



U.S. Department of Health and Human Services  
Assistant Secretary for Planning and Evaluation  
Office of Disability, Aging and Long-Term Care Policy

# **UNDERSTANDING UNLICENSED CARE HOMES: FINAL REPORT**

September 2015

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This report was prepared under contract #HHSP23320100021WI between HHS's ASPE/DALTCP and Research Triangle Institute. For additional information about this subject, you can visit the DALTCP home page at <https://aspe.hhs.gov/office-disability-aging-and-long-term-care-policy-daltcp> or contact the ASPE Project Officer, Emily Rosenoff, at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C. 20201. Her e-mail address is: [Emily.Rosenoff@hhs.gov](mailto:Emily.Rosenoff@hhs.gov).

# UNDERSTANDING UNLICENSED CARE HOMES: Final Report

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September 2015

Prepared for  
Office of Disability, Aging and Long-Term Care Policy  
Office of the Assistant Secretary for Planning and Evaluation  
U.S. Department of Health and Human Services  
Contract #HHSP23320100021WI

The opinions and views expressed in this report are those of the authors. They do not necessarily reflect the views of the Department of Health and Human Services, the contractor or any other funding organization.

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## ACRONYMS

The following acronyms are mentioned in this report and/or appendices.

AAA	Area Agency on Aging
ACL	HHS Administration for Community Living
ADA	Americans with Disabilities Act
ADL	Activity of Daily Living
AG	Attorney General
APS	Adult Protective Services
ASPE	HHS Office of the Assistant Secretary for Planning and Evaluation
BHSL	Pennsylvania Bureau of Human Services and Licensure
CMS	HHS Centers for Medicare and Medicaid Services
DADS Dom Care	Texas Department of Aging and Disability Services Domiciliary Care
EMS	Emergency Medical Services
HCBS	Home and Community-Based Services
HFR	Healthcare Facility Regulation
HHS	U.S. Department of Health and Human Services
IADL	Instrumental Activity of Daily Living
LME	Local Management Entity
LTSS	Long-Term Services and Supports
MCO	Managed Care Organization
NAMI	National Alliance for Mental Illness
NDRN	National Disability Rights Network
P&A	Protection and Advocacy Agency
PCRR	Personal Care Risk Reduction

RCF	Residential Care Facility
SME	Subject Matter Expert
SSA	U.S. Social Security Administration
SSI	Supplemental Security Income
SSP	State Supplementary Payment

# EXECUTIVE SUMMARY

## ES.1. Introduction

There is a critical challenge of providing housing and supportive services for particularly vulnerable groups, including individuals: who have severe and persistent mental illness or other disabilities, were formerly homeless, or older adults who have limited financial resources. Unlicensed care homes--which provide room, board and some level of services for two or more unrelated individuals, but are not licensed or certified by the state--fill some of the gaps in the availability of housing and services for these populations. Some of these places are legally unlicensed, while others operate without a license illegally. Although little is known about unlicensed care homes, a variety of signals, including media reports, highlight potential safety and quality concerns.

The goal of this exploratory study was to understand how unlicensed care homes function as a residential care option; the types of individuals who reside in them; their characteristics, including their quality and safety; and policies that influence the supply of and demand for these homes. Through a targeted series of interviews and a scan of the literature, we sought to contribute foundational information about unlicensed care homes. Although the scope of our research was limited--involving a small number of interviews with subject matter experts (SMEs) and interviews with informants in three communities in three states--the findings have relevance for national, state, and local policies and practices and for future research.

## ES.2. Methods

We conducted an environmental scan primarily focused on information spanning a five year period from 2009 through 2014. The scan included published peer-reviewed and grey literature, including abuse blogs and media reports about legally and illegally unlicensed residential care homes. Few peer-reviewed articles have been published on unlicensed care homes, but numerous media reports were examined.

Following the environmental scan, we conducted interviews with SMEs on the topic of unlicensed care homes. The environmental scan and SME interviews informed state selection for site visits. After recommending six states for site visits, the U.S. Department of Health and Human Services Office of the Assistant Secretary for Planning and Evaluation and the research team selected three communities in three states for on-site visits: Atlanta, Georgia; Raleigh/Durham, North Carolina; and Allegheny County, Pennsylvania. The team conducted interviews with key informants in each of these communities.

### **ES.3. Findings**

Based on the findings from this exploratory study, unlicensed care homes appear to be widespread in some areas within some states. They are commonly run in single family residences, but also were reported to operate inside buildings that had been schools or churches. Findings from the environmental scan highlighted issues of safety, abuse, and exploitation in unlicensed care homes; however, the source material, including media reports, tend to highlight negative and sometimes sensational stories, which may or may not represent the norm in unlicensed care homes. Though outside the scope of our focus, some of the searches also produced media reports and grey literature about concerns in licensed care homes; however, reports about unlicensed care homes and the quality of care described therein was sometimes worse than those for licensed care homes.

Site visit findings were largely consistent with those of the environmental scan, and despite increased attention to unlicensed care homes in some states, key informants highlighted issues of safety, abuse, and exploitation. However, our key informants (including representatives of adult protective services, ombudsmen programs, and police and fire departments) were informed about unlicensed care homes only in response to complaints or emergencies, which may have biased their views of these homes. Although some SMEs and key informants provided a few examples of unlicensed care homes where residents receive what they categorized as good care, it appears that abuse, neglect, and financial exploitation of these vulnerable residents is commonplace.

### **ES.4. Populations Served and Conditions in Unlicensed Care Homes**

Based on our findings, the residents of these homes are extremely vulnerable. While some unlicensed homes reportedly serve elderly and physically disabled residents, key informants noted that many also serve persons who were formerly homeless, persons who may have substance use disorders, persons with severe and persistent mental illness, and parolees. Some of these homes also serve mixed populations (e.g., elderly residents as well as individuals with severe and persistent mental illness).

Interview findings indicate that many residents of unlicensed care home are Supplemental Security Income (SSI) beneficiaries. Several informants explained that some unlicensed care home operators require residents to make the care home operator or the operator's designee their representative payee for SSI benefits, and that some operators also collect food stamps, medications, or other resources from residents, which the operators can then sell for profit.

Key informants also commonly described the conditions in unlicensed care homes as abusive, financially exploitative, and neglectful of residents' basic needs, and depicted situations that involved false imprisonment of the residents and repeatedly moving the residents from one facility to another, both within and across states, to evade law enforcement. One SME pointed out that many unlicensed care home cases are analogous to human trafficking, such as when residents are held against their will and then moved from one location to another to avoid detection; however, the current federal definition of human trafficking specifies that the trafficking is done for the purpose of labor or sex, and not for the collection of public benefits (U.S. Department of State, 2015). Informants expressed other specific concerns about unlicensed care homes, including improper management of residents' medications; unsafe, unsanitary, and uncomfortable living environments; theft of utilities from neighbors; and fraudulent collection of government payments (e.g., not reporting residents' deaths and continuing to collect their SSI payments).

## **ES.5. Strategies for Identifying and Addressing Quality in Unlicensed Care Homes**

Strategies for identifying and addressing quality in legally and illegally unlicensed care homes appear to differ across states. Interview discussions often touched on the question of how best to identify illegally unlicensed care homes, and key informants noted this as a major challenge. In the states we visited, a common theme across interviews was that addressing quality in illegally unlicensed care homes tends to focus on shutting down the operations. In contrast, identifying and addressing quality in legally unlicensed care homes was only minimally discussed; however, in at least one of our site visit states, interviewees felt that it was feasible to identify these homes, given the existence of listings of these homes.

The most prevalent strategy used by state and local officials to identify illegally unlicensed care homes is responding to complaints. Licensure offices and other agencies or organizations respond to complaints made by concerned citizens, including family members and friends of residents, neighbors of unlicensed care home operators, health care providers serving unlicensed care home residents, firemen, ambulance services, police, and licensed care home operators. Notably, the strategy of responding to complaints limits the amount of information available about unlicensed care homes about which complaints are not made (i.e., possibly better quality homes). Key informants recommended more proactive strategies for identifying unlicensed care homes, such as tracking individuals' benefits (e.g., SSI) to unlicensed care homes, obtaining lists of unlicensed care homes from health care and advocacy organizations that refer individuals to them, and utilizing owners of licensed or legally unlicensed facilities as a source of information about illegally unlicensed care homes.

Key informants recommended several tactics to address poor quality in unlicensed care homes, but the overall strategy consistently discussed was to shut down these homes. Informants noted that interagency, multidisciplinary teams at state and local

levels are imperative to the success of shutting down unlicensed care homes, and to address the various issues involved in such closures, such as meeting the housing and services needs of residents, addressing any criminal behaviors of the care home operators, and ensuring the safety of the house or facility and neighboring properties. The informants recommended the formation of teams including a range of stakeholders, including state licensure officials, Adult Protective Services (APS), ombudsmen, police, firefighters, emergency medical services, code enforcement, and local advocacy organization workers.<sup>1</sup>

To address unlicensed care homes, states commonly use a strategy that includes penalty systems that fine operators as a way to try and close illegally unlicensed care homes. However, according to interview participants, fines have had little impact on closing the homes, as they were often unenforceable and rarely paid.

Additionally, states may implement public awareness campaigns to support identification of unlicensed care homes. Two of our three site visit states aimed to enhance awareness of poor and inadequate unlicensed care homes by increasing education for the public and key stakeholders: Pennsylvania held a statewide education and marketing campaign to inform the public about unlicensed care homes, and Georgia conducted training sessions to educate law enforcement and first responders about these homes.

## **E.6. Policy and Practice Implications**

Based on our exploratory research, we found that a number of factors may have an effect on the demand for unlicensed care homes. According to SMEs and key informants, the following factors are likely drivers of the demand for unlicensed care homes in their communities or states:

- The policies that licensed care homes have against admitting residents who exhibit behavior problems and those who have substance use disorders, or to discharge residents who develop these problems.
- The modest payments made by SSI or State Supplemental Payments to residential care homes, which may be inadequate to cover expenses in licensed facilities.
- The closure of large mental health institutions and concomitant transition of previously-institutionalized individuals with severe and persistent mental issues to community-based care settings, such as legally unlicensed care homes.

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<sup>1</sup> State regulations govern whether ombudsmen can access and advocate for residents in unlicensed care homes; thus ombudsmen may be limited in their ability to serve on these teams.

- The financial pressure hospitals feel to free up hospital beds sometimes results in discharges to unlicensed care homes, both unintentionally and for expediency.

## **ES.7. Conclusions and Caveats**

While this was a limited exploratory study, our findings point toward serious issues with unlicensed care homes, as well as gaps in our knowledge, and they have important implications for future research on unlicensed care homes. We relied on a targeted literature review, interviews with a small number of SMEs, and site visits to just three communities, all of which limited the scope of our findings. Also, the information collected from newspapers, ombudsmen, APS staff, or other agency reports (by their very nature) skew towards negative events. Thus, although our findings consistently highlighted concerns about safety and quality, we cannot assess the generalizability of these findings and concerns. Additionally, some of what we heard about policies that affect demand for and supply of unlicensed care homes was based on the opinions of the individuals interviewed and may not be representative of others' views, and we do not have data to support these viewpoints. While experts may speculate on changing market dynamics, we do not have a reliable estimate of the unlicensed care home market prior to these policies taking effect, so we do not know what the market would have been without such policies. However, even with those limitations, we know that in the communities we visited, there were significant health and safety concerns for residents, as well as concerns about financial exploitation and government fraud. Finally, as noted later in the report, many individuals seek care in unlicensed care homes because they are in other undesirable situations, such as experiencing chronic homelessness or being unnecessarily institutionalized. It was outside the scope of this project to examine the alternatives to unlicensed care homes or the health, safety, or appropriateness of those other environments. Additional research on unlicensed care homes will be valuable to build our understanding of the role--intended or unintended--of these places in our long-term services and supports systems, and the policies affecting it.

# 1. INTRODUCTION

There is a critical challenge of providing housing and supportive services for particularly vulnerable groups, including individuals: who have severe and persistent mental illness or other disabilities, were formerly homeless, or older adults who have limited financial resources. Providers of housing and care services that are licensed by the state, such as nursing homes and residential care facilities (RCFs), serve some of these individuals. However, unlicensed care homes, which provide room and board and some level of personal care services, but are not licensed by the state, fill some of the gaps in the availability of housing and services for these populations. These unlicensed care homes are referred to by several different names in different states, such as “board and care homes,” “boarding homes,” and “adult care homes.” Regardless of what they are called, this study focuses on places that provide room and board and sometimes provide personal care to two or more unrelated individuals, but whose operators are not licensed or certified by the state. All states license residential care such as assisted living, and most states license small adult care homes, often referred to as adult foster care (Carder, O’Keeffe, & O’Keeffe, 2015). But there are homes providing room, board, and personal care that either fall outside the bounds of the state licensure requirements or are deliberately avoiding state licensure requirements. Some states permit unlicensed care homes to operate legally under the guidance of state regulation; others do not. In either case, while states regulate and provide some level of monitoring and oversight of licensed care homes, state and local oversight of unlicensed care homes can be minimal or non-existent, and these facilities provide questionable care and services. And regardless of whether states have regulations concerning unlicensed homes, many operators choose to operate illegally unlicensed homes. Media and state reports have highlighted homes operating deliberately illegally--that is, they are avoiding required licensure or certification (Tobia, 2014; Georgia Association of Chiefs of Police Ad Hoc Committee on At-Risk Adult Abuse, Neglect & Exploitation, 2013). Further, evidence exists from several states that there are still unlicensed residential care homes and that, in some states at least, the number of unlicensed facilities is increasing.

More information exists about licensed RCFs than unlicensed care homes, thus knowledge of the unlicensed care homes is limited. This lack of knowledge contributes to the need for the government and policy makers to have a better understanding of unlicensed care homes. Therefore, the purpose of this project was to conduct exploratory research on unlicensed care homes to understand more about their prevalence, factors contributing to their prevalence, their characteristics (including their overall quality and safety), and the types of residents they serve. In this study we sought to identify:

- Characteristics of unlicensed care homes and the residents they serve.
- Conditions (including quality and safety) of unlicensed care homes.

- Strategies for identifying illegally unlicensed care homes.
- Strategies used to address health, quality and safety issues in unlicensed care homes.
- Policies affecting the supply of and demand for unlicensed care homes.
- Areas for future research and potential data sources related to unlicensed care homes.

This report describes the methods used to conduct the study, summarizes the information learned from an environmental scan and the results from interviews with subject matter experts (SMEs) and site visits, discusses implications of the findings and, based on the study findings, offers recommendations for future research on unlicensed care homes.

## 2. METHODS

The goal of this study was to provide foundational information intended to answer or provide insight into the study research questions. To accomplish this we conducted an environmental scan, including a review of the peer-reviewed and grey literature and interviews with SMEs. We also conducted site visits to a total of three communities in three states, including interviews with local and state-level key informants. Although limited in scope, the study provides foundational information about unlicensed care homes based on a narrow review of the literature and the reports of select SMEs and key informants in three states.

### 2.1. Literature Review

The objective of the literature review was to identify current information (2009-2014) on both legally and illegally unlicensed RCFs and to inform the conduct of SME interviews and site visits to communities in three states. The literature review was not an exhaustive effort, but rather a targeted scan of information on unlicensed care homes in the peer-reviewed and grey literature, abuse blogs, and media reports.

PubMed and other database searches yielded very little literature related to unlicensed RCFs. General search terms included *unlicensed*, *not licensed*, *unregulated*, *adult*, *elderly*, *residential care*, and *assisted living*. Targeted search terms incorporated specific licensure category names for each specific state. Most of the literature we found referenced problems in and the prevalence of unlicensed residential care homes prior to 2009, or addressed abuse and exploitation of adults living in licensed facilities. Many publications also focused on quality of care or other issues related to unlicensed care staff. On the other hand, grey literature--that is, reporting databases, blogs, and media reports--produced more results about unlicensed care homes. Study staff screened each of the collected articles, blogs, and reports to identify relevant material for review.

### 2.2. Subject Matter Expert Interviews

We utilized the information obtained in the literature review, in addition to our own expertise, that of our consultant, as well as that of U.S. Department of Health and Human Services (HHS) Office of the Assistant Secretary for Planning and Evaluation (ASPE) and the HHS Administration for Community Living (ACL) staff familiar with unlicensed care homes, to develop an initial listing of SMEs to interview. Potential SMEs were included in the initial listing based on their familiarity with residential care regulations, experience in and research about residential care, experience working with the potential target populations of unlicensed care homes, and knowledge of Medicare and Medicaid payment policies and home and community-based services (HCBS)

waiver programs. Following the development of the initial list of SMEs, we divided the list into two categories: (1) a subset of individuals identified as “key experts” who would be prioritized for interviewing because we determined they had relevant information related to unlicensed care homes; and (2) individuals identified as “potential experts” who would first be vetted to determine their level of knowledge about unlicensed care homes. The team conducted brief vetting calls with the second subset of SMEs to determine their appropriateness for an interview; if they were not deemed appropriate, they were asked whether they knew of any other potential interviewees. After completing the vetting calls, we emailed an introductory letter explaining the purpose and goals of the research to the potential interviewees. In several cases, the potential interviewees did not have direct knowledge on the topic of unlicensed care homes, and were not interviewed, but referred us to interviewees with more knowledge on the topic.

We completed 17 interviews with SMEs. Two interviews were completed with representatives from the Federal Government, seven with representatives from state agencies, three with representatives from policy organizations, one with a representative from a national advocacy group, and four interviewees were researchers knowledgeable about unlicensed care homes. Interview questions were based on respondent expertise, and were tailored for each respondent. Thus, no more than nine individuals were ever asked the same question. SME interviews primarily focused on federal and state policies that may impact the prevalence of unlicensed care homes. Each interview began with a general question to ascertain what the interviewee knew about unlicensed care homes. We then asked questions specific to the type of SME, including:

- What gaps unlicensed care homes may fill in the spectrum of long-term services and supports (LTSS)?
- Which states have had an increase or decrease in the number of unlicensed care homes and why?
- What is the scope of concerns in unlicensed care homes, including quality of care, safety, sexual or physical abuse, and financial exploitation concerns?
- How do states address unlicensed care homes, and if states or other organizations maintain lists of unlicensed care homes (legal or illegal)?
- What federal and state policies affect the supply and demand of unlicensed care homes?

