

Choices and consequences:

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

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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.

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.

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 supported by a grant from the Robert Wood Johnson Foundation. The full report is available at <http://ltc.georgetown.edu>.



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