

**Community-Based Residential Care Settings as Rebalancing Vehicles:  
State Strategies to Make Them More like Home than like Institutions**

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## Preface

In 2003, Congress directed the Centers for Medicare & Medicaid Services (CMS) to commission a study in up to 8 states to explore the various management techniques and programmatic features that states have put in place to rebalance their Medicaid long-term care (LTC) systems and their investments in long-term support services towards community care. In October 2004, CMS accordingly commissioned this study to examine that topic. The states of Arkansas, Florida, Minnesota, New Mexico, Pennsylvania, Texas, Vermont, and Washington are participating in this 3-year study of rebalancing. For the study, CMS defined rebalancing as reaching “a more equitable balance between the proportion of total Medicaid long-term support expenditures used for institutional services (i.e., Nursing Facilities [NF] and Intermediate Care Facilities for the Mentally Retarded [ICFs-MR]) and those used for community-based supports under its state plan and waiver options.” CMS further clarified that a balanced LTC system “offers individuals a reasonable array of balanced options, particularly adequate choices of community and institutional options.”

The products for the study include state-specific case studies that look qualitatively and quantitatively at each state’s management approaches to rebalance their long-term care systems; the first set of those reports that review each state’s experiences up to July 2005, and a Highlight Report summarizing all 8 States and an update report on specific changes up to July 2006 have already been released. Final case studies on each of the 8 states for the period to December 2007 as well as a series of 6 Chartbooks with special quantitative analyses more extensive follow-up are scheduled for release in the summer of 2008,. The other products for the study are comprised of a series of 6 papers, called *Topics in Rebalancing*. Each topic paper highlights an issue of importance in state rebalancing efforts, and each draws on experiences in some or all of the 8 States in the rebalancing study to illustrate the issue. A list of all products with web links for completed documents is provided in the Appendix. Various products are posted on the CMS website at [http://www.cms.hhs.gov/NewFreedomInitiative/035\\_Rebalancing.asp#TopOfPage](http://www.cms.hhs.gov/NewFreedomInitiative/035_Rebalancing.asp#TopOfPage), on <http://www.hcbs.org>, and on the study director’s website at University of Minnesota at <http://www.hsr.umn.edu/LTCResourceCenter>.

For this particular Topic Paper, *Community-Based Residential Care Settings as Rebalancing Vehicles: State Strategies to Make Them More like Home than like Institutions*, we drew on our longitudinal state case studies and a wide range of interviews with state officials and representatives of advocacy groups. We also reviewed documents and web materials with a special emphasis on licensure and program rules. We consulted with national experts and telephoned advocates in the participating states, including personnel at state chapters of AARP and the ARC, in order to gather stakeholder perceptions of characteristics that make a group residential setting worthy of the term community care setting. We thank everyone who took the time to share their experiences and impressions. We also thank our CMS project officer, Kathryn King, for her continual assistance. The findings and conclusions in the paper are those of the authors and do not necessarily reflect those of CMS, its staff, or any State officials. We hope that this topic paper will stimulate discussion, and we welcome any comments or reactions.

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## Executive Summary

This topic paper addresses the extent to which group residential settings for participants in long-term support programs have characteristics that enable community living (or conversely, the extent to which they resemble institutions), and what states do or could do to encourage the former. Using policies for community residential settings for adults in the 8 participating States (AR, FL, MN, NM, PA, TX, VT, and WA) and drawing on views of state officials, advocates, and providers, the specific goals were to conceptually identify criteria that make a setting reflect community rather than institutional living; describe models that meet these criteria; discuss state policies and strategies to maintain community living and prevent the slide towards institutionalization of group residential settings; discuss any difference in community residential settings according to age or disability group; and to discuss strategies for States to inform themselves about and alleviate institutional characteristics in their providers of community residential services.

We identified and elaborated on five criteria that can be viewed on a continuum and together make a residential setting less or more institutional in nature, namely: residential scale and characteristics; privacy; autonomy, choice, and control within the residential setting; integration of residents in the setting with the greater community; and resident control over moving to, remaining in, or leaving the setting.

State levers to influence the nature of community residential settings and avoid institutional characteristics include regulatory standards for settings; vendor standards; quality assurance programs; eliciting of self-reported experience of consumers and their agents and developing a data base with this information and other objective measures of community integration; training initiatives on privacy, autonomy, choices, and community integration for state staff, surveyors, ombudspersons, case managers, providers, and others; making information available to help them make comparative selection of residential settings initially and to move to new settings; and attention to fair housing issues.

States varied in the kinds of standards they develop. Standards developed for physical settings, for characteristics of consumers permitted to be served in the setting (sometimes called admission and retention standards), and standards for staffing and programming can each be used to accentuate either community or institutional characteristics of the setting.

In a state-by-state review, we identified that most states had the same building blocks for community residential settings. Sometimes, licensure standards created barriers to the residential features desired. We also used the state-by-state review to identify and highlight innovative practices.

Some conclusions include:

- Residential services to persons with developmental disabilities were more often provided by licensed providers rather than in licensed facilities. This model may offer more flexibility for integration into the community.

- Most States had regulatory barriers that interfered with community living in group residential settings. These were less prominent in Minnesota (where no case-mix limits were established for assisted living) and perhaps least prominent in Vermont.
- Often community residential settings, even small group homes, were licensed, partly because reimbursement was tied to the setting rather than the person. Uncoupling that tie might be helpful.
- Many of the States promulgated information about the quality of the community residential settings, and Texas in particular included information about resident's rights. This would seem a promising avenue to enhance residential features.
- For residential criteria such as those suggested here were to be accepted, widespread education would be needed for service providers, case managers, regulators, and even the general public. States could lead in that effort.
- States tended to lack systematic information about whether their community residential settings were adhering to residential criteria. Some features and policies of the settings could be incorporated into a data base as could data from surveys and complaint investigations, but systematic direct reports from samples of consumers and their agents would be the only source of information on some criteria.
- Most of the States had made efforts to improve the quality of their institutions, increase the residential nature of the settings and the privacy, and individualize care to a greater extent. Nonetheless we did not really identify substantial numbers of nursing homes or ICF-MRs (except perhaps those with 6 or fewer residents) that met residential criteria. It would probably be easier to build up the service capacity in community residential settings while guarding against them becoming institutional than to transform those already licensed and functioning as institutions.

## **Community-Based Residential Care Settings as Rebalancing Vehicles: State Strategies to Make Them More like Home than like Institutions**

### **Introduction**

#### Goals

This topic paper addresses the extent to which group residential settings for participants in long-term support programs have characteristics that enable community living (or conversely, the extent to which they resemble institutions), and what states do or could do to encourage the former. The goals for this topic paper were to:

- Conceptually identify characteristics of settings that make it possible for residents of these settings to exercise maximum autonomy and choice and to experience maximum community integration.
- Describe models that seemed to particularly meet the criteria for community-based rather than institutional services.
- Discuss state strategies to maximize choice and community integration for LTSS participants living in those settings, and to prevent these community-based residential care settings from becoming new institutions.
- Discuss any differences in group residential care settings available to different target populations receiving long-term support services, including older participants, participants with physical disabilities, and participants with developmental disabilities.
- Discuss strategies that may be in place, if any, for States to identify settings that exhibit institutional characteristics and strategies States might employ to effectuate meaningful change towards settings that do merit the designation community-based residential services.

#### Scope

As community-based group residential settings, we include all licensed or registered settings or providers of residential services other than nursing homes and Intermediate Care Facilities for Mental Retardation (ICF-MRs). The Topic Paper also touches on supportive services wrapped around housing, although distinctions are sometimes difficult to make under these circumstances

between supportive housing services, on the one hand, and in-home and attendant services, on the other. At the other end of the spectrum, it is sometimes difficult to distinguish between small ICF-MRs and small nursing homes that have achieved culture change, on the one hand, and community group residential settings, on the other. When residential care facilities or group homes seem to mirror institutions in lack of privacy, fixed routines for all residents, and limits on resident choice, the boundaries between them and institutions become blurred. Using the eight states in the Rebalancing Research as a laboratory, we sought to describe the range of group residential options utilized for participants in HCBS programs and their regulatory underpinnings and to characterize such life in such settings as consistent with community versus institutional living. In this topic paper, we consider community residential settings for adults only.<sup>1</sup>

#### Relevance to Rebalancing

Rebalancing is measured, in part, by comparing institutional utilization and expenditure to community utilization and expenditure. When such calculations are made, group residential settings such as assisted living, adult group homes, adult foster homes, and other residential care settings conventionally are placed on the community side of the ledger; only nursing homes, ICF-MR's, hospitals, and state institutions are placed on the institutional side.<sup>2</sup> Although community-residential settings can offer residents a great deal of flexibility, autonomy, individualization, and potential for community integration, some advocates and policymakers

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<sup>1</sup> Determination of elements of a community setting as opposed to an institutional one for children requires an additional set of considerations related to normative growth and development of minor children, roles of parents, and the functioning of the child welfare systems, and school systems. Consideration of these issues is beyond the scope of this topic paper. We note that the virtual elimination of orphanages in the last few decades and the push towards family reunification and/or prompt clarification of parental rights so that as many children as possible can be reared in permanent homes rather than foster home at as early an age as possible suggests a general repudiation of institutions as residences for children.

<sup>2</sup> In annual tables prepared by Thompson MedStat to describe how all 50 states balance HCBS and institutional services, Medicaid participants in group residential settings are counted under HCBS expenditures. The 2006 Medstat data are on the web, last visited, May 20, 2008 at [http://www.hcbs.org/moreInfo.php/source/150/doc/2027/Medicaid\\_HCBS\\_Waiver\\_Expenditures\\_FY\\_2001\\_through](http://www.hcbs.org/moreInfo.php/source/150/doc/2027/Medicaid_HCBS_Waiver_Expenditures_FY_2001_through)

have concerns that many group residential settings could be considered to be institutions similar to those the Olmstead decision ruled against. State officials and advocates must understand and monitor what goes into the “black box” of community-based residential settings, and how this compares to nursing homes, ICF-MRs, long-stay hospitals, and state institutions. This issue came to the fore when the original legislation for the Money Follows the Person demonstration, incorporated in the Deficit Reduction Act of 2005, defined an eligible community setting for discharge from nursing homes as the person’s own home or the private home of a relative or friend, or a group residential setting housing no more than four people. Advocates for seniors suggested that assisted living apartments were equivalent to private homes regardless of how many apartments were in the complex, and ultimately more explanatory definitions were placed around what would make an assisted living apartment qualify as a discharge destination for the demonstration.

The topic becomes more complicated because institutions themselves are changing in some states. For example, in many states all or most ICF-MRs are small (housing 6 or fewer individuals) and arguably it is difficult to distinguish those ICF-MRs from group homes.<sup>3</sup> Also, culture change efforts, albeit slow, are underway to improve nursing homes. In a few instances, small nursing home settings seem to afford as much or more privacy and individuality than many large residential care facilities or assisted living settings. It is possible, for example, that residents share rooms in assisted living settings, whereas some nursing homes are single-occupancy only unless by choice.

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<sup>3</sup> During our final site visits to New Mexico, key informants told us that most ICF-MRs could not be distinguished from group homes and, in fact, MR/DD providers might operate settings with both licenses within the same residential community.

### Approach to Topic Paper

To prepare this topic paper, we reviewed all materials collected from the eight states in the course of developing longitudinal case studies. We also collected additional information from web sources (buttressed by phone calls) about the regulations or certifications that governed group residential settings; typically, information about residential services for participants in MR/DD programs separated from information about residential services for seniors, with settings predominately serving seniors more likely to be licensed entities. We developed preliminary criteria for community versus institutional services by consulting experts and advocates, as well reviewing relevant literature and research. Considering all eight states, we then reviewed the rules for all licensed or registered settings other than nursing homes and Intermediate Care Facilities for Mental Retardation (ICF-MRs) that are used as settings within HCBS waivers or state-plan LTSS services. We also include some supportive services wrapped around housing, although in these circumstances distinctions are difficult to make between supportive housing services, on the one hand, and in-home and attendant services on the other. Using the eight states in the Rebalancing Research as a laboratory, we sought to describe the range of group residential options, and to characterize them in terms of characteristics that are consistent with home and community-based services and characteristics that are institutional. While developing this paper, we conducted interviews with staff of the Arc (reflecting advocacy for persons with MR/DD and staff of state AARP chapters (reflecting advocacy for seniors) in participating states; some of this feedback was elicited during site visits for state case studies in November and December 2007, some in telephone interviews in the spring of 2008, and some in email correspondence in the Spring of 2008. The point of the inquiries was to explore how advocates

for various constituencies define the characteristics of an institution, as opposed to a community setting, and any concerns that they express over this issue.

