Long-Term Care Systems Change for the Aged and Americans With Disabilities: State Profiles

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Emerging Leaders Program

The U.S. Department of Health and Human Services' (HHS) Emerging Leaders Program is designed to identify college graduates interested in a career with HHS and provide them with an on-the-job training experience that will prepare them for that career. The Emerging Leaders Program is intended for the best graduates who are eager to make contributions to HHS. The program allows participants to explore diverse career fields that involve their educational background while providing them with the skills and experience needed for a career with HHS. During the program, Emerging Leaders have unique professional opportunities, including close interaction with various agency executives, as well as with public, private, nonprofit, and advocacy organizations. As a part of their experience, Emerging Leaders are required to complete a group project under the direction of HHS agency staff. This paper is the result of a group project sponsored by the U.S. Administration on Aging in collaboration with the Administration on Developmental Disabilities and the Substance Abuse and Mental Health Services Administration.

EXECUTIVE SUMMARY

Long-term care (LTC) reform is happening across the Nation and some States are using systems change as an opportunity to better coordinate across aging and disability networks. The overarching goal of these efforts is to increase access to home and community-based services for people with disabilities of all ages. While the needs of older adults and people with disabilities are distinct, they rely on many of the same long-term support services. The U.S. Department of Health and Human Services (HHS) has adopted an LTC Systems Change Framework that identifies four areas of reform: access, services, financing, and quality. Using the HHS framework as a guide, this paper examines promising practices in LTC reform in four States: Oregon, South Carolina, Vermont, and Wisconsin. As part of our examination of systems change in these States, we will consider how their LTC reform efforts have impacted collaboration across aging and disability networks.

INTRODUCTION

Since the Supreme Court's 1999 *Olmstead Decision* and the subsequent New Freedom Initiative (NFI) in 2001, all States are challenged to examine and modify their respective long term care (LTC) systems to provide comprehensive health care services appropriate to the needs of older Americans and people with disabilities. More specifically, the NFI executive order laid out the directive that Federal, State, and local agencies and organizations should collaborate to remove barriers to community living for older people and people with disabilities or long-term illnesses. Agencies across the U.S. Department of Health and Human Services (HHS) have responded to the need for LTC reform with multiple grant programs and technical assistance for States. Many States have also used this opportunity to increase coordination and collaboration across their aging and disability networks. HHS as a whole has adopted a LTC Systems Change Framework that provides one model for reforming LTC. This framework includes the following areas of reform to increase a consumer's ability to utilize home and community-based services (HCBS):

- Access: Comprehensive information about available services, simplified eligibility requirements, single access points.
- Services: Consumer choice in types of settings and providers.
- Financing: Seamless funding across services that supports consumer choice.
- Quality: Evaluation to ensure quality of services across care settings.

Using the HHS LTC Systems Change Framework as a guide, this paper examines promising practices in LTC reform in four States: Oregon, South Carolina, Vermont, and Wisconsin. As a part of the examination, we consider how each State's reform efforts have affected collaboration across aging and disability service networks. Program information was obtained through interviews with current and former State officials who were instrumental in LTC reform in their States. In addition to information about each of the four component areas of the LTC Systems Change Framework, interviewees were asked to provide insights regarding the impact of their State programs on integrating services across aging and disability networks, consumer use of and satisfaction with services, future plans for reform, and advice to other States implementing LTC reform.

The structure of the following State profiles is based on a standard interview created by the Emerging Leaders work group with input from the U.S. Administration on Aging (AoA), U.S. Substance Abuse and Mental Health Services Administration, and U.S. Administration for Developmental Disabilities. Based on knowledge of LTC reform efforts across the Nation, States with innovative programs were identified. Each State profile provides the following information:

- **Scope of the State Model.** This section provides a brief overview of and, in some cases, the history of the State's LTC reform program.

- **Program Features.** In this section, the features of each model program are presented in relation to the HHS LTC Systems Change Framework. Interviewees were asked to discuss aspects of their State programs, illustrating reform in access, services, financing, and quality.

- **Impact.** The effects of LTC reform on coordination and collaboration between aging and disability networks is discussed. Additionally, this section compares the original intended program outcome with actual observed effects on consumers' use of and satisfaction with LTC services.

- **Future Plans for Collaboration.** While each of the featured States has made great strides in LTC reform, there is still potential for increased coordination of the aging and disability networks. This section highlights specific plans in place to produce more collaborative relationships between service networks.

- **Advice for Other States** – All of the individuals interviewed for this profile have had extensive involvement in LTC reform in their respective States. This section discusses some of the "lessons learned" to benefit others who may be interested in replicating parts of the featured models in their own States.

OREGON

Scope of the State Model

The mission of the Oregon Department of Human Services (DHS) is, "[To assist] people to become independent, healthy, and safe" (OR DHS, n.d.). The most significant aspect of the Oregon model for integration dates back to the 1990s, when the Oregon State legislature created a progressive policy that brought the financial and administrative sides of the LTC system under one division at the State level. The office created by this integration was then called the Senior and Disabled Services Division. State-funded HCBS, along with program activities of the Older Americans Act, were housed in this division. Oregon combined the Medicaid budget and LTC administration and regulation into a single agency, and services to seniors and people with physical and developmental disabilities were streamlined.

The Oregon DHS was reorganized in 2001, consolidating its eight health services divisions into three clusters. Portions of the former Senior and Disabled Services Division, Mental Health and Developmental Disability Services Division, and Vocational Rehabilitation Office were consolidated into the Seniors and People with Disabilities Office. Mental health services are now housed within the Health Services branch of DHS.

In Oregon, both LTC services and Medicaid are administered on a local level, rather than out of a central State office. Administration of LTC was transferred to local public agencies after the State legislature determined that local agencies should be responsible for public programs. Likewise, Medicaid is administered out of each service area, and all Medicaid users develop their own waivers and handle their own budgeting and tracking.

