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Table of Contents

l.	Int	ntroduction and Executive Summary	
II.	Background		6
	a.	Historical Foundations	
	b.	Role of ARFs Today	
	c.	Funding Structures of ARFs	
III.	Critical Emerging Themes		9
	a.	Accountability: An Abandoned Population	
	b.	Market Conditions: An Impending Boiling Point	
	c.	Equity and Quality Care: Beyond Structural Outcomes	
IV.	Discussion		16
	a.	Historic and Continued Systemic Failure	
	b.	From Surviving to Thriving	
	c.	An Imminent Threat	
V.	Moving Forward		18
	a.	Invisible No Longer: The Need for Data	
	b.	Ignored No Longer: The Need for Immediate Relief	
	c.	Neglected No Longer: The Need for Investment and Systemic Change	
VI.	Conclusion		22
VII.	Ref	References 2	

I. Introduction and Executive Summary

Definitions

Adult Residential Facilities (ARFs) are "non–medical facilities that provide room, meals, housekeeping, supervision, storage and distribution of medication, and personal care assistance with basic activities like hygiene, dressing, eating, bathing, and transferring. This level of care and supervision is for people who are unable to live by themselves but who do not need 24-hour nursing care" (California Behavioral Health Planning Council, 2018, p. 3). Historically and colloquially called board and care homes, these facilities are an important form of housing for adults with serious mental illness (SMIs), including seniors.

Purpose

The purpose of this report is to sound the alarm for the immediate action needed to keep this industry alive through an examination of its history, functions, and structure with particular attention to the vast amount of unknown information. The report is guided by historical and recent literature as well as conversations with advocates, practitioners, operators, families, researchers, and residents, supplemented by site visits to Los Angeles ARFs and service providers.

Summary

An exploration of three critical emerging themes guides this report's finding. Through the lens of accountability, it is concluded that a lack of central responsibility alongside extreme data gaps have essentially separated ARFs and their residents from the collective public and institutional support. When examining the market conditions of ARFs, this lack of central accountability has contributed to static funding structures that have made ARFs financially nonviable for decades, disincentivizing quality care and new market entry. This has led to a continued closure of facilities that has only worsened with time. Further, there is a lack of equitable access to quality care due to funding structures and a central lack of care standardization. The current system disadvantages those without personal or familial resources as well as those living in California counties with limited or no care

options. In addition, existing state funding structures of care facilities for other populations, such as those with Intellectual or Developmental Disabilities (IDD), are more financially lucrative and discourage the operation and opening of care facilities for those with SMIs.

Recommendations

The report declares that immediate and urgent action is necessary to avoid the closure of facilities and subsequent negative outcomes for former residents, particularly homelessness. Due to the baffling amount of unknown information surrounding this industry, the primary recommendation is for the funding and execution of research to gain a full picture of the present-day state of this industry and the people involved in it. This will greatly inform solutions for these problems and bring the struggles of residents and operators into greater light. Effects of decades of disinvestment and the COVID-19 pandemic led to the second recommendation of this report, that an immediate state-wide State Supplementary Payment patch of \$65-\$125 per resident per day be initiated to curb facility closures and continue operations until long-term solutions can be researched and enacted. Finally, the recognition that long-term, systemic change is both necessary and long overdue leads to the report's final recommendation, that a state-wide advisory group that oversees the execution and implementation of research in this industry must be created, paying special attention to systemic problems and prioritizing quality care and Housing that Heals.

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II. Background

a. Historical Foundations

Understanding the importance of ARFs that house people with SMIs is best accomplished by first understanding how these facilities came into existence and prominence.

State hospital closures brought thousands of people out of institutional care

In the 1960s, the changing political tide washed over the state mental hospital system in favor of a community-based care approach to mental health. In turn, the decades following saw an extreme liquidation of state mental health hospitals; Blaustein and Viek (1987) report that California's hospital bed capacity plummeted from 37,000 to 5,000 over the period from 1960 to 1985, which, accounting for population growth, **left an estimated 50,000 Californian's** that would have entered the state hospital system **in community care settings**. The state hospital system had been rightfully criticized for inhumane practices and for locking away one of the most vulnerable populations in society. However, their closure created an uncertain future for the thousands of former and would-be patients of the system.

ARFs functionally replaced state hospitals in caring for people with SMIs

For many former patients, serious mental illness impaired their ability to successfully manage their daily lives in an independent setting. Further, there were many former patients who lacked familial or community ties and/or personal resources to tap into, complicating entry into a community system. These realities revealed the need for a level of care that was not as intense as continuous medical care but was more supportive than independent living within an outpatient community care system (Emerson et al., 1981, p. 771). Subsequently, as the state hospital population sharply declined throughout the 1960s, large numbers of former patients shifted from a centralized institutional setting to a range of sheltered care facilities throughout the community driving the proliferation of ARFs. Indeed, by 1973 over 12,000 former patients had transitioned to these facilities, greatly outnumbering the remaining hospital population (Emerson et al., 1981, p. 771).

