Alzheimer's disease or related dementias. These Ombudsmen then deliver this training to the staff at facilities across their state.
 - ▶ A few State Ombudsmen described approaches to improve service for lesbian, gay, bisexual, or transgender (LGBT) residents. These efforts include working with their state's LGBT council or advocacy group to improve the experience of residents who identify as LGBT; leading seminars and presentations on providing care and services for an aging LGBT population; promoting models of organizational inclusivity for facilities, and developing training for Ombudsmen on how to provide better advocacy for LGBT consumers. One State Ombudsman noted that identifying appropriate services and supports for transgender individuals can be especially challenging. As awareness about the needs of the transgender community evolve, additional staff training for both facility staff and Ombudsmen may be needed to support the unique needs of this population.
 - ▶ In response to CMS's National Partnership to Improve Dementia Care in Nursing Homes, one Ombudsman program partnered with organizations in their state to reduce antipsychotic drug use among residents with dementia. The partnership's education and training efforts emphasize person-centered care and non-pharmacological interventions. Activities include a Music and Memory Project, direct-care staff training, resident and family education, and a mentoring program in which nursing homes with low antipsychotic utilization rates serve as mentors to facilities with higher rates. The State Ombudsman reported that the state's nursing homes have been among the country's most improved in reducing use of antipsychotics, even surpassing the goals set by CMS in establishing this initiative.
- Organizing/participating in multidisciplinary/multiagency coalitions, councils, work/community groups, and meetings to identify and advocate for solutions to improve the quality of long-term care services for special populations.

- ▶ One State Ombudsman reported regular participation in a work group of representatives from law enforcement, hospitals, the Department of Health and Welfare, emergency medical services, and Adult Protective Services (APS) to strategize on ways to prevent discharges, particularly among residents with dementia-related behaviors that are difficult to manage. In another state, a medical parole program was implemented that allows for the Department of Corrections to place a paroled inmate in a long-term care facility. The State Ombudsman developed a communications agreement with the Department of Corrections stipulating that the Ombudsman be notified when a former inmate is placed in a skilled nursing facility and the conditions of their parole. This agreement ensures that any Ombudsmen advocacy on the individual's behalf is consistent with those conditions.
- ▶ To support advocacy for populations with special needs, Ombudsmen reported working with various agencies with expertise in these areas. For example, 54% of State Ombudsmen and 45% of local Ombudsmen reported working with Behavioral and Mental Health Departments in carrying out their work. In addition, 53% of State Ombudsmen discussed efforts to promote person-centered care (culture change) in long-term care facilities.
- ▶ Some State Ombudsmen provide or anticipate providing more services to veterans, and are working to establish and cultivate partnerships with the Veterans' Administration (VA). One Ombudsman explained that they were asked to provide advocacy services to veterans residing in a community living center (i.e., nursing home) in a state VA hospital. While State Ombudsmen are interested in providing services to these veterans, implementation involves considerable coordination with the VA to establish appropriate protocols and lines of authority (e.g., access to records and confidentiality).
- Proposing legislation to address gaps and problems affecting special populations.
 - ▶ One State Ombudsman reported working with a disability council to testify on laws to improve the lives of individuals with disabilities in long-term care (e.g., testifying on financial exploitation and abuse).

Changes in the Provision of Long-Term Services and Supports

Growth in Care Options and Shifting Utilization across Facilities

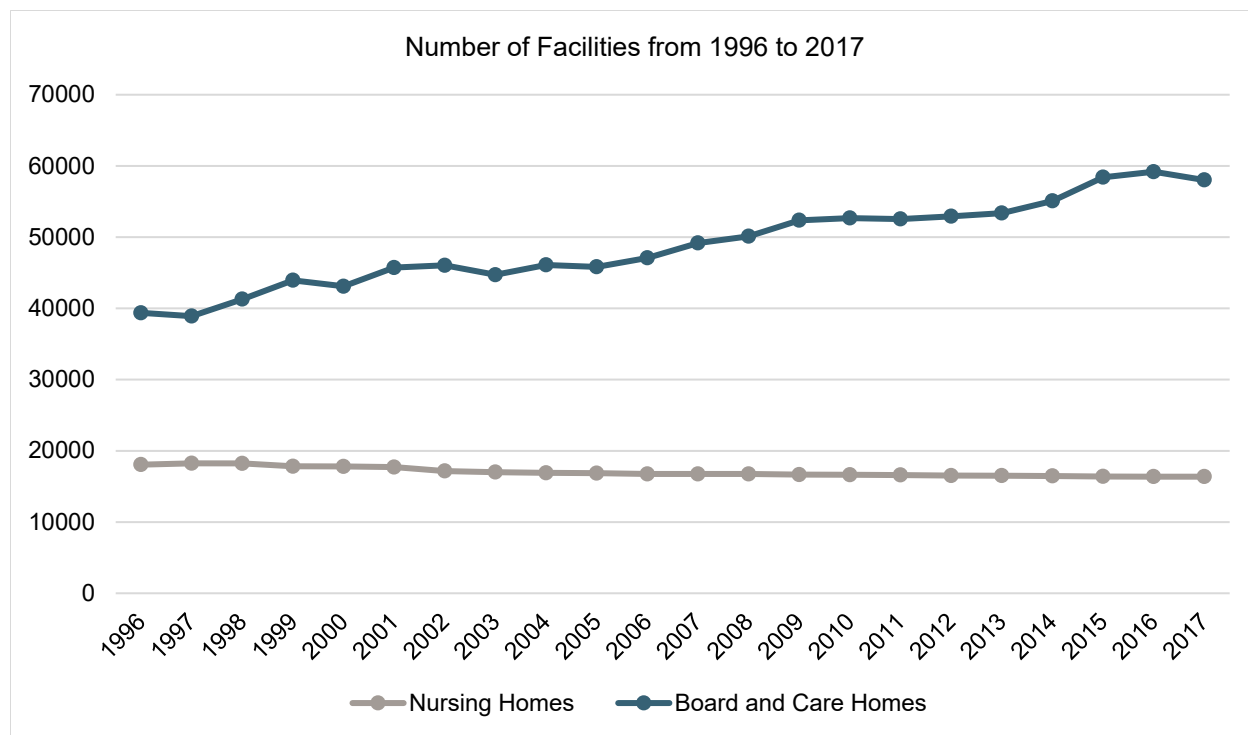
Over the last several decades, board and care homes (also known residential care communities, including assisted living facilities) have proliferated in response to growing numbers of older adults, longer life expectancy, and consumer demand for alternatives to nursing homes. While nursing homes have traditionally served as the setting for individuals requiring skilled nursing care or assistance with activities of daily living, older adults have long preferred to “age in place,” either in their homes or within their communities, if they can access the necessary supportive services.

Against the backdrop of these larger trends, a number of federal and state initiatives have been introduced to promote consumer choice and independence, as well as to rebalance LTSS provision toward more cost-effective HCBS instead of institutional care. As the nation’s primary payer of institutional and community-based LTSS for low-income Americans, Medicaid has played a significant role in these rebalancing efforts. These mechanisms have developed in a somewhat piecemeal fashion over time. Beginning in the early 1980s, states began taking steps to develop alternatives to institutional care through use of the Medicaid section 1915(c) waiver program. This allows states to offer a wide range of HCBS to beneficiaries who would otherwise qualify for institutional care. The shift was further stimulated in the 1990s by the Supreme Court’s *Olmstead* decision as well as states’ obligations to integrate people with disabilities into the community under the Americans with Disabilities Act.

More recently, states have been afforded new or expanded opportunities under the Affordable Care Act (ACA) to improve access to, and delivery of, Medicaid LTSS. HCBS options include the Balancing Incentive Program (BIP), the Money Follows the Person (MFP) Rebalancing Demonstration Program (originally enacted under the Deficit Reduction Act of 2005 (DRA)), the Section 1915(i) HCBS State Plan Option, the Section 1915(k) Community First Choice (CFC) State Plan Option, the Home Health State Plan Option, and the Financial Alignment Demonstration for Dual-Eligible Beneficiaries. Each program has different eligibility and service provision requirements and may be used alone, or in combination with other programs. Because state-based implementation of these Medicaid HCBS options is discretionary, there is enormous state-level variation in the size and scope of HCBS programs. However, 2013 marked the first year that many states devoted a greater percentage of Medicaid LTSS spending to HCBS than to institutional services (Wenzlow et al., 2016), indicating a meaningful shift in the overall balance of how and where LTSS are provided.

Exhibit 3 depicts the shift in LTSS from nursing homes to board and care homes using NORS data. Between 1996 and 2017, the number of nursing homes declined by about 18%, while the number of board and care homes rose by 55%. More than half of the latter are relatively small—between four and 25 beds—although larger facilities (over 50 beds) house a majority of long-term care residents (ASPE, 2015).

Exhibit 3: Number of Nursing Homes and Board and Care Homes from 1996 to 2017 (NORS)



Decreases in nursing home usage have been particularly evident in states with large rural areas. According to NCHS (2016), more than a third of nursing home beds in Illinois, Nebraska, Oklahoma, and Utah were empty in 2015. The national occupancy rate for nursing homes in the same year was 80%. While some facilities closed for health and safety standard violations, far more appear to have closed in response to financial pressures from policies that encouraged people to choose community-based options (Healy, 2019).

