



What Does It Take? Improving Housing Choices for Medicaid-Eligible Mississippians Needing Long-Term Care

Executive Summary

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Introduction

Individuals with disabilities desiring to live independently in Mississippi are hindered by the state's scarcity of both affordable, accessible housing and the community-based services to help them to live in the community of their choice, in the housing of their choice.

I needed a place to live, and the Mississippi Gulf Coast, this is pre-Katrina, had oodles of new construction. And I looked and I looked . . . There were incredible violations of the new construction requirements for fair housing in the new apartment dwellings. There were virtually no single family homes without expensive modifications that a person using a wheelchair could use. I ended up selecting the only option I could find where I could be personally independent—go the bathroom and take a shower. But I couldn't find anything that was truly affordable. I did not have the choice that other people have of assessing where I could afford to live and making that choice. If you get out of your range you're kind of doomed eventually.

Participant, BRIDGE Statewide Community Forum
LIFE, Inc. Annual Conference
March 16, 2006, Jackson, Miss.

Individuals with disabilities in Mississippi *are* living in the housing of their choice with viable long-term care services. Some have sufficient financial support to create the appropriate long-term services and accessible housing that allow them to live in the community. Others have educated themselves, successfully networked or found resources to reach their goal of community living. Yet many people with disabilities who rely on Medicaid for their long-term care are hampered from choosing the housing they dream of because specific barriers prevent them from connecting the housing resources and long-term support services they need. Surprisingly, by simplifying and eliminating unnecessary policies, procedures and practices, with no loss of accountability or fiscal discipline, many individuals can live more independently.

What Is Long-Term Care

Long-term care is often measured in terms of the need for “activities of daily living” (ADLs)—bathing, dressing, eating and toileting (O'Brien, 2005). Long-term care “can be provided at home, in the community or in various types of facilities . . .” (Centers for Medicare and Medicaid Services, 2007).

In Mississippi, almost one in four individuals has a disability of some type—607,570 people age 5 and above from a total population of 2,844,658 (U.S. Census, 2000). The state's disability rate is 23.6%, higher than the national rate of 19.3%. Disabilities become more prevalent with age. Almost one-third of all Mississippians with disabilities are over the age of 65. Mississippi ranked highest in the nation in the percentage of disabilities per population for the 65 and over age group at 54.3% in 2005 (U.S. Census, 2005).

Institutional Long-Term Care Consumes Large Portion of State's Support Dollars

Medicaid has grown by leaps and bounds since its creation in 1965 as a health insurance program for low-income people (Smith et al., 2005). This federally and state funded program is the largest health insurance program in the United States and the largest source of funding for long-term care—47.4% of all the nation's long-term care spending in 2003 (O'Brien, 2005). In fiscal year 2006, 33.2% of the total U.S. Medicaid budget—\$298.7 billion—was spent on long-term care (Burwell, Sredl and Eiken, 2007). In fiscal year 2006, Mississippi's total Medicaid expenditures were \$3,272,008,246 (Burwell et al., 2007). At \$1,026,001,080, long-term care expenditures comprised 31.4% of the state's total Medicaid expenditures in 2006.

Mississippi spent 87.9% (\$901,663,226) of its fiscal year 2006 long-term care dollars (\$1,026,001,080) on institutional services, the highest percentage of long-term expenditures for institutional services of any state in the nation (Burwell et al., 2007). This amount included expenditures of \$648,078,648 for nursing home services and \$253,584,578 for intermediate care facilities/mental retardation (ICF/MRs). The national average for institutional care is 60.6%. Mississippi's long-term care totals also included expenditures of \$3,637,492 for

personal care, \$12,511,756 for home health and \$108,188,606 for all the home- and community-based waivers (Burwell et al.).

Home-Based Care Is Markedly Less Expensive than Institutional Care

In fiscal year 2002, elderly Medicaid recipients used institutional services at an average of \$38,780 per enrollee. Community-based services for the elderly averaged \$17,176 (Sommers, 2006). For the same period of time, people with disabilities receiving care in their communities had an average spending total of \$34,930 compared to \$76,331 for Medicaid recipients with disabilities using institutional care (Sommers, 2006).

In 2004, there were 2,054 participants in Mississippi's home- and community-based waiver for individuals with developmental disabilities (MR/DD Waiver), with the waiver cost per participant as \$15,450. The total spending on this waiver—\$31,734,057—was 11% of the overall spending on developmental disabilities, ranking the state 50th in the nation. The annual cost of care per person for Mississippi's state operated institutions of more than 16 people for 2004 as \$90,328. Annual cost of care per person for ICF/MRs with 15 or fewer persons in Mississippi was \$67,849 for the same period of time (Braddock et al., 2005).