ARFs developed in widely ranging sizes, fashions, and approaches

As the state shuttered hospitals, it shifted responsibility of care for this population from a public centralized system to a dispersed private, and largely unmonitored or regulated system. This approach

meant that ARFs were "developed in an unplanned and ad hoc fashion," with facilities ranging from single family homes with three or four residents to those with over 50 fifty beds (Segal and Kotler, 1989, p. 2). Motivations for opening an ARF during this period were diverse; many ARFs were opened by former state hospital employees who wished to continue working with this population (Segal and Kotler, 1989). For others, a simple analysis of supply and demand meant that there were opportunities for profit. These varying motivations and a lack of regulatory or centralized authority at the time meant that each facility was unique in its size, level and approach to care, and financial operations.

b. Role of ARFs Today

With these historical foundations the importance of ARFs today can be placed into context.

A need for continued care still exists

While state hospitals may no longer be an appropriate or acceptable form of care, the reality of chronic, severe mental illness is that, for some, **independent living is not an option**. The overrepresentation of people with SMIs within the population of people experiencing homelessness or experiencing incarceration is a manifestation of this reality. While it is estimated that around 5.2% of US adults suffer from a serious mental illness, 26% of the unsheltered population is reported to live with a chronic mental illness (NAMI, 2021; LAHSA, 2020). Working a steady job, performing daily tasks, and managing their mental illness may prove to not be feasible, which, without support, can lead to homelessness. It is important to note that not every person with an SMI ends up experiencing homelessness; some receive care from their families, others may end up in the criminal justice system or in an Institute for Mental Disease (IMD).

ARFs are a uniquely necessary form of housing

Adult Residential Facilities represent a critical yet shrinking form of long-term non-institutional housing that meets the needs of the people experiencing serious and persistent mental illness in the community. The assistance with medication management, meals, and other activities of daily living (ADLs) in ARFs are crucial needs for many with SMIs. In recent years, other housing options such as permanent supportive housing (PSH) have garnered significant attention and funding. While PSH is a life changing and effective strategy for the housing of many people, often permanent supportive housing is not supportive enough for a particularly vulnerable cohort of this population. This understanding is something that advocates of ARFs have been saying for decades; Segal and Kotler (1989) describe it

best, saying "we must move toward [an] understanding that some people with mental illness continue to need the kind of care and supervision that was once available in the state hospital but without the oppression that was a concomitant of that care" (p. 6). Further, if a person experiencing homelessness is institutionalized (hospital, IMD, prison) for more than 90 days, they no longer meet the federal definition of homelessness and ARFs become the only housing option they are eligible for (National Alliance to End Homelessness, 2012).

c. Funding Structures of ARFs

ARF funding structures represent arguably the largest historical and current issue contributing to the imminent crisis of ARFs today.

Three major avenues of funding exist:

1. Private pay

In this model, a resident's 'rent' is paid in full by private dollars from either personal or familial wealth. This cost varies widely by facility and can be significantly burdensome. Due to the high cost and proportion of residents who have no familiar support or connection, private pay historically makes up a small portion of funding (Emerson et al., 1981).

2. SSI/SSP payments

For those who lack familial or other financial support structures, federal Supplemental Security Income (SSI) and State Supplementary Payments (SSP) disability income are the sole source of sustenance for many residents. In 2021, this amounts to a combined \$1,217.37 per month (Social Security Administration, 2021). Residents pay a vast majority of this income to the ARF for 'rent;' government-imposed limits on this rent ensure that the individual has some, albeit miniscule, leftovers for personal expenses. In 2021, this rent limit was \$1079.37 per month, leaving \$138 per month for individual expenses and just about \$36 per day for ARF operators (CANHR, 2021). For simplicity's sake, this report will refer to the combined California SSI/SSP rates as 'SSI".