### **2.3. Site Selection and Site Visits**

Site visit locations were based on the information gathered in the environmental scan, SME interviews, and a review of residential care regulations. For example, as part of interviews with SMEs, we asked them to recommend potential key informants to meet

with during site visits. Based on the information gathered, we determined key criteria for site visit location selection, including having good leads/contacts for identifying key informants in the state, and having geographic variation across states. We targeted site visits in communities that varied according to whether the state: (1) has legally unlicensed care homes; (2) has a list of unlicensed care homes; and (3) ranks among the highest or lowest in HCBS waiver expenditures.

### **2.3.1. Site Selection**

Based on the criteria noted above, we recommended six states to ASPE as possible site visit locations: Georgia, Indiana, Maryland, North Carolina, Pennsylvania, and Texas. After discussions with ASPE, we identified three states and communities within each state as site visit locations: Atlanta, Georgia; Raleigh/Durham, North Carolina; and Allegheny County, Pennsylvania. These locations were selected based on their differences across the selection criteria domains described above, as well as our understanding of the environments surrounding unlicensed care homes in each of the locations, and our ability to identify potential informants in each of the selected locations.

### **2.3.2. Site Visits**

During each site visit we interviewed state licensure agency staff to obtain a broad perspective on the regulations surrounding residential care in each of the states. Additional key informants for the site visit interviews were selected based on information provided by the SMEs or what we learned from the environmental scan. For example, in Georgia it recently became a misdemeanor to operate an unlicensed care home, therefore we aimed to speak with law enforcement officials who had been involved in the process of investigating unlicensed care homes. In Pennsylvania counties, a multidisciplinary team called the Personal Care Risk Reduction (PCRR) team helps to address illegally unlicensed care homes; thus we attempted to interview key informants involved in this process. Key informants for each site visit location included representatives of local public safety organizations such as law enforcement or firefighters, Adult Protective Services (APS) staff, and ombudsmen. Additional key informants participating in interviews during site visits included local hospital discharge planners (North Carolina), representatives of organizations providing services to residents of unlicensed care homes (Georgia), and local advocacy organizations including National Alliance on Mental Illness (NAMI), Disability Rights North Carolina and Disability Rights Network of Pennsylvania. Although we attempted to conduct interviews with operators of unlicensed care homes on our site visit states, we could not identify or gain access to any.

Key informant interviews focused on local context, state and local policies that may impact or affect the demand for unlicensed care homes, and informants' direct experiences with unlicensed care homes. Like the SME interviews, each key informant interview began with a general question to ascertain what the interviewee knew about unlicensed care homes. We focused on a range of questions, including:

- How do agencies handle specific complaints about unlicensed care homes?
- Which agencies get involved when addressing unlicensed care homes?
- What concerns are there about the quality of care and safety in unlicensed care homes?
- What populations do unlicensed care homes serve?
- What types of reports of mistreatment do the agencies receive?
- What are the interviewees' thoughts on the best strategies to identify unlicensed care homes?

Results of key informant interviews from site visits, as well as the SME interviews and the literature review, are presented in the Findings section that follows.

## 3. FINDINGS

Findings from our limited number of interviews with site visit key informants and SMEs are consistent with the information found during the environmental scan. Both the information we collected about unlicensed homes in the literature review and that which we collected through interviews mostly paint a negative view of these settings. Newspaper and media reports generally focus on what they view as the dramatic; the positive aspects of unlicensed care homes are often omitted from these reports. Similarly, by nature of their jobs, many of our interview participants, including APS staff, ombudsmen, police, and fire department personnel, typically hear about care homes when there are complaints or emergencies. Consequently, although we attempted to elicit information about the positive aspects of unlicensed care homes, key informants largely provided us with a less favorable view of unlicensed care homes. Furthermore, illegally unlicensed care homes continue to exist because they try to avoid detection; therefore, favorable reports of unlicensed care homes are minimal. Study findings should be viewed in light of these limitations.

Although limited in scope, the findings of this exploratory study provide important foundational information about current conditions in some unlicensed care homes, factors that may influence demand for these homes, and strategies to identify them and address their quality.

In this section, we summarize results of the literature review and interviews with SMEs and key informants. Key informant interviews were conducted in three communities across three states: Allegheny County, Pennsylvania; Atlanta, Georgia; and Raleigh/Durham, North Carolina. Site visit summaries, which provide more state-specific information, and information on other states considered for site visits, are included in **Appendix A**.

### 3.1. Summary of Literature

We found little published information about unlicensed residential care homes; in fact, the scan revealed that most of the literature about conditions in RCFs covered licensed residential care or were about unlicensed care staff. What information exists reflects a concern about the conditions under which residents in these places live. Most of the literature and media reports reviewed focused on the pitfalls of unlicensed care homes and the poor quality and safety provided in these settings. No positive literature was found, which, as noted earlier, may be reflective of the fact that nothing is published about these places unless they are discovered because they are being investigated for poor care or resident exploitation or abuse. In regard to the prevalence of unlicensed care homes, state-level estimates were only reported for Georgia, Maryland, and

Florida. Further details on findings from the environmental scan can be found in **Appendix B**.

Our examination of the Medicaid Fraud Control Unit reports (2009-2013) showed that only a couple cases were reported to the media; the rest had not made the news. We found three cases in Florida of charges against unlicensed RCFs involving allegations of false imprisonment, resident neglect, grand theft, and/or operating an unlicensed assisted living facility; and three cases in Nevada of neglect and/or criminal offenses while operating without a license (one where the accused also operated a licensed facility). A separate search of a few state Attorney General (AG) reports of unlicensed RCFs identified six cases of successful prosecutions in New York, Nevada, Florida, and California for operating an RCF without a license--and, in several cases, for gross neglect. The information focused on specific cases, but not on how many of these places exist in these states.

Using information from a HHS Administration on Aging report, provided by the National Ombudsman Reporting System (2009-2013), we identified reports regarding unlicensed facilities in five states: Maryland, Michigan, Nevada, Florida, and Georgia, as well as the District of Columbia. Ombudsmen reported increasing numbers of RCFs operating without a license in both Maryland and Nevada. None of the reports provided evidence on the prevalence of unlicensed care homes in these states or the magnitude of the issue statewide.

We hypothesized that states that do not have well-funded HCBS programs may have a higher incidence of illegally unlicensed homes than states with more robust HCBS programs. If states have reduced funding for HCBS needed by low-income elderly and disabled individuals, then licensed care homes, which may have higher rates and fees than unlicensed homes, may no longer be an option for these individuals, or they may be faced with a potentially longer waiting list for licensed care homes. As a result, we also examined HCBS expenditures in a select number of states. Using the 2012 annual Medicaid LTSS expenditures report produced by Truven, we identified the ten states that spent the highest percentage of their LTSS expenditures on HCBS and the ten that spent the least. We then examined if those percentages might be related to the number of unlicensed care facilities in those states. Targeted searches of media reports in states with the lowest percentages of their LTSS expenditures on HCBS (New Jersey, Mississippi, Indiana, Florida, and Michigan) did not yield more reports on unlicensed care facilities than those with the highest spending rates for HCBS (Arizona, Vermont, Alaska, Minnesota, and Oregon). With one exception--Georgia--the same held true for the ten states with the greatest increase in HCBS spending since 2010: Virginia, Ohio, Maine, Rhode Island, Alabama, Tennessee, Georgia, New Hampshire, Massachusetts, and Delaware.

From our review of states' regulatory information on licensed residential care categories during the development of the sampling frame for the 2014 National Study of Long-Term Care Providers, and our review of ASPE's Compendium of Residential Care and Assisted Living Regulations and Policy (2015), we found that 30 states require

residential care homes to be licensed if they have at least one bed. Massachusetts exempts small private-pay homes from licensure. According to the regulations, some states also allow residential care homes to be legally unlicensed if they have 1-2 beds. Ten states (Delaware, Georgia, Louisiana, New Jersey, New Mexico, North Carolina, Oklahoma, Rhode Island, South Carolina, and Washington) require residential care homes to be licensed if they have at least two beds. Six states (Colorado, Iowa, Illinois, Maine, Missouri, and Vermont) license starting at three beds; Vermont exempts small private-pay homes. In one state, Pennsylvania, three bed residential care homes are legally unlicensed. Pennsylvania begins licensure with four beds, but the state has locally certified domiciliary care (Dom Care) homes that serve 1-3 residents. Lack of clarity in licensure regulations regarding minimum bed size required by licensure also exists in a few states. Maryland, Mississippi, and the District of Columbia have no minimum bed size for licensure, implying that some residential care homes can be legally unlicensed. New Jersey and Tennessee have a licensure category that specifies the maximum number of beds required for licensure, but not a minimum, which also implies that in these states some residential care homes may be legally unlicensed.

Several states (California, Pennsylvania, Maryland, and Mississippi) publish notices of how and where to report unlicensed care facilities, which implies that these states may be experiencing problems with unlicensed homes. However, our literature search did not reveal any estimates of the prevalence of unlicensed residential care homes in most of these states. Media reports were usually about an action by a licensing agency, Medicaid Fraud Unit, APS, or the police arresting an operator; these reports do not provide much information about the extent to which unlicensed homes exist in the state.

Three reports are worth noting separately. The first, a six-state study on elder abuse in RCFs conducted by Hawes & Kimbell (2010) for the U.S. Department of Justice found that unlicensed homes remain a serious, largely unaddressed problem in some states, with the magnitude of the problem remaining unknown. Estimates of the number of unlicensed RCFs, as detailed in this report, were in the hundreds in two states: one state estimated more than 200 unlicensed homes in contrast to their 400 licensed facilities; and the other state estimated more than several hundred unlicensed homes but noted there was no reliable count. In the latter state, it was said that unlicensed homes “flourished in the larger cities, particularly those that had significant populations of poor elders and persons with mental illness who had been released from state mental hospitals” (Hawes & Kimbell, 2010).

A paper by Tobia (2014) describes the state of unlicensed residential care in one county in Maryland, where as many as 78 unlicensed care homes may be serving as many as 400 individuals. According to the report, these warehoused residents are vulnerable older adults with “hard to place” mental health needs and paroled individuals. Other estimates of the number of unlicensed care homes in the state range from 500 to 1,500 within one metropolitan area. Because of the potential for a large loss of life from fires in these places, comprehensive emergency management planning and practices are reported to be needed to proactively protect those at risk (Tobia, 2014).

Finally, a peer-reviewed publication by Perkins, Ball, Whittington, & Combs (2004) provides insights into why an operator continues to operate an unlicensed care home. Though it is outside the time period of our environmental scan, the case study describes how regulatory requirements meant for large assisted living facilities are too stringent and expensive for small residential care homes. Operators of small care homes lack knowledge of licensure regulations and how to navigate the different government agencies, and there is a perceived lack of respect from government staff regarding the quality of care that non-professional staff can provide in these small residential care homes.

As described in Section 2, to inform the selection of states for site visits, we looked closely at the information available for six states where the environmental scan or SMEs indicated unlicensed care homes likely exist. Based on this information, we chose three states, and subsequently identified three communities within those states, to visit and conduct case studies.<sup>2</sup> Following is a summary of the literature, media coverage, and regulations for those three states (Georgia, Pennsylvania, and North Carolina).

## **Georgia**

Reporters from the *Atlanta Journal-Constitution* analyzed thousands of inspection reports and interviewed state and local officials, social service providers, and advocates, and then published a series of articles on the status of affairs in unlicensed residential care homes (Schneider & Simmons, 2012a; Schneider & Simmons, 2012b; Schneider & Simmons, 2012c). The reporters described cases of abuse in which residents were being beaten and burned, locked in basements or other rooms, given buckets for toilets, and had their benefit checks taken from them. Licensure staff admitted they only learn about the unlicensed facilities when someone reports them. State inspection staff, already overwhelmed with large caseloads, were required to obtain search warrants to execute searches, a time-consuming process, when trying to follow up on reports of unlicensed homes. In 2011, only two such warrants were obtained.

Advocates reported a growing number of unlicensed facilities and difficulties distinguishing them from boarding homes or other types of RCFs. Unlicensed homes were described as less expensive than licensed facilities but as shabbier and offering fewer services. Residential care homes that are legal often serve as covers for or conduits to illegal homes. Oversight was spread across several agencies and depicted as convoluted and overstretched. Local efforts were noted to be inconsistent and uncoordinated because authorities were unfamiliar with the laws.

As a result of the newspaper exposé, Georgia enacted new stronger laws. It is now a misdemeanor to operate an unlicensed RCF. Efforts are now under way to provide

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<sup>2</sup> We found a number of publications and media reports in both Florida and Texas (e.g., the *Miami Herald* newspaper series in Florida, and the U.S. Department of Justice report in Texas), and a few media reports and a research report on unlicensed care homes in Maryland; however, these states were not selected as site visit states.

workshops that clarify the new laws about unlicensed care facilities and how law enforcement and other agencies can work together to identify and investigate crimes against at-risk adults and prepare the necessary components for successful prosecutions. Concerns remain that agencies do not have the resources to monitor and follow through with the appropriate actions (e.g., finding emergency placements for residents, prosecuting violators, ensuring that the facility remains closed and has not reopened in another location) for the unlicensed facilities.

## **Pennsylvania**

Residential care homes that serve three or fewer residents are legally unlicensed in this state. Per one report, the Department of Public Welfare lacks the legal authority to inspect, require plans of correction, or fine these facilities; however, APS can act on referrals of abuse (Pennsylvania Health Law Project & North Penn Legal Services, 2007). The Department of Public Welfare also can take action against boarding homes and similar facilities that house four or more people if they are providing personal care services because they are considered illegally unlicensed. A 2010 annual report from the Department noted that the number of illegal residential care homes had increased from four homes in 2009 to 27 in 2010, most of them located in the Philadelphia area (Pennsylvania Department of Public Welfare, 2011). In 2012, the Secretary of the Department of Public Welfare noted that the state continues to struggle with illegal operators and asked all Pennsylvanians to join in the fight and report any unlicensed homes or activities because “unlicensed care is deadly” (Pennsylvania Department of Public Welfare, 2012).

In one court case, the judge deemed a “boarding house” as an unlicensed residential care home because only three of the six people renting rooms received personal care from the owner’s licensed home care agency, even though four actually needed those services. The fact that four people should have been receiving personal care services made the home eligible for licensure as a residential care home--not the fact that three people were receiving the services (which would make it under the legal limit).

## **North Carolina**

The environmental scan did not yield peer-reviewed publications or reports about unlicensed residential care in North Carolina. New stringent eligibility criteria for state plans to cover services in group homes serving persons with mental illness have reportedly made it financially difficult for the adult care homes and group homes to continue operating, and some have reportedly been forced to close. From our review of the regulations, we identified that North Carolina likely has legally unlicensed care homes (e.g., boarding homes serving 4-5 residents who do not require 24 hour supervision), and we suspect that illegally unlicensed care homes also exist. The recent changes to state regulations for community living arrangements are also reportedly becoming more favorable toward independent living, which may lead to an increase in the number of unlicensed facilities.

The remainder of this section summarizes findings from interviews with SMEs and site visit key informants, and also includes additional information from the environmental scan.

## **3.2. Populations Served and Conditions in Unlicensed Care Homes**

SMEs and site visit key informants noted that individuals being served in unlicensed care homes are very vulnerable adults. They noted that some unlicensed care homes provide good care; however, SMEs and other informants consistently reported substantial concerns about neglect, unmet health needs, unsafe and unsanitary conditions, abuse, financial exploitation, false imprisonment, and moving residents to different care homes across communities and states to evade detection. In fact, these concerns extended across illegally and legally unlicensed homes, and some stakeholders reported these concerns also exist about care being provided in some licensed residential care homes.

### ***3.2.1. Populations in Unlicensed Care Homes***

Residents of unlicensed care homes are vulnerable adults. The majority of key informants reported that unlicensed care homes primarily, though not exclusively, serve individuals with severe and persistent mental illness. There were reports that while unlicensed homes in some states (such as Maryland) serve elderly and physically disabled residents, many also serve a clientele who once were homeless, persons who may have substance use disorders, and individuals who were formerly incarcerated. Key informants also noted that unlicensed care homes may serve mixed populations within the same home (e.g., elderly residents as well as individuals with severe and persistent mental illness).

Interviews with key informants also indicate that many residents are poor and receive Supplemental Security Income (SSI) benefits from the U.S. Social Security Administration (SSA); the SSI program pays benefits to disabled adults and children who have limited income and resources. Several SMEs and key informants noted that individuals who had only SSI to pay for care have few options for housing and care, and often end up in unlicensed care homes. Additionally key informants indicated that many unlicensed care home residents who receive SSI payments participate in Social Security's Representative Payment Program, whereby payments are managed by an individual or organization that is representing the beneficiary because the beneficiary is unable to manage the payments independently. Several informants reported that it is common for the operator of an unlicensed care home, or representatives designated by the care home operator, to serve as the representative payee for the residents.

### **3.2.2. Service Provision**

The vast majority of key informant reports emphasize often alarming conditions in unlicensed care homes. However, several SMEs and key informants noted that some unlicensed care homes are good and provide a clean, safe environment for individuals who might otherwise be homeless. The primary concern expressed about the unlicensed homes that were otherwise safe was that they might not be able to provide the level of care and services needed by the residents (e.g., medication supervision for residents with severe and persistent mental illness). Another concern expressed by some of the individuals interviewed was that even those unlicensed homes that were clean or free of neglect and abuse, commonly have safety hazards and do not meet the fire safety codes required of licensed facilities. Consistent with information from the environmental scan, key informant interviews indicate that some unlicensed homes use basements to house residents, including residents who do not have the capacity to exit safely in the event of a fire or similar emergency, such as those who are unable to climb the stairs and those receiving hospice care.

