



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



ADULT DAY SERVICES:

A KEY COMMUNITY SERVICE FOR OLDER ADULTS

July 2006

Office of the Assistant Secretary for Planning and Evaluation

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This report was prepared under contract #HHS-100-03-0025 between HHS's ASPE/DALTCP and the Research Triangle Institute. For additional information about this subject, you can visit the DALTCP home page at http://aspe.hhs.gov/_/office_specific/daltcp.cfm or contact the ASPE Project Officers, Gavin Kennedy and Emily Rosenoff, at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C. 20201. The Project Officers can be reach through email at: Gavin.Kennedy@hhs.gov or Emily.Rosenoff@hhs.gov.

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July 2006

Prepared for
Office of Disability, Aging and Long-Term Care Policy
Office of the Assistant Secretary for Planning and Evaluation
U.S. Department of Health and Human Services
Contract #HHS-100-03-0025

The opinions and views expressed in this report are those of the authors. They do not necessarily reflect the views of the Department of Health and Human Services or the Research Triangle Institute.

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EXECUTIVE SUMMARY

Over the past two decades, state and federal long-term care spending on home and community services has increased, primarily through Medicaid waiver programs. Most of the research and policy literature on home and community services for elderly persons has focused on home care and residential care, including adult foster care and assisted living. Little attention has been paid to adult day services (ADS)--a nonresidential community service provided outside the home. Three major adult day services models are generally recognized: a social model; a health or medical model, which is sometimes combined with the social model; and a specialized model. This report will refer to all models generically as ADS.

The first ADS program was a geriatric day hospital program established in 1960 in Greensboro, North Carolina. The program evolved to become a community service to meet caregivers' need for respite in order to work, fulfill other obligations, and recover from the demands of continuous care. Many caregivers who use ADS are providing care to family members with dementia who need constant supervision to assure their safety.

The social model of ADS provides a secure environment, assistance with some activities of daily living (ADLs), and therapeutic activities aimed at helping participants to achieve optimal physical and mental functioning. In the health or medical model, ADS programs also provide skilled nursing and rehabilitation services and many programs combine both models. Specialized models are targeted to specific groups, such as individuals with HIV/AIDS, multiple sclerosis, acquired brain injuries, or mental illness. Most ADS programs serve a large proportion of participants with some degree of cognitive impairment, but some programs specialize in the care of individuals with dementia.

ADS programs are of interest to states because of their potential to delay or prevent nursing home placement, in large part by supporting informal caregiving. Informal caregivers are the backbone of the nation's long-term care system. Over seven million Americans provide 120 million hours of care to about 4.2 million elderly persons with functional limitations each week. The estimated economic value of this care ranges from \$45-\$96 billion a year. Research has found that caregivers who experience stress and burden are more likely to institutionalize relatives suffering from dementia. Once the physical resources of caregivers decline and other home and community resources (paid or unpaid) are unavailable, nursing home placement is more likely.

States are also interested in the potential of ADS to reduce health care costs by providing health monitoring, preventive health care, and timely provision of primary care, particularly for individuals at risk for incurring high medical costs. These include elderly individuals who are dually eligible for Medicare and Medicaid--called dual eligibles--who comprised 18 percent of all Medicare beneficiaries in 2000 but accounted

for 24 percent of total Medicare spending. Similarly, in 2002, they represented 16 percent of all Medicaid enrollees but 42 percent of program spending.

All states fund some form of ADS through either their Medicaid state plan or a waiver program, and in fiscal year 2005, Congress funded a Medicare demonstration of the provision of home health benefits in ADS programs.

However, little is known about the provision, use, or outcomes of ADS, particularly the medical model, and the ADS industry's capacity to provide health services. Research has been hampered by the considerable variation in the characteristics of ADS programs both within and across states, and by a lack of data.

Purpose of Study

The purpose of this study is threefold: (1) to inform policymakers about the current and potential role of ADS in the health care and long-term care systems as determined by state regulation; (2) to identify operational and regulatory issues facing ADS providers under different ADS models and in different regulatory and financing environments; and (3) to provide information that can guide future research and policy analysis on ADS for elderly persons generally and on medically-oriented ADS specifically.

Methodology

The study used several qualitative research methods, including: (1) an in-depth review of state approaches to regulating ADS; (2) consultation with a Technical Advisory Group, subject experts, state regulatory and Medicaid staff, and state provider associations; and (3) site visits to ADS providers in five states: Georgia, Illinois, Maryland, North Carolina, and Washington. See Appendix A for detailed information about the methods employed.

Regulatory Findings

States vary in their regulatory approaches. Half of the states license ADS providers, ten states certify them, four states require licensure for one ADS model and certification for another, and 13 states use some other type of regulation, such as contractual requirements for providers receiving public funding. The majority of states require inspections that often coincide with initial or annual certification or license renewal, and several stipulate that unannounced visits can be performed at any time. Providers of Medicaid-funded ADS must meet applicable state licensing and regulatory requirements and in over half of the states, must meet additional Medicaid requirements.

Most states regulate ADS to allow the provision of medical services. They provide general parameters for who may or may not be served but do not specify admission and discharge criteria. For example, they lack specific provisions regarding the types or level of functional or health needs that should prevent admission or trigger discharge.

Required and Optional Services

In most states, parameters regarding who can be served are determined indirectly through provisions regarding mandatory and optional services that indicate the level-of-care participants may receive. ADS providers are generally required to furnish assistance with ADLs and health monitoring. States that regulate adult day health care as distinct from adult day care require the former to furnish additional services, including skilled nursing services, medication administration, and physical, occupational, or speech/language therapy.

The majority of states require licensed personnel to administer medications. Some states permit unlicensed staff to do so under nurse delegation provisions. Most states require written policies for medication management and administration and many have requirements related to self-administration of medications.

Staffing Requirements

Most states specify minimum mandatory staff-to-participant ratios. Nearly two-thirds require one staff person to every six or eight participants. The highest ratio is one staff person for every four participants and the lowest ratio is one staff person for every ten participants. Some states require different ratios for different types of ADS programs and/or specific types of participants, for example, those with dementia and those with extensive needs. Required staffing ratios for persons with dementia are generally 1:4, but Michigan requires 1:3. Several states do not have minimum staff-to-participant ratios and allow providers to determine the number of staff based on their own assessment of the number necessary to meet participants' needs.

Virtually all states require specific types of staff for ADS programs, for example, a program, director, activities director and a nurse. Requirements for nurses vary from part-time to full-time, and whether they must be "available" or on-site at all times. Because most states require staffing consistent with participants' needs, licensed nurses are always required if ADS providers are mandated to furnish skilled nursing services.

Training Requirements

Nearly all states have orientation, initial, and ongoing training requirements, but they are minimal. Some states' requirements are general, while others specify the content of training and the number of hours required. Most states require at least one staff trained in first aid and CPR to be on duty at all times. About half of the states have special training requirements for staff who serve individuals with dementia.

Site Visit Findings

The ADS providers we visited are providing both health and long-term care services to impaired older persons, a high proportion of whom are unable to live alone. Informal care supplemented by ADS is enabling them to remain in their homes. The age range in the programs is 21 through 90-plus, but with the exception of the program serving persons with HIV/AIDS, all served a primarily elderly population.

Whether an ADS program serves younger adults--including those with mental retardation and other developmental disabilities and those with acquired brain injuries--depends on a combination of regulatory requirements and funding streams for these population.

The majority of program participants have extensive functional limitations, due to physical or mental impairments or a combination of both. Providers estimate that about 50-80 percent of older participants have cognitive impairment--with or without a diagnosis of dementia. Many have chronic health conditions requiring daily health monitoring and skilled nursing services. The licensed nurses employed by these ADS providers provide preventive and primary health care and coordinate this care with participants' primary care physicians.

Most providers felt that participants' functional and nursing needs have increased over the past few years and several providers felt that it was due to the increasing recognition of ADS as a viable alternative to nursing home and assisted living placement. Providers reported that they try to serve everyone who needs assistance, but the number of people with severe needs who can be served (e.g., individuals who need two persons to assist with toileting) is limited by the number of staff available.

Services Provided

Providers identified ADL assistance and medication administration as the most frequently provided services. Programs operating as combined or health/medical models also provided health monitoring, health education, and skilled nursing services.

Providers believe that their goals are to enable participants to remain in their homes as long as possible, and to maximize participants' cognitive and physical functioning, both maintaining function and restoring function lost due to social isolation and lack of stimulation. Many providers said that the ability to simultaneously offer different types of programming according to functional level was essential to ensuring optimal functioning.

Operational and Policy Issues

None of the ADS providers could meet their costs solely through private payments and public program reimbursement. Nearly all of the providers receive a significant percentage of their operating revenue from Medicaid and other public funding sources and all said that the reimbursement rate did not cover their costs. Several programs use part-time, flex-time, and on-call staff so they do not have to carry staff overhead when the census is low.

Some providers set their private pay rate higher than cost to subsidize the lower than cost reimbursement from public programs. Several programs depend on a significant amount of in-kind contributions and volunteers, and many programs rely on subsidies from parent organizations and charitable organizations during budget shortfalls. To assure a daily census that will meet operating costs, providers have to continually market their services, and some have had to allocate a substantial amount of their budget to do so.

Because some states require ADS providers to furnish transportation and others do not, transportation issues varied among the states. Whether or not they were required to provide transportation, and apart from funding concerns, virtually all providers said that participants' transportation needs posed a major logistical challenge and took up a great deal of staff time.

Several programs reported high retention rates for certified nursing assistants and other staff such as activity directors; others reported high turnover. Those that reported difficulty recruiting did so for professional staff--registered nurses (RNs) and rehabilitation therapists--noting that professional staff can earn more in other health care and long-term care settings.

For staff members who stay, providers attribute their retention to: (1) the work environment, which is less demanding than other long-term care settings; (2) higher staff-to-participant ratios than are found in assisted living and nursing facilities; (3) staff who value their role in a program that has a mission to serve the community; and (4) longstanding relationships with participants.

Regulatory Issues

Providers said that compared to other long-term care settings, ADS regulations set ideal rather than minimum standards. Providers felt that most state requirements regarding staffing and training were necessary to provide good care. They objected to requirements that they believed increased costs without increasing the quality of care, such as having to document staff arrival and departure times and some physical plant requirements. Providers noted other regulatory issues unique to their states.

Conclusions and Research Recommendations

Based on our study findings, we have drawn several conclusions.

Regulation

- The method states use to regulate ADS varies considerably, as does the content of the regulations. However, states generally distinguish between ADS and adult day health services, and have more extensive requirements for the health model. In general, staffing requirements are more stringent than those for residential care settings, particularly requirements for licensed nurse staffing in adult day health programs and programs that combine a social and medical model of care.
- In some states, regulations appear to limit providers' flexibility to provide services that meet caregivers' needs, such as arbitrary restrictions on the number of service hours that may be provided on weekends.
- It is likely that the considerable state variation in regulatory approaches will continue in the near future. In states without licensure, providers disagree about whether the industry should be licensed. One argument for doing so is that long-term care insurers will not reimburse ADS unless they are furnished by licensed entities. Providers in Washington noted this difficulty but those in Illinois did not.

Some providers would support licensure if it led to an increase in reimbursement rates and others believe it would aid in their marketing efforts to recruit private pay participants. However, in states that do not license ADS providers, some fear that licensing would be added to Medicaid requirements rather than replacing them.

- Adult day health services are part of the continuum of both health and long-term care services. In the states we visited, ADS providers are furnishing preventive care, health monitoring, and skilled nursing services to individuals with chronic illnesses and physical and cognitive impairments. Some providers are also serving adults under age 65, depending on regulatory requirements and the funding streams for this population.