3. County/agency patches

Counties or government agencies such as the Veterans Administration and the Department of Mental Health may offer additional monthly subsidies for ARFs to provide extra services for a resident or to accept a resident that is difficult to place. Examples of patches include those for

behavioral management assistance, hygiene and grooming assistance, and providing transportation for medical or psychiatric visits. Subsidy patch amounts vary depending on type and location but range from additional \$15 - \$105 per day (California Behavioral Health Planning Council, 2018). These patches are reliant on continued funding and approval from the county/agency and therefore may only exist for periods at a time, **making them an unsustainable long-term and overarching solution.**

Historically and presently, all three of these funding streams can and do exist within the same ARF. A few residents may be private pay, a few may have patch X from DMH, another few patch Y from homeless services, and the remainder may be fully reliant on SSI. This payment structure has existed for decades, and the most recent comprehensive breakdown of this funding comes from the late 1980s. At that time, Segal and Kotler (1989) found that 75% of ARF income came from SSI, 20% from mixed sources, and 6% private pay. As will be discussed later, advocates and operators report that the importance of patches, though inequitably distributed, has greatly increased.

III. Critical Emerging Themes

Three major thematic elements have emerged from the examination of ARFs historically and presently that are key to understanding the issues faced by this industry and how to move the needle forward. This section explores each of these in depth and the evidence base for them.

a. Accountability: An Abandoned Population

The historical proliferation of ARFs in an unintentional and varied manner in the wake of deinstitutionalization set the stage for long-term regulatory and institutional support problems.

Lack of central responsibility

The latter half of the 1970s and early 1980s saw attempts at creating a regulatory infrastructure for the now-booming ARF industry; important in this attempt is the 1976 Keys Amendment to the Social Security Act, requiring states to create and enforce standards for homes with residents receiving Supplemental Security Income (SSI) (Flint and Applebaum, 1993). In California, the California Department of Social Services (CDSS) Community Care Licensing (CCL) Division is the regulatory body for

ARFs, setting and enforcing guidelines. Historically, the primary and almost sole role played by this body has been as a licensing agency; they have not been involved in monitoring or tracking the industry, residents, or non-structural outcomes. Until the 2020 passage of AB-1776, which will require CDSS to begin collecting and reporting on which ARFs and Residential Care Facilities for the Elderly (RCFEs) accept residents with SMIs and to report on facility closure, the data collected by the department did not have enough detail to determine what facilities serve what populations and how the facilities are utilized. In practice, this means that for over 40 years no central agency in California has been tracking or taking responsibility for the outcomes and operations of ARFs serving those with SMIs. The state has largely failed to transfer this onus of responsibility for this population to any systems or organizations post-deinstitutionalization, leaving the industry floundering in open waters.

Lack of scholarly investment

With a lack of centralized data collection by the state and most counties, the onus of knowledge production surrounding ARFs has been left up to academia, nonprofits, and advocates. A review of the literature reveals a small range of information on operations and economics of ARFs as well as resident experience in these facilities, both positive and negative. The most striking insight from the literature however is it's spread over time. A vast majority of the research and writings come from the 1980s and 1990; this literature highlights mostly histories of ARFs and the problems that they were facing at the time. Around the turn of the century, the literature runs silent. It seems very little, if any, scholarly attention was paid to this industry again until the tail end of the 2010s. This has left a 20-year data gap in which essentially no information on the status of the industry, its outcomes, its struggles, its successes, or its residents is available. Commencing with the Stanton Fellowship of Kerry Morrison around 2018, advocates have begun to reopen the conversation on ARFs, highlighting the current dismal status of the industry and calling for additional data (California Behavioral Health Planning Council, 2018; Kelly et al., 2018).

b. Market Conditions: A Funding System that Never Worked

Due to a lack of central data keeping and significant needs for research, a full present-day market analysis of ARFs does not exist. However, anecdotal and limited-scope reports or media attention analyzing funding structures, examining facility closures, and exploring historical market struggles reveals the dire situation of the industry and paints a picture of a market that has been set up to fail.

SSI has not kept up with inflation

Without varied or robust regulatory and funding structures, the base rate SSI has been and is the main institutional support of ARFs. Historical literature is useful in illustrating how support has diminished; Emerson et al. (1981) report that the SSI rent cap for ARFs was \$401 in 1981. According to the US Bureau of Labor Statistics' CPI Inflation Calculator, this amounts to \$1264.35 in 2021 dollars, which is \$184.98 per month higher than the rate currently stands. From this simple evaluation of inflation, it is clear that SSI rent payments to ARFs have proportionately diminished over time. In some counties, patches may help close this gap, but due to extreme variety in patch amounts and availability some facilities may be able to close that gap easier than others.