### **3.2.3. Health, Safety, and Sanitary Conditions**

The nature of health and safety concerns described by key informants were wide-ranging and often included neglect and the risk of death to residents. Consistent with findings from the environmental scan, stakeholders (including SMEs and site visit key informants in the three communities we visited) repeatedly raised a variety of concerns about neglect of residents' health care needs and unsafe and unsanitary conditions in unlicensed care homes. Specific concerns included:

- Managing resident medications improperly.
- Providing unsafe housing conditions, including overcrowding of resident rooms, housing many more residents in bedrooms than is allowed by state licensure regulations, housing residents in storage sheds, basements, and attics that were unsafe, unsanitary, and made egress difficult for frail or disabled residents.
- Having buildings that were infested with bedbugs, other insects, and rodents.
- Failing to consistently provide running water and electricity, or having unsafe or illegal electrical wiring.
- Failing to have safety equipment available, such as smoke detectors and fire extinguishers.
- Locking residents in rooms or chaining the doors at night to prevent residents from leaving the facility, which imprisoned residents and placed them at risk in case of fire.

- Preventing residents from using the bathrooms after a certain time at night and providing buckets for residents to use rather than toilets.
- Locking refrigerators or pantries to limit resident access to food between meals, with some residents being malnourished and dehydrated and one resident breaking into a neighbor's home for food.
- Failing to promptly report resident deaths, including more than one instance of leaving a dead body in the facility or back yard.

### **3.3. Abuse, Neglect, and Financial Exploitation**

As with health and safety concerns, the environmental scan and interviews conducted with SMEs and key informants revealed myriad concerns about abuse, neglect and financial exploitation. Specific concerns raised by SMEs and site visit informants are highlighted in this section.

#### **3.3.1. Abuse and Neglect**

Concerns about abuse and neglect were a major topic of discussion during interviews, and they extended across illegally and legally unlicensed homes. Information from interviews with key informants also revealed incidents of emotional and physical abuse, including intimidation, and threats. Cases of physical abuse, such as residents being beaten and burned as described in the environmental scan, were also reported during interviews. Several key informants expressed concern about neglect of the health needs of residents because of too few or inadequately trained staff, particularly in regard to the care of residents who have severe and persistent mental illness and need monitoring of their conditions and reactions to medications. Furthermore, some key informants noted that some unlicensed homes fail to provide or arrange treatment for residents' conditions in order to avoid bringing the attention of authorities.

#### **3.3.2. Financial Exploitation**

Similar to the information summarized in the environmental scan, interviews with key informants revealed that unlicensed care homes make money off of residents in sophisticated and profitable ways. The following are some examples of financial exploitation depicted during interviews; these examples are discussed at greater detail below:

- Operators of unlicensed care homes collecting the residents' medications and selling the medications on the street for cash.
- Operators seizing the residents' food stamps and selling them for cash.

- Operators forcing the resident to name the operator as the representative payee for government payments, such as SSI, and controlling the use of that money.

Treatment of residents as a commodity was a common theme across interviews. Key informants described instances of operators making money off of vulnerable residents in a variety of ways that involved theft from residents and theft from government programs. For example, SMEs indicated that law enforcement investigators have discovered operators of unlicensed homes with scores of electronic cards for food stamp benefits that belonged to current and former residents. One SME explained that the operators sell the food stamps for cash. In this kind of scam, food stamp benefits are reportedly stolen from residents, who are then provided with little or outdated food, and may subsequently go hungry or beg or steal food from neighbors.

Key informants noted that the possibility for theft from residents and from government programs also exists with the practice of operators taking control of residents' monthly income from SSA. According to reports and state-level investigators, many of the residents in unlicensed homes are living on SSI or Social Security Disability Income. Most key informants stated that many unlicensed care home operators receive the income from the SSA directly, either in the name of the resident or by requiring the resident to name the operator or someone else as a representative payee. One SME also noted that some unlicensed care home operators take residents' veteran's benefits. By taking control of the resident's benefits, the operator controls the resident's funds, and should be using those funds for room and board and other beneficiary expenses. However, key informants emphasized that in some cases, the residents become tethered to the operators through financial exploitation and emotional manipulation, and as a result are unable to leave these abusive and exploitative situations. They also noted that, despite receiving payment for room, board, and services, some unlicensed care home operators provide subpar or poor quality accommodations and services to residents.

The frequently reported act whereby the operator of an unlicensed home makes money from their control of vulnerable residents and moves these residents from one unlicensed care home to another to avoid detection, led one SME to refer to it as "human trafficking." Currently human trafficking is defined as "the act of recruiting, harboring, transporting, providing, or obtaining a person for compelled labor or commercial sex acts" (U.S. Department of State, 2015), however, one SME recommended expanding this definition to include the situation in which an administrator for the unlicensed care homes seize and maintain control of vulnerable individuals in order to maximize revenue by taking the public benefits that the individual may be receiving. This key informant also emphasized that unlicensed care home operators tend to work with a network of collaborators who support moving residents between homes to avoid detection by legal authorities, and also help with re-recruiting residents and reopening a care home after an unlicensed care home is closed down. The key informant likened these networked operations to organized crime:

*"The other thing we are seeing too is that people [operators] are well networked, and within a day or two people are identified and going back, herding them up*

*again...they are well networked so we look at them as organized crime organizations.”*

We heard stories from SMEs and site visit informants of operators recruiting vulnerable individuals from psychiatric wards of hospitals, from acute care hospitals through the hospital discharge planners, from homeless shelters, and directly from the street, similar to those we found in media reports (see Appendix B for details). With regard to recruiting residents from hospitals, we also heard of unlicensed care home operators receiving payments of up to a month’s fees from hospitals anxious to discharge the residents to free up hospital beds. One key informant shared a specific example of an operator targeting individuals in hospitals:

*“Hospitals are putting them on the street. One woman was marketing heavy to the hospitals, and taking them to the licensed facilities, and then moving them to the unlicensed facilities, in result to those types of facilities. That’s what they’re doing, targeting individuals with cognitive impairment.”*

Further, key informants reported that many operators require residents to surrender all forms of identification “for safe keeping” by the operator. This makes it difficult, if not impossible, for residents to leave the facility, a difficulty sometimes exacerbated by limiting residents’ access to their funds, to the facility phone, and, as noted above, by locking residents in their rooms or the facility. We also heard from nearly all state-level informants that some operators routinely shifted residents from one address to another if an APS worker, other advocate, or potential regulator showed up at the facility asking questions. In essence, unlicensed care home operators have several opportunities for gaining almost absolute control over these residents who are physically, cognitively, and financially vulnerable.

Moreover, unlicensed care home operators have an opportunity to operate virtually unchecked in terms of seizing control of the residents’ government benefits. During interviews, informants talked about situations in which the operators of unlicensed care homes continue to be the representative payee and continue collecting the SSI checks of residents even after the resident moved out of home. We also heard of operators not reporting the death of a resident to SSA so the operator could continue collecting the resident’s checks from the government.

One key informant described the selling of residents from an unlicensed care facility located in a house. The operator of the facility had recently received and accepted an offer to sell the house, and so was closing down the facility. In preparation for closing, the operator “turned over the residents to other operators for a fee of \$100 per resident.”

### **3.4. Strategies for Identifying Legally and Illegally Unlicensed Care Homes**

One of the points made by key informants is that states have very few, if any, strategies to easily identify unlicensed care homes. Most state licensure offices, county offices, or advocacy agencies use a complaint system to identify unlicensed care homes. This reactive strategy underscores the difficulty states and local agencies have in identifying unlicensed care homes.

Almost all SMEs and key informants recommended more proactive strategies to identify unlicensed care homes. These included: (1) tracking individuals' public benefits; (2) obtaining lists of unlicensed care homes from health care and advocacy organizations that refer individuals to them; (3) accessing information from emergency response personnel; and (4) utilizing owners of licensed facilities as a source to identify illegally unlicensed care homes. It is important to note that legally unlicensed care homes are not typically tracked by local community agencies, organizations or states. Most state informants said legally unlicensed care homes did not fall under state regulatory purview, and thus were not monitored (or investigated unless there is a complaint).

#### **3.4.1. Complaint Systems**

As described by all informants, complaint systems are the most common strategy used for a state or locality to become aware of unlicensed care homes. State licensure offices primarily depend on complaints via phone calls<sup>3</sup> that come first to a local county APS or regional licensure or monitoring office. These local and regional offices--as well as ombudsmen and other national, state, and local advocacy groups--receive complaint calls from a variety of sources including residents' family members; members of the general community such as neighbors or other providers; and medical and service providers (e.g., hospital or clinic doctors, nurses, social workers) who interact with residents inside and outside of unlicensed homes.

Although these complaint systems are not specifically designed to identify and track unlicensed care homes, some states use the complaint systems in this way. Multiple SMEs stated that licensure offices and agencies like APS are not equipped to track unlicensed care homes. For example, one SME from a state licensure office reported that their database does not include information on whether the call pertains to a licensed or unlicensed care home. One SME from an advocacy organization in Pennsylvania shared that they use an Excel spreadsheet to track illegally unlicensed care homes identified as a result of a complaint. They capture key variables such as the name and any aliases of the illegally unlicensed care home; the owner's name and whether they own more than one unlicensed care home; the licensure status (formerly licensed, never licensed, operating illegally); and any relevant information about the complaint (e.g., investigation dates, or dates any residents were moved/relocated).

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<sup>3</sup> Complaints can also be received by fax, letter, or email. We primarily heard about phone complaints.

Other states also track complaint calls as a means for identifying unlicensed care homes. For example, Georgia reported an increase in complaint calls about unlicensed residential care homes from 2013 to 2014. Pennsylvania lists the number of enforcement actions taken against illegally unlicensed residential care homes in their annual report on personal care homes, but this information may not be representative of how many complaints about unlicensed care homes are made (see the state summaries in **Appendix A** for more details).

Notably, reliance on complaints to identify unlicensed care homes limits identification of these homes to those that raise concerns about safety or quality. As noted by one SME, unlicensed care homes that provide good care and a safe environment may intentionally not be brought to the attention of state agencies nor be reported by these agencies when they learn of these homes:

*“We do receive reports, about 6 months ago someone wrote to me about their mother who was getting care in an unlicensed home...she was getting wonderful care, she wasn’t going to report it. I’m not going to report it. She was getting good care and it was something the mother could afford.”*

### **3.4.2. Tracking Public Benefits and Representative Payees**

Many residents in unlicensed care homes receive SSI, and some residents may qualify for waivers to provide long-term care services in HCBS. Multiple SMEs and key informants suggested following or tracking these benefits as a way to identify individuals in unlicensed care homes. Additionally, agencies such as The National Disability Rights Network’s Protection and Advocacy Agency (NDRN P&A) could potentially use representative payee data to identify unlicensed care homes. The NDRN P&A reportedly has suggested that SSA require representative payees to self-identify if they own a residential care home (licensed or unlicensed). If the SSA implements this requirement, it could become a potential source for identifying unlicensed care homes. One SME, who works on the Representative Payee Project,<sup>4</sup> mentioned that this project only investigates a sample of individuals who are representative payees for 15 or more individuals. The SME noted that this approach misses individuals who are representative payees for fewer than 15 individuals and as such may miss operators of small unlicensed residential care homes.

### **3.4.3. Referral and Placement Agencies and Discharge Planners**

Many key informants and SMEs discussed how homeless shelters, advocacy organizations, and churches or other faith-based organizations often serve as a resource to link vulnerable individuals who cannot afford the expense of a licensed care home to unlicensed care homes instead. As such, key informants speculated that these types of organizations may maintain lists of residential care homes. Some SMEs and key informants noted that if lists could be obtained from these organizations, they could

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<sup>4</sup> See <http://www.disabilityrightswa.org/stop-fraud-and-abuse-rep-payees>.

then be compared to state licensure lists to determine whether the residential care homes are unlicensed.

In addition, hospital discharge planners reportedly work with placement agencies to find housing for patients who cannot return home alone. One key informant in Allegheny County shared a list of seven current placement agencies that likely have registers of illegally unlicensed care homes.

Key informants from Georgia and Pennsylvania reported that hospitals and hospital discharge planners (or their contractors) often place patients in unlicensed care homes (described in more detail in Section 4). As such, they could be a key source for learning about currently unlicensed care homes.

#### ***3.4.4. First Responders: EMS, Firefighters, and Police***

Most key informants and SMEs suggested that first responders such as EMS, firefighters, and police are potential sources for identifying unlicensed care homes because they respond to emergency calls received from or about them. Some key informants noted that EMS personnel are a better source than firefighters to learn about unlicensed care homes in a community because EMS personnel respond to all emergency calls while firefighters do not. One SME, who was a firefighter and paramedic who has responded to calls from several unlicensed care homes, stated that he often had more comprehensive listings of unlicensed care homes than the local ombudsman.

Interview results indicate that police may also be helpful in identifying unlicensed care homes, but the extent of that help may vary from state to state and across communities within states. For example, key informants in Allegheny County, Pennsylvania, stated that police in rural areas of the county are more responsive to reports of unlicensed care homes than are the city police. Although this might not be the case in other states, in this community it appears that rural police may be more helpful than those in urban areas in identifying unlicensed care homes.

#### ***3.4.5. Legally Unlicensed and Licensed Care Home Operators***

Licensed care home operators were also identified as potential sources for identifying unlicensed care homes. During site visits, key informants reported that owners of licensed care homes often report operators of unlicensed care homes to authorities. SMEs indicated that such reports can be used to identify unlicensed care home operators. Key informants in Pennsylvania speculated that owners of legally unlicensed care homes may have direct experience operating an illegally unlicensed home or know someone operating one, and therefore may be able to help identify unlicensed homes or their operators.

### **3.5. Strategies for Addressing Issues in Legally and Illegally Unlicensed Care Homes**

Almost all SMEs and key informants we interviewed offered strategies to identify, monitor, or close unlicensed care homes. Very little discussion centered on improving the quality of unlicensed care homes. Discussions with SMEs and key informants explicitly differentiated between legally and illegally unlicensed care homes only minimally, but the opinion of SMEs and key informants we interviewed seemed to be that state efforts to address legally unlicensed care homes should focus on monitoring and improving quality, whereas state efforts to address illegally unlicensed care homes should be on identifying these homes and shutting them down.

One strategy recommended by key informants to address unlicensed care homes is to change the regulations to reduce the number of unlicensed care homes that operate legally. Another strategy is the creation and involvement of interagency and multidisciplinary teams at the state and local levels, which based on our key informant interviews appears to be a successful strategy. Regulatory changes and the role of multidisciplinary task forces (which are relevant to both legally and illegally unlicensed care homes) are described next, followed by a summary of the strategies discussed during interviews to identify and shut down illegally unlicensed care homes and to monitor and improve quality in legally unlicensed care homes.

#### ***3.5.1. Regulatory Licensure Changes***

Making changes to licensed care home regulations is one example of how states may address unlicensed care homes. Not all states license all residential settings with as few as one resident, as Georgia does; therefore many states, such as Pennsylvania, legally allow some unlicensed care homes to operate.

Before 2005, Pennsylvania allowed residential care homes with 1-8 individuals to be legally unlicensed. However, there were many reports of poor conditions in legally unlicensed care homes. In 2005, Pennsylvania changed the regulations so all residential care homes with four or more individuals had to be licensed by the state, but 1-3 bed residential care homes still could be legally unlicensed. Although this regulation reduced the number of legally unlicensed care homes and reduced their capacity to three or fewer residents, many key informants in Pennsylvania noted that this had the unintended consequence of spurring many more illegally unlicensed care homes to open. As a result, Pennsylvania enacted a strategy to address the illegally unlicensed care homes, which included providing the Pennsylvania Bureau of Human Services and Licensure (BHSL) the ability to serve warrants and creating the PCRR team mentioned earlier and discussed in the next section.

#### ***3.5.2. Interagency and Multidisciplinary Teams***

A coordinated, interagency, multidisciplinary effort across state and local agency and organizational levels is an important component to addressing unlicensed care

homes. This became evident during discussions with informants in Pennsylvania and Georgia; it has also been reported in the literature, as we found in the environmental scan. In Georgia, informants talked about the Abuse, Neglect and Exploitation Workgroup, which is led by the Georgia Bureau of Investigation and is comprised of individuals from several state, local and federal agencies. The PCRR teams in Pennsylvania are similar, and are based at the local level working in coordination with state licensure offices. Key informants described the way the teams function. A local ombudsman and APS supervisor lead the PCRR team and maintain lists of both known illegally operating homes and those that are potentially illegal operations. Complaint calls are received by each participating agency, therefore the team meets monthly to share complaints about potentially illegal unlicensed care homes. Once an unlicensed care home is identified, the PCRR team works closely with the both the state and regional licensure offices to take the necessary steps to deal with the home. These steps include site visits to suspected illegally unlicensed care homes, during which an ombudsman may inform residents of their rights, APS may conduct abuse or neglect investigations, licensure staff may assess whether the residents should be in a licensed care home based on the level of service needs, and code enforcement staff may determine if the home meets regulatory code requirements. The team works together to track homes they identify as unlicensed and then monitors them until the home is closed.

Although a coordinated, multidisciplinary effort appears necessary to comprehensively address unlicensed care homes, several key informants discussed the lack of ombudsman jurisdiction to access residents in unlicensed care homes. State regulations appear to vary widely in regards to ombudsman jurisdiction. In Pennsylvania and Georgia, key informants indicated ombudsmen are permitted to make site visits to unlicensed care homes if complaints are received, although access can be denied by the operator. In contrast, in North Carolina (and other states not included in our site visits) ombudsmen have no authority in or responsibility for residents in unlicensed care homes according to state regulations. One key informant explained how North Carolina regulations restrict ombudsman activity in unlicensed care homes, stating “*our structure is pretty clear as far as the accountability,*” implying that the regulations make ombudsmen unaccountable for residents in unlicensed care homes.