Because ADS providers must meet Medicaid state plan or waiver contracting requirements to furnish services to Medicaid beneficiaries--either in addition to or in lieu of state licensing or certification requirements--they are regulated at a level which allows them to furnish health-related and medical services as well as long-term care services to elderly persons with a high level of nursing and medical needs.

Program Models

- The number of purely social ADS programs may decrease as more providers offer combined or health/medical models. Social programs appear to be at a disadvantage because many participants disenroll as they age and their health and functional needs increase. A combined program offering both a social and medical model appears to be the most financially viable.

The literature on caregiver stress has pointed out the need to use a social model of ADS when people are not so impaired, to help prevent “burnout,” and many providers noted a need for this model. Others point out that specialized social programs are essential for individuals with dementia who do not have ADL impairments and medical needs. However, these programs may not survive due to: (1) the pressure to serve large numbers in order to meet fixed overhead costs and regulatory requirements, and (2) the need to meet the health and functional needs of increasingly older and more impaired participants, particularly if they want to be Medicaid providers.

Funding and Reimbursement

- A unique feature of ADS relative to nursing homes and residential care settings is their reliance on multiple funding sources to cover operating costs. While Medicaid is the primary public funding source for ADS providers through either a waiver program or the state plan, in the five states we visited reimbursement rates were not sufficient to meet costs. To remain financially viable and serve non-Medicaid eligibles who cannot afford to pay for some or all of the services they need, ADS programs must find other sources of funding.

Other funding sources include state and local program funds, Veterans Administration funds, the Social Services Block Grant, Older Americans Act funds, private payments--both out-of-pocket and from long-term care insurance, contributions from local service agencies such as United Way, and charitable contributions obtained through significant and ongoing fundraising efforts. Every ADS program we visited also relied extensively on in-kind contributions and numerous volunteers. The combination of funding sources, each with its own rules, greatly complicates the administration of ADS and can limit providers' flexibility to meet consumer's needs.

- States that pay flat rates create a disincentive for providers to admit participants with severe impairments. Some states pay either hourly rates or have tiered rates for different levels of care.
- The cost of ADS is relatively inexpensive compared to home care. Agencies charge as much as \$20-\$25 for an hour's visit by a home health aide and \$85 or more for a half-hour visit by an RN. The national average daily cost for the social

model of ADS is about \$54, for the medical model about \$59, and for the combined model about \$57.

In the five states we visited, some providers furnished only the minimum number of hours required by public programs to receive the daily rate--never fewer than four. In other states, providers furnished up to 11 hours a day on the daily rate. Despite the relatively low cost of ADS, the five states we visited do not appear to be interested in expanding the availability of ADS generally--or medically-oriented ADS specifically.

Operational Issues

- Lack of transportation and the high cost of transportation are major impediments to the use of ADS.
- Without greater public recognition of the role ADS can play in maintaining adults of all ages with disabilities in home and community settings, it is unlikely that ADS programs will see an increase in private pay participants.

Although some providers and experts feel that public knowledge about ADS has improved, all acknowledge that it lags far behind public knowledge and understanding of other long-term care options. Even though ADS allow significantly impaired nursing home-eligible participants to remain at home or living with family, providers believe that the public still thinks that ADS are the adult equivalent of child care. This perception would appear to be widespread, as evidenced by a 2002 article in the *Wall Street Journal* titled "When Your Parents Need a Baby-Sitter: Adult Day Care Centers in Short Supply."

Other erroneous perceptions are that ADS are only for the poor, only for the rich, only for "old people," or only for people with dementia. To alter these perceptions, the industry may need to engage in public education efforts. While the national ADS association supports a change in the name from adult day care to ADS, providers need to use the terms that public programs use in order to qualify for funding.

Recommendations for Future Research and Policy Analysis

Based on anecdotal evidence from providers and families, ADS enable informal caregivers to continue providing care in the home, thereby delaying or preventing institutionalization. More research is needed to document the long-term care cost-savings of these programs. Such research could guide state policymakers who have to carefully target expansions of home and community services to assure the cost-effectiveness of limited resources.

ADS also appear to offer a means to reduce health expenditures. Washington's Medicaid agency is conducting a study examining clinical outcomes and medical expenditures for adult day health participants who reside in adult family homes. While the final results of this two-year study are not yet available, preliminary analysis has demonstrated overall cost-savings. Given the potential for health care cost-savings, particularly as the population ages, other states may want to consider analyzing Medicaid data to determine the cost-effectiveness of ADS.

Such research would provide much-needed documentation to determine whether an expansion of ADS that provide health services is warranted.

1. INTRODUCTION

Over the past two decades, state and federal long-term care spending on home and community services has increased, primarily through Medicaid waiver programs. Most of the research and policy literature on home and community services for elderly persons has focused on home care and residential care, including adult foster care and assisted living. Little attention has been paid to adult day services (ADS)--a nonresidential community service provided outside the home for less than a full day. Three major ADS models are generally recognized: a social model; a health or medical model, which is sometimes combined with the social model; and a specialized model. This report will refer to all models generically as ADS.¹

The first ADS program was a geriatric day hospital program established in 1960 in Greensboro, North Carolina. ADS evolved to become a community service that meets caregivers' need for respite in order to work, fulfill other obligations, and recover from the demands of continuous care. Many caregivers who use ADS are providing care to family members with Alzheimer's disease and other dementias who need constant supervision.

The social model of ADS provides a secure environment, assistance with some activities of daily living (ADLs), and therapeutic activities aimed at helping participants to achieve optimal physical and mental functioning. In the health or medical model, ADS programs also provide skilled nursing and rehabilitation services and many programs combine both models. Specialized models are targeted to specific groups, such as individuals with HIV/AIDS, multiple sclerosis, acquired brain injuries, or mental illness. Most ADS programs serve a large proportion of participants with some degree of cognitive impairment, but some programs specialize in the care of individuals with dementia.

ADS programs are of interest to states because of their potential to delay or prevent nursing home placement in large part by supporting informal caregiving. Informal caregivers are the backbone of the nation's long-term care system. Over seven million Americans provide 120 million hours of care to about 4.2 million elderly persons with functional limitations each week. The estimated economic value of this care ranges from \$45-\$96 billion a year.² Research has found that caregivers who experience stress and burden are more likely to institutionalize relatives suffering from dementia. Once caregivers' physical resources decline and other home and community resources (paid or unpaid) are unavailable, nursing home placement is more likely.³

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All states fund some form of ADS through either their Medicaid state plan or a waiver program, and in fiscal year 2005, Congress funded a Medicare demonstration of the provision of home health benefits in ADS programs.

However, little is known about the provision, use, or outcomes of ADS, particularly the medical model, and the ADS industry's capacity to provide health services. Research has been hampered by the considerable variation in the characteristics of ADS programs both within and across states, and by a lack of data.

Purpose of Study

The purpose of this study is threefold: (1) to inform policymakers about ADS' current and potential role in the health care and long-term care systems as determined by state regulation; (2) to identify operational and regulatory issues facing ADS providers under different ADS models and in different regulatory and financing environments; and (3) to provide information that can guide future research and policy analysis on ADS for elderly persons generally and on medically-oriented ADS specifically.

Methodology

The study used several qualitative research methods, including: (1) an in-depth review of state approaches to regulating ADS; (2) consultation with a Technical Advisory Group, subject experts, state regulatory and Medicaid staff, and state provider associations; and (3) site visits to ADS providers in five states: Georgia, Illinois, Maryland, North Carolina, and Washington. See Appendix A for detailed information about the methodology.

Organization of Report

Following this introduction, Section 2 provides a brief overview of the limited research on ADS conducted to date. Section 3 presents an overview of state approaches to regulating ADS for elderly persons, which briefly summarizes the content of a companion report --*Regulatory Review of Adult Services*--conducted as part of this study.⁵ Section 4 presents the findings from site visits to ADS providers in five states and Section 5 presents providers' and stakeholders' views on regulatory issues in their states. Section 6 presents conclusions and recommendations for future research and policy analysis.

Appendix A presents detailed information on the study's methodology. Appendix B provides regulatory summaries for the five site visit states. Appendix C lists the members of the Technical Advisory Group.

2. OVERVIEW OF ADULT DAY SERVICES RESEARCH

There is a paucity of empirical research on ADS. A 2001 review of the literature found only 45 articles published between 1975 and 1999 on a range of ADS topics.⁶ In 1987, the Robert Wood Johnson Foundation (RWJF) initiated the *Dementia Care and Respite Services Program*, the first national ADS demonstration program, in cooperation with the Alzheimer's Association and the Administration on Aging. The national program office was located in the Wake Forest University School of Medicine. Studies funded through this program demonstrated that ADS programs for people with dementia can provide needed services--including medical services--to individuals with a wide range of needs and still be financially viable in the private pay market. RWJF then launched the *Partners in Caregiving* program to apply the lessons of the demonstration in 25 program sites. The program has since disseminated the lessons from these demonstrations to ADS programs throughout the country.

Between 2001 and 2002, Wake Forest University conducted a national survey of ADS providers that examined four major areas: (1) characteristics of the program such as age, type of organization operating the program, licensure or certification status, operational policies, and staffing; (2) services provided, such as meals, transportation, personal care services, and therapeutic, social, medical, and nursing services; (3) the characteristics of participants, including age, ethnicity, condition or diagnosis, Medicaid status, ADL status, living situation, length of stay, and reason for discharge; and (4) rates and reimbursement sources. The survey also asked providers about any operational concerns or problems.⁷

The study found that the 37 percent of ADS provider offered a social model of care (no nursing services furnished), 21 percent provide a medical model (nursing services and in some instances rehabilitation therapies furnished), and 42 percent provide a combined social and medical model. Twenty percent exclusively serve individuals with dementia. The average total enrollment was 42 participants and the average daily attendance was 25. The average length of stay was two years. The three major problems providers cited are inadequate funding; difficulty recruiting and retaining staff; and difficulty maintaining census and attendance levels needed to cover operating costs.

In 2001, Rutgers Center for Health Policy conducted several studies to guide policy regarding ADS in New Jersey. The state provides these services to over 9,000 beneficiaries through its Medicaid state plan as well as through certain waiver programs. With about 10-15 new facilities applying for licensure each year, the state is concerned about continued increases in annual Medicaid expenditures for adult day health services with no limits set on the number of participants.⁸

The first study was a literature review of adult day health services with a focus on studies that could inform the potential use of a needs-based reimbursement model for adult day health service participants.⁹ This review reported that the primary reason for using ADS is caregiver respite. Whether caregivers will use the service depends on the severity of impairment, nursing and rehabilitation needs, associated caregiver burden, and the fit between the services offered and the needs of the participant. Prior nursing home use, a history of mental illness, stroke, or cancer, and paying for services privately increased the likelihood of clients' full-time attendance at ADS programs.¹⁰

The typical user is a 75-year-old White woman who lives with a spouse or another relative. Many participants have chronic illnesses and multiple dependencies in ADLs including toileting and eating. ADS users are more likely than home health users to have some type of dementia that requires constant supervision. Other populations using day health services include children and adults with developmental disabilities and children who have unstable medical conditions and/or are technologically dependent.¹¹

The second study was a national survey of adult day health service programs.¹² Its purpose was to examine the characteristics of publicly financed adult day health services programs. The study focused on the largest program in each state, which in most cases was funded by either the Medicaid state plan or an Aged and Disabled waiver program.

The study's primary goal was to identify commonalities and differences across various program characteristics and reimbursement approaches. The program characteristics described for each state in the study are: type of funding; eligibility criteria; types of assessments used; services provided; and reimbursement methods. The report also provides an estimate of the number of facilities and participants.