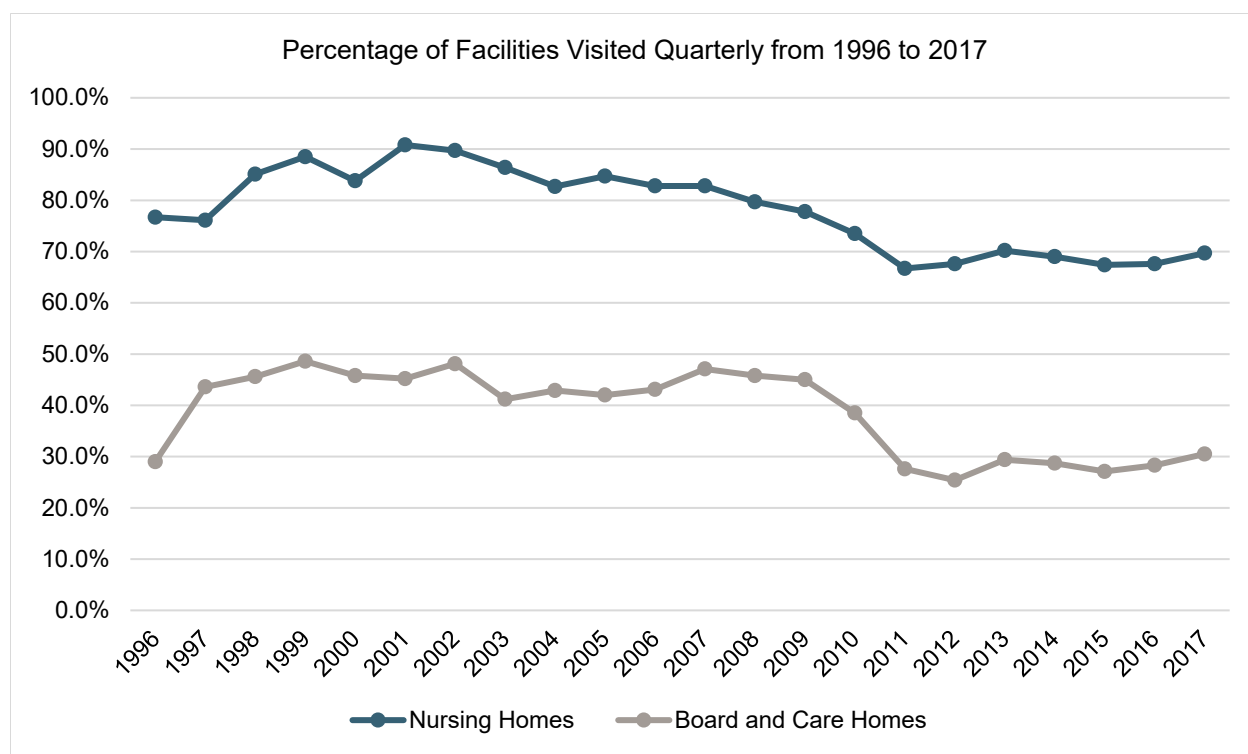
Because the Ombudsman program is federally mandated to cover both nursing homes and board and care homes, the increase in the older adult population and the growth of board and care homes or residential care communities have important operational implications for the program. Over time, the Ombudsman program has had to provide services to larger numbers of consumers who live in a wide variety of settings. Whereas nursing homes house a relatively large number of residents, board and care homes, assisted living, and similar communities typically house smaller number of residents, and some settings house as few as two residents. This creates practical challenges for resident advocacy because it can take many more visits to board and care homes to reach the same number of people that reside in a single nursing home.

Although many State Ombudsmen agree that a non-institutional setting is preferred if the resident’s care needs are properly met, over a quarter of State Ombudsmen also reported that increasing utilization of board and care homes has impacted the program’s work. Some raised concerns about the quality of some of the less regulated care homes, providers’ lower awareness of the Ombudsman program, and the obstacles to making regular visits to these small, but numerous residential settings. In addition to the smaller number of people living in board and care homes compared to nursing homes, board and care homes are often geographically dispersed throughout the state, making them difficult to visit regularly – especially for programs experiencing staffing and funding challenges.

Coverage of rural areas presents special challenges for Ombudsman programs. State Ombudsmen report that long travel distances and the costs to reach rural facilities make routine visits challenging, particularly for those facilities that are located in remote regions with poor-quality roads or areas that are only accessible by plane. In addition, several State Ombudsmen reported that the long-term care community in less populated areas cope with very few options for specialty care (such as dementia or mental health care) and attracting qualified staff to work in very rural regions is difficult. Moreover, recruiting staff in rural areas is a challenge not only for providers, but also for Ombudsman programs.

In response to these challenges, State Ombudsmen reported prioritizing nursing home visits over board and care visits, particularly when resources are limited. As shown in Exhibit 4, Ombudsman programs have largely focused on nursing home visits relative to board and care homes, even as the number of board and care homes continues to grow. In FFY 2017, there were over twice as many Ombudsman quarterly visits to nursing homes (68%) than to board and care homes (30%). As discussed above, the larger share of visits to nursing homes arises at least in part because nursing homes tend to be larger, and therefore nursing home visits can be more efficient in reaching a greater number of residents.

Exhibit 4: Percentage of Quarterly Visits Made to Nursing Homes and Board and Care Homes from 1996 to 2017 (NORS)

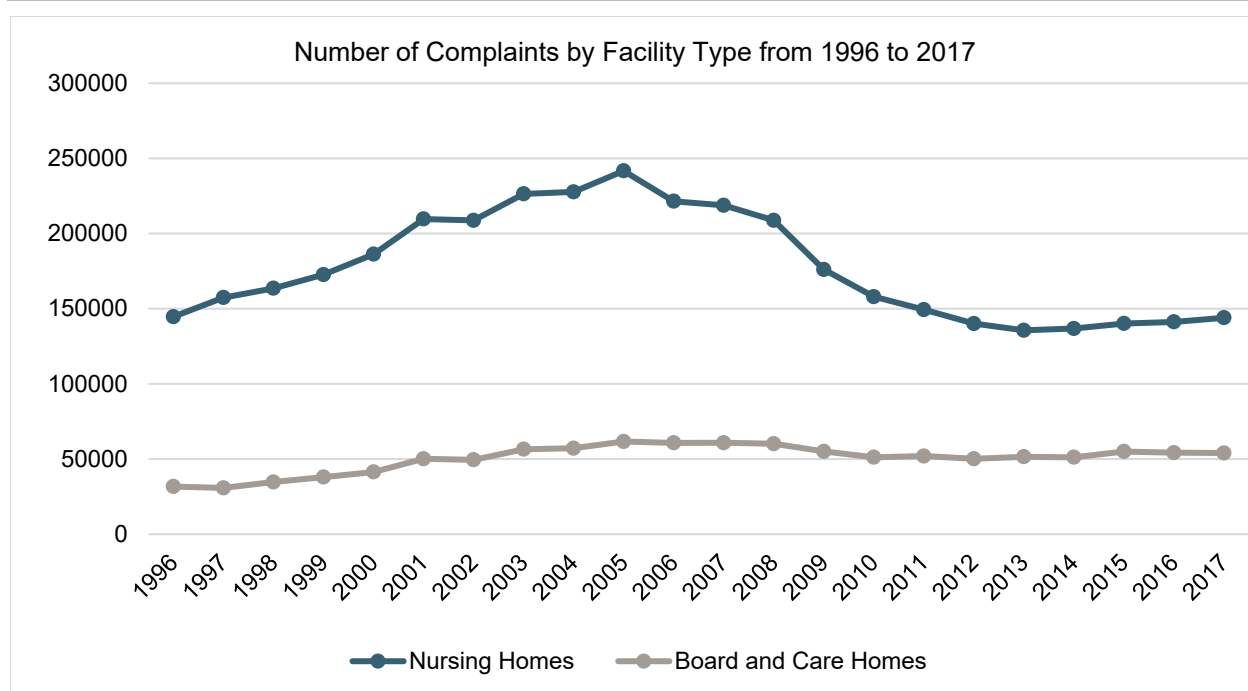


When asked about activities that cannot be fully carried out due to a lack of resources, 50% of State Ombudsmen reported that regular nursing home visits fell into this category. The percentage is even higher for board and care homes, where 69% of State Ombudsmen reported that regular visits to these settings are not fully carried out because of resource limitations. When resources are constrained, State Ombudsmen also reported prioritizing individual advocacy activities over systems advocacy activities. Whereas 23% of State Ombudsmen reported being unable to fully carry out complaint investigation and resolution activities due to lack of resources, 48% reported not being fully able to facilitate public

comments on proposed legislation, laws, regulations, policies and actions. In addition, State Ombudsmen reported not being fully able to conduct research and policy analysis to inform systems advocacy work (42%) and analyze and monitor federal, state, and local laws, regulations, and other government policies and actions (38%).

Exhibit 5 shows the number of complaints that Ombudsman programs handle by facility type between 1996 and 2017. Historically, Ombudsmen have addressed more complaints in nursing homes than in board and care homes, due in part to their greater frequency in visiting nursing homes. In FFY 2017, there were over two and a half times more nursing home complaints (144,003) than board and care complaints (53,984).

Exhibit 5: Number of Complaints in Nursing Homes and Board and Care Homes from 1996 to 2017 (NORS)



In a landscape characterized by increasing program demands, State and local Ombudsmen reported important differences in their ability to have effective relationships with nursing home and board and care home staff, as shown in Exhibits 6 through 8. State and lead local Ombudsmen (those identified as having managerial responsibilities), were asked about the effectiveness of their statewide programs and local Ombudsman entities, respectively. Local Ombudsmen (those without managerial responsibilities) were asked about their individual relationships with the two types of providers. Overall, State, lead local, and local Ombudsmen were more likely to report effective relationships with nursing homes, compared to board and care homes. This finding is consistent with the observation that a greater share of Ombudsmen visits are dedicated to nursing homes than board and care homes. While local Ombudsmen tended to report higher levels of effective relationships with both types of providers than did State Ombudsmen, State Ombudsmen were asked to report on their statewide program (rather than local Ombudsman entities or their individual relationships with providers). Comparisons between respondent groups, then, should be interpreted with caution because of these differences in question wording.