Key agencies and team members involved in local or state teams to address unlicensed care homes include APS, ombudsmen, building code enforcement, social workers and first responders such as EMS, police, or firefighters, and other representatives from local advocacy groups such as Disability Rights. Each of these agencies is able to address different elements of the complex situations that exist within unlicensed care homes, including the needs of residents, as well as issues with the building and any criminal acts of the operators.

### **3.5.3. Education: Statewide or Interagency**

Key informants from Georgia and Pennsylvania shared examples of efforts to increase awareness of unlicensed care homes through education or marketing for the

general public or the agencies they involve in addressing unlicensed care homes. Key informants in Georgia described training sessions to educate law enforcement and first responders about unlicensed care homes. In Pennsylvania informants described a public education campaign including advertisements warning people about placing their loved ones in unlicensed care homes. In addition, the APS staff in Pennsylvania had recent communications with local hospital discharge coordinators informing them about known illegally unlicensed care homes and asking them not to discharge patients to these settings; however, key informants noted that hospital discharge planners continue discharge individuals to known unlicensed care homes.

#### **3.5.4. State Law, Jurisdiction, and Penalties for Illegally Unlicensed Care Homes**

The enactment of state laws or penalties and fines related to the operation of illegally unlicensed care homes is a strategy that states can use to address illegal unlicensed care homes. Key informants in all three site visit states provided examples of how this might happen. Georgia law changed in 2015, making it a misdemeanor to operate an unlicensed residential care home if abuse, neglect, or exploitation were found to have occurred there. Compared to our other site visit states, Georgia has the harshest law against operators of unlicensed care homes. Pennsylvania's BHSL and the North Carolina Adult Care Licensure Office and Mental Health Licensure Office will offer to work with unlicensed residential care homes to help facilitate licensure. In Pennsylvania, one key informant noted that this assistance is given only to those operators who have opened their first illegally unlicensed care home without realizing they needed to be licensed; assistance is not provided for those who are repeat offenders.

Pennsylvania and North Carolina have some similarities in how they address unlicensed care homes. Both states use a penalty system to fine operators for illegal operations. These fines (\$50 for a first offense in North Carolina and \$500 for a first offense in Pennsylvania) become more severe if criminal activity or a resident's death is involved. One key informant in North Carolina indicated that fines for the operation of unlicensed care homes have little impact on closing the homes, are rarely collected, and are not enforceable by their agency because the operation of an unlicensed care home is considered a criminal offense, and thus under the purview of law enforcement. Informants said that many local sheriffs and District Attorneys are not supportive of following through to enforce penalties, nor do they press charges against the operators. In addition, one key informant stated that penalties for operating unlicensed care homes are similar to only a Class C offense, which is "equivalent to fishing without a license." In contrast, in Pennsylvania, the BHSL has the authority to execute a warrant to investigate a suspected illegally unlicensed care home. While North Carolina's licensure offices do not have this same authority, key informants in North Carolina did note that most unlicensed care home operators allow them entry even without legal authority. Pennsylvania's BHSL is currently working on an amendment to create a graduated fine system for those operators who continue their illegally unlicensed care homes after they have been ordered to cease operations. According to key informants, this graduated

fine system is intended to be a “bigger hammer” to stop “belligerent repeat illegal operators.”

### **3.5.5. Monitoring and Improving Quality in Legally Unlicensed Care Homes**

Some key informants described frustration with the lack of monitoring and lack of jurisdiction by the licensing offices to access or track legally unlicensed care homes. As discussed earlier, Pennsylvania is a state that legally allows unlicensed residential care homes, if they serve three or fewer individuals. Two key informants spoke about the lack of oversight of these homes and the concern for the well-being and safety of their residents. Because these homes are legally unlicensed, the state licensure office has no jurisdiction to monitor them, but APS may receive complaints about them. One key informant from Pennsylvania spoke about the difficulty in handling reports of neglect or abuse in legally unlicensed care homes:

*“...we will have repeated incidences, or alleged incidences [at legally unlicensed residential care homes] and we don’t report to anyone [any agency or the state] either. That makes it difficult for the licensing agencies to understand what’s going on because they don’t have the information and aren’t privy to it.”*

One key informant also emphasized that the limited monitoring of legally unlicensed care homes limits the state’s ability to identify and subsequently address any issues of quality or safety in these settings.

## **3.6. Potential Data Sources or Listings of Unlicensed Care Homes**

As part of this study, we sought to identify potential data sources or listings of unlicensed care homes that may be useful in efforts to understand how widespread unlicensed care homes might be, and whether these settings can be identified for future research purposes, both in the states we visited and in other states. While no comprehensive nationwide list of unlicensed care homes exists, the environmental scan identified one state (Florida) and one city (Houston, Texas) that maintain listings of unlicensed care homes. Also, Indiana state law requires legally unlicensed assisted living facilities to submit disclosure forms to the Family and Social Services Administration within the Division of Aging; thus, the state may be able to compile a listing of legally unlicensed facilities. However, site visit key informants and SMEs we interviewed were unaware of any such lists of unlicensed homes and could not identify existing methods for tracking them.

Although they did not know about existing listings, several informants suggested potential ways to develop a list of unlicensed care homes. These include tapping into fire/EMS databases to identify addresses of care homes that could be unlicensed, and tracking multiple SSI payments that go to a single representative payee at the same address. Several key informants mentioned that hospital discharge planners sometimes discharge patients to unlicensed care homes (described in more detail in Section 4), and as such they might be a potential source for compiling a list of these homes.

As noted in Section 3.4.1, one SME from an advocacy organization in Pennsylvania noted that they log specific information concerning names and dates into an Excel spreadsheet once a complaint has been lodged against an illegally unlicensed care home. The advocacy agency also collects information about whether the operators own more than one unlicensed care home. While this may be a promising source of unlicensed homes only in Allegheny County, Pennsylvania, similar tracking mechanisms may be used or developed for use in other communities as well.

## 4. POLICY AND PRACTICE IMPLICATIONS

SMEs and key informants discussed a number of factors that may have an effect on the supply of and demand for unlicensed care homes. They noted that the following may have heightened the demand for unlicensed care homes:

- The admission and discharge policies of licensed care homes.
- The modest payments made by SSI or State Supplemental Payments to residential care homes, which may be inadequate to cover expenses in licensed facilities.
- The closure of large mental health institutions and concomitant transition of previously-institutionalized individuals with severe and persistent mental illness to community-based care settings, such as legally unlicensed care homes.
- The financial pressure hospitals feel to free up hospital beds quickly, which sometimes results in discharges to unlicensed care homes, both intentionally and unintentionally.

Each of these factors is discussed in more detail in the sections that follow.

### 4.1. Licensed Care Home Admission and Discharge Policies

Some SMEs noted that many licensed facilities are unwilling to admit or retain individuals with severe and persistent mental illness, intellectual disabilities, or challenging behaviors. Indeed, results from the National Survey of Residential Care Facilities indicate that only 40% of licensed RCFs admit individuals with behavior problems, and just 55% admit individuals with moderate to severe cognitive impairment (Greene et al., 2013). For many such individuals, their only options may be unlicensed facilities or homelessness.

SMEs also discussed the fact that some residents are involuntarily discharged from licensed care homes when they exhaust their funds. If ombudsmen become aware of such discharges, they will likely attempt to assist individuals or their families to find licensed options, but they can only provide aid if they are notified. Absent assistance from the ombudsman or other support in finding affordable licensed care options, unlicensed care homes may be the only option these individuals have.

## **4.2. Modest Public Benefits**

SMEs and key informants consistently noted that many low-income individuals cannot afford licensed facilities, which makes the less expensive unlicensed care home an attractive option, and thus contributes to the existence of unlicensed care homes. As noted in earlier sections, many unlicensed care home residents receive federal SSI benefits, and many unlicensed care homes receive these benefits directly through the SSI representative payee program. However, SSI payments are low, and most states supplement these payments with a State Supplementary Payment (SSP). Currently, 46 states provide some type of SSP (SSA, 2015). However, a few states (such as Georgia and Texas) provide those supplements only to residents in residential care homes certified to offer services covered by Medicaid. The payments also vary considerably from state to state, and are quite modest in some states (e.g., from \$46 to \$100 per month). Incentives this modest provide little encouragement for residential care homes to incur the cost of licensure if their primary clientele has only SSI to pay for care. SMEs mentioned the lack of SSPs to residential care home residents who receive SSI as a factor that encourages the existence of unlicensed care homes.

## **4.3. Closing Institutions**

Multiple key informants discussed the impact that policy changes regarding community-based care have had on unlicensed care homes in their communities, including state efforts to comply with the Americans with Disabilities Act (ADA) requirements. For example, in Allegheny County, Pennsylvania, informants noted that the closure of Mayview Psychiatric Hospital in 2008 resulted in the displacement of persons with mental illness. One key informant estimated this hospital served 3,700 patients at its peak. Although the residents who were moved out of this hospital may have been relocated to licensed facilities when the hospital closed, the fact that such institutional settings are no longer an available option may have encouraged unlicensed care homes to open. Indeed, several key informants in Allegheny County reported that the closure of Mayview Psychiatric Hospital led to an increase in the prevalence of illegally unlicensed care homes in the county. Several SMEs also noted inadequate funding and housing options for persons with severe and persistent mental illness or intellectual disabilities who have been moved out of state facilities may contribute to demand for unlicensed care homes, because these individuals may not be able to afford the cost of a licensed care home.

## **4.4. Hospital Discharge**

Several key informants discussed the role hospitals and hospital discharge planners potentially play in referring patients to unlicensed care homes. Hospitals and hospital discharge planners are responsible for the safe discharge of individuals into the community, but some hospitals may have policies that incentivize the discharge of individuals to unlicensed care homes.

Many key informants and SMEs suggested that discharge planners face difficulty placing residents in licensed care homes because these homes often do not accept patients who only have SSI (or otherwise have little money), and they often will not accept individuals with a history of mental illness, substance abuse, or those who are homeless. Unlicensed care homes commonly will accept these individuals and many market themselves to discharge planners. Key informants in two states confirmed that some hospitals there contract with placement agencies that, in turn, place individuals in unlicensed care homes, particularly individuals with limited resources and mental health issues. As described earlier, some of our key informants noted that hospital discharge planners knowingly discharge these individuals to unlicensed care homes to alleviate the immense pressure they are under to facilitate quick patient turnover, and some hospitals reportedly will pay unlicensed care homes to admit these individuals.

In Allegheny County, key informants said that some hospitals use placement agencies to assist with difficult discharges (e.g., persons with severe or persistent mental illness, the homeless, or persons with little money). In Georgia, key informants also noted that hospitals directly discharge individuals to unlicensed care homes and some pay the first month of the resident's fees. As one informant in Georgia reported, "the hospital will say 'this is an expensive bed, you need to get [the patient] out.' The latest thing with hospitals, not only discharging to substandard places, the hospital is paying for the first month because it's cheaper than an expensive hospital bed."

## 5. LIMITATIONS, CONCLUSIONS AND POLICY IMPLICATIONS

Based on the findings from this exploratory study, illegally unlicensed care homes appear to be a problem for at least some states; the residents of these homes are extremely vulnerable, and while some are elderly and physically disabled, many have severe and persistent mental illness. Abuse, neglect, and financial exploitation of these vulnerable residents appear common. While we visited only three communities, the concerns articulated by the case study respondents were echoed by SMEs from other areas of the country and are consistent with the literature and media reports in the environmental scan. These preliminary findings are worth considering as policy makers implement federal, state, and local policies and practices that may relate to unlicensed care homes. Although exploratory in nature, these findings point toward concerning issues with unlicensed care homes as well as gaps in our knowledge, and have important implications for future research on unlicensed care homes.

### 5.1. Study Limitations

We relied on a targeted literature review, interviews with a small number of SMEs, and site visits to just three communities, all of which limit the scope of our findings. Also, the information gathered during informant interviews about unlicensed homes primarily painted a negative picture of these places. Newspaper and media reports generally focus on what they view as the dramatic; the positive aspects of unlicensed care homes are often omitted from these reports. Similarly, APS and ombudsmen staff receive complaints about quality, violations of resident rights, and allegations of abuse. Indeed, many key informants emphasized that they only knew about unlicensed care homes because of complaints being made about them. Thus, although our findings consistently highlight concerns about safety and quality, we cannot assess the generalizability of these findings and concerns, and our findings only minimally address unlicensed care homes that are safe and provide quality care. Additionally, what we heard about the policies that affect demand for and supply of unlicensed homes, and how unlicensed homes can be identified or detected, may not be representative of the situation in other states. Findings from this study are necessarily limited by the number of experts we identified and states we visited. Also, new HHS Centers for Medicare and Medicaid Services (CMS) policies on waivers and where waiver services may be provided may alter the prevalence of legally and illegally unlicensed care homes across the nation. Finally, as noted in the report, many individuals seek care in unlicensed care homes because they are in other undesirable situations, such as experiencing chronic homelessness or unnecessarily institutionalized. It was outside the scope of this project to examine the alternatives to unlicensed care homes or the health, safety or appropriateness of those environments.

## 5.2. Conditions in Unlicensed Care Homes

Much of the information we gathered from the environmental scan, from SME interviews, and from site visit informants raises concerns about the conditions experienced by residents in unlicensed residential care homes. Although there were some reports of clean and safe unlicensed homes, the negative findings about conditions were predominant. Additionally, several SMEs and key informants noted that in many cases unlicensed homes are the only option, other than homeless shelters or living on the streets, for some of these residents.

Findings also indicate that conditions in some unlicensed care homes are unsafe, abusive, financially exploitative, and neglectful of residents' basic needs. Further, in site visits and the literature, we found reports of situations that were repeatedly depicted as involving activity that was similar to "human trafficking" and "false imprisonment" of vulnerable individuals. In addition, the reports of financial abuse also may represent considerable financial fraud of federal programs including SSI, food stamps, and the programs paying for resident medications (i.e., Medicare and Medicaid).

These findings highlight a set of potentially serious problems and issues. First, there is a lack of information about the effect of various state and national policies on the vulnerable individuals the policies were designed to protect and whose well-being they were intended to enhance. Second, the findings highlight the need for federal and state agencies to determine the nature and scope of financial fraud being committed by operators of unlicensed residential care homes. Third, the findings suggest it is important to determine the nature and scope of abuse neglect and unsafe conditions experienced by people who have low incomes and physical and intellectual or cognitive disabilities. Fourth, study findings also suggest that efforts are needed to understand the differences in conditions between legally and illegally unlicensed care homes, as well as how illegally unlicensed care homes successfully evade licensure.

A wide range of specific concerns about unlicensed care homes were identified in this study, including improper management of residents' medications; unsafe, unsanitary, and inadequate living environments; failure to adequately feed residents; and monetary theft of benefits. Given these diverse concerns, SMEs and site visits interviewees suggested that coordinated efforts across a range of stakeholders, including state licensure agencies, ombudsmen, APS, law enforcement, and others may be necessary to address unlicensed care homes. At least two states have demonstrated that coordinated efforts can effect changes to laws and policies and create at least initial disincentives or barriers to the operation of illegally unlicensed care homes.

## 5.3. Strategies for Identifying Unlicensed Care Homes

Although a substantial amount of information and suggestions about methods of identifying unlicensed care homes came from site visits to communities in three states

(Pennsylvania, North Carolina, and Georgia), whether any of these strategies will apply to other states or other communities is unclear. Further, receipt of a complaint was the most commonly cited method to spur identification of an unlicensed care home. However, this likely is not a viable method for detecting the population of illegally unlicensed residential care homes. Thus, one implication of the study is that it may be worthwhile in one or more states or communities to test and evaluate other methods of detecting illegally unlicensed care homes. Finally, in some states, SMEs and the environmental scan identified legally and illegally unlicensed residential care homes that were referred to as boarding homes or board and care homes. Some of these housed mainly older residents. One issue that remains to be determined is the conditions or criteria by which such places constitute “unlicensed residential care homes.” For example, is it defined by the services the home offers, the services needed by residents, or the services provided to the residents in the unlicensed care setting. Clarifying this definition will be critical to understand the prevalence of unlicensed residential care homes, as well as the characteristics of residents in these homes.

#### **5.4. Strategies for Addressing Conditions in Unlicensed Care Homes**

As noted, we found the prevalence of legally and illegally unlicensed residential care homes varies by state. One of the SMEs shared comments from ombudsmen that the numbers of unlicensed homes in some states are increasing, while in other states, they reported that they had not heard about unlicensed care homes. Further, some of the ombudsmen reported that if an unlicensed home was providing good care, they did not report it to the licensure agency. Thus, we lack information about unlicensed care homes in most states, and even in our study states there were no reliable counts of illegal unlicensed care homes.

Despite this lack of information about prevalence, we heard about many strategies for addressing the existence of unlicensed care homes and the conditions in them. States have a variety of options for reducing the prevalence of both legally and illegally unlicensed residential care homes, such as changing regulations and coordinating across agencies to address these homes. We also heard suggestions from some SMEs and state stakeholders for improving safety and quality. However, the effectiveness of these strategies in monitoring or otherwise addressing the prevalence of unlicensed care homes is unknown.

SMEs and key informants also noted that states varied in their licensure laws and their ability to enter and investigate unlicensed care homes without a warrant issued by a judge. One of our study states made it a crime to operate an illegally unlicensed residential care home, and some states have the capacity to penalize unlicensed care homes with monetary fines.

None of these approaches or strategies completely addresses the concern about providing a safe environment and quality services to the vulnerable individuals being

served in unlicensed care homes. Demographic trends are placing an increasing number of older persons at-risk for needing residential long-term care, but many of these same individuals have out-lived their savings or had low incomes to start. Further, implementation of the Olmstead decision has increased the demand for residential long-term care settings and services. While it is outside the scope of this project to investigate alternatives to unlicensed care homes, we speculate that increasing the supply of alternatives for affordable housing with services would reduce the market for unlicensed homes.

