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The availability of community-based long-term care services to the low-income population

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Acknowledgements

The author would like to thank the state and local program administrators and staff who so generously shared their time and expertise during the preparation of this report. They provided a great deal of information and were very patient and helpful in clarifying program details.

The author also appreciates the assistance of many experts familiar with long-term care programs and policies who were consulted during the design phase of the project. Thanks to Andrea Abrahamson at the Washington State Protection and Advocacy System, Donna Folkemer at the National Conference of State Legislatures, Marty Ford at The ARC of the United States, Kim Glaun, currently at the Medicare Rights Center, Muffy Lavigne at United Cerebral Palsy, Katie Maslow at the Alzheimer's Association, and Patricia Nemore at the Center for Medicare Advocacy.

Several people associated with Georgetown University's Institute for Health Care Research and Policy also made significant contributions to this report. Emily Ihara assisted with interviews and data collection efforts. Karen Pollitz and Richard Sorian were very helpful during the planning stages of the project. Colleagues who reviewed drafts of the report include Jeffrey Crowley, Judith Feder, Robert Friedland, Emily Ihara, Harriet Komisar, Lee Shirey, and Tim Westmoreland. Their comments and insights improved the report considerably. However, only the author is responsible for the content of this paper. The Georgetown University Long-Term Care Financing Project is funded by a grant from The Robert Wood Johnson Foundation, Princeton, NJ.

Executive summary

Choices and consequences:

The availability of community-based long-term care services to the low-income population

Laura Summer

In the United States, the Medicaid program finances long-term care services for people with limited financial resources, including many who become needy after paying for medical or long-term care. The majority of Medicaid long-term care spending is for institutional facilities, but 29 percent of spending—just over $22 billion—is for home and community-based care. This proportion has more than doubled over the last decade and is expected to keep growing. Medicaid is by far the major source of funding, but most state long-term care systems also include some Medicare services, state and community-funded programs, and services that are provided locally using federal funds from sources such as the Older Americans Act or Social Services Block Grants.

Although all states have programs designed to provide a range of community-based long-term care services, access to this type of care is not always assured. Among states, the programs vary considerably in terms of who is eligible to receive services, the types and amounts of services for which coverage is provided, and whether services are currently available. For example, states may target benefits provided through the Medicaid home and community-based waiver programs to particular groups of people, and may set limits on the number of people that can receive benefits through the programs. Thus, people in need of community-based long-term care fare differently from state to state. They may fare differently within states as well. Moreover, all states must contend with limited resources and with the prospect that, as the population ages and consumers become more assertive about their preferences for care, the number of people who need community-based long-term care services likely will grow. An examination of how current policies and practices affect outcomes for individuals who need community-based care can improve policymakers' understanding of the issues as they contemplate the design of current and future long-term care programs.

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Study approach

This study uses three hypothetical applicants, or "cases," to illustrate the variation across states regarding the manner in which community-based long-term care services are provided, particularly through the Medicaid program. The applicants are three adults with different disabilities and needs who are facing new situations that cause them to seek services. To simplify the study, each is assumed to be financially eligible for Medicaid.

- Mrs. Alice Adams is an 83-year-old woman who has been diagnosed with terminal cancer. She would like to remain at home with her husband for the duration of her illness.
- Mr. Bob Bailey is a 30-year-old man who has just been paralyzed from the waist down as the result of a spinal cord injury from an automobile accident. When he leaves the hospital he would like to return to his home, live independently, and return to work.
- Ms. Carol Casey is a 22-year-old who has mental retardation as a result of complications during birth and has been diagnosed with autism. Her family has just moved to the state. They would like her to live at home, but they need help with her care, particularly with a program of supervised daily activities.

Many past efforts have examined what type of care is potentially available in states. This project differentiates between what is potentially available and what could actually be provided at a point in time in communities in four states—Colorado, Mississippi, New Jersey, and Wisconsin. The states were chosen to show a broad range of possible arrangements for providing long-term care services. The intent of the study is not to identify "better" or "best" practices among states. Rather, it is to describe the various policies and practices currently in use. Structured interviews were used to conduct detailed discussions with state officials and two or three regional and local program administrators in each state about the types of programs and services available for each of the applicants.

Study findings: How would the applicants fare?

Respondents indicated that the three cases are fairly typical of the people they routinely see. There was general agreement that if they qualified financially, all three would be eligible for Medicaid long-term care benefits. Each of the four states has established programs that potentially provide the full complement of services that Mrs. Adams, Mr. Bailey, or Ms. Casey might need. Ultimately, though, they would have difficulty arranging for community-based care in some of the localities.

Among the applicants, Mrs. Adams is most likely to obtain community-based assistance through the Medicaid program. In a few locations she might be put on a waiting list for services, or she might face uncertainty about the availability of service providers. Mr. Bailey would not fare as well. He would encounter waiting lists in a number of places, and service providers may not always be available because he needs more care, and needs it routinely in the early morning and late evening. The person least likely to be able to receive

adequate care and remain at home is Ms. Casey. In every instance she would be put on a waiting list for most services, and could not expect to receive most program benefits for a year or more.

The applicants will encounter waiting lists in some locations

Mrs. Adams and Mr. Bailey would not have to contend with waiting lists for home and community-based waiver programs in Colorado or New Jersey, but would be put on waiting lists in Mississippi and in many communities in Wisconsin. In every locality, Ms. Casey would be put on a waiting list for at least some community-based services. The need for day habilitation services—vocational or daily living skills training, prevocational services, or supported employment—is the factor that most limits her access to care. Her age is another factor that makes her situation particularly difficult. She is just past the age to qualify for services that are available through the educational system, yet as an adult she faces long waiting lists for services in most communities.

The range of services varies

A person participating in a waiver program in one state may have a service package very different from someone participating in another state. In Mr. Bailey's case, for example, the Caregiver Assistance Program in New Jersey offers a menu of 13 services. The major waiver programs in Colorado and Wisconsin also provide a broad array of services. In Mississippi, Mr. Bailey could participate in one of three waiver programs, all of which offer different sets of services, and so could receive some services, but not others. One of the most problematic services for Mrs. Adams and Mr. Bailey is the home modifications they need. There was agreement among respondents that since Mrs. Adams has a terminal illness, they might be reluctant to recommend extensive home modifications. Mr. Bailey's need for home modifications and special medical equipment is extensive relative to many others who need long-term care. Limits on spending may mean that equipment for him will have to be purchased in stages.

The types and amounts of care recommended for the applicants differ

In the case of Mrs. Adams, almost every one of the local program administrators interviewed noted that the amount of services she receives will depend in part on what her husband can provide, but each person had different assumptions about what he could or should provide. Although a similar set of household services was recommended across sites, the total number of hours per week recommended ranged from just a few hours to 30. There was also a wide range in the number of hours recommended for Mr. Bailey and Ms. Casey. One respondent suggested that Mr. Bailey would need 4 to 6 hours of personal care services, while another said that 6 to 12 hours would be appropriate. In part these differences represent state policies regarding the types of services and number of hours covered under programs, and in part they are the result of discretion on the part of the people making recommendations for care.

A shortage of providers might have an impact on access to community-based care

Respondents in Mississippi did not report problems with the availability of providers, but in some communities in other states there would be a shortage of caregivers for Mrs. Adams and for Mr. Bailey. Respondents noted that agencies may not have providers available. It may be particularly difficult for care planners to find care for Mr. Bailey because, given that he plans to return to work, he will need a caregiver who will work consistently in the early morning hours. Housekeeping, chore, and personal care services are most likely to be limited by the lack of providers. These are physically demanding, low-paying, unskilled jobs, and respondents noted that the agencies providing these services must compete with businesses such as McDonald's and Wal-Mart for workers. Respondents from urban areas generally had fewer concerns about whether providers will be available, but they did voice more concerns about the quality of care that is provided.

Chance and timing play a role in the availability of care

In discussing Mrs. Adams's case, more than one respondent said, "If she is lucky…" Some are referring to whether there is a waiting list in a particular community. Others discuss the uncertainty related to the availability of service providers. Finally, some indicate that if Mrs. Adams is "in the right place at the right time" she will be more likely to get all the services she needs. In the case of Mr. Bailey, one respondent noted that he would do better "if he got lucky" and was referred to the right program. Officials in one county noted that the timing would be right for Mrs. Adams and Mr. Bailey because the closure of nursing home beds made funding available for more community-based care. Similarly, if Mrs. Adams, Mr. Bailey, or Ms. Casey had to rely on community-funded services to fill gaps in their care plans, their success in receiving services would depend, in great part, on whether funds are available at the time they need services.

Well-informed applicants are likely to fare better

Officials noted that the outcome of inquiries made by the families of Mrs. Adams, Mr. Bailey, and Ms. Casey regarding the availability of long-term care services might depend on how savvy, connected, or aware they are regarding the availability of services. If they are able to ask about specific programs, if they know what kind of questions to ask, and if they request brochures and documentation in writing, they will be more likely to get the services they need. Or, if they have an advocate to help them through the process, they may have a more favorable outcome.

How do variations in program policies affect outcomes?

Policy decisions related to program structure, rules, and operations have an impact on the experience that each applicant would have in each community.

Waiting list management policies affect the availability of care for individuals

Commonly, waiting lists are managed chronologically. All states have policies to move people up on the waiting list if there are emergency situations or changes in circumstances that affect the health or safety of applicants. Some localities have developed policies related to other special circumstances. In some places, for example, Mrs. Adams would be given priority because she has a terminal illness.

In Colorado, Ms. Casey might fare better than in many other states because families of children with mental retardation or developmental disabilities are allowed to place their children on waiting lists at age 14 for adult services. In other states they can be placed on a waiting list for adult services only when they become adults and no longer qualify to receive services through the educational system. In New Jersey, where waiting lists are kept by type of service, Ms. Casey would have to wait for some services such as day habilitation, but she could receive other support services and, therefore, it might be feasible to piece together care and keep her at home.

Decisions about categorical eligibility criteria affect access to care

Most home and community-based service programs target specific categories of participants. Others provide services to anyone with disabilities who meets the financial and functional eligibility requirements. With a less categorical approach, no one is excluded because of factors such as age or the cause of their disability. A less categorical approach also has the potential to shorten waiting times for some groups, but lengthen waits for others. Waiting times are generally shortest for Mrs. Adams and longest for Ms. Casey because there is a fair amount of turnover in programs for the elderly and disabled, but people with mental retardation or developmental disabilities tend to be eligible for assistance for years. Decisions about categorical eligibility can have other far-reaching consequences. For example, one reason community-based care is more available now than in the past is because of the work of advocates for particular constituencies such as people with mental retardation and people with developmental disabilities. The strong coalitions that have developed to help promote, develop, and monitor community-based programs may not be as effective if programs are organized differently.