SSI rent payments have historically been too small

Providing three meals and two snacks a day, medication management, laundry, 24-hour staff, and more while also paying for rent, insurance, payroll, and taxes has been a difficult feat to pull off on fixed SSI income for decades. The literature shows that 40 years ago ARFs were struggling to provide all the pieces of quality care while relying on SSI. Indeed, Flint and Applebaum (1993) report that "One of the most common concerns voiced by adult care operators and long-term care policy analysts involves the financing available for board and care homes" (p. 398) while Blaustein and Viek (1987) declare that "the main pressure in maintaining a board and care home is financial" (p. 752) and Emerson et al. (1981) relay that SSI funding models "generate recurrent pressure to reduce costs, and hence often the quality of care" (p. 778). This shows that regardless of inflation, the SSI rate has been insufficient to cover the costs of care for decades.

Financial viability on SSI alone is no longer possible for many

The California Behavioral Health Planning Council (2018) reports that without substantial subsidies, **ARFs** with 15 beds or less cannot financially survive on SSI. For larger facilities, economies of scale may be useful in lowering individual care costs, still, however, "rarely is the SSI/SSP amount sufficient to cover the costs" (California Behavioral Health Planning Council 2018, p. 6). Some operators report that they are not deciding between whether to create new programs or upgrade facilities with their available funds but rather that the decision lays between whether to pay for food or to pay the electric bill. The set monthly costs of providing structural operations has and does greatly exceed their static monthly income, pushing many into a deficit that either puts them into recurrent debt or forces them to close.

Patches are crucially needed but are not long-term solutions

Years without financial viability on SSI has led to county/agency patches being the only thing keeping the lights on for many. In the words of one Los Angeles ARF operator interviewed for this report, as it pertains to the DMH patch, "If the Enriched Residential Care program ends today [Thursday], we'll be closed by Sunday". While the intention of patches is rooted in providing extra funding for additional service or levels of care, they have instead become the final stopgap in keeping this industry alive. While this lifeline of funds is vital in keeping the doors of ARFs open, its benefits are unevenly spread and quite fragile. Patches are not available in every part of the state or may not be sufficient and not every resident qualifies for a patch. Patches may also end after a period with no guarantee of replacement funds. Due to these qualities, patches cannot be considered a sustainable solution to the funding problems of ARFs.

No incentive to enter the market exists

Due to decades of financial unviability, incentives to enter this market have been largely nonexistent since the original inflow of deinstitutionalized patients. Historical literature shows that in the 1980s, most ARF operators were already unable to *break even*. Therefore, as there has been little change in the funding structures of these facilities, and payments to ARF operators have lagged inflation, economic viability is dismal. Anyone potentially interested in entering this market who has done an analysis of costs for rent, food, utilities, payroll, insurance, and more in comparison to potential income could see that **the potential for return on investment is not just negligible but may be nonexistent**. While official numbers of how many people have entered the market in the past five years do not exist, advocates believe it is negligible, if any, and that the trend continues to suggest a net loss of beds and facilities.

Decades of ignoring this unsustainable economic system have created an aging and dying industry that no one is willing or able to step into.

Continued closures confirm the problem

Without the assurance of a financially viable, sustainable funding mechanism – more stable than the 40+ years of relying upon SSI and the varying levels of assistance provided by patches – **the reality faced by many operators is that closing is the only option.** After the boom of facility creation as state hospitals closed, the industry soon began a steady bust. For example, in San Francisco alone, from 1977 to 1987, the city lost 45% of ARF beds and anticipated to lose another 10% (Blaustein and Viek, 1987). This loss of beds has continued in the decades to follow. On the state level, a 2018 survey showed a loss of 783 beds

In the past ten years amongst just the 22 California counties that responded (California Behavioral Health Planning Council, 2018). It is important to note that these bed losses are not due to a lack of demand; those same 22 counties reported a need for an additional 907 beds, showing that **not only do lost beds need to be replaced but that there is an even greater need for more beds** (California Behavioral Health Planning Council, 2018). Due to the work of advocates, Los Angeles County has recently begun tracking bed loss; in their first report, LADMH disclosed that between January 2016 and December of 2019, Los Angeles County lost 1,226 beds (Sherin, 2019). This trend has continued in the county, with the most recent report announcing the closure of an additional 18 ARFs, representing 111 beds, from January to August 2021 (Sherin, 2021). Historically and presently, **financial challenges are documented as the primary reason for these closures** (Kelly et al., 2018; Blaustein and Viek, 1987). As decades without investment has progressed, advocates feel that ARFs are closing at an alarming and accelerating rate, reaching a critical point today where **most of the industry may be on the verge of collapse.**

c. Equity and Quality Care: Beyond Structural Outcomes

The effects of accountability and market conditions lead this report to highlight equity and quality care as its final theme. Residents and operators of ARFs have been ignored in discussions about supportive housing in the realm of homeless policy, and any policy lens applied to helping this industry stay afloat must also address the quality of life and importance of community in these residential settings. This will be accomplished through an analysis of quality care within ARFs and the range of disparate access and outcomes.