Some argue there are individuals who cannot be served in the community, especially people who have significant behavioral needs or complex medical needs. Information from the National Health Interview Survey on Disability and the Residential Information Systems Project estimated 92% of all Americans with intellectual or developmental disabilities live with families, spouses or alone, and 6% live in community-supported living arrangements. Only 1% live in large institutions and only 1% live in nursing homes. In states with no institutions, all individuals

requiring such care live in other settings (Research and Training Center on Community Living, 2005).

Moving into the Community

Long-term care services required by Medicaid-eligible consumers more often than not are linked to a “brick and mortar” place, such as an institution or nursing home. Sometimes, the problem is that services are too connected, with certain services only being available to clients if they actually live at a particular facility. This seems ironic when consumers most often need housing to move into the community.

The Centers for Medicare and Medicaid has identified housing as a critical element for state Medicaid systems transitioning from institutional settings into the community. The lack of affordable, accessible housing is cited by individuals and organizations as the single largest barrier to community inclusion. Even though affordable housing has been developed for people with low incomes, there is still a lack of integrated, affordable, accessible and visitable housing available for people with disabilities and the elderly (Klein, 2007).

In planning for coordinated housing and services, it is best to separate housing from services—to focus on housing but not forget that services will be needed, and when services are considered, know that housing will be involved. Consumers can then choose housing and services in a coordinated way to meet their needs and those of their family.

Mississippi’s Housing

People with disabilities can live successfully in their communities. But adults with disabilities usually have low incomes, making low wages if they work or relying on family or the benefits available to them if they are unable to work. Affordability is a primary issue for Medicaid-eligible individuals with

disabilities. Affordable housing is usually considered to require no more than 30% of a family’s income (Bernstein et al., 2006).

There is no data on the supply of accessible housing in Mississippi. Census information used in the state’s Consolidated Plan reports there were 1,161,953 housing units statewide in 2000.

“Affordable housing assistance in Mississippi also depends upon a large network of local lenders, housing authorities, community action agencies, nonprofit organizations and local governments . . .” (Mississippi Consolidated Plan, 2005). Both federal and state agencies provide assistance with housing in Mississippi.

Recommendations

These recommendations address the central question of this report, which is, “What does it take to create a system for Medicaid-eligible Mississippians with disabilities needing long-term care who want to live in their communities in the housing arrangements of their choice?”

Mississippi has a rigid menu of long-term care options for low-income individuals:

- nursing homes for the frail elderly
- institutions, large and small, for people with developmental disabilities.

These facilities seemed, at one time, to be the best way to provide services in a poor rural state with limited funding for services and housing. But these systems were created years ago, and much has changed since that time.

Multifaceted solutions are needed to reorder the long-term care and housing systems in Mississippi. The actions needed are both obvious and subtle. Mississippi’s current system did not happen overnight, and changes will not happen overnight.

The first thing to consider in making any change is mindset. **We must focus on the community as the best place for**

individuals with disabilities and the frail elderly to live and receive services. We also must focus on opportunities to create exemplary communities with strong service delivery infrastructures. Finally, we must see change as a way to seize opportunities to maintain a reasonable state budget for long-term care.

Life is not one-size-fits-all for any individual with or without disabilities or chronic illness. States that have been most successful at improving long-term care opportunities for their citizens focus on providing residents with an array of services. Mississippi must aim for additional options that improve the quality and community orientation of services. Affordable, accessible housing of all types and a variety of long-term care services must be available in all the state's communities.

These recommendations derive from a number of sources considered by Project BRIDGE: 1) a focus group of Medicaid-eligible recipients from across the state, 2) a statewide community forum of individuals with disabilities and their families, 3) the Project BRIDGE Action Council consisting of long-term care and housing providers, advocacy groups, policymakers, and individuals with disabilities and chronic illness and their families, 4) information gathered on the state's current systems for long-term care and housing derived from agency documents, 5) the review of information and systems from other states and federal agencies. The System Performance Review Committee met with members of the Action Council to further distill the information gathered into recommendations.

The Systems Performance Review Committee of the Project BRIDGE Action Council advised the recommendations should be integrated just as the services should be. For this reason, recommendations are grouped into three categories: Policies, Programs and Services, and Research, but are

not listed in terms of priority. All must be implemented.

Policies

Policies, simply put, are laws, rules and regulations. There are policies that regulate home- and community-based waiver slots and home- and community-based waiver funding. Policies also regulate local public housing authorities and their preferences used to determine housing priorities. Policies can be changed.