Financial eligibility rules also determine who can participate

To simplify this study, it was assumed that all three applicants were financially eligible for Medicaid. It is important to note, however, that financial eligibility rules differ from state to state. For example, the asset or resource limits for Mr. and Mrs. Adams would be $3,000 in Colorado and Wisconsin, and $6,000 in Mississippi and New Jersey. Thus, if the Adamses had assets of $5,000, Mrs. Adams would be eligible for coverage in just two of the four states. If Mr. Bailey's income were above the eligibility limit, he still might be able to qualify for Medicaid in New Jersey or Wisconsin because both states have optional *Medicaid Medically Needy Programs*, which allow applicants to deduct medical expenses from countable income to qualify financially for coverage. Colorado and Mississippi do not have *Medically Needy Programs*.

The process used to determine functional eligibility might be an important determinant of the availability of care

Participants in Medicaid home and community-based service waiver programs must meet at least the same functional eligibility criteria that a state has established for nursing facility care. The criteria vary by state, however. Standardized assessment tools and functional eligibility criteria are used in most instances to make determinations about functional eligibility, and where they are not, states are moving toward more uniform procedures. But people who perform functional assessments must still exercise some discretion. In discussing Mrs. Adams, for example, some respondents commented that in the case of an 85-year-old frail woman with a terminal disease, "We could find a way to make her eligible" or "We could find reasons to check the boxes [on the functional assessment instrument]." Even where waiting lists exist, a common sentiment was, "We would never let someone like that go without."

The mix of program benefits can affect people's ability to remain in the community

Where there are waiting lists for waiver program services, the ability of applicants to remain at home is not assured. In states like New Jersey and Wisconsin that offer optional personal care services as an entitlement under the Medicaid state plan, people who have full Medicaid coverage have a better chance of being able to remain in the community. If Mrs. Adams or Mr. Bailey were waiting for waiver services in Wisconsin, for example, they could still receive some personal care services, and there is a chance that a community-based organization may be able to help with other services.

When Mr. Bailey is ready to return to work, his ability to do so and receive affordable care also could depend on whether the state where he lives has established a Medicaid Buy-In Program, which would allow him to pay premiums and continue to receive coverage through the Medicaid program. Mississippi, New Jersey, and Wisconsin operate Medicaid Buy-In Programs. Colorado is planning to establish one.

The personal care services available under the Medicaid state plan are not the services Ms. Casey needs to remain at home. Faced with long waiting lists for Ms. Casey, most respondents indicated that they would try to make referrals to community-based programs for her, though they do not know if space would be available at those programs. Others, aware that waiting lists are shorter for some of the other waiver programs, suggested making referrals to waiver programs for the elderly and disabled. But they noted that Ms. Casey would probably not qualify because she does not have physical disabilities.

The care planning process also has an impact on the receipt of services

Once people are determined to be eligible for services, care planners work with them to specify the type and amount of services they can receive. Respondents noted that the training, knowledge, and skill of care planners can influence care plans, as can the degree to which the consumer is involved in the care planning process. Care planners have a difficult job because they are often expected to formulate plans that are optimal for individual clients, but that also conserve resources so that the maximum number of clients can be

served. Although care planners are conscious of cost, they are not necessarily aware of whether their practices result in the most cost-effective manner of delivering services. Generally, program administrators said that they try to be careful of spending so that the more and less expensive clients will "balance out," but the extent to which care planners have the training and tools to accomplish this varies.

Efforts to ease provider shortages, including payments for family and friends, can have an impact on the availability of care

When respondents spoke about the shortage of providers for personal care services, most of them noted that beneficiaries in the home and community-based waiver programs have the option of identifying family members or friends who can be paid to provide personal care services. Respondents from rural areas, particularly, where care providers are scarcer, discussed the advantages of this option. With limited program resources, however, some respondents said that it is important to consider what services family or friends would provide even without pay. Paying family or friends to provide care is only one strategy that can be used to increase the supply of providers. Some states are also examining reimbursement rates and are considering how to make caregiving jobs more attractive.

Consumers are more likely to get the services they need when they have access to information about all available services

Some respondents noted that the services people receive depend in part on what they ask for, but most people are not aware of all the options for care that they may have. In an effort to assist applicants, some states have developed "single entry point" systems. One advantage of single entry point systems is that presumably program officials who work there are well informed about a range of programs and services. Not all single entry point systems are the same, however. Some are places where people can apply for program benefits. Others simply provide general information and referrals. Another means to help people learn about services is to provide information and training about all available services to consumers and to a wide range of professionals who can convey the information to people who may need long-term care services.

Conclusion

Currently, individuals with limited financial resources who seek to remain in their homes and receive community-based long-term care services would fare differently across states and within states. In the absence of a federal program for long-term care, people in the United States who need long-term care are not guaranteed the same protections across the country. Under the current system, with Medicaid accounting for the bulk of publicly financed care, the factor that has the most impact on the availability of community-based long-term care services is whether states are more or less willing to devote resources to long-term care programs in general and to community-based care in particular.

The choices states make about how to spend limited funds reflect priorities with regard to who receives services and what services they receive. The same person might be financially eligible to receive Medicaid or other publicly financed services in one state, for example, but not in another because

the financial eligibility criteria for program participation vary from state to state. Similarly, the criteria used to determine whether applicants qualify for program services on the basis of functional impairment are not consistent across states.

An individual who does meet financial and functional eligibility criteria would likely be offered different types and amounts of services in different locations. This occurs, in part, because of the mix of available services. For example, personal care services could be offered to any qualified applicant in states that have opted to cover this service through their Medicaid programs, but the availability of personal care services would not be guaranteed in states that have opted to provide a different mix of long-term care services. The design of state waiver programs also affects the array of services that are offered. In states with comprehensive waiver programs, individuals and care planners can choose among a broad range of services, but in states with a number of waiver programs targeted to certain populations or services, some services may be available through one program, but not another, and states' choice of waiver program will have an impact on the availability of services. Access to services also can vary within states that target waiver services to populations in particular geographic locations.

Discretion on the part of care planners also may have an impact on the types and amounts of services offered. For example, some care planners are more apt than others to take the availability of informal support into account when they develop care plans. Some are more conscious of costs and therefore may take the financing source into consideration when they make recommendations for particular types of care, or they may be inclined to recommend fewer hours of service. Finally, individuals who have a good sense of what they need and are knowledgeable about the types and amounts of services that potentially are available are likely to fare better. Some localities have made an effort to help consumers become better informed by establishing single points of entry for long-term care services.

Whether individuals actually receive the services they need also varies by location. The same individual might be put on a waiting list for services in one state, but not another. And within states, there are waiting lists in some localities, but not in others. A shortage of service providers in some areas also may have an impact on the availability of care.

Currently, most publicly funded long-term care programs are organized by cause or type of disability. The structure of waiver programs in most states limits the numbers of people with specific types of disabilities that can be served. The choices that states make can be more favorable for some individuals than others. For example, applicants with some types of disabilities may have to wait longer than others to receive community-based care. When resources are limited, an alternate approach is to provide services to people with all types of disabilities who need long-term care according to when they apply for care.

Long-term care programs in states continue to evolve. A better understanding of the impact that current policies have on access to care for individuals can help policymakers determine how to provide optimal long-term care services to the greatest number of people at an acceptable level of spending.

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Introduction

Increasingly, people who need long-term care request that they receive services in the community. Publicly funded programs are evolving to provide alternatives to institutional care for consumers. All states have programs designed to provide a range of community-based long-term care services to the low-income population, but the programs vary considerably in terms of who is eligible to receive services, the types and amounts of services for which coverage is provided, and whether services are available when they are needed. Thus, people in need of community-based long-term care fare differently from state to state. They may fare differently within states as well.

This study uses three hypothetical applicants to illustrate the variation across states regarding the manner in which community-based long-term care services are provided, particularly through the Medicaid program. It also shows what variation in program design might mean in practice. The purpose of the study is to provide information to policymakers as they contemplate the design of long-term care programs. Some states have long-term care programs that are more extensive and more comprehensive than others. Regardless of the level of assistance provided, however, all policymakers grapple with the same basic issue: how to finance a reasonable level of care at an acceptable level of spending.

Background: Options for community–based long–term care

In the United States, the Medicaid program finances long-term care services for people with limited financial resources, including many who become needy after paying for medical or long-term care. Medicaid is a major source of financing for long-term care and the most extensive nationwide program providing coverage for an array of supportive services that people with disabilities need to function daily.

States have considerable flexibility in designing their Medicaid long-term care programs. Thus, Medicaid really is not one program, but more than 50 programs. Medicaid is by far the major source of funding, but all states use a combination of funding sources and programs to provide long-term care services at home or in the community for the low-income population. Many state long-term care systems also include services available through Medicare, and state- and community-funded programs. In addition, some services that are provided locally use federal funds from sources such as the Older Americans Act, Social Services Block Grants, Community Development Block Grants, or Community Action Programs.

The range of possible long-term care options financed through Medicaid and other funding sources is described below. Options available in the four states featured in this study also are described.

Long-term care service options financed by the Medicaid program for individuals with low incomes living at home

In 2000, Medicaid, which is jointly funded by the federal and state governments, paid for about 48 percent of long-term care spending in the U.S.[1] Within Medicaid, the majority of long-term care spending is for institutional facilities, but 29 percent of spending—just over $22 billion—was spent for home and community-based care in 2001. This proportion has more than doubled over the last decade and is expected to keep growing.[2] People receive home and community-based care in their own homes or in community settings such as group homes, foster homes, or assisted living facilities. The delivery of home and community-based care is becoming more common as consumers request this type of service and states respond.

The three benefits that account for most Medicaid spending on home and community-based long-term care are:

- Home health services, which all states must cover under their Medicaid State Plans
- Personal care services, which states may opt to cover under their Medicaid State Plans, and
- Services provided through home and community-based waiver programs, which allow states to waive certain federal requirements to provide home and community services to some individuals who otherwise would require institutional care.

In 2001, home health services accounted for about 11 percent of Medicaid spending for home and community-based care, personal care services accounted for 24 percent, and waiver programs accounted for 65 percent.[3]

There are a number of considerations related to decisions about whether states should offer services under Medicaid state plans or through home and community-based waiver programs. Offering services under the state plan is a more inclusive approach because services must be available to anyone who requires them. Budgetary concerns might make states wary of offering optional state plan services, however, because it is difficult to predict how many people will need the services and how much it might cost to provide them. The cost of waiver programs is more predictable. States might target the waivers to different groups of people, such as the elderly and people with disabilities, or those with mental retardation or developmental disabilities. They set limits on the number of people who can receive services. States also are free to determine the services that will be covered, the settings where they will be provided, and even the geographic area where they will be provided. In some instances, states design waiver programs to provide services for people who are not eligible for Medicaid state plan benefits. Waiver programs, for example, often have higher income eligibility limits than the regular Medicaid program. Waiver programs also provide coverage for some services that cannot be covered under the regular state Medicaid plan such as chore services, respite care, and environmental modifications.

State Plan Services

The Medicaid program provides coverage for a set of services specified in each state's Medicaid state plan. Coverage for some services is mandatory. For example, individuals who have full Medicaid coverage can receive hospital, physician, laboratory, and X-ray services. States also are required to provide transportation related to medical care. Coverage for services such as physical

therapy, occupational therapy, case management, prescription drugs, personal care, and hospice care, also is available at a state's option. States determine whether there will be limits on the amount, duration, or scope of services and what the limits will be.