Lack of consensus around quality care creates uneven outcomes

Since its formation, the industry has not had uniform agreement on what constitutes 'quality care.'

Definitions and opinions abound, and the idea of quality care may be different between stakeholders.

Due to this, regulatory processes have historically centered on structural factors over quality and outcomes (Flint and Applebaum, 1993). This is the role that CCL still plays today, ensuring that facilities have working sprinklers, plumbing, heating, safe food preparation and more. These structural factors are crucial for the safety of residents but ignore that the point of ARFs is to provide not only shelter but also care. Without a regulatory framework for monitoring and setting standards for care and resident outcomes, these standards are left up to the individual operator to create and execute within the limits of their minimal resource pool. This lack of uniformity regarding care creates diverse settings

between facilities that may be more beneficial than a uniform approach in addressing unique individual care needs, but it also contributes to uneven and inequitable outcomes. In short, this means that **not all** ARFs are created equal, and some have different or more beneficial conditions and outcomes than others.

Individual resources create uneven care outcomes

Access to quality care in many cases can be linked to personal or familial resources. Since ARFs vary greatly in their approach to care and outcomes, facility choice is a crucial determinant of quality of life. This inherently privileges private pay clients; those with personal or familial resources that can pay more than the SSI rate have access to elite facilities with preferential accommodations and robust treatment options (Emerson et al, 1981). Particularly as facilities become less keen to accept SSI-only clients because they cannot afford to provide care, those without individual resources are left with the fewest and least preferred options. This, combined with the fact that most ARF residents rely on SSI creates a system that disincentivizes quality care and rehabilitation for the poor as facilities prioritize the choice of residents around payment scenarios that promote survival and structural outcomes. In turn, this vulnerable population that is largely unable to work or live independently can be left without access to quality (or any) care.

State financial structures create uneven care outcomes

A comparison of systemic financial structures further reveals how people with SMIs lack equitable access to quality care. Though ARFs serving those with SMIs vary greatly in their level and quality of care, they must all conform to largely the same state financial structure. The SSI reimbursement rate is set, and all facilities must manage their approach to care and operation based on that rate alongside the potential for patches based on the individual resident and county conditions. However, residential facilities serving other populations in California, such as people with intellectual disabilities, utilize a different system. The state has a tiered reimbursement system for these facilities that depend on level of care provided and people served; as of January 2021, these rates ranged from \$1079.39/month to \$9,515/month (CA Department of Developmental Services, 2021). This financially allows for more operators to provide higher levels of care and increases equitable access to quality care regardless of individual financial status. While the needs of the people with intellectual disabilities are inherently unique from those with serious mental illness, levels of care in many cases are similar or could be similar if the resources existed. This comparison is useful in highlighting how California is already utilizing

different approaches to funding residential care facilities as well as how funding for ARFs is a systemic problem. Inequitable access to state resources is something that has been recognized by operators and advocates for decades. One study from 1987 recognized that this disparity has contributed to the lack of market entry, with new operators refusing SMI clients in favor of better funded IDD clients (Blaustein and Viek, 1987). Anecdotal evidence further suggests that even three decades after this study was written, this preference continues to contribute to the loss of SMI beds. Given the financial impossibility of serving SMI clients, some operators are shifting their facilities to serve IDD clients so that they can stay in business. SMI clients are further marginalized in this way, creating an equity gap in available care options that impacts both quality and inventory.

Geography creates uneven care outcomes

Geographical inequities are also central. As this industry has diminished over decades of disinvestment, the availability of beds and quality of those beds is extremely variant depending on geography. In fact, advocates express concern that some counties do not have *any* facilities within their borders. This variation leads to a significant number of residents being placed outside of the county they live in. A 2018 survey in which included responses from one third of California counties showed that almost every responding county had engaged in out-of-county placements, sometimes placing people multiple hours away from their families and communities (California Behavioral Health Planning Council, 2018). This occurs not only due to supply issues within counties but quality of care concerns as well. For some, available facilities in one particular county do not have enough positive outcomes or high enough levels of care, leading people to move far away to receive better services. These geographical limitations of access to care and access to quality care further create inequities for people with SMIs.