Exhibit 6: Effectiveness of Statewide Ombudsman Program’s Relationship with Nursing Homes and Board and Care Homes (State Ombudsmen)

Overall, how would you rate the effectiveness of your statewide program’s relationship with the following types of facilities and providers?	Nursing Homes N=51	Board and Care Homes N=51
A majority of the relationships are effective	51%	39%
Some of the relationships are effective	47%	49%
A few of the relationships are effective	2%	12%
None of the relationships are effective	0%	0%

Missing=1

Exhibit 7: Effectiveness of Local Ombudsman Entity’s Relationship with Nursing Homes and Board and Care Homes (Lead Local Ombudsmen)

Overall, how would you rate the effectiveness of your local program’s relationship with the following types of facilities and providers?	Nursing Homes N=188 ^a	Board and Care Homes N=173 ^b
A majority of the relationships are effective	68%	53%
Some of the relationships are effective	29%	37%
A few of the relationships are effective	3%	9%
None of the relationships are effective	0%	1%

^a Missing=1; ^b Missing=7, Not applicable=9

Exhibit 8: Effectiveness of Local Ombudsmen’s Relationship with Nursing Homes and Board and Care Homes (Local Ombudsmen)

Overall, how would you rate the effectiveness of your relationship with the following types of facilities and providers?	Nursing Homes N=295 ^a	Board and Care Homes N=279 ^b
A majority of the relationships are effective	66%	59%
Some of the relationships are effective	28%	36%
A few of the relationships are effective	5%	4%
None of the relationships are effective	0%	1%

^a Missing=3, Not applicable=10 ; ^b Missing=6, Not applicable=23

In open-ended follow-up questions, Ombudsmen were asked to describe factors that informed their assessments of effectiveness. Although all types of Ombudsmen reported that a regular presence in facilities and positive working relationships as key factors, the salience of these two factors varied by roles. Whereas 20% of State Ombudsmen and 22% of lead local Ombudsmen reported that a regular presence was important for effective relationships, 12% of local Ombudsmen reported maintaining a regular presence as important. Much larger percentages of lead local and local Ombudsmen (32% and 47%, respectively) reported that establishing positive working relationships with facility staff are major contributing factors. Eleven percent of lead local Ombudsmen also reported that relationships are more effective if facility staff view the Ombudsman program as a resource, whether that involves reporting issues before they become complaints, seeking training, or connecting residents to available resources.

Another 19% of local Ombudsmen reported that the knowledge, confidence, and experience level of the Ombudsman is an important factor in the effectiveness of relationships with facility staff.

Other contributors to effectiveness depended on provider setting. With respect to board and care homes, 15% of State Ombudsmen reported that the strength of the state’s regulations for these facilities is a major driver of the effectiveness of the program’s relationships. Indeed, a key difference between nursing home and board and care homes that affects resident advocacy concerns the source and stringency of regulatory oversight. Whereas nursing homes are regulated at the federal level and provide greater protections for residents, board and care homes are licensed and regulated at the state level, and regulations vary widely. For example, many states have regulations concerning training for direct-care workers, but the number of hours of required training can range from one to 80 (ASPE, 2015).

Given state-level variation in staffing and other standards, State Ombudsmen differed in their perceptions of the extent to which state regulations facilitated efforts to advocate for board and care home residents. Exhibit 9 shows that 43% of State Ombudsmen reported that regulations for board and care homes in their state were sufficient. Another 45% found them sufficient in some circumstances and settings, while 12% felt that they are not sufficient for any setting type. These results suggest that more than half of State Ombudsmen (57%) have difficulty serving residents in at least some residential care settings due to a lack of strong state regulations to support their advocacy work.

Exhibit 9: Sufficiency of State Board and Care Home Regulations to Enable State Ombudsman Programs to Adequately Serve Residents (State Ombudsmen)

Do the state regulations that govern board and care homes and similar facilities provide sufficient provider guidance to enable your statewide program to advocate for residents of those settings?	State Ombudsmen N=51
Yes, they do provide sufficient guidance to advocate for residents in those settings	43%
A mix, depending on the type or size of the setting	45%
No, they are not sufficient for any setting type	12%

Missing=1

In interviews, about one-quarter of State Ombudsmen reported that lack of strong regulations for board and care homes makes serving those residents more challenging compared to nursing home residents. Whereas nursing home federal regulations enable programs to refer facilities to requirements they must follow, states’ assisted living regulations are relatively less stringent, making it harder for programs to protect residents and resolve their complaints. One State Ombudsman noted weaknesses in regulations for the required level of care in assisted living facilities, particularly for special needs populations, such as those with Alzheimer’s disease or other dementias. This ambiguity allows board and care, assisted living and similar homes to accept residents for whom they may not be able to provide adequate care. Other reported weaknesses may result from board and care regulations that attempt to cover a wide range of facility sizes. One State Ombudsman noted that their state’s regulation is written to address both the small, six-bed homes, as well as the larger assisted living facilities. Further, notions of adequate staffing may differ between providers and residents. Lastly, one State Ombudsman noted that movement from one type of residential setting to another can be confusing to residents who expect the same resident protections and rights to apply in all settings.

Consistent with these observations, Exhibit 10 shows the relationship between State Ombudsmen’s perceived effectiveness in board and care homes and their perceptions concerning the adequacy of regulatory guidance for board and care homes in their states and territories. State Ombudsmen who

reported sufficient guidance were more likely to report that the majority of their statewide program’s relationship with board and care homes are effective.

Exhibit 10: Effectiveness of Ombudsman Program’s Relationship with Board and Care Homes and Sufficiency of Board and Care Home Regulations (State Ombudsmen)

Overall, how would you rate the effectiveness of your statewide program’s relationship with providers of board and care homes?	State regulations for board and care homes provide sufficient guidance to advocate for residents N=22	Sufficiency of state regulations for board and care homes depends on the type or size of the setting N=22	State regulations for board and care homes are not sufficient for any setting type N=6
A majority of the relationships are effective	64%	18%	17%
Some of the relationships are effective	27%	64%	83%
A few of the relationships are effective	9%	18%	0%
None of the relationships are effective	0%	0%	0%

Missing=2

In addition to federally-mandated responsibilities for nursing homes and board and care homes under the OAA, 17 State Ombudsmen reported having authority to serve in-home consumers receiving LTSS. Under state statutes or other provisions, these states and territories expanded Ombudsman services to individuals who receive HCBS in their own homes or communities, outside of facilities. Exhibit 11 lists these states and territories.

Exhibit 11: LTCOPs with Home Care Responsibility

State/Territory		
Colorado	Iowa	Rhode Island
District of Columbia	Maine	Vermont
Delaware	Minnesota	Virginia
Georgia	Ohio	Wisconsin
Idaho	Pennsylvania	Wyoming
Illinois	Puerto Rico	

It should be noted that although programs are not prohibited from providing services to individuals beyond those defined in the OAA, they must use resources other than those appropriated through federal law (such as general state revenues or other funds) to support this work (AoA, 2015).

Responsibility for home-care advocacy has existed almost since the program’s inception, with the earliest report of in-home services from the Wisconsin Ombudsman program in 1981. While states and territories may gain or lose authority for home-care advocacy (and for this reason, the composition of states with this authority may change over time), the overall level of responsibility has steadily increased over the last 40 years, with the loss of authority in some states and territories offset by gains in others. Based on available historical data, approximately eight states were responsible for home care in the 1980s. The number increased to 10 in the 1990s (data were first collected by the National Long-Term Care Ombudsman Resource Center in 1994 and again in 1999), 12 in 2007, and 14 in 2013. In the current study, 17 State Ombudsmen reported having authorization to serve in-home consumers in 2017.

Across programs with authority for in-home advocacy, the scope, funding, and implementation of these requirements varies widely. According to two reports prepared by NASUA⁵ (first in 2001 and updated in 2007), a majority of programs have responsibility for investigating complaints regarding HCBS under Medicaid waivers but they may also serve individuals covered by other services (alone or in combination). These services include state-funded home care, home health agency services, OAA home care programs, private pay home care, adult foster care, adult day services, hospice and public housing, and relocation follow-up. Other differences in scope may pertain to whether programs engage exclusively in complaint handling or if systems advocacy is included as part of their responsibilities. Funding for these activities come from a variety of sources (such as state general funds, Medicaid administrative funds, provider fees, and grants) or it may be absent altogether. As of the 2007 report, state legislatures of Indiana and Virginia provided no additional funding to support their mandated home care advocacy activities. In terms of implementation, programs vary in staffing for home care complaint handling (use of any Ombudsman, dedicated staff, and/or volunteers), training requirements, policies and procedures, and use of formal agreements (such as memoranda of understanding) with other agencies (e.g., APS, Medicaid waiver programs) to address home care advocacy.

It should be noted that there are instances where Ombudsman programs without responsibility for home care advocacy also investigate complaints regarding home care services. This may occur during periods of resident transitions – whether the complaint concerns identifying a new residence or needs related to health care. For example, some programs provide advocacy for individuals moving from one setting to another (e.g., transitioning to the community from nursing homes) or for long-term care facility residents who receive additional home care services that are arranged by facilities to supplement care needs.

Overall, home-care complaints represent a very small percentage of total complaints handled by the Ombudsman program. According to NORS in FFY 2017, 25 Ombudsman programs reported handling 1,277 home-care complaints (one percent of all complaints addressed by the program).⁶ Of this number, 10 programs did not have explicit state level authority to serve consumers of in-home services. Only 10 programs handled more than 10 home care complaints, only one of which did not have state level authority to serve consumers of in-home services. Among the 17 programs authorized to serve consumers of in-home services, 88% reported handling any home-care complaints, ranging from one complaint to 281 complaints.

Exhibit 12 presents State and lead local Ombudsmen's reports of their program's effectiveness in home care. Most State and lead local Ombudsmen reported that some to a majority of the program's relationships are effective, although a greater percentage of State Ombudsmen felt this way (81% compared to 66%). Compared to State Ombudsmen, lead local Ombudsmen were more likely to report that a few of the relationships with in-home service providers are effective, and seven percent of lead local Ombudsmen reported that none of the relationships are effective. As a reminder, State Ombudsmen are responding to questions in the context of their statewide programs and lead local Ombudsmen are reporting on their local entities.