### **Criteria for Community versus Institution**

Nursing homes, ICF-MRs, State regional MR/DD facilities (which have different designations in different states), and long-stay hospitals are, by definition, institutions for the purposes of HCBS waivers that provide alternatives to institutions. The term “institution,” however, does not have a precise definition, despite many decades of sociological study of institutions and their effects on their clientele and staff. Goffman referred to “total institutions” as a place of residence where all parts of the lives of the individuals under the institution are subordinated to and controlled by the authorities of the institution. Control is exerted through hierarchy and routine, and depersonalization of the individuals in the institution. The individuals are cut off from larger society for a period of time and lead an “enclosed, formally administered round of life.”<sup>4</sup> Total institutions vary in type and purpose: Goffman identified 5 types: 1) places organized to protect the larger community against a threat (like prisons); 2) places of voluntary retreat (such as monasteries), 3) places organized to accomplish some work task, such as military units, ships, or boarding schools; 4) places established to care for people who are felt unable to care for themselves and, 5) finally, who are also seen as a communal threat (such as mental hospitals, at least as historically perceived), and, finally, places designed to care for people who are thought to be both incapable and harmless. Institutions that have provided LTSS over the last sixty years fall into one of the last two groups. Institutions for those deemed harmless but incapable, such as most long-stay nursing homes and most ICF/MRs are more permeable to

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<sup>4</sup> Erving Goffman’s classical work is typically referenced in discussions of institutions, particularly Goffman, E (1961). Asylums: Essays on the Social Situation of Mental Patients and Other Inmates. Garden City, NY, Anchor Books.

outside influence than most total institutions because family members and other outsiders have some access and influence and residents have some control over needing to stay there.

Commenting on nursing homes as institutions, Steven S. Foldes notes that in modern plural societies, “individuals sleep, play, and work in different settings, with different co-participants, under different authorities, and without a comprehensive, rational plan.”<sup>5</sup> The distinguishing feature of institutions, including nursing homes, is that the barriers separating these three spheres of life (sleep, work, and play) break down and the activities largely occur in the same place and under the same authority:

Each phase of the member’s daily activity is carried on in the immediate company of a large group of others, all of whom are treated similarly and required to do mostly the same things together. All phases of the day’s activities are scheduled . . . And the various enforced activities are brought together into a single rational plan purportedly designed to fill the official aims of the institution (pp. 26-27).

The total institution is “a social hybrid, part residential setting and part formal organization (p.31).” In institutions, the legal authority and the liability rest with the management. To suggest that the residents have voluntarily ceded the authority over their lives to the management (analogous to the notions in participative democracy that citizens cede authority to governments) is an implausible fiction when residents have little real control. Such settings, therefore, cannot be considered communities in the usual sense of the word; anthropological studies back this up by showing that residents in such institutions tend to have few social ties to each other. Even if resources were increased, physical settings improved, and the training and availability of staff were increased, thus easing the tension between efficiency and individualized attention, Foldes suggests the nursing home would still be a total institution rather than a home:

For no resource or ‘fix’ can alter the function of the nursing home as an organization designed, in part, to manage the behavior or the invisible old and sick in American society. . .

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<sup>5</sup> Foldes, S.S. (1990). Life in an institution: A sociological and anthropological view. In Kane, RA & Caplan, AL (eds). *Everyday Ethics: Resolving Dilemmas in Nursing Home Life*. New York, Springer Publishing, 21-36.

And as Goffman helps us understand, the organization of this human warehouse subsumes the good intentions of individual actors within bureaucratic social framework that functions to regiment the resident's daily lives in order to manage their behavior (p. 31).

The various community  
group residential settings  
where LTSS participants

***Five criteria can help array living places on the continuum between a community home and an institution. They are: residential scale and characteristics; privacy; autonomy, choice and control within the residential settings; integration with the greater community; and resident control over moving to, remaining in, or leaving the setting.***

live must not be permitted to develop the characteristics of institutions sketched out above.

Determining whether a group residential setting veers towards a community LTSS setting or an institutional setting involves a combination of factors related to the physical setting (including size), the individualized choices and opportunities for the residents living there, the extent to which the residents lives are bounded by the institution, and the locus of control regarding conduct in the setting and tenure there. After discussion with national and state advocates, we identified five general criteria that reflect community settings, on one end of the continuum, and institutions, on the other. These are: residential scale and characteristics; privacy; autonomy, choice, and control within the residential setting; integration with the greater community; and resident control over moving to, remaining in, or leaving the setting

### Residential Scale and Characteristics

*Definition: A setting is more deserving of community status to the extent that it adheres to residential scale and residential hallmarks in private spaces for residents and in shared spaces. The smaller number of residents in the setting, the more residential it is, but, at some number of residents (be it 5 or 16 or a different number), the setting has crossed a threshold that renders it institutional.*

In defining scale, the complexity is how to count self-contained apartments or suites or rooms in residential hotels: i.e., whether each singly-occupied apartment or hotel room unit is a

residence for 1, or whether the number in the setting is determined by the total number of apartments or hotel rooms. Many urban dwellers live in apartments for their entire lives, and create homes that are residential in nature in large apartment complexes. An apartment-style assisted living setting for seniors with a hundred or more apartments could, therefore, meet the criteria for scale and residential characteristics, assuming that other criteria were met that relate to control over one's life in the setting, which are discussed below. We argue that a self-contained apartment of any size with separate access, a full bathroom, and a kitchen or kitchenette, or a residential hotel room or suite that is self-contained meets the criterion of community as far as scale and residential characteristics. Other criteria, discussed below, may tip that setting towards or away from an institution. Similarly, although living in residential hotels is not the norm in the United States, some people, particularly men, do make their homes in such settings, and they too meet the criterion for a community dwelling in terms of scale and residential nature.

Because the number of people dwelling in a setting influences its scale and residential nature, some disability advocates have suggested that no community group residential setting in the community should house more than 4 people. Leaving aside the issue of apartments and the elements that might need to be present to render apartments residential in nature, the number of residents in other group residential settings has been considered a factor in considering whether a setting has a residential nature. Data displays have long divided group homes and residential care facilities between those with fifteen or fewer residents, and those with 16 or more, and some states (Arkansas, among our group) have developed separate regulations for settings with fewer than 15 residents versus those with 16 or more. Other states have developed a separate class of licensure or certification for very small family settings and specify the maximum number of

residents who may be in the setting (for example 3 residents in domiciliary care homes in Pennsylvania or 6 residents in adult foster homes in Minnesota); regulations may also dictate other requirements such as for live-in staff, service levels, and environmental features to enhance mobility or safety. Longitudinal data developed by researchers at the University of Minnesota Center for Community Integration uses fine gradations of numbers of people served in residential settings with categories of 1-3 residents, 4-6, 7-15, and 16+. <sup>6</sup> These analyses are predicated on a view that the fewer residents in a group setting the more normalized and residential the environment is likely to be.

An institution has recognizable physical hallmarks: long corridors, large common living spaces visible from the entrance, functional “standard issue” furnishings, drab or neutral décor, large-scale sitting rooms and dining rooms, and commercial kitchens and laundries that are frequently off limits to residents. Signs and instructions may be posted on walls and doors. A private home also has hallmarks—usually a kitchen, a living-room, a bedroom, and a bathroom with furnishings and décor that is an expression of the tastes and interests of those dwelling there. Individual taste and preference, of course, dictates an individual’s vision of home; the ability to paint, decorate, and furnish the premises as one pleases helps define community living.

In multifamily dwellings, such as residential apartment buildings and condominiums, the individual apartment unit is the home, and the various shared spaces in the building and grounds are placed and decorated in a way that a visitor would not consider that he or she was entering an institution. When unrelated individuals share a house in a residential area, each person’s private space may be limited to a bedroom (with or without its own bathroom). The degree of access

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<sup>6</sup> See Prouty, RW, Smith, G, & Lakin, KC (Eds.) (2007). Residential services for persons with developmental disabilities: Status and trends through 2006. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

each resident has to the kitchen, living areas, porches, yards, and other shared spaces, the kinds of materials used for furnishings and fixtures, and the size of the spaces renders a setting more or less residential in nature.

### Privacy

*Definition. A setting is more deserving of community status to the extent that no adults share sleeping quarters unless by choice and that the residents can lock their living space and control access to their sleeping quarters. Thus, to meet the criterion of privacy, the bedroom quarters must be single- occupancy unless by choice. The closer the living quarters are to being served by its own full and unshared bathroom adjoining the sleeping quarters, the further the setting is on the continuum towards meeting the privacy criterion of a community setting.*

When unrelated individuals live in a group home or residential care facility, many of which are licensed entities, whether individual residents have a private room for their living space and their access to other kinds of shared spaces will be bounded by state regulations (some of which are meant to protect residents), payment rates for publicly subsidized consumers, and market expectations. If the economics of rental prices or reimbursement rates for publicly subsidized residents requires unrelated adults to share their quarters, the resident cannot be said to have chosen to share, any more than it is logical to say that nursing home residents in shared rooms because of Medicaid reimbursement rules or the limits of their own financial resources can be said to have chosen to share their living quarters).

The definition of privacy is best met if the resident may lock his or her door from the outside when out of the living quarters, and from the inside while inside the living quarters, and that staff or landlords can enter the living quarters only with permission or under special circumstances. (In apartment complexes and hotels, staff must abide by strict rules for using a

pass key to enter the rented premises.) The ability to lock the space and clear expectations for access of others to the space offers residents security for their personal possessions and some assurance about the extent to which their private activities or conversations are monitored. Clearly, residents or their agents have the right to permit care or cleaning personnel to enter the quarters, though the timing of such entry should be controlled by the resident or his/her agent. (Consider the analogy of hotels with their “privacy” notices to restrict entry of housekeepers.) Some residents may be unable to physically manipulate locks or their cognitive status may raise questions about their ability to exit safely if they lock their living quarters. Under such circumstances, some residents or their agents may opt that the door not be locked (unless perhaps they are away from the premises for an extended time), but the privacy criterion would be met if the general understanding is that the resident’s living space is private and that entry by staff and visitors occurs under circumstances agreed to by the resident or the resident’s agent.

Relatively new technologies, such as “Granny cams” that permit observation of a resident’s room from outside that room, including observation by staff and remote observation by family members, raise challenges for privacy and a debate between privacy and supposed safety and protection. To the extent that a setting allows residents to be subject to such observation and monitoring without their permission, it is moving away from the definition of community and towards that of institution on the privacy criterion.

On the privacy criterion, the bathrooms and bathing areas fall into a grey area. The strictest criterion would require that each resident’s living quarters be served by a bathroom for its exclusive use (preferably “en suite” but possibly on a shared corridor) and that the bathroom contain a shower or tub. A more moderate criterion would allow sharing of lavatories and bathing rooms, but establish a minimum number of people per bathroom and bathing room and a

minimum distance between these rooms and the sleeping area. An even less stringent criterion would develop expectations for minimal sharing and high proximity to sleeping quarters for lavatories, but permit communal showers or common-use shower and bathing areas at some distance from the sleeping quarters (such rules characterize many institutions, including most nursing homes).

Easy and exclusive access to a bathroom takes on particular importance for many people with physical disabilities, many of whom are elderly, because the combination of urinary urgency and limited mobility means that some residents are at risk of becoming incontinent if their access to a lavatory is limited by the need to traverse a distance or by someone else using the lavatory at the time they need it. Dignity and bodily privacy are also at stake if bathrooms and/or shower and bathing rooms that are distant from sleeping quarters or if residents must be dressed to enter common space to reach the bathroom.