## 5.5. Implications for Policy

Findings indicate that a variety of policies may have an impact on the supply of and demand for unlicensed care homes. For example, some states have adopted policies including licensure regulations that allow legally unlicensed care homes to operate. In some instances, these places may be certified or otherwise listed at a local level, but they may not be monitored by the state for quality and safety issues. As such, limited information is available about the quality of care and services provided in legally unlicensed care homes. States with concerns about the prevalence of unlicensed care homes may wish to examine their licensure regulations, as these may influence the supply of and demand for unlicensed care homes, either because the complexity of some regulations makes them hard for operators to understand, or because they might contain loopholes that operators can easily exploit. States with concerns about quality and safety in unlicensed care homes may also wish to examine their requirements for monitoring legally unlicensed care homes and the information available about safety and quality in these places.

Many low-income individuals cannot afford the cost of licensed residential care homes, and some residents exhaust their private funds in licensed facilities and are discharged with no options other than lower cost care homes, some of which may be unlicensed. Furthermore, many licensed facilities are unwilling to admit or retain individuals with challenging behaviors. For many of these individuals, their only option may be unlicensed facilities. States with concerns about vulnerable adults' access to housing with services may wish to examine their admission and discharge requirements for licensed care homes.

These findings suggest that as states continue to move toward serving more of their Medicaid beneficiaries in the community rather than in institutions, consideration should be given to ensure appropriate safeguards are in place for these beneficiaries. As states are working to meet their ADA obligations as reaffirmed in *Olmstead vs. L.C.*, they may need to pay particular attention to ensuring the availability of sufficient and affordable licensed care homes or other supportive housing options that offer person-centered care in a safe and appropriate environment.

## **6. RECOMMENDATIONS FOR FUTURE RESEARCH**

The information collected as part of this exploratory study was intended to provide a foundation for a more complete understanding about unlicensed care homes and the gaps these homes might fill as housing options for persons with low incomes. While the information herein is not generalizable--it is based on a targeted scan and a limited number of interviews--it does highlight the fact that unlicensed care homes appear to be a problem in at least some states. However, gaps in our knowledge about unlicensed homes remain, and several issues raised during interviews with key informants warrant further investigation. The following section presents individual research topics and identifies the related questions that might guide future research on unlicensed residential care homes.

### **6.1. Legally Unlicensed Residential Care Homes**

As noted in Section 4.1, states use a variety of definitions or criteria that allow some homes to operate legally without a license. In addition, SMEs noted variability across states in the availability of resident advocacy and protection through such agencies as the ombudsman program. However, while SMEs reported variability in licensure requirements and the authority, responsibility and funding of ombudsmen agencies with respect to unlicensed homes, there is very little information available about legally unlicensed homes, including the characteristics of residents, their care and service needs, and their preferences. There is no systematic information about the actual nature or range of conditions in legally unlicensed homes (e.g., safety, quality of care, issues of abuse and neglect), or provision of services and care through Medicare or Medicaid home health, private attendants, or HCBS waivers.

These are important issues since they affect many vulnerable adults who have physical, intellectual, or cognitive disabilities. Moreover, the 1976 Keys Amendment to the Social Security Act requires states to assure that SSI recipients do not reside in substandard facilities, and states must annually certify that this is true. Research about legally unlicensed care homes might focus on collecting information about characteristics of legally unlicensed care homes, the services they offer and the residents they serve, such as through a larger number of site visits and interviews with ombudsmen and state regulatory agencies or through a survey of the operators of legally unlicensed homes in states or areas that maintain lists of these homes, such as Florida, Georgia and Texas. This research might also address whether the Keys Amendment is achieving its goal of protecting the well-being of SSI recipients.

## **6.2. Illegally Unlicensed Residential Care Homes**

Although we heard about a range of conditions in illegally unlicensed homes, including neglect, abuse, and financial exploitation, it is unclear whether this is the norm or whether the findings are skewed because of the types of key informants we interviewed. Informants did note that while some places are bad, some unlicensed care homes may be fairly decent. Given the types of key informants interviewed for this study, and the limited viewpoints captured, more information is needed to understand the characteristics of unlicensed care homes and the residents they serve.

One way to collect this information to develop a frame of unlicensed care homes and conduct a small scale study of unlicensed care home operators. It is worth noting that this research activity would require developing an operational definition of “unlicensed residential care home,” since definitions vary considerably across and sometimes within states, as some focus on services offered, some on size, and some on the characteristics of the residents.

## **6.3. Financial Exploitation, Abuse of Residents' Rights, and Program Fraud in Unlicensed Residential Care Homes**

It is important to note that we do not know whether the types of financial exploitation and abuse described by the SMEs and key informants occur in both legally and illegally unlicensed care homes, or how commonplace they are. However, these are issues that warrant additional research.

The issue of financial exploitation is described in detail in Section 3.3.2. Operators often gain control of residents’ funds by becoming the representative payee for residents receiving SSI, a common payer source in unlicensed residential care homes. Even with relatively low payment rates, operators can make profits by cutting corners in housing and services and trafficking in the federal benefits they seize from residents. Some trawl for residents, picking residents up off the street, from homeless shelters, and from hospitals, and routinely shift residents from one facility to another in order to keep their occupancy rates high. In addition, investigations by Georgia law enforcement officials indicated that there is considerable fraud with respect to SSI, Social Security, residents’ personal needs allowances, Medicare and Medicaid, and the food stamp program.

Such practices violate residents’ rights, and the profit-enhancing practices of the operators, such as limiting the availability of food, water, and other basic needs, endanger residents’ lives and well-being. It is important to learn if such abuses and frauds are limited to a small number of communities or if they are more widespread.

## 6.4. Other Research Ideas Suggested by Subject Matter Experts or Individuals Interviewed in State Site Visits

Additional potential research questions or issues were raised by one or more SMEs or arose from our state site visits or the environmental scan. Some of these ideas may be relevant for agencies other than or in addition to ASPE, such as the National Institute of Justice, CMS, or ACL.

- **Resident Case Mix.** Many SMEs reported that persons with severe and persistent mental illness are the majority of residents in unlicensed residential care homes. However, some SMEs and key informants also noted that many of these individuals with psychiatric conditions are older, having aged in state institutions, and that persons 65 years of age and older who receive SSI payments also often live in unlicensed care homes. Some SMEs suggested that state policies affect the mix of residents in unlicensed care homes. Other SMEs reported that efforts to discharge or divert residents from nursing facilities to community-based settings led to greater use of licensed RCFs and noted instances in which residents who exhausted their private funds might have no options other than unlicensed residential care homes. Thus, future research might be warranted to determine the characteristics of residents in unlicensed care homes and whether they differ across legally and illegally unlicensed homes. Research could also examine whether and how federal or state policies might affect the resident mix in unlicensed care homes.
- **Ombudsmen.** As noted, the responsibility and authority of ombudsmen in unlicensed care homes--even in terms of receiving and acting on complaints--varies from state to state. In addition, states differ in whether they provide additional funds to the ombudsman program, over and above the federal funds from the Older Americans Act. Future research could be conducted to describe the nature of ombudsman involvement in unlicensed care homes and how it differs across states. It might also determine which states provide additional state funding to the ombudsman program, and whether the level of available resources is a limitation on ombudsman involvement in unlicensed care homes.
- **Abuse and Neglect.** Instances or allegations of physical and psychological abuse and neglect of residents were reported by SMEs and key informants and highlighted in the environmental scan. Although such issues are not restricted to unlicensed care homes, as they are known to occur in licensed care facilities as well, future research might examine and describe the mechanisms states use to detect, investigate, and resolve allegations of abuse or neglect in unlicensed residential care homes and how they compare to the mechanisms used to identify and resolve instances of abuse and neglect in licensed care homes.

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## APPENDIX A. STATE SUMMARIES

### A.1. Georgia

#### Site Selection

Georgia was selected as a state for our site visit because of the state's actions surrounding unlicensed care homes described during interviews with SMEs, and the numerous news reports about unlicensed care homes in the state. In the past 15 years, the issues surrounding unlicensed personal care homes in the state have become more prominent, and coordinated action across several agencies has been taken to address them. The state has started training sessions to educate law enforcement and first responders about unlicensed care homes, and these education efforts may contribute to the state's ability to identify unlicensed personal care homes.

#### Key Informants

The research team interviewed 12 key informants in Georgia. Key informants included representatives from several agencies, including the state Healthcare Facility Regulation (HFR) and APS offices, local fire departments, local and state law enforcement and ombudsmen, and a church-affiliated provider of day services used by individuals who live in unlicensed care homes.

#### State Regulations

Facilities providing or arranging for housing, food service, and one or more personal services for two or more unrelated adults must be licensed by the state as a personal care home. Licensed personal care homes are required to assist with personal services, supervise self-administration of medication, and provide social activities, as needed. A facility that advertises or represents via verbal communication that it provides personal assistance is required to make personal services available to its residents. In other types of residential care, if the care is arranged or managed by the owner, manager, or staff of the building, home, or community, then the facility must be licensed. Provision of housing plus one or more personal services requires a personal care home (or other licensed facility) permit. At least one administrator, on-site manager, or responsible person must be on duty 24 hours per day, seven days a week, and all staff must be trained as personal care workers within 60 days of hire. In addition to serving the elderly, personal care homes can exclusively serve persons with serious mental illness and/or intellectual and developmental disabilities, on condition that the home is appropriately staffed and is capable of providing the needed care within the scope of its license.

With the passage of a new law in July 2012, it is a misdemeanor to operate an unlicensed personal care home, and if an unlicensed care home is linked to abuse, neglect, or exploitation, the violation is considered a misdemeanor. Along with funding to cover relocation of residents, this legislation empowers state and local multidisciplinary teams to collaboratively plan and coordinate efforts to identify, investigate, and pursue any necessary regulatory enforcement or legal action against unlicensed facilities.

## **Local Context**

In Georgia, all unlicensed personal care homes are illegal, and thus to remain in operation they try to avoid being identified. Discussions with key informants in the state suggest Georgia has a high prevalence of these homes. This is evidenced by the number of reports and complaints received about unlicensed personal care homes, the number of hours spent by law enforcement officials on investigating unlicensed personal care homes, and the estimates given of the numbers of unlicensed care homes that are operating in the state (reported by one informant as one unlicensed care home for every licensed home).

Based on the collective feedback of a diverse group of key informants, unlicensed personal care homes appear to be prevalent and problematic in the state. Of the approximately 1,400 complaints received by APS each year, an estimated 20% pertain to unlicensed personal care homes. APS professionals there estimate three reports or complaints about unlicensed personal care homes every month in the metro Atlanta area, and about one complaint or report about unlicensed personal care homes every three months in rural areas of the state. One interviewee, who interacts with residents of unlicensed care homes on a daily basis, estimated that for every licensed personal care home in Georgia there is one unlicensed care home.

Several examples of unlicensed personal care homes were described by key informants during the site visit. Most commonly, interviewees depicted unlicensed personal care homes operating in residential areas within single family houses that are rented by the unlicensed care home operator, but some interviewees described unlicensed care homes operating in a variety of other structures (e.g., closed churches and schools). Notably, most key informants said the operator of a licensed home may also operate one or more unlicensed homes, often in the same neighborhood and often in collaboration with friends or family members.

One example, described by multiple key informants, looked like a nice physical environment and was affiliated with a local church, but the operator of the home was taking the residents' money while abusing, imprisoning, and exploiting them. This home initially drew the attention of the authorities because of a sexual assault case in which one of the residents was raped by a sex offender. Other issues were identified during the subsequent sexual assault investigation, including abuse at the hands of the operator who beat the residents, false imprisonment in which individuals were locked inside rooms, and financial exploitation. According to several key informants in the

state, including APS and law enforcement officials, the property, which they referred to as a boarding home, was being rented by the operator, members of the church served as the representative payees for the residents, and the money was then pooled together and given to the operator. They described this as an example of operators running unlicensed care homes strictly for the money. One key informant reported that during the investigation of this home, it also was discovered that the operator was taking the residents' food stamps.

One of the key informants, who operates a day program that serves many individuals who are residents of unlicensed care homes, also described the 20 year history surrounding the operation of unlicensed care homes. State and local funding that was designated for clean-up activities in preparation for the 1996 Summer Olympic Games in Atlanta was used to encourage homeless individuals (often with mental illness) to leave the city. According to the key informant, these individuals were given one-way bus tickets out of the city under the stipulation that they never return. Those individuals who remained in the city were placed in day programs. Following the Olympics, funding for these day programs was not renewed, and all but one of these programs ceased operations. Presumably, this led to an increase in need for LTSS for these populations. More recently within the City of Atlanta, the gentrification of some neighborhoods has resulted in increased property values and rents, which has caused some unlicensed care home operations to relocate to less expensive areas. Thus, unlicensed care homes close and leave one area of the city, but reopen in another area, contributing to the difficulty of identifying and permanently shutting down these places, while also disrupting the residents' access to day services and other community-based sources of support nearby the original care home location.

In the past few years, Georgia has developed an interagency task force including law enforcement and social services agencies which has trained and prepared many staff to deal with these homes. This task force has also coordinated raids on unlicensed homes and has pushed for changes to laws regarding these homes. In August 2013, the law to prosecute an unlicensed personal care home operator was used for the first time.

### **State and Local Policies Related to the Supply of and Demand for Unlicensed Care Homes**

According to one key informant in the state, moving individuals from institutions for mental illness with an inadequate plan for housing these individuals has contributed to an increase in the numbers of people available for unlicensed personal care homes to serve, thus motivating the opening of unlicensed care homes. In many cases, the cost of care in other settings is too high for what individuals with severe and persistent mental illness can able to afford on their SSI stipend.

State policies do not require hospital discharge planners to discharge patients to licensed care homes, thus permitting discharge to unlicensed care homes. Individuals who are poor, experiencing homelessness, or individuals with a mental illness who

cannot return home or have no home to return to after being discharged from the hospital are a source of clients for unlicensed care homes. Several key informants reported that unlicensed care home operators “troll” the psychiatric wards of facilities like Grady Memorial Hospital, looking for residents. Hospital discharge planners are not required to check the licensure status of the place to which they are discharging patients, and often discharge them to unlicensed homes. According to many of the key informants interviewed, hospitals are increasingly under financial pressure to discharge patients to free up beds, which is believed to contribute to the ability of unlicensed care homes to fill beds and stay in business. Thus, unlicensed care home operators are known to directly market themselves to hospitals and to pick up patients at the hospitals when they are discharged, and some hospitals have been known to pay a month of the residents’ fees at the unlicensed home to secure a quick discharge from the hospital. However, the long-term placement of individuals after discharge to an unlicensed care home may be unstable, and no follow-up by the hospital with the patient after placement was described.

### **Motivations to Be Unlicensed**

As described by the majority of key informants, the primary motivation to maintain an unlicensed care home is to maximize profit. Obtaining licensure would require operators to pay the costs of additional and qualified staff and service provision. In the view of the majority of key informants, the operators of unlicensed homes do not want to have to pay for more staff to provide needed services. The inability or unwillingness to provide appropriate care for residents at an affordable cost also was noted by key informants as a motivator to not pursue licensure. Ultimately, several key informants acknowledged and emphasized that remaining unlicensed is lucrative if the care home operator successfully avoids detection by the authorities.

### **Characteristics of Residents and Unlicensed Care Homes**

Findings from the interviews suggest that the majority of unlicensed care home residents in the metro Atlanta area have severe and persistent mental illness and are highly vulnerable to exploitation. One key informant noted that residents of unlicensed care homes commonly require assistance with activities of daily living (ADLs), such as getting dressed, as well as assistance with instrumental activities of daily living (IADLs), such as taking medications and managing and accessing transportation to medical appointments.

In addition to the church-affiliated home described above, examples of the types of places where unlicensed homes operate included an old elementary school as well as single family homes in residential neighborhoods. Although the majority of key informants described unlicensed care homes as unsafe environments where residents are abused, neglected, or exploited, it also was noted that some unlicensed care homes may provide quality care in safe and clean environments.

## **Health and Safety Concerns**

Health and safety concerns for residents were a major topic of interview discussion. Concerns expressed across several interviews included providers locking residents in rooms; locking food away so that it is inaccessible to residents; using basements to house individuals, including individuals who are unable to climb the stairs and those on hospice; providing accommodations that are unclean, infested with bedbugs, and lack heat, air conditioning or running water. In addition, one key informant indicated that operators of unlicensed care homes have illegally obtained electrical service utilities through covert connections with neighboring homes.

## **The Scope of Abuse and Exploitation Concerns**

Interview results indicate that the majority of unlicensed care homes investigated by state officials and local APS agencies involve situations in which residents are not being cared for properly. The majority of examples of mistreatment included resident physical and emotional abuse, neglect, or financial exploitation. In multiple interviews, unlicensed care home operators were described as being involved in human trafficking, and also were specifically noted by APS and law enforcement officials to traffic residents across state lines, specifically into Florida and Alabama, to avoid legal action in Georgia. A core pattern of exploitation described in interviews included the operator of unlicensed homes finding vulnerable individuals who need housing and supportive services (such as from hospitals or homeless shelters), requiring these individuals to transfer their SSI payments to the operator or one of the operator's agents in order to become a resident of the unlicensed care home, severely limiting the residents' ability to leave the facility, and relocating the residents to alternate locations to avoid detection. Unlicensed care home operators also were described as sometimes having select residents act in a role of authority over other residents, such as beating the other residents to control their behaviors.

One key informant described a recent (2015) case of human trafficking in which a care home operator who was closing a home was explicitly selling residents for \$100 each to other personal care home operators.