⁵ The reference to the National Association of State Units on Aging (NASUA) reflects the name of the organization when the report was published. In 2010, NASUA subsequently changed its name to the National Association for States United on Aging and Disabilities (NASUAD). In August of 2019, NASUAD changed its name to ADvancing States.

⁶ In NORS, in-home complaints are reported within the larger category of "Other Non-Facility Settings."

Exhibit 12: Effectiveness of Ombudsman Program’s Relationship with In-Home Service Providers (State and Lead Local Ombudsmen)

Overall, how would you rate the effectiveness of your state/local program’s relationship with in-home service providers?	State Ombudsmen N=16 ^a	Lead Local Ombudsmen N=28 ^b
A majority of the relationships are effective	25%	28%
Some of the relationships are effective	56%	38%
A few of the relationships are effective	19%	28%
None of the relationships are effective	0%	7%

^a Missing=1; ^b Missing=4

In open-ended questions, Ombudsmen were asked to describe factors that informed their assessments of effectiveness. Among State Ombudsmen who reported that a majority of their relationships with in-home service providers are effective, many explained that they had been serving this population for many years and had developed good communications and a strong understanding of this service population. They reported having success in resolving issues for these programs’ consumers, noting that providers responded adequately to their recommendations concerning consumer rights. Among those who reported that some of their relationships with in-home service providers are effective, some explained that program limitations (such as time or resources) prevented them from establishing strong relationships with providers, and that there were inconsistencies in the quality of in-home care provided to consumers. One State Ombudsman noted that the lack of a comprehensive provider association in their state made it difficult to facilitate effective communication. The main reasons for rating only a few of the relationships as effective included the newness of in-home care as part of the Ombudsman’s jurisdiction, the rapid growth and closure of in-home service providers, and lack of program resources to establish regular contact with providers. Exacerbating these challenges is the nature of complaints that arise in non-institutional settings. One State Ombudsman reported that compared to nursing homes, consumer complaints initiated at home or in the community can be more complex and labor-intensive to investigate because of the number of providers with whom they need to consult and coordinate (such as a specialist or home health aide), who may not work together in the same setting.

With respect to lead local Ombudsmen, 34% reported that the small number of complaints from these settings resulted in limited overall contact with providers and this hindered relationship building. Seventeen percent described having collaborative or “working” relationships with in-home service providers, while 10% reported that the Ombudsman program is seen more as an adversary or a “nuisance.” A few lead local Ombudsmen also noted staff turnover or shortages, as well as weaker regulations in in-home care settings as contributing factors to less effective relationships.

Growth in Acuity Levels across Facilities

The distinction between nursing homes and other residential care communities has become somewhat blurred over time as residents’ level of acuity has increased across settings (Han et al., 2016; Carlson, 2014). Han et al.’s (2016) analysis of the 2010 National Survey of Residential Care Facilities found that more than half of assisted living facilities admitted residents with considerable health care needs, including some who needed nursing-level care for transfers, medication, and eating or dressing. Staffing for these facilities mostly consisted of resident care aides, however, with only half utilizing higher-level licensed providers such as registered nurses. In fact, the Han et al. report showed that smaller facilities tended to admit residents with higher care needs despite having fewer licensed nurses than larger

facilities. Additional data from Caffrey et al. (2012) showed that almost 40% of residents in residential care facilities received assistance with three or more activities of daily living (ADLs), more than 40% had Alzheimer’s disease or other dementias, and nearly 75% had been diagnosed with at least two of 10 common chronic conditions such as high blood pressure and heart disease.

Nearly 21% of State Ombudsmen described increasing resident acuity in residential care settings and, in some cases, in nursing homes as well. While some nursing homes may prioritize short-term rehabilitation residents, State Ombudsmen seemed particularly concerned with residential care settings that admit residents who require high levels of nursing care without having adequately trained or appropriately licensed staff to provide needed care. Ombudsmen are finding that residential care facilities are home to some residents whose frailty and complex medical needs require the type of skilled nursing care that is characteristic of a nursing home. Some Ombudsmen also noted that residential care communities are becoming default mental health institutions.

Some issues related to increased resident acuity are reflected in State Ombudsmen’s reports of complaints they find most challenging and time-consuming to address. Of the 16 broad types of complaints,⁷ State Ombudsmen reported complaints relating to nursing home admission, transfer, discharge, and eviction were both the most challenging and most time-consuming to resolve (Exhibit 13). These types of complaints include transitions resulting from facility closures and emergency relocations. Perhaps due to their frequency, 20% of State Ombudsmen also reported that their programs are most effective at resolving complaints related to admission, transfer, discharge, and eviction. Additionally, 79% of State and local Ombudsmen reported that their programs have expertise in addressing involuntary discharges and transfers.

Other notable findings concern resident care and staffing. Care-related issues were generally not perceived to be particularly difficult to resolve, but were reported to be time-consuming when they arose. In contrast, one-fourth of State Ombudsmen reported that staffing problems were among those most difficult to resolve, but none reported that these issues were the most time-consuming. This may be partly due to the limitations in Ombudsmen’s ability to address staffing issues.

In interviews, one-third of State Ombudsmen reported that their programs were receiving an increasing number of complaints related to staffing, such as insufficient staffing levels, inadequate training, and high staff turnover. Several State Ombudsmen reported inadequate staffing as the underlying source of quality problems in long-term care facilities. Because facility staffing is largely outside the program’s control, however, there is little that Ombudsmen can do to handle this issue, other than to pursue more systemic reform. For example, one State Ombudsman reported establishing a workgroup to develop legislation to improve the state’s staffing standards in nursing homes. The move was prompted by increasing complaints from nursing home residents about staff and direct appeals from certified nursing assistants to the Ombudsman program. Among other requirements, the legislation removed incentives for facilities to keep lower staffing levels, established minimum staffing requirements based on resident acuity, and required that direct care staff be available at all times. To develop this legislation, Ombudsman program staff met with residents, family members, nursing home staff, legislators, and other stakeholders to ensure that recommended staffing changes were informed and well-supported. The legislation was passed in 2009. Although there have been periodic threats to the legislation’s staffing standards, the Ombudsman program has successfully advocated to protect the standards by encouraging stakeholders

⁷ When reporting complaint data in NORS, programs record complaints that they handle using 16 broad complaint codes and 133 detailed complaint codes. The study’s survey used NORS’ 16 broad complaint categories when asking Ombudsmen about the types of complaints that their programs resolve.

to call legislators, testify when the opportunity arises, and write letters to the state’s commission that examines rate setting.

Exhibit 13: Complaints that are Most Challenging, Time-Consuming, and Effective at Resolving in Nursing Homes (State Ombudsmen)

Complaint Category	Most Challenging to Resolve N=52	Most Time Consuming to Resolve N=52	Most Effective at Resolving N=51^a
Abuse, gross neglect, exploitation	10%	4%	6%
Access to information by resident or resident’s representative	0%	0%	10%
Admission, transfer, discharge, eviction	37%	54%	20%
Autonomy, choice, preference, exercise of rights, privacy	4%	13%	39%
Financial, property (except for financial exploitation, which is included in the first response option)	6%	2%	0%
Care	6%	23%	18%
Rehabilitation or maintenance of function	2%	0%	0%
Restraints – chemical and physical	2%	0%	0%
Activities and social services	2%	0%	0%
Dietary	0%	0%	2%
Environment	0%	0%	2%
Policies, procedures, attitudes, resources	4%	0%	4%
Staffing	25%	0%	0%
Certification/Licensing agency	0%	0%	0%
State Medicaid agency	0%	0%	0%
System/Others	4%	4%	0%

^a Missing=1

With respect to board and care homes, State Ombudsmen similarly reported that complaints relating to admission, transfer, discharge, and eviction were most challenging to resolve, although a smaller proportion of respondents found them particularly time-consuming to address, as seen in Exhibit 14. Other issues that were particularly challenging or time-consuming for Ombudsmen to resolve in board and care homes included policies, procedures, attitudes, and resources; and issues relating to resident care. Almost one-fifth of State Ombudsmen considered policies and related issues for board and care homes to be particularly difficult to resolve, compared with only four percent who found these issues to be challenging to address in nursing homes. This may reflect the greater specificity of regulations for nursing home policies and procedures in most states. With respect to the effectiveness of Ombudsman programs in resolving complaints, over half of State Ombudsmen (54%) reported that their programs were most effective at resolving complaints related to autonomy, choice, preferences, exercise of rights, and privacy. These types of complaints can often be resolved by coordinating with facility staff and are generally focused on an individual resident. Some states also have residents’ rights outlined in state law or regulation for board and care homes which provide Ombudsmen additional tools to advocate on behalf of residents.