A 2001 review of the literature on the effectiveness of ADS programs found that the majority of research focused on three major areas: (1) the ability of ADS programs to maintain or improve the functioning of participants; (2) the effect of ADS program use on caregiver characteristics, such as stress and care burden; and (3) the ability of ADS programs to delay or prevent nursing home placement.¹³ Most of the caregiver literature has focused on individuals providing care to family members with dementia.¹⁴

The authors of the review noted that because the literature on ADS is diverse in terms of focus, design, and client population, drawing conclusions is difficult. Nonetheless, they stated that ADS programs are more of a supplement to informal care than a substitute for nursing home care. Some analysts would dispute the validity of this conclusion based on methodological issues in the studies reviewed. In particular, the lack of a demonstrated effect on nursing home use may be due to insufficient use of ADS. For example, to prevent nursing home placement, ADS may need to be used 4-6 hours a day five days a week rather than four hours a day twice a week.

Research on caregiving and the institutionalization of cognitively impaired older persons suggests that the effect of community services on nursing home placement is

also dependent on other factors in addition to the frequency and duration of ADS use. These include the timing of use--whether it occurs early in the caregiving experience or after a caregiver has "burned out"--and family preferences.

Another study of ADS funded by the National Multiple Sclerosis Society is currently underway. This study is conducting a comprehensive evaluation of Multiple Sclerosis Adult Day Programs (MSADPs), using case studies, cost analyses, and outcomes analysis. The study aims to determine the costs of developing and maintaining MSADPs, and to identify their outcomes, including quality of life, health status, functional status, rates of institutionalization, and complications.

Interest in ADS research among advocacy organizations for older and disabled Americans has been limited. The Alzheimer's Association and the American Association of Retired Persons (AARP) offer fact sheets for their membership on choosing ADS providers, but neither has funded research on ADS. The National Council on Aging funded the National Institute on Adult Daycare in the early 1990s, but the institute is no longer operating.

3. OVERVIEW OF ADULT DAY SERVICES REGULATIONS

This section first describes four approaches to regulating ADS in key areas and highlights similarities and differences among them. It then provides an overview of key regulatory provisions. Its content is drawn from the *Regulatory Review of Adult Day Services*, which examines regulatory provisions particularly relevant to understanding the role ADS play in the health care and long-term care systems.¹⁵ For example, the review does not cover physical plant requirements or provisions related to record-keeping or medication storage policies. Because the focus of the review is on services for elderly persons, regulatory or Medicaid contractual requirements for ADS providers who exclusively serve individuals with mental retardation or other developmental disabilities are also not covered.

Regulatory Approaches

Exhibit 1 indicates each state's regulatory approach. The majority of states regulate ADS by requiring either licensure or certification. A few states license one type of ADS and certify another, and 13 states have other requirements, sometimes in addition to licensing and certification.

Whatever the regulatory approach, the majority of states have requirements addressing the same issues, for example, required and optional services, medication administration, staffing, training, and monitoring. States that require licensure do not appear to have more requirements or more stringent or prescriptive requirements than do states that require certification or that use some other regulatory approach. In general, ADS providers who want to serve publicly-funded clients--including those eligible for Medicaid--must meet all applicable regulatory requirements. If there are none or they are not considered adequate, public programs have contractual requirements that providers must meet.

While many states have different standards for social and medical models of ADS, they do not mandate the provision of a particular type of care. However, ADS providers who want to serve Medicaid beneficiaries must generally--but not always--offer a medical or a combined model of care.

We did not identify any rationale that would explain why some states have chosen one regulatory approach over another. Anecdotally, we heard that "adult day care" is often perceived as an adult version of child care--providing meals, supervision, some activities, and not much else--and that the regulatory structure in some states has not yet "caught up" with industry practice. This could explain why some states, such as Washington, do not license what is essentially a medical service provided under its

Medicaid state plan. Stakeholders in some states that do not require licensure said that the contractual requirements of public programs, particularly Medicaid, are sufficient.

The National Adult Day Services Association (NADSA), which represents providers, supports greater regulation to assure quality of care, for example, by requiring a minimum amount of activity programming. They would also like to see model regulations, which might help assure more uniform regulations among the states. However, as discussed later in this report, many ADS providers believe that compared to the regulation of other long-term care settings, ADS regulatory requirements are based on ideal rather than minimal standards.

Licensure

State approaches to licensure vary. Some states license a single type of program; others cover two or more program types under a single licensing category. For example, Maine licenses two types of programs--adult day health services and social ADS programs--as Adult Day Services. Some states require separate licenses for specific types of programs in addition to basic licensure. In Maine, either of the two program types may operate a night program that provides services to persons with dementia, but must have a separate license to do so and must keep record-keeping distinct.

Several states permit ADS to be co-located in other licensed facilities, for example, a nursing home or assisted living facility. Minnesota, for example, requires an identifiable unit in a licensed nursing home, hospital, or boarding care home that regularly provides day care for six or more functionally impaired adults, who are not residents of the facility, to be licensed as an adult day care center or ADS center.

States do not generally license by levels of care or license dementia-specific facilities or programs. However, many have specific provisions in their standard ADS licensing requirements for providers serving individuals with dementia. The provisions generally relate to staffing and training, such as requiring higher staff-to-participant ratios and dementia-specific training.

Certification

Ten states require certification in place of licensure. Of these, Alaska, Colorado, Ohio, Indiana, and Wisconsin require only Medicaid providers to meet ADS certification standards. Like states that license ADS providers, some states that require certification distinguish between different types of ADS programs. For example, Ohio requires ADS programs to be certified by the Ohio Department of Aging as “enhanced” or “intensive”.

A few states certify Alzheimer’s programs separately from other ADS programs. For example, Iowa certifies dementia-specific ADS programs and Colorado certifies specialized ADS centers to provide intensive health supportive services for participants with a primary diagnosis of Alzheimer’s or other dementias, Multiple Sclerosis, brain

injury, chronic mental illness, developmental disabilities, or individuals post-stroke who require extensive rehabilitative therapies.

Both Licensure and Certification

Only four states have both licensure and certification requirements, generally for different types of programs. Kentucky licenses Medicaid providers of adult day *health* care but certifies adult day care and Alzheimer's respite programs. Nevada requires all facilities offering adult day or adult day health care to be licensed (including Medicaid waiver and state plan providers) but requires Medicaid state plan providers to also meet adult day health care certification standards. Maryland licenses two types of ADS--day care and medical day care--but only requires certification for a social adult day care program. California licenses adult day programs and adult day healthcare centers (ADHCs) and requires the latter to also be certified.

Other Required Provider Agreements

States that neither license nor certify generally require publicly-funded ADS providers to enter into official, most often contractual, agreements with a state agency, specifying that they will comply with requirements. These states do not have any requirements for providers who serve only private pay clients. For example, Alabama requires adult day care providers receiving Department of Human Resources funds to enter into contracts with the Office of Social Service Contracts. Elderly and Disabled Waiver providers must have specific approval to offer adult day health care from the state Medicaid agency and must meet Medicaid requirements.

Washington requires adult day care or day health centers that serve Medicaid clients to contract with the Department of Social and Health Services, an Area Agency on Aging, or other departmental designees. Medicaid providers must comply with the rules in the Washington Administrative Code for adult day care and adult day health care services.

Two states have operating standards for providers. Michigan's Office of Services to the Aging has operating standards for publicly-funded providers of adult day care services. Services may be provided only under an approved area plan through a formal contractual agreement between the Area Agency on Aging and the service provider. Oregon has only voluntary operating standards for ADS providers. All ADS providers (except for licensed long-term care facilities providing ADS programs) are required to register their programs with the Department of Human Services, Seniors, and People with Disabilities and state their intent to voluntarily comply with the standards.

The Commission on Accreditation of Rehabilitation Facilities (CARF) offers voluntary accreditation to adult day health services programs as a way to maintain standards and assure quality. Since 1998, CARF has provided accreditation for adult day healthcare services (ADHS) programs through an agreement with NADSA. One

state--Idaho--developed provider guidelines in accordance with CARF standards and requires adult day care programs to operate under these guidelines.

State Definitions of Adult Day Services

The majority of states regulate only one or two types of ADS. In states with two types, the primary difference is that one has to furnish skilled nursing care and other health services and the other does not.

For example, in Washington, *adult day care* is defined as a supervised daytime program providing core services appropriate for adults with medical or disabling conditions that do not require the intervention or services of a registered nurse (RN) or licensed rehabilitative therapist acting under the supervision of the client's physician. *Adult day health care* is defined as a supervised daytime program providing skilled nursing and rehabilitative therapy services in addition to core services provided in adult day care.

Definitions of ADS generally do not state that they are a social, combined, or medical model. Rather, they include a statement of their purpose, thresholds for the number of people who can be served, limits on the number of hours a person may be served, and parameters for who may or may not be served. Several examples follow.

- Georgia defines *adult day services* as a program for providing a safe group environment with coordinated health and social services aimed at stabilizing or improving self-care as well as preventing, postponing, or reducing the need for institutional placement. Their purpose is to provide support for elderly individuals who cannot fully function independently but who do not need 24-hour nursing care. Participants may have physical, social, and/or mental impairments, need assistance with ADLs less than that requiring placement in an institution, or have recently returned home from a hospital or institutional stay.
- Rhode Island defines *adult day services* as a community-based group program designed to meet the bio-psychosocial needs of adults with impairments through individual plans of care. These structured, comprehensive, nonresidential programs provide a variety of health, social, and related support services in a protective setting. By supporting families and other caregivers, ADS enable participants to live in the community.

States also define ADS by setting thresholds for the number of participants that will trigger regulatory requirements and by setting minimum and maximum hours for service provision. States do not vary much with regard to thresholds. The maximum number that triggers regulation is typically between three and five individuals unrelated to the provider. Tennessee is an exception, setting the threshold at ten individuals.

States' requirements regarding minimum and maximum services hours are more varied, and most set only maximums. In Idaho participants may be served during any part of the day but for fewer than 14 hours. Iowa's maximum is 16 hours in a 24-hour period. Some states, such as Kansas, require only that programs operate fewer than 24 hours a day. Tennessee defines adult day care services as those provided for more than three hours but fewer than 24 hours per day.

Provider Requirements

The regulation of a service targeted to frail elders and individuals with disabilities needs to assure that providers can meet their clients' needs. To do this, states specify parameters for who can be served, and service requirements, medication administration, staffing and training.

Parameters for Who Can Be Served

Most states lack specific admission, retention, and discharge criteria. States that have these criteria--such as Alabama--have general requirements only (e.g., requiring providers to discharge participants whose needs they can no longer meet or when participants' present an immediate and serious risk to their or others' health, safety, or welfare). The lack of specific admission and discharge criteria in effect allows providers to determine who they will serve.

Most states have provisions related to involuntary discharge. For example, Vermont's rules limit involuntary discharges to the following situations: (1) the participant's care needs exceed those an adult day center is certified to provide, (2) an adult day center is unable to meet the participant's assessed needs, or (3) the participant presents a threat to himself or herself or to other participants or staff.

In most states, parameters for who can be served are set indirectly by specifying mandatory and optional services. States that require or permit providers to offer skilled nursing services in effect allow them to serve individuals who need such services.

Required and Optional Services

All states list required and optional services for each type of ADS that they license, certify, or otherwise regulate, for example, for adult day care and adult day health care. States generally require all ADS providers to furnish ADL assistance and health monitoring. Health education; physical, occupational, and speech therapy; and skilled nursing services are less likely to be cited as either required or optional, but states generally require adult day *health* services or *medical* adult day service providers to furnish these services.¹⁶

For example, Virginia requires *ADHCs* to meet the needs of each participant, and specifies that a minimum range of services must be available to every Medicaid ADHC

recipient, including nursing services and rehabilitation services. Virginia further specifies that centers can admit recipients who need skilled services only if professional nursing staff are immediately available on-site to provide them.