The goal of the policy was to increase the number of options available to seniors and people with disabilities. Its adoption was based on the philosophy that people are entitled to HCBS in the same way that they are entitled to nursing home care. Once people are financially and physically eligible for nursing care in Oregon, they are able to choose between nursing care or home and community options. The funding is available to pay for care in whichever setting a recipient chooses.

Program Features

Access

The Oregon Single Entry Point System, which was developed in the early 1980s, is a strong example of integration across service networks. Single entry points provide a single place for people to access information about all of the services they need. Integration happened early in Oregon because the Oregon Health Plan, Medicare, and Medicaid were all included in the Single Entry Point System. Area agencies determine eligibility for multiple assistance programs, including Medicaid, food stamps, and cash assistance. Oregon residents are also able to access social services and community living options from these local agencies.

The Mentally Retarded and Developmental Disabilities (MRDD) System broke down the barriers to community living through institutional closure. In the early 1990s many States closed

their institutions. The crucial strategy for Oregon, which crystallized closure of large institutions, was mobilization of advocates. Parents of children with disabilities and self-advocates who were on waiting lists for institutional care demanded access to services. Community-based services were less expensive than institutionalization; therefore, more people could be served with community-based care, so many people came off the waiting list for these services. Institutional closure was necessary to improve access to HCBS.

People with mental illness gained access to community settings when the Mental Health Division started a housing program. The State Housing Development Agency financed small group homes and other options for people with mental illness. Over a thousand units have been made available. The partnership with the housing agency made community living an option for many more people with mental illness in Oregon.

Nationally, persons with mental illness who are not on Medicaid have difficulty accessing adequate services. For those who are Medicaid eligible, the clinical and institutional services available are relatively comprehensive. Services are often more adequate when Medicaid funding is available since State legislators can use Medicaid to receive Federal matching funds, as opposed to using only State funding for such services.

Services

Much work has been done in Oregon to educate doctors about community-based services for the elderly and disabled. Many doctors believed that nursing homes were more effective than community-based services, so helping doctors to understand the benefits of using home and community services instead of institutions was important. It is necessary for doctors to see the value of different options because they influence whether a person goes directly to a nursing home or back into the community after being released from the hospital.

Some nursing homes are not supportive of residents returning to their communities, and this attitude results in tension in the LTC community. Early on, Oregon nursing homes were resistant to community-based services. In Oregon, unlike some other States, some nursing home owners bought assisted living facilities and home health agencies. Once these facilities diversified and branched out into community-based services, there was less friction because some of the competition between nursing facilities and community-based services dissipated. It is rare for people to move between settings, and this effort to keep people in the same place has also helped to decrease tension between the two care settings. In the MRDD system, there are very few providers. The government controls all of the institutions serving the MRDD population, with no involvement from private providers. Because the MRDD providers are a product of government financing, State officials make an effort to work cooperatively with them. When the stakeholders convene, a representative of the providers is always present.

In the mental health arena, there is tension between State and county service delivery systems. The mentally ill access services on a county basis. The county relies on beds being available in State hospitals, but hospitals generally are not able to keep up with the demand. There is a need for more HCBS for this population. It is hard to find employment services for the mentally ill since there is no funding for it, and they are not usually included in vocational rehabilitation or other nonmedical activities.

Finance
Oregon has achieved seamless funding for the elderly and physically disabled, with funds housed within a single budget. For the MRDD population, if there is a waiver, then there is also seamless funding. There is generally no seamless funding for persons with mental illness. Most funding for the mentally ill is applied to medical care, with very little funding for community services. Chronic care providers, who provide primary care for Medicaid recipients and those with dual eligibility for Medicare and Medicaid, have coordinated meetings and discussions and have implemented seamless funding between medical and LTC providers; this coordination has most often taken place in managed care organizations.

Quality
It is difficult to maintain quality in community-based settings. For elderly and physically disabled populations in nursing homes, there are institutional protocols in place. Oregon has also developed a protocol for assisted living facilities and other residential care settings with six or more people. The State has a significant presence in assisted living facilities and adult foster homes.

Adult foster homes with five or fewer residents have licensure categories and are operated on the local level. With over 2,000 adult foster homes across the State, Oregon does not have the resources to monitor quality in all of them on a routine basis. The counties operate them with State supervision. While case managers visit their clients and the State has the right to license and inspect facilities, no regular monitoring takes place. Most quality checks are completed when State officials respond to outside complaints. Adult Protective Services is under the same department as the facilities, so officials can respond directly to complaints.

In Oregon, consumer choice, not service quality, has been seen as the most important issue in LTC reform. When the U.S. Centers for Medicare and Medicaid Services (CMS) has performed audits on services chosen by Oregon Medicaid recipients, they have found some clients in substandard home environments. Client choice has been paramount, but individuals do not always access the available services.

Consumer satisfaction surveys are now being conducted, and Oregon has recently received grant funding to focus on quality. There has been a movement in State government to develop performance measures. Agreeing on measurable quality outcomes is particularly important for aspects of quality of care that tend to be difficult to measure, such as freedom from abuse.

Impact

Impact on Networks
Across networks there has been minimal impact on integration under Oregon's model for LTC reform. The networks are still separate aside from single entry points for determining eligibility for assistance at the local level. Providers in different agencies are energized by the thought of combining networks. MRDD providers have done some excellent work on quality assurance, and this has gained interest from other groups. Ultimately, treatment networks are separate, but there is some collaboration.

Both the aging and disabled service networks in Oregon work with the Federal government on waivers and HCBS. Advocates for people with mental illness would like them to be grouped into the same office with seniors and people with disabilities at the State level. Programmatically there have not been many changes; policy, regulation, and the Older Americans Act were not moved to new offices during the DHS reorganization in 2001. The State model of integration is not being used at the county level yet. The MRDD population is still grouped with the mentally ill population at the county level.

The populations being served have not seen much change since the State reorganization. The Elderly and Physically Disabled benefits and services were already integrated. The addition of the DD population to the Elderly and Physically Disabled was unique, and now other States are following this model. The administration for the Oregon DD population is integrated at the policy level, but the population is still served by separate HCBS providers.