Home health services are mandatory Medicaid services, but states may set criteria for who receives the services. Beneficiaries do not have to meet the same level of care criteria required for nursing facility care. Nor is eligibility for Medicaid home health services linked to the need for a skilled level of health care, as it is in the Medicare program. Service eligibility criteria must be based on medical necessity, but the definition of medical necessity is left to each state. Federal rules require that physicians order home health services as part of a written plan of care. Home health services include nursing services or home health services provided by certified home health agencies, and medical supplies, equipment, and appliances suitable for use in the home.[4]

About half of states have opted to cover the optional personal care services. There are no federal rules regarding the type or level of impairment a person must have to receive benefits. Basically, personal care services are provided to persons with disabilities and chronic conditions to help them perform tasks such as bathing, dressing, or preparing meals that they would normally do themselves if they did not have a disability. There is considerable variation in the criteria states use to determine eligibility for personal care services. For example, states provide personal care services for people who have different types and numbers of limitations. The number of hours of assistance needed also is used as a service criterion in some states.[5] The services are generally provided by home health agencies, or some states allow consumers to hire service providers through consumer-directed organizations or on their own. The range of services provided under the benefit differs from state to state. New Jersey and Wisconsin cover personal care services under their state plans. About 15,000 people in New Jersey and 10,500 in Wisconsin receive the services. Colorado and Mississippi do not cover personal care services.

Home and community-based waiver services

Medicaid home and community-based waiver programs allow states to provide long-term care services in a home or community setting to individuals who otherwise would require institutional services reimbursable by Medicaid. At a minimum, beneficiaries that receive home and community-based waiver services must meet the same categorical and functional criteria that are used in the state for nursing facility care. Stricter functional eligibility criteria also may be used.

All states have established home and community-based waiver programs, but the size and scope of the programs differ considerably.[6] Currently, some 274 Medicaid waiver programs for home and community-based services are in operation.[7] Some services commonly provided through waiver programs include case management, homemaker services, home health services, respite care, day care, transportation, chore services, and environmental modifications. Generally, states determine the types and amounts of services that can be provided. Within these limits, care planners make recommendations regarding the type and amount of services for each applicant and then make arrangements with home health agencies or other agencies to provide the care. Increasingly, consumers

are becoming more involved in the care planning process, however.

About 38 percent of waiver program participants are people with mental retardation and developmental disabilities, but they account for 75 percent of waiver program expenditures. About 60 percent of waiver program participants are elderly people and others with physical disabilities, but spending for this group represents only 24 percent of spending for all waiver program participants.[8]

Medicaid Buy-In Programs

Medicaid Buy-In Programs are a new option for states, which account for a very small portion of Medicaid spending, but are potentially important for people with disabilities when they return to work. States may establish programs that allow people aged 16 to 64 with disabilities who are working, and therefore have incomes that would make them ineligible financially for Medicaid benefits, to purchase health insurance coverage through the Medicaid program and receive Medicaid state plan benefits. In some states they may be able to get services provided through home and community-based waiver programs as well. State Medicaid programs establish financial eligibility requirements for the programs. States set premiums and cost-sharing requirements for program participants within upper limits that are tied to workers' income. Mississippi, New Jersey, and Wisconsin operate *Medicaid Buy-In Programs*. Colorado is planning to establish a *Medicaid Buy-in Program*.

Other long-term care service options for individuals with low incomes living at home

In addition to Medicaid-funded services, people with long-term care needs also may rely on the Medicare program for a limited set of services. They may benefit from state-funded programs, some of which provide a broad range of services and some of which are service specific. And they may receive help from community organizations that use federal funds for specific services.

The Medicare Program

Medicare is a federal health insurance program that provides coverage for individuals aged 65 and older, and for people with permanent disabilities who are under age 65. People who receive Medicare and Medicaid benefits are called "dually eligible." Medicare's home health benefit enables homebound enrollees needing intermittent skilled care to receive care at home. To qualify for Medicare's home health benefit, a Medicare enrollee must need intermittent skilled nursing care, or physical or speech therapy or continuing occupational therapy; be unable to leave home under normal circumstances; and have the need for home health care certified periodically by a physician. For people who meet the eligibility criteria, Medicare will pay for six types of visits provided by a Medicare-certified home health agency: skilled nursing care; home health aide services; physical, speech, and occupational therapy; and medical social services. In addition to visits, Medicare covers most medical supplies and a portion of the cost of durable medical equipment furnished by home health agencies.[9]

State-Funded Programs

Some state-funded programs are similar to Medicaid home and community-based waiver programs, but they provide coverage or services to people who do not qualify for the waiver programs. States also fund programs that provide particular services not available from other sources. In addition, some states sponsor demonstration projects to test new approaches to providing care. The Departments of Rehabilitation Services

or Vocational Rehabilitation in each state also have some resources to help people with disabilities who want to work.

Colorado's state-funded *Home Care Allowance Program* provides a monetary allotment that can be used to pay a friend or relative for providing unskilled care. It is used particularly for people who do not qualify for waiver programs, but can be used, if necessary, while someone is receiving waiver services. Approximately 5,400 people participate in the program.

In New Jersey, the state-funded *Personal Assistance Services Program (PASP)* provides routine nonmedical assistance to about 500 people with disabilities who work, attend school, or are involved in community or volunteer activities. The state-funded *Jersey Assistance for Community Caregivers* program provides a variety of in-home services and supports similar to those provided by the Medicaid waiver program for the elderly and people with disabilities. It targets people aged 60 and older who otherwise would qualify for placement in a nursing facility, but wish to remain at home and who are financially ineligible for Medicaid or Medicaid waiver services. New Jersey's *Personal Preference Program* is a demonstration project that provides cash and counseling in lieu of specific services, for people who need at least six months of personal care.

Wisconsin's state-funded *Community Options Program (COP)* is very similar to the Medicaid *Community Options Waiver Program*. It provides community-based services to anyone who would otherwise qualify for institutional care, regardless of the reason for their disability. It also serves some people who do not meet the home and community-based services waiver eligibility criteria. It is the most flexible long-term support benefit in Wisconsin, with no disallowed services. Services for some individuals are funded entirely through *COP*, and it can be used to supplement services for people in other programs. Some 2,800 people receive services through *COP*. *Pathways to Independence* is a demonstration project sponsored by the Robert Wood Johnson Foundation, operating in Wisconsin. The program provides an employment consultant, training, counseling, and education related to a plan to return to work.

Other Services Available in the Community

Many communities provide services designed to "fill the gaps" for people who have long-term care needs, but might not need a comprehensive set of services or might not qualify financially or functionally for more comprehensive programs. Community services are also particularly important for individuals who are trying to piece together care while they wait for more comprehensive programs. Community-sponsored services include shopping, meal preparation, or companion services provided by volunteers, funds to purchase equipment, and funds or volunteers to help with home repairs. Many communities also have special transportation services for the elderly or disabled. Through the Older Americans Act, all states receive funds to distribute for community-based services for the elderly. Home-delivered meals or transportation are services commonly provided with funds from the Older Americans Act. Community Development Block Grant or Community Action Program funds are available in some communities to help with home modifications and repairs. Social Services Block Grants to states also can be used for services such as adult day care, employment services, counseling, and meal preparation and delivery.

Study Approach

The design of publicly financed long-term care programs varies across states. Past research has examined what services potentially are available in states. This project seeks to determine what services would be available in a timely manner and whether those services would be adequate so that individuals could live in the community. In other words, the project differentiates between what is potentially available and what could actually be provided if an eligible individual were to apply for services at a particular point in time.[10]

The project uses three hypothetical applicants, or "cases" to illustrate the variation across states regarding the manner in which community-based long-term care services are provided, particularly through the Medicaid program. The cases were developed following consultation with researchers, advocates, and state officials familiar with long-term care programs and policies. The cases represent three adults with different disabilities and needs who are facing new situations that cause them to seek long-term care services at home. Each is assumed to be financially eligible for Medicaid, with income and assets that fall within the program eligibility limits. The cases are described in Box 1. Briefly, they are:

- Mrs. Alice Adams, an 83-year-old woman who has been diagnosed with terminal cancer.
- Mr. Bob Bailey, a 30-year-old man who has just been paralyzed from the waist down as the result of a spinal cord injury sustained in an automobile accident.
- Ms. Carol Casey, a 22-year-old who has mental retardation as a result of complications during birth and has been diagnosed with autism.

Structured interviews were used to conduct detailed discussions with officials in four states—Colorado, Mississippi, New Jersey, and Wisconsin—about the types of programs and services that are potentially available for each of these individuals. Interviews also were conducted with regional and local program administrators in two or three localities in each state. State officials were asked to identify local program administrators. Administrators in 10 localities were interviewed for each case. The interviews were conducted between February and May of 2002.

The four states were chosen to show a broad range of possible arrangements for providing long-term-care services. For example, two of the states—New Jersey and Wisconsin—offer the optional personal care services benefit under the Medicaid state plan, but the other two do not. With the exception of Mississippi, the states have home and community-based care programs that are solely state funded. Mississippi, New Jersey, and Wisconsin offer new *Medicaid Buy-In Programs* that allow some people with disabilities who are working to purchase health insurance coverage through the Medicaid program.

The four states also were chosen because they provide home and community-based care to different proportions of the state's population. Data collected on total Medicaid participants using Personal Care Services under the Medicaid state plan and *Home and Community-Based Waiver Program* services in each state show that

Colorado and Wisconsin rank among the top third of states with regard to total users per 1,000 population. New Jersey is in the middle third and Mississippi is in the bottom third.[11] The proportion of Medicaid long-term care funds spent for home and community-based services also differs among the states. It ranges from a high of 51 percent in Colorado to a low of 9 percent in Mississippi. New Jersey and Wisconsin spend 18 percent and 36 percent, respectively.[12] Descriptions of the Medicaid waiver programs that provide coverage for community-based long-term care in each of the four states are provided in Boxes 2 and 3.

The intent of this study is not to identify "better" or "best" practices among states. Rather, it is to describe the various policies and practices that currently are in use and to show how variations in program design may affect outcomes for individuals. The purpose of the study is to provide information to policymakers as they contemplate the design of long-term care programs.

State, regional, and local program administrators and care planners were asked to talk about issues related to the following:

1. Would the individual be eligible for community-based long-term care services?
2. What services does the individual need?
3. What care plan would be recommended?
4. Is coverage for the recommended services currently available?
5. Are providers available for the recommended services?
6. Would this individual be able to stay in the community?

Although they were willing to discuss which services could be provided and which are likely to be available, some respondents said that the cases are not sufficiently detailed to elicit complete care plans. Others provided care plans. It is important to note that the responses reported here reflect the situation at a point in time. Circumstances can change quickly in states, however, particularly as budgets change. Another caveat regarding the responses is that respondents were not asked for detailed comments about the quality of services. It is also important to note that to a certain extent the information reported reflects the assumptions, opinions, and practices of individuals. It is possible that practices differ within programs and agencies.

