

VISION SHARED
Long-Term Care
Taskforce Report

DECEMBER, 2007

Executive Summary

- West Virginia, along with other states in the country, is facing an unprecedented growth in the over 65 population over the next 20 years.
- The need for long-term care (LTC) services will also grow very dramatically while the size of the workforce will shrink in comparison.
- West Virginia is challenged by its current rates of disability, hypertension and obesity.
- With clear population, health and disability challenges, West Virginia needs to move more aggressively to improve its current system, educate the public about current opportunities and future LTC needs, and expand opportunities for individualized services delivered in a person's home and reduce the costs of institutional care.
- There is broad agreement on the elements of a comprehensive LTC system.
- People need access to LTC information that is clear and understandable and they need to know where they can find it.
- People need that information often when there is a crisis and they need independent counseling to help them, often when the person needing care is being discharged from a hospital or admitted to a care facility.
- People need to know in a timely manner what public support, if any, they can expect to help them.

- Financing LTC is both a private and public responsibility.

The Long-Term Care Task Force of Vision Shared recommends that West Virginia adopt the following goals and take the following action steps.

- 1. By 2010, the state will have a single point of entry system established to enable consumers to go to a centralized, neutral source of information and assistance which also provides preliminary screening for services, eligibility, assessment of functional and financial capacity, service authorization, monitoring and reassessment.**
- 2. By 2009, require and implement person-centered planning throughout the long-term care system. Person-centered planning means a process for planning and supporting the individual receiving services that builds upon the individual's capacity to engage in activities that promote community life and that honors the individual's preferences, choices, and abilities. This process involves families, friends, and professionals as the individual desires and requires.**
- 3. On an ongoing basis, the public and private sector shall work cooperatively to strengthen the availability of needed long-term care services so that the full range or continuum of services is available to all citizens.**
- 4. On an ongoing basis, the public and private sector will support, implement and sustain prevention services to improve the quality of**

life for people with disabilities and elderly people and to delay the need for long-term care services.

5. On an ongoing basis, promote meaningful participation by consumers, their families and other interested parties by establishing a broad based LTC team both at the community level and at the state level authorized by the state health plan on which there is active participation by consumers, families and interested parties in developing the LTC system as benchmarks are identified and achieved and goals are met and revised.
6. In addition, develop and implement a consumer education program that educates the public about long-term care issues, available resources and the ongoing need for planning by consumers and their families.
7. By 2010, establish a quality management system that's primary consideration is the evaluation of the person receiving supports and the desired outcomes.
8. On an ongoing basis, develop a coordinated approach to all oversight by streamlining and integrating rules to assure the highest practical physical, mental and psychosocial wellbeing of the individual with a focus on outcomes.
9. By 2009, develop and implement career building strategies to attract and recruit into LTC careers an increasing number of capable, committed workers and to retain the capable workers currently in the system with a focus on the

development of this critical profession. In addition, develop needed supports for informal caregivers to maintain their important role in long-term care services.

10. By 2009, begin the adaptation of financing structures that support a new system in a more equitable manner with more support of individuals having choices in the type and location of their care.
11. By 2009, require and implement person-centered advance care planning throughout the long-term care system. Person-centered advance care planning means a process for educating the person and family about end-of-life care options and offering assistance in completion of advance directives and the Physician Orders for Scope of Treatment form based on the person's preferences. This process empowers the individual to make informed choices about future medical treatment options while the person retains the capacity to decide what he or she wants. It honors the individual's preferences, choices, and abilities. This process involves families, friends, and professionals as the individual desires and requires.

CHAPTER I: Introduction

Beginning in 2011, there will be a retirement boom that will extend over the next 20 years. Those who are members of the baby boom generation will turn 65 and will need retirement income to pay for living expenses and for expenditures for acute care not covered by Medicare. That same group of people will have long-term care needs such as bathing, dressing, or eating that they cannot do for themselves due to a disability. Medicare is designed to cover only a limited portion of an individual's long-term care needs. People turning 65 now will on average need long-term care for several years and incur substantial costs, although the variations around the average will be significant. This is the real challenge to policymakers today. Because of the increasing number of older and disabled citizens, it is essential that progress is made in preparing this state to meet its citizen's needs for long-term care. We can either wait for the perfect storm or make yearly progress toward developing a comprehensive, coordinated long term care system integrated system for the state by establishing goals and priorities now and establish a process to accomplish them.

There are well established hallmarks of a comprehensive long-term care system. These include a single state organization responsible for all functions; access to multiple funding sources; streamlined functional and financial eligibility; a comprehensive point of entry; a full array of home and community based services and institutional services; consumer directed services; and quality assurance in all locations for long-term care services. These are the basic components that can be added to by a state as any plan is developed.

In addition to the human costs of quality care, there is a huge economic impact in that the provision of long-term care represents a

significant source of output, employment and income within West Virginia that will grow along with the growing needs for long-term care services throughout the state.

Let's look at the reality of West Virginia's growing elderly population and the efforts made in West Virginia over the years. West Virginia's population is growing older, not only in absolute numbers but also relative to the total population of the State. In 2000, 276,895 West Virginians were 65 or older. The U.S. Census Bureau projects that number will rise to 292,402 by 2010 and 426,443 by 2030—from 15.3% of the population to 16% in 2010 and 18.9% in 2030. In 2030 West Virginia is projected to be one of only ten states to have more people 65 and older than under 18.