Interviewees noted that unlicensed care home operators often take the residents' identification cards and personal paperwork upon admission. This was described as limiting the capacity of the resident to relocate. If the homes are closed and the residents' identification cards and personal paperwork are not able to be retrieved, this poses challenges for residents to get SSI payments and medications. Although recognized as important, the state has not yet begun investigating cases of financial exploitation. To reduce abuse, several informants indicated that state officials should target closing unlicensed care homes.

## **Strategies to Identify Unlicensed Care Homes**

Currently at the state level, the primary strategy used in Georgia to identify unlicensed care homes is through complaints, including complaints from neighbors, residents, residents' family members, and hospitals serving residents of unlicensed care homes. These complaints may be made to the police, APS, ombudsmen, and the Department of Community Health, HFR Division. Key informants in metro Atlanta also indicate that the state conducts interviews with residents during investigations and closures of unlicensed home to gain a better understanding of how individuals end up in these homes. According to findings from these interviews, there are a few different pathways into unlicensed care homes, including unlicensed homes receiving residents directly from hospital discharges, representatives of unlicensed homes picking up residents from homeless shelters, and owners of licensed facilities taking residents to unlicensed homes. Given their direct linkage to unlicensed care homes, these three sources (hospitals, homeless shelters, and licensed personal care homes) are potential sources of information for identifying unlicensed care homes.

## **Strategies to Address Unlicensed Care Homes**

To address the issues surrounding quality and safety in unlicensed care homes, key informants described a process involving the investigation of complaints by visiting the home and interviewing residents and staff (which may necessitate getting an inspection warrant if denied entry upon arrival), then providing a written cease and desist letter if the investigation results indicate that the home should be licensed, issuing fines of \$100 per day per resident, and prosecuting the operator. The main goal of these efforts is to shut down facilities where residents are financially exploited, abused, neglected, or subject to unsanitary and unsafe conditions. Informants consistently emphasized the critical need for collaboration between multiple agencies, including law enforcement, APS, ombudsmen, the Department of Behavioral Health, and HFR, in order to address the potentially unsafe environments in unlicensed care homes, ensure the needs of the residents are met, address the criminal acts of the operators, and attend to the buildings themselves. In addition to the \$100 per resident per day fine placed levied against unlicensed facilities, a representative of the state reported that the Georgia legislature has added operating an unlicensed personal care home, which is a criminal offense, to the list of crimes that make it impossible to apply for a license to operate a personal care home.

## **Areas for Future Research and Potential Data Sources**

In Georgia, much of the current focus on unlicensed personal care home investigations involves cases of resident abuse and neglect. Few of the investigations focus solely on financial exploitation. Key informants indicated financial exploitation in unlicensed care homes is an area for future research.

Cross-state human trafficking is another area for future research. Some interviewees reported that unlicensed care home operators sometimes run homes in

more than one state, across state borders to avoid arrest, and may be trafficking residents across state borders as well. According to key informants from APS and law enforcement, care home operators and residents crossing state borders poses several challenges that make it difficult to ensure the safety of residents and address the criminal activities of the operators. These challenges include differences in laws and regulations pertaining to care homes across states, and the lack of cooperative arrangements across states to facilitate tracking residents or operators who traverse state borders.

By interviewing residents of unlicensed care homes, HFR is trying to understand the pathways that individuals take to end up in these situations. Most key informants noted that hospital discharge is a critical juncture at which individuals can be directed to, or end up in, unlicensed care homes. Future research examining the role of hospital discharge planners and strategies to prevent discharge to unlicensed care homes appear warranted.

Interview findings also suggest that research is needed on the best strategies for identifying unlicensed care homes and effectively closing them down. Interview findings indicate that a key element of a successful strategy is collaboration across multiple agencies. Key informants expressed a desire for future research that helps to categorize the necessary organizations and the number of personnel hours needed from each organization at each phase of the processes to identify, investigate, and close unlicensed homes; determine the optimal tactics to effectively implement investigation and closure; and develop a safe and seamless relocation and follow-up plan for residents.

## **A.2. North Carolina**

### **Site Selection**

Information gathered from the environmental scan and SME interviews revealed reports that unlicensed care homes exist in North Carolina. The state has also been in the news based on actions resulting from state compliance with the *Olmstead* decision which has moved adults with mental illness from institutional settings into less segregated settings in the community. We chose the Raleigh/Durham area for the site visit because it is where the state licensing agency is located and because of recent media reports of unlicensed group homes. We conducted most key informant interviews in Durham, with some additional interviews across the region, including Raleigh.

### **Key Informants**

We conducted nine total interviews with ten key informants, including state licensure officials and staff from the North Carolina NAMI in Raleigh. In Durham County we interviewed key informants from APS, Group Care Monitoring Services, a local

hospital discharge planner, a local ombudsman, and one local law enforcement official, who also serves on a crisis intervention task force.

## **State Regulations**

In North Carolina, facilities providing or arranging for housing, food service, and 24-hour scheduled and unscheduled personal care services to two or more unrelated adults must be licensed as an adult care home or a group home. Licensure for adult care homes and mental health group homes falls under two separate state statutes, and therefore two separate regulatory offices oversee different types of licensed care homes. North Carolina's Adult Care Licensure Office licenses two levels of adult care including family care homes and adult care homes. Family care homes serve 2-6 residents and adult care homes serve seven or more residents; both can choose to serve only elderly persons (55 years or older or any adult who has a primary diagnosis of Alzheimer's disease or other form of dementia) or to serve a mixed resident population. At least one administrator, on-site manager, or responsible person must be on duty 24 hours per day, seven days a week, and all staff must be trained as personal care workers within 60 days of hire. The North Carolina Mental Health Licensure Office licenses group homes for adults with mental illness.<sup>5</sup> These homes also serve two or more adults.

## **Local Context**

Overall, key informants were able to provide little information about the prevalence of illegally unlicensed care homes (henceforth referred to as unlicensed care homes); informants we spoke with at both the state, local licensure office and APS reported that they do not currently systematically monitor or track unlicensed care homes. We were only able to obtain an estimate on the number of unlicensed care homes from the Durham County Group Care Monitoring Office. Durham County key informants estimated that since 2012, approximately five calls have resulted in cases being investigated as potential unlicensed care homes. Of these, three were determined to be unlicensed care homes. There were no reports of varying frequencies of unlicensed facilities between urban and rural areas.

Key informants at the state level were able to provide estimates of the number of complaints they have received pertaining to unlicensed care homes, but not estimates of the number of unlicensed care homes. One state key informant stated that her office receives one to two calls a month pertaining to unlicensed adult care homes, but she noted that these calls are sporadic. Another state-level key informant was unable to estimate how many calls the agency receives that result in investigations of unlicensed group homes for persons with mental illness. However, a representative from a state advocacy agency estimated that about 2%-3% of their 4,800 calls annually, or approximately 120 calls statewide per year, were related to unlicensed facilities.

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<sup>5</sup> The North Carolina Office for Mental Health Licensure also licenses group homes for adults with developmental disabilities (5600B) and group homes for adults with substance abuse issues or chemical dependency. However, we did not focus on these populations in the interview.

Key informants described both state and local infrastructure issues related to the prevalence of unlicensed care homes in the state. Two key informants thought that the ongoing statewide mental health reform, which began in 2002, has exacerbated issues related to the general lack of infrastructure and knowledge about needs of persons with mental illness. They indicated that they are unaware of any assessment of need related to licensed mental health group homes in the state. They speculated that there may not be enough licensed mental health group homes available to care for persons with mental illness, and that unlicensed group homes can potentially fill that gap.

All key informants described how the Local Management Entity-Managed Care Organization (LME-MCO) oversees the provision of mental health services in Durham County. The LME-MCO oversees contract services in a four county area. While we were specifically told by two key informants that the LME-MCO can only contract mental health services and supports to licensed group homes, these same key informants also shared specific examples of the LME-MCO unknowingly contracting services to unlicensed group homes. This implies that the LME-MCO does not always check licensure status before coordinating services in unlicensed group homes. We were told that after discovering a group home is unlicensed (via information from the state), the LME-MCO will ask the state to fast track licensure because there are no other licensed housing options available to this vulnerable population.

### **State and Local Policies Related to the Supply and Demand for Illegally Unlicensed Care Homes**

Two key informants mentioned that changes to the state's Medicaid Personal Care Services program had a direct impact on available funding for group homes that serve individuals with mental illness. In 2013, the minimum number of ADLs needs required for individuals to qualify for reimbursement for personal care services in group homes increased. This had a direct impact on the operating budgets of licensed group homes. The state made bridge funding available to those group homes impacted by this funding change, but one key informant said that according to a recent report, very few group homes accessed this bridge funding. This key informant was concerned this had contributed to group homes closing, which may have resulted in a gap that unlicensed facilities are filling.

U.S. Department of Justice settlements were also discussed by one key informant. In 2012, the state mandated that large adult care homes (seven or more beds) housing only individuals with mental illness had to close because they were considered institutional settings. As a result, 3,000 individuals with mental illness were transitioned into community-based supported housing. This key informant indicated that this change likely increased the need for licensed group homes, and unlicensed group homes may have also opened as a way to fill the need created as a result of these closures.

## **Motivations to Be Unlicensed**

Many of the key informants stated that individuals who operate unlicensed care homes are motivated by economic opportunities; but they also stated that in some cases, these operators may not know they need to be licensed. For instance, they may start by caring for one resident, and gradually take in more individuals without realizing there are state regulations governing homes caring for two or more unrelated adults. Costs for bringing the building up to code to meet state regulatory requirements may be another reason why operators of care homes choose to remain unlicensed.

## **Characteristics of Residents and Unlicensed Care Homes**

Multiple key informants described unlicensed care homes as primarily serving persons with mental illness. Very little was mentioned about elderly residents living in unlicensed homes; only one informant reported that unlicensed adult care homes may serve a mixed population (e.g., elderly residents in addition to residents with mental illness).

Informants noted that unlicensed care homes vary in their appearance and condition. Some key informants reported that the living conditions in these places can be subpar. Others described instances where the unlicensed care homes can be located in either low-income neighborhoods or higher-income neighborhoods, and that they blend in with other houses, which makes them difficult to identify or locate unless reported by the community. One key informant shared a specific case of a repeat offender that operates an unlicensed adult care home out of a double-wide trailer. Per state regulations, this is not considered a permanent structure, and therefore does not meet the appropriate building requirements to be a licensed facility.

## **Health and Safety Concerns**

Overall, the local agency representatives described the condition of unlicensed care homes as unsafe. State informants did not provide information on the services provided in the unlicensed care homes stating that the sample of unlicensed care homes they see is too small to make an accurate approximation of the conditions. Local key informants primarily expressed concerns regarding inadequate nutrition provided to residents and inappropriate medication management practices. Anecdotal examples of residents wandering outside of their home and onto neighbor's property, which typically generates a complaint call from the neighboring homeowner, were also provided. Although licensed homes were generally depicted by key informants as safer than unlicensed homes, one key informant emphasized that quality of care is not contingent on licensure status; licensed homes may also have health and safety concerns.

## **The Scope of Abuse and Exploitation Concerns**

Multiple key informants reported that financial exploitation was the biggest concern surrounding unlicensed care homes. For example, one key informant described a recent

case of a representative payee in an unlicensed care home who was not managing a resident's money correctly, by providing food on a specific schedule and not providing it when the resident was hungry and requested food. In contrast, a key informant stated that complaints of physical and mental abuse are the issues that most often draw attention to unlicensed care homes. State key informants emphasized that they could not make estimates about the scope of abuse and exploitation issues because unlicensed care homes are not systematically monitored.

### **Strategies to Identify Unlicensed Care Homes**

Identification of unlicensed care homes is triggered by complaint calls to state or local authorities by community members or family members. These calls spur investigations that sometimes result in the identification of unlicensed care homes. In several cases at both the state and local level, unlicensed facilities were reported to authorities or licensure offices by the operators of licensed facilities. In these cases, licensed operators were reportedly worried that the unlicensed operators would house residents from whom the licensed homes operators could have profited.

One potential strategy suggested by an interviewee for proactively identifying unlicensed care homes is to hold community meetings to inform community members about unlicensed care homes, including ways to identify them and how to notify APS and licensure officials if they suspect an unlicensed home operation. Another key informant suggested that it would be key to involve the LME-MCO because they cover a four county area and must receive calls that are about unlicensed care homes.

### **Strategies to Address Unlicensed Care Homes**

Key informants described a coordinated effort between the state licensure offices and the local group care monitoring office once there is recognition that a complaint call is about an unlicensed facility. One key informant stated that if a call comes in and the name of the care home that is being reported is unknown, then the next step is to call the state licensure office. Next, the local group monitoring office or the state would attempt a site visit. Unlicensed care homes are not required by law to open their doors to the state licensure office because the state licensure office does not have the legal authority to enter them. However, key informants at the state said that operators of suspected unlicensed care homes usually do open their door for inspection.

The state investigates the types of services that are provided to residents on site in order to determine if a license is required. If the facility is providing licensable services in an unlicensed setting, the state then sends a cease and desist letter, copying the LME-MCO and the local APS. One key informant noted that the state or the LME-MCO can conduct follow-up to assess whether a facility that received a cease and desist letter does, in fact, close down. If the facility does not close, law enforcement (not the state licensure offices) fines the illegal operation \$50 for the first offense and \$500 for each additional offense. However, even if the home continues to operate, the fines are rarely enforced or collected. It was noted that many sheriffs and District Attorneys do

not want their resources to go to cases of this nature unless serious and numerous complaints lead them to believe the group home is a major problem. No other coordinated agency efforts beyond the state licensure office, APS, and the LME-MCO were described by key informants.

### **Areas for Future Research and Potential Data Sources**

One informant suggested research that examines the homeless population and the availability of affordable housing as a way to better understand the environment that may be conducive to supporting unlicensed care home operations. Additionally, interviewee discussions revealed a lack of ombudsman involvement in unlicensed care homes, which is another area for future research. A review of state regulations around long-term care ombudsmen could reveal gaps and opportunities in how ombudsmen can access and advocate for residents in unlicensed care homes. Key informants did not offer any information on potential ways to identify unlicensed care homes or existing databases of these places.

## **A.3. Pennsylvania**

### **Site Selection**

Pennsylvania was selected as a site visit location because of the state's past and current experiences with illegally unlicensed personal care homes. In 2005, Pennsylvania state regulations for personal care homes were changed, reducing the minimum number of residents a personal care home could serve from seven to four. The new regulations were implemented to monitor and provide oversight of personal care homes with four or more residents, while reducing the number of homes that legally did not require licensure. As a direct result of this regulation change, many personal care homes in Pennsylvania became illegally unlicensed and either shut down, became licensed, or continued to operate illegally. Multidisciplinary PCRR teams were then formed at the county level to address the relocation of residents to licensed facilities and to investigate illegally unlicensed personal care homes in coordination with the state licensure office. Allegheny County was specifically chosen as the site visit community because of their currently active PCRR team, which continues to address illegally unlicensed personal care homes. The state is also unusual in that it allows a category of care homes to operate as legally unlicensed homes.

### **Key Informants**

The research team completed seven interviews with eight participants that included both state and local community stakeholders. Key informants included representatives from the state licensure office. In Allegheny County we interviewed key informants from APS, and local ombudsmen and placement coordinators from the local Area Agency on Aging (AAA) who work directly with licensed and unlicensed personal

care homes, as well as other staff from a local disability advocacy agency and a local fire department.

## **State Regulations**

In Pennsylvania, facilities providing or arranging for housing, food service, and one or more personal care needs for four or more unrelated adults must be licensed as personal care homes. Licensed personal care homes are required to assist with personal services including ADLs and IADLs, and can include supervision of medication administration and provision of social activities, as needed. Per state regulations, residential settings providing room, board and personal assistance with three or fewer residents who have at least one personal care need do not meet the requirements for licensure as a personal care home and are legally unlicensed. Dom Care homes, which also provide care to three or fewer individuals, are governed and regulated by the state with the authority to certify, supervise and monitor delegated to the local AAA.

## **Local Context**

At the state level, Pennsylvania investigates a relatively low number of illegally unlicensed personal care homes per year. One key informant estimated that approximately 25 cases are investigated annually, with about half that number determined to be illegally unlicensed personal care homes. The state's annual Personal Care Homes Report provides the number of illegally unlicensed personal care homes that result in enforcement actions and details the historical trend of the number of enforcement actions taken against illegal unlicensed personal care homes. From 2008 to 2013, Pennsylvania reported a stable trend of investigating about ten illegally unlicensed care homes per year with the exception of 2010 when they investigated 27 cases, about three times more than in other years.<sup>6</sup>

At the local level, one key informant estimated that members of the Allegheny PCRR, along with the state licensing office, have investigated approximately five illegally unlicensed personal care homes in their specific geographic region over the past two years. Key informants stated that many illegally unlicensed personal care homes they investigate are being operated by repeat offenders who have done this in the past; these same operators just open new illegally unlicensed personal care homes once they are found out.

Key informants noted that it is important to know the history of Pennsylvania's personal care home regulation changes in order to understand why and how the state has addressed illegally unlicensed personal care homes. Although these regulatory changes occurred ten years ago, multiple key informants reported that many more licensed personal care homes have continued to close in recent years. One key informant estimated that approximately 3,000 licensed personal care homes have ceased operations in Allegheny County since the 2005 regulatory changes. Most

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<sup>6</sup> See [http://www.dhs.state.pa.us/cs/groups/webcontent/documents/report/c\\_102850.pdf](http://www.dhs.state.pa.us/cs/groups/webcontent/documents/report/c_102850.pdf).

interviewees also agreed that there are likely more illegally unlicensed personal care homes than they are aware of. They indicated that these unlicensed personal care homes are filling the gap left by the closing of licensed personal care homes. It is important to note that most key informants did not speak to or have direct experience with very small (1-3 beds) legally unlicensed personal care homes, and therefore could not estimate the prevalence of these types of homes or compare them to illegally unlicensed personal care homes.