Box 1: Three Cases for Discussion

Case A: Mrs. Alice Adams

Mrs. Adams is 83 years old. She lives with her husband who is 85 and in good health, though frail. They have a very limited income and have both Medicare and Medicaid coverage. Recent surgery and radiation therapy for cancer left Mrs. Adams weak. Unfortunately, she just learned that despite these interventions, the cancer has spread. She now has a terminal illness. She knows she will become weaker as the disease progresses. Mrs. Adams can no longer do housework or prepare meals. She needs help dressing and she is having difficulty climbing the stairs in the couple's two-story home. She also needs help caring for a wound that has become infected following the surgery and radiation. Both Mrs. Adams and her husband are hoping she can receive assistance at home.

Case B: Mr. Bob Bailey

Mr. Bailey is a 30-year-old man who has just been paralyzed from the waist down as the result of a spinal cord injury sustained in an automobile accident. Prior to the accident, he was an active man with no medical problems. He is a computer programmer who works as a consultant to several small firms. Mr. Bailey makes a modest living, owns his own home, and has a small amount of savings. He does not have health or disability insurance. Mr. Bailey is just beginning to think about what he will need: more frequent medical care, assistance with all the activities he has always taken for granted, such as getting in and out of bed, dressing, eating, bathing, using the toilet, and getting around. He knows he will need a wheelchair and that modifications will have to be made to his home to accommodate his new lifestyle. He is determined to live at home and return to work.

Case C: Ms. Carol Casey

Ms. Casey is 22 years old. She has mental retardation as a result of complications during birth and has been diagnosed with autism. She lives with her mother and her 15-year-old sister. The family has just moved back to the state to help care for Ms. Casey's grandmother. Currently Ms. Casey's mother is not employed, though she has worked as a part-time receptionist in the past and would like to look for work again as soon as she gets her family settled. Ms. Casey does best in a very structured environment and needs constant supervision. With direction from someone she knows she can perform simple tasks, but she does not have the capacity to solve problems independently, and because of safety concerns, she cannot be left alone. She has been living at home and attending an adult day program where she received some vocational training. Ms. Casey's mother has been told that her daughter has the potential to work regularly in a supervised setting.

Ms. Casey's mother needs help with her daughter's care, but she does not want her to be placed in an institution. Her mother believes that she can care for Ms. Casey at home with some help. In addition to direct services, including a day program, Ms. Casey's mother knows that she will have to arrange for transportation since she does not own a car. She would like to arrange for some respite care and for some counseling for herself and for her daughter. She knows there may be different community-based options for Carol and would like to learn about all of them.

Box 2: Medicaid Home and Community-Based Waiver Programs that Provide Coverage Primarily for the Elderly and People with Physical Disabilities in the Four Study States

Mrs. Adams and Mr. Bailey are interested in receiving care in their homes. The following is a description of the major Medicaid waiver programs in each state that would potentially provide coverage for this type of care. Colorado has one large waiver program. The three other states have several different waiver programs that may be relevant.

Colorado

· The *Home and Community-Based Services for the Elderly, Blind, and Disabled Waiver Program (HCBS-EBD)* provides services for approximately 15,000 people who are elderly or have disabilities.

Mississippi

· The *Elderly and Disabled Waiver Program* provides services for about 8,000 individuals over age 21 who are elderly or have disabilities.

· The *Independent Living Waiver Program* provides personal care attendant services for almost 300 people who are severely orthopedically or neurologically impaired and are capable of directing their own care.

· The *Traumatic Brain Injury/Spinal Cord Injury Waiver Program* targets services to about 100 people with traumatic brain or spinal cord injuries.

New Jersey

· The *Community Care Program for the Elderly and Disabled (CCPED)* provides a limited set of services for about 3,500 individuals aged 65 and older who have Medicare or other health insurance.

· The *Caregiver Assistance Program (CAP)* provides services for about 800 people aged 21 through 64 with disabilities, and individuals aged 65 and older who qualify because of functional limitations. It provides the broadest range of services for individuals living in their own homes.

· The *Community Resources for People With Disabilities Program,* formerly known as *Model Waivers 1, 2, and 3,* serves about 250 Medicaid beneficiaries of all ages who have functional disabilities.

Wisconsin

· The *Community Options Waiver Program (COP-W)* provides services for 11,000 people who are elderly or have physical disabilities.

· The *Community Integration Waiver Programs (CIP)* also provide community-based care as an alternative to institutional care. *CIP-II* provides the same benefits as the *COP-W Program* for about 3,000 people who are elderly or have physical disabilities.

· The *Family Care Program* is a pilot program designed to provide the full range of long-term care services to about 6,000 people with all types of disabilities in five counties through capitated county-run Care Management Organizations. Several funding sources are combined to finance the program.

Box 3: Medicaid Home and Community-Based Waiver Programs that Provide Coverage Primarily for People with Mental Retardation or Developmental Disabilities in the Four Study States

Ms. Casey's family is interested in caring for her at home. The following is a description of the major Medicaid home and community-based waiver programs in each state that would potentially provide coverage for this type of care. Colorado, Mississippi, and New Jersey each have one relevant waiver program, but Wisconsin has implemented a series of similar waiver programs at different times.

Colorado

·The *Supported Living Services Waiver Program* enables almost 3,000 adults with mental retardation or developmental disabilities to live in their own homes or family homes.

Mississippi

·The *Mental Retardation/Developmental Disability Waiver Program* assists almost 1,500 people with mental retardation or developmental disabilities.

New Jersey

·The *Community Care Waiver Program* provides services for about 7,600 individuals with mental retardation or developmental disabilities.

Wisconsin

·The *Community Integration Waiver Programs (CIP)* provide community-based care as an alternative to institutional care. *CIP-IA* and *CIP-IB* are programs that divert people from institutional care or help people with mental retardation or developmental disabilities relocate from institutions back to the community. About 3,500 people participate in the program.

·The *Community-Supported Living Arrangements Waiver Program (CSLA)* serves the same population as *CIP-IB*. Not every county has a *CSLA* waiver, but where they exist, they provide the same menu of services as the *CIP-IB* waiver program to about 6,000 people living in settings where they have control.

·The *Family Care Pilot Program* also provides services to people with mental retardation or developmental disabilities in most of the counties where it operates. A total of 6,000 people, with all types of disabilities participate in the program.

How would the applicants fare?

Respondents indicated that the three cases are fairly typical of the people they see routinely. There was general agreement that if they qualified financially, all three would be eligible for Medicaid long-term care benefits. Each of the four states has established programs to provide the full complement of services that Mrs. Adams, Mr. Bailey, and Ms. Casey might need. Ultimately, though, they would have difficulty arranging for community-based care in some of the localities.

Among the applicants, Mrs. Adams, a frail older woman with terminal cancer, is most likely to obtain community-based assistance through the Medicaid program. In a few locations she might be put on a waiting list for services or she might face uncertainty about the availability of service providers. Mr. Bailey, a 30-year-old man who has just been paralyzed from the waist down after an automobile accident, would not fare as well. He would encounter waiting lists in a number of places, and service providers might not always be available because he needs more personal care and needs it routinely in the early mornings and late evenings. The person least likely to be able to receive adequate care and remain at home is Ms. Casey, a 22-year-old with mental retardation and autism. In every instance she would be put on a waiting list for most services and could not expect to receive most program benefits for a year or more.

Mrs. Adams

In most localities, coverage for home and community-based care would be available for Mrs. Adams when she needs it. Of the four states, there is only one, however, where Mrs. Adams can be confident not only that she will have coverage for the services she needs, but also that all the service providers she needs will be available to care for her. Colorado does not have waiting lists nor do officials report that there is a serious shortage of service providers.

With Medicare and Medicaid coverage, Mrs. Adams is "dually eligible" for some services. Medicare will pay for her immediate needs, particularly those related to wound care. In addition, some home health care services could be provided during the period when she is receiving skilled care for the wound. Related medications and medical supplies also would be covered. For the longer term, there is general agreement that Mrs. Adams would meet the functional eligibility requirements for home and community-based care through the Medicaid program. The Medicare hospice benefit also could be used to pay for some of the other cancer-related services Mrs. Adams needs. Medicaid coverage would entitle Mrs. Adams to medicine and medical supplies not covered by Medicare. In every location, home-delivered meals would be provided with funding from waiver programs or from sources such as the Older Americans Act. Most respondents noted that the need for services will increase as Mrs. Adam's condition deteriorates.

Financial eligibility rules could affect program participation

Mrs. Adams already had both Medicare and Medicaid coverage when she was diagnosed with terminal cancer

and realized that she would need some long-term care services. If she did not have Medicaid coverage already, however, she would have had to submit a Medicaid application, which would be reviewed to determine whether she meets the program's financial eligibility criteria and to determine whether she meets the functional eligibility requirements for long-term care services. Since financial eligibility rules for the Medicaid program vary across states, Mrs. Adams could have been eligible for some services in one state, but not another.

Financial eligibility rules for home and community-based waiver programs are similar in the four states, but the income and asset limits for Medicaid state plan services differ. Thus, if Mrs. Adams were on a waiting list for waiver services, but needed home health care or other state plan services, she might fare differently in the four states because of her financial circumstances. For example, the income limits used in Colorado and New Jersey are tied to the Supplemental Security Income, or SSI, program. The income and resource limits are higher in New Jersey because the state has taken advantage of the option to raise the income limits for the elderly to a level as high as 100 percent of the federal poverty line. Mississippi, too, has raised the income limit to 100 percent of the federal poverty line. In addition, the state disregards income between 100 and 135 percent of the federal poverty line, effectively raising the income eligibility limits to 135 percent of the federal poverty line. Resource standards also vary. The resource limits for Mr. and Mrs. Adams would be $3,000 in Colorado and Wisconsin and $6,000 in Mississippi and New Jersey. Thus, if the couple had a qualifying income, but assets of $5,000, they could receive Medicaid coverage in just two of the four states studied.

If Mr. and Mrs. Adams's income were too high to qualify for the Medicaid program, but they had substantial medical expenses, they would have another option, in some states, to qualify for Medicaid through the *Medicaid Medically Needy Program*. Under this option, medical expenses incurred over a budget period up to six months can be deducted from countable income. If the resulting amount is less than the state's medically needy income limit and the applicant meets the resource limits, Medicaid coverage is provided for the remainder of the budget period. Two of the four states—New Jersey and Wisconsin—have *Medically Needy Programs*.

Respondents generally agree on the care plan for Mrs. Adams

Mrs. Adams would qualify for long-term care services. The criteria used to make functional eligibility determinations for Mrs. Adams vary by state, however. Although the methods used to determine functional eligibility for Mrs. Adams would differ by state and locality, all of the respondents concluded that she would be eligible for Medicaid community-based long-term care services. They noted that Mrs. Adams would likely have relatively modest needs for a limited period of time. Some commented that in the case of an 85-year-old frail woman with a terminal disease, "We could find a way to make her eligible" or "We could find reasons to check the boxes [on the functional assessment instrument]." Even where waiting lists exist, a common sentiment was, "We would never let someone like this go without."