And West Virginians tend to be sicker than most. The 2003 West Virginia Behavioral Risk Factor Report, a yearly assessment of risk factors in the state, cites West Virginia as ranking third highest nationally in the prevalence of obesity, first in the prevalence of hypertension, and first in overall disability rate--more than one quarter of adults were disabled because of physical, mental or emotional problems.

The increasing age and continuing high rate of disability and chronic illness strain an already fragmented and inadequate long-term care system. And the costs continue to rise.

In FY 2005 the West Virginia Medicaid program spent \$807 million on long-term care services (in both federal and state dollars)-up from \$678 million in FY 2003.

This problem has not gone unnoticed by the state, the federal government or major foundations. A variety of pilot programs have been initiated and a diversity of study groups and reports issued over the past quarter

century.

Since 1982, West Virginia has implemented an Aged and Disabled Home and Community based Medicaid Waiver program offering in-home care for eligible clients.

In 2005 the State incorporated Cash and Counseling program allowing citizens to direct and manage their own personal assistance services according to their own needs.

In 1986, then Governor Moore convened the Continuum of Care Board Task Force to evaluate West Virginia's frail elderly and report with findings and recommendations concerning the provision of adequate long term care services for this segment of the population. That report advocated "a comprehensive long-term care policy" that "would provide a true continuum of care, coordinating the current fragmented service delivery system, filling present gaps in the delivery of services as well as supplementing and supporting the care given to older people by family and friends."

In 1997-1998 the work of a task force created to draft and test a uniform assessment process led to the West Virginia Health Care Authority underwriting the computerized senior and Disabled Persons Assessment Pilot Program. The program met the majority of project objectives, but was dropped, however, due to budgetary constraints and the inability to find ownership for the future project expansion to day-to-day operation.

In a letter to the Chairman of a Health Care Planning Commission in 1992, Governor Caperton reiterated a commitment to the principle that "all senior citizens should have the opportunity to make informed choices about care options so that they may remain close to their families and friends or choose

institutional care."

In 1994 the State held a day-long Health Care University for legislators as part of a health Care Reform project that the Governor called for the state to "Implement and coordinate all health care services into community care networks by July 1, 1997." The goal was to create "a coordinated system serving the health care needs of the whole individual, rather than a fragmented series of encounters or episodic treatment" by delivery of managed care for an enrolled population.

In 2001, the West Virginia Center for Healthcare Policy and Research and the West Virginia Health Care Authority issued a report on Progress and Potential in West Virginia's Community Long-Term System whose purpose was to "to provide West Virginia policy makers with an overview of the state's community long-term care system for elderly and physically disabled consumers, and to identify policy options to improve or enhance the system." The report focuses on community-based long-term care services and looked at a number of challenges, including issues of ease of entry into the system, an institutional bias, coordination, quality assessment, data analysis, and the recruitment and retention of qualified workers. It concluded:

West Virginia has made considerable progress in the development of its community long-term care system, but it has many important challenges ahead. These challenges do not need to be addressed all at once, nor do changes need to be implemented immediately statewide. The State should consider prioritizing system improvements and piloting changes on a regional basis. Given the considerable differences between West Virginia's cities and its rural

areas, system changes will need sufficient flexibility to accommodate regional variation.

Concern for a single-point of entry into the long-term care system surfaced again in 2003 when the federal Administration on Aging and Centers for Medicare and Medicaid Services launched the Aging and Disability Resource Center initiative. West Virginia was one of the first participants, and is currently running the program at two sites with plans to expand into additional sites in the state.

This past year, in 2006, West Virginia submitted an application for a Money Follows the person grant and Charleston Area Medical Center (CAMC) announced a Program for the All-Inclusive Care for the Elderly (PACE) grant as part of the Geriatric Center for Excellence that is currently being developed by CAMC. While the PACE program has been in operation since 1973 nationally, this is one of the first designed to reach a rural population.

While the problems of long-term care have been recognized, evaluated and prioritized for years, major design to accomplish the significant change on the institutional or governmental level has not kept up with the recommendations from all the studies that have been done. Much, if not most, of one's travels through the system remain unchanged. And the problems whether in terms of finances, workforce, continuity or coordination of care-remain.

There is no question that the importance of the long-term care system on the economic welling-being of the state is absolutely critical. Yet it is also unquestionable that the workforce has not been developed adequately to meet the upcoming deluge of needs that must be met.

It is in this context that the present Long-Term Care Task Force was convened by Vision Shared. The task force, which is made up of both governmental entities working in the area and representatives from the private sector has taken as its working definition:

Long-term care consists of diverse, integrated medical and non-medical services provided over a variety of disciplines, by a variety of providers, and over a sustained period of time to ensure the maximum potential physical, mental, and social functioning of the individual. It is designed to form a natural transition and reintegration with short-term care.

This expanded definition extends long-term care services well into the area of chronic disease care and management, fully incorporating the notion of "healthy aging". Most significantly it once again highlights the need for integration and coordination between a variety of workforce personnel, institutions, and funding sources that have historically operated independently or competitively, or have historically been ignored.

This work group established as its purpose the goal of developing a roadmap for future progress toward meeting the long-term care goals that are looming over this state in the near future. We hope that policymakers can use this report as a direction in which to go and as a tool for evaluation of progress and future decisions in this area. Do we wait for the perfect storm or do we act in a rational manner to ensure that our citizens get the services they need? As Robert Kennedy once said "There are those who look at things the way they are and ask why . . . I dream of things that never were and ask why not?"