Multiple key informants spoke about a reduction in the number of Dom Care homes in the state and how this reduction may also give rise to illegally unlicensed personal care homes. One key informant estimated there are approximately 526 Dom Care operations in the state. Interviewees had varying opinions on the causes for Dom Care homes closing. One key informant indicated that this reduction is due to the increasing numbers of HCBS waivers giving potential Dom Care residents the option to live alone in apartments. Another interviewee suggested that it is becoming more difficult to recruit individuals to be Dom Care operators because of the competing demands on their time.

Informants stated that Allegheny County has other specific contextual issues that may contribute to the existence of illegally unlicensed personal care homes. Many key informants regarded the closing of Mayview State Psychiatric Hospital in 2008, which was located in Allegheny County, as an important factor contributing to the gap of services and affordable housing available for individuals with mental health diagnoses. One interviewee estimated that at its peak, this hospital served 3,700 patients. Multiple key informants spoke about the significant impact of the closure of this hospital in Allegheny County and the western part of the state as it relates to the possible continued proliferation of illegally unlicensed personal care homes.

Multiple key informants also spoke about the lack of affordable housing in Allegheny County. One key informant stated that one in four residents of Allegheny County are over age 60, and that this population presents a growing need for affordable residential care homes. In addition to the aging population, many key informants agreed that the lack of affordable supportive housing options for individuals with a mental health diagnosis is also a concern for Allegheny County and surrounding counties. The aging housing stock in Allegheny County was also a cause of concern for a few key informants, as it relates to the number of pre-existing buildings that cannot meet the state regulatory building code requirements for licensed personal care homes. This, they fear, could lead owners to operate illegal unlicensed personal homes.

Key informants mentioned that state funding and regulatory mechanisms specific to Pennsylvania had a direct influence on the state's capacity to address illegally unlicensed personal care homes. The Pennsylvania State Lottery funds the Pennsylvania Department of Aging. A few key informants noted that this funding arrangement affords state and local agencies the resources and time needed to investigate illegally unlicensed personal care homes. The state's BHSL office also has the legal authority to act as an enforcement agency. This department can request

administrative search warrants to enter suspected illegally unlicensed personal care homes.

### **State and Local Policies Related to the Supply of and Demand for Illegally Unlicensed Care Homes**

All of the key informants shared their perspectives about what is driving the closure of personal care homes. Most interviewees reported that the personal care home regulation change in 2005 caused a loss of small personal care homes due to the increased costs associated with meeting the standards set forth in the regulations. Costs for operating a licensed personal care home can include state fees for licensure, structural renovations or changes to meet required building codes, paying for staff to be on-site 24 hours per day, and paying for and providing adequate staff training.

These increased costs have also impacted the populations that licensed care homes will accept, according to multiple key informants. One interviewee estimated that licensed personal care homes used to reserve 50% of their beds for individuals who only had SSI benefits and now this amount has decreased to fewer than 25%, leaving SSI recipients with fewer licensed options. In more extreme cases, other personal care homes have stopped accepting any persons whose sole source of income is SSI. Multiple key informants suggested that, as a result, these residents are primarily being served by illegally unlicensed personal care homes.

Key informants also cited the process of discharging patients from hospitals in Allegheny County as a potential source for linking individuals with illegally unlicensed personal care homes. These key informants agreed that because discharge planners are under pressure to quickly discharge hospital patients to contain hospital costs, they must have a list of care homes (including licensed and illegally unlicensed personal care homes) that they can reference if the discharge planner has no other option for placement. The Allegheny County PCRR has sent letters to hospitals and their discharge planners informing them about known illegally unlicensed personal care homes to which they should not discharge patients; however, according to two key informants, discharges to these homes have continued. One key informant provided additional information, stating that hospitals in Allegheny County use placement agencies to help find residential settings for discharges, and that illegally unlicensed personal care homes are used as an option. In these cases, the hospital reportedly pays the placement agencies a fee to find a personal care home, and the placement agencies also receive monetary incentives from the personal care homes for referrals. This key informant shared a list of seven placement agencies that work with hospitals in Allegheny County.

Multiple key informants expressed concern about other state policies related to reductions in funding for mental health services and supports as potential contributors to a gap that illegally unlicensed personal care homes can fill. One key informant specifically mentioned a 10% cut to state funding for mental health in 2012 while

another key informant mentioned block grants as a potential contributor to lower funding amounts for mental health services and supports.

Many key informants noted that regulatory loopholes provided potential ways that operators of illegally unlicensed personal care homes can persist and evade licensure. The Pennsylvania BHSL provides specific documentation to potential operators and consumers outlining situations that do not have to be licensed by the state. Multiple key informants said some operators know the regulations better than the state regulatory agency and can therefore find creative ways to evade licensure.

Local key informants gave more specific examples of how operators evade licensure by having a mixed population living in their homes. For example, a care home with three persons with at least one personal care need might also house three people with personal care needs whose community housing arrangement is covered by the U.S. Department of Veterans Affairs. This results in different payment streams and different regulatory agencies that have responsibility for different residents in the same residence. An operator with this population mix can avoid licensure because each agency is only responsible for the residents that are enrolled in their program or waiver. In another example of differing payment sources, a key informant described a housing situation with three Dom Care residents plus three other residents who can live independently; this care home did not require state licensure as a personal care home. However, in Allegheny County, key informants stated that locally the regulation is interpreted and applied differently, and that a Dom Care facility could not have more than three residents total, regardless of the case mix or payment mix.

### **Motivations to Be Unlicensed**

Key informants were divided in their opinions on the motivations for operating illegally unlicensed personal care homes. Many interviewees mentioned monetary motivations of operators as one factor. Interviewees pointed to financial incentives related to managing SSI recipients' checks as one specific motivator. Another motivation to operate an unlicensed care home, equally mentioned by key informants, relates to costs directly associated with meeting building code requirements specified in the regulations. Homeowners, for example, may have property they cannot rent because the building is not up to code, so to generate income from the property, they begin operating an illegally unlicensed personal care home. Other key informants stated that some operators do not want the state regulating or monitoring their business. In contrast, most key informants agreed that some operators start out with a smaller one to three bed legally unlicensed home and gradually end up caring for more residents, not realizing that doing so requires the home to be licensed. A few interviewees agreed that in cases such as this, the operators are motivated by their desire to care for people; they are just not aware of the licensure requirements.

## **Characteristics of Residents and Unlicensed Care Homes**

As described by the majority of interviewees, the primary populations residing in illegally unlicensed personal care homes are vulnerable, with few financial resources. While many key informants stated that illegally unlicensed personal care homes primarily serve adults with a wide spectrum of mental health disorders, they also noted that some of the residents in unlicensed care homes are frail and elderly individuals. Some residents were also described as transitional or homeless, while others were described as persons with substance use disorders.

Multiple key informants provided details of two specific cases of illegally unlicensed care homes. One was a fairly large ranch style house that accommodates 15-23 individuals at any one time. According to one key informant, this illegally unlicensed care home had recently housed a mix of residents and family members, including four related family members (two children and two adults), two persons under the care of a local hospice, and one individual who was receiving methadone treatment. This key informant also noted that the residents frequently transition in and out of the home, as is often the case with illegally unlicensed personal care homes. Multiple key informants also described another illegally unlicensed personal care home with several tenants, including a 91 year old man who had been tied to a chair with a sheet so he would not fall when the owner had to leave the home.

## **Health and Safety Concerns**

With regards to the safety of unlicensed care homes, the majority of key informants agreed that the lack of clean and safe housing was a primary safety concern. Some key informants described illegally unlicensed personal care homes as filthy and potentially filled with rodents and insects; they also noted that these homes are unsafe structures that could be condemned. Some operators use homes that do not meet personal care home building code regulations; for example, the home may lack proper ramps for wheelchair access.

Key informants were also concerned about a lack of specific services inside illegally unlicensed personal care homes. Improper medication assistance and management were most commonly noted by key informants as problematic; informants were concerned that operators or staff of illegally licensed care homes may not be properly trained in medication management and administration. Key informants also mentioned other resident health concerns including neglect, lack of water, malnourishment, and bed sores or pressure ulcers resulting from inadequate care. Two key informants noted that they only see the worst cases of illegally unlicensed personal care homes, so they could not offer examples of adequate or good care that may occur in those they do not investigate. In contrast, one key informant stated that one repeat illegally unlicensed facility had housed residents who had thrived there and had benefited from living in the home.

## **The Scope of Abuse and Exploitation Concerns**

The majority of key informants interviewed cited emotional abuse including intimidation and neglect as the most common forms of abuse observed or reported in unlicensed care homes. Financial abuse was the most commonly cited form of exploitation and the fastest growing form of abuse in illegally unlicensed personal care homes. Examples of financial exploitation described by key informants include the operator becoming a resident's representative payee and then withholding a resident's money, and pocketing profits while providing inadequate care and services or no services at all. Another specific example included a resident moving from a home where the operator was their representative payee and the operator continued to collect their SSI check.

## **Strategies to Identify Unlicensed Care Homes**

The state primarily uses reports to their complaint system to identify illegally unlicensed personal care homes. The state and local agencies mostly rely on complaints from the general public and county agencies. The agencies do not typically get complaints from residents inside the home, although if the home is bringing in services such as home health or hospice nurses, those outside agency staff could file reports that result in the identification of an illegally unlicensed personal care home.

The AAA office, APS, Disability Rights Network, and state or regional licensure offices can receive complaints concerning resident care that may lead to the discovery of illegally unlicensed personal care homes. The PCR team shares the complaints they receive about potential illegally unlicensed personal care homes between the AAA, APS, Disability Rights Network, code enforcement and state licensure office. Lists of both known illegal and potentially (identified but not yet confirmed) illegal operations are maintained by APS and the local ombudsman who lead the team. Once an illegally unlicensed personal care home is identified, it is tracked at the local level to see if it has moved, or, in the case of closure, if it has reopened. The regional and state licensure offices are closely involved in this process.

In the recent past, the state has had public education campaigns to inform the public about illegally unlicensed personal care homes. One key informant shared that, as part of such a campaign in 2012, advertisements were placed in metropolitan areas warning the public against placing people in illegally unlicensed personal care homes. The same message was also sent to hospital discharge planners and to rehabilitation discharge planners. At the local level, APS and the ombudsman have informational brochures on their agency websites for the purpose of educating individuals and families about residents' rights. One key informant stated this posted information, as well as general education sessions out in the community; for example, in senior centers or nursing homes, leads to some complaints that can generate investigations into personal care homes that may be identified as illegal operations.

A few key informants suggested cross-referencing different agency lists as another potential source for identifying unlicensed care homes. One key informant suggested that lists of available housing maintained by a local homeless housing assistance program may include illegally unlicensed personal care homes. Another safety official stated that their department can keep automated notes on potentially dangerous places, like unlicensed personal care homes, so that if they are called out to a repeat offender, the team on call automatically gets the notes. He also noted that they were not currently using the system in this way, and that it is mostly used to note unsafe locations (e.g., places known for drug trafficking and drug use, or for having dangerous dogs).

### **Strategies for Addressing Unlicensed Care Homes**

A few strategies exist in the state for addressing illegally unlicensed personal care homes. Key informants described the regulatory agency's ability to work with an operator of an illegally unlicensed personal care home to help facilitate the home obtaining licensure. However, we did not hear any specific examples of this from the state or local level. The state regulatory agency can send letters to illegally operating facilities and fine them \$500. If an illegally unlicensed personal care home continues to operate, the state regulatory agency has the authority to take out a warrant on the operator ordering her to cease operations. One state key informant told us that the state licensure office is currently working on an amendment to add a graduated fine system which would increase fines overtime for those operators who are repeat offenders which could potentially serve as a deterrent to continuing illegal operations.

Multiple interviewees suggested that it was important to quickly involve code enforcement and local health departments in efforts to close an illegally unlicensed personal care home. If the illegally unlicensed personal care home can be deemed unsafe, code enforcement has the authority to condemn the building and shut the illegal operation down. In this example, the residents would have to be relocated, and the PCRR team would assist in this effort. However, key informants told us that often in these cases, the operator may have another building where the residents could be moved. If residents are able to self-determine and choose where they want to live, they may choose to go with the operator to a new residence. Local health departments can also get involved in trying to shut down illegally unlicensed personal care homes. They can fine the operator directly which may lead to the unlicensed care home being forced to shut down.

### **Areas for Future Research and Potential Data Sources**

Key informants suggested interviewing individuals from other agencies to learn more about illegally unlicensed personal care homes or to obtain potential lists of illegally unlicensed personal care homes. Due to services being brought into these homes, interviewees thought further interviews with home health staff or hospice staff may yield additional information or lists of unlicensed personal care homes that may include illegally unlicensed establishments. As noted above, placement agencies work with Allegheny County hospitals and discharge planners, therefore these agencies may

also have lists that include illegally unlicensed personal care homes. Community safety personnel recommended interviewing local code enforcement divisions for thoughts on illegally operating unlicensed care homes, and consulting EMS personnel because they go out on every 911 call to a house or home and may have more experience with unlicensed care homes compared to firefighters.

Multiple key informants also stated that interviews with small licensed personal care home operators may result in learning more about the motivations for operating an illegally unlicensed personal care home. Multiple key informants also stated that a Dom Care operator with the maximum of three individuals may be considering adding other residents or has possibly tried it before, therefore interviews with some Dom Care Operators may yield a unique perspective on the motivations to operate unlicensed care homes. Owners of current small licensed personal care homes are also potential sources of information; they will be able to fully describe the monetary costs associated with licensure, and these costs appear to be one reason why some people choose to operate illegally.

## APPENDIX B. FINDINGS FROM THE ENVIRONMENTAL SCAN

### B.1. State Regulations Affecting Unlicensed Residential Care Facilities

From our review of states' regulatory information on licensed residential care categories during the development of the sampling frame for the 2014 National Study of Long-Term Care Providers, and our review of ASPE's Compendium of Residential Care and Assisted Living Regulations and Policy (2015), we found the following.

#### No Legally Unlicensed Residential Care Homes Are Allowed in Some States

- Thirty states require residential care homes to be licensed if they have at least one bed.<sup>7</sup> Massachusetts exempts small private-pay homes from licensure.

#### However, Legally Unlicensed Residential Care Homes Are Possible in Several States

- One-bed and two-bed residential care homes are lawfully allowed in several states. Ten states (Delaware, Georgia, Louisiana, New Jersey, New Mexico, North Carolina, Oklahoma, Rhode Island, South Carolina, and Washington) require residential care homes to be licensed if they have at least two beds. Six states (Colorado, Iowa, Illinois, Maine, Missouri, and Vermont) license starting at three beds, noting that Vermont, like Massachusetts, exempts small private-pay homes.
- Three-bed residential care homes are lawfully allowed in at least one state. One state, Pennsylvania, begins licensure with four beds, but the state has locally certified Dom Care homes that serve 1-3 residents.
- Licensure regulations lack clarity regarding requirements for minimum bed size. Three states (District of Columbia, Maryland, and Mississippi) have no minimum bed size for licensure, implying that some residential care homes can be lawfully unlicensed. Two states (New Jersey and Tennessee) have a category that specifies a maximum but not a minimum.

Using the 2012 annual Medicaid LTSS expenditures report produced by Truven, we identified ten states that spent the highest percentage of their LTSS expenditures on

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<sup>7</sup> These are Alaska, Arizona, Arkansas, Connecticut, Florida, Hawaii, Idaho, Indiana, Kansas, Kentucky, Massachusetts, Michigan, Minnesota, Montana, Nebraska, Nevada, New Hampshire, New York, North Dakota, Ohio, Oregon, South Dakota, Texas, Utah, Virginia, West Virginia, Wisconsin, and Wyoming.

HCBS and those that spent the least. We then looked to see if those percentages might be related to the number of number of unlicensed care facilities in those states. Targeted searches of media reports in states with the lowest percentages (New Jersey, Mississippi, Indiana, Florida, and Michigan) did not yield a higher number of reports on unlicensed care facilities than those with the highest spending rates for HCBS (Arizona, Vermont, Alaska, Minnesota, and Oregon). The same held true, with one exception (Georgia), for the top ten states with the greatest increase in HCBS spending since 2010: Virginia, Ohio, Maine, Rhode Island, Alabama, Tennessee, Georgia, New Hampshire, Massachusetts, and Delaware.

## **B.2. Legal versus Illegally Unlicensed Residential Care Facilities**

A few articles described the difficulties in identifying unlicensed residential care, such as distinguishing them from places called boarding homes, shelter care, sober homes, rehabilitation homes and publicly subsidized housing that arranges services for residents. In addition, as one ombudsman report noted, it is often difficult to determine whether a place is an illegally unlicensed residential care home because of the difficulty of obtaining access to the suspected home to make the determination. For example, one ombudsman report from Florida noted the difficulty in identifying an unlicensed care home due to the quantity and quality of evidence needed to obtain a search warrant in order to enter the home and positively identify a place as providing unlicensed care or housing residents who must be cared for in a licensed facility. In addition, many unlicensed care homes operate as family businesses in single family dwellings allowing shifting of residents to avoid detection by regulators (Tobia, 2014). Below we present a sample of the varying state definitions of lawfully unlicensed and illegally unlicensed residential care homes.

### **About Legally Unlicensed Facilities**

- *Some states allow legally unlicensed facilities to assist with ADLs and administer medication, but do not allow them to provide 24-hour supervision.* In California, assisted living services can be provided by a licensed home health agency in unlicensed publicly subsidized housing (low-income housing projects, apartment houses, retirement hotels, village models, and private homes). These legally unlicensed residential care homes are exempt from licensure because they do not provide 24-hour supervision, though residents may be receiving intermittent skilled nursing care, and help with ADLs, medication administration, and social activities.
- *Some states allow them to assist with ADLs, but do not allow them to administer medication.* In Indiana, legally unlicensed residential care homes serving fewer than five residents can provide assistance with at least one ADL, assistance with medications or meal reminders, or two scheduled supportive services, but cannot administer the medications.