Respondents indicated that the core group of services Mrs. Adams needs include the following:

- Nursing care for her wound

- Other home health care, perhaps the services of a home health aide, while she is receiving care for the wound
- Medical supplies and medicine
- A set of services (some of which can be combined or substituted for others) to keep the household functioning, including
    - Personal care services
    - Homemaker or housekeeping services
    - Chore services
    - Respite care
- Environmental modifications or other provisions to respond to the difficulty that Mrs. Adams is having climbing the stairs
- Case management
- Home-delivered meals.

Recommendations for the amount of service differ somewhat

Generally, respondents indicated that the amount of services Mrs. Adams needs would fall well within the established service limits. There are differences, however, in the amount of care recommended for Mrs. Adams. Almost every respondent noted that the amount of services Mrs. Adams receives will depend somewhat on what her husband can provide, but each person had different assumptions about what he could or should provide. One respondent noted, for example, that since Mr. Adams probably cannot cook, the maximum number of meals should be ordered for Mrs. Adams so the two could share the food that would be delivered. Another respondent assumed that Mr. Adams would be able to do chores in the home. Although a similar set of household services was recommended across sites, the range in the total number of hours of personal care and housekeeping services was substantial. Commonly, the recommendation was for 5 to 10 hours of household-related care per week, but the recommendation was as low as 2 to 6 hours per week in one location and as high as 30 or more hours per week in another. Looking just at respite services, recommendations varied from 4 to 8 hours per week. The average recommendation was for about 6 hours of care from a home health aide or housekeeper each week, and about 6 hours of personal care and perhaps some respite care. Home-delivered meals were recommended uniformly.

Modifications to the home pose the biggest challenge

It is unlikely that home modifications would be provided for Mrs. Adams in Mississippi. They are not a covered service under the *Elderly and Disabled Waiver Program* and therefore would be available only if other community resources were available. There was agreement among respondents from other states that since Mrs. Adams has a terminal illness, they might be reluctant to recommend extensive home modifications. Some suggested that a "stair climber" could be installed, but that alternatives should be considered first. It might be possible, for example, to have Mrs. Adams live downstairs. A hospital bed could be brought in and if there were a downstairs bathroom or powder room, some modification could occur. Another possible solution is to hire someone to help Mrs. Adams get up and down the stairs in the morning and evening. One official noted that the bid process for home modifications takes a considerable amount of time and therefore might not be practical for someone with a terminal illness. No one indicated that environmental modifications would not

be done, but this is one area where Mr. and Mrs. Adams might have to be more assertive in requesting services.

Mrs. Adams will encounter waiting lists in a few locations

Mrs. Adams would be able to participate in home and community-based waiver programs in Colorado and New Jersey because funding is currently available to serve all qualified applicants. In parts of Mississippi and Wisconsin, however, she would have to wait to participate in the waiver programs. Where waiting lists exist, the wait could range from a few months to a year. Mrs. Adams could receive community-based long-term services under the pilot *Family Care Program* in five Wisconsin counties because they provide coverage on an entitlement basis. Another Wisconsin county currently has the capacity to serve Mrs. Adams because the recent closure of 35 nursing home beds has made room for more community-based care. Prior to that, however, people were on waiting lists for over one year. Officials note that once the newly available "slots" are used, a waiting list will have to be developed again.

Mrs. Adams might have difficulty remaining in the community while she is on a waiting list for waiver services

If Mrs. Adams knows she will be on a waiting list for a short time, and Mr. Adams or other relatives or friends can provide some assistance, she might be able to remain in the community. Her chances are better in Wisconsin than in Mississippi, because Wisconsin provides personal care services as an entitlement under the Medicaid state plan. For example, coverage for some homemaker services and limited case management services would be available to Mrs. Adams. Some services that Mrs. Adams will need are not covered, however, so if she needs respite care or home modifications while she is on the list for a Medicaid waiver program, she will not be able to stay at home.

A shortage of providers might also limit the availability of services in the community

Although coverage for needed community-based services would be available to Mrs. Adams in most localities, the provision of the services is not guaranteed because, in some cases, service providers are not available for all the services Mrs. Adams needs. Several respondents indicated that there is a shortage of caregivers, particularly for home health, housekeeping, chore, and personal care services. In those places, Mrs. Adams might find that the lack of long-term care providers threatens her ability to remain in the community for the duration of her illness. She might fare better if she had family members, other than Mr. Adams, or friends or neighbors who were willing to provide some of the personal care services she needs. There is an option, in all four states, for family members or friends to become paid care providers.

Chance or timing might play a role in the availability of services

In discussing Mrs. Adams's case, more than one respondent said, "If she is lucky…" Some are referring to whether there is a waiting list in a particular community. Others discuss the uncertainty related to finding service providers. Finally, some indicated that if Alice Adams is "in the right place at the right time" she will be more likely to get all the services she needs.

The timing would be right for Mrs. Adams in the Wisconsin community, where the closure of nursing home beds made funds available for community-based care just at the time she would

need care at home. If she had applied for services earlier or after all the available slots for community-based care had been used, however, she would be put on a waiting list.

Mr. Bailey

Initially, Mr. Bailey will spend some time in the hospital and then potentially in a rehabilitation facility. Some of his needs related to physical and occupational therapy will be met there and he might be outfitted with a wheelchair. Medicaid will pay for the immediate care he receives in those settings. For the longer term, Bob Bailey will likely need coverage through the Medicaid home and community-based waiver programs to be able to live at home and return to work, because there is the potential to receive the broadest range of services, including environmental modifications, through the waiver programs. Mr. Bailey could not be assured of receiving home and community-based waiver services in most of the communities studied, either because he would encounter waiting lists for services or because he would face a shortage of service providers.

Mr. Bailey potentially can draw on a variety of other federal, state, or locally funded programs for services such as transportation or vocational counseling. In all of the states, the Departments of Rehabilitative Services or Vocational Rehabilitation can play a role in assisting Mr. Bailey. Additional funds or labor for equipment and environmental modifications might be available through Community Development Block Grants or Community Action Programs in some places. These programs in combination with Medicaid personal care services might be an option for Mr. Bailey in some places.

As Mr. Bailey's circumstances change, his needs and options might change as well. When he returns to work, his earnings could threaten his financial eligibility for Medicaid and therefore the availability of some of the care he needs to live and work independently. In three of the four states—New Jersey, Mississippi, and Wisconsin—he could apply for the *Medicaid Buy-In Program*, which allows him to purchase Medicaid coverage if his income is above the financial eligibility limits for regular Medicaid coverage, but below the higher *Buy-In Program* limits. He would not have this option in Colorado, which does not have a *Buy-In Program*, but which does plan to establish one.

The first challenge could be to obtain and maintain health insurance coverage

The assumption in this study is that Mr. Bailey's income and assets are sufficiently low that he will qualify for Medicaid. If that were not the case, his chances of qualifying for Medicaid coverage would be better if he lived in a state, such as New Jersey or Wisconsin, which has a *Medicaid Medically Needy Program*. This option would allow him to deduct medical expenses from his countable income to try to qualify financially for coverage.

Mr. Bailey also will have to be sure that when he returns to work, both his income and any assets that he might accumulate fall within the financial eligibility limits for the *Medicaid Buy-In Program*. To accomplish this, he will have to become familiar not only with the income and asset limits, but also with the methodology used to calculate income and assets in the state where he lives. States might choose to disregard, or not count, certain portions of earned or unearned income. Rules also differ, among states, as to which assets are counted and whether a portion of the value of particular assets can be disregarded. Mr. Bailey will have to monitor his finances, and might have to adjust his work schedule to be sure that

both his income and any assets that he might accumulate fall within the financial eligibility limits for the program.

The mix of services Mr. Bailey needs will likely change over time

The elements of the long-term care plan most commonly recommended for Mr. Bailey include:

- Equipment such as a wheelchair
- Home modifications to accommodate a wheelchair such as a ramp and widened doors, and possibly modifications in the bathroom
- Some physical and occupational therapy, especially initially
- A home health aide or a personal care attendant to help with activities of daily living
- Assistance with housekeeping and chore services
- Assistance with transportation.

The range of services varies

Depending on where he lives, Mr. Bailey would choose among different services. For example, the *Caregiver Assistance Program* in New Jersey offers a menu of services that includes 13 services: case management, respite care, homemaker services, environmental accessibility adaptations, personal emergency response systems, home-delivered meal service, caregiver and recipient training, social adult day care, special medical equipment and supplies, chore services, transportation, attendant care, and home-based supportive care. The major waiver programs in Colorado and Wisconsin also provide a broad array of services. In Mississippi, Mr. Bailey could participate in just one of three waiver programs. The *Independent Living Waiver Program* provides two services: case management and personal care attendant services. The *Traumatic Brain Injury/Spinal Cord Injury Waiver Program* provides case management, respite services, attendant care, environmental adaptations, and specialized medical equipment. The *Elderly and Disabled Waiver Program* provides adult day health care, home-delivered meals, homemaker services, transportation, respite services, and home health visits. At present, all of the waiver programs in Mississippi have waiting lists, so the services that Mr. Bailey receives eventually would probably depend on which waiver program has funds available.

The recommended amount of care varies

Estimates by local program administrators and care planners vary regarding the number of hours of personal care Mr. Bailey needs. One respondent suggested that he would need 2 to 4 hours of personal care daily, while another said that 6 to 12 hours would be appropriate. Realistically, the number of hours of personal care needed depends on the mix of other services he is receiving. The number of hours needed will likely change over time as Mr. Bailey's condition changes. Initially, he is likely to need more help. If too few hours are provided, he might have difficulty remaining at home. As he becomes more independent, he might need fewer hours of care.

Mr. Bailey might have to make choices regarding home modification and equipment

Mr. Bailey's need for home modifications and special medical equipment are extensive relative to many others who need long-term care. Limits on spending might mean that equipment for him will have to be purchased in stages in some places. One respondent noted that because there are limits on spending

for home modifications, Mr. Bailey might only be able to get part of what he needs initially. Some programs make provisions so that the cost of equipment such as a wheelchair ramp can be prorated over a year. As a result, the total cost of care will fall under the monthly spending targets.

Waiting lists would be problematic in two states

Mr. Bailey would not have to contend with waiting lists in Colorado or New Jersey, but he would be put on a waiting list in Mississippi and in most communities in Wisconsin. Like Mrs. Adams he would benefit from the recent closure of 35 nursing home beds in one Wisconsin county, which has made room for more community-based care. It is interesting to note that Mr. Bailey would be put on a waiting list for the *Community Options Waiver Program* in one of the five counties in the state participating in the pilot *Family Care Program*, even though the *Family Care Program* is designed to provide long-term care benefits on an entitlement basis. The reason for this is that the county designed its program to be an entitlement for people over age 60, but not for others. Although Bob Bailey could not receive services there, he would be entitled to services in the four other pilot counties.

Mr. Bailey might have one other option in Wisconsin. The state has set aside a pool of money to provide community-based services to people who currently are in institutions. These funds are administered by the state. Therefore, when people apply to the state for funds to relocate from a nursing facility, they can bypass the county-administered waiting lists for home and community- based services programs. There is a chance that if Mr. Bailey were to go to an institution, and then apply to leave the institution, he could receive community-based care much more quickly.