In short, this Introduction has recited a number of West Virginia initiatives, projects,

programs, and the like that span some 35 years from 1973 to present. The baby boomers give the state at most another 5 years to perfect the Long Term Care system for our ever increasing population of elderly citizens, a process upon which we must urgently embark starting today!

CHAPTER 2: National Overview

As the “baby boom” generation nears what has been normal retirement age, both the public and private sector are re-examining whether their systems are ready for the changes in demand for services that will occur. State and local governments have certainly been looking at a range of issues impacting employment, housing, transportation and medical care. Not surprisingly, the issue of long-term care for individuals with disabilities and chronic care needs is being discussed all over the country. This section of the report addresses what states around the country have been doing to prepare for this rising demand for services knowing that, in survey after survey, people strongly express the desire to receive long-term care services at home (AARP Surveys, 2002-07). In a recent letter supporting the Community Choice Act, AARP stated that 89 percent of people over 50 say that they want to remain in their home as long as possible (AARP Letter, 2007).

First, it should be acknowledged that states have been developing community-based systems of long-term care (LTC) for individuals with disabilities or chronic care needs for over 30 years. There have been many reasons for this development. Some of them include: the increased desire of people to live independently in their homes and communities; federal, state and local government financing; state and local commitment to developing and organizing services; and strong consumer advocacy with policymakers at all levels of government. That said, the largest source of funding for LTC has been Medicaid. 2004 data show that Medicaid pays for 42% of all LTC expenditures (Kaiser Commission,

2006). When Medicaid was enacted in 1965, it required that nursing facility services be covered for individuals 21 years of age and older. Although home health and rehabilitation services were optional benefits that could be covered by state Medicaid programs, nursing facility care was the only long-term care service that was mandatory. In 1971, states were also given the option of covering services in intermediate care facilities for the mentally retarded (ICFs/MR) and many states added those LTC services (ASPE, 2000).

Home and community-based services (HCBS) became more of an option for people after 1981. Congress amended the Medicaid law and allowed states to apply to the Secretary of the U.S. Department of Health and Human Services (HHS) for a “waiver” of federal law to allow Medicaid payment for long-term care services provided in the home or community. Services provided under a waiver had to be an “alternative” to institutional care and the individual receiving services needed to meet the existing test for medical need for institutional services (ASPE, 2000).

Although this was seen as a big change in the Medicaid program and a large opportunity for states wanting to provide those alternatives, spending on home and community-based services was not even 10% of total Medicaid LTC expenditures by 1988. Institutional spending remained over 90% of Medicaid LTC expenditures (ASPE, 2000).

The early 1990's saw much larger growth in the amount of Medicaid spending on home and community-based services (HCBS). This increase was certainly due, in part, to demand for more cost-effective services due to decreasing state revenues. But there was also increased consumer demand for community services as alternatives to

institutional care and the increased demand that public ICFs/MR be downsized or closed. By 1995, over 19% of Medicaid LTC dollars were being spent on HCBS. This trend continued throughout the late 1990's and by the year 2000, over 28% of Medicaid LTC spending was for HCBS (Burwell, 2004).

In 1999, the United States Supreme Court ruling in the Olmstead case created even more incentive for states to continue to move in the direction of creating HCBS for individuals with disabilities of all ages. A concise statement of this decision is that individuals with disabilities covered under the American with Disabilities Act of 1990 (ADA) cannot be institutionalized if they want, and are able, to receive appropriate support services in a community setting, subject to the reasonable financial limitations of a state. Many states used this decision as a reason to further enhance their development of HCBS and other states were sued and had to increase services because of court decision or lawsuit settlement. The latest Medicaid expenditure reports show Medicaid HCBS at almost 40% of total Medicaid LTC spending (Burwell, 2007).

Although most of the motivation for developing home and community-based services first came from consumer and government advocacy, later fueled by the Olmstead decision, a number of policy makers believed that long-term care services should be viewed as any other service in the marketplace and that the state role was to establish a "level playing field" and let providers compete for customers. Many had become tired of the fierce battles over reimbursement by a variety of provider groups and by charges of favoritism. Others believed that competition would increase both quality and cost-effectiveness and that consumer demand and expectations would

be better satisfied (Auerbach, 2006).

Federal Funding for LTC Systems Change

In 2001, the Centers for Medicare and Medicare Services (CMS) began awarding grants to states to develop the infrastructure needed to support integrated, community living for individuals with disabilities of all ages. It was part of President Bush's New Freedom Initiative and it was viewed as a direct response to the 1999 Olmstead decision. There was a clear message from the federal government that it wanted to assist states in complying with the mandates of the Americans with Disabilities Act. One of the first grant categories, named Real Choice for Systems Change Grants, was very broad and allowed states to propose any "systems change" they thought necessary to support community living. Also in 2001, CMS funded grants to states to develop community-integrated personal assistance and supports, and funded states and independent living centers (ILCs) to develop nursing facility transition programs (www.cms.hhs.gov/NewFreedomInitiative).

Although states has already been working to develop programs and structures to increase HCBS options, these grants created new opportunities for states which had not accomplished as much development as well opportunities for other states to build upon and enhance what they had already achieved. A March 2007 communication from CMS states that approximately \$280 million in Systems Change Grants for Community Living grants had been awarded to 50 states, 2 territories and the District of Columbia (CMS Compendium, 2007). There has also been other federal and foundation grant funding which has allowed states and other stakeholders to develop the structures needed to support HCBS. States

have also worked in areas where there has been no grant funding. The sections below will identify many of those federal and state investments.