Some elements of privacy go beyond the attributes of the physical setting and concern the way staff behave to respect personal and information privacy. If personal and health information is shared with staff members or personal assistants that have no need or permission to know, and if such information is discussed with residents in the presence or hearing of other residents, the setting is veering towards institutional rather than community standards. In the community, individuals are largely in control of when and to whom their personal information is disclosed. Also the conventions about forbidding entry into a resident's private space, looking into drawers and cupboards and private papers, and interrupting private conversations between residents or between residents and guests render a setting closer to community and further from an institution. In an institution, the needs of the organization to deliver care and adhere to routines

trump the personal preferences of the clientele for how they spend their time, and certainly trump any privacy concerns.

One of the most sensitive and least discussed aspects of privacy concern the ability of residents to pursue their romantic and sexual lives and to engage in consensual sexual relationships without interference. Obviously, having single-occupancy living quarters facilitates such relationships, but so too do the attitudes and behavior of staff and the norms governing personal care workers and staff in the setting.

The discussion of privacy is made more complex by the varying needs of participants for help to compensate for physical or intellectual impairment or both. Personal care workers and attendants who help individuals with intimate services (dressing, bathing, and toileting) or who help them with communication, including reading, will have access to the participants' personal space, possessions, and documents, and will obviously be in a position of trust with regard to personal and health information. In consumer-directed models of service, the participants or his/her agent establishes the conditions and expectations for the personal care workers and the latter is accountable to the consumer rather than to facility staff or a case manager.

#### Autonomy, Choice, and Control Within the Residential Setting

*Definition. A setting is more deserving of community status to the extent that residents have control over how they spend their time in that setting, including how they arrange their private quarters, how they spend their time in their private quarters, and who they see in their private quarters; and how free they are to use shared spaces according to their own timetable (always with deference to others living in the group setting) and in association with others from inside and outside the residence). The more control the residents have over the timing of going*

*to bed, the timing of getting up in the morning, the timing and nature of meals and snacks, and the way they spend their time and lead their lives, the more the setting meets community criteria.*

This criterion of choice and control for the individual living in the setting seems straightforward. Because a group residential setting is a social setting (as is a family or an apartment complex or a neighborhood) freedom of behavior is limited by rules of conduct to avoid disruption or disturbance of others in the setting. (for example, late-night noise or loud music that could disturb others is typically not permitted in many social settings, and people are not free to expose others to dangers by failure to protect the premises or allowing entrance of people who would do harm). The hope would be that in community settings the rules governing resident behavior are relatively few, logical, and developed and agreed to by the individuals in the settings themselves.

One element of control and choice includes the choice of intimate associates. Key informants have suggested that lack of choice about roommates or people with whom living space is shared is perceived as a problem for participants who are moving to community residential settings. To the extent that such participants have private living space, the issues are somewhat mitigated.<sup>7</sup>

### Integration in the Greater Community

*Definition. A setting is more deserving of community status to the extent that the persons living there have ready access to the greater community for activities of interest to them and appropriate for their age, including education, employment, recreation, and commerce.*

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<sup>7</sup> In researching this topic paper, we noticed that some providers of residential services post advertisements that offer some information about who is already living in settings where there are vacancies. Persons seeking residential accommodations can take into account the age and gender mix and other characteristics of those already in the settings. It is unclear whether persons already in the setting have similar voice in selecting a new resident who is joining them. Although such selection by current residents is common and often arbitrary with regard to condominium membership, it is unclear whether exclusion of a new resident by existing residents in a small family home would constitute discrimination that is unallowable under Medicaid.

Many elements will be involved in a resident's ability to interact with the larger community. First, the policies and practices of the setting must permit residents to leave the setting for individualized pursuits. Second, access to transportation and, if needed, assistance outside the living setting will also be important. Third, the proximity and accessibility of restaurants, theaters, shops, parks, banks, libraries, churches, and a range of resources will also be resources will also affect the possibilities for integration into the community as opposed to isolation in the living setting. The attitudes of people and establishments in the surrounding community will also affect the degree of community integration feasible, as will basic disability friendly provisions such as curb cutouts, talking elevators, and other specific accommodations for people with mobility or visual impairments.

#### Resident Control over Moving to, Remaining in, or Leaving the Setting

*Definition. A setting is more deserving of community status to the extent that the persons living there have exercised a choice to move in, have housing rights that allow them to remain in the setting regardless of temporary or permanent changes in their health status, and have the right to seek different housing.*

If the individual or his/her agent has a direct relationship to the landlord in terms of paying the rent and holding a lease or rental agreement that governs the conditions of residency, he or she is more likely to experience the role of tenant in housing rather than recipient of a assistance to meet health care needs. If personal services are part of the rental agreement, the more the resident can negotiate the specific services he or she wishes to receive, the more the setting comports with community care.

In some instances the payment for room and board and any associated services is reimbursed directly to the provider by a third party such as Medicaid or an insurer, which introduces a sense

that the person living there is not really the customer. Even in instances when the person with a disability or his or her agent is billed directly for rent and any associated services, that resident may have a greater or lesser ability to tailor services in the setting due to the policies that prevail. Much purpose-built licensed assisted living, for example, is predicated on an economic model that expects the resident to utilize a specific set of services from the licensed setting itself or an affiliated provider. Arguably, this reduction of choice permits economies of scale that allow the program to offer cost effective services. The more the services available are bundled into fixed packages or levels, the less the resident is able to tailor those services to meet his or her own needs and preferences.

Most states have developed licensure or other regulations (e.g. certification) for residential care and assisted living settings. To the extent that the regulations include “admission criteria” and “discharge criteria” that dictate the types and levels of disability allowed in the setting, the resident will have less flexibility in whether he or she can remain there. Services to residents in assisted living settings are often included in Medicaid waivers (either as part of a general aging or disability or combined waiver or as a specialized waiver for residential settings) and, in those cases, the person must qualify for the institutional level, typically the nursing home to use the waiver services. However, the regulatory language often contains provisos that prohibit service to some subset of those who could be served in a nursing home. For example, the rules may require discharge (or eviction) of people who need help in transferring, or who cannot protect themselves in an emergency, or who need regular nursing care, or who need certain specific procedures. Even if it is possible for settings to receive a waiver of those rules on an individual basis, the existence of such limitations introduces uncertainty for the resident and diminished his or her control over remaining in the living situation.

The extent to which fair housing rules pertain to community living situations is particularly unsettled. Some states, and some programs within states, separate the pricing and billing for housing from that for services, making it theoretically possible for an individual to remain in the housing even if services have been discontinued for a variety of reasons (including noncompliance by the participant). But to the extent that the setting can “discharge” or, using housing terminology, “evict” a resident because of his or her care needs, that setting is veering away from the criteria of home and community. Adults with disabilities are not evicted from their rental units in the community based on the extent of their disabilities or the amount of help they need. Typically, failure to pay the rent or irresponsible treatment of the premises is the only grounds for eviction. Anyone attempting to remove an adult from his or her home as a matter of adult protective service (e.g. to protect the safety of the person being moved or of others) must meet a stringent legal test. The burden of proof is on the agency that would take action to show that the resident cannot live safely in the setting. In group community residential settings where participants receive LTSS, the burden of proof may be reversed—i.e. the resident may need to prove that he or she can safely live in the setting with care needs met.

### **State Levers to Influence the Nature of Group Residential Settings**

For the most part the 8 states participating in the Rebalancing Research have similar building blocks for community based residential settings. Their licensure, certification, and/or vendor payment rules establish a variety of entities including settings in private homes that are permitted to serve very few participants to a variety of other group home and residential care settings, some mandating substantial privacy and independence-enhancing features, and some prohibiting models based on mandatory shared occupancy. Very typically, community residential settings

to serve persons with ID/DD are regulated differently and by a different authority than are those setting serving elderly persons and other adults with physical disabilities.

States have a variety of levers that they may use to influence the nature of community residential settings with the intent of ensuring that they are not and do not become institutional in nature. To that end, States may combine any of the following strategies:

- use their licensing or certification authority to establish minimum expectations;
- establish conditions for vendors receiving state funds;
- develop and sustain the community criteria through multifaceted quality control and quality improvement programs, including use inspection and enforcement capabilities, complaint resolution mechanisms, and ombudsman programs;
- build data about consumer's experience through direct surveys of consumers or their agents; this is particularly important for those aspects of consumer control, choice, and community integration that cannot be elicited in any other way except asking the consumer;
- make information available to consumers about the nature and policies of the available residential programs, their price, their quality record, and the feedback received by their residents;
- develop training on these issues—privacy, autonomy, choice, and community integration—as they apply in residential settings for surveyors, ombudspersons, care providers, and others;
- recognize that fair housing is relevant to these living settings and develop a unified set of policies across state agencies about the circumstances under which participants can be asked to leave the housing.

Licensing rules can be organized in a variety of ways. For example:

- States may establish expectations for the physical setting, including size, privacy, and independence-enhancing features. The latter are sometimes called “amenities” and seen as luxuries for low-income participants although they may be necessary to permit independent functioning. Such regulations set boundaries on residential quality, privacy, and choice and control in the setting.
- States may establish criteria for resident characteristics allowable in various settings; such admission and retention criteria tend to limit individual participant's control over where they may live or whether they may remain in a setting where they already live.

- States may establish standards on the qualifications and numbers of staff required in certain settings and the programs and protections that must be present. Such standards may also limit choices of residents as to how they live.

## **State by State Overview**

### Arkansas

Residential settings for seniors and persons with physical disabilities. The Office of Long-term Care in the Arkansas Department of Health licenses nursing homes, ICF-MRs, residential care facilities, and assisted living. In 2001, Arkansas promulgated licensure standards for 2 levels of Assisted Living before any units were operating. Level 2 assisted living may serve persons who could be in nursing homes and nursing home certifiability is, of course a criterion for waiver coverage. The availability of assisted living settings has grown rapidly, though they are not found in all counties. Arkansas has worked to facilitate construction of affordable assisted living with monthly rents in the \$350 to \$400 range (in 2006 prices.) By 2007, Arkansas had 14 Level 1 Assisted Living settings located in 10 counties with a capacity for 721 people, and 27 Level 2 settings located in 19 counties with a capacity for 1353 people. Five (5) settings with capacity for 360 people did not have a Medicaid contract; all were in Pulaski County where Little Rock is located and where no Assisted Living settings accept Medicaid. Table 1 describes standards for various licensed community residential settings in Arkansas.

As the table shows, Arkansas rules for Assisted Living are positive in establishing an expectation of private living quarters with normal independence enhancing amenities for residents, and it is also positive that non-medical transportation is envisaged as a waiver service. On the negative side, residents are required to move out if they come to resemble those in nursing homes with higher levels of need. Arkansas established rules for post-acute head injury

residential treatment settings that are permit extensive sharing of bedrooms and bathrooms and expect considerable capacity for the participants in the setting. At present only one such facility operates in the state. Arkansas has not yet developed rules for an Adult Foster Home or Family Home program, but is eager to develop that capacity.