Intended Versus Actual Impact

Oregon State government in the mid-1990s was focused on one outcome: reducing the number of people in institutions and thereby increasing the number of people using HCBS. Years later, the number of people in institutions versus community-based care is still the main outcome of interest.

Now, more people are served overall because community-based services cost less than nursing facilities. At the time the new LTC policy was established, nursing home costs were rising dramatically. The legislature saw LTC reform as a well-received program, so funding was increased year after year. Seniors and people with disabilities had their programs funded each year because constituents liked the services being provided. There were never explicit goals to increase the number of people being served or to save money; it was just a popular program that seemed to work well.

For the Medicaid eligible there were good outcomes, including a dramatic shift to community-based care. The numbers of institutionalized individuals decreased, and those in community-based care increased. The initial goals were met, but quality measures were never imbedded into the plans.

Future Plans for Collaboration

Oregon is about to enter long range planning to further transform its LTC system. With over half of the LTC population being served at home, Oregon is proud of the large population receiving home and community-based services. Currently, though, the State is facing a financial crisis, and State planners must determine how to sustain the system with the growing population of aging baby boomers.

Oregon is beginning to consider ways to combine LTC and acute care since this is not currently done in a comprehensive way. Because the population of people aged 85 and older is growing, States are beginning to rethink how to link the separate programs into a single network. This may be an overwhelming task.

Advice for Other States

Oregon created a cohesive policy in the 1990s that many States have been unable to achieve even today. The driving factor behind the LTC policy reforms was a single-minded pursuit of HCBS. Oregon controlled costs and decreased the use of institutional care by housing funding, regulation, and policy in a single State department. They created one division because it was too difficult to integrate just by collaborating across offices. Once programs are in one place it is possible to create the cohesive policy necessary for integration. Oregon has a single system with a single funding stream (with categorical differences).

It is important to bring the stakeholders together and discuss each group's interests along the way. If government involvement may have a negative impact on private providers, there is a need to get together and have discussions. States must reach out to providers, since legislators dislike disagreement between the two groups. They want State government to provide models for compromise.

States cannot overlook the number of stakeholders that will be involved in the debate over LTC reform. Seniors were a vocal group in the beginning of Oregon's discussions to move more people out of institutions. Seniors were active and believed they had a right to community-based services. In some States, interest and advocacy groups such as the AARP are also interested in LTC systems reform.

It is important for States to determine the extent to which nursing home owners also own assisted living facilities or other community-based services. The State must reach out to facilities (nonprofit and private) to encourage diversification of services. This decreases competition between nursing facilities and community-based settings.

In order for people to have a choice, they must have a single entry point for determining access. They must know whether they qualify for public programs before they move to a nursing facility. Once people have been in a nursing home they begin to lose touch with their community support system.

When a person is placed in a nursing home on a temporary basis, a consultation should be provided soon afterward to create a plan to return to the community. People must not be kept waiting until they become disconnected from their communities. Needs must be reassessed in a timely manner to ensure that people are not overlooked and forgotten in institutions.

The regulatory piece of Oregon's LTC program is important. Oregon serves more people because they delegate to lay people. Nurses monitor and provide instruction but do not do everything themselves. Policy control allows them to delegate tasks. This delegation makes it important to concentrate on the work force that provides direct care. States must figure out how to retain employees in nursing homes and community-based settings.

States sometimes grapple with strong counties. It is important for States to start a dialogue with local agencies if they feel that integration is important. It is easier to have these discussions in

good financial times, and integration must be proven to be financially advantageous for systems change to happen. The State can realign systems if there are resources to provide support.

Unless otherwise cited, information on Oregon was obtained through interviews with James Toews, Director, Oregon Seniors and People with Disabilities Office (telephone conversation with Jennifer Johnston, April 28, 2005), and Roger Auerbach, former Director, Oregon Senior and Disabled Services Division, December 1995–January 2001 (telephone conversation with Jennifer Johnston, April 26, 2005).

SOUTH CAROLINA

Scope of the State Model

South Carolina's populations of older people and people with disabilities receive LTC services through its Department of Health and Human Services (DHHS) Bureau of LTC Services (BLTCS) and the Lieutenant Governor's Office on Aging. The BLTCS, responsible for almost all Medicaid long-term care policy, sets and monitors policies for home and community-based services (HCBS). DHHS formerly housed South Carolina's State Unit on Aging, an office with a more administrative role, under the Bureau of Senior Services (BSS). On July 1, 2004, the BSS was moved out of DHHS and responsibility for South Carolina's Older Americans Act programs was transferred to the Lieutenant Governor. The Lieutenant Governor's Office on Aging is currently the State Unit on Aging as defined in the Federal Older Americans Act. The Office on Aging works with a network of 10 Area Agencies on Aging and local aging service providers in the State's 46 counties (as well as with other State agencies, regional and local organizations, and the private sector) to develop and manage programs for the older citizens of South Carolina.

South Carolina has effectively created a consumer oriented single access point structure through which its older citizens and citizens with physical disabilities are able to access institutional and community Medicaid supports. South Carolina undertook several primary goals in developing the features of its program. These goals include: 1) improving access to the information that consumers need to make choices and decisions that enable them to remain at home and in the community; 2) shifting control about service decisions to the consumer and the consumer's representative; and 3) better educating consumers about home and community-based options. In conjunction, these goals aim to break down the barriers to community living and reform the South Carolina LTC system by changing the option of home care as the "last resort" to home care as the consumer's option of first choice.

Program Features

Access

South Carolina's 13 regional DHHS offices have long been the single access points for Medicaid LTC services. More recently, South Carolina has made innovative use of information technology to develop a comprehensive information and referral system that further improves consumers' single access points for LTC services. This Web-based system, known as SC Access, is a free and confidential service of the Office on Aging and the South Carolina Aging Network. The initial development of the SC Access database was made possible through a grant from the U.S. Centers for Medicare and Medicaid Services (CMS). SC Access is a database of aging and disability programs that includes information about Medicaid home and community-based services, Aging Network services, and support providers that offer these and other services. The goal of this system is to empower people to make informed choices about their services, regardless of funding source.