Key Building Blocks of Coherent LTC Systems Management

A few years ago, CMS developed a method by which states could be evaluated on whether they were meeting the needs of their citizens for long-term care services and supports. It called these the “key building blocks of coherent systems management” of long-term services. The “building blocks” included the broad categories of access, financing, services and quality (CMS, 2003 (b)). CMS has used this analysis repeatedly in describing state efforts to rebalance their long-term support systems and using this methodology continues to be a good way to examine states’ progress on developing and managing LTC.

Access

The first key building block in a well-managed long-term care support system is access. Access can be defined as marketing to the public about where to get comprehensive information, delivering that information in an unbiased, understandable manner, referral to an appropriate service, counseling on long-term care options, simplified and streamlined eligibility, and establishing service delivery for those who qualify for public services. Individuals and families need to know where to find information, understand their options, receive timely notice of program eligibility and have needed services begin as soon as possible. People often move to nursing facilities because they are unaware of the alternatives, cannot afford the alternatives without some public financing or cannot piece together often disjointed community

services into a coherent program that can help them remain at home, if that is their choice.

States have received federal assistance in developing most of these components through grants to create Aging and Disability Resource Centers. Beginning in 2003, the U.S. Administration on Aging and CMS have collaborated on funding 43 grants to states, territories and the District of Columbia (D.C.). Although a number of states had highly developed “single point-of-entry” systems, most states had only begun such development (www.adrc-tae.org). The sections below describe most of the access elements on which states have been working.

Information and Assistance on LTC Services

Many states have developed specific web sites where people can go to find out information about long-term care, the variety of services available, and sources to contact for more information. Additionally, many states have electronic or other written tools to help people decide what type of services might best meet their needs. Many also have interactive features on their web sites which allow individuals to enter certain data that are more specific about the services they need, and where they live, resulting in a listing of service providers in that area which provide those services. A number of states are also working to put electronic applications for public services on those web sites, in addition to numerous links to other web sites for more information (www.adrc-tae.org).

States also continue to establish toll-free telephone numbers where people can call for information about long-term care options, services, and available providers. These calls are normally answered by people who

know what is offered in a specific geographical area and can be more precise in their assistance. Of course, with both web sites and toll-free telephone lines, people need to know that they exist and states have done some significant outreach and marketing to make people know about these resources.

Options Counseling

Options counseling is a service generally defined as knowledgeable LTC specialists working with individuals and families to examine LTC service choices, residential settings and financing. This type of counseling can be done in advance of individuals needing LTC services and can focus on planning for future needs. A number of states, such as Minnesota, have developed counseling programs that offer this option to all its residents (Auerbach and Reinhard, 2005). In these instances, counseling can occur in people's homes and in the offices of a government or nonprofit agency. However, most people seek counseling when there is an immediate need for services. In these instances, counseling may need to occur in hospitals and nursing facilities (www.adrc-tae.org).

A growing number of states have developed options counseling programs, also called diversion programs, which focus on providing information about LTC choices while people are in hospitals and nursing facilities. Hospital-based programs focus on people who would otherwise be discharged to a nursing facility. While many individuals may need rehabilitation after a hospital stay, others would be able to return directly home if they knew that there were home health and nursing services available to them. Indiana has been developing a hospital-based diversion program for a number of years and funds area agency on

aging staff to be in hospitals to work with hospital discharge staff and give people information on alternatives to institutional care (Reinhard, 2006). Other states, such as Washington, Minnesota and New Jersey, send staff to nursing facilities to visit people soon after admission and counsel them on LTC choices (Auerbach, 2006). These programs have proven crucial to states trying to give people choices of services and settings and create a balance between institutional and community-based care.

Streamlined Eligibility

The Administration on Aging and CMS have made streamlined eligibility one of the major objectives of the Aging and Disability Resource Centers (www.adrc-tae.org). In order for people to have "real" choice of LTC services, they need to know what public support they can receive in a timely manner. Many states have established programs and many states have begun programs to make Medicaid eligibility determination quickly so that a person being discharged from a hospital knows what and how long services will be delivered to them in their homes (www.adrc-tae.org). Likewise, people recently admitted to nursing facilities need to know what services they could obtain if they were discharged from that facility.

States have approached this issue in a number of different ways. Some have focused on speeding up the eligibility process for all who apply for LTC services by finding ways to streamline the administrative processes. More states have chosen to focus streamlining on those who would otherwise become unnecessarily institutionalized. Although states use different methods to determine which applications get priority, states have been employing what is called presumptive eligibility determination. This concept

generally means that the state would normally ask an individual and family a series of questions about income and assets. Based on the responses, determinations are made, with a few days or less, about whether the person is eligible. In those instances, the state then does a “regular” eligibility determination and confirms whether the original presumption was correct (www.adrc-tae.org). At first, states were reluctant to use this method because if a person proves not to be eligible, the federal government will not provide matching funds. However, states have been so accurate that none have abandoned their presumptive programs for fear of losing federal matching funds.

Financing

The second key building block, financing, can be divided into two major areas: global or unified budgeting; and individualized budgeting and consumer direction. States have developed and are developing programs in both of these areas and both reflect a direct response to the desires of consumers to have choices in services and settings and to have control of how those services are delivered.