Table 1. Community Residential Settings in Arkansas

<b>Assisted living</b>	<b>Level 1</b>	<b>Level 2</b>
Persons served	Housing or delivery of services to persons not medically eligible for NH level of care or do not receive services through Medicaid 1915 HCBS Waiver.	Housing or delivery of services to persons who are medically eligible for NH level of care or who receive services through Medicaid 1915 HCBS waiver. If facilities have both Level 1 and Level 2, they must use separate wing or section for Level 2.
Services		Attendant care for ADL assistance, therapeutic recreation, medication assistance or administration, periodic nursing evaluations, limited nursing services, non-medical transportation; pharmacist consulting services.
Physical setting	All units must be independent apartments including a kitchen that is a visually & functionally distinct area within the apartment or unit. Each unit of new construction shall have a minimum of 150 sq. ft per person or 230 for two persons	
Room sharing	A unit must be single occupancy except where residents are husband and wife or are two consenting adults who have requested and agreed in writing to share a unit. No more than two persons may occupy a unit. Each unit must have a separate and complete bathroom with a toilet, bathtub or shower, and sink.	
Move-out criteria	Level I facilities may not provide services to residents who: 1) Need 24-hour nursing services except as certified by a licensed home health agency for a period of 60 days with one 30 day extension; 2) are bedridden; 3) Have transfer assistance needs that the facility cannot meet with current staffing; or 4) present a danger to self or other or engage in criminal activities.	Level II facilities may not provide services to residents who: 1) need 24-hour nursing services; 2) are bedridden; 3) have a temporary (no more than 14 consecutive days) or terminal condition unless a physician or APN certifies the resident's needs may be safely met by a service agreement developed by the doctor; 4) have transfer assistance needs that the facility cannot meet with current staffing; or 5) presents a danger to self or others or engages in criminal activities.
<b>Post-Acute Head Injury Facility</b>	Detailed regulations for settings serving people age 18+ with head or neurological injuries. Lay out expectations for services and resident protections. Residents must be able to self-medicate or have medication needs met by home health agency. Long list of when they must be discharged. No more than 3 residents are allowed per room, & no more than 6 sharing lavatory, and bath & shower needed for every 10 people.	
<b>Residential care facility</b>	Provide services 24 hours a day to individuals older than 17 who are not capable of independent living and who require assistance and supervision. Residents must be independently mobile, capable of responding to reminders and guidance from staff, and capable of self-administering medication. Staffing standards provided based on size.	

Residential settings for persons with ID/DD. Supportive housing programs for people with developmental disability in Arkansas are provided as part of the repertoire of services

potential offered by licensed Community Development Disability Providers. As of January 2008, the Division of Developmental Disabilities, which licenses and conducts quality assurance activities for such settings, listed 89 licensed providers under Medicaid waivers. More than half of these offered supportive living services, many of them in multiple counties. Some large

**Figure 1. Example: the Arc of Arkansas**  
The Arc of Arkansas has developed a track record of acquiring historic properties free or at low price and using preservation tax credits to renovate them into accessible apartments, many of which are low rent. For example, the East Side Lofts project renovated a vacant auditorium of Central High School in Little Rock into a new 1- and 2-bedroom apartment complex with universal design. Similarly the Hot Springs High School Lofts is the historic restoration of the high school of former President Bill Clinton, into thirty-two (32) loft-style apartments. The Arc is also restoring the Majestic Hotel in Hot Springs, and has restored several railway stations into obstacle-free housing. At the website <http://www.arcarts.org/> viewers can see before and after photos of the sites and note how the historic features were preserved at the same time as the sites were rendered accessible. Some of the photos show participants in Arc programs now living in those locations.

providers offer a wide range of programs including ICF-MRs, residential care settings (called group homes sometimes), and rental units where they provide supportive living. The Division of Developmental Disabilities is in the process of establishing new rules for “center-based programs.” Still in the comment period, the draft includes mandatory training for board members, expectations for individualized service plans and participation in consumer satisfaction surveys. The Arc of Arkansas has been a leader in developing low-income accessible housing in historic buildings in Little Rock and elsewhere in the State (see Figure 1).

Institutional sector. The Arkansas Office of Long-Term Care (OLTC) is offering incentives for nursing homes to change their culture towards individualized care, and modifying nursing home regulations to encourage such developments. The Office also is offering incentives for the construction of Green House ® nursing homes and developing a special section of nursing home

regulations to permit the universal worker concept inherent in small-house nursing home for facilities approved by OLTC.

Arkansas distinguishes between ICF-MRs with fewer and more than 16 residents; the larger ICF-MRs have higher staffing expectations and more rules. Arkansas has the highest population of people per capita living in six (6) state-operated Human Development Centers, which now are licensed as large ICF/MRs and divided into smaller living units. Efforts have been ongoing to encourage community integration and local employment for residents of these Centers though they seem to remain institutional in nature and, according to website descriptions they are said to house many participants with severe disabilities.

#### Florida

Residential settings for seniors and persons with physical disabilities. The Division of Health Quality Assurance in the Florida Agency for Health Care Administration (AHCA) licenses and regulates nursing homes, ICF-MRs, homes for special services, and transitional living facilities under its Long-Term Care Unit. A separate Assisted Living Unit licenses and regulates Assisted Living settings in Florida. As Table 1 shows, Florida licenses a basic assisted living program and also offers three add-on licenses to facilities to operate Extended Congregate Care, Limited Nursing Services, or Limited Mental Health Services. The regulatory requirements for privacy and independency-enhancing features are minimal; assisted living apartments are possible under the same license in the private market. The rules require that residents be discharged if they need extensive nursing services.

Residential settings for persons with ID/DD. The Florida Agency for Persons with Disabilities (APD) is responsible for the Medicaid waiver programs for participants with ID/DD and for quality assurance in those programs. APD emphasizes supportive living services and

residential habilitation services, which may be received in participants own homes (parental homes or independent living settings established by the participant) or in licensed settings. Florida licenses over 1500 residential settings (or group homes). APD and AHCA have entered into a partnership with the Delmarva Foundation (Florida’s Quality Improvement Organization) to monitor and improve the quality of waiver services. Recent materials for consumers emphasize the expectations they should have for an individualized and respectful treatment, and encourage consumers to seek a different group home if they are dissatisfied with where they are living.

Table 2. Community Residential Settings in Florida

<b>Assisted Living (AL)</b>	
Types	AL setting must have a general ALF license. They may also hold specialized licenses: 1. An extended congregate care (ECC) license allows facilities to provide more extensive ADL assistance and nursing services. 2. A limited nursing services (LNS) license allows certain defined nursing services 3. A limited mental health (LMH) license allows facilities to serve low-income, chronically mentally ill residents and is required if ALF serves 3 or more people with mental illnesses.
Physical Plant Requirements	Private resident units must provide a minimum of 80 sq ft of usable floor space and multiple-occupancy resident rooms must provide a minimum of 60 sq ft per resident. An additional minimum of 35 sq ft of living and dining space per resident is required.
Residents per Room & Bathroom	Prior to October 17, 1999, a maximum of four persons were permitted for multiple occupancy however facilities licensed or renovated six months after October 17, 1999 must have a maximum occupancy of two persons. One toilet and sink per six residents and one bathing facility per eight residents is required. Shared bathrooms are permitted and a facility must provide one toilet and sink per six residents and one bathing facility per eight residents.
Move-In/Move-Out Requirements	To be admitted, a resident must be capable of performing ADLs with supervision or assistance; not require 24 hour nursing supervision; be free of state II, III, or IV pressure sores; be able to participate in social and leisure activities; be ambulatory; and not display violent behavior. A resident must be discharged if he or she is not longer able to meet the admission criteria or is bedridden for more than seven days. Residents must not require 24-hour nursing care unless they are receiving service from a licensed hospice coming into the setting.
<b>Adult Family Homes</b>	These residential-style homes may be licensed to serve up to 5 people with needs for care. The providers must live in the setting. They may not serve participants with 24-hour nursing needs.

Institutional sector. Florida has a strong movement for culture change in nursing homes, the Florida Pioneer Network, which has been supported enthusiastically (including financially) by the nursing home trade associations. The AHCA use the Civil Monetary Trust fund is being used to fund innovative practices in Florida nursing homes.

Minnesota

Residential settings for seniors and persons with physical disabilities. The Compliance Monitoring Division of the Minnesota Department of Health licenses and inspects nursing homes, boarding homes, and home care agencies (see Table 3).

Table 3. Community Residential Settings in Minnesota

<b>Housing with Services</b>	Assisted Living is registered as a Housing with Services Establishment. If they claim to offer Assisted Living, they meet additional requirements required by a 2006 statute.
Description	A Housing with Services establishment provides sleeping accommodations to one or more adult residents and offering or providing for a fee, one or more regularly scheduled health related services or two or more regularly scheduled supportive services.
Physical Plant Requirements	Establishment must comply with state and local building codes.
Services	Home care services must be provided or arranged from a home health agency (Class A) or a Class F agency licensed only to provide services in Assisted Living Establishments. Residents have separate rental agreements for housing and purchase agreements for services; they have a right to purchase services from different home care providers of their own choice.
Move-In/Move-Out Requirements	The federal Fair Housing Act, Americans with Disabilities Act, Minnesota Landlord-Tenant Law, and the Minnesota Human Rights Act apply to persons applying to lease a unit in a registered Housing with Services establishment. The assisted living establishment must offer a registered nurse (RN) assessment prior to move-in. Health care services may be terminated without impacting the resident's housing status. Thirty day notice, with certain exceptions, must be given to terminate health care services and assistance must be offered in finding another health care provider.
<b>Boarding Care Home</b>	The home provides personal or custodial care only for five or older adults or people with disabilities. Examples of personal or custodial care include: help with bathing, dressing, or other personal care; supervision of medications which can be safely self-administered; plus a program of activities and supervision required by persons who are not capable of properly caring for themselves.
<b>Supervised Living Facility</b>	SLFs are licensed by the Department of Human Services in conjunction with the counties. They are facilities in which there is provided supervision, lodging, meals and in accordance with provisions of rules of the Department of Human Services, counseling and developmental habilitative or rehabilitative services to five or more persons who are developmentally disabled, chemically dependent, adult mentally ill, or physically disabled. It provides a residential, homelike setting and services include provision of meals, lodging, housekeeping services, health services, and other services provided by either staff or residents under supervision. Class A facilities are for ambulatory and mobile persons who are capable of taking appropriate action for self-preservation under emergency conditions as determined by program licensure provisions, and. Class B facilities are for those who are not ambulatory or mobile and cannot take action for self-preservation in emergencies.
<b>Adult Foster Care</b>	Licensed by Department of Human Services in conjunction with counties. AFC provide sleeping accommodations and services for 1-5 adults. The rooms may be private or shared and the dining areas, bathrooms and other spaces are shared family style. Adult foster care homes are designated as either Family or Corporate. A Family Adult Foster Care must: a) be the home of the license holder and (b) the license holder must be the primary caregiver. A Corporate Adult Foster Care is used when the license holder is a corporation, and the license holder does not reside in the licensed site. The Corporate Adult Foster Care home usually uses shift staff to care for the residents.

Assisted living settings, known in Minnesota as Housing with Services Establishments are not licensed but they are registered. Furthermore, the conditions for their use of the term Assisted Living Services are governed by a 2006 statute that took effect in January 2008. A Housing with Services establishment must hold or work with an agency that holds either a Class A home care license, which is held by Medicare Certified Home Health Agencies or a Class F home care license, which permits practice only to Housing With Services Establishments and limits the kinds of tasks that can be done. This approach was designed to offer more autonomy and flexibility to residents by

### Figure 2. Example: Roommates on ArcLink

This matching service, available in Minnesota, matches housing vacancies with persons with disabilities. Landlords describe types of accommodations, neighborhoods, & special interests of current housemates. People with disabilities (or their agents) create listings with zip codes of preferred locations and details of desired accommodations and special interests or needs. For security, listings omit names and street addresses.



**LEFT.** If you or someone you know has sustained a brain injury, here's an opportunity to share a home with three other people. The home is wheelchair accessible, with four bedrooms on one level, and is located in a quiet neighborhood. Staff is trained in working with people with brain injuries and is available up to 24 hours per day.

**RIGHT.** Very large home, on beautiful acreage. Super clean. Currently three men live here, between their 30s and 50s. Home has five bedrooms; 2 bedrooms upstairs, 2 bedrooms downstairs, & a bedroom to accommodate overnight sleep staff. Long-term staff experienced in supporting people with challenging behaviors is on duty in this home.



**ABOVE.** Very spacious, wheelchair friendly home! Has a handicapped accessible van on site. One male and two female roommates, varying in ages. Staff are experienced in meeting health care needs.



**BELOW** 4 bedroom rambler; wheelchair friendly. Three women in their 30s and 40s currently reside here. Home is within walking distance to shops and entertainment; on bus line.