IV. Discussion

a. Historic and Continued Systemic Failure

State hospitals were closed in part due to the belief that society can and should do better to care for and protect those with serious mental illness. In practice however, this ideal was never achieved. The closure of one system without the transfer to another significantly dropped the onus of responsibility for this population, allowing it to fall through the cracks and deeply struggle for decades. Fragmented and piecemeal actions by counties and agencies have attempted to slow the bleeding and keep this vital industry alive, but the greater ignorance of its systemic problems have left operators and residents in a state of extreme fragility, threatening long term stability and survival. The simple fact that reviewing literature on problems in ARFs from the 80s and 90s feels like it could have been published in 2021 shows how little attention has been paid to ARFs and the communities of residents and families that depend upon them. This fact also speaks to the resiliency of savvy operators to keep food on the table and water running through decades of systemic failure, even if at great cost to themselves. For example, one Los Angeles operator interviewed for this report disclosed that they have incurred over \$250,000 in debt trying to keep their facility open. As this population and industry has been ignored over the years, these systemic issues have only compounded. Overall, the responsibility of caring for people with SMIs cannot, should not, and must not be relegated to individuals who must make extreme sacrifices to do so. **Effective systems of care are long overdue.**

b. From Surviving to Thriving

In the discussion of ARFs and housing for people with SMIs, the ability for this population to not only survive but also to thrive must be centered; people with serious mental illness deserve to live with dignity, purpose, and in community. For too long, ARFs have been unable to focus on anything beyond survival. Facilities are falling apart due to years of deferred maintenance, staffing is limited, budgets for programs and activities to improve wellbeing are nonexistent, and most are too overwhelmed to deal with anything beyond essential operations. In response, Advocates Teresa Pasquini and Lauren Rettagliata published their 2020 report "Housing that Heals: A Search for a Place Like Home for Families Like Ours", calling for California to reevaluate its models of psychiatric care and prioritize whole person care. It is not enough to make sure that the lights are on and that something edible is on the table. The multifaceted challenges of residents require a multifaceted approach. There is a need for whole person care that goes beyond a person's SMI and addresses co-occurring challenges such as substance abuse, health issues, or other life challenges. Further, conversations with residents of ARFs have shown

a desire for investment in community and purpose building activities such as gardens, support groups for life skills, work, hobbies, and games.

Moving towards a theory of change that prioritizes Housing that Heals is the only ethical and logical way forward. In the 1960s, state hospitals received public backlash as they treated people with SMIs like they were not humans; if the community-based care system is going to be different than the institutions of the past, it must center residents as people deserving of a life with purpose and quality care.

c. An Imminent Threat

This report is not the first to call attention to the histories and current struggles of the ARF system, but by compiling the drivers and roots of the financial, market, equity, quality, and accountability arms of this problem it hopes to showcase that these struggles can be ignored no longer. **More than 40 years of disinvestment have slowly whittled away at the one form of housing that has the potential to assist a vulnerable population in leading a safe, healthy, and purposeful life.** The industry has reached an imminent turning point as operators report that the COVID-19 pandemic has greatly increased costs, and while some pandemic relief has come, the complications and continued expenses of the pandemic may be the final nail in the coffin for many. Without immediate change, this precious housing stock may disappear completely.

The facilities that do remain will likely be inaccessible to many poor and marginalized people as some operators have stopped accepting clients that are on SSI without any additional patches. When asked what this reality means for those clients, one operator said, "They'll end up on the street". With the already extreme homelessness crisis in California, the closures of ARFs and lack of access means a new wave of vulnerable people living on the streets with no sustainable way to house them. Media reports have already shown cases of ARFs that after closing see former residents move across the street onto the sidewalk (Grover and Corral, 2019).

Further, samples of ARFs in Los Angeles County show that in many cases most residents have lived in their ARF for five years or longer. Anecdotal evidence suggests that it is not uncommon for residents to stay in one facility for 10, 15, even 20+ years. The closures of ARFs and the SSI funding model mean the loss of *stable* and healing *long-term* housing for thousands. With that in mind, what does the ignorance of this crisis say for our desire to end homelessness? What will it mean for those who were formerly

homeless and have been stably housed and managing their mental illness for years to be back on the streets? Undoubtedly, some will reenter cycles of substance abuse or rotate through hospitals and the criminal justice system. Tragically, for some this will also mean premature death at the hands of drugs, the elements, inadequate care, or the criminal justice system. **Literally, lives are at stake**. The plea of this report is that the onus of responsibility for effectively caring for this vulnerable but extremely valuable population finally be picked back up.

V. Moving Forward

With urgent action, the grave human injustices that are looming as this industry collapses may be averted. Discussions with operators, residents, families, and advocates inform the three main avenues for moving forward that this report recommends,

a. Invisible No Longer: The Need for Data

The 2020 passage of AB-1776 was a crucial step in addressing the lack of central state tracking and the industry's decades-long data gaps, however, this bill only addresses the most basic of data and leaves large, continued gaps.

Subsequently, to fully understand these problems, their nuances, and effective long-term solutions, comprehensive state-wide research is urgently necessary.