Global or Unified Budgets

The concept of a state adopting a “global” or “unified” budget was given encouragement by CMS’ earliest pronouncements about its “money follows the person” strategy for LTC services. It described money follows the person as a system in which a market-based approach would allow individuals more choice over the location and type of services they receive and have the financing move with the person to the most appropriate and preferred setting, as his or her needs change (CMS, 2003 (a)). While that definition appears a bit cumbersome, it

contains a number of value statements. First, that a LTC system should be “market-based”, meaning that there should be no preference for one set of services over another and that consumers should be able to choose from a marketplace of offered services. Second, that this market approach should afford more choice to the individual. Finally, that financing should be available for any offered service, in any setting chosen by the consumer, and be responsive to changes in needs.

For many years, consumers have faced a public system, especially in Medicaid, where there were services they were entitled to get if they were eligible and others for which they needed to wait. The entitlement services were ones that individuals needed to receive in an institution; other services, for which there was not an entitlement and often a waiting list, were home and community-based services (ASPE Primer, 2000).

As states responded to the demand for more choices in services and settings, most understood the challenges associated with having funding for institutional services in a different budget, and often administered by different state agencies, than HCBS. In those instances, if people chose HCBS, one had to make sure there was budget money available and a waiver “slot”. If a person chose an institution, an “entitled” service, one could assume that budgets would be adjusted to provide those services. Many states have made changes necessary to avoid this conflict by either merging budgets for long-term care and/or ensuring that money flows relatively easily from the institutional budget to the HCBS budget as the desire for HCBS increases (Auerbach, 2006). New Jersey is a state that is currently working on this concept and all the changes needed to fully implement it.

Nursing Facility Transition and Money Follows the Person

The U.S. Department of Health and Human Services has been giving grant funds to states to develop programs to “transition” individuals out of institutions since the late 1990’s. In 2001 and 2002, CMS funded 22 states and 10 independent living centers to develop and implement nursing facility transition programs (CMS Compendium, 2007). The concept was to offer individuals the choice of receiving services in community settings, if they were able, and assist them to move out of the facility and receive appropriate services. There have been many successful programs developed and implemented. Perhaps the most recent prominent one was in Texas. Called “Money Follows the Person”, Texas allowed monies spent on Medicaid-financed individuals in a nursing facility to “follow” people if they transitioned from a nursing facility. Well over 12,000 people have moved out of nursing facilities under this program (www.dads.state.tx.us).

In 2007, CMS began a new round of funding for institutional transition programs called Money Follows the Person Rebalancing Demonstration Awards. The awards pay for community-based services for the first year after a person has transitioned from an institution and focuses on eliminating barriers to people living in the settings of their choice. 30 states and the District of Columbia have received federal awards of about \$1.4 billion dollars over 5 years for transitioning almost 38,000 people (www.cms.hhs.gov/NewFreedomInitiative).

Individualized Budgeting and Consumer-Direction

Although the concept of consumer direction has most recently been defined as including

the concept of individualized budgets, consumer direction began many years before individualized budgets were implemented. States such as Oregon have included the philosophy of consumer direction in their Medicaid waiver programs for at least ten years before states began implementing their first individualized budget programs. The concept of consumer direction meant that the consumer had the right to hire, train and direct the providers who delivered their personal care services. It also meant they had the ability to fire the individual delivering the services, if they were not satisfied with the services.

The concept of individualized budgets, with authority to purchase goods and services beyond those normally provided under Medicaid programs, began with the cash and counseling demonstrations of the late 1990’s. With major help from the Robert Wood Johnson Foundation and strong support from the federal government, Arkansas, Florida and New Jersey began pilot programs that determined individuals’ need for services, the normal cost to provide those services, and then provided that money in an individualized budget for a person to choose the goods, services and providers they wanted. These demonstrations were closely evaluated especially for cost and quality (www.mathematica-mpr.com). Based on the evaluations, CMS decided that these demonstrations were successful and took action to make it easier for states to implement these programs. It created a program called Independence Plus and facilitated approval of Medicaid waivers to implement them (www.cms.hhs.gov/independenceplus). In 2003, CMS also funded grants to 12 states to develop Independence Plus programs (CMS Compendium, 2007). In addition, in the Deficit Reduction Act of 2005, Congress

made it even easier to make a “cash and counseling” program part of the regular Medicaid program (see U.S.C. Title 19, Section 1915 (j)). There are well over 30 states, including West Virginia, which have implemented or are developing these programs.

Services

The next key building block is services. Consumers want the choice of HCBS, but there has been and needs to be additional focus on this area. Without sufficient services available and providers to deliver them, consumers will not have the choices they want and need. It is important to note that states have been expanding the variety of services they offer people who need HCBS and have focused on issues related to rural and other underserved areas, but there is also much that needs to be done in that area. Two key areas where states have worked and realize that there is so much more to be done are housing and workforce.

Housing

States have been working in a variety of ways to address the needs of individuals with disabilities for affordable, accessible housing. Although housing is not a LTC service per se, it is a key to someone being able to remain independent and receive services in their home. A number of states have been working with their state housing finance agencies to develop new affordable, accessible housing whether through new construction or rehabilitation of existing buildings. Many efforts have been geared to specific disability populations, such as group homes, and others have been geared more generally. Over the years, Oregon has contributed public financing to build approximately 40 assisted living facilities and developed well over a thousand housing

units for individuals with mental illness. Arkansas more recently has been developing affordable assisted living and other states are doing the same (www.ncbcapitalimpact.org). One strategy has been to convince the housing finance agency to give “points” in competitive funding proposals to developers who propose accessible units in affordable buildings.