**ABOVE** Married couple looking to share living expenses in two-bedroom supportive apartment. Staff is available 24/7.



separating the housing from the services. In practice, some confusion has been engendered among consumers about the conditions of the services they are buying and when prices might change. The Department of Health, along with stakeholders, has developed a guide to help consumers make choices among these establishments.<sup>8</sup> Minnesota is participating in a Roommate Matching Website which generates a listing of information about vacancies in residential settings with photos and the kind of details that anyone would wish for in choosing housing to one's taste and integrated with the community (Figure 2).

Minnesota covers services in Assisted Living Establishments within its Elderly Waiver. Previously these services were called Assisted Living and Assisted Living +, but to avoid confusion with the 2006 law, the waiver was amended to call them Customized Living and 24-hour Customized Living Services. Customized Living Services can also be provided under the Elderly Waiver to residents of Boarding Homes or Adult Foster Homes. A separate Bill of Rights for Assisted Living has also been developed.<sup>9</sup> Some programs for older people, particularly for those with dementia, have been established in residential homes where the owner has taken out two Corporate Foster Care licenses (e.g., for separate floors of a home, or for 2 parts of a duplex).

Residential settings for persons with ID/DD. The Disability Services Division of the Department of Human Services (DHS) is responsible for managing all HCBS waiver services except for older people, and for licensing and monitoring quality within many residential services. DHS monitors and inspects the 219 ICF-MRs in the state, for example, though the federal part of the certification is done by the Department of Health. In conjunction with the counties, DHS presently licenses 16 MR/DD Residential Services settings that are not ICF-MRs

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<sup>8</sup> See Assisted Living Uniform Consumer Information Guide at [http://www.health.state.mn.us/divs/fpc/profinfo/cms/als/UCIG\\_july2007.doc](http://www.health.state.mn.us/divs/fpc/profinfo/cms/als/UCIG_july2007.doc).

<sup>9</sup> See [http://www.health.state.mn.us/divs/fpc/consumerinfo/CHCBORAL\\_eng\\_reg.pdf](http://www.health.state.mn.us/divs/fpc/consumerinfo/CHCBORAL_eng_reg.pdf).

serving 94 people, 47 Residential Services for Adults with Mental Illness serving 1236 people; 4565 adult foster care settings, serving more than 16,000 people; 312 supervised living facilities serving 1799 people; and 98 child residential facilities serving 1670 people.<sup>10</sup> (In addition, the Department of Corrections operates 40 residential settings for children, many of whom have disabilities.) In Minnesota the residential programs licensed by the DHS and those licensed by the Department of Health are not cleanly divided by target population.

Group Residential Housing (GRH) supplement. Group Resident Housing (GRH) program is a state-funded income supplement program that pays for room and board costs for low income adults who have been placed in a licensed or registered setting with which a county human service agency has negotiated a monthly rate. Over 4300 GRH settings have been in MN GRH funds are to be available to pay for room and board in housing with services (HWS) establishments, in

**Figure 3. Example: J's Farm**

A Special Needs Trust can be set up to buy a home for the benefit of a disabled adult child. The trust owns the home and contracts with a service provider to license the home as adult foster care and provide necessary services to the resident(s). The provider leases the home from the trust. Participants receive their services under a waiver, and receive their GRH room and board payments, if they are financially eligible. An example of this arrangement is J's Farm, located in Morris, MN. When it became necessary to sell the grandparents' farm where Justin had visited every Monday of his life coming from the group home in town, his family decided to start their own home for young adults with special needs. The farm was purchased and a contract was made with Prairie Community Services in Morris to run home.

settings licensed by DHS as a foster care provider, or a licensed board and lodge which are not registered as HWS. The county is responsible to establish the group residential housing contract with the provider. If a GRH payment is being made for a person, the person or person's family may only supplement the GRH room and board rate if they are paying for something not covered

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<sup>10</sup> The Department of Human Services provides a website with detailed listings by county of all the different types of settings the department licenses, last visited June 6, 2008 at [http://www.dhs.state.mn.us/main/idcplg?IdcService=GET\\_DYNAMIC\\_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=id\\_017167](http://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=id_017167)

in the base room and board rate. For example, if the base room and board rate pays for a bed in a double room, the family may pay extra for a private room. (See example in Figure.)

A county human service agency must approve placement in the GRH setting, GRH may make service payments for disabled and elderly adults in foster care and other settings if the person cannot access service payment from another sources, such as Home and Community waivers, almost 11% of whom are seniors. Of waiver clients under 65 years of age, 39 percent are on the Mental Retardation/Related Conditions waiver; 15 percent are on other waivers, Community Alternative Care, Community Alternatives for Disabled Individuals and Traumatic Brain Injury and 19 percent are general assistance clients. At total of \$84,100,000 was spent in FY 2007, the average monthly payment for room and board and services per recipient was about \$458, the majority of the settings – about 4,200 – is adult foster care settings. All GRH payments are made to the GRH vendor on behalf of the eligible recipients.

Institutional sector. As described in Minnesota case studies and Topic Paper Number 5 on the Future of the Nursing Home, Minnesota is trying to give incentives for

nursing homes to develop single rooms and to develop more individualized services. As yet, Minnesota has not established any small-house nursing homes, but has examples of nursing homes organized into neighborhoods and households. In ID/DD services, Minnesota has eliminated almost all its state-run large institutions, in part by creating small state-run ICF-MRs.

**Figure 4. Example: Lake Owasso Residence**  
Lake Owasso Residence is a residential treatment facility operated by Ramsey County (home of St. Paul) for 64 adults with developmental disabilities. It originated as a tuberculosis ‘preventorium’, a safe place to house children whose families were infected with tuberculosis. Later, it became a home for disabled children and in the 1960’s it became a home for adults, ages 17-50. Today, it is comprised of 8 new single-level homes with separate bedrooms for each of 8 residents, a kitchen, great room and front and back patio areas. The campus-like setting on a lake provides central walking and biking paths and lake access with a dock for boating. Integration of the residents into the community is attempted through an active volunteer program where residents are matched with volunteers who work with them one-on-one towards greater self-sufficiency and escort them to community wide activities.

Lake Owasso Residence is an example of a transformation of a large institution into what is meant to be an inviting residential setting well integrated into the community. However, some commentators would still consider it institutional in nature because residents do not appear to be self-directing (Figure 4).

New Mexico

Residential settings for seniors and adults with physical disabilities. The Division of Quality Improvement within the New Mexico Department of Health licenses and inspects nursing homes, ICF/MRs, and adult residential care facilities (the term used to license assisted living settings as well as developmental disability group homes in New Mexico). Table 4 describes licensed settings in New Mexico. As in other States, privacy is not assured in regulations and facilities are not allowed to retain residents who need continuous nursing care or have specifically listed problems.

**Table 4. Community Residential Care Settings in New Mexico**

<b>Residential Care Facilities</b>	
Description	Facilities are any congregate residence, or building for 2 or more adults, which have the primary purpose of providing the resident (either directly or through contract services) with programmatic services, room, board, and assistance with Addles.
Physical Plant Requirements	Private resident units must be a minimum of 100 square feet and semi-private resident units must provide a minimum of 80 square feet of floor space per resident.
Residents per Room & Bathroom	A maximum of two residents is allowed per resident unit. A minimum of one toilet, sink, and bathing unit must be provided for every eight residents. Each facility shall provide at least one tub and shower or a combination unit to allow residents' bathing preferences.
Move-In/Move-Out Requirements	Facilities may not retain residents requiring continuous nursing care, which may include, but is not limited to, the following conditions: ventilator dependency; stage III or IV pressure sores; or any condition requiring either chemical or physical restraints. Facilities also may not retain individuals whose physician certifies that placement is no longer appropriate.

New Mexico is undertaking strategic planning for long-term support services, and emphasizes use of telemedicine, and creating a public transportation infrastructure, and developing affordable housing options. To do the latter, the State proposes to:

- Educate city councils and zoning authorities about “senior and disabled friendly” development practices and universal concepts to encourage the inclusion of these practices in zoning codes, ordinances and building requirements.
- Locate new publicly supported housing for disabled persons and seniors throughout communities near public transportation or, if not near public transportation, require property owners to provide reasonable transportation services to residents to meet health and social support needs.
- Require that new affordable housing projects are available for grandparents raising grandchildren.
- Expand funding for handicapped accessible housing and housing modification programs that enable persons with disabilities to live where they choose in their communities through the use of a self-directed waiver and other funding sources.

As more individuals are aging-in-place, often until close to the end of their life, the neglected but important topic of end-of-life information and practices is seldom addressed. Most people die in a hospital or nursing home – an expensive and not very pleasant option. End-of-life strategies identified by New Mexico include: establish two residential hospice centers a year; add geriatric palliative care training to UNM medical and nursing schools; and educate individuals about advance directives, living will and biological processes related to death.

New Mexico has several Rural Development 515 affordable housing complexes funded by the United States Department of Agriculture. Hacienda Orgullo Apartments, a 32 unit facility located in Truth or Consequences is designed for wheel chair accessibility and each apartment has a fenced front yard. The Senior Joint Office on Aging, located nearby, is responsible for coordinating services for the residents.

Residential options for persons with ID/DD. The Developmental Disabilities Support Division (DDSD) in the Department of Health manages services for persons with developmental disabilities. Residential settings serving no more than four persons that are operated by one of the 176 developmental disability providers that are certified by the DDSD are exempted from

licensure as an Adult Residential Care facility. The DDS builds its approach around the individualized service plan and is informed by the goal that people with developmental disabilities should be able to live independently in the community. Figure 4 illustrates a creative example of a setting for women with autism.

**Figure 5. Example: Mandy's Special Farm**  
Mandy's Special Farm, licensed as an Adult Residential Care Facility, is home to six women with autism, of various abilities, and ages 18 to 30 upon admission through end of life. This working farm is located in South Valley, New Mexico on 4 acres of land. The home functions as a working farm with animals and a vegetable garden where residents are encouraged to participate. There is a huge kitchen designed so that each woman has their own work space. The cost is around \$40,000 a year per person.

Institutional Sector. New Mexico has 37 licensed ICF/MR facilities in New Mexico serving over 270 residents. (NMHCA). In New Mexico, the average number of residents per ICF/MR is 7.65.

Initiatives to improve nursing homes are not especially oriented towards transforming nursing homes into community settings, but rather to protecting residents in a variety of ways. The Department of Aging and Long Term Services, for example, prominently described Granny Cams on its Website and suggests that concerned relatives discuss with the ombudsman how they can secure this technology. The website reads in part:

If you have reason to suspect your loved one is being abused, neglected, or exploited while living in a nursing home, call the local Ombudsman office. An Ombudsman will investigate to determine if a granny cam will be helpful and if so, will explain the process of using a Program granny cam.

New Mexico law allows residents of long-term care facilities or their surrogates to monitor the care that residents receive in their rooms with audio and video equipment.

Also, a state regulation requires that facilities notify residents about their right to install the equipment and make reasonable efforts to assist in the installation, such as providing access to power sources and a secure space to mount the device. The facilities also are required to match residents with roommates who support having monitoring equipment in their rooms.

Residents or their families are required to pay the costs of the equipment and installation, but the Aging and Long-Term Services Department is identifying funds to help families who cannot afford the cost of the equipment. For more information on borrowing a camera, email Ombudsman . . .<sup>11</sup>

This enthusiasm for electronic monitoring, taken to the point of requiring facilities to match residents as roommates whose families also support the monitoring, seems the reverse of moving nursing homes away from institutional models.