Mr. Bailey's ability to remain in the community while he is on a waiting list for waiver services will depend on the availability of other services

Mr. Bailey would not face waiting lists in Colorado or New Jersey. In Mississippi, where he would be put on a waiting list, it is unlikely that he could remain in the community, because few of the services he needs are available there other than through the waiver programs. In Wisconsin, Mr. Bailey might be able to receive some personal care services he needs, assuming that providers are available, because they are covered by the Medicaid state plan. Mr. Bailey also has an urgent need for modifications to his home, however. While he is on a waiting list for more comprehensive care, there is a chance that a community-based organization might be able to help with this. Environmental modification services related to Mr. Bailey's return to work might be available through the Department of Vocational Rehabilitation. Another possibility in Wisconsin is a "one-time payment" for home modifications or equipment from the state-funded *Community Options Program*. There is no guarantee, however, that resources will be available when he needs to have the modifications done.

The biggest challenge for Mr. Bailey will be finding personal care providers

Respondents report not only that there is a shortage of personal care providers, but also that it is particularly difficult to find caregivers who will work consistently in the early morning hours. Given that Mr. Bailey plans to continue working, it is likely that that is when he will need care. One respondent noted that for this reason, agencies are reluctant to take on clients with the kind of needs Bob

Bailey has. In some communities, program administrators say they must make many telephone calls and resort to personal appeals to recruit providers for clients with care needs that are substantial and require a consistent schedule. Mississippi is the only state where respondents did not indicate that it would be difficult to find appropriate providers to care for Mr. Bailey once he is off the waiting list and therefore eligible to receive care. As with Mrs. Adams, he would have the option of identifying family members, neighbors, or friends to become paid caregivers for personal care services in all four of the states.

Ms. Casey

The Casey family has a strong desire to keep Carol Casey at home, but to accomplish this they must be able to arrange for her to participate in a structured day program. The sources of coverage for this type of service are limited. The family would have to rely primarily on Medicaid home and community-based waiver programs. The types of services that Ms. Casey needs are very different from those covered under Medicaid state plans. Whereas Mrs. Adams and Mr. Bailey can use the personal care services available under the Medicaid state plans in New Jersey and Wisconsin, Ms. Casey needs different services to remain at home.

The financial eligibility criteria for home and community-based waiver services and for Medicaid state plan services would be similar across states for Ms. Casey. The general consensus is that with substantial mental retardation and a clear diagnosis of autism, Ms. Casey is likely to be eligible for services. Also, respondents in every location report that the type of service providers she needs are available. Ms. Casey would have to wait for services, however. She is just past the age to qualify for any of the services that are available to children with developmental disabilities through the school system. Yet as an adult she faces long waiting lists for services in all of the localities.

Day services are a key component of Ms. Casey's care plan

Respondents recommended a range of services for Carol Casey. They include:

- Day habilitation, which can include skills training, prevocational services, or supported employment or other day services such as daily living skills training or a sheltered workshop
- Transportation to daytime activities, which often is part of the day habilitation program
- Supportive home care
- Personal care
- Recreational therapy, social support, or community participation
- Respite care or in-home support
- Case management
- Counseling for Ms. Casey and her mother.

Most respondents said that if space were available in a vocational support or day program, Ms. Casey would attend five days a week for about six hours each day. Given that day services are not currently available, however, respondents were reluctant to indicate the quantity of other services that would be provided. They did note that the number of hours of care Ms. Casey would receive depends, in part, on how much care her mother or grandmother might be able to provide. One respondent noted that it might be prudent for the family to try to get some paid care for the grandmother so that Ms.

Casey's mother would have more time to care for her daughter. Respite care was uniformly recommended and would be provided anywhere from about three days each month in some places to six days each month in others. Some services, such as recreational therapy or social support, were recommended in only one location. Behavior support or intervention services were recommended in several locations, though the amount recommended initially ranged from 60 hours per year to 40 hours per year to "as needed."

In every location, Ms. Casey's family would have to contend with long waiting lists

Not only would Ms. Casey be placed on waiting lists in each of the localities examined, she also likely would have to wait a year or several years to receive services. In New Jersey Ms. Casey would be on waiting lists for types of services rather than for a specific program. Currently, there is a waiting list of approximately 18 months for day habilitation services, but family support services would be available. Ms. Casey would probably be able to receive some respite care, some counseling, and a cash subsidy between $1,000 and $2,000 per year that can be used for other needs. Coverage for these services would be helpful, but would not necessarily be sufficient to keep Ms. Casey at home. If Ms. Casey could not be left alone safely, and her mother had to go to work to support the family, there would be an option for emergency day placement in New Jersey. Because it would be an emergency placement, however, it may not be as appropriate as other placements for Ms. Casey, and she would be kept on a waiting list for a more appropriate placement.

In Colorado, each Community Centered Board maintains a waiting list for the *Supported Living Services Program*. Although all of the Boards have waiting lists, some are much longer than others. Applicants can be placed on waiting lists in a service area other than where they live. Colorado also allows parents to place their children on waiting lists for adult services when they are aged 14 or older. If Carol's family had been living in Colorado earlier and put her name on a waiting list for services when she was a young teenager, her wait for services as a young adult would be shorter.

Faced with long waiting lists, officials suggested some alternatives

Most respondents indicated that they would try to make referrals to community-based programs for Ms. Casey, though they do not know if space would be available at those programs. In Mississippi, there are some local work activity centers and supported employment sites. In Wisconsin, some counties have contracts with agencies that provide direct services such as day programs and vocational programs. Wisconsin also has sheltered workshops, which would not be ideal for Ms. Casey, but may be a possibility if a county has a contract with a sheltered workshop and there is an opening.

Some respondents suggested that although Ms. Casey would have to wait for services through waiver programs for people with mental retardation or developmental disabilities, she might be able to qualify for some services through one of the other waiver programs. In Colorado, for example, the *Elderly and Disabled Waiver Program* is open to people with developmental disabilities, though they must have physical impairments as well, and therefore Ms. Casey is not likely to qualify. A respondent from Mississippi suggested that Ms. Casey might be able to get some personal care services through the *Elderly and Disabled Waiver Program*. The day services would not be as

structured as day habilitation, but might be an option while she waits for more appropriate services. There is a waiting list for the *Elderly and Disabled Waiver Program* in Mississippi as well, however. Also, Ms. Casey probably would not meet the functional eligibility standard for the program. The rationale for making referrals to waiver programs for the elderly and disabled, even though those programs also have waiting lists, is that people leave those programs more quickly than they leave the waiver programs for people with mental retardation or developmental disabilities. Therefore, the waiting time for some services, even if they are not ideal services, can be shortened.

Another strategy was suggested in Wisconsin where there are waiting lists for the *CIP-IA* and *CIP-IB* programs. Respondents suggested that it might be possible to make room for some younger people with developmental disabilities in these waiver programs if some of the older clients were willing to move to other waiver programs. For example, if there were older people who no longer take advantage of services such as day habilitation services available through the *CIP* program, but need the types of supportive services available to the frail elderly through the *Community Options Program*, they might be approached about changing waiver programs. This would have to occur on an individual basis, however, and it is unlikely to have a great impact on the waiting list for the *CIP* programs.

Most respondents admitted that they did not know if any of these strategies would be effective, but they were clearly interested in taking creative approaches to try to find help for Ms. Casey and her family. It is possible that the Caseys can piece together some services, but to provide adequate care at home, Ms. Casey's mother would likely have to become a full-time unpaid caregiver instead of getting a paying job, and this simply might not be financially feasible.

How do variations in program policies affect outcomes?

All states and localities have to make decisions about how to spend limited funds. Decisions regarding program design and operation reflect different philosophies and have an impact on the availability of services. An examination of the three cases indicates that access to community- based long-term care services is affected by decisions made with respect to:

- Waiting list management policies
- Categorical eligibility
- Financial eligibility rules
- The process used to determine functional eligibility
- The mix of program benefits
- The care planning process
- Efforts to ease provider shortages
- The availability of information about services.

Waiting list management policies affect the availability of care

Medicaid home and community-based waiver programs generally cover the full complement of long-term care services that Mrs. Adams, Mr. Bailey, and Ms. Casey need, but the number of people who are served is limited. When funds are not available to serve all applicants, waiting list policies must be developed. For the most part, states provide guidance, but waiting lists are managed locally. Commonly the lists are managed chronologically. All states have policies to move people up on the waiting list if there are emergency situations or changes in circumstances that affect the health or safety of applicants. Some localities have developed policies related to other special circumstances. In Wisconsin, for example, some counties give priority to people like Mrs. Adams who have been diagnosed with a terminal illness. When there is a waiting list for the *Model Waiver Programs* in New Jersey, it is managed at the state level and priority is given to applicants with needs that are particularly difficult to address.

Generally, waiting lists are maintained for particular programs. When people reach the top of the list they can receive a set of services that is appropriate to their circumstances. But waiting lists also can be kept for particular services rather than for programs. In one New Jersey community, for example, family support services are currently available for Ms. Casey, but day habilitation services are not. If she can receive some services while she is on waiting lists, for others it may be feasible to piece together care and keep her at home, but keeping her at home would be more difficult if she had to wait for all services.

Some states have policies that anticipate the change in eligibility that occurs when people "age out" of the educational system. In Colorado, for example, children with developmental disabilities can be put on the waiting list for adult services at age 14. This ensures that when they need adult services they will be at the top of the list. The situation in Wisconsin is very different. People cannot be put on a waiting list until they meet the eligibility criteria and have a demonstrated need. Young adults with developmental disabilities would likely

have their needs met through the school system until age 22, but cannot be put on the waiting list until they turn 22 and their needs are no longer being met. As a result, young adults who have transitioned out of special education and are no longer receiving services might lose some of the skills they developed in school while they are waiting for adult services. Recognizing this, one county in Wisconsin has obligated county funds to ensure that young adults who have been in special education classes and received vocational training have a supportive work environment. Budgetary problems threaten the county's ability to sustain this policy, however.

Decisions about categorical eligibility affect access to care

Most Medicaid home and community-based services waiver programs provide services to particular categories of people, such as the elderly, or people with physical disabilities, mental retardation, or developmental disabilities. The alternative is to focus more on functional disabilities, regardless of the reason the disabilities occur. When the categorical approach is used and waiting lists are necessary, some types of applicants, particularly the elderly, generally can receive services relatively quickly because there is faster turnover in the programs that serve them. By contrast, people with developmental disabilities tend to be eligible for assistance for years, so the waiting time for those programs is very long. Programs that are designed to be more generic than categorical, such as the *Family Care Program* pilot project in Wisconsin and the *Community Resources for People with Disabilities Program* in New Jersey, have more flexibility in the way program funds are used.