Exhibit 14: Complaints that are Most Challenging, Time-Consuming, and Effective at Resolving in Board and Care Homes (State Ombudsmen)

Complaint Category	Most Challenging to Resolve N=52	Most Time Consuming to Resolve N=52	Most Effective at Resolving N=52
Abuse, gross neglect, exploitation	4%	6%	2%
Access to information by resident or resident’s representative	0%	0%	10%
Admission, transfer, discharge, eviction	40%	31%	8%
Autonomy, choice, preference, exercise of rights, privacy	8%	31%	54%
Financial, property (except for financial exploitation, which is included in the first response option)	4%	4%	0%
Care	13%	15%	12%
Rehabilitation or maintenance of function	0%	0%	0%
Restraints – chemical and physical	0%	0%	0%
Activities and social services	0%	0%	4%
Dietary	0%	2%	4%
Environment	0%	2%	0%
Policies, procedures, attitudes, resources	19%	8%	4%
Staffing	12%	0%	0%
Certification/Licensing agency	0%	0%	2%
State Medicaid agency	0%	0%	0%
System/Others	0%	2%	2%

State Ombudsmen also reported that the complaints that Ombudsman programs handle are currently more complex and challenging than they were in the past, moving away from requests for assistance with daily needs to more urgent concerns such as discharges and evictions. Exhibit 15 shows the top 10 most frequent complaints by facility type in FFY 2017. These complaints reflect the detailed complaint codes (rather broad complaint categories presented in Exhibits 13 and 14) used in NORS. For residents of both nursing homes and board and care homes, the most frequent complaint pertained to “discharge/eviction – planning, notice, procedure, implementation, including abandonment.” According to historical NORS data, the most common type of complaint addressed by Ombudsmen in nursing homes between 1997 and 2010 were failures to respond to requests for assistance (such as transfers to chairs/bed), followed by discharge/eviction. For the last seven years, discharge/eviction topped the list of the most frequently reported complaints handled by the program. As described earlier, of the broader complaint categories, those related to “admission, transfer, discharge and eviction” were reported to be the most challenging and time-consuming to resolve.⁸ In board and care homes, the most common complaints addressed by Ombudsmen in recent years (2017, 2016, and 2014) were discharges and evictions. Prior to that time, the most frequent complaints concerned medications or food service (1996-2013, 2015).

⁸ According to NORS, “discharge/eviction – planning, notice, procedure, implementation, including abandonment” is one of seven types of complaints that falls under the broad complaint code of “admission, transfer, discharge, and eviction.”

Exhibit 15: Top Ten Most Frequent Complaint Types (NORS)

Complaint Ranking	Nursing Homes	Board and Care Homes
1	Discharge/eviction-planning, notice, procedure, implementation, including abandonment	Discharge/eviction-planning, notice, procedure, implementation, including abandonment
2	Failure to respond to requests for assistance	Medications – administration, organization
3	Dignity, respect – staff attitudes	Food service - quantity, quality, variation, choice, condiments, utensils, menu
4	Medications – administration, organization	Dignity, respect – staff attitudes
5	Resident conflict, including roommates	Equipment/building - disrepair, hazard, poor lighting, fire safety, not secure
6	Personal hygiene (includes nail care & oral hygiene) and adequacy of dressing & grooming	Cleanliness, pests, general housekeeping
7	Food service - quantity, quality, variation, choice, condiments, utensils, menu	Resident conflict, including roommates
8	Care plan/resident assessment - inadequate, failure to follow plan or physician orders	Accidental or injury of unknown origin, falls, improper handling
9	Symptoms unattended, including pain, pain not managed, no notice to others of changes in condition	Personal property lost, stolen, used by others, destroyed, with-held from resident
10	Accidental or injury of unknown origin, falls, improper handling	Care plan/resident assessment - inadequate, failure to follow plan or physician orders

Growth in Managed Long-Term Services and Supports (MLTSS)

Adding momentum to the movement toward HCBS is the growing interest among states in capitated managed long-term services and supports (MLTSS) delivery systems. Under MLTSS, managed care organizations (MCOs) act as the state’s agents to negotiate contracts with providers and arrange beneficiary services. In this arrangement, MCOs absorb full financial risk and agree to deliver covered services for a fixed amount. By contracting with MCOs to deliver health care services to Medicaid and/or Medicare beneficiaries, states hope to reduce program costs and better manage health service utilization.

Over time, an increasing number of states have implemented MLTSS programs. In 2009, only six states operated MLTSS programs (Anthony and Nevitt, 2016). By 2015, 22 states operated these programs, and 11 more were in the planning stages. By 2016, nearly three-quarters of Medicaid beneficiaries were enrolled in Medicaid managed care (MMC) programs (Anthony and Nevitt, 2016), and this growth has included increased use of MLTSS.

MLTSS programs vary by state, differing in the populations served (e.g. younger people with disabilities, people that are only Medicaid-eligible, Medicare/Medicaid dual-eligibles), and the services covered (e.g. HCBS, supported employment services) (National Health Policy Forum, 2012). The transition from fee-for-service to a managed care system has broad implications for enrollees in terms of their ability to navigate the system, access services, and understand their rights.

To ensure that Ombudsman programs’ staff and volunteers are knowledgeable about the complexities of their state’s MLTSS program, some state Ombudsman programs have developed intensive MLTSS training programs. Thirty-seven percent of State Ombudsmen, 38% of lead local Ombudsmen, and 35% of local Ombudsmen reported partnering or coordinating with MCOs in carrying out their work. Four State

Ombudsmen mentioned collecting data on activities related to managed care, including the quantity and types of managed care complaints received by the program.

Additionally, as consumers continue to move toward managed LTSS options, some Ombudsman programs' roles have expanded to cover MCO members. For example, Iowa has a Managed Care Ombudsman Program that is a division of the Office of the SLTCO. The Managed Care Ombudsman Program "advocates for the rights and needs of...Medicaid managed care members who live or receive care in a health care facility, assisted living program or elder group home, as well as members enrolled in one of Medicaid's seven home and community-based services waiver programs" (Iowa Department on Aging, 2016). The Managed Care Ombudsman Program provides education and information regarding members' rights, advocacy, and complaint resolution when members are unable to resolve an issue with their MCO. It also assists with appeals when members are dissatisfied with MCO decisions.

Furthermore, recent changes in delivery of LTSS require that the program provide educational opportunities to MCOs. Because MCOs typically operate under a medical model, Ombudsmen must educate them on issues such as self-determination and basic rights that may not be familiar to these providers or easily translated into practice or routine workflows.

In some states, Ombudsman programs for managed care settings are separate from the LTCOP. For example, Minnesota has an Ombudsman for Public Managed Health Care Programs which "helps enrollees get needed health care and resolve billing problems...[and] provides information and assistance with the managed care grievance and appeal process available through the health plan and the state" (Minnesota Department of Human Services, 2017). From an operational point of view, this administrative separation may require the Ombudsman program to work with the Managed Care Ombudsman to ensure residents receive the support they need from the appropriate Ombudsman entity.

Nineteen percent of State Ombudsmen reported that their states had implemented managed long-term care programs. Some described positive relationships while others expressed concern that these programs limit coverage for people who need LTSS in ways that a non-managed care system would not. Additionally, other Ombudsmen described an impact on workload as they familiarized themselves with managed care regulations and other recent federal and state directives related to long-term care. They noted that because consumers often look to the Ombudsman program as a resource on these issues, Ombudsmen must quickly educate themselves on these topics. Eleven percent noted that while their states do not currently have managed long-term services and supports, they anticipate these changes in the near future and expect that they will impact their states' long-term care landscape and Ombudsman program.

New Regulations in Long-Term Care Delivery

In response to the growth and increasing diversity of populations and settings, significant new regulations have been implemented for both institutional and residential settings that aim to improve oversight and quality of care. On October 4, 2016, the Centers for Medicare & Medicaid Services (CMS) published the first major revision to federal nursing home standards in over a quarter of a century. The nursing home regulations are authorized by the Nursing Home Reform Act, passed as part of the Omnibus Budget Reconciliation Act of 1987 (OBRA 87). OBRA 87 is widely considered to be landmark legislation because it led to sweeping reforms that improved quality of care and established resident rights in nursing facilities that accepted payment from CMS.

In March of 2014, CMS published the first regulations to establish standards for facility-based settings that are funded through Medicaid HCBS. As states come into compliance with the regulations, CMS is taking an active oversight role to ensure compliance with the settings standards, in addition to any existing state laws and regulations.⁹

Released in 2016, CMS specifically addressed the provision of managed LTSS for the first time in its Medicaid and Children’s Health Insurance Program (CHIP) Managed Care Final Rule. Inclusion of managed LTSS in the rule reflects states’ expansion of this delivery system model since the last revision to Medicaid managed care regulation.

While the impact of each of these regulations is far reaching for states and long-term care providers, the changes also affect the Ombudsman program, albeit to varying degrees. Because the Ombudsman program serves settings affected by CMS’s regulations, it needs to be familiar with any updated provisions regarding the financing or other aspects of LTSS service delivery. Ombudsman program staff must at minimum be trained on the complexities of all final rules because of the program’s role as a consumer advocate. In this section, we discuss the relationship between recent regulatory developments and Ombudsman program service delivery.

Nursing Home Regulations

Medicare and Medicaid Programs; Reform of Requirements for Long-Term Care Facilities that participate in Medicare and Medicaid

In September of 2016, CMS issued the “Medicare and Medicaid Programs; Reform of Requirements for Long-Term Care Facilities that participate in Medicare and Medicaid” (hereafter referred to as the “Nursing Home Regulations”). Despite significant changes in the nursing home industry over the past several decades, this was the first comprehensive revision to existing nursing home regulations since they were first issued in 1991. The new regulations reflected an evolution in the theory and practice of long-term care service delivery and safety, and they implemented important provisions of the Affordable Care Act (ACA) (Tritz et al., 2016). The 2016 nursing home regulations addressed five major themes:

- **Person-centered care:** maintaining and improving existing protections, choices, care and discharge planning
- **Quality:** quality of life and quality of care, including quality assurance and performance improvement

⁹ Previously, oversight of HCBS settings was limited to requirements in states’ Medicaid plans, while residential care settings had been governed almost entirely by state laws and regulations (ASPE, 2015).

- **Facility assessment and competency-based approach:** accounting for diversity in populations and facilities, and focusing services on individual needs
- **Alignment with current HHS initiatives:** reducing unnecessary hospital readmissions and healthcare-acquired infections, improving behavioral healthcare, and safeguarding residents against unnecessary use of psychotropic medications
- **Implementation of legislation:** This includes ACA provisions related to compliance and ethics programs, quality assurance and performance improvement programs, and dementia care and abuse awareness training, as well as provisions of the Improving Medicare Post-Acute Care Transformations (IMPACT) Act, such as discharge planning requirements for skilled nursing facilities (SNFs).