Statewide industry and investment data

While the state will begin tracking the current availability and loss of beds, important questions surrounding the status of the industry and the investment needed to both keep it alive and allow it to thrive still exist.

Areas that deserve research include:

- Number of licensed and unlicensed residential facilities serving those with SMIs and number of beds broken down by county
- Number of additional beds needed
 - By county
- Number of individuals living in an ARF outside of their home county

- Cost of entry into market
 - Land, license, renovation, staffing, training, insurance, ROI
- Estimates of new market entry in the last five years
- Estimated true cost of providing effective care
 - o How does the true cost differ from available funding?

Resident demographic data

Beyond knowing how many ARF beds exist, there is a need to understand who is filling those beds. By examining demographic characteristics of residents, a full understanding of the role ARFs play in stabling housing vulnerable and marginalized populations can be created.

Characteristics of interest include:

- Mental Illness Diagnoses
- Co-occurring Diagnoses
 - o Understanding substance use and other health issues of residents
- Resident tenure in facility
- Age spread of residents
- Gender identity of residents
- Racial and ethnic identities of residents
- Sexual orientation of residents
- Geographic origin
 - o Place of birth as well as location of home community
- Conservatorship status
 - O Who is or has been an LPS conservatee?
- Residential status prior to system entry
 - o How many residents were homeless, living in an institution or incarcerated?

Operations and Operator Data

This set of information is key in documenting the current financial status of ARFs, understanding how funding models need to adjust for financial viability, as well as upcoming trends in the industry.

Areas of interest include:

- Demographic data of operators
 - o Age of operators to understand future trends of retirement
- · Amount of debt held
- Average monthly margins
 - O How many operators are running a consistent deficit?
- · Breakdown of resident funding

- What percentage are private pay? SSI? What patches (if any) are being utilized and how much do they pay?
- Estimates of deferred maintenance
 - Type of maintenance and cost
- Estimates of monthly fixed costs
 - Food, utilities, insurance, payroll, taxes, programs, maintenance
- Staffing estimates
 - Current number and role, estimated need
- Ownership structure
 - Family owned, private companies, nonprofits

b. Ignored No Longer: The Need for Immediate Relief

Decades of institutional neglect have created an extreme and urgent crisis for ARFs that without immediate relief could see this fragile industry collapse. While the comprehensive data highlighted above is extremely necessary to develop an informed long-term strategy, **immediate relief pending the activation of that strategy is needed**.

These considerations lead the second recommendation of this report which is the immediate enaction of a temporary increase in the SSP rate or addition of state-wide patch in the amount of an additional \$64-\$125 per resident per day minimum to keep this industry alive.

Key considerations:

- Providing housing, 24-hour service, three meals a day, two snacks a day, medication
 management, laundry services, and more is simply not possible on \$36 a day. In comparison,
 the average cost of a hotel in California, a room without any of these services, is estimated
 around \$118 per room per night (Champion Traveler, 2020).
- Decades of neglecting the practical needs of this industry has meant that there is no time left
 for incremental or deferred increases in order to avoid closures and industry collapse.
- The diverse and inequitable range and availability of county/agency patches makes providing a state-wide patch/SSP increase the best way to immediately slow operator's financial hemorrhaging and prevent imminent closures.

This report recommends the patch/SSP increase be continued until adequate state-wide research can inform how funding structures need to be permanently changed to not only keep facilities open but to create incentive for entry and providing quality care. While this is a significant investment on the state's

part, advocates believe the cost of providing this immediate relief will be less than the cost to the state and local governments if ARFs shutter and leave thousands on the streets, in hospitals, and in the criminal justice system.

c. Neglected No Longer: The Need for Investment and Systemic Change

Today, around 60 years after the beginning of deinstitutionalization in California, the state must once again reevaluate its system of caring for the seriously mentally ill. This system, or lack thereof, has been documented and recognized as broken for over 40 years. California must finally face this issue for the sake of thousands of lives. Rather than leave the system to create itself once again, intentional planning is necessary to avoid the pitfalls of the past.

This leads this report's final recommendation, which is the creation of a state-appointed advisory group, comprising of advocates, operators, families, counties, government agencies, and legislators.