Generally, states permit medical models of ADS to serve individuals with a high level of nursing and medical needs, which is to be expected since the majority of states cover ADS in waiver programs that require individuals to meet the state's nursing home level-of-care criteria. However, because states' level-of-care criteria vary considerably, individuals who are nursing home eligible in one state may have greater or lesser needs than those who are nursing home eligible in another state.

A few states use a flexible approach to regulating services, basically requiring providers to meet the needs of their clientele, whatever they may be. Under this approach, if providers admit someone who needs physical therapy they must either furnish it or arrange for its provision.

Medication Administration

In most states medication administration is not a required service except for adult day *health* care providers. The majority of states require licensed personnel to administer medications.

States that permit unlicensed staff to administer medications generally require that they do so under nurse delegation provisions, though a few require only consultation with a physician or pharmacist, or specific medication training. Vermont, for example, requires an adult day center to have the capacity to administer medications to its participants and requires a medication management policy that describes a center's medication management practices with due regard for state requirements, including the Vermont State Nurse Practice Act. An adult day center must provide medication management under the supervision of a RN or a licensed practical nurse (LPN) who is under the direction of a RN.

Most states require providers to have written policies for medication management and administration. For example, Georgia requires adult day care programs to have a written policy for medication management designating specific staff to be authorized and trained to assist with the administration of medications, and designating the program's role in the supervision of self-administered medications and/or staff-administered medications.

Many states also specify requirements related to self-administration of medications. For example, Texas requires individuals who self-administer their medications to be assessed at least monthly by licensed nursing staff to determine if they are still capable of self-administration.

Staffing Requirements

States vary with regard to the number of staff required for ADS programs. Most mandate minimum staff-to-participant ratios, ranging from 1:4 to 1:10. Some states require different ratios for different types of ADS, and some states specify both a required ratio and a recommended ratio. Some states require more staff when serving participants with greater needs, but allow providers to determine when additional staff are needed.

Georgia, for example, requires programs to have, in addition to administrative staff, a minimum of one direct service staff person for each eight nonseverely impaired participants or for each four severely impaired participants. The state does not specify what constitutes severe or nonsevere impairment, leaving this determination to the provider.

Several states do not have minimum staff-to-participant ratios and allow providers to determine the number of staff, requiring only that they be “sufficient” to meet participants’ needs. For example, Idaho requires that staff be adequate in number and skill to provide essential services but does not define essential services. The state further specifies that the number of staff per participant must increase “appropriately” if the number of participants in day care increases, or if the degree of severity of participants’ functional or cognitive impairment increases. However, we identified no guidance for what constitutes an “appropriate” increase. The state has more specific requirements for Medicaid providers, who must have a minimum of one staff for every six participants, and a 1:4 ratio when serving a high percentage of participants who are severely impaired.

Staffing for persons with dementia. Twenty-five states have special provisions for serving individuals with dementia, most of which relate to staffing and training requirements. Required staffing ratios for persons with dementia are generally 1:4, though Michigan requires Dementia Adult Day Care programs to have a minimum staff/volunteer/student-to-participant ratio of 1:3.

Some states specify higher staff-to-participant ratios for people with cognitive impairment who may or may not have a dementia diagnosis. In Minnesota, adult day care/services centers that serve both participants who are capable of taking appropriate action for self-preservation under emergency conditions and those who are not, are required to maintain a staff-to-participant ratio of 1:5 for participants not capable of self-preservation and 1:8 for those who are capable.

Types of Staff. In addition to staffing ratios, virtually all states require specific types of staff for ADS programs. The major difference in requirements between adult day care and adult day health care is that states require the latter to have licensed nurses available in some capacity (e.g., as full-time or part-time employees or as consultants). Because most states require staffing consistent with participants’ needs, licensed nurses are required if they need skilled nursing services.

Colorado, for example, requires all ADS centers to provide nursing services to regularly monitor participants' ongoing medical needs and supervise medication administration. These services must be available a minimum of two hours daily and must be provided by a RN or LPN, or by a certified nursing assistant (CNA) under the direction of an RN or an LPN. Supervision of CNAs must include consultation and oversight on a weekly basis or more according to the participants' needs. Specialized ADS centers providing a restorative model of care must have sufficient staff to provide the following: (1) nursing services during all hours of operation provided by an RN or LPN, or by a CNA under the supervision of an RN or LPN, and (2) therapies to meet the restorative needs of the participants.

In some states, the Medicaid program has specific requirements for nurse staffing to assure that waiver participants' needs are met. For example, South Carolina requires an LPN on site whenever waiver clients are present, and Texas requires a minimum of one RN or licensed vocational nurse on site eight hours per day, and further requires that sufficient licensed nursing staff must be on site to meet the nursing needs of the clients.

Training Requirements

Virtually all states have orientation, initial, and ongoing training requirements, but they are minimal. Some requirements are quite general, while others specify the type of training and the number of hours required. Most states require at least one staff trained in first aid and CPR on duty at all times. For direct care workers, Utah requires only eight hours of initial orientation training designed by the director to meet the needs of the program, plus ten hours of work-related training annually.

Delaware, on the other hand, requires aide orientation and training to include at least 40 hours of instruction and supervised practicum on specific topics, including personal care services; process of growth, development, and aging; principles of infection control; observation, reporting, and documentation of participant status; maintaining a least restrictive environment; and verbal/nonverbal communication skills.

South Carolina does not specify a minimum number of training hours, instead requiring each facility to: (1) provide a written orientation program to familiarize new staff members with the facility, its policies and procedures; and (2) an in-service program to ensure that all employees continue to understand their duties and responsibilities.

States with specific training requirements for ADS providers who serve persons with dementia generally specify the content of required training. For example, Minnesota requires that the facility's direct care staff and their supervisors be trained in problem solving with challenging behaviors and communication skills. California requires training regarding the use and operation of egress control devices (i.e., those preventing participants from leaving the facility), the protection of participants' personal

rights, wandering behavior and acceptable methods of redirection, and emergency evacuation procedures for persons with dementia.

Monitoring

The majority of states require inspections--most of them annual inspections that coincide with an initial license application and annual license renewal. Several states also stipulate that unannounced visits by state personnel can occur at any time. Only one state--Alaska--does not have external monitoring. The state does not license ADS providers and requires only that adult day care programs conduct internal evaluations of their operation and services at least annually. However, site visit inspections are required for programs receiving state grant funds.¹⁷

States vary considerably in the frequency of required inspections. Delaware requires regular inspections only once in a three-year period but North Carolina monitors Adult Day Health (ADH) Programs at least monthly to assure compliance with standards and also conducts an annual inspection. Arizona renews licenses for two years, as opposed to one year, if a licensee has no deficiencies at the time of the licensure inspection. Montana conducts routine, unannounced licensure inspections every one to three years and a license's duration is dependant on the number and type of deficiencies found. If any deficiencies relate to the health, safety, and welfare of a resident, a provisional license or a one-year license is issued.

A few states specify provisions to address complaints. For example, the Arkansas Office of Long Term Care conducts complaint inspections in adult day health care facilities to determine their validity, and in Missouri the state makes unannounced visits for investigative purposes when complaints have been filed regarding a program.

Medicaid Contracting Requirements

All states fund ADS for elderly persons through either their Medicaid state plan or waiver program or both: six under the state plan only; 36 under 1915(c) waivers only; seven under both; and two under an 1115 waiver.

Providers of Medicaid-funded ADS must meet all applicable regulatory requirements: licensure, certification, or other arrangements. Also, Medicaid generally requires ADS providers who furnish adult day health services to waiver participants to meet additional standards than those the state requires for licensure or certification. Over half of the states require ADS providers to meet additional Medicaid provisions:

Alaska	Idaho	Nebraska	Oklahoma
Arizona	Kansas	Nevada	South Carolina
California	Maine	New Hampshire	Texas
Delaware	Maryland	New Jersey	Vermont
District of Columbia	Minnesota	New Mexico	Virginia
Florida	Mississippi	North Dakota	
Georgia	Missouri	Ohio	

Mississippi's additional requirements for Aged and Disabled waiver providers include more detailed parameters regarding who they can and cannot serve. Missouri licenses adult day care but has more extensive staffing requirements for Aged and Disabled waiver providers of adult day health care. South Carolina licenses adult day care services but has additional requirements for Community Long-Term Care Medicaid waiver providers related to nursing staff-to-participant ratios and care managers.

EXHIBIT 1. Approach to Regulation by State				
Licensure and Certification Requirements^a				
State	Licensure Only	Certification Only	Both Required	Other
Alabama				■
Alaska		■		
Arizona	■			
Arkansas	■			
California			■	
Colorado		■		
Connecticut		■		
Delaware	■			
District of Columbia		■		■
Florida	■			
Georgia				■
Hawaii	■			
Idaho				■
Illinois				■
Indiana		■		
Iowa		■		
Kansas	■			
Kentucky			■	
Louisiana	■			
Maine	■			
Maryland			■	
Massachusetts				■
Michigan				■
Minnesota	■			
Mississippi				■
Missouri	■			
Montana	■			
Nebraska	■			
Nevada			■	
New Hampshire	■			
New Jersey	■			
New Mexico	■			
New York				■
North Carolina		■		
North Dakota				■
Ohio		■		
Oklahoma	■			
Oregon				■
Pennsylvania	■			
Rhode Island	■			
South Carolina	■			
South Dakota				■
Tennessee	■			
Texas	■			
Utah	■			
Vermont		■		
Virginia	■			
Washington				■
West Virginia	■			
Wisconsin		■		
Wyoming	■			
Total	25	10	4	13

^a For more detailed information, please consult the individual state profiles in the Regulatory Review at <http://aspe.hhs.gov/daltcp/reports/adulday.htm>. For example, Kentucky requires licensure or certification depending on the type of services offered; adult day health care is licensed and adult day care is certified.

4. SITE VISIT FINDINGS

We conducted site visits in five states: Georgia, Illinois, Maryland, North Carolina, and Washington. See Appendix A for information about the methods used to select the states and the three to four providers we visited in each state. This section describes the characteristics of these providers.

General Impression of Physical Structure

Traditionally, adult day care has been offered by small nonprofit programs and located in donated or low-cost space such as a church basement. Several providers described these settings as sub-optimal primarily because they are not accessible for people with moderate to severe physical impairments, but also because they lack storage and office space, food preparation areas, and space for different program activities. Additionally, the physical setting is often not inviting, lacking daylight and comfortable attractive furniture.

While some social model ADS are still offered in such settings, the health or combined social/health model programs require physical settings that are accessible to individuals with severe physical impairments. Most of the programs we visited were recommended because they were considered “state of the art” and were in either retrofitted or purpose-built space designed to serve the needs of an impaired population. Only one program was in a very old freestanding building that clearly lacked adequate space, but it is relocating to a new purpose-built building in 2006.

Three programs were in commercially zoned buildings--one in a shopping center. All designed the interior to function as an ADS program, with multiple rooms for different functions. One program operating as part of a social service nonprofit, had sufficient space to run two separate programs--one for participants with moderate to severe cognitive impairment and one for higher functioning participants.

Some providers design their physical space to have a home-like ambiance. One program serving primarily urban African-American participants displays African-American cultural items thematically throughout its center to create a comfortable setting that affirms clients' heritage. Another has separate rooms with different design themes, including a “Men's Club” for the few male participants who want to engage in activities that do not interest the predominantly female participants, such as playing cards.

Most providers stated that furnishing a pleasant physical setting that avoided an institutional character was critical to attracting participants. In their experience, if a program's physical environment is poor, it can decrease utilization, particularly by middle-class/private pay individuals, even if the program has a reputation for excellent

care. With the exception of the programs in new purpose-built space, most providers said they would like to improve their space to better suit their needs. They cited a need for more storage, more office space, and additional space to fun activities simultaneously.