Implementation of the 2016 nursing home regulations is being carried out in three phases, with full compliance required by November 28, 2019 (however, on July 16, 2019, CMS proposed to delay implementation of certain Phase 3 requirements for one year). Although these changes are expected to have an impact on nursing home quality of care, the full effect is unlikely to be evident for some time. However, some of the new regulations are already impacting the Ombudsman program and its effort to serve nursing home residents. The National Consumer Voice for Quality Long-Term Care (2017a, b, c) summarized the changes that are likely to have the greatest influence on Ombudsman programs:

- A copy of a resident’s transfer/discharge notice must be sent to a representative of the Office of the SLTCO. CMS subsequently clarified the type of notices that are required to be sent under this provision;
- Prohibition of pre-dispute binding arbitration agreements, and subsequent suspension of that prohibition (described further below);
- A requirement that nursing homes provide immediate access to any resident by “any representative of the Office of the State Long-Term Care Ombudsman (Office of the SLTCO).” Previously, the regulations only provided immediate access to the State Ombudsman;
- Facilities must allow representatives of the Office of the SLTCO to examine a resident’s records in accordance with state law;
- Facilities must not prohibit or discourage residents from communicating with federal, state, or local officials, including federal and state surveyors and representatives of the Office of the SLTCO;
- Facilities must have sufficient nursing staff with the appropriate competencies and skill sets to provide nursing and related services to assure resident safety and attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident. A sufficient staffing level is determined by resident assessments and individual plans of care and considering the number, acuity, and diagnoses of the facility’s resident population in accordance with the facility assessment required in §483.70(e);
- Nursing homes must post contact information for the Office of the SLTCO; and
- Nursing homes that are closing must notify the Office of the SLTCO.

Arguably, changes in resident discharge and transfer provisions have had the most impact on Ombudsman programs. Among the 74% of State Ombudsmen who reported the new nursing home regulations as a major federal policy change that impacts the Ombudsman program, 64% specifically mentioned the requirement for facilities to send notices of involuntary transfers and discharges to the Ombudsman program. Because the regulation did not specify whether notification was limited to the nature of the discharge, facility staff widely interpreted this requirement to include all transfers and discharges, regardless of reason. This resulted in an influx of notices received by many Ombudsman programs (particularly in those states that did not already have notification requirements), diverting staff attention to managing the flood of paperwork.

CMS later issued a clarification that only notices of involuntary (or facility-initiated) transfers or discharges must be provided. Despite this clarification, some Ombudsmen reported continuing to receive a large number of unnecessary notifications and needing to dedicate staff time to verify that the notices were in fact related to involuntary discharges. Given the influx of notices, some State Ombudsmen developed new processes or procedures to address the tremendous increase of notices. They also reported providing training and education to nursing home staff to help them understand the requirements and reduce unnecessary work for both nursing home staff and Ombudsmen. Many also reported that involuntary nursing home discharges and the effort to find placements for discharged residents represented a large share of their workload, particularly in areas with large numbers of nursing home closures.

Initially, the Nursing Home Regulations included a prohibition against forced pre-dispute binding arbitration agreements. These require prospective residents to agree to settle disputes without turning to the court system as a condition of admission to a facility. A lawsuit brought by the American Health Care Association (AHCA; the largest nursing home provider association), however, resulted in suspension of this requirement (Collier 2019). A few State Ombudsmen expressed concern that this suspension would weaken protections for nursing home residents who wish to bring a claim of abuse, neglect, or other quality of care issues against a nursing home.

Multiple State Ombudsmen noted disappointment about the vagueness of the requirement for nursing homes to have “sufficient” staff, with appropriate competencies and skill sets. While they noted that the current requirement is a step in the right direction, they pointed out that it lacks specificity and strength to compel facilities to establish minimum staffing requirements, such as standards based on minimum numbers of direct care hours for each resident. Some states are advocating for stronger state-level requirements to address the federal regulation’s limitations.

Provisions of the Nursing Home Regulations that address access for both Ombudsmen and residents are widely viewed as a positive change that will enhance the program’s ability to serve residents. Some Ombudsmen also highlighted the requirement for nursing homes to notify the program of an impending closure, noting that this allows programs to coordinate with other partners in the aging network to ensure that residents have safe, coordinated transitions to new homes.

Home and Community-Based Services (HCBS) Settings Final Rule

Medicaid Home and Community-Based Services Settings Final Rule

Medicaid-funded HCBS provide LTSS that allow low income older adults and persons with disabilities to remain integrated in their communities (Edwards, 2014). In January of 2014, CMS issued the Medicaid Home and Community-Based Services Settings Final Rule (CMS-2249-P2). These regulations addressed several sections of Medicaid law that stipulate how states may use federal Medicaid funds to pay for HCBS, and they established quality requirements for provider settings that are eligible for reimbursement for Medicaid HCBS. States and care settings must comply with the new requirements by March 2022.

In the HCBS Settings Final Rule, CMS required settings that qualify as home and community-based to:

- Be integrated in and supports full access to the greater community;
- Be selected by the individual from among several setting options;
- Ensure individual rights of privacy, dignity, respect, and freedom from coercion and restraint;
- Optimize autonomy and independence in making life choices, and
- Facilitate choice regarding services and who provides them.

The Final Rule specifies additional requirements for provider-owned or controlled HCBS residential settings that serve individuals who receive Medicaid-funded HCBS:

- The individual must have a lease or other legally-enforceable agreement providing similar protections;
- The individual must have privacy in the unit and lockable doors, choice of roommates, and freedom to furnish or decorate the unit;
- The individual must control their own schedule, including access to food and visitors at any time; and
- The setting must be physically accessible.

These HCBS setting requirements exclude nursing facilities and other institutions from serving as Medicaid-funded home and community-based settings. The requirements also outline characteristics of care settings that are presumed not to be home and community-based. These include settings in the same building as a facility that provides inpatient treatment, settings on the grounds of, or immediately adjacent to a public institution, and settings that isolate individuals. Providers must show evidence that they meet the HCBS setting requirements to continue providing services under Medicaid HCBS programs.

One-third of State Ombudsmen reported the HCBS Settings Final Rule to be a major change affecting their programs. Included in Ombudsman programs' coverage of board and care homes are a number of settings that are affected by the settings rule, such as assisted living facilities. Other than what is required in states' Medicaid plans, there has been virtually no federal oversight of HCBS settings, and residential care settings have been governed almost entirely by state laws and regulations (ASPE, 2015). For this reason, the regulation is especially important for programs in states where LTSS provision favors HCBS over nursing homes. For several of these State Ombudsmen, the regulation is viewed as a positive development that will benefit residents who utilize Medicaid. The 2014 HCBS setting requirements established a regulatory framework that provides the Ombudsman program with additional remedies when resolving complaints in these settings, and it also provides additional opportunities for systems advocacy to support improvements to state HCBS systems. In general, Ombudsmen perceived the new regulatory requirements as tools that programs can use to advocate on behalf of consumers.

As states evaluate their HCBS settings for compliance with the 2014 regulations, State Ombudsmen described needing to familiarize themselves with the complexities of the regulation and to serve as a resource to stakeholders. Part of this challenge involves determining whether a facility is community-based in order to participate in the Medicaid program. One State Ombudsman noted that because assisted living facilities are often physically attached to nursing homes, whether a facility is an assisted living facility or nursing home is sometimes not readily evident. For facilities that do not qualify as meeting the settings rule, the State Ombudsman reported that the program will need to help transition residents to other facilities that are not deemed institutional. Ombudsmen report that this is expected to be a hard and painstaking process, both for residents and for programs.

In addition, one consequence of the HCBS Settings Final Rule is that some providers may not be able to comply with the requirements, thereby forcing service recipients in those settings to move elsewhere, or to find an alternative source of funding (other than Medicaid) to continue receiving services in their current setting. In these situations, Ombudsmen may be called upon to provide information and complaint resolution assistance with transitions, or they may need to work with other agencies if a facility closes due to loss of Medicaid funding. Given that many state and local Ombudsman programs struggle to conduct regular visits to HCBS settings (National Long-Term Care Ombudsman Resource Center, 2015), programs may have limited capacity to respond to all complaints if a state determines that many existing care settings do not meet the new HCBS settings requirements.

Medicaid Managed Care Final Rule

Medicaid and Children's Health Insurance Program (CHIP) Managed Care Final Rule

In April of 2016, CMS released its Medicaid and Children's Health Insurance Program (CHIP) Managed Care Final Rule. The Final Rule included Medicaid MLTSS, which are delivered through capitated Medicaid managed-care programs instead of fee-for-service arrangements. Key goals of these regulations included advancing delivery system reform and improving accountability and transparency. The managed-care regulations became effective in July 2017, but some provisions will be phased in over three years (Center for Medicaid and CHIP Services, n.d.). This reform was implemented in part because of the growth in managed care described earlier, the rules for which were last updated in 2002.

In states that operate MLTSS programs, State Ombudsmen reported the need to quickly educate themselves as well as staff and volunteers on the regulations in order to effectively advocate for consumers. As with the HCBS Settings Final Rule, other agencies and consumers turn to the Ombudsman program as a resource. For this reason, staff must be trained on the regulations to interpret them for members and provide guidance on how to best respond. State Ombudsmen also reported that any rule that affects the population the Ombudsman program serves also means that the program must monitor the regulation's release and participate in commenting on federal requirements.

Updated Legislation and New Regulation for the Long-Term Care Ombudsman Program

As outlined in the OAA, states must meet specific requirements for Ombudsman programs but also exercise considerable discretion in fulfilling program functions in a manner that best serves their older adult populations. States can expand program responsibilities (e.g., supporting recipients of in-home services) and administer their programs in multiple ways (e.g., organizational location at both the state and local levels). This flexibility, as well as differing interpretations of the Act in the absence of formal guidance, has resulted in considerable state-level variation in the structure, operation, and effectiveness of Ombudsman programs.