The purposes and roles of this advisory group are to:

- Oversee the completion of state-wide data-collection and research
- Implement and adopt recommendations from scholarly research
- Create and implement recommendations for addressing the lack of central regulation,
 accountability, and standards of quality care within ARFs serving people with SMIs
- Create and implement recommendations for investing in whole person care models to further the ideals of Housing that Heals

VI. Conclusion

By reviewing the historical roots of ARFs serving those with SMIs, this report has displayed how a broken system has endured decades of neglect, leading to an impending boiling point that threatens the

existence of this precious housing stock. Without key research and data, immediate relief, and systemic change and long-term investment, the ability for thousands of Californians with mental illness to lead purposeful, safe, and healthy lives will be severely jeopardized. This report does not claim to have to all the answers on how to solve this crisis but is confident that the voices of operators, advocates, and residents can be ignored no longer. With resources and structural support, this industry can successfully care for and transform the lives of one of the most vulnerable populations of society. California cannot afford, morally and fiscally, to allow this industry to shutter. The best time to act on this issue was when it surfaced decades ago. The second-best time to act is now.

VIII. References

- Blaustein, M., & Viek, C. (1987). Problems and needs of operators of board-and-care homes: A survey. *Psychiatric Services*, *38*(7), 750–754. https://doi.org/10.1176/ps.38.7.750
- CA Department of Developmental Services. (2021, January 22). *Reimbursement rates*. CA Department of Developmental Services. Retrieved October 18, 2021, from https://www.dds.ca.gov/rc/vendor-provider/vendorization-process/vendor-rates/.
- California Behavioral Health Planning Council . (2018). (issue brief). *Adult Residential Facilities (ARFs):*Highlighting the critical need for adult residential facilities for adults with serious mental illness in California. (pp. 1–26).
- CANHR. (2021, September). *Residential Care/Assisted Living SSI fact sheet*. CANHR. Retrieved October 18, 2021, from http://canhr.org/factsheets/rcfe_fs/html/rcfe_fs.ssi.htm.
- Champion Traveler. (2020). Cost of a trip to California & the cheapest time to visit California. Champion Traveler. Retrieved October 18, 2021, from https://championtraveler.com/price/cost-of-a-trip-to-california-us/.
- Emerson, R. M., Rochford, E. B., & Shaw, L. L. (1981). Economics and enterprise in board and care homes for the mentally ill. *American Behavioral Scientist*, *24*(6), 771–785. https://doi.org/10.1177/000276428102400604
- Flint, W., & Applebaum, R. (1993). The impact of ideology on regulation: The case of Board and Care Homes. *Journal of Aging Studies*, 7(4), 395–408. https://doi.org/10.1016/0890-4065(93)90007-7
- Grover, J., & Corral, A. (2019, November 19). *How the star of a high school musical ended up homeless and overdosing on La Streets*. NBC Los Angeles. Retrieved October 18, 2021, from

- https://www.nbclosangeles.com/news/local/hollywood-homeless-mayor-garcetti-calebohio/2223884/.
- Kelly, C., Wilson, B. B., Morrison, K., & Weissman, B. (2018). (issue brief). A Call to Action: The Precarious State of the Board and Care System Serving Residents Living with Mental Illness in Los Angeles County (pp. 1–16). Los Angeles, CA: Los Angeles County Mental Health Commission Ad-hoc Committee on LA County's Board and Care System.
- LAHSA. (2020, September). 2020 Greater Los Angeles Homeless Count Results. LAHSA. Retrieved October 18, 2021, from https://www.lahsa.org/news?article=726-2020-greater-los-angeles-homeless-count-results.
- NAMI. (2021, March). *Mental health by the numbers*. NAMI. Retrieved October 18, 2021, from https://www.nami.org/mhstats.
- National Alliance to End Homelessness. (2012). *Changes in the HUD definition of "homeless"*. National Alliance to End Homelessness. Retrieved October 18, 2021, from http://endhomelessness.org/wp-content/uploads/2012/01/changes-in-hud-definition-homeless.pdf.
- Pasquini, T., & Rettagliata, L. (2020). (issue brief). *Housing That Heals: A Search for a Place Like Home for Families Like Ours* (pp. 1–62).
- Segal, S., & Kotler, P. (1989). Do We Need Board and Care Homes? ms. Retrieved October 8, 2021.
- Sherin, J. (2019). (rep.). *Addressing the Ongoing Board and Care Crisis*. Los Angeles, CA: Department of Mental Health.
- Sherin, J. (2021). (rep.). *Addressing the Ongoing Board and Care Crisis*. Los Angeles, CA: Department of Mental Health.
- Social Security Administration . (2021). Supplemental security income (SSI) in California 2021. Social Security Administration . Retrieved October 18, 2021, from https://www.ssa.gov/pubs/EN-05-11125.pdf.
- U.S. Bureau of Labor Statistics. (n.d.). *CPI inflation calculator*. U.S. Bureau of Labor Statistics. Retrieved October 18, 2021, from https://www.bls.gov/data/inflation_calculator.htm.