The primary factor that influenced the physical character of a building was, not surprisingly, affordability. Whether for-profit or nonprofit, providers said that the availability of financing was the key factor determining the quality of the physical structure and amenities, such as fully accessible bathing facilities, multiple rooms to permit activity programming according to participants' functional level and interests, and attractive and secure outdoor space for smokers and wanderers. Some facilities had outdoor space that could not be fully utilized because it was not secured for persons who wandered. One center that served only persons with dementia designed their indoor space to safely permit wandering.

Nonprofits are able to raise private funds and several of the programs we visited were in well designed and nicely furnished buildings that had been built with funds obtained from a major donor or through a capital fundraising campaign. Programs affiliated with a parent organization often benefited from the availability of space that could be retrofitted, and one operated in a public housing site that provided a large amount of space at a very low rent.

One nonprofit organization that provides ADS and nursing home services in different locations on a single campus built a very modern and well-equipped ADS center. Another program affiliated with a nonprofit hospital received an interest free multiyear loan to purchase a building and renovate it to serve as an ADS center. Another was developed as part of a new senior center, which was built with a significant amount of donated funds.

One nationally known program had a large enclosed outdoor terrace and garden so participants who wandered could do so safely. This same facility had toileting and bathing facilities specifically designed for persons with severe disabilities. For example, toilets were placed in the middle of a room rather than against a wall to facilitate two and three staff assistance. The bathing room had an adjustable height bathtub with a hinged door to enable safe transfers.

One program is newly housed in a multipurpose building physically connected with a Senior Center. The building is called a "Health and Wellness" Center and it houses other programs in addition to the ADH Program. One of the Center's goals is to foster use by people of varying ages and needs in order to promote integration of different disability and age groups with the "well" elderly who use the senior center. This building has a state of the art exercise facility designed to serve both able-bodied and disabled individuals, and a \$1.5 million computer center, donated by a foundation, which includes all the latest technology to enable people with all types of disabilities to use it. Participants in both the senior center and the ADH Program will use the computer center and exercise facility.

One unique program serving persons with HIV and AIDS shared a building with a nursing home with lots of outdoor space--patios and terraces--amenities for family and visitors, attractive décor and art work. Staff noted that the facility could not have been built without a multiyear capital fundraising campaign.

While the buildings that had many windows and lots of natural daylight were the most attractive, one program director said that windows in general, and particularly those with nice views are a major problem when serving people with dementia, who become distracted by the view. In many cases, the view of the outdoors “cues” the person to stop participating in activities and to leave the building.

Finally, some providers mentioned the need for stability as an important requirement for physical space. Two providers--one with a program in a nursing home and one in a church--were recently given short notice to find other space. In one case, the provider spent many months looking for new space, which he found in commercial space that he designed specifically for his program. While the new space is much more functional and attractive, the monthly rent increased by several thousand dollars, necessitating a major marketing effort to increase the daily census to cover the added cost.

Organizational Affiliations

The ADS programs we visited were either freestanding entities or affiliated with another organization. Parent organizations included a hospital, an organization providing a range of long-term care services in multiple settings, a nonprofit social service agency serving seniors, a for-profit company with centers in multiple states, a regional and national advocacy organization, and a health care organization that included nursing homes and rehabilitation facilities.

One program was provided by a nonprofit Community Council on Aging in a small town. Many of the parent organizations operated multiple ADS programs, and some provided other services including home health services. Providers described advantages and disadvantages for both freestanding and affiliated programs.

Several of the affiliated organizations felt that operating within a parent organization was not only desirable but necessary for financial viability. The program serving persons with HIV and AIDS said they could not operate as a freestanding facility because the hospital with which they were affiliated made substantial annual contributions, for example by providing group health insurance for its employees. Other programs mentioned both financial and in-kind contributions, including: administrative support; subsidizing the gap between the cost of ADS services and reimbursements; paying for liability insurance; facilitating equipment purchases; marketing/development and training support; and subsidizing transportation costs.

Several providers felt that being affiliated with a well-known and reputable entity gave them credibility within their community, ultimately helping to attract clients. However, others felt that being part of a larger organization offering multiple services could be a disadvantage because they were just one service among many competing for space and resources. One provider noted that the board of directors of the parent organization did not include anyone knowledgeable about their program. Another noted that the parent organization expected the program to contribute part of its revenue to overall operating expenses, but also noted that the organization subsidizes their costs when they have a shortfall.

Providers in freestanding centers cited the advantage of designing and running their programs according to their own vision, and having boards of directors who are very committed to the program. In several states, an individual with an interest in serving elderly and disabled persons in a particular community had established the freestanding center we visited. In one case, an individual established a center after experiencing difficulties in securing ADS for her elderly parent. This individual began her program in a church but later moved to a freestanding building when she became a Medicaid provider.

The primary disadvantage cited for being a freestanding facility was not having another entity to fall back on in the event of budget difficulties. One provider with a freestanding program said that three-month delays in Medicaid reimbursement made it difficult to cover costs.

One of the two for-profit programs we visited noted that they were disadvantaged by this status in the fundraising arena and would probably convert to nonprofit status because the for-profit status afforded no advantages.

In Washington, Georgia, and North Carolina, several nonprofit programs depended on annual fundraising for a significant portion of their revenue. The nonprofit programs in Maryland and Illinois relied instead on increasing and maintaining an adequate census and on financial and administrative support from parent organizations. However, one freestanding program did rely on annual contributions from board members and another received small grants from the organization's foundation arm. These funds are used to subsidize participants who can not afford the full number of days they would like to attend. Several providers expressed an interest in pursuing fundraising.

Population Served

The age of ADS participants in the five states ranged from 21 through 90+. With the exception of the program serving persons with HIV/AIDS, all of the programs served a primarily elderly population.¹⁸ For example, in one program, 71 percent of participants are between the ages of 70 and 89. Providers reported serving more females than males, although some programs with Veterans Administration (VA) funding had a higher proportion of males.

Most of the programs served a few younger adults. Whether younger adults are served often depends on the age-related eligibility requirements for publicly-funded programs. Generally, if ADS are covered by Medicaid programs that serve adults 18 and older, such as Aged and Disabled waiver programs or Washington's state plan ADH Program, adults of all ages who meet the service criteria can be served. In Maryland, medical day care is funded through the Medicaid state plan for "medically handicapped" adults age 16 or older. If a state funds distinct ADS programs for older and younger adults--as does Illinois--all things being equal, programs in these states will be less likely to serve both older and younger adults in the same setting.

One provider noted that even if a program is marketed as a senior service, persons under age 65 or their families want to use the service because there are no other day programs available. One provider we visited has a specialized program for adults of all ages with acquired brain injuries, and most are under age 65.

Whether a program serves younger adults with mental retardation and other developmental disabilities (MR/DD) depends on a combination of factors. If a program has to be certified, licensed, or contracted separately to serve this population, it is less likely that providers who serve an elderly population will do so. In some states, a major incentive for providers to serve individuals with MR/DD is the more generous Medicaid reimbursement for individuals in MR/DD waiver programs. Several providers reported that the reimbursement they receive for just a few MR/DD participants makes up for the under-cost reimbursement rates for Aged and Disabled waiver participants. In Illinois, some providers were interested in serving persons with MR/DD in order to increase their daily census.

In three of the states providers said they are serving more younger adults and persons with MR/DD than they used to. Those they serve are not able to participate in traditional MR/DD programs either because of severe functional impairment, medical complexity, or multiple diagnoses. However, as noted above, providers have less of an incentive to serve this population if they need a separate contract or need to meet additional regulatory requirements to do so.

One provider noted that interest in ADS by the MR/DD community is growing significantly because a lot of services for younger people are not accessible or are not available five days a week. Another provider said that some parents do not want to send their family member to settings that serve only individuals with MR/DD, preferring a more heterogeneous population in terms of age and diagnosis. She also noted that while many of the MR/DD participants have individual goals that need to be addressed during the day they can also participate in the regular programming. One provider in North Carolina noted that the MR/DD case managers usually are impressed with the care, the level of activity and involvement, and the socialization these individuals receive from his program.

Another provider noted that these participants' only other options would be to stay at home with a full-time caregiver or be in an institution. They come to ADS for the same reasons as do senior participants: safety; socialization; activities; health monitoring and nursing services; and caregiver respite. After finding that they could successfully work with young adults with MR/DD, one program began marketing to adults of all ages with special needs and about 40 percent of their participants are under 65. Another program reported that about 20 percent of its participants are persons with MR/DD and all are in the Aged and Disabled waiver serving persons 18 and older.

Participants' Functional Limitations

With the exception of the program serving persons with HIV/AIDS, the majority of program participants have extensive functional limitations due to physical or mental impairments or a combination of both. Many programs reported that over half their participants needed help with ADLs including help with eating and toileting. Many have had strokes and both physical and cognitive impairments as a result. One program reported that over half of its participants who are on the waiver receive some in-home assistance in addition to ADS.

The prevalence of dementia is high. All providers said over half of their participants have dementia and many without this diagnosis have cognitive impairment of some type, caused by stroke, Multiple Sclerosis, acquired brain injury, or MR/DD. One program reported that in all four of its sites, 80 percent or more of the participants have cognitive impairment, whether or not they have a dementia diagnosis.

Providers in general said that mixing ages, functional levels, and diagnoses in a program had advantages. In most cases, it can be a positive experience because participants interact with and take care of each other in many ways, thereby encouraging socialization and mental stimulation. However, they noted that activities need to be structured according to functional abilities and that individuals with behavioral issues often require separate programming so they will not disturb the other participants.

One provider said that when designing activities, differences in age were less of an issue than differences in functioning, with the exception of music-related activities, with musical preferences being clearly differentiated by age group. The Alzheimer's Family Care Center believes it is essential to operate their programs according to a "clustering of care" philosophy, which separates participants by stages of the disease. One provider noted that cognitively intact persons relate better to those with MR/DD than do persons with dementia who do not understand their condition. Another said that some of their elderly participants assume a teaching and mentoring role with the MR/DD participants.

Health and Medical Conditions

Many participants have significant medical needs, requiring daily health monitoring and skilled nursing services. In Washington, because Adult Day Health Care is a Medicaid state plan medical service that requires participants to need skilled nursing or rehabilitation services on a daily basis, participants have a high level of need. In Maryland, Medical Day Care is also a Medicaid state plan service that requires participants to be “medically handicapped” and in need of health maintenance and restorative services. In Georgia, Illinois, and North Carolina, where Medicaid participants were receiving ADS through the waiver program, many had chronic health conditions, such as diabetes, high blood pressure, or congestive heart failure, which they cannot self-manage due to cognitive impairment. Their nursing needs included catheter and dressing changes, blood sugar testing, daily medication management and administration, and health monitoring.

The primary service provided by the ADS program serving people with HIV/AIDS is medication management and administration. The population this program serves is at high risk for noncompliance because of the large number of medications they need--the minimum is thirteen--and a high proportion have co-occurring disorders such as serious mental illness and chemical dependency, many with associated cognitive impairment. In addition, many are dually diagnosed and some are homeless and considered “un-housable” due to drug use and criminal activity, including setting fires.

Because lack of compliance could lead to the development of drug resistance, assuring a 95 percent medication compliance rate is the program’s major goal and the outcome by which they measure their success. The program gives the participants their doses in whatever form they need them: daily, weekly, or monthly. The provider said that without this medication service, individuals would have to go to a pharmacy every day because Medicaid will not fill a prescription more than five days prior to the renewal date.