States have also been working with local public housing authorities to gain preference for individuals with disabilities to receive housing choice vouchers for subsidizing rent in existing units. Some states have been successful in convincing housing authorities to give preference to individuals transitioning out of institutions (www.ncbcapitalimpact.org). This obviously gives more people the opportunity to transition if they know they have access to an affordable, accessible place to live. In 2004, CMS gave grants to 7 states and D.C. to work on programs to integrate long-term supports with affordable housing. In addition, another 5 states continue to work on housing issues through CMS' 2005 and 2006 Systems Transformation Grants (CMS Compendium, 2007). Finally, a number of states have followed Massachusetts' early leadership in developing “housing locator” web sites where a person searching for affordable, accessible housing can be matched up with a landlord offering such rental units. Most of these web sites are interactive and allow people to put in their requirements for accessibility, affordability and geographic preference, and have listings generated which meet their preferences.

Workforce

This is a very big issue for ensuring that services are delivered to a person where they

want them and how they want them delivered. The demand for workers generally will become even more acute as the baby boom generation retires, but even today the demand for home care workers, in addition to workers in community residences, is tremendous (Friedland, 2004). As usual, there are many ways to analyze and explain how states are addressing these issues, but one way is to look at efforts to address the needs of the paid workforce and the needs of the family and unpaid workforce.

States have been working on a number of issues relating to the paid workforce. First, states have begun to raise the wages of home care workers and other direct service workers through their Medicaid programs. Others have explored and implemented ways to ensure that workers are covered by health and workers' compensation benefits. Some have worked on initiatives to provide career ladders for workers and to work with supervisors on mentoring and inclusive decision-making. In addition, many have worked with education and training institutions to ensure that there are resources available to train people for these positions now and in the future. This includes work to promote paid caregiving as an honorable and reasonably compensated profession (www.paraprofessional.org).

The issue of family caregivers is a very difficult one. In many cases, the work of family caregivers is the only reason why an individual needing LTC does not end up in an institution. Families provide a huge amount of unpaid caregiving especially to younger children, older adults and individuals with intellectual disabilities who are often on long waiting lists for government services (National Family Caregivers Association, 2003). The federal government acknowledged this issue

through passage of the National Family Caregivers Act aimed at providing education, training, peer support and respite services aimed directly at the caregiver. Although this was a major policy breakthrough and allowed many states to follow with new and expanded programs, the money attached to this legislation has not met the need. States have developed their own respite and "family support" programs, most which focus on relief for the caregiver and added education about the caregiving process. In 2004 and 2005, CMS awarded 20 grants to state nonprofit organizations to develop Family-to-Family Health Information and Education Centers designed to provide information for family caregivers delivered by other family caregivers (CMS Compendium, 2007).

Finally, states have been analyzing and amending their nurse practice acts to allow family caregivers to do more direct tasks, some under the supervision of a nurse. In addition, many, if not most, of the individualized budget programs mentioned above allow consumers to hire providers of their own choosing, including family members (www.cashandcounseling.org).

Quality

The final key building block is quality. CMS has done a lot of work in the past years defining what it expects from states in assuring quality in its HCBS programs. It has adopted an HCBS Quality Framework which outlines a method for quality program design and quality management functions. Program design addresses topics such as service standards, provider qualifications, assessment, service planning, monitoring participant health and welfare. Quality management encompasses three functions to assure quality: discovery; remediation; and continuous improvement. States have been

working on developing systems to discover when services are not being delivered, when a provider is not delivering services in an acceptable manner and when the health and welfare of program participants may be suffering. They have also been focusing on ensuring that there are backup systems for individuals when services are not delivered (www.cms.hhs.gov/HCBS/downloads/qualityframework.pdf).

States have also adopted a variety of new and more extensive ways to ask consumers themselves to rate the quality of delivered services and CMS has continued to develop tools to help states improve HCBS quality (www.cms.hhs.gov/HCBS/02_QualityToolkit.asp). In 2003 and 2004, CMS awarded 28 grants to states for developing quality assurance and quality improvement in HCBS. An additional 7 states continue to work on development and enhancement of their quality management systems through the 2005 and 2006 CMS Systems Transformation Grants (CMS Compendium, 2007).

References

AARP: *Letter to U.S. Senator Harkin in Support of the Community Choice Act, October 4, 2007*. Accessed at www.aapd.org.

Auerbach, R.: *Improving Long-Term Care Services in Tennessee: Meeting the Changing Needs of a Growing Population*. AARP Tennessee. April 2006.

Auerbach, R. and Reinhard, S.: *Minnesota Long-Term Care Consultation Service*. Rutgers Center for State Health Policy, New Brunswick, N.J. September 2005.

Burwell, B. and others: *Medicaid Expenditures for Long-Term Care Services,*

FY 1998 through FY2006. The Medstat Group. Cambridge, MA. 2006.

Centers for Medicare and Medicaid Services: *Real Choice System Change Grants, Compendium 6th Edition*. Washington, D.C. March 2007.

Centers for Medicare and Medicaid Services: *"Money Follows the Individual" Rebalancing Initiative*. Washington, D.C. 2003 (a).

Centers for Medicare and Medicaid Services: *State Efforts to Rebalance Their Long Term Support Systems and Enable "Money to Follow the Person"*. Washington, D.C. 2003 (b).

Friedland, R.: *Caregivers and long term care needs in the 21st century: Will public policy meet the challenge?* Georgetown University Long-Term Care Financing Project. Washington, D.C. 2004.

Kaiser Commission on Medicaid and the Uninsured: *Medicaid and Long-Term Care Services*, Washington, D.C. July 2006.