SC Access comprises two components: 1) a searchable, online database with detailed information about available services for older people, people with physical disabilities, and

people with cognitive disabilities; and 2) a network of Information and Referral (I&R) Specialists to help people find the information they need and obtain services.

For efficient operation of the SC Access system, each of the 10 South Carolina Area Agencies on Aging funds an I&R Specialist. I&R Specialists take calls from the public at toll-free telephone numbers and answer questions about aging and disability services. The specialists can access online information for people who do not have Internet access, can answer questions about the online database, and can contact providers at the request of consumers. Partial funding for the I&R Specialists is provided by AoA.

South Carolina is further utilizing information technology in its development of a consumer friendly online Medicaid application, which attempts to streamline the Medicaid application process. The application, sponsored by an Aging and Disability Resource Center (ADRC) grant, translates Medicaid application fields into questions easily comprehended by consumers. Once consumers answer the online questions, the program inserts this information into appropriate parts of the application. The application can then be printed out and submitted by mail. South Carolina aims to make this program available statewide and is currently piloting online application submission.

Services

South Carolina provides case management support for services used under its traditional Medicaid HCBS waiver, the Elderly and Disabled (E/D) waiver, and also provides more options for self-directed support under the SC Choice Waiver. Through these services, the State is allowing consumers more flexibility and autonomy in choosing the supports they need.

South Carolina implemented a case management system for services under the E/D waiver in 1991 in order to expedite consumers' receipt of requested services. The case management system includes intake and assessment data for everyone who receives long-term support though a Medicaid waiver in the community as well as those in nursing facilities. Experienced case managers prepare an initial service plan, and other case managers provide ongoing case management for consumers. Case managers actively involve consumers in the development of individualized service plans. Senior case managers go over options for services and providers with the consumer and help the individual choose supports based on individual preferences and the needs identified in the case managers' assessments.

The SC Choice Waiver, which falls under the E/D Waiver, is a new part of the Medicaid waiver program that started as a pilot and is now being offered statewide. SC Choice is a self-directed waiver program that gives consumers flexibility in developing a plan that meets their own health care needs. Waiver clients who select SC Choice can also use South Carolina's case management system. Individuals are assigned a care advisor who assists in developing an individual budget plan. The consumer has the ability to choose nontraditional service providers, such as family members and friends, to provide care services. This waiver succeeds in giving consumers the ability to choose who provides their care, which is particularly useful in underserved rural areas. Consumers have expressed satisfaction in their ability to hire trusted caregivers through SC Choice.

Both the E/D and SC Choice Waivers also provide a system of provider accountability known as Care Call. Care Call is a call-in electronic monitoring system which records when a provider comes to work and when a provider leaves work. The Care Call system provides independent verification that providers were in a consumer's home for a specific period of time and facilitates billing for provider services. Under this system, SC Choice consumers do not have to handle payment of providers themselves.

Finance

The E/D Waiver and the SC Choice Waiver are the main funding supports of LTC services for older persons and persons with disabilities in South Carolina. E/D Waivers provide for a traditional budget from which provider payments are made, whereas SC Choice provides for an individualized budget.

Under the SC Choice Waiver, consumers have the ability to purchase assistive technology devices and other items that address their needs within the budget. Consumers are able to access their account information at all times in order to keep track of how much money is available for services and other needs. In addition, SC Choice consumers have the ability to negotiate payment rates with the providers they choose, using any money saved toward other items or services.

Funding under The National Family Caregiver Support Program has further aided South Carolina in expanding self-directed options for its consumers. The program, administered through regional Area Agencies on Aging, provides families taking care of an individual aged 60 or older with awards of vouchers. Families can use the vouchers, usually totaling several hundred dollars a year, to purchase services that reduce the caregiver's burden or that increase the independence of the person who needs support services. There is flexibility in how caregivers can spend vouchers, but they are often used to fund respite services, home modifications, and assistive technologies.

Quality

South Carolina provides quality assurance for services under the E/D Waiver via review of the case management process by case manager supervisors and central office staff. Additionally, review of provider requirements is conducted through visits to provider sites 30 days after a provider's first service to a waiver participant and annually thereafter.

Regarding the quality of SC Choice consumer-directed programs, there was initial concern about how the progress of self-directed services would be monitored and how to ensure quality control when consumers are making decisions. Overall, feedback from the consumers themselves and from the consumers' families is remarkably positive. Both cite appreciation for the ability to exercise more control over who provides care and when care is provided. In addition, some qualify the care received under the SC Choice program as superior since family members and other trusted individuals are often hired as caregivers.

To date, an objective evaluation of the services provided under SC Choice has not yet been completed. However, South Carolina has contracted with the University of South Carolina School of Public Health for evaluation of the waiver. The results of this evaluation will soon be available.

Impact

Impact on Networks

Representatives from the South Carolina State Agencies on Aging, DD, mental health, and affiliated advocacy groups have been involved, to some extent, in shaping SC Access and SC Choice through participation in focus groups and forums. Through participation in Systems Change advisory committees on the State level, representatives from the aging and DD networks, as well as advocacy and professional groups from both communities, provided input into the initial stages and design of the process for both the web based information system and the self directed waiver.

South Carolina has attempted to involve aging, DD, and mental health groups in the use of SC Access. A short term care management component has been added to the database whereby agencies for these various groups can make interagency referrals electronically on behalf of consumers, thereby limiting the need for consumers to repeat information to each agency. Still, the impact on collaboration between these networks in South Carolina has not been as successful as originally hoped. Although representatives from the DD and mental health communities have taken part in advisory committees and some training on LTC reform topics, demand for training from these groups has been low.