Increase in Acuity

Most providers felt that the level of participants’ needs has increased over the past few years for a number of reasons: (1) a higher prevalence of people with moderate to severe dementia; (2) participants staying for longer periods and becoming more frail as they age (the average stay in the programs was two years and some as high as four years); (3) prospective payment systems for acute care resulting in people being discharged from the hospital with greater needs; (4) tightening of states’ nursing home level-of-care criteria; (5) a certificate of need program for nursing homes, resulting in a shortage of nursing home beds and more impaired people in the community; (6) new medications keeping people living longer with chronic conditions; and (7) a general movement of younger people with disabilities out of institutions to the community. Some stated that ADS provides a support network to keep these people in the community

because their informal caregivers cannot provide care without respite, particularly if they are working.

Several providers felt that increased acuity levels were due to the increasing recognition of ADS as a viable alternative to nursing home and assisted living placement. Caregivers who can not afford those options utilize ADS when a family member becomes more frail or impaired. The provider who said she did not see too much of a change in participants' level of need over the past ten years, said that families are requesting more services, such as bathing, personal care, more weekday hours, and Saturday hours.

Limitations on Who Can Be Served

Overall, providers reported that they try to accommodate everyone who needs assistance, but noted that they take clients on a case-by-case basis and have turned away individuals who exhibited aggressive behavior towards others or were a clear danger to themselves. Most noted that ADS are usually a caregiver's last hope of maintaining their family member in the community, and so they try to serve everyone who needs services.

One program with limited space said it could not accept participants with behavior problems that agitate other participants (e.g., roaming too much, shouting, or grabbing objects). Most of the programs said they use a trial period--from two to four weeks--for new participants if providers have concerns about being able to meet their needs and having them adequately adjust. The most common cause for not serving an individual was uncontrollable combative or violent behavior.

Another factor that restricts who can be served is the amount of assistance needed, generally for toileting. If it takes more than one staff person to assist in toileting--and particularly more than two--whether or not a person can be served will depend on staffing and how many others with this level of need they are already serving. One provider said they serve one person who needs a three person toileting assist, but only because he has been in the program for 18 years. All programs can usually serve a few individuals who need this level of assistance, but if many needed it, they would have to hire more staff and the reimbursement rate would not cover expenses. In order to handle very heavy care clients without increasing staff, some programs stagger attendance for these individuals; for example serving one from 9 AM to 1 PM and the other from 1 PM to 5 PM.

Once admitted, providers said they try to keep participants as long as they need the service and noted an average length of stay of over a year up to several years--with most citing two years. One provider felt the length of stay may shorten in the coming years because participants are arriving sicker and more impaired. A common reason for leaving is a move to institutional care--often after an acute episode--and some providers noted that participants often die within a year of leaving.

One provider said its waiver participants generally stay in the program an average of 26 months and the majority do not leave for nursing home placement but for other reasons, including a family move or death. A provider serving primarily African-American participants reported that those who are discharged typically stay in their homes due to cultural fears of potential mistreatment in a nursing home. Several other providers also noted that African-Americans are less likely to utilize nursing homes than are Caucasians.

Providers stated that from half to 80 percent of their participants--virtually all with dementia--would not be able to live without a full-time caregiver and the respite afforded by ADS. ADS are the only option for caregivers who work and cannot afford private help at home. All providers believed their programs prevented or delayed nursing home placement, while acknowledging that some caregivers will never willingly put their loved one in an institution.

Services

Programs identified ADL assistance and medication administration as key services. In addition, programs operating as a combined social/health model or a health/medical model provided other nursing services--health monitoring, health education and skilled nursing services--delivered by RNs. Providers must either directly provide services to meet participants' needs--in accordance with state regulatory or contractual requirements--or arrange or contract with others to provide them. Physical, occupational and speech/language therapies were generally provided on-site by therapists who directly bill Medicare or Medicaid, but some providers furnished or arranged for transportation from the program site to facilities that offer these therapies.

The level of social work services varied. One program provides social work as a core service and has a full-time social worker who handles the initial participant assessment, participates in case reviews with the RN/Director, and helps families resolve issues that might lead to a refusal to admit or a discharge based on an individual's behavioral issues. Other programs had part-time or contractual social work staff.

The primary service that distinguishes ADS from other long-term care settings is activity programming. While residential care and nursing homes provide some level of activities for their residents, their availability is not the primary reason the resident is in these settings.

ADS providers, on the other hand, view the provision of activities as a primary purpose of their programs. Activity programs are designed to encourage participants to function at their highest possible level and most providers tailor programs by functional level--both physical and cognitive. Several programs run 2-4 activity groups concurrently. Two providers assign individuals to specific activities based on a cognitive

assessment, and one noted they may choose to join a different activity group as long as they are not disruptive in that group.

Many programs have some physical activity programming, which are designed so that individuals with different functional levels can participate, some with staff assistance. One program alternates between active (exercise) and passive (reminiscing) activities in addition to having programming tailored to functional level. Several providers said that caregivers of persons with dementia reported that engaging in a wide range of activities helped participants sleep better at night because they were more tired than if they had just spent the day at home watching television. This in turn allowed caregivers to sleep better and decreased their stress.

Many providers and direct care staff felt that the ability to offer breakout sessions and simultaneous programming by functional level was integral to insuring that their participants perform at the highest possible physical and mental level. Several providers noted that family members are often surprised when they see their family member engaged in a range of activities because while they are at home they only watch television. Providers believe that the social environment and activities offered in their programs maintains and in some cases improves both physical and cognitive functioning.

Role of Adult Day Services in the Health and Long-Term Care Systems

Providers felt strongly that ADS are an important component of community-based long-term care and play a key role in preventing and delaying both assisted living and nursing home placement. They felt that they offer programming and services that maximize participants' cognitive and physical functioning, by both maintaining function and restoring function lost due to social isolation and lack of stimulation.

Some providers stated that receiving assistance with ADLs in an ADS program benefits participants more than receiving the same assistance in their homes because participants develop supportive relationships with both staff and others attending the program, and engage in physical and mental activities not available at home. Several providers noted that the higher staff-to-participant ratio in ADS programs allows for more one-on-one contact with staff than is available in assisted living and nursing facilities.

Providers also felt that ADS play a crucial role in chronic care management for community-dwelling adults of all ages who have disabilities. They believe that the provision of medical and nursing services on-site, particularly health monitoring, health education, and skilled nursing services, enables them to successfully serve an increasingly impaired population with complex medical needs and chronic health problems.

They noted that because all staff know the participants, they can quickly identify emerging health problems, which are quickly addressed, thus preventing or delaying the development of acute conditions necessitating emergency room or hospital use. Washington's Medicaid agency is conducting a study examining clinical outcomes and medical expenditures for Adult Day Health participants who reside in Adult Family Homes. While the final results of this two-year study are not yet available, preliminary analysis has demonstrated overall cost-savings. The Medicaid agency is using these findings to support a request for a rate increase.

Several providers remarked that their participants rarely, if ever, have open wounds or other skin problems that often lead to infections and additional medical problems because staff routinely monitor skin condition and provide skin care.

Several providers felt that Medicare should cover the medical services they furnish, in addition to paying for speech/language, physical and occupational therapy. However, a nurse in one program opposed Medicare payment, because she felt it would turn what is essentially a social program that also meets participants' health needs into a medical program with too much regulation.

Operational and Policy Issues

We asked providers to tell us about operational and policy issues and how these issues have affected their ability to provide services. (Provider views on regulatory issues are discussed in the next section.)

Funding

Nearly all of the providers receive a significant percentage of their operating revenue from Medicaid and other public funding sources such as VA programs, the Social Services Block Grant, Older Americans Act, and state programs. Private long-term care insurance provided a very small amount of revenue in a few programs. One provider said that reimbursement by long-term care insurance companies is increasing, but that people with long-term care insurance seem to move more quickly to assisted living because it is a covered service.

The proportion of revenue from private payments varied among programs. In one program, half of the participants were covered by Medicaid, about 28 percent by other public funding sources, and only 18 percent were private pay. Other programs have between 20 and 50 percent private pay participants. According to one provider the proportion that is private pay depends on the socioeconomic status of the neighborhood where the program is located.

Some providers set their private pay rate higher than cost to subsidize the lower than cost reimbursement from public programs. However, they said they had to be careful not to set it so high that it deters private pay participants. Several programs offer

sliding scale subsidies for their private pay participants. They generally use public funding sources--such as Older Americans Act funds--or charitable contributions--such as United Way funds--to subsidize private payments.

A provider in Georgia noted that some non-Medicaid funding sources had recently changed their financial eligibility policy to deem the income of family members to be available to the participant. This policy has resulted in higher required co-payments, which some people cannot afford, causing them to leave the program. This provider noted that Medicare Part D prescription coverage could have a similar effect because people who are no longer deducting prescription drug costs will have higher "available" income for purposes of determining eligibility for public funding and calculating co-payments.

Most publicly-funded participants receive ADS through one source of payment, typically Medicaid. But a number of programs combine funding sources to provide comprehensive care, for example, using VA funds to pay for two days of services a week and block grant funds for a third day. Virtually all providers we visited said they could not operate their programs without Medicaid funding.

To assure a daily census that meets operating costs, providers have to continually market their services, and some have had to allocate a substantial amount of their budget to do so. Some of the programs in Washington, Georgia, and North Carolina said they could not survive financially without substantial fundraising, in-kind contributions, and volunteer services. One center had an annual budget of \$985,000, of which \$172,000 comes from fundraising activities. Two programs said they have to raise \$500,000 annually to cover expenses.

Several programs depend on a significant amount of in-kind contributions and volunteers. One program said the landlord had not raised the rent for a number of years as a way of contributing and hundreds of volunteers provided assistance with activities, socialization, special events, landscaping, and building upkeep. In addition, 25 volunteers spent significant time over a year to raise over \$2 million to build a new facility.

Many programs rely on subsidies from parent organizations and charitable organizations during budget shortfalls. For example, when Georgia froze waiver admissions and one program had insufficient revenue to cover costs for 18 months, its parent organization used its reserves to keep the center open. On another occasion when Medicaid cutbacks and a new claims processing systems resulted in diminished revenues, United Way and county funding was used to meet expenses.

One provider planned to establish an endowment to support its program. Two programs are starting weekend respite to increase revenue and one is considering renting its buses to outside groups when not being used (e.g., on evenings and weekends) to generate revenue. Two providers were considering becoming a home care provider to serve their adult day participants at home.

Despite the reliance on Medicaid funding, all of the providers said that the Medicaid rate does not cover costs. For example, in North Carolina, the statewide median cost for a combined social/health model is \$51 a day, but the waiver program pays only \$36.51 a day. Some states require a minimum number of hours for their daily rate--none less than four. Others do not specify a minimum. Many providers said their state is paying for a basic level-of-care but the participants need intermediate or intensive services, which state regulations require them to furnish.

In 2004, both Maryland and Illinois raised the Medicaid reimbursement rate, but providers reported it still did not cover costs. ADS providers in North Carolina last received a rate increase in 1999 and the Washington Medicaid agency is supporting a 16 percent rate increase, which the state association hopes will be approved in 2006. In Georgia, providers did not expect an increase in Medicaid reimbursement rates sufficient to cover the costs of providing ADS.

In several states, the state Medicaid agency and/or state legislatures are examining ADS programs and funding within a larger context, including Medicaid waiver applications and statewide long-term care systems change, but it is not clear how these efforts will affect the ADS industry. For example, Maryland is awaiting Centers for Medicare and Medicaid Services approval of an 1115 Medicaid Managed Care Waiver program--called *Community Choice*--that will include medical adult day care. ADS providers are hoping that the managed care organizations (called community care organizations under the waiver) will contract with adult day medical service providers to furnish services and manage clients with chronic health conditions to prevent hospitalizations. They are also hoping they will be paid based on the level-of-care a person needs rather than the current flat daily rate.