### Pennsylvania

Residential settings for seniors and persons with physical disabilities. The Division of Quality Assurance in the Department of Health includes the Bureau of Facility Licensure and Certification, which licenses and inspects nursing homes, and a Bureau of Community Program Licensure and Certification, which includes in its purview licensing and inspecting ICF-MRs. Personal Care Homes, which at 1500 strong constitute the most developed residential sector in Pennsylvania, are licensed and inspected by the Division of Public Welfare. So far, settings that hold themselves out as Assisted Living, including assisted living apartments, are licensed as Personal Care Homes. Assisted Living is a newly approved service under Pennsylvania HCBS waivers. It is expected that assisted living facilities will be held to a higher standard of privacy, amenity, and service than Personal Care Homes in general, but regulations are not expected until 2009, after which they are expected to be regulated as a subset of Personal Care Homes. Finally, Domiciliary care (Dom Care) resembles adult foster homes in other states. They are licensed by each Area Agency on Aging but are for all adults aged 18 and above, and are often used to house persons with developmental disabilities. Dom Care has potential for flexibility and individualization. Experience with Dom Care has not been recently studied, and it appears that

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<sup>11</sup> On web, last visited June 6, 2008 at [http://www.nmaging.state.nm.us/Granny\\_Cameras.html](http://www.nmaging.state.nm.us/Granny_Cameras.html).

their use and nature would vary with the AAA area where they are recruited and licensed. Table 5 summarizes the provisions for these settings.

Table 5. Community Residential Care Settings in Pennsylvania

<p><b>Personal Care Homes (PHs)</b></p>	<p>Residences that provide shelter, meals, supervision and assistance with personal care tasks, typically for older people, or people with physical, behavioral health, or cognitive disabilities who are unable to care for themselves but do not need nursing home or medical care. PHs are usually privately-owned, although some are operated by local governments or non-profit agencies and are licensed to care for as few as four people and as many as several hundred. The Department of Public Welfare inspects each PCH annually and investigates complaints.</p> <p><b>Physical Plant Requirements</b>                  Resident bedrooms must be a minimum of 80 square feet and multiple-occupancy bedrooms must provide a minimum of 60 square feet per residents.</p> <p><b>Residents Allowed per Room</b>                  A maximum of four residents is allowed per bedroom. No more than two residents are permitted in each secure dementia care unit bedroom.</p> <p><b>Bathroom Requirements</b>                  There must be at least one toilet for every six or fewer users, including residents, staff persons, and household members. There must be at least one bathtub or shower for every 10 or fewer users.</p> <p><b>Move-In/Move-Out Requirements</b>                  Residents eligible for nursing home care may not be admitted into a PCH. Admission of residents with special needs is allowed only if the home complies with certain additional staffing, physical site, and fire safety requirements.</p>
<p><b>Assisted living residences</b></p>	<p>Assisted living residences are currently licensed under the Public Welfare Code as personal care homes (PCHs). A new Pennsylvania law addressing assisted living, Act 56 of 2007 was passed on July 25, 2007. The new law defines assisted living residences and requires the Department of Public Welfare to promulgate a separate set of regulations to govern the licensure and operation of assisted living residences. Some homes currently licensed as personal care homes may meet the new regulatory definition, but many facilities will continue to be governed by the PCH regulations. The new law will establish minimum standards for building, equipment, operation, care program and services, training and staffing, for the issuance of licenses and the regulations must meet or exceed the regulations for PCH. Final regulations should be published sometime in year 2009.</p>
<p><b>Domiciliary care</b></p>	<p>Domiciliary care homes, known as Dom Care, are small family residences that ordinarily house 3 or fewer residents; the owner of the home is the live-in provider. Rooms are either single or double. Doms are licensed by the Area Agencies on Aging, paid negotiated rates, and case managers from the AAAs oversee services. SSI consumers receive supplemental payments. Residents must be 18+, mobile and able to protect themselves in an emergency. Regulations do allow for larger Doms, housing 4 to 9 residents, and special rules have been developed for those larger homes. A statement of rights for Dom Care residents emphasizes that they should be able to go out in the evenings, have their privacy respected, and should be free of unreasonable restrictions.</p>

Residential Settings for Persons with ID/DD. Personal care homes and Doms, as discussed in the previous section, are widely used by persons with developmental disabilities. In addition,

the Developmental Services Division, through their regional offices, licenses mental retardation services providers who offer panoply of community services. The providers are listed by services, including community homes (group homes for fewer than 9 residents), large community homes (group homes for 9 or more), and Family Living (which includes Lifesharing and Companion Living).

Institutional sector. Pennsylvania was the first state to develop a nursing home culture change coalition and various efforts are underway to make nursing homes less institutional and to improve quality of care. Despite exemplary facilities, the effort is still an uphill battle. State officials in Pennsylvania are instead concentrating on helping the nursing home sector shrink, and are trying to develop models based in independent housing complexes with attached PACE sites (called LIFE in California). For this strategy no license at all is needed for the residential setting.

### Texas

Residential settings for seniors and persons with physical disabilities. Through the Department of Aging and Disability Services (DADS), Texas has developed an unusually cohesive set of cross-disability policies at the state level for regulation and quality assurance, for access to services, and for provider relationships. Nursing homes, ICF-MRs, and Assisted Living settings (including the smaller Type C, which is sometimes called Adult Foster Care), as well as HCBS providers, are all regulated by and receive quality assurance directives from the office of DADS' Assistant Commissioner for Regulatory Affairs, and all providers fall under the purview of DADS' Assistant Commissioner for Provider Services. Texas has incorporated a wide range of community residential settings under the general heading, Assisted Living. (See Table 6.)

On the positive side, Texas regulations articulate a strong message about intended consumer choice and control in assisted living. Less positively, the elaborate array of types of assisted living and the requirement that residents in Type E or in some circumstances Type A or C will need to leave if there needs increase introduces complexity in consumer choice. Standards for privacy and residential amenities are also minimal.

**Table 6. Community Residential Care Settings in Texas**

Definition	Assisted living facilities provide food and shelter to four or more persons unrelated to the owner and personal care services in large apartment-like settings or private residences. They are driven by a service philosophy that emphasizes personal dignity, autonomy, independence, and privacy. Assisted living services should enhance a person's ability to age in place in a residential setting while receiving increasing or decreasing levels of service as needs change. Texas licenses assisted living facilities in four categories based on resident's physical and mental ability to evacuate in an emergency and whether nighttime attendance is necessary.
Types	<p><u>Type A:</u> For residents who are physically and mentally capable of evacuating the facility unassisted; do not require routine attendance during nighttime sleeping hours; and capable of following directions under emergency conditions.</p> <p><u>Type B:</u> For residents who may: require staff assistance to evacuate; be incapable of following directions under emergency conditions; require attendance during nighttime sleeping hours; or need transfer assistance. Permanently bedfast residents are not permitted.</p> <p><u>Type C:</u> A 4-person facility which meets the minimum standards and program rules for enrollment as an adult foster care facility. Non-licensed adult foster care (AFC) Providers and residents must live in the same household and share a common living area. With the exception of family members, no more than three adults may live in the foster home unless it is licensed.</p> <p><u>Type E:</u> Residents must be physically and mentally capable of evacuating the facility unassisted, including those using wheelchairs and able to transfer independently. Must not need routine help in sleeping hours. Type E facilities may not administer medications but may only supervised self-medication and general residents' welfare. They may not provide substantial ADL help.</p>
Physical plant	Bedroom usable floor space for Type A and Type E facilities must be at least 80 square feet for a single-bed room and not less than 60 square feet per bed for a multiple-bed room. Bedroom usable floor space for Type B facilities must be at least 100 square feet per bed for a single-bed room and not less than 80 square feet per bed for a multiple-bed room. Type C facility, bedrooms must have at least 80 sq ft of floor space in a single-occupancy room and at least 60 square feet of floor space per client in a double-occupancy room.
Sharing of rooms & bathrooms	A maximum of four residents is allowed per resident unit. No more than 50 percent of residents can be in units with more than two residents. All bedrooms must be served by separate private, connecting, or general toilet rooms for each gender. A minimum of one water closet, lavatory and bathing unit must be provided on each sleeping floor.
Move-in & move out criteria	Facilities must not admit or retain persons whose needs cannot be met by the facility or by the resident contracting with a home health agency.

Residential settings for persons with developmental disabilities. Given DADS' approach to working on functional lines across disability groups, the licensed settings described in Table 6 apply to individuals with developmental disabilities. DADS operates four HCBS waivers that are alternatives to state schools and ICF-MRs. Participants enrolled in most of these waivers may live in any one of four residential assistance types: they may receive supported home living services live in their own home or their family's home; they may receive foster/companion care while living in the home of a foster care provider or in their own residence with a companion care provider; they may receive supervised living services while residing in a 3-bed or 4-bed home and is owned or leased by the program provider and where overnight staff is available if the individual needs assistance during the night; or they may receive residential support while living in a 3-bed or 4-bed home that is owned or leased by the program provider but requires an awake staff while the individual is present in the residence. Program providers meet the standards for vendors under these waivers and the residential settings that they own or lease are operated under those auspices rather than individual licenses. DADS maintains a remarkable website that allows consumers or case managers assisting consumers to look up all providers, including providers for specific waivers and, therefore, including mental retardation providers by county or city and review the services they provide and their quality record.<sup>12</sup>

Institutional sector. Generally speaking DADS concentrates on developing a wide variety of options and systematically assuring that consumers in institutions are presented with choices rather than directly attempting to make the institutional sector more community-like. However,

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<sup>12</sup> In preparing this Topic Paper, we tested the information on mental retardation providers and found that many of the providers listed provided a wide range of residentially based services. We also noted that the quality information included instances when the judgment was made that the rights of consumers were violated. See website, last visited June 7, 2008 and choose any city or county to get an idea of the information provided at [http://facilityquality.dads.state.tx.us/ltcqrs\\_public/nq1/jsp2/qrsSelCounty\\_Zip1en.jsp?MODE=P&LANGCD=en&P ROGTYP=6](http://facilityquality.dads.state.tx.us/ltcqrs_public/nq1/jsp2/qrsSelCounty_Zip1en.jsp?MODE=P&LANGCD=en&P ROGTYP=6).

Texas has been hospitable to the concept of small-house nursing homes such as Green House<sup>®</sup> and three Green House projects are operating in Texas. The quality improvement programs operated by DADS attempt to enforce consumer rights across all provider types, and to present best practices in nursing homes and institutions for persons with mental retardation. In particular efforts are underway within the State-run Mental Retardation Facilities to develop new staff positions and to emphasize, among other things, the following best practices: standardized person-directed planning, values-based culture training, assessment tools for side-effects of medications, incident trend analysis, rights assessments; improved comprehensive quality reviews; positive behavior support training and service provision; training on prevention and management of aggressive behavior; and statewide reduction in restraints and restrictive practices.<sup>13</sup> Although the large state institutions may still remain more institutional than community-like in nature, success with these initiatives will surely enhance the ability of consumers to exercise choice, control, and autonomy within their settings, which is one of the hallmarks of reducing institutional aspects of life.

### Vermont

#### Community residential settings for seniors and persons with physical disabilities in Vermont.

Vermont has developed a strong capability for small-scale community-based residential settings in local communities (see Table 7). All are licensed and monitored by the Division of Licensing and Protection within the Department of Aging and Independent Living (DAIL). Residential care homes (Level III and IV) are the most established sector. They are often very small (and function like Adult Foster homes in other states). Considering the population and size of

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<sup>13</sup> See draft of Report Update for State Mental Retardation Facilities, Fiscal Years 2008-2009 prepared by the Texas Department of Aging and Disability Services as required by the Legislature, on web, last visited June 8, 2008 at <http://www.dads.state.tx.us/homepage/stateschoolreport2008.pdf> .

Vermont, the supply and its distribution is good. Special therapeutic homes are also in good supply, and many of these are also small.