- **Expand and Formalize Long-Term Care Task Force** – The legislature must expand the Mississippi Long-Term Care Technical Advisory Group (TAG), created in February 2007, by including additional groups, particularly housing, to keep long-term care issues in the public eye. The Mississippi Long-Term Care Technical Advisory Group (TAG) is making their recommendations on long-term care services to the legislature during the 2008 Regular Session, but there is still much to be done. Within the purview of this group, the legislature must revisit the progress of the Mississippi Access to Care (MAC) Plan. In 2000 and 2001, a tremendous amount of time and effort went into the MAC Plan to address the issues related to the *Olmstead* decision. The Division of Medicaid was the lead agency in coordination with the Department of Mental Health, the Department of Health, the Department of Education, the Department of Human Services and the Department of Rehabilitation Services. The MAC Plan was published in 2001, followed by an implementation plan in 2003. While the MAC Web site remains online via the Medicaid Web site, limited information is available on what happened in subsequent years. Which of the MAC Action Plan items have been completed? Has the effort stalled? The legislature must hold a hearing on the progress of the MAC Plan. Institutional dollars can be used more efficiently.

- **Single Point of Contact** – Mississippi must make it a priority to develop a single point of contact for services for people with disabilities and the frail elderly. A single point of contact has proved essential in many states making the transition to community-based services. The Division of Aging and Adult Services, Mississippi Department of Human Services received a grant for a pilot Aging and Disability Resource Center (ADRC) in partnership with the Central Mississippi Area Agency on Aging in 2005. The ADRC is a comprehensive resource and referral center and when fully implemented will assist with the establishment of eligibility for public programs and services. Beginning as a pilot project working in limited counties, the ADRC is expanding statewide. Fully implemented, the ADRC satisfies the MAC Plan recommendation—“establish a single point of intake.” The Area Agencies on Aging (AAAs) located in the state’s Planning and Development Districts (PDDs) already provide a number of community services for senior adults. ADRCs have been used effectively in 43 states as the single entry point for their community long-term care services. It is important that the single point of contact provides actual resources and not just serves as a point of referral.

- **Money Follows the Person** – Mississippi must implement a true “money follows the person” policy of long-term care services. Money follows the person refers to the flexible financing of long-term services that allows the funds provided for Medicaid supported facility services to move with the individual to the most appropriate community setting. Funding follows an individual with disabilities or chronic illness moving from an institutional setting into a community living situation. Texas and a number of other states have used this concept to transition individuals from nursing facilities into the community.

House Bill 528, passed during the regular 2007 Mississippi Legislative Session, has a section authorizing the transfer of funds allocated for nursing facility services for eligible residents to cover services available through the state’s five home- and community-based waivers, but it is unclear how this is being administered.

- **Encourage Public Housing Authorities (PHAs) Statewide to Make the Needs of People with Disabilities a Priority** – Advocates must develop an organized effort to attend PHA meetings and promote individuals with disabilities and the elderly as a priority population for the state’s PHAs. The system of 55 public housing authorities in Mississippi can be confusing. Some provide low-rent public housing, some provide Section 8 vouchers, and some, principally regional housing authorities, provide both. Meetings are held annually to determine priorities for the PHAs. People with disabilities must be represented at these meetings.

- **Develop an Incentive Program to Assist Nursing Homes in Moving from Providers of Institutional-Based Care to Providers of Community-Based Care** – The legislature must provide incentives to assist nursing homes in becoming the best providers of community-based long-term care services. These incentives would include business rewards as well as training activities. States that have been successful in making the change from institutional care to community-based care have an array of long-term care solutions. In 2006, there were 199 licensed skilled nursing facilities located in communities across the state. Nursing facilities are the state’s specialists in providing long-term care. They can lead the way in maintaining business quality, providing jobs and saving state funds.

- **Promote Incentives for Long-Term Care Insurance** – Mississippi must promote

long-term care insurance for its citizens. During the 2007 regular session, the Mississippi Legislature passed Senate Bill 2337 to provide an income tax credit for the premiums paid for long-term care insurance. Mississippi joined many other states offering tax incentives that go beyond the incentive currently offered by the federal government. While this will not help Mississippi's neediest citizens, it would ease the burden middle income citizens impose on long-term care services in time of need and free up more family resources for applicable family members.

Programs and Services

Programs and services are defined simply as "the way things work." Programs and services are actions taken toward a goal. The following recommendations affect the programs and services being provided to Medicaid-eligible individuals.

- **An Energetic, Coordinated Public Information Strategy** – A concerted, concentrated ongoing public awareness strategy must be launched jointly by multiple agencies to provide the best information on long-term care and housing. One unique concept: provide information on community services and housing together in a uniform, statewide effort. Participants in both the focus group and the community forum held by Project BRIDGE, said it was difficult to get clear information on Mississippi's home- and community-based waivers. Information on affordable, accessible housing was also hard to gather because multiple agencies are involved in providing assistance for owner and rental housing in all areas of the state. All the agencies involved have brochures, regional offices, Web presences, and some have had public awareness campaigns, but obviously these are not enough. The ADRC has developed a comprehensive media plan. The implementation of this plan may provide an opportunity for contribution to this recom-

mendation. Often the quality of information received by Medicaid-eligible individuals and their families is dependent on the knowledge of the regional office personnel.