Nonprofit providers can apply for grant money, accept tax-deductible donations, and can receive other state or local tax exemptions, such as a fuel tax exemption in Maryland. For-profit providers are not eligible for these subsidies to cover operating costs yet face the same funding challenges as nonprofit providers.

Transportation

Because some states require ADS providers to furnish transportation and others do not, transportation issues varied among the states. ADS providers in Illinois and Maryland are required to provide transportation and several felt that the two primary challenges were high gas prices and logistical issues related to transporting multiple clients who attend the program at different times from a wide geographic area.

Maryland includes transportation in its Medicaid ADS rate and Illinois Medicaid pays for transportation using a separate rate. In both states, providers said they needed to provide their own drivers and lease and/or buy transport vehicles, which were very expensive. Para-transit services are not available in all areas but one provider noted that when it is available, some participants with mild impairments are able to use it.

In neither state does the transportation reimbursement rate cover actual costs, and to subsidize the rate, some programs charge private pay clients a separate transportation fee. One restricts the program's service area because the state only requires the provision of transportation within a designated service area. Participants who live outside this area have to make their own arrangements and most are brought to and from the program by family members.

Whether or not they were required to provide transportation, and apart from funding concerns, virtually all providers said that participants' transportation needs posed a major logistical challenge, which took up a great deal of staff time. Some larger programs had full-time transportation coordinators. In other programs, staff spent a considerable amount of time arranging and coordinating transportation across a large service area and coordinating transportation scheduling with programming. In many programs, drivers make several morning and afternoon trips and some participants spend as much as an hour getting to and from the program because the driver has to pick them and others up from a large geographic area.

North Carolina, Georgia and Washington do not require ADS providers to furnish transportation, yet most providers cited transportation issues--both cost and logistical--as a major problem and a barrier to program attendance. A provider in Georgia said that even if participants were able to use public transportation, it would be unaffordable for many families, with round-trip bus fare costing \$80 a month. Providers noted that many participants are transported by family members and the remainder use nonprofit or publicly-funded transportation. Providers in Washington mentioned logistical issues more often than cost issues because the state has an effective para-transit program that charges only \$1.50 per round trip.

Providers in Georgia cited the most problems, which they blamed on the state's recent decision to outsource transportation for all disability programs to a for-profit company. The drivers have not been trained to deal with riders who have mental disabilities and there is considerable turnover among transportation providers. One company gave only a day's notice that it would no longer be providing services.

When gas prices increased after Hurricane Katrina, the state ruled that ADS programs were not medically necessary and did not provide transportation for two days. Because many participants had no other source of transportation, the program's nurse had to drive to their homes to give them their medications and no reimbursement was provided for her time.

Georgia providers also cited Medicaid transportation rules as a barrier to program participation (e.g., limits on the number of trips per day). One participant who needed to visit his physician had to be taken home rather than back to the program because Medicaid would not pay for a third trip from the program back to his home. One provider said that while transportation funding is drying up in their geographic area the demand is growing due to an increase in both the aged population and in need.

Staffing

Programs varied with regard to recruitment and retention issues--some had them and some did not. Those that reported difficulty recruiting did so for professional staff--RNs and rehabilitation therapists--noting that professional staff can earn more in other health care and long-term care settings. Another program said they had been successful recruiting professionals largely because they offer tuition reimbursement.

Several programs reported high retention rates for CNAs and other staff such as activity directors. Several had direct care staff with fairly lengthy tenures, in some cases, averaging five or more years, but other programs said that CNAs do not stay long because of the low pay.

For those who stay, providers attribute their retention to the work environment, which is less demanding than other long-term care settings, which often require shift rotations, night work, 12-hour shifts, and more physically demanding work with bed-bound clients. They also cited higher staff-to-participant ratios than are found in assisted living and nursing facilities, which lowers the caseload for direct care staff. Finally, providers said that staff value their role in a program that has a mission to serve the community as well as their long-term relationships with participants.

Several programs use part-time, flex-time, and on-call staff so they do not have to carry staff overhead when the census is low. One noted that they purposely under-staff and call on a pool of temporary and part-time workers when needed.

Virtually all providers we spoke with felt that the state-mandated staff-to-participant ratios were needed to provide good care. A provider in North Carolina noted that the mandated staff ratios for ADS are higher than those for any other long-term care setting including nursing homes.

5. PROVIDER AND STAKEHOLDER VIEWS ON REGULATORY ISSUES

This section presents the views of ADS providers and stakeholders on regulatory issues in their respective states. Stakeholders comprise state regulatory and Medicaid staff and representatives of state provider associations. Please refer to Appendix B for a regulatory summary of each of the five states.

Providers in several states said that compared to other long-term care settings, ADS regulations set ideal rather than minimum standards. One noted that while higher standards are desirable from a quality of care perspective, given low reimbursement rates they are not affordable from a business perspective.

Providers in the five states we visited felt that most state requirements regarding staffing and training were appropriate, but objected to requirements that they believed increased costs without increasing the quality of care. For example, a provider in Washington said that the state requires ADS providers--but not nursing homes and hospitals--to have "bacteria resistant" carpet or other approved flooring. He said he could not afford to replace all of the carpet in his facility with this type of carpet or, alternatively, with some other approved material. Providers in several states mentioned that some documentation requirements were unnecessary and burdensome, such as the need to document staff arrival and departure times. Other regulatory issues are unique to each state and are described next.

Georgia

The state currently has a voluntary licensing standard because it has not appropriated funds to administer the licensing program. If funds are appropriated and licensing mandated, some providers are concerned that licensing requirements will not *replace* the existing Medicaid contract requirements, but will be *added* to them. One provider noted that home health agencies are licensed by the state but must meet Medicaid requirements to be reimbursed. Because the Medicaid and licensing requirements are similar but not identical, providers have to document the same task twice to meet the different requirements, causing a great deal of additional work. The staff training requirements also differ because the two monitoring entities did not agree on a single standard, which has doubled the requirements. Providers are concerned that if ADS licensure is mandated, a similar situation will occur with ADS.

One provider said that the state used to have separate regulations for the ADS social model for people with dementia but subsequently merged them with Medicaid's requirements. The merger doubled providers' costs because in every instance the higher standard was adopted for both dementia and nondementia participants: space per client, staff ratios, staff qualifications, staff training, and record-keeping.

Another provider complained about the fast pace of regulatory change--every few months instead of every 2-3 years--which made it difficult for providers to adapt and comply. For

example, the state changed the nutrition regulations to require providers to furnish two additional servings of specific food items per day. To do so, providers had to either find cost-savings in other program areas or increase revenues, which is difficult to do without sufficient advance notice. This provider also expressed concern that regulations were being promulgated without industry input.

The Medicaid agency recently enacted a policy change that requires programs to be in operation a full year before applying to be a waiver provider, a process that can take an additional six months. The rationale is to prevent new programs from expecting that Medicaid will fund their center, but one provider noted that its effect could be to deter the establishment of any new ADS programs.

Illinois

Providers and stakeholders did not mention any regulatory issues, possibly because the state does not require ADS providers to be licensed or certified. ADS providers who want to serve Medicaid clients must contract with the state Department on Aging (DOA) under the Community Care Program (CCP). Providers and state-level contacts in Illinois felt that licensure or certification requirements were not needed because the CCP regulations are equivalent to such requirements.

They said that to date, the lack of licensure has not negatively impacted the industry. Providers noted that the contracts with the state's DOA have been accepted by long-term care insurers in lieu of licensure. However, they indicated that if insurers did not accept the contract, they would probably support ADS licensure or certification. One informant noted some resistance to licensure from the DOA because it would place ADS programs under the Department of Public Health, which would then be responsible for oversight.

Maryland

The state published new draft licensing regulations in November 2004, but they have not yet been adopted. Several providers felt that some of the proposed staffing requirements were more appropriate for nursing facilities that have greater financial resources than adult day centers. In particular, they expressed concern about a proposed requirement to have a full-time director for a center with 35 or more participants, stating that this requirement would impose a financial burden on smaller centers. Currently, a full-time director can work part-time at multiple centers operated by the same organization.

Providers also felt that a proposed requirement for health care practitioners to review assessments every 30 days is burdensome and they also expressed concerns about the amount of proposed civil penalties for deficiencies. Currently the state levies no penalties and providers feel those proposed are very high. One regulatory issue that has divided providers is a change in the staff-to-participant ratio from 1:6 to 1:7. The Maryland Association of Adult Day Services supported the change as a cost-saving measure, but another provider association--Leaders of Excellence in Adult Day Care--did not because they believed it would have a negative impact on the quality of care.

North Carolina

Providers noted that the industry is covered by rules and regulations imposed by agencies that are not under the control of the certifying body. Some feel that new sanitation, building, and fire codes--particularly the requirement for sprinklers--have made it nearly impossible to open, expand, or even change ownership of an ADS program, because changing ownership requires a new certification, which results in the building no longer being grandfathered under the old codes. The state's Provider Association said that many programs operate in older buildings that do not meet the new codes.

This problem has been compounded by the recent enactment of legislation regarding the provision of "specialized care" in group homes and family care homes. One provider noted that any county or state monitor can decide that an ADS program serving people with a particular diagnosis is providing "specialized care," which requires that the program be re-certified as such. When re-certified, the program loses its grandfathered status under former building codes, and the program has to close until current codes can be met. In many cases the program closes permanently because it has been operating in a facility, such as a church, which does not have sprinklers, and the program cannot afford to install them.

Another regulatory issue cited by some providers is the lack of a uniform interpretation of certification standards statewide and widely varying enforcement. The lack of consistent interpretation and enforcement of certification standards by county departments of social services is particularly difficult for providers who have centers in different counties. Fifty-eight of the state's 100 counties have ADS and each county monitor can interpret the standards differently. Another complaint is that ADS are monitored monthly--much more frequently than nursing homes, adult care homes, or any other senior/adult service.

One provider felt that ADS regulations were increasingly driven by a medical model of care that increased costs, sometimes unnecessarily. For example, requiring an RN for eight hours a day to perform medical monitoring when in most cases an LPN could handle this responsibility, particularly in small programs, drives up costs unnecessarily. On the other hand, an RN in another program said she needed to be on site eight hours a day because the 45 participants attended the program at different times--some in the morning and some in the afternoon.

Washington

The state does not require licensure and one provider felt that it was needed for reimbursement, reputation, viability, and credibility. He said that his program is accredited by CARF and without this accreditation, long-term care insurers would not reimburse then for services provided. Another provider who is receiving long-term care insurance payments for a few participants said that not having licensure was a major hurdle to receiving payment. One said that they could not compete for the Medicare Demonstration project because they are not licensed.

As in North Carolina, providers were concerned about major variations in counties' interpretations of regulations for enforcement purposes. For example, one county wants to know exactly how much time is spent on rehabilitation services for each participant, while another county is not interested in this information. One provider noted that many participants are eligible for Medicaid coverage because they need daily rehabilitation services and that requiring

providers to furnish a specific amount of rehabilitation services to maintain eligibility can be a major problem for some programs given the low Medicaid reimbursement rate.

One provider said that staffing requirements can be unrealistic, noting that to open a program, the state requires an administrator, program director, RN, activity coordinator, a physical therapist/occupational therapist or speech therapist, and a social worker. While the administrator and program director may be the same person, all of these staff are required even if the program at start-up has only eight or ten participants. Several providers expressed concerns that the recent increases in requirements for RN and skilled rehabilitation personnel staffing were not matched by an increase in reimbursement.

One informant said that many providers feel the Medicaid ADS eligibility criteria are too stringent; others are upset because the state no longer allows ADS providers to determine eligibility. Because the state felt that some providers were admitting people who should not be eligible, it recently delegated eligibility determinations to the Area Agencies on Aging. However, because no funding was appropriated for this activity, eligibility determinations are often delayed, creating funding problems for providers.