Wisconsin's *Family Care Program* pilot project is an experiment designed to eliminate waiting lists by pooling funds from all publicly financed long-term care programs, and making community-based care and institutional long-term care an entitlement for all individuals with disabilities. However, one of the five pilot counties for the *Family Care Program* has chosen to offer the *Family Care Program* only to people aged 60 and older. This policy has allowed the county to eliminate a large waiting list for elderly applicants. If Mrs. Adams lived in that county she would receive all of the services she needs, but because the county has taken a categorical approach to providing care, Mr. Bailey and Ms. Casey would be placed on waiting lists. If Bob Bailey and Carol Casey lived in other *Family Care* counties, they would not have to wait.

A less categorical approach has the potential to shorten waiting times for some groups, but lengthen waits for others. Also, community-based care is more available now than in the past because of the work of advocates for particular constituencies, such as individuals with mental retardation or developmental disabilities. The strong coalitions that have developed to help promote, develop, and monitor community-based programs might not be able to be as effective if programs were organized differently.

Financial eligibility rules also affect access to care

The choices states make about financial eligibility rules can have a major impact on eligibility for services. Income and resource tests are used to determine financial eligibility. Generally, Medicaid financial eligibility rules for the elderly or people with disabilities are based on rules for the federal *Supplemental Security Income Program*, or SSI.[13] The maximum monthly SSI benefit is used as the limit for "countable" income. But states also have options to expand eligibility. For example, they may raise the income limits for the

elderly to a level as high as 100 percent of the federal poverty line. Income eligibility limits in Colorado and Wisconsin are tied to the SSI program. New Jersey has increased the income limits to 100 percent of the federal poverty line. The income limits are highest in Mississippi because the state not only has increased the income limits to 100 percent of the federal poverty line, but also uses a different method to count income. States are allowed to disregard portions of income when they determine countable income, effectively raising the income eligibility limits. Mississippi disregards income between 100 and 135 percent of the poverty line.

The *Medicaid Medically Needy Program* option allows states to provide coverage to people who otherwise would have too much income to qualify for benefits, but have high medical bills. Two of the four states—New Jersey and Wisconsin—have *Medically Needy Programs*. One other option is available to states to expand income eligibility limits for people who require long-term care. States may establish a special income limit for people who need institutional care as high as 300 percent of the maximum SSI benefit, and they may extend this option to people who receive home and community-based waiver services. All four states have adopted this option.

Resource limits also vary among states. If states choose to use the same resource limits used in the SSI program, program participation is limited to individuals who have less than $2,000 and couples who have less than $3,000 in resources. States may increase the limits to $4,000 for individuals and $6,000 for couples in some instances. They also may use more liberal methods of counting assets.

The process used to determine functional eligibility may be an important determinant of the availability of care

Participants in Medicaid home and community-based service waiver programs must at least meet the same functional eligibility criteria that a state has established for nursing facility care. The criteria vary by state, however. Also, states may use more restrictive criteria for the home and community-based services programs. In Colorado, for example, applicants are screened not only to see if they meet the nursing facility level of care standard, but also to determine whether they have particular functional impairments. Applicants for the home and community-based waiver programs in Mississippi must meet more stringent requirements than people who receive nursing facility care. For example, Mrs. Adams and Mr. Bailey would be screened not only to see if they meet the nursing facility level of care, but also to determine if they have difficulties in at least three of their activities of daily living. New Jersey and Wisconsin use the same standard of care for nursing facilities and for home and community-based waiver services.

The amount of autonomy that assessors have varies. Standardized assessment tools and functional eligibility criteria are used in most instances, and where they are not, states are moving toward more uniform procedures. For the most part, Colorado, Mississippi, and New Jersey have developed specific forms, criteria, and scoring systems to be used across the state. In Wisconsin, counties are not required to use specific tools. There has been a great deal of reliance on the expertise of care planners, but currently the state is testing a more objective process that uses a computerized instrument to make eligibility determinations. People who perform functional assessments must

exercise a certain amount of discretion. The guidance and tools they have to use are helpful, but they still must make judgements as they interview applicants and review supporting documents.

The mix of program benefits can affect people's ability to remain in the community

All states use a combination of funding sources and programs to provide long-term care services, including Medicaid state plan services, a number of different Medicaid home and community-based waiver programs, state and community-funded programs, and services provided locally that use Federal funds obligated for specific purposes. Where Medicaid waiver program services are available, community-based care is a viable alternative to institutional care, but if there are waiting lists for waiver programs, the ability of applicants to remain at home is not assured.

In states like New Jersey and Wisconsin that offer optional personal care services as an entitlement under the Medicaid state plan, people who have full Medicaid coverage have a better chance of being able to remain in the community even if there are waiting lists. If Mrs. Adams were on a waiting list for waiver services in Wisconsin, for example, she could probably receive homemaker or housekeeping services and limited case management services, but services such as respite care or home modifications would not be available. Mr. Bailey might be able to receive the personal care services he needs, but not home modifications, unless they can be provided by a community-based organization.

When Mr. Bailey is ready to return to work, his ability to do so and receive affordable care also could depend on whether the state where he lives has established a *Medicaid Buy-In Program*, which would allow him to pay premiums and continue to receive coverage through the Medicaid program. Mississippi, New Jersey, and Wisconsin operate *Medicaid Buy-In Programs*. Colorado is planning to establish one.

Ms. Casey has few alternatives other than the home and community-based waiver programs. Some respondents suggested that although Ms. Casey could not receive services through waiver programs for individuals with mental retardation or developmental disabilities, she might be able to qualify for some services through one of the other waiver programs. This is unlikely, given that she does not have physical disabilities, but faced with long waiting lists, respondents were eager to suggest alternatives.

The care planning process also has an impact on the receipt of services

Once it is determined that individuals are eligible for services, care planners work with them to develop a plan, which specifies the type and amount of services they can receive. In part, differences in the types and amounts of care recommended represent state policies regarding the types of services and number of hours that can be covered, and in part they are the result of discretion on the part of care planners. Respondents noted that the training, knowledge, and skill of care planners could influence care plans. Assumptions that care planners make about the extent to which applicants have help at home might affect recommendations for the amount of care. The process of developing a care plan was described by one respondent as a puzzle, which should be pieced together in a particular order: family, friends, community-sponsored services, Medicare, and finally, Medicaid state plan and waiver services.

Care planners have a difficult job because they are often asked to formulate plans that are optimal both for the individual clients and in terms of serving the maximum number of clients. All care planners are conscious of costs, but some are more aggressive about limiting costs than others. Most programs have established monthly or annual spending caps for individuals, though the caps may be aggregated so that in practice the guiding principle, according to some respondents, is to be careful of spending so that the more and less expensive clients will "balance out." In discussing budget constraints, some respondents noted that services would have to be limited while others said that there are no service limits. This might point to differences in practice and to the need for some more specific guidance regarding appropriate methods to control costs. Although care planners are conscious of cost, they are not necessarily aware of whether their practices result in the most cost-effective manner of delivering services.

In some places, care plans are reviewed by other program officials who must approve them based in large part on whether the plans conform to certain budgetary targets. This approach potentially provides more consistency among care plans developed by different planners and provides program officials with more information about and control over spending. It alleviates some of the tension that can occur when care planners are asked to consider the needs of individuals and the need to conserve program resources. But it also adds a layer of review to the process and leaves final decisions with people who do not have a relationship with the applicant.

Because some consumers ask for more control over their care, many states are experimenting with consumer direction options, which might range from consumer involvement in the planning process to providing cash benefits to consumers who then purchase and manage their own services. Regardless of the approach that is used to make care plans, however, they must still conform to program rules and must take resource limitations into account.

Efforts to ease provider shortages, including payments for family and friends, can have an impact on the availability of services in the community

Even when coverage for community-based services is available, the provision of the services is not guaranteed because, in some cases, service providers are not available. Respondents from urban areas generally had fewer concerns about whether providers will be available, but they did voice more concerns about the quality of care that is provided.

Housekeeping, chore, and personal care services are most likely to be limited by the lack of providers. One official noted that these are physically demanding, low-paying, unskilled jobs and that they compete with McDonald's for workers. Another said that although they do not face provider shortages now, they might after a new Wal-Mart opens. Respondents from New Jersey and Wisconsin mentioned that home health agencies are closing in some areas, and they cited low Medicaid reimbursement rates as one reason the agencies say they cannot continue to operate.

Some people have the option of identifying family members or friends who can be paid to provide care

Federal Medicaid law allows family members to be paid caregivers, with the exception of family members who are legally responsible for the care of an

individual, such as spouses and parents of minor children. There also is an option to pay neighbors or friends. When respondents spoke about the shortage of providers for personal care services, most of them noted that beneficiaries in the home and community-based waiver programs have the option of identifying family members or friends who can be paid to provide personal care services. They noted that people who otherwise would not become care providers are often willing to work for someone they know. Some people may be willing to give up paid employment to provide care, but can only do so if they receive some compensation. With limited program resources there also are concerns, however, that in some instances family members or friends might be paid for services they would provide even without pay. To exercise more control over this option, some states approve payments to family members or friends for personal care services on an individual basis.

It is important to note that paying family or friends to provide care is only one strategy that can be used to increase the supply of providers. States set reimbursement rates for providers. Some states are examining reimbursement rates and are considering what steps can be taken to make caregiving jobs more attractive.

All four states give beneficiaries in the home and community-based waiver programs the option of identifying family members or friends who can be paid to provide personal care services. Mississippi adopted this policy particularly to ease the potential shortage of providers in rural areas and to provide consumers with maximum freedom of choice. In Wisconsin's *Community Options Program* and *Family Care Program*, all relatives can be paid caregivers. Generally, family members or friends cannot be paid caregivers for personal care services provided under Medicaid state plans. Thus, the type of benefit may have an impact on who can provide care.

Consumers are more likely to get the services they need when they have access to information about all available services

Officials noted that the outcome of inquiries made by the families of Mrs. Adams, Mr. Bailey, and Ms. Casey regarding the availability of long-term care services might depend on how savvy, connected, or aware they are regarding the availability of services. If they are able to ask about specific programs, if they know what kind of questions to ask, and if they request brochures and documentation in writing, they will be more likely to get the services they need. Or, if they have an advocate to help them through the process, they are more likely to have a favorable outcome.

The rules associated with options for care can be confusing.

In Wisconsin, Mr. Bailey's ability to receive comprehensive community-based services could depend on whether he learns about the availability of state funds to relocate people from institutions to the community, and whether he has someone to help facilitate his move to an institutional setting and then later to the community. He might or might not learn about this option since it is not the intended path to community-based care. Much depends on the knowledge and the inclination of the person who is advising him about his options. If he is aware of this option, he is more likely to be able to stay in the community over the long term. Similarly, Bob Bailey will likely fare much better if he is referred to the demonstration project, *Pathways to Independence*. The project is designed specifically to help people with disabilities

who are returning to work understand the opportunities and options they have, and to help them understand how they can benefit most effectively from the large number of programs that might offer assistance.

In New Jersey, where a larger number of programs exist, applicants have many options, but the process of obtaining services also can be complicated. There are several programs, for example, for which Alice Adams potentially would qualify. Officials in New Jersey note that Mrs. Adams might receive a different set of services depending on where she first inquires and what she asks for. If her doctor suggests that she look into Medicare hospice services, for example, she might follow up on that and simply not be aware that she has other options. Given that she also has Medicaid coverage, she might be told that she can receive some personal care services, but she may not know about the *Caregiver Assistance Program* or the *Community Care Program for the Elderly and Disabled*, two Medicaid waiver programs.