- **Statewide Long-Term Care and Housing Summit** – A statewide summit must be held to bring together long-term care providers and housing providers to generate new ideas and new collaborations. This simultaneous education on community services and housing can bring together developers, builders and social service providers and generate a turning point for community living, funding, universal design and tax credits for the state.

- **Initiate a Statewide Searchable Housing Database** – The state must develop and implement a statewide housing database such as Socialserve (www.socialserve.com). Socialserve is a Web-based searchable database being used by some states and agencies as a tool for finding housing, including rental housing, Section 8 housing, accessible housing, housing for sale and services. After Hurricane Katrina, Socialserve.com launched an emergency housing site for five states, including Mississippi, that is accessible by participating agencies. The current cost is \$44,000 a year for the entire state. Socialserve should be a joint project of multiple agencies.

- **Case Management** – Mississippi's service agencies must develop a coordinated and collaborative case management system via interagency agreement. All of the state's service agencies have their own case managers who focus their efforts on their priority areas. One client receiving services from several agencies currently might have several case managers. While case management is new to the housing area, it has proved to be very effective in helping low-income and homeless clients adjust to life in their own home as well as community life and tap into the services they need.

- **Person-Centered Planning** – More individuals with disabilities in Mississippi must have the opportunity to have person-centered plans. State agencies must continue to explore person-centered planning and integrate its use through all service systems, particularly those that have impact on long-term care. Person-centered planning has gained ground in Mississippi, with several initiatives providing training in recent years. These life plans for individuals with disabilities are directed at every aspect of their life, which can include for the client living in the community in the housing of their choice and receiving appropriate home- and community-based services that meet their needs.

- **Training for Long-Term Care and Housing Professionals** – The state must fully embrace crosstraining for long-term care and housing professionals for the provision of best practice services. Most agencies' case managers focus on the services provided by that agency. They know the programs provided by their agency and do a good job for their clients. If long-term care service providers knew more about housing, their services would be more effective for those clients wanting to live in the community. Likewise, housing providers could better help their clients if they knew the ins-and-outs of available long-term care services. From lessons learned through 10 years of administering housing initiatives for the elderly and individuals with disabilities, IDS has been able to share information with other agencies but a significantly more widespread effort is needed.

- **Recognize and Value Direct Support Professionals** – Mississippi must build a friendlier environment and more effective system for direct support professionals. The buzz phrase from a popular movie several years ago was “build it and they will come.” Many individuals with disabilities need the

assistance of personal care attendants to live in the community, and they are deeply concerned about the difficulty of finding good workers and the small salaries they are authorized to pay workers through the home- and community-based waivers.

- **Annual Convening of Fair Housing Organizations, Property Managers, Owners** - Involved Mississippi agencies must convene an annual meeting for the state's fair housing organizations and property owners and managers to familiarize more people with fair housing laws, especially as they pertain to accessibility and affordability. There is considerable need. The Office of Fair Housing and Equal Opportunity (FHEO) at the U.S. Department of Housing and Urban Development administers and enforces federal laws and establishes policies that make sure all Americans have equal access to the housing of their choice. Fair housing is not an option, it's the law.

- **Develop a Coordinated, Community-based Transportation System** – Mississippi must develop a statewide coordinated, community-based transportation system that provides affordable, accessible, flexible services for individuals with disabilities who want to live in the housing of their choice and receive their services in their communities. Every needs assessment for people with disabilities and the elderly has established transportation as a priority. People with disabilities must have flexible, accessible, affordable transportation to get where they need and want to go from the doctor's office to school to the grocery store to church to the movies. For several years, there has been legislation introduced to create a transportation task force, and the Mississippi Department of Transportation has worked on comprehensive planning, but it's time to move beyond planning.

Research

Research is the careful collection of information about a particular subject, in this case, long-term care services and affordable, accessible housing.

- **What Has Been the Impact of the Change to Home- and Community-Based Services on Agencies and Their Staffs in Other States?** – This research may be currently available in multiple documents. In 2007, the Centers for Medicare and Medicaid Services granted a series of state profile tool grants for assessing states' long-term care systems. A review of the information from these grants should provide a beginning round of impact information from the states that received these grants.
- **What Kind of Market Demand Information Do Mississippi Builders Need to Take More Interest in Supplying Housing for People with Disabilities and the Frail Elderly?** – This particular information could be handled via a telephone or online survey. It is very doable research and simply begs for funding for manpower and technology, perhaps as a joint project for the Mississippi Development Authority, the Home Builders Association of Mississippi and several advocacy organizations.



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