The Office on Aging has attempted to foster network collaboration between these various groups, with a particular focus on the DD network. Within the last year, it sponsored a 2-day retreat for aging and DD groups at a rural church center on topics of interest relating to LTC reform issues. An ADRC grant provides funding for Area Agencies on Aging to hire disability specialists to support collaboration between aging and disability networks on the regional level. The DD network's participation in this hiring process has further facilitated collaboration between the two networks.

Intended Versus Actual Impact

To date, South Carolina's efforts have resulted in increased consumer control over the services they receive, where they receive them, and who provides them. Consumer decision-making has improved due to access to more information services (through SC Access and through I&R Specialists). These factors have led to increased consumer and caregiver satisfaction with the process of accessing and utilizing LTC services, including HCBS. As South Carolina continues to develop its information systems, it will continue to provide consumers with more power for consumer direction.

Despite the success of these developments, some of the changes to the LTC system took longer than originally anticipated. During the development of SC Access, South Carolina experienced State reorganization, movement of the State Unit on Aging out of the DHHS, loss of a larger IT department, and significant staff turn-over. While the final result has been well worth the energy expended to affect change in the LTC system, these unforeseen changes caused the project to take more effort and time than anticipated.

South Carolina's intent to break down barriers between various network groups through its development of consumer self-directed services has also proven difficult. A major barrier to

institutionalizing these changes across network agencies has been that funding for program sustainability is coming solely from the aging funding streams (e.g., Older Americans Act and the E/D Waiver). Long-term buy-in from all groups will not occur until all groups are able to financially invest in these LTC reform efforts. South Carolina's budget crisis over the last several years has severely hampered the possibility for financial investments.

Future Plans for Collaboration

South Carolina continues planning for further reform of its LTC system and for collaboration between the various existing networks that utilize LTC services. The Office on Aging hopes to create real excitement over the availability and uses of SC Access among the aging, DD, and mental health communities. The Lieutenant Governor plans on organizing a demonstration of SC Access during a meeting of representatives from all State agencies in the summer of 2005. The Office on Aging projects that State agencies may use SC Access as a model for creating their own on-line resource access points and hopes to collaborate with other State agencies to add resources to the system as necessary.

Advice for Other States

Information technology is a powerful tool that South Carolina has utilized to develop LTC reforms that focus on the consumer. States should invest in the development of IT resources, such as SC Access, that will increase their consumers' access to the LTC services the State provides. By improving consumers' abilities to access information, both consumers and providers benefit. Other IT systems, such as Care Call, increase the accountability of direct service providers and streamline the provider billing process; such a system is a wise investment for States looking to maximize the services received by their consumers.

South Carolina's attempts to foster collaboration between aging, DD, and mental health networks have met with limited success, but where successful, have resulted in the better use of resources. Therefore, despite financial constraints, such collaborations should be encouraged wherever possible.

Unless otherwise cited, information on South Carolina was obtained through an interview with Barbara Kelley, Deputy Director, South Carolina State Unit on Aging (telephone conversation with Denise Sanchez, May 5, 2005).

VERMONT

Scope of the State Model

In accordance with their mission to "assist older persons, children and adults with disabilities to live as independently as possible" (State of Vermont, 2004[1]), Vermont provides services for disabled and elderly populations through the Department of Aging and Independent Living (DAIL). DAIL was established in 2004 when Vermont's Department of Aging and Disabilities joined together with the Division of Developmental Services (formerly of the Department of Developmental and Mental Health Services) and Children's Personal Care and Hi-technology Programs (formerly from the Office of Vermont Health Access) within the Agency of Human Services. This agency provides older Vermont citizens and those with physical and developmental disabilities information that allows them to choose care that best meets their needs. DAIL now encompasses the following varied agencies: the Division of Disability and Aging Services, the Division of Vocational Rehabilitation, the Division for the Blind and Visually Impaired, and the Division of Licensing and Protection (State of Vermont, 2004[1]).

With the goal of "shifting the balance" from utilization of nursing homes to that of HCBS, Vermont passed Act 160 in 1996 to move funding from nursing homes to home-based care. This was due largely to efforts by key advocates in the political arena of the department who were able to streamline funds from nursing homes to support home and community services. Medicaid's nursing home entitlement had resulted in a system where more individuals were placed in nursing homes than in home-based care options. The State anticipated that increased funding for HCBS would result in reduced spending for nursing facilities. The strategy of shifting the balance proved successful; when Act 160 was passed in 1996, 88 percent of the State's expenditures for LTC went to nursing homes, whereas currently only 68 percent of funds are used for nursing care. By reducing institutional spending, the State was able to expand existing programs and provide one-time awards to enhance providers' service delivery capabilities. In addition, the State awarded flexible funds annually to local long-term care coalitions to fill gaps and test new program concepts.

Program Features

Access

According to State officials, access has not been a major problem in Vermont. The system has been in place for the past 10 years, so citizens are aware of it, and agencies know how it works. Additionally, as Vermont is a small State, it is able to focus more on community-based services, but it does not have single access points in the community. Consumers enter the system through a variety of agencies such as Area Agencies on Aging, Home Health Agencies, and Day Services for Adults, among others.

Still, despite the system's history and the beliefs of State officials, a number of older persons do not know whom to call for services. The State has had a toll-free number for many years, and it is puzzling to some in DAIL why so many elders still do not know how to access LTC services. As such, the State recognizes the need to improve and expand its public information.

While access has not been viewed as a problem in Vermont, adequately serving individuals with different and changing needs remains a challenge. Once recipients are eligible for assistance, they may find it difficult to access services that meet their evolving needs. Caseworkers stay attuned to changes in availability of services to ensure that the client is being properly served. Vermont has developed a responsive support system so that the State is able to adapt to the evolving needs of the aging and disabled communities.

The DAIL provides a unified assessment process for LTC patients, and the results are streamlined through the appropriate agencies. Data is also collected to monitor local LTC expenditures on nursing facilities and community-based services.

To continue toward its goals, Vermont has applied for the 1115 LTC Waiver through the U.S. Centers for Medicare and Medicaid Services (CMS), which will allow its citizens equal choice and access to nursing homes or home-based care. The Section 1115 Medicaid demonstration program will combine HCBS and nursing home funding into a single LTC budget, entitling individuals in greatest need to care in either setting.