**Table 7. Group Residential Care Settings in Vermont**

<p><b>Residential Care Homes</b></p> <p><i>DAIL web data, 2007</i>                  --2172 Level III homes; 50 of them serve 15 or fewer residents.                  --60 of the Level III homes serving 1344 people have ERS capacity; 14 serve 15 or fewer residents                  --there are 7 Level IV homes serving 75 people; all serve 15 or fewer.</p>	<p>RCH is a place, however named (excluding a licensed foster home for children) which provides, for profit or otherwise, room, board and personal care to 3 or more residents unrelated to the home operator. Residential care homes are divided into two groups, depending upon the level of care they provide, as follows:</p> <p>Level III, which provides personal care, defined as assistance with meals, dressing, movement, bathing, grooming, or other personal needs, or general supervision of physical or mental well-being, including nursing overview and medication management as defined by the licensing agency by rule, but not full-time nursing care. Some Level III settings offer Extended Residential Services (ERS) capacity, meaning they agree to serve more residents with heavy needs.</p> <p>Level IV, which provides personal care, as described above, or general supervision of the physical or mental well-being of residents, including medication management as defined by the licensing agency by rule, but not other nursing care.</p>
<p><b>Home for the Terminally Ill</b></p>	<p>A place providing services specifically for three or more dying people, including room, board, personal care and other assistance for the residents' emotional, spiritual and physical well-being. A home for the terminally ill shall not be considered a nursing home, residential care home or any other facility regulated by this chapter.</p>
<p><b>Assisted living residence supply in next cell across</b></p>	<p><i>DAIL website indicates that in 2007 there were 7 licensed AL Residences with capacity to serve 287 people</i></p>
<p><b>Definition</b></p>	<p>Assisted living means a program which combines housing, health and supportive services for the support of resident independence and aging in place within a homelike setting. Assisted living promotes resident self-direction and active participation in decision-making while emphasizing individuality, privacy and dignity.</p>
<p><b>Physical Plant Requirements</b></p>	<p>Private resident units must be a minimum of 225 square feet (160 in pre-existing structures), excluding bathrooms and closet. Each resident unit shall include a private bedroom, private bath, living space, kitchen capacity, and a lockable door.</p>
<p><b>Privacy of Rooms and bathrooms</b></p>	<p>All resident units must be private occupancy unless a resident voluntarily chooses to share the unit. All resident units must have a private bathroom.</p>
<p><b>Move-In/Move-Out Requirements</b></p>	<p>Assessment must be done by a registered nurse within 14 days of move-in. Resident may be discharged if they pose an immediate threat to themselves that cannot be managed through a negotiated risk agreement or to others. If a facility is able to do so, it may retain residents who need: 24 hour on-site nursing care; are bedridden for more than 14 consecutive days; are dependent in four or more activities of daily living; have severe cognitive decline; have a stage III or IV pressure sores; or have a medically unstable condition.</p>
<p><b>Therapeutic community care homes</b>  <i>DAIL website data lists 60 therapeutic homes</i></p>	<p>These are places that provide treatment to 3 or more residents with major adjustment problems, for example, because of alcoholism, drug abuse, mental illness, or delinquency.</p>

As of 2005, Assisted Living was introduced as a licensure category with the intent of emphasizing aging in place and the separation of housing and services. Therefore, the standards developed for Assisted Living Residences emphasize retention rather than circumstances under which residents must leave. The environmental standards ensure private accommodations for those who wish them, not just for bedrooms but for bathrooms.

In December 2007, DAIL made available an Assisted Living Toolkit for operators, which includes ample recognition of the importance of individual choice. The concept of negotiated risk agreements to resolve matters of disagreement between resident preference and management concerns about liability are woven through the document and clear instructions are provided for how to complete such a negotiated risk agreement. If the resident is not competent

**Figure 6. Examples: Vermont Innovation**

*Home Share* programs are located in Champlain Valley and central Vermont. Each program offers match and follow-up services to people with a home to share and to those seeking an affordable housing option. The typical home provider is an older person who will benefit from the present of another person. In return for reduced or free rent, the companion provides the older person services such as homemaking, meal preparation, home maintenance and other services. In Chittenden County the program also matches frail elders with live-in or hourly caregivers who provide person personal care, meal preparation and other services.

*South Burlington Community Housing (SBCH)* project provides independent living options including handicap-accessible apartment units and Medicaid Waiver-funded personal care services. Residents live in independent apartments with personal care services available 24/7. They must be capable of self-directing their care, meet HUD financial eligibility, require at least hours of personal care/per day and be willing to participate in a shared care service delivery model.

*Rental Assistance Programs* Multiple Section 8 programs are administered by the Vermont State Housing Authority (VSHA) for rental assistance. The Project-Based Voucher and Moderate Rehabilitation program are project specific housing rather than open market housing. The subsidy is attached to the unit and not to the person. The Shelter Plus Care program provides rental assistance to homeless people with disabilities. Supportive services, at least equal in value to the rental assistance, must be funded from other sources. The Mainstream Housing program funds rental assistance for non-elderly disabled families with the primary purpose of enabling disabled families to rent affordable private housing. Section 8 Existing Housing Choice Voucher program permits persons to select their own housing unit anywhere in the state where VSHA has the authority to operate, provided the unit meets housing quality standards and certain rent limitations.

to enter into such an agreement, his or her agent can do so on the resident's behalf.<sup>14</sup> Vermont has also developed a wide range of innovative housing financing programs (see Figure 6).

States that are encouraging a particular form of housing with services often need to enter into partnership with various developers and housing providers. To that end, Vermont has entered into a fruitful partnership with the Cathedral Square Corporation (see Figure 7), a major Vermont Housing Provider.

Community  
residential settings for  
people with  
developmental  
disabilities. The  
Division of Disability  
and Aging Services  
within DAIL lists a  
variety of Housing and  
Residential Supports  
open to their waiver  
and State Plan

**Figure 7. Example: Cathedral Square Corporation, Vermont**

The most prolific provider of housing for seniors and individuals with special needs in Vermont is the Cathedral Square Corporation (CSC). This non-profit organization owns and/or manages 23 housing communities located in four Vermont counties. Each housing option is uniquely designed to serve distinct populations a chance to live independently in a safe and secure apartment at an affordable price. Cathedral Square offers three different types of senior housing: independent senior housing, shared housing, and assisted living. In the independent housing, on-site staff assists residents to access resources and programs designed to help them age with dignity and grace (not in place) and any resident requiring more assistance with activities of daily living will receive priority admission to shared housing and assisted living residences.

Shared housing offers private rooms with baths in a home-like setting where residents share three meals per day in a common dining room. There is a resident manager on-site and activities, transportation and housekeeping services are provided. The intent of this type of housing is to promote independence through interdependence with others living there and is preferred housing for those residents seeking a social and family-like atmosphere.

Assisted living (state licensure category) requires at a minimum, a private bedroom, private bath, living space, kitchen capacity, and a lockable door. In addition, CSC provides personal care services 24 hours a day including assistance with bathing, dressing, and medication reminders. Amenities include: three meals per day, housekeeping services, Wellness Center, whirlpool room, beauty salon, daily activities

participants. All the licensed services previously mentioned are listed, including residential care

<sup>14</sup> Negotiated risk agreements were first developed in Oregon as a mechanism for extraordinary care planning to honor resident preferences as much as possible. A recent on line report commissioned by the US Office of the Assistant Secretary for Planning and Evaluation discusses the evolution of this concept nationally. See Jenkins, R, O'Keeffe, J, Carder, P, & Wilson, KB (2006). Study of Negotiated Risk Agreements in Assisted Living, on web, last visited June 6, 2008, at <http://aspe.hhs.gov/daltcp/reports/2006/negriskes.htm>. Also see DAIL (2007) Vermont Assisted Living Tool Kit: Operations and Financial Tools for Assisted Living Providers and/or Developers, on web, last visited June 6, 2008 at <http://ddas.vermont.gov/ddas-publications/publications-resident-alt/publications-resident-documents/vt-assisted-living-tool-kit> Vermont rules are more permissive than those in Oregon where it is impermissible for an agent to enter into a negotiated risk agreement on behalf of a person who is cognitively impaired.

homes, assisted living residences, and Special Therapeutic Homes. Other possibilities include congregate shared housing (where several unrelated persons have private bedrooms and share common spaces, some meals, and housekeeping services), home sharing (where home sharing providers assist s elders and persons with disabilities to live independently in their own homes by matching them with others who seek affordable housing and/or caregiving opportunities); and supportive living services to people in their own homes. The 15 non-profit developmental disability service providers in Vermont that coordinate services (10 geographically designated and 5 specialized) utilize services creatively to arrange residential settings for persons with developmental disability in private homes where often the participant is the only persons served in the home. With the integration of services to all age and disability groups, DAIL is now trying to develop similar individually tailored opportunities for seniors for whom settings have been difficult to find because of dual diagnoses or labeled “behavior problems.” The Vermont final case study describes a pilot with a dozen seniors for whom the living situation was identified not by the Area Agencies on Aging or home health agencies that are the focal point for services to seniors but by DD agencies with greater experience in tailoring residential settings.

Institutional Sector. Vermont has virtually no institutional sector for persons with DD; the state has 2 small ICF-MRs, each serving fewer than 6 participants. Presently the state is exploring whether small, community-based nursing homes are feasible.

### Washington

Community residential settings for seniors and persons with disabilities. All residential settings for participants of any age or disability are regulated and monitored for quality by the Division of Residential Services in the Aging and Disability Services Administration (ADSA), which licenses nursing homes, adult family homes, and boarding homes (see Table 8).

Table 8. Community Residential Care Settings in Washington

<b>Adult Family Homes</b>	Adult Family Homes are regular neighborhood homes where staff assumes responsibility for the safety and well-being of the adult. A room, meals, laundry, supervision and varying levels of assistance with care are provided. Some provide occasional nursing care. Some offer specialized care for people with mental health issues, developmental disabilities or dementia. The home can have 2 to 6 residents.
<b>Boarding Homes (including Assisted Living service package)</b>	
Definition	Boarding homes are facilities in a community setting where staff assumes responsibility for the safety and well-being of the adult. Housing, meals, laundry, supervision, and varying levels of assistance with care are provided. Some provide nursing care. Some offer specialized care for people with mental health issues, developmental disabilities, or dementia. The home can have seven or more residents. Intermediate Care Facilities for the Mentally Retarded (ICF/MR) are certified settings within this state licensure category.
Service package types for Medicaid payment.	Boarding homes that serve Medicaid clients are contracted by Washington State to provide different levels of service packages. 1. Adult Residential Care (ARC). This service package includes helping residents with self-administration of medications (e.g. a reminder to take it or the medication handed to him/her) and personal care (e.g. bathing, dressing, personal hygiene), and limited supervision for safety. 2. Enhanced Adult Residential Care (EARC). This service package includes all of the services as listed in the ARC package above and medication administration, and occasional nursing care. 3. Enhanced Adult Resident Care – Specialized Dementia Care Services. This service package includes all services as outline in the EARC package and additional services for a resident with dementia. 4. Assisted Living (AL). This service package includes a private apartment. Some type of nursing care must be provided occasionally and help is available for medication administration and personal care.
Physical Plant Requirements	--Resident rooms must be a minimum of 80 square feet for a single occupancy room and shared resident units must provide a minimum of 70 square feet. --Boarding homes with an AL contract with the state must provide a private room with a kitchen area and private bathroom. The room must be a minimum of 220 square feet, excluding the bathroom
Privacy in Rooms & Bathrooms	--A maximum of four residents is allowed per resident units for boarding homes licensed before 7-1-89. After that a maximum of two residents is allowed per unit. --Boarding home with a contract for EARC must have no more than 2 residents per room. --Boarding homes with an AL contract with the state must have single occupancy unless by resident choice for shared occupancy. --One toilet and one sink are required for every eight residents and one bath/shower is required for every 12 residents. --Boarding homes with an AL contract with the state must offer a private bathroom to each resident.
Move-In/Move-Out Requirements	The board home may admit and retain an individual as a resident only if 1) it can safely and appropriately serve the individual with appropriate available staff who provide the scope of care and services described in the boarding home's disclosure information and make reasonable accommodations for the resident's changing needs; 2) the resident does not require the frequent presence and frequent evaluation of a registered nurse, excluding those individuals who are receiving hospice care or individuals who have a short-term illness that is expected to be resolved within 14 days as long as the board home has the capacity to meet the individual's identified needs; and 3) the individual is ambulatory, unless the boarding home is approved by the Washington state director of fire protection to care for a semi-ambulatory or non-ambulatory residents.

Adult family homes (called Adult Foster Homes in some other states) may have 2 to 6 residents. Some are specialized for particular diagnoses or needs. Boarding Homes is a broad licensure category for any community facility serving 7 or more residents. ICF-MRs, for example, are licensed as boarding homes but also are inspected against federal certification standards. Any Assisted Living setting in the private sector, including luxurious apartment settings, is licensed as a boarding home and technically needs to meet only those minimum standards, though the market tends to demand privacy and amenities.