6. CONCLUSIONS AND RESEARCH RECOMMENDATIONS

Based on our study findings, we have drawn several conclusions.

Regulation

- The method states use to regulate ADS varies considerably, as does the content of the regulations. However, states generally distinguish between ADS and adult day health services, and have more extensive requirements for the health model. In general, staffing requirements are more stringent than those for residential care settings, particularly requirements for licensed nurse staffing in adult day health programs and programs that combine a social and medical model of care.
- In some states, regulations appear to limit providers' flexibility to provide services that meet caregivers' needs, for example, arbitrary restrictions on the number of service hours that may be provided on weekends.
- It is likely that the considerable state variation in regulatory approaches will continue in the near future. In states without licensure, providers disagree about whether the industry should be licensed. One argument for doing so is that long-term care insurers will not reimburse ADS unless furnished by licensed entities. Providers in Washington noted this difficulty but those in Illinois did not.

Some providers would support licensure if it led to an increase in reimbursement rates and others believe it would aid in their marketing efforts to recruit private pay participants. However, in states that do not license ADS providers, some fear that that licensing would be added to Medicaid requirements rather than replacing them.

- Adult day health services are part of the continuum of both health and long-term care services. In the states we visited, ADS providers are furnishing preventive care, health monitoring, and skilled nursing services to individuals with chronic illnesses and physical and cognitive impairments. Some providers are also serving adults under age 65, depending on regulatory requirements and the funding streams for this population.

Because ADS providers must meet Medicaid state plan or waiver contracting requirements to furnish services to Medicaid beneficiaries--either in addition to or in lieu of state licensing or certification requirements--they are regulated at a level which allows them to furnish health-related and medical services as well as long-term care services to elderly persons with a high level of nursing and medical needs.

Program Models

- The number of purely social ADS programs may decrease as more providers offer combined or health/medical models. Social programs appear to be at a disadvantage because many participants dis-enroll as they age and their health and functional needs increase. A combined program offering both a social and medical model appears to be the most financially viable.

The literature on caregiver stress has pointed out the need to use a social model of ADS when people are not so impaired, to help prevent “burnout” and many providers noted a need for this model. Others point out that specialized social programs are essential for individuals with dementia who do not have ADL impairments and medical needs. However, these programs may not survive due to: (1) the pressure to serve large numbers in order to meet fixed overhead costs and regulatory requirements; and (2) the need to meet the health and functional needs of increasingly older and more impaired participants, particularly if they want to be Medicaid providers.

Funding and Reimbursement

- A unique feature of ADS relative to nursing homes and residential care settings, is their reliance on multiple funding sources to cover operating costs. While Medicaid is the primary public funding source for ADS providers through either a waiver program or the state plan, in the five states we visited reimbursement rates were not sufficient to meet costs. To remain financially viable and serve non-Medicaid eligibles who cannot afford to pay for some or all of the services they need, ADS programs must find other sources of funding.

Other funding sources include: state and local program funds, VA funds, the Social Services Block Grant, Older Americans Act funds, private payments--both out-of-pocket and from long-term care insurance--contributions from local service agencies such as United Way, and charitable contributions obtained through significant and ongoing fundraising efforts. Every ADS program we visited also relied extensively on in-kind contributions and numerous volunteers. The combination of funding sources, each with its own rules, greatly complicates the administration of ADS, and can limit providers’ flexibility to meet consumer’s needs.

- States that pay flat rates create a disincentive for providers to admit participants with severe impairments. Some states pay either hourly rates or have tiered rates for different levels of care.
- The cost of ADS is relatively inexpensive compared to home care. Agencies can charge as much as \$20-\$25 for an hour’s visit by a home health aide and \$85 or more for a half-hour visit by an RN.¹⁹ The national average daily cost for the

social model of ADS is about \$54, for the medical model about \$59, and for the combined model about \$57.

In the five states we visited, some providers furnished only the minimum number of hours required by public programs to receive the daily rate--never fewer than four. In other states, providers furnished up to 11 hours a day on the daily rate. Despite the relatively low cost of ADS, the five states we visited do not appear to be interested in expanding the availability of ADS generally--or medically-oriented ADS specifically.

Operational Issues

- Lack of transportation and the high cost of transportation are major impediments to the use of ADS.
- Without greater public recognition of the role ADS can play in maintaining adults of all ages with disabilities in home and community settings, it is unlikely that ADS programs will see an increase in private pay participants.

Although some providers and experts feel that public knowledge about ADS has improved, all acknowledge that it lags way behind public knowledge and understanding of other long-term care options. Even though ADS allow significantly impaired nursing home eligible participants to remain at home or living with family, providers believe that the public still thinks that ADS are the adult equivalent of child care. This perception would appear to be widespread, as evidenced by a 2002 article in the Wall Street Journal titled "When Your Parents Need a Baby-Sitter: Adult Day Care Centers in Short Supply."²⁰

Other erroneous perceptions are that ADS are "only for the poor," "only for the rich," only for "old people," or only for people with dementia. To alter these perceptions, the industry may need to engage in public education efforts. While the national ADS association supports a change in the name from adult day care to ADS, providers need to use the terms that public programs use in order to qualify for funding.

Recommendations for Future Research and Policy Analysis

Based on anecdotal evidence from providers and families, ADS enable informal caregivers to continue providing care in the home, thereby delaying or preventing institutionalization. More research is needed to document the long-term care cost savings of these programs. Such research could guide state policymakers who have to carefully target expansions of home and community services to assure the cost-effectiveness of limited resources.

ADS also appear to offer a means to reduce health expenditures. Washington's Medicaid agency is conducting a study examining clinical outcomes and medical expenditures for Adult Day Health participants who reside in Adult Family Homes. While the final results of this two-year study are not yet available, preliminary analysis has demonstrated overall cost-savings. Given the potential for health care cost-savings, particularly as the population is aging, other states may want to consider analyzing Medicaid data to determine the cost-effectiveness of ADS.

Such research would provide much-needed documentation to determine whether an expansion of ADS that provide health services is warranted.

ENDNOTES

1. Discussions of other studies or states that use different terms will use those terms.
2. Numbers are based on data from the 1994 National Long-Term Care Survey. More recent data are not readily available. *Supporting Informal Caregiving* in Smith, G., O’Keeffe, J., et al. (2000). Understanding Medicaid Home and Community Services: A Primer. U.S. Department of Health and Human Services. Available at <http://aspe.hhs.gov/daltcp/reports/primer.htm>.
3. Gaugler, J.E., Kane, R.L., Kane, R.A., Clay, T., Newcomer, R. (2003). Caregiving and Institutionalization of Cognitively Impaired Older People: Utilizing Dynamic Predictors of Change. *The Gerontologist*, 43(2), 210-229.
4. Dual Eligibles: Medicaid’s Role for Low-Income Medicare Beneficiaries. (January 2004). Kaiser Commission on Medicaid and the Uninsured. Available at <http://www.kff.org/medicaid/loader.cfm?url=/commonspot/security/getfile.cfm&PageID=30741>.
5. Siebenaler, K., O’Keeffe, J., O’Keeffe, C., Brown, D., Koetse, B. *Regulatory Review of Adult Day Services: Final Report*. RTI International. August 26, 2005. Available at <http://www.aspe.hhs.gov/daltcp/reports/adultday.htm>.
6. Gaugler, J.E., Zarit, S.H. (2001) The Effectiveness of Adult Day Services for Disabled Older People. *Journal of Aging and Social Policy*, 12(2):23-47.
7. A presentation of key findings from this study are available at: <http://www.rwjf.org/reports/grr/037535.htm#contents>.
8. Scotto Rosato, N., Lucas, J.A., Howell-White, S. (May 2005). *State Adult Day Health Services Programs: A National Profile (2001-2002)*. Rutgers Center for State Health Policy. Available at <http://www.cshp.rutgers.edu/PDF/StateAdultDayNationalProfile-June%202005.pdf>.
9. Lucas, J.A., Scotto Rosato, N., Lee, J.A., Howell-White, S. (August 2002). *Adult Day Health Services: A Review of the Literature*. Rutgers Center for State Health Policy. Available at <http://www.cshp.rutgers.edu/PDF/AdultDaycareLitRev.pdf>.
10. Ibid.
11. Ibid.

12. Scotto Rosado, N., Lucas, J.A., Howell-White, S. (May 2005). *State Adult Day Health Services Programs: A National Profile (2001-2002)*. Rutgers Center for State Health Policy. Available at <http://www.cshp.rutgers.edu/PDF/StateAdultDayNationalProfile-June%202005.pdf>.
13. Gaugler, J.E., Kane, R.L., Kane, R.A., Clay. T., Newcomer, R. (2003) Caregiving and Institutionalization of Cognitively Impaired Older People: Utilizing Dynamic Predictors of Change. *The Gerontologist*, 43(2):219-29.
- Hedrick, S.C., Rothman, M.L., Chaka, M., Inui, T.S., Kelly, J.R., Erath, J. (1993) Overview and Patient Recruitment in the Adult Day Health Care Evaluation Study. *Medical Care*. 31(9 Suppl.), SS 3-14.
- Hedrick, S.C., Chaka, M., Erath, J., Rothman, M.L., Kelly, J.R., Inui, T.S. (1993) Implication of the Adult Day Health Care Evaluation Study for Program Revision and Research. *Medical Care*. 31(9 Suppl.), SS 104-15.
- Another study by the Department of Veterans Affairs in the early 1990s--the Adult Day Health Care Evaluation Study--utilized randomized assignment to treatment and control groups and found that while the program supplied appropriate care, the results for cost-effectiveness were mixed. The authors recommended better targeting and cost controls as possible ways to improve cost-effectiveness.
14. Joseph Gaugler of the University of Kentucky built on his research in long-term care for chronically disabled older adults and Alzheimer's Disease, collaborating with experts in the area of caregiving research, such as Steven Zaria, to address ADS in several studies reported in the research literature. Their published research includes:
- Gaugler, J.E., Zarit, S.H. (2001) The Effectiveness of Adult Day Services for Disabled Older People. *Journal of Aging and Social Policy*, 12(2):23-47.
- Gaugler, J.E., Jarrett, S.H., Zaria, S.H., Parris Stephens, M.A., Townsend, A., Greene, R. (2003) Adult Day Service Use and Reductions in Caregiving Hour: Effects on Stress and Psychological Well-being for Dementia Caregivers. *International Journal of Geriatric Psychiatry*, 18(1):55-62.
- Gaugler, J.E., Jarrett, S.H., Zaria, S.H., Parris Stephens, M.A., Townsend, A., Greene, R. (2003) Respite for Dementia Caregivers: The Effects of Adult Day Service Use on Caregiving Hours and Care Demands. *International Psychogeriatrics*, 15, 37-58.
15. Siebenaler, K., O'Keeffe, J., O'Keeffe, C., Brown, D., Koetse, B. *Regulatory Review of Adult Day Services: Final Report*. RTI International. August 26, 2005. Available at <http://www.aspe.hhs.gov/daltcp/reports/adultday.htm>.

16. Because the purpose of this study is to better understand the role of ADS in addressing elderly persons' health and functional needs, we did not look at services such as emergency services and nutritional services that are provided to all residents regardless of their functional or health status.
17. We did not identify this requirement in the rules; a state staff person who reviewed the profile provided this information.
18. The director of the Illinois Adult Day Services Association reported that out of 60 member programs, only two target a nonelderly population; one predominately serves persons with MR/DD, and the other persons with mental illness.
19. Costs cited by home health agencies in North Carolina. Costs in other states and major cities may be higher.
20. "When Your Parents Need a Baby Sitter: Adult Day-Care Centers in Short Supply," *Wall Street Journal*, December 19, 2002.