In New Jersey, applicants also might not understand that the provision of one type of service might preclude the receipt of another. Within the Medicaid program there are a number of options, many of which have different names and are associated with different service providers. Mrs. Adams might receive services covered under the Medicaid state plan on a fee-for-service basis or through a managed care plan. She might not be sure if she is enrolled in a managed care plan. She also might not know that if she enrolls in a Medicaid waiver program for long-term care services, she will have to leave the managed care program. Although they are both Medicaid programs, she might have to change service providers when her enrollment changes. At a later stage, if Mrs. Adams feels she needs Medicaid hospice services, she would have to disenroll from the waiver program in order to receive hospice benefits through the Medicaid state plan.

Respondents in New Jersey and Wisconsin note that from an administrative perspective it would be best to try to accommodate Mrs. Adams and Mr. Bailey using Medicaid state plan services first, because the funds for state plan services are not capped. If they can be used for some clients, limited waiver funds will be available to serve others. Waiver service programs might provide more comprehensive or appropriate services, and might provide a greater choice of service providers, however. For example, environmental modifications are not included under the state plan. Unless applicants know about the full range of available programs, they might not understand, when state plan services are recommended, that they have other options.

In most places, Ms. Casey's family has fewer options, but the outcome could be very different if the Caseys are well informed and are aggressive about understanding all the options. Carol Casey's family could benefit, for example, from knowledge about waiting list policies in Colorado. Each Community-Centered Board maintains a waiting list for the *Supported Living Services Program*. Although all of the Boards have waiting lists, some are much longer than others. The program has waiting list guidelines, which specify that applicants can be placed on waiting lists in a service area other than where they live. Moving to a new area of the state might or might not be feasible for Ms. Casey's family, but if they know that it is an option they might consider it. Similarly, if her family knows that the *Family Care Program* in Wisconsin could provide community-based care for

Ms. Casey in certain locations, they might consider a move in that state as well.

The application process can have an impact on the availability of information

The application process differs among states when individuals who are elderly or have physical disabilities inquire about or apply for benefits. In Colorado, for example, all applicants must go to *Options for Long-Term Care Single Entry Point* offices where referrals and case management are provided. In Mississippi, the waiver program for which the person is applying determines the point of entry. Area Agencies on Aging in District Planning and Development Districts take applications for the *Elderly and Disabled Waiver Program,* but the Department of Rehabilitation is the entry point for the *Independent Living Waiver Program* and *The Traumatic Brain Injury/Spinal Cord Injury Waiver Program*. There is a single entry point—*NJ EASE*—for the elderly in New Jersey, but they are not required to use it. There is no single entry point for younger people with physical disabilities in New Jersey, however. Once they inquire about services, nurses visit them to conduct preadmission screening for the waiver programs. In Wisconsin, the elderly and people with physical disabilities can apply for services at county-based *Community Options Program* offices. In some counties, however, applicants can go to *Aging and Disability Resource Centers*, which provide information, referral, and assistance, as well as applications for the appropriate programs and services. All counties with *Family Care Programs* have *Aging and Disability Resource Centers*, as do some other counties.

The application process is more consistent across states for people with mental retardation or developmental disabilities. In Colorado, people apply for the *Supported Living Services Waiver Program* through Community-Centered Boards across the state. Eligibility assessments and referrals for *The Mental Retardation/Developmental Disability Waiver Program* in Mississippi are made at five regional centers across the state. People with mental retardation or developmental disabilities also are required to apply for services at regional offices operated by the Division of Developmental Disabilities in New Jersey. In Wisconsin, individuals with mental retardation or developmental disabilities apply at County Human Services Agencies or at *Aging and Disability Resource Centers* in some counties.

Some states have developed "single entry point" systems. One advantage of single entry point systems is that, presumably, program officials who work there are well informed about a range of programs and services. At present, there is a good deal of variation regarding how much care planners know about the availability of services. Some focus just on the program with which they are associated, while others are more familiar with a broad range of services in the community. Another advantage of a single entry point system is that consumers can get the information they need in one place.

Not all single entry point systems are the same, however. Some are places where people can apply for program benefits. Others simply provide general information and referrals. In Colorado, for example, Mrs. Adams would have to apply for services at an *Options for Long-Term Care* single entry point office. In New Jersey she could visit *NJ EASE, the New Jersey Easy Access, Single Entry Program,* which provides information and referrals to senior citizens and their families. Mrs. Adams is not required to visit a *NJ EASE* office in order to receive services, and

state officials were not certain that Mrs. Adams would be referred to *NJ EASE* if she made initial inquiries elsewhere. They noted that she might receive a different set of services depending on where she first inquires and what she asks for.

Another consideration for single entry point systems concerns who they are designed to serve. The *Aging and Disability Resource Centers* operating in some Wisconsin counties are the only places among the states in this study where all three applicants could go to get information and assistance regarding long-term care services.

Establishing a single entry point system is one approach that can be used to help individuals or families learn about available services. Another is to provide information and training about all available services to consumers and to a wide range of professionals across the state who work with people who might need long-term care.

Conclusion

Currently, individuals with limited financial resources who seek to remain in their homes and receive community-based long-term care services would fare differently across states and within states. In the absence of a federal program for long-term care, people in the United States who need long-term care are not guaranteed the same protections across the country. Under the current system, with Medicaid accounting for the bulk of publicly financed care, the factor that has the most impact on the availability of community-based long-term care services is whether states are more or less willing to devote resources to long-term care programs in general and to community-based care in particular.

The choices states make about how to spend limited funds reflect priorities with regard to who receives services and what services they receive. The same person might be financially eligible to receive Medicaid or other publicly financed services in one state, for example, but not in another, because the financial eligibility criteria for program participation vary from state to state. Similarly, the criteria used to determine whether applicants qualify for program services on the basis of functional impairment are not consistent across states.

An individual who does meet financial and functional eligibility criteria would likely be offered different types and amounts of services in different locations. This occurs, in part, because of the mix of available services. For example, personal care services could be offered to any qualified applicant in states that have opted to cover this service through their Medicaid programs, but the availability of personal care services would not be guaranteed in states that have opted to provide a different mix of long-term care services. The design of state waiver programs also affects the array of services that are offered. In states with comprehensive waiver programs, individuals and care planners can choose among a broad range of services, but in states with a number of waiver programs targeted to certain populations or services, some services may be available through one program but not another, and a state's choice of waiver program will have an impact on the availability of services. Access to services also can vary within states that target waiver services to populations in particular geographic locations.

Discretion on the part of care planners also might have an impact on the types and amounts of services offered. For example, some care planners are more apt than others to take into account the availability of informal support when they develop care plans. Some are more conscious of costs and therefore may take into consideration the financing source when they make recommendations for particular types of care, or they may be inclined to recommend fewer hours of service. Finally, individuals who have a good sense of what they need, and are knowledgeable about the types and amounts of services that potentially are available, are likely to fare better. Some localities have made an effort to help consumers become better informed by establishing single points of entry for long-term care services.

Whether individuals actually receive the services they need also varies by

location. The same individual might be put on a waiting list for services in one state, but not another. And within states, there are waiting lists in some localities, but not in others. A shortage of service providers in some areas also might have an impact on the availability of care.

Currently, most publicly funded long-term care programs are organized by cause or type of disability. The structure of waiver programs in most states limits the number of people with specific types of disabilities that can be served. The choices that states make can be more favorable for some individuals than others. For example, applicants with some types of disabilities might have to wait longer than others to receive community-based care. When resources are limited, an alternate approach is to provide services to people with all types of disabilities who need long-term care according to when they apply for care.

Long-term care programs in states continue to evolve. A better understanding of the impact that current policies have on access to care for individuals can help policymakers determine how to provide optimal long-term care services to the greatest number of people at an acceptable level of spending.

Notes

[1] Calculations based on data from: "Table 1: Medicaid Expenditures for Long-Term Care Services: 1989–2001" in Medicaid Long-Term Care Expenditures 2001, available at http://www.hcbs.org/data/medicaid_lte2001.htm, accessed 30 September 2002; and "Table 9: Personal Health Care Expenditures, by Type of Expenditure and Source of Funds: Calendar Years 1993–2000." in the National Health Expenditures Tables (Washington DC: The Center for Medicare and Medicaid Services), available at http://cms.hhs.gov/statistics/nhe/historical/t9.asp.

[2] Calculations based on data from: "Table 1: Medicaid Expenditures for Long-Term Care Services 1989–2001," in *Medicaid Long-Term Care Expenditures 2001*, available at http://www.hcbs.org/data/medicaid_lte2001.htm, accessed 30 September 2002.

[3] Ibid.

[4] Gary Smith et al., *Understanding Medicaid Home and Community Services: A Primer* (Washington, DC: U.S. Department of Health and Human Services, 2000).

[5] Ibid.

[6] Arizona operates its Medicaid long-term care program under a capitation arrangement using an 1115 waiver.

[7] American Public Human Services Association, *1915 (c) Waiver Services*, 2000, available at http://www.nasmd.org/waivers/hcbwaiverdatabase.pdf, accessed 5 May 2003.

[8] Calculations based on data from: M. Kitchener and C. Harrington, *Medicaid 1915(c) Home and Community Based Waivers: Program Data, 1992–1999*, 2001, available from http://www.hcbs.org/data/kaiser/WaiverTable1.pdf and http://www.hcbs.org/data/kaiser/WaiverTable2.pdf, accessed 30 September 2002.

[9] Centers for Medicare and Medicaid Services, *Your Medicare Benefits 2002*, available at http://www.medicare.gov/Publications/Pubs/pdf/10116.pdf, accessed 8 January 2003; and Centers for Medicare and Medicaid Services, *Medicare and You 2003*, available at http://www.medicare.gov/Publications/Pubs/pdf/10050.pdf, accessed 8 January 2003.

[10] A recent report from the U.S. General Accounting Office examines the availability of Medicaid home and community-based long-term care services for elderly individuals. See: U.S. General Accounting Office (GAO), *Long-term Care, Availability of Medicaid Home and Community Services for Elderly Individuals Varies Considerably* (Washington DC: GAO, 2002).

[11] C. Harrington et al., "Met and Unmet Need for Medicaid Home and Community-Based Services in the States," *Journal of Applied Gerontology* (forthcoming).

[12] Calculations based on data from: The Resource Network on Home and Community Based Services, *State by State*, available at http://www.hcbs.org/state_by_state.htm, accessed 30 September 2002.

[13] An exception to the SSI coverage requirement allows states to use their 1972 state assistance eligibility rules instead of the federal SSI rules. Eleven states have elected this option. They are known as "209(b)" states.

About the Project

The *Georgetown University Long-Term Care Financing Project* pursues analysis designed to stimulate public policy discussion about current long-term care financing and ways to improve it. The project is funded by a grant from The Robert Wood Johnson Foundation. More information about the project and other publications can be found at http://ltc.georgetown.edu

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