National Family Caregivers Association and Arno, P.: *Prevalence and Economic Value of Family Caregiving*, 2003.

Office of the Assistant Secretary for Planning and Evaluation (ASPE), U.S. Department of Health and Human Services: *Understanding Medicaid Home and Community-Based Services: A Primer*. Washington, D.C. October 2000.

Reinhard, S. and Farnham, J.: *Indiana's Efforts to Help Prevent Unwanted Nursing Home Residence*. Rutgers Center for State Health Policy, New Brunswick, N.J. February 2006.

www.aarp.org/research/longtermcare

www.cashandcounseling.org

www.cms.hhs.gov/HCBS/downloads/qualityframework.pdf

www.cms.hhs.gov/HCBS/02_QualityToolkit.asp

www.cms.hhs.gov/independenceplus

www.cms.hhs.gov/NewFreedomInitiative

www.dads.state.tx.us

www.mathematica-mpr.com/disability/cashandcounselingpubs.asp

www.ncbcapitalimpact.org

www.paraprofessional.org

CHAPTER 3: Recommended Goals and Action Steps

Goal #1

By 2010, the state will have a single point of entry system established to enable consumers to go to a centralized, neutral source of information and assistance which also provides preliminary screening for services, eligibility, assessment of functional and financial capacity, service authorization, monitoring and reassessment.

Current Issues

Although there is a 211 system that has been established to provide referral services, it has not been well publicized and it provides only the first level of information to consumers. This would give consumers additional referrals for more information rather than actually assistance in obtaining services. Additionally, the Bureau of Senior Services has established eight Aging and Disability Resource Centers in different counties in the state to provide a one-stop shop for consumers to locate services. This is modeled after the concept of one-stop service centers and can ultimately be an important aspect of the long-term care system. The Bureau has also placed many resources on their website. There needs to be growth of these programs and a strengthening of the services available at these sites. There are also family resource networks in each county that were established to coordinate services. However, their ability to assist those in need of long-term care services is inconsistent throughout the state.

Recommended Actions

1. The single point-of-entry system (SPE) should be developed by building on the resources available through the existing Aging and Disability Resource Centers. The system should allow consumers access to centralized sources of neutral, helpful information through electronic means such as a web site, toll-free telephone lines and through face-to-face communication. Individuals should receive tools to do a self-assessment of need for service, in addition to having an in-person individualized assessment. The individualized assessment should focus on individuals and their support systems and concentrate on both strengths and needs. The result of the assessment should also include a focus on what services could be provided by family and friends and what services could be supplied by the government or other private providers.
2. It is recommended that the Bureau of Senior Services more fully develop a web site which includes a comprehensive data base of available services and providers by community and region and which contains helpful neutral information about long-term care services. In addition, the web site should contain useful tools which people can use to determine need for services and potential eligibility for public programs.
3. It is recommended that a toll-free number be established to complement the web site and that the telephone line be staffed 7 days a week and at least 12 hours a day. State and local agencies must also be available to consult with people

needing information on a face-to-face basis.

4. It is recommended that all state agencies paying for or providing long-term care services be required to conduct needs assessments that focus on the strengths families and consumers bring to their care situation. Long-term care consultations should be given to all individuals who request help, regardless of whether they are qualified to receive public services.
5. The single point-of-entry system should be a place to meet the needs of all individuals with disabilities who need assistance. It should be a centralized, neutral and trusted source for information about available long-term care services and services should be available to determine eligibility for a wide range of publicly funded programs including Medicaid, food stamps, housing, transportation, employment and energy programs and assistance. The SPE should be able to conduct both financial and functional assessment of eligibility wherever individuals need them. Often eligibility determinations are needed at hospitals and other institutions.
6. It is recommended that state agencies develop a single point-of-entry system, and the technology to support that system, where people can find out whether they qualify for public support for a wide range of programs including Medicaid, food stamps, housing, transportation, employment and energy programs and assistance. Eligibility workers need to be able to travel to places

where people need that information to support crucial life decisions and to support a hospital or nursing facility discharge process. People should know on a timely basis whether they will be eligible for public support and this would include making eligibility determinations using a presumptive eligibility process. This function will require that all agencies that determine eligibility will have to work together to advance the current system to a stage at which it is more user friendly and more open to those who need the services.

7. The single point-of-entry system must utilize all available means to gather useful and sufficient neutral information and tools which assist people in the planning and delivery of long-term care services. People should be able to access information electronically, by telephone or in-person, and that information should be available not only at government offices, but at doctor's offices, hospitals, care facilities and other public and private places. The single point-of-entry must do active and aggressive outreach so the public can use this vital information at times and places that are convenient to them.
8. The single point-of-entry system should be the place where a plan for services and supports is developed, whether or not that plan involves public funding. If the plan involves public funding, the SPE should be able to develop and receive approval for starting services in a timely manner. It should also have the responsibility for ensuring that high

quality cost-effective services are delivered and that consumers are satisfied with their services. Whenever appropriate, consumers should be reassessed to ensure that existing services are continuing to meet their needs.

Goal #2

By 2009, require and implement person-centered planning throughout the long-term care system. Person-centered planning means a process for planning and supporting the individual receiving services that builds upon the individual's capacity to engage in activities that promote community life and that honors the individual's preferences, choices, and abilities. This process involves families, friends, and professionals as the individual desires and requires.