Other detail is added if the setting has a contract to provide services to Medicaid waiver participants. Both Adult Family Homes and Boarding Homes may have such contracts. Boarding Homes with ADSA contracts may provide basic adult residential care (ARC), enhanced adult residential care (EARC), or assisted living (AL); different stipulations for environment, privacy, and services adhere to these different levels. The AL category requires apartments and private occupancy, therefore having the greatest potential for residential scale and characteristics and privacy. Boarding homes in general have much more minimal requirements. The rules do require participants to leave the settings, even AL residents, if the facility is judged unable to meet their needs. Washington emphasizes safety a great deal in its definitions of its licensed environments, which militates against resident control over move-outs. On the other hand, Washington pays great attention to its Nurse Delegation program, which enables AL settings and boarding homes in general to meet some safety concerns through services delegated by a nurse. In its Money Follows the Person Demonstration, which in Washington is called Pathways to Community Living, ADSA intends to AL settings more closely to see if there are some residences in which leases can be modified to allow the participant more control over their environments than most current agreements do.

Residential settings for persons with ID/DD. Given the functional integration at the ADSA, individuals with intellectual or developmental disabilities are able to use the same licensed categories of services as any other person with a disability, though some adult family homes and boarding homes may specialize in developmental disability. As in other states, persons with ID/DD may live in homes that they rent or own with agencies providing the level of needed wrap around supportive services. Participants receiving services from the Division of Developmental Disabilities also have the option of companion homes (one person living with a provider); alternative living, which is habilitation services in own home; or supports in the family home by an individual or an agency.

Institutional sector. Efforts have been made to stimulate culture change in Washington nursing homes, and innovative models are available in the state. The ADSA website calls all its residential settings including nursing homes “assisted Living” and gives a great deal of attention to showing consumers and their advisors how to choose a type of setting (adult family home, boarding home [including assisted living residence], or nursing home, and how to choose a provider within each type. Although it is more difficult to find the web page for nursing home survey and certification in Washington than in most states, a deliberate choice has been made to model thinking where nursing homes will not be the first recourse for people who cannot stay in their homes.

Washington has a lingering institutional population in state-run Residential Habilitation Centers. Efforts have been made to improve life in these institutions by creating smaller entities and by encouraging community integration although the ultimate hope is to close many or all of them; unions and parents of long-time residents have been a lobby group against those efforts. In the meantime, the state has conducted a study to see how additional revenue might be

recouped to offset the expense of running underutilized institutions (which detracts from community care) and to anticipate how those assets might ultimately be used (see Figure 8).

**Figure 8. Example: Market Study of Washington Residential Habilitation Centers**

Many states struggle with what to do with the state's aging institutions as their utilization declines, and how to reduce the very high costs per institutional resident as the settings are downsized. The Division of Developmental Disabilities (DDD) in ADSA, operates five Residential Habilitation Centers (RHC)—i.e. state-run MR-DD regional centers. Lakeland Village, the oldest of the institutions, first opened in 1915. In 1967, the RCHs housed over 4,000 residents, but currently just over 1,100 residents live in them. As a result of the decline in population and an increase in upkeep and capital investment a study was conducted to consider possible alternative uses of the land and facilities. Findings included:

- None of the facilities is limited to serving only its current population.
- All 5 campuses are under-utilized and have capacity for growth.
- All 5 five campuses suffer a degree of functional obsolescence.
- Local zoning will constrain alternative uses of each campus.

The RHCs can be ranked as to their value to state.

The report concluded that 2 sites had potential alternative uses and market values of up to \$32.7 million dollars; 3 schools had excess property (residential, agricultural, and timber land) valued at \$7.7 million dollars that could be sold with no impact on current operations. (Harvesting timber from the excess property at one facility could generate an additional \$5.7 to \$7.0 million in revenue to the state.) The immediate campuses at three locations have no significant marketable value beyond their current use.

## **Innovations and Creative Concepts**

As we performed the overview in the 8 States, we identified creative concepts, some of which were highlighted in the state-by-state sections. Below is a longer list:

- Accessibility modifications can be offered not only in a private home but in an adult foster home or group home to allow a resident who wishes to remain in the setting. For example, if he or she needs a wheelchair for mobility, in Minnesota it is common for the county to provide funds to retrofit door widths or a bathroom in that setting specifically for that individual – often at a cost in excess of \$25,000.
- Integration of multi-family developments could meet disability needs in the context of regular, low income housing.
- Integration of skilled nursing beds integrated into assisted living facilities (both long and short stay), as is permitted in Arkansas Level II assisted living licensure and could encourage aging in place, though some critics worry that it would also simply encourage providers to seek higher reimbursement and lead to making the assisted living more institutional.

- Home sharing, in private single family unit, where the elderly person pairs up with another capable individual seeking affordable housing for minimal or no rent who agrees to perform basic chores around house.
- Roommate and housemate listing services such as were illustrated in Minnesota and which allow potential residents to look at features of the neighborhood and community as well as the composition of existing residents.
- Shared housing offers private rooms with baths in a home-like setting where residents share three meals per day in a common dining room with a resident manager on-site and activities, transportation and housekeeping services are provided such as is offered in Vermont.
- Alternatives to standard 4 person group home could be developed using Companionship Programs and Home ownership.
- Changing HUD 202 program model could allow more development of housing with services as opposed to independent living buildings. Housing without support services is in lesser demand because healthy older persons do not necessarily need or choose senior housing and prefer to stay in their own residential housing with added modifications until they do need services.
- Requiring that new affordable housing projects are available for grandparents raising grandchildren is a strategy found helpful in New Mexico.
- Educate city councils and zoning authorities about “senior and disabled friendly” development practices and universal concepts to encourage the inclusion of these practices in zoning codes, ordinances and building requirements.
- Partnering with nonprofit and proprietary developers can accelerate innovative models as in the example of the collaboration between the State of Vermont and the Cathedral Square Corporation.

### **Factors that may Facilitate or Hinder the Desired Residential Features**

Commonly licensing takes into account both the physical space and the service packages.

This form of licensing often allows for multiple-occupancy rooms, bathrooms shared with large numbers of people, and square footage per resident which is below the Federal minimum for nursing homes.

When services in community residential setting are paid for under HCBS waivers, eligible residents must be eligible for the alternative form of care, usually nursing homes. However, the regulations we reviewed are rife with expectations that residents leave the setting if their disability reaches a certain level—for example, bedridden for 2 weeks, unable to transfer, unable to rescue oneself in an emergency, or simply needing 24-hour nursing care (which is a slogan not an actual need because even in nursing homes virtually no resident receives 24-hour nursing care). Thus, assisted living or residential care may be seen as suited for only a segment of the nursing home population.

Encouragement of negotiated risk agreements (Texas, Vermont, Washington), emphasis on aging in place (Texas), and nurse delegation programs (Arkansas, Texas, Washington) are all facilitators of resident autonomy, particularly with regard to remaining in the setting. However contradictions may occur that undermine those features. In Texas, for example, there is incongruence between the strongly professed resident's right to age in place and the stringent licensure categories stipulating the level of care allowed in each of the 4 types of assisted living facilities.

If the housing component of residential care settings is unaffordable then those who spend down to the Medicaid waiver, are likely to need to move to another setting or, at a minimum, may need to leave their units and move to a smaller unit ear-marked for Medicaid. Spend-down in assisted living has been identified as a problem in purpose-built assisted living in Minnesota, but not in HUD housing where assisted living services are appended; in the latter situation, the tenants already have affordable rents based on income. To the extent that housing and service prices are disclosed, consumers might make more prudent shopping decisions.

In Minnesota among these 8 states (and also in Connecticut) the resident is assured a choice of service provider other than the provider designated to offer services in the Assisted Living. This undoubtedly increased freedom of choice but does not take into account the economies of scale used by an AL setting so as to be able to offer a range of services.

It is becoming more common for some residential settings to focus on specific health conditions such as post-acute head injury, autism, multiple sclerosis, mobility impairment, and challenging behavior. Advocates disagree on whether this homogeneity of clientele is an advantage or a feature that resembles an institution.

### **State Knowledge of Community versus Institutional Nature of Settings**

Some institutional elements in community residential settings have been encouraged in State regulations that permit sharing of bedroom accommodations among strangers or establish very small minimum dimensions for private and public spaces in the settings. This encourages minimums to become maximums. However, States typically do not know how many and which facilities do offer single occupancy rooms and apartments (or for that matter single occupancy nursing home rooms). If that and other information about physical structures and autonomy enhancing features were collected routinely and publicized, this might also allow the marketplace to encourage more normalized living settings. Minnesota collects information on single rooms as part of its nursing home report card and could incorporate similar information into assisted living report cards.

Information about how much choice and control individuals have within the settings and how much opportunity they have for integration with the larger community is more elusive to collect because it depends not only on structural elements (for example, proximity of community resources, adequacy and proximity of transportation, policies enunciated by the facility on rules

about visitors, sign-out and the like), but also on what is actually experienced by the residents. Some information can be gathered from periodic inspections and complaint investigations, and various states, notably Texas, post that information on the web for consumers. But complaint and inspection data are haphazard and may not reflect the actual bulk of resident's experiences. Therefore, direct surveys to residents and/or their agents are necessary. States that use the Core Indicator Survey or the Participant Experience Survey already have some information about the participant's perceived ability to choose where he or she lives and to exercise control in his or her life. If criteria such as the ones we advanced for discussion in this Topic Paper were accepted, a next step would be to make those criteria operational with measures made through direct questions to consumers.

Some states, for example Florida, have waivers that are specific to assisted living. For States like Minnesota consider assisted living services as one service in a large Elderly Waiver, there are difficulties in easily developing benchmarks about participants by the kind of setting where they live. Also when long-term support services are provided by managed care entities, again the information base may be insufficient. For example, it would be useful to know whether participants in various living situations, controlling for their levels of disability, are able to work in the community, but data systems may not easily allow for that information to be extracted.

### **Discussion and Conclusions**

Community based residential settings cannot be looked at in isolation. It is said that it takes a village to raise a child and it may also take a community-wide effort to sustain seniors and persons with disability in the community. It takes the combined efforts of supportive housing (not just bricks and mortar) designed to be accessible to the physically handicapped, safe and secure for people with cognitive disabilities (including persons with ID/DD and persons with

Alzheimer's disease while featuring privacy and residential scale for all. There needs to be an abundant array of services offered including transportation, employment opportunities, and access to shopping. There also needs to be a social infrastructure to facilitate social connections.

We found that residential services to persons with developmental disabilities were more often provided by licensed providers rather than in licensed facilities. This model may offer more flexibility for integration into the community.

In all the States we found some regulatory barriers that interfered with community living in group residential settings. These were less prominent in Minnesota (where no case-mix limits were established for assisted living) and perhaps least prominent in Vermont.

Most often community residential settings, even small group homes, were licensed, partly because reimbursement was tied to the setting rather than the person. Uncoupling that tie might be helpful.

Many of the States promulgated information about the quality of the community residential settings, and Texas in particular included information about resident's rights. This would seem a promising avenue to enhance residential features.

For residential criteria such as those suggested here were to be accepted, widespread education would be needed for service providers, case managers, regulators, and even the general public. States could lead in that effort.

States did not have systematic ways to know whether their community residential settings were adhering to residential criteria. Some features and policies of the settings could be incorporated into a data base as could data from surveys and complaint investigations, but systematic direct reports from samples of consumers and their agents would be the only source of information on some criteria.

Most of the States had made efforts to improve the quality of their institutions, increase the residential nature of the settings and the privacy, and individualize care to a greater extent. Nonetheless we did not really identify substantial numbers of nursing homes or ICF-MRs (except perhaps those with 6 or fewer residents) that met residential criteria. It would probably be easier to build up the service capacity in community residential settings while guarding against them becoming institutional than to transform those already licensed and functioning as institutions.