To address variability in Ombudsman program service delivery and effectiveness across and within states and territories, two recent legislative and regulatory activities were undertaken. In 2015, ACL promulgated the State Long-Term Care Ombudsman Programs Final Rule (made effective in 2016), the first regulation focused specifically on States' implementation of the Ombudsman program. Coinciding with the regulation's implementation period, Congress renewed its commitment to providing services to older adults and reauthorized the OAA in 2016. Together, the LTCOP Final Rule and the provisions relating to Ombudsman programs in the reauthorized Act sought to protect vulnerable adults by strengthening Ombudsman programs.

This section describes the experiences of Ombudsman programs in meeting the requirements of the updated legislation and new regulation.

2016 Reauthorization of the Older Americans Act

The reauthorization of the OAA in 2016 included the following important changes and clarifications to the LTCOP:

- Authorized Long-Term Care (LTC) Ombudsman programs to serve all LTC facility residents, regardless of their age. [Section 711(6)]
- Clarified that the State LTC Ombudsman is responsible for the fiscal management of the Office of the State LTC Ombudsman. [Section 712(a)(2)]
- Clarified that LTC Ombudsman programs may work to resolve complaints on behalf of residents unable to communicate their wishes, including those lacking an authorized representative. [Section 712(a)(3)(A)(i) & (a)(5)(vi)]
- Required State LTC Ombudsmen to ensure that residents have private, unimpeded access to the program. [Section 712(a)(3)(D)]
- Required LTC Ombudsman programs to actively encourage, and assist in the development of resident and family councils in long-term care facilities. [Section 712(a)(3)(H)(iii) & (a)(5)(vii)]
- Authorized LTC Ombudsman programs to serve residents transitioning from a LTC facility to a home-care setting, when feasible. [Section 712(a)(3)(I)]
- Clarified that the LTC Ombudsman program is considered a "health oversight agency" for purposes of the Health Insurance Portability and Accountability Act (HIPAA). [Section 712(b)(3)]
- Applied OAA disclosure provisions to all LTC Ombudsman program information (rather than only "files and records") and clarified exceptions for disclosure of information relating to residents unable to communicate their wishes, including those lacking an authorized representative. [Section 712(d)(2)(c)]
- Provided specific examples of individual and organizational conflicts of interest, requiring remediation or removal of such conflicts. [Section 712(f)]
- Required that each State LTC Ombudsman or designee participate in training provided by the National Ombudsman Resource Center. [Section 712(h)(4)]
- Required the Director of the Office of Long-Term Care Ombudsman Programs to collect and analyze promising practices related to responding to elder abuse, neglect, and exploitation in long-term care facilities. [Section 201(d)(3)(M)]

Older Americans Act (OAA) Reauthorization Act of 2016

On April 19, 2016, the Older Americans Act Reauthorization Act of 2016 was signed into law to further promote the dignity and independence of older adults in their homes and communities and protect residents in long-term care facilities and other settings from abuse, neglect, and exploitation (see text box). To improve and strengthen the Ombudsman program's effectiveness, the reauthorization focused on key clarifications and changes related to the service population (which now includes all long-term care residents, regardless of age), responsibilities for fiscal management of the program, disclosure of information, and remedying individual and organizational conflicts of interest. To help bring consistency to program service delivery, the reauthorization also included provisions related to training and development of resident and family councils.

State Long-Term Care Ombudsman Programs Final Rule

ACL embarked on an historic undertaking in 2015 by promulgating the State Long-Term Care Ombudsman Programs Final Rule (hereafter, Final Rule) to clarify OAA provisions, particularly those that are unique to the program. First published February 11, 2015, and made effective July 1, 2016, the Final Rule focused its regulatory guidance on areas of greatest inconsistency in program implementation. Key provisions of the Final Rule focused on the following areas:

- State Agency Policies (45 CFR §1321.11)
- Establishment of the Office of the State Long-Term Care Ombudsman (45 CFR §1324.11)
- Functions and Responsibilities of the State Long-Term Care Ombudsman (45 CFR §1324.13)
- State Agency Responsibilities Related to the Ombudsman Program (45 CFR §1324.15)
- Responsibilities of Agencies Hosting Local Ombudsman Entities (45 CFR §1324.17)
- Duties of the Representatives of the Office (45 CFR §1324.19)
- Conflicts of Interest (45 CFR §1324.21)

To help bring programs into compliance with the new regulation, ACL's Central and Regional Offices and the National Long-Term Care Ombudsman Resource Center provided training and technical assistance to programs through conferences, webinars, and by providing a Frequently Asked Questions (FAQs) document. During the study's data collection (2017-2018), programs were still actively working toward meeting Final Rule requirements. Given this schedule, this report offers early findings on State Ombudsmen's as well as stakeholders' perceptions of the impact of implementing the Final Rule and the reauthorized OAA on program operations. The clarifications that State Ombudsmen discussed as most salient for the program included:

- The Office of the State Long-Term Care Ombudsman must be a distinct entity, separately identifiable within the state or territorial unit on aging (SUA) or other agency or organization in which it is housed or connected;
- The State Ombudsman must be able to carry out mandated systems advocacy activities, making independent determinations and establishing positions of the Office, without representing the positions of the State agency or other entity housing the Office; and
- Examples of individual and organizational conflicts of interest, and the requirement to remedy these conflicts through policies and procedures, or if necessary, changes to state statutory language or program location.

Most federal staff, national stakeholders, and State Ombudsmen reported that implementation of the reauthorized OAA and Final Rule were positive developments that will eventually strengthen the program's service delivery. Given the historic nature of the regulation, in many ways, the Final Rule eclipsed changes that were outlined in the OAA reauthorization in terms of its impact on programs. Ombudsmen and stakeholders reported that they allocated considerable effort to understand and implement the Final Rule as well to educate entities with which they coordinate.

Many federal staff and stakeholders reported that the Final Rule provided needed clarification around the role of the Ombudsman program and its relationship to other entities that serve older and vulnerable adults. Key stakeholders acknowledged that the Ombudsman program operated very differently across and within states and territories, and that these differences can lead to misunderstandings among partners and program staff at the state and local levels. The OAA reauthorization, and especially the Final Rule, served as useful tools to help educate the broader community about the role of the program and its staff.

Given that State Ombudsmen frequently reported challenges with effectively communicating the role and uniqueness of the Ombudsman program and its need for independence to host agencies as well as entities with which they coordinate, many expressed appreciation for having its autonomy more clearly defined in the Final Rule. The Final Rule's description of the Office of the State Long-Term Care Ombudsman when established in a state agency as "a distinct entity, separately identifiable and located within or connected to the State agency" underscored the OAA's vision of the Ombudsman program's independence. The regulation also clarified the State Ombudsman must be free to comment on policies and legislation without obtaining prior approval from the State agency. It additionally clarified that state policies and procedures must exclude the State Ombudsman and local staff from any state lobbying prohibitions that are inconsistent with the OAA in order for Ombudsmen to engage in mandated systems advocacy activities.

Despite provisions to ensure program independence, however, political or bureaucratic pressures can still prevent State Ombudsmen from having the freedom to engage in systems advocacy. A few State Ombudsmen noted that their SUA or state government host agencies struggled to understand the need for programmatic independence, and another explained that in practice, advocating for independence can be challenging when the State agency is responsible for hiring, firing, and evaluating the State Ombudsman's performance. Some State Ombudsmen also noted similar difficulties for local Ombudsmen whose host agencies have been slow to recognize that the role of an Ombudsman extends beyond individual advocacy. Having these programmatic elements more clearly defined in the Final Rule helped Ombudsmen communicate these long-standing requirements to other entities.

Many State Ombudsmen also praised the additional guidance and clarification regarding individual and organizational conflicts of interest. As a result of these provisions, State Ombudsmen and SUA Directors were, at minimum, required to consider whether their program's placement within a state agency was appropriate, mitigate or remedy any organizational conflicts, and where prohibited conflict existed, remove the conflict (i.e., some State Offices and local Ombudsman entities relocated to a different host agency to eliminate organizational conflicts). State Ombudsmen also were required to report their conflicts, remedies, and removals in NORS which is then reviewed by ACL for compliance. Other State Ombudsmen implemented new policies and procedures, developed MOUs, or secured separate legal counsel to mitigate existing conflicts. State Ombudsmen also discussed working with their SUAs and state legislatures to update statutes to enable compliance with the new regulations.

Although many State Ombudsmen perceived that the Final Rule will strengthen and bring consistency to the Ombudsman program's service delivery, they also reported challenges associated with implementing the new regulations, for both Ombudsman programs and entities with which they coordinate. Some stakeholders expressed concern about the provision that Ombudsmen cannot be mandatory reporters for abuse or neglect. One respondent viewed this as an ethical issue, and another was concerned about potential gaps in service in states where APS does not serve nursing home residents. Although other regulatory agencies such as the state survey agency may serve as the lead investigator, one State Ombudsman noted that Ombudsmen are often the primary intake for responses to cases of resident abuse or neglect. These scenarios required partnering agencies to review their own practices to determine if changes were needed to address potential gaps. Another stakeholder was concerned about privacy issues related to residents' personal information, especially in the case where small town residents and their families may know the Ombudsman outside of their role in the program and may not want to share their information. It is important to note that the Final Rule clarified requirements regarding disclosure of resident identifying information and requires policies to identify, remedy, and remove individual conflicts of interest because of concerns shared by the stakeholder.

One point of agreement among federal staff, stakeholders, and State Ombudsmen is that promulgation and implementation of the Final Rule were significant undertakings for all parties that support Ombudsman program operations. In developing the Final Rule, ACL invested heavily in working with, and obtaining buy-in from numerous federal staff, State Ombudsmen, and stakeholders in the aging network to ensure that the regulation addressed common concerns and areas of confusion. As one federal staff member described it, ACL sought "more consensus on the front-end, for more ownership on the back-end." ACL's Central and Regional Office staff spent considerable time working with State Ombudsman programs to examine program structure, laws, regulations, organizational placement, and policies and procedures to help the programs understand areas that needed to be addressed, and to develop compliance plans. State Ombudsmen and program staff, in turn, dedicated substantial effort to understanding and implementing the regulation.

Although the Final Rule went into effect on July 1, 2016, not all states were compliant at the time data were collected for this study. As of March, 2017, ACL had approved plans submitted by a majority of states that outlined the steps they would take to come into compliance, as well as timelines for completing those steps. Some programs were already compliant and simply needed to put their policies and procedures into writing. Others needed to make structural changes such as relocating the Office out of the state agency to eliminate conflicts of interest, or to secure changes to their state statutes. Because programs are subject to the schedule of state legislative sessions, programs' ability to make the required updates varied considerably – from months to years.

Discussion

In response to both consumer preference and the rising need for LTSS over the last few decades, HCBS options have grown significantly. The expansion of care options has been accompanied by federal and state initiatives that encourage use of home and community-based care settings. For the Ombudsman program, the increasing number and diversity of populations and settings present important challenges and opportunities for service delivery. The Ombudsman program is not only required to advocate for a larger number of residents overall with more complex needs and special vulnerabilities, but programs must adapt to these expanding demands with resources that have not kept up with the program's operational needs.

Over time, the types of complaints that the Ombudsman program handles have become more complex and difficult. According to historical NORS data, the most common type of complaint addressed by Ombudsmen in nursing homes between 1997 and 2010 were failures to respond to requests for assistance (such as transfers to chairs/bed), followed by discharges and evictions. For the last seven years, "discharge/eviction – planning, notice, procedure, implementation, including abandonment" have topped the list of the most frequently reported complaints handled by the program. Of the broader types of complaints, those related to "admission, transfer, discharge and eviction" are the most challenging and time-consuming to resolve. Part of these trends stem from increasing numbers of people with complex care needs and high acuity, including individuals with dementia and behavioral health issues. Compounding these issues are the challenges that occur when these special populations move across settings or between facilities. Ombudsmen in our study, as well as results from earlier research, indicate that facilities are more likely to involuntarily discharge a resident when care needs become challenging. Ombudsmen described limitations in their ability to fully resolve certain types of complaints, particularly when problems ultimately reside outside the program's control, such as regulations that result in inadequate staffing or geographic considerations that preclude delivery of services to address special residential or care needs.

In addition to the changing nature of complaints that programs handle, Ombudsmen must provide advocacy services to residents living in larger numbers of settings than in the past. Although the growth in less-restrictive settings is viewed by many as a positive development, this shift comes with important challenges, including ensuring regular facility visits and effective advocacy against the backdrop of considerable variability in state-level regulations.

These changes in the long-term care landscape compel programs to direct resources and advocacy efforts to areas of greatest need. At a time when many programs are experiencing fiscal and other resource constraints, programs have prioritized individual advocacy over systems advocacy and visits to nursing homes over board and care homes. Limited resources also compel programs to cultivate partnerships with other state and local agencies to support program implementation. State Ombudsmen are also turning to new regulatory reforms to help promote quality of care and protect resident rights and safety.

Indeed, although the growth in the older population and the diversification of long-term care settings have been underway for several decades, only more recently have changes in legislation and regulations been implemented to support better oversight and care for consumers. Within just two years, CMS released three major regulations to modernize oversight of nursing homes and HCBS settings, and ACL published the first Ombudsman program regulation. The revised Nursing Homes Regulations, HCBS Settings Final

Rule, Medicaid Managed Care Rule, and State Long-Term Care Ombudsman Programs Final Rule were all released between 2014 and 2016.

While each regulation represents a milestone in reforming long-term care service delivery and provides the Ombudsman program with additional tools to advocate for residents, the concurrent implementation of these regulations within a short period of time has strained program resources. To varying degrees, each regulation requires that Ombudsman programs expend considerable effort to respond to the changing regulatory environment. This is especially true for meeting the requirements of the LTCOP Final Rule. While some states were already in compliance and only needed to formalize current practices and policies, other states needed to relocate programs and/or revise state statutes, policies, and procedures. This may take months to years, depending on each state's legislative schedule.

The last five years have witnessed an unusually intense period of regulatory and legislative activity in the long-term care delivery system, and consumers are expected to reap the benefits of these collective investments over time. Regulations and legislation alone, however, cannot assure quality long-term care without sustained advocacy. Indeed, implementation of some standards outlined in the recent Nursing Home Regulations are already under threat, as CMS has revised the rule around use of pre-dispute arbitration clauses and has proposed revisions to the 2016 requirements.

Most State Ombudsmen report that considerable work remains to advance resident rights, quality of care, and quality of life. While the Ombudsman program has long struggled to meet its legislative mandates due to lack of sufficient funding, the combined impact of demographic, industry, and regulatory changes has created additional strain on programs' capacity. As the long-term care delivery system evolves, Ombudsman programs will continue adapting to changing demands, yet they can only do so effectively with adequate resources that support full program implementation. To keep pace with changes in the long-term care landscape, increased funding for the program is critical to serve an ever-growing population of older adults with more complex needs who live in a diverse array of residential and non-residential care settings.

Glossary of Terms & Acronyms

Aging network – The OAA established a national network of federal, state, and local agencies to plan and provide services that help older adults to live independently in their homes and communities. Collectively, this structure of agencies is referred to as the aging network. The national aging network is headed by the Administration on Aging and includes 56 state and territorial units of aging (SUAs), 622 Area Agencies on Aging (AAAs), and over 260 Title VI Native American aging programs (AoA, 2019).

Area Agency on Aging (AAA) – AAAs are public or private nonprofit agencies designated by a state to address the needs and concerns of older persons at the regional and local levels. AAAs are primarily responsible for a geographic area (e.g. a planning and service area or PSA), that is either a city, a single county, or a multi-county district (ACL, 2019).

Board and care homes – These homes include residential care facilities, adult congregate living facilities, assisted living facilities, foster care homes, and other adult care homes similar to a nursing facility or board and care home which provide room, board, and personal care services to a primarily older residential population. See also “residential care community/facility.”

Home and community-based services (HCBS) – HCBS refers to types of person-centered care delivered to individuals with functional limitations who need assistance with everyday activities (such as getting dressed or bathing) in their home or community. HCBS are often designed to enable people to remain in their homes, rather than moving to a facility for care and generally fall into two categories – health services and human services. HCBS programs may offer a range of services from one or both types of services (CMS, 2019: <https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/info/hcbs>).

Long-term services and supports (LTSS) – LTSS encompasses the broad range of paid and unpaid medical and personal care assistance that people may need when they experience difficulty completing self-care tasks as a result of aging, chronic illness, or disability. Long-term services and supports include, but are not limited to, nursing facility care, adult daycare programs, home health aide services, personal care services, transportation, supported employment, and assistance provided by a family caregiver (Reaves & Musumeci, 2015).

National Association of States United for Aging and Disabilities (NASUAD) – Founded in 1964, NASUAD is a non-profit association representing the nation’s 56 officially designated state and territorial agencies on aging (SUAs). Their mission is to design, improve, and sustain state systems delivering home and community-based services and supports for people who are older or have a disability, and their caregivers (NASUAD, 2019). In August of 2019, NASUAD changed its name to ADvancing States.

National Long-Term Care Ombudsman Resource Center (Resource Center) – The Resource Center provides support, technical assistance and training to the 53 State Long-Term Care Ombudsman Programs and their statewide networks of local Ombudsman entities. Funded by ACL, the Center is operation by Consumer Voice, in cooperation with NASUAD. The Center’s objectives are to enhance the skills, knowledge, and management capacity of the State programs to enable them to handle residents’ complaints and represent resident interests in both individual and systems advocacy (Resource Center, 2019).

National Ombudsman Reporting System (NORS) – NORS is the administrative data collection tool for the LTCOP. Used by Ombudsman programs since 1996, NORS provides national and state-specific data on programmatic efforts, including facility visits, complaint types and resolution, consultations, resident and family councils, community education and program information such as funds expended and numbers of program staff. States report aggregated data annually to the Administration for Community Living (ACL),

Nursing homes – Also referred to as nursing facilities, these homes are licensed by the state to offer residents personal care as well as skilled nursing care on a 24-hour/day basis. These include skilled nursing facilities. Services provided include nursing care, personal care, room and board, supervision, medication, therapies and rehabilitation (ASPE, n.d.).

Residential care community/facility – Similar to board and care homes, a residential care community refers to a type of long-term care facility, regardless of setting, that provides at a minimum, room and board, around-the-clock on-site supervision, and help with personal care such as bathing and dressing or health-related services such as medication management. Facility types include but are not limited to: assisted living; board and care home; congregate care; enriched housing programs; homes for the aged; personal care homes; adult foster/ family homes and shared housing establishments that are licensed, registered, listed, certified, or otherwise regulated by a state (NORS OMB#0985-0005).

State Unit on Aging (SUA) – State or territorial units on aging (SUAs) are designated state-level agencies that are responsible for developing and administering multi-year state plans that advocate for and provide assistance to older residents, their families, and in many states, for adults with physical disabilities. The SUA is the grantee of the federal funds designated for the LTCOP, and as a result, has certain responsibilities to the LTCOP (e.g. providing personnel supervision and management for the State Ombudsman and representatives of the Office who are employees of the SUA) (ACL, 2019).

The National Consumer Voice for Quality Long-Term Care (Consumer Voice) – The Consumer Voice is the leading national voice representing consumers in issues related to long-term care, helping to ensure that consumers are empowered to advocate for themselves. They are also a primary source of information and tools for consumers, families, caregivers, advocates, and Ombudsmen to help ensure quality care for individuals (Consumer Voice, 2019).

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