Services

The Vermont DAIL offers older people and people with disabilities the option of enrolling in the Attendant Services Program (ASP). ASP funds permit eligible individuals to hire and manage their own personal care attendants at no cost to the participant. The participant may hire any legal worker[*], including a spouse, a feature that has made the program attractive to consumers and a reason for its success.

DAIL performs the human resource functions for the attendants, such as timekeeping, payroll, and background checks. This allows clients to have greater autonomy in choosing a caregiver with whom they are comfortable and compatible, while also expanding the network of caregivers in the State beyond usual channels.

As a small State with small, close-knit communities, Vermont is unique in the fact that the majority of its LTC services are community-based. DAIL has oversight of multiple agencies that provide support for LTC services. The State of Vermont's Web site for the Department of Aging and Independent Living contains links and contact information for appropriate resources for a variety of different needs. Vermont Service Net acts as a one-stop-shop for services to the aging and disabled, featuring links and contact information for services throughout the State, and can be searched by geographic location or by type of service most needed, including emergency resources. Its resources for advocacy, case management, financial assistance, and in-home help can be used for the aging and the disabled, while it also features resources that may be useful only to more specific groups, such as those living with Alzheimer's Disease or visual impairments (State of Vermont, 2003).

The Vermont Assistive Technology Project was designed to ensure the integration of Assistive Technology within all services to aging and disabled Vermonters. With two try-out centers, older people and people with disabilities are able to meet with experts to determine the ways that

[*] Participants may not hire a civil union partner or an individual with a substantiated history of abuse, neglect, or exploitation.

assistive technologies can be integrated into their lives to promote independent living, sensory abilities, mobility, and to meet other needs. This Project is funded through the Adaptive Equipment Revolving Loan Fund and grants from private donors. These technological advances have enabled clients to have a higher quality of living in the community with fewer services from traditional caregivers (State of Vermont, 2004[2]).

Financing

Providing seamless funding for those who are aging and/or disabled has been a challenge for Vermont, as there are currently several different agencies, each with unique funding streams. Some communities have been able to provide seamless funding on a small scale using a small pot of flexible funds to serve those who fall outside of typical funding streams. Also, when the Department of Aging and Disabilities merged with the Division of Developmental Services, DAIL found ways to consolidate funds from four sources into one and was able to make services more consumer-based. The State is implementing a "cash and counseling" system, which allows consumers to control their own funding and determine how to purchase services that best fit their individual needs. While seamless funding is not yet in place system-wide, Vermont's home-based care waiver program is generous, flexible, and seamless once the recipient is in the system. Additionally, the 1115 LTC Waiver from CMS will help DAIL move toward more integrated funding streams for its clients.

Quality

Although Vermont does not have a formal quality management system, the State has been able to maintain a high standard of care for its aging and disabled populations. The State frequently monitors participants' service plans. Case managers, who are viewed as the front line for ensuring that participants' needs are being met, contact each participant at least once per month and conduct face-to-face visits every 60 days. Case managers also perform annual reassessments, unless a new service plan is needed sooner due to a change in a participant's situation. Case managers are also subject to certification standards established by DAIL. These standards include passing a State-administered exam and participation in a minimum of 20 hours of professional development or training. Case managers must meet these criteria in order to be certified.

Vermont's Division of Licensing and Protection also conducts licensure surveys with major providers of LTC services—nursing homes, home health agencies, residential care homes, and assisted living residences—to determine the ability of these facilities to meet peoples' care needs. In addition, the State conducts annual telephone and mail surveys with participants to determine their satisfaction with the quality of services, the degree to which the services meet their needs, the timeliness and scheduling of services, treatment by caregivers, and overall quality of life. Data from these surveys is reported across the State and regions, and it guides quality improvement efforts at both levels.

Finally, Vermont's waiver programs have established negotiated risk agreements that case managers can initiate when a participant's actions are perceived to conflict with his or her own safety and health. The risk agreement describes the participant's needs, available services, and potential risks to the participant and is used when a participant is aware of the consequences of

his or her actions and yet refuses to accept services that may reduce the risk of harm (Medstat, 2003[2]).

Vermont's home-based care system has natural checks and balances, which are an important feature of the quality monitoring process. Services are delivered by different agencies, yet they all look for problems and are able to report them.

Impact

Impact on Networks

Vermont has been able to establish collaborative relationships across different networks and merge departments successfully, yet there remains the need to eliminate silos and categorical services that still exist in the funding and delivery of services. The DAIL is continuously developing new mergers, such as the public guardianship program for the elderly and developmentally disabled. DAIL also produced a successful collaboration between the agencies working with mental health and the aging, where money has been given to local Area Agencies on Aging to subcontract with mental health agencies bringing mental health workers directly into these agencies' offices. This provides the agencies' clients quicker access to mental health services. While Vermont has also fostered relationships with transportation and housing agencies, there are still people who lack adequate housing and transportation, and DAIL is looking for ways to break down those barriers.

Intended Versus Actual Impact

Vermont's overall goal is to "promote progress toward community integration of services, and provide real choice about how, where, and by whom services and supports are delivered" (Clearinghouse, n.d.). Vermont's efforts to reform long-term care and break down the barriers to community living have shown signs of positive changes. More unified care plans have emerged where each client has one case manager monitoring services and one agency contracting services. This is especially appealing to clients and their families because it is a more seamless system. It is appealing to agencies because it saves money and duplication of efforts across networks.

Vermont's collaborative relationships have afforded more flexibility in the delivery of services to people who are aging and have physical and developmental disabilities. Due to this flexibility in delivery, Vermont has quadrupled the number of people in home-based care since the 1990s. In addition, the system has become more consumer-focused and consumer-driven. Vermont anticipates that these collaborative relationships will foster greater consumer satisfaction, develop a simpler, more consumer-focused system, and serve more people with expanded services using the same levels of funding while still maintaining their high levels of quality and consumer satisfaction.

Future Plans for Collaboration

The Department of Aging and Independent Living realizes that theirs is an evolving process, and future plans for collaboration involve a variety of stakeholders, such as the AARP, Community of Vermont Elders, Center for Independent Living, Coalition for Disability Rights and other

provider groups. The Department believes that bringing these groups into the planning stages early on is paramount to the success of the collaborations and providing citizens with the services they want and need.

Advice for Other States

States looking to improve collaboration between aging and disability networks should look at unequal enrollment in entitlement programs. Agencies can be held back by populations pursuing entitlements unless they find ways around it, such as applying for the 1115 waiver. This waiver allows States to become more consumer-focused, and helps them to be more successful in providing services to those who need it most in ways that are most desirable to consumers.

States should also bring together different advocates to emphasize commonalities. While there are some differences between these populations, the many similarities make it important to have the support of diverse advocates when pursuing system reform.

Finally, States should give consumers a choice. Regardless of their age and/or disabilities, people generally want to stay home and be part of their communities. Vermont's efforts to "shift the balance" from nursing homes to home-based care settings and the inclusion of the words "choice" and "options" in their policy goals reflect the State's commitment to affording its citizens the opportunity to choose the care options that best fit their needs.

Unless otherwise cited, information on Vermont was obtained through an interview with Patrick Flood, Commissioner, Vermont Department of Aging and Independent Living (telephone conversation with Melody Johnson Morales, May 4, 2005).

WISCONSIN

Scope of the State Model

Wisconsin's efforts to reform its LTC system have been a work in progress since the early 1980s when the State-funded Community Options Program (COP) began to offer community care options. COP allows Wisconsin residents to stay in their own homes and communities due to the growing cost of institutional and nursing home care. COP also enables seniors and people with serious long-term disabilities to access services and locate funding for services not offered by other LTC programs.

A major strength of the program is its use of care managers, who link consumers to services in their communities. Income guidelines are used to determine whether COP will absorb all or part of the cost for LTC services. If a client's income is above guidelines, COP will only cover a portion of the total cost and the client is responsible for the balance. By 1987, all of Wisconsin's counties were participating in COP.

In January 1987, Wisconsin received approval of the COP-Waiver request from CMS. The COP-Waiver was another attempt to reduce the financial burden placed on the State and provided an additional funding alternative for LTC services. The COP became a national model offering flexibility for home and community-based supports and services.

Even though the COP was recognized as a national model, Wisconsin community members and State leaders continued to make it better. In 1998, then Governor Tommy G. Thompson, introduced a new pilot program for LTC services, called Family Care, in this excerpt from his State of the State address, "The current long-term system is intimidating, complex and sterile. There are 40 ways to access the system, people don't know how to get the appropriate care because it's so complicated, and the concerns of families are often ignored…Family Care…will combine our LTC programs into one system to provide the maximum range of care options for seniors and disabled. It is built upon consumer choice and one stop shopping for services" (Thompson, 1998).

Since 1998, the Family Care program has been implemented in five Wisconsin counties. Entitlement is the key element of this integrated reform of Wisconsin's LTC system for seniors and people with disabilities. ADRCs were also added to supplement Family Care in 1998. Wisconsin has benefited from addressing reform of LTC with a focus on continuous refinement.

Program Features

Access

In 1998, Family Care was unveiled in response to the Governor's desire to consolidate all long-term care dollars into one capitated, risk-based system. The Family Care benefit created a single access point to LTC services. Family Care serves older people and people with physical and developmental disabilities. A key feature of Family Care is the Care Management Organization (CMO). CMO manages and delivers the Family Care benefit by combining funding and LTC

services into one flexible benefit. It offers comprehensive, flexible LTC options, allowing consumers to tailor their care plans to fit their individual needs.

In the same year, Wisconsin created a State-based ADRC as a second component to Family Care. Wisconsin's ADRC offers one-stop-shopping for seniors and people with disabilities to access information on LTC services, counseling on LTC options, prevention activities, assistance, and advice from benefit specialists (State of Wisconsin, 2004).

Wisconsin also participates in the Program for All Inclusive Care for the Elderly (PACE) through CMS. PACE is a program with a unique capitated managed care benefit for the frail elderly provided by a nonprofit or public entity that features a comprehensive medical and social service delivery system. It uses a multidisciplinary team approach in an adult day health center supplemented by in-home and referral service in accordance with participants' needs (State of Wisconsin, 2004). PACE is a program within Medicare and is an option States can provide to Medicaid beneficiaries as well.

Services

Wisconsin's Care Management Organization (CMO) provides access to Family Care either through purchase of service contracts with providers or through direct service by CMO staff. Available in five counties, each CMO is authorized to manage care for members across a range of care settings. Each CMO member receives an interdisciplinary team composed of a registered nurse and social worker/case manager. This team can expand to include other health care professionals as appropriate to individual health situations. Assessment for all members of a CMO includes activities of daily living, physical health, nutrition, communication, self-determination, mental health, and cognition.

CMO members actively participate in developing their individual care plans. CMOs place an emphasis on providing members with support and information to make informed decisions. Based on this, CMOs coordinate the delivery of adult day care, home modifications, home delivered meals, and supportive home care. Home care services include home health, mental health, skilled nursing, occupational therapy, physical therapy, and speech therapy. Additionally, CMO members who are eligible for Medicaid can utilize Medicaid's fee for service for those home health services that Family Care does not cover. The interdisciplinary team assists CMO members in communicating with doctors and assists in managing treatments and medications.

Other services under CMO include pre-vocational services, supporting employment, and transportation services. Arguably, autonomy to make independent decisions on the local level is one of the overall strengths of the CMO interdisciplinary team. This management freedom allows CMO interdisciplinary teams to authorize services not specifically mentioned as benefits as long as justification exists (State of Wisconsin, 2004).

Wisconsin's ADRC also offer counseling services for individuals seeking LTC. Part of this service is preadmission consultation for individuals entering nursing facilities, home-based residential facilities, adult family homes, or residential apartment complexes. The objective is to provide individuals with information so informed decisions can be made. ADRCs provide up-to-

date information on government and private benefits as well as providing technical assistance when problems come up with Medicare, Social Security, or other benefit programs. ADRCs can also complete an assessment of potential eligibility into Family Care or other case management programs for individuals who are not in Family Care.

Finance
Family Care and CMO allow money to follow the person, even if the eligible person moves to another county. Also, as mentioned above, COP is not an entitlement program whereas Family Care is an entitlement once an individual becomes eligible. ADRCs are currently located in nine counties and expansion is set to incrementally bring the rest of Wisconsin's counties into the ADRC network. Wisconsin began its ADRC with State money in 1999, and the State has expanded its network of ADRCs since then through funding cosponsored by AoA and CMS.

Family Care increases cost effective coordination of LTC services by creating one flexible benefit that includes an increased number of health care services that might not be available in other Wisconsin LTC programs. Members or their authorized representatives work with CMO interdisciplinary teams to have more control over their LTC budgets and choice of providers.

Quality
The Wisconsin State LTC plan includes PACE as an optional Medicaid benefit. The Family Care program also models some elements of PACE into CMO, such as the use of interdisciplinary teams to provide services to eligible members. This is an example of using the quality of one program and integrating elements into another.

Positive results of CMO success include more cost effectiveness when compared with institutionalized care for similar populations. Consumer satisfaction with services and care management is high in Wisconsin's waiver programs. Family Care sites (in 5 counties) scored high on 14 consumer outcome indicators according to data from the Wisconsin Division of Health Care Financing (State of Wisconsin, 2004).

Another positive aspect of Wisconsin's LTC reform involves the implementation of prevention activities in several counties. Examples of these prevention efforts include the development of a chronic disease self-management program, assessment procedures for people at high risk of injury due to falls, bone density scanning and follow-up, and in-home assessments by a clinical nurse to evaluate nutrition, medication use, and other health and safety factors (State of Wisconsin, 2004). The use of preventive health interventions may decrease the need for some LTC services.

Impact

Impact on Networks
Wisconsin's community care programs have increased collaborations between community providers. However, there has been difficulty in developing mechanisms to make sure older people receive funding for home and community-based services. Overwhelmingly, the majority of LTC funds go to people with DD. This impacts older people since they often spend more time on waiting lists than people with disabilities.

One impact on the aging and disability networks involves more centralized leadership of LTC since the Wisconsin Bureau of Aging and Long Term Care Resources and the ADRCs work hand in hand. They accomplish this even though they are in separate bureaus. The two programs have historically been housed in the same bureau, so though they are now separate, they are familiar with each other and continue to collaborate on providing services to the community.

Intended Versus Actual Impact

Wisconsin's intended overall impact was to shift the number of persons in nursing home facilities and State institutions to home and community-based care. There is data to indicate that the State has been successful in achieving this goal. For example, in 1995, there were 1,236 people placed in State institutions versus 817 placed in community-based care; by 2003, the numbers shifted to 772 placements in State centers and 1,165 community placements. In addition, usage of nursing homes versus community care has shifted. In 1985, approximately 29,000 people were in nursing home facilities versus 3,600 people in community care facilities. By 2003, the number of people in nursing homes had decreased to 23,000 compared to 20,000 people utilizing community-based care, and Wisconsin State officials project that use of nursing homes and community-based care will converge at 20,000 people each in 2005. It is expected that these trends will continue into the future (State of Wisconsin, 2004).

Future Plans for Collaboration

While Wisconsin residents do experience less institutionalization and have increased access to HCBS, many older people and people with disabilities are still on the waiting list for these services. As mentioned above, there is also a bias against serving older people compared to people with disabilities, despite an equally long HCBS waiting list for both populations. The State's future plans include efforts to facilitate more collaboration among the Wisconsin DRCs, CMOs, and counties to address this imbalance.

There is a strong interest among State legislators in expanding the Family Care program to additional counties. Still, certain financial limitations must be addressed before all of Wisconsin's 72 counties can participate in Family Care.

Advice for Other States

Since 1982, a major factor that has kept Wisconsin's LTC reform efforts moving forward is the strong political influence of its counties. For other States in which counties may have less political impact, some of the Wisconsin programs of LTC reform may not be replicable. On the other hand, Wisconsin does have a model program and an evolving system driven by the desire to create community capital, to lower spending per capita, and to increase consumer choices over LTC services and information. The community-driven nature of Wisconsin's LTC reform efforts may be the most important factor in the State's success.

Unless otherwise cited, information on Wisconsin was obtained through interviews with Donna McDowell, Director, Wisconsin Bureau of Aging and Long Term Care Resources (email

correspondence with Gary Quinn, May 10, 2005), and Gail Propsom, Policy Analyst for Long Term Care Policy/Systems Change, Wisconsin Bureau of Aging & Long Term Care Resources (telephone conversation with Gary Quinn, May 10, 2005).

CONCLUSION

Consistently, promising practices in reforming LTC have created new initiatives that reflect the needs of consumers while balancing fiscal challenges. This paper highlights what each of the four States featured deemed important to their own aging and disabled populations. Expanding consumer choices and strengthening collaborative efforts were two key elements in restructuring programs, in addition to identifying key stakeholders to push forward LTC policy initiatives. Keeping the consumer at the core of program development was also critical for each State, and careful and systematic planning has proven successful in empowering consumers to assume control over their own long-term care services

These States provide a foundation of promising practices and experience to guide other States interested in restructuring their own LTC systems. Challenges still remain, particularly regarding outdated polices that offer no latitude for change, and much is left to learn in creating cost-effective systems to ease financial burdens. Additional actions are also needed to foster relationships between agencies and across service networks. Reforming the Nation's LTC systems and increasing collaboration across networks for more efficient delivery of home and community-based services are both crucial to our future abilities to provide comprehensive LTC services to an ever-growing population of consumers.

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