Current Issues

Although there is a perception that the state does person-centered planning now, many on the Task Force believe that decisions are ultimately made based on the services presently available in each community rather than on the needs of the individual. Because of the structure of services, those who need long-term care are often required to take services that they do not need to get the services they do need. As the authorizers of service and payment, professionals have the power to drive the care planning process. In some LTC settings, care conferences are held without the presence of the person receiving care. It is critical that the consumer be an active participant in organizing their care.

This Administration has made great efforts to provide options for consumers. Medicaid

has an Options program that gives consumers the ability to manage their own care and to hire and fire their own caregivers. Other programs in the state have worked to enable consumers to leave nursing homes and move back into the community with the needed supports. Approximately five years ago, legislation was passed to authorize a change in the Medicaid program that allowed people with disabilities to go to work and pay for Medicaid on a sliding scale which has enabled over six hundred people to go to work and pay for their Medicaid coverage. Another program supported by the administration for many years is the Specialized Family Care Program which was created to support persons who were deinstitutionalized as a result of a court case. Over three hundred West Virginia families have taken these individuals into their homes and care for them and make them a part of a loving and supportive family.

These are positive efforts that need to be duplicated statewide. The task force believes that the individual receiving services needs to be the central figure in deciding what is needed and flexible services need to be provided based on those needs. Some believe that the words "person centered care" are often used but that the real meaning of the concept is not completely understood by those who are decision makers in this process.

Recommended Actions

1. All state government agencies administering long-term care services should convene a working group including the elderly and individuals with disabilities and their families and service providers to research the way long-term care planning is currently conducted in all

state programs. The group should focus on consumer and family participation in the planning process and the process by which decisions are made about what services are authorized.

2. Based on its research and study of best practices in other states, the working group should recommend a new system of care planning and service authorization which focuses on the needs and preferences of the individual receiving services and is not limited to a specific prescribed set of services. The group should also research and recommend additional options for individuals to choose self-directed services programs, which have been proven to give more service flexibility to the consumer and improve consumer satisfaction and outcomes without costing additional money.
3. Once adopted, state agencies must sponsor training in the new person-centered care planning process so that all administering entities, consumers, families and providers understand the process and the outcomes it seeks to achieve.

Goal #3

On an ongoing basis, the public and private sector shall work cooperatively to strengthen the availability of needed long-term care services so that the full range or continuum of services is available to all citizens.

Current Issues

There is no single agency responsible for the creation of new long-term care services or

systematic way to assess gaps in the system, and study trends. Various entities are now conducting studies of unmet needs, but the lines of responsibility are unclear. These responsibilities need to be clear and supported by the Administration. Resource development works most successfully at the local level and then moves to the state level. A more coordinated approach would be helpful to the development and financing of LTC services. The Long-term commission should work to clarify the lines of responsibility in developing new services based on community needs.

Recommended Actions

1. State government should complete a state survey, by geographical region, of all available long-term supports and services needed by individuals with disabilities of all ages. Government should then adopt a methodology to determine adequacy of services and supports based on populations in geographical regions. Services and supports should include all long-term care services provided in both public and private sectors and include housing, transportation and employment. Government should then have a detailed list of where the supply of services is inadequate to meet the needs of people, by region. Regional entities should be established by the long-term care commission to gather the needed data and to appropriately plan for the future of each region.
2. It is recommended that the Bureau of Medical Services examine the services offered under the Medicaid Aged and Disabled Waiver and to add those services necessary to keep people independent and living in

their own homes. The Bureau should at least consider adding personal care, home modification and respite services to the Waiver.

3. The Bureau of Medical Services should also consider utilizing the Deficit Reduction Act opportunity to offer home and community-based services as a Medicaid State Plan service for people who have lesser needs than an institutional level-of-care, but are at risk of unnecessary institutionalization.
4. The Bureau of Medical Services is strongly encouraged to look at bringing the PACE model to the state. This will create additional opportunities for individuals with special needs to receive the services they need in their local community. The concept of PACE is the creation of an all inclusive community for the elderly to continue to live in their community with whatever supports are needed. This model could be an important training opportunity to assist in establishing a coordinated system of care.
5. The Bureau of Medical Services must develop a coherent and consistent strategy and practice to encourage and pay for the delivery of tele-health services. In the long-term care area, tele-health could be used to support independent living for people in their homes by use of electronic monitoring, telephone consultation and other electronic communication.
6. It is recommended that the Governor assign responsibility for provider recruitment to a specific entity

within state government. That entity should engage public and private sector providers and provider associations, provider training institutions and consumers in addressing the issue of adequate supply of services. Local public and private entities should also be engaged because many service providers only operate within a specific region of the state. Future needs for services must also be studied and planning must be accomplished to meet those needs. The Governor shall receive reports from this entity on an annual basis.

7. It is recommended that there be established a Long-Term Care Commission within state government which would include agencies with responsibility for long-term care services. It should include housing, transportation, employment and education departments. Accessible and affordable housing is a key to supporting people's long-term care needs in their own homes. People need transportation not only to get to medical appointments, but to remain integrated in their local community. Employment, whether paid or volunteer, both encourages independence and the mental stimulation needed to maintain and improve health. Education is vital not only for the person receiving care, but their families and other providers who are needed to support their independence.

Goal #4

On an ongoing basis, the public and private sector will support, implement and sustain prevention services to improve the quality of life for people with

disabilities and elderly people and to delay the need for long-term care services.

Current Issues

Strong prevention and chronic disease management programs are critical to preparing the aging and disabled population for healthy lives for longer periods of time and to postpone the