- *Some states allow them to assist with medication storage but not with ADLs.* In Maryland, licensure is not required for a provider who serves individuals who are dependent on the provider for room, board, and control and security of their medication but do not need assistance with any ADL. Further, it is the responsibility of the owner to determine whether the home needs a license.
- *In some states, residents can pay for their own personal or medical care in an unlicensed facility.* In Michigan, residential care homes that provide room, board, supervision, and protective oversight, but not personal assistance with ADLs or medication assistance (residents can contract out for personal care), are not required to be licensed. However, residents may pay for such services or receive them through Medicaid waivers. In Iowa, boarding homes serving three or more individuals who require supervision or need assistance with ADLs are registered but not licensed. Residents in need of medical assistance such as nursing care can pay for such care from an outside provider, and the facility does not have to be licensed as “assisted living.” Some larger facilities operate as unlicensed “residences” by requiring residents to contract with a separate corporation for provision of all ADL or nursing services.
- *In some states, facilities that provided room, board, and “control and security of medication” could be legally unlicensed.* The facility operators were authorized to make the decision on their own (Tobia, 2014).

In addition to legally unlicensed residential care homes, there are a variety of places that operate illegally. In some cases they avoid licensure by holding themselves out as not providing services or housing residents that would require a license under state law. In other cases, the unlicensed facility simply ignores the law and operates below official “radar.”

### **About Illegally Unlicensed Facilities**

- *Some illegally unlicensed facilities deny services are being provided.* In Florida, operators of illegal homes use a variety of schemes to hold themselves out as not requiring licensure. They deny services such as assistance with medication are being provided to residents, or assert they are only providing housing for alcoholics, ex-convicts or people with mental health issues to avoid having to become licensed. One Florida media report estimated there were hundreds of congregate living facilities across the state that escaped state oversight because no agency regulates them (Savchuk, 2013). Called shelters, rooming houses, sober homes, they have names like Home Sweet Home, House of Joy and Nurse’s Loving Heart. Some have residents that receive Medicaid funded services.
- *Some continue to operate after their license expired or was revoked.* Media reports described operators that continued to operate after their licenses expired or were revoked.

- *Legal homes serve as conduits to illegally unlicensed homes in some instances.* Media reports described operators with licensed facilities who also operated a series of unlicensed homes in secret. In Georgia, they advertised themselves as licensed and admitted residents to the licensed facility and then shifted residents to their illegally unlicensed homes.
- *Some operators remain undetected by moving residents from one facility in one state to another facility in another state.* In one case well publicized by the media, residents of one unlicensed facility in Pennsylvania were moved between Pennsylvania, Texas, Virginia and Florida to escape law enforcement. According to a six-state study conducted by Hawes & Kimbell for the U.S. Department of Justice (National Institute of Justice) in 2010, when seriously substandard quality, neglect or abuse were discovered in unlicensed facilities, some closed the home in question but shifted residents to other legally or illegally unlicensed care homes to avoid detection or penalties. This shifting of residents from one unlicensed home to another to avoid detection and oversight was also described by the media in Texas and Georgia.

### **Reasons for Not Seeking Licensure**

The study by Hawes & Kimbell also provided reasons operators do not seek licensure, including: inability to meet fire safety codes (e.g., installing sprinklers), lack of state supplemental payment for SSI residents or Medicaid waiver funds (which can be restricted to licensed facilities), and avoidance of inspections and sanctions/fines for not meeting state regulation. An earlier study by Perkins, Ball, Whittington, & Combs (2004) provided these reasons from the perspective of one small unlicensed care home operator:

- Regulatory requirements meant for large assisted living facilities are too stringent and expensive for small residential homes.
- There is a lack of knowledge regarding the licensure requirements or about how to navigate the different government agencies.
- Government staff lack of respect for the care provided in small residential care homes by non-professional licensed staff.
- Public funds, like state supplements, are inadequate.

### **B.3. Concerns about Safety, Abuse, Neglect, and Financial Exploitation**

We found reports of Medicaid fraud in unlicensed care homes in Florida and Nevada between 2009 and 2014 involving charges of false imprisonment, resident

neglect, grand theft, and/or operating an unlicensed assisted living facility (National Association of Medicaid Fraud Control Units, n.d.). Texas and Georgia had numerous cases of unlicensed homes in deplorable conditions: infested with insects, lacking air conditioning or heat, residents sleeping on the floor, faulty wiring, no bathroom access, residents deprived of food or fed scraps, and theft of medications. There were several reports of false imprisonment of residents who were kept locked in residential homes, sometimes deprived of their identification papers in Florida, Georgia, Indiana and Texas. Theft of government benefit checks (e.g., SSI, Social Security, food stamps, Medicaid, veteran's checks) was common, with one case in which operators diverted more than \$790,000 to themselves. Other charges included: murder, sex trafficking, sexual abuse from staff or other residents who were registered sex offenders, racketeering, forced labor, and fire setting by residents with severe and persistent mental illness. Poor quality of care, instances of physical abuse, toxic combinations of medication, and use of stun guns, were also reported (National Association of Medicaid Fraud Control Units, 2015).

- *Georgia*: In one expose, the *Atlanta Journal-Constitution* analyzed thousands of inspection reports and interviewed state and local official, social service providers, and advocates, and then published an article on the status of affairs in unlicensed personal care homes. The reporters described cases of abuse in which residents were being beaten and burned, locked in basements/rooms, given buckets for toilets, and had their benefit checks stolen from them (Schneider & Simmons, 2012a; Schneider & Simmons, 2012b; Schneider & Simmons, 2012c).
- *Illinois*: A story released on the *This American Life* radio podcast described a scam where individuals with substance use disorders were sent from Puerto Rico to supposed rehabilitation centers in Chicago where they were to be provided with housing, food and counseling services, only to find themselves in crowded, unlicensed rehabilitation centers, their passports and other identifying information taken from them. A follow-up story revealed that these unlicensed rehabilitation centers may have been selling the identities of the victims on the black market for as much as \$2,500. Some victims later found that their credit had been ruined by someone who illegally used their identity (Glass, 2015). Fraud reports have been filed with the U.S Department of Housing and Urban Development for the misuse of funds to send users from Puerto Rico to unlicensed rehabilitation centers in the United States.
- *Pennsylvania*: In 2012, the Secretary of the Department of Public Welfare stated that the state continues to struggle with illegal operators and asked all Pennsylvanians to join in the fight and report any unlicensed homes or activities because “unlicensed care is deadly.”

## B.4. What Are States Doing to Address the Problem?

There appears to be a general lack of recognition about the extent of the problems with unlicensed residential care homes in the United States. Licensure agencies in only three (Texas, Alabama, and New Mexico) of the six states studied in the U.S. Department of Justice Report (Hawes & Kimbell, 2010) acknowledged a significant problem with unlicensed facilities. In another state in that study, only consumer advocates and ombudsmen reported the existence of unlicensed facilities. In another report, a representative of the Arizona Department of Health Services stated that unlicensed assisted living facilities were not a problem because licensed operators monitor the industry and report illegal activity (Arizona Department of Health Services, n.d.). This conflicted with other media reports that describe Arizona citizens calling for closing the loopholes in state laws to prevent “imposter” senior living facilities that use false advertising (Azmfairall, 2013).

### Positive Actions by States to Improve Oversight of Unlicensed Facilities

Several states have taken steps to improve oversight of unlicensed facilities, often as a result of newspaper exposés on unlicensed residential care homes.

- *Some legislatures made it a felony to operate an unlicensed care home.* The first conviction in Florida is a felony; in Georgia, first conviction is a misdemeanor, second is a felony.
- *Some assess fines for continuing to operate an unlicensed facility.* Florida can impose fines of up to \$1,000 a day, however it was noted that owners often disappear when discovered to avoid being fined).
- *In some states (Arizona and Vermont), it is illegal to refer an individual to an unlicensed facility.*
- *Some publish notices of how and where to report unlicensed care facilities.*
  - California, Pennsylvania, Maryland, and Mississippi publish notices of how and where to report unlicensed care homes, which implies that these states may be experiencing problems with unlicensed homes.
  - Florida publishes a listing of unlicensed homes but it does not correspond with the media reports of the number of unlicensed care homes identified by state inspectors.
  - The Texas Department of Aging and Disability Services (DADS) website (2015) states that the agency is aware of some unlicensed residential care homes and is either working to get the homes licensed and to comply with health and safety requirements or is in the process of closing them. A phone number is provided if someone has a question about the licensure status of a facility.

- *Cooperative efforts are underway amongst state and local agencies in some states.*
  - In Florida, the Secretary of the Agency for Health Care Administration told a senate committee that the agency wanted to work more with law enforcement.
  - In Georgia, efforts are now under way to provide workshops for law enforcement that clarify the new laws about unlicensed care homes and how law enforcement and agencies, such as aging and licensure can work together to identify and investigate crimes against at-risk adults and prepare the necessary components for successful prosecutions.
  - In the District of Columbia, an ombudsman reported that they were involved in collaborative efforts with University Legal Services, Department of Mental Health, Department of Accountability and other groups, such as APS.
  
- *Funds are being allocated to relocate residents out of unlicensed residential care.*
  - In Georgia, the number of complaints about unlicensed facilities rose from 253 in fiscal year 2013 to 293 in fiscal year 2014, with at least one-third of claims being substantiated. One prominent case required more than 40 people in law enforcement and social service agencies to investigate and close a home, find placements for the residents being displaced, and prosecute the violators. In response, the legislature has appropriated \$260,000 to relocate residents identified as living in unlicensed care homes.
  
- *Enforcement actions are being taken.*
  - A 2010 report from the Pennsylvania BHSL noted that enforcement actions against illegal personal care homes had increased from four homes in 2009 to 27 in 2010 (most were located in the Philadelphia area). However, as recently as 2013, the number had decreased to ten enforcement actions.<sup>8</sup> The Department of Public Welfare can take action against boarding homes and similar facilities that house four or more people if they are providing personal care services because they are considered illegally unlicensed. A judge deemed a “boarding house” as an unlicensed personal care home because four of the six residents *needed* personal care services and not based on the three residents actually receiving the services (under the legal limit required for licensure).
  - In Texas, when the bill that would have authorized DADs to inspect and license unlicensed residential care homes, legislation was enacted that permitted cities to license RCFs not licensed by the state licensure agency. The City of Houston established legislation that requires boarding homes housing three or more individuals to register with the city. Boarding homes are allowed to provide the following services beyond room and board: light housecleaning, transportation, money management, and assistance with self-administration of medication, but no personal care service.

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<sup>8</sup> See [http://www.dhs.state.pa.us/cs/groups/webcontent/documents/report/c\\_102850.pdf](http://www.dhs.state.pa.us/cs/groups/webcontent/documents/report/c_102850.pdf).

## Failed Legislative Efforts to Improve Oversight

- In Arizona, a bill to strengthen the elder abuse and fraud laws failed to pass again after being introduced in three previous sessions.
- In Iowa, legislation to restrict the actions of some operators of large licensed assisted living facilities to recategorize or redefine themselves as a “residence,” (e.g., boarding home) that does not require licensure was proposed but did not pass.

## Ongoing Issues for Licensure Agencies

Frustrations continue among licensure agencies and advocates with unlicensed care homes, and residents are largely unprotected by licensing agencies (Hawes & Kimbell, 2010).

- *Agencies have inadequate resources or authority.*
  - Licensure agencies in many states lack the legal authority to inspect, require plans of correction, or fine these unlicensed facilities. Further, when a licensed facility surrenders its license (or the license is revoked) but it operates as an unlicensed residential care home, regulatory and advocacy agencies no longer have the authority to inspect the facility, unless there is a complaint filed (Tobia, 2014).
  - Licensure staff only learn about the unlicensed residential care homes when someone reports them. State inspection staff, already overwhelmed with large caseloads, are required to obtain warrants to execute searches, a time-consuming process, when trying to follow up on reports of unlicensed homes and determine whether the home is illegal.
  - Concerns remain that agencies do not have the resources needed to monitor and follow through with the appropriate actions to cope with unlicensed care homes (e.g., finding emergency placements for residents, prosecuting violators, ensuring that the illegally unlicensed residential care home remains closed and has not reopened in another location). Licensure and APS have the same difficulties in terms of moving residents out of unlicensed facilities into good supportive housing sites (Hawes & Kimbell, 2010).
- *There exists confusion over the authority of other agencies.*
  - In some states, APS has very limited responsibility and involvement. If a home is illegally unlicensed, they tend to refer the case to the licensure agency for resolution. However, as in some other states, APS in Pennsylvania can act on referrals of abuse for elderly residents (age 60+). And APS often plays a critical role in relocating residents with an illegally unlicensed home is closed. As noted, jurisdictional disagreements exist as to whether licensure agencies or APS agencies are responsible for the illegally unlicensed facilities.

- *There have been limited prosecutions by the legal system.*
  - Some states have too few inspectors to detect and investigate allegations about unlicensed homes and too little time and manpower to bring a prosecutable case to the AG's office. In one state, the AG only received nine cases in the entire year; in another state they handled only 2-3 cases a year. (Hawes & Kimbell, 2010).
  - The 2014 annual report for DADS shows that the number of referrals to the AG increased from two to nine for injunctive/other relief and civil penalties. County and District Attorney referrals declined from 29 in 2010 to six in 2014.
  - Our search of state AG reports of unlicensed RCFs identified only six cases of successful prosecutions in New York, Nevada, Florida, and California for operating a residential care home without a license--and in several cases, gross neglect in these homes.
  
- *Ombudsman programs are not adequately involved.*
  - Nevada stated that no interagency procedures were in place to handle complaints about unlicensed board and care homes in a timely and efficient manner (Ryan, personal communication).
  - A local ombudsman in Maryland stated that they had no authority to inspect an unlicensed home and therefore did not have reliable knowledge about whether unlicensed care homes exist, how many individuals are living in such homes or what level of care or assistance those residents needed (Tobia, 2014).
  - Ombudsmen program does not extend to unlicensed facilities (Hawes & Kimbell, 2010).
  
- *Safety issues affect local fire departments.*
  - Several reports noted that local law enforcement, EMS, and fire departments had frequent interactions with unlicensed residential care homes. One former fire department battalion chief reported that the elderly living in unlicensed residential care homes are hidden from the view of public health agencies, social service agencies, and ombudsman programs --the entities that generally protect and advocate for older people and individuals with disabilities. He noted that residents with disabilities in unlicensed homes were at risk during fires and natural disasters such as tornados, hurricanes, and severe storms. He argued that comprehensive emergency management planning and proactive practices were needed to protect those at risk in unlicensed homes. He recommends additional research, enhanced coordination and cooperation among local agencies, education for first responders about unlicensed group homes and how to identify at-risk individuals, and stronger advocacy for risk reduction strategies to prevent fires that involve large loss of life (Tobia, 2014).

## B.5. Prevalence and Which States Are Having an Increase

Estimates of the prevalence of unlicensed residential care homes are lacking for most states. A six-state study conducted by Hawes & Kimbell in 2010 for the U.S. Department of Justice, National Institute of Justice, found that unlicensed homes remain a serious, largely unaddressed problem in some states, with the magnitude of the problem remaining unknown. Unlicensed homes tended to flourish in larger cities where there were significant numbers of low-income elderly and people with mental illness released from state mental hospitals. Alabama's APS agency estimated that there were more than 200 unlicensed homes in the state, in contrast to their 400 licensed facilities.

Several states (California, Pennsylvania, Maryland, and Mississippi) publish notices on their websites of how and where to report unlicensed care facilities, which implies that these states must be experiencing problems with unlicensed homes. Florida publishes a listing but it does not correspond with the media reports of the number of unlicensed care homes identified by state inspectors. Below are examples from the environmental scan that provide some estimates of the number of unlicensed care homes:

- *Maryland*: A representative of the licensure agency estimated 500 unlicensed illegal assistive living facilities and noted the fine line between a boarding home and assisted living. From a county perspective, one ombudsman and housing officer estimated that perhaps there may be less than 20 lawfully unlicensed facilities and less than five illegally unlicensed, however Tobia's team found that there may be as many as 78 unlicensed care homes serving as many as 400 individuals in that county. An estimate for another locality in Maryland was much higher, with twice as many unlicensed homes as licensed, or about 1,500 facilities, many of which operate out of single family dwellings (Tobia, 2014).
- *Florida*: A media report stated that in 2012 the licensure agency received more than 200 complaints about unlicensed activity and confirmed 62 were unlicensed—a 60% increase since 2010. In the first half of 2013, 37 other unlicensed homes had been identified.
- *Indiana*: An Indianapolis news article stated that the area had far more unlicensed than licensed facilities.
- *Texas*: A 2007 media report, outside the scope of this review but important to mention, notes that city officials in Dallas estimated that there were at least 350 unlicensed, unregulated board and care homes that house 2,500 people across the city, and likely there were more than that (Hancock, 2007).
- *Maryland, Nevada, and Florida*: The National Ombudsman Reporting System noted an increase in unlicensed care homes in these states, but no unlicensed care reports from any state provided evidence on the prevalence of unlicensed care.

## B.6. Types of Residents

Most of the literature or media reports were not specific about the types of residents served in unlicensed residential care. Typically, the reports refer to physically or mentally disabled adults, some with disease specific conditions, or just described as mentally ill or elderly. A California report mentioned that disabled or homeless adults often prefer unlicensed facilities because they have fewer restrictions. Tobia's report (2014) described residents of unlicensed facilities as vulnerable older adults with "hard to place" mental health and paroled individuals who are warehoused. One Maryland media report suggested residents are those released from rehabilitation centers with no families in the area.

## B.7. How People Find Out that a Facility is Unlicensed

There was not much attention paid to the original sources who identified an unlicensed facility, but in some articles or media reports, the case came to light due to a death that occurred in the facility that had to be investigated, neighborhood complaints of numerous vans, ambulances or police cars at the home, or calls from concerned family members about the status of a resident. We did not find any report where a government agency was proactive and discovered the case on its own initiative or because of routine monitoring of unlicensed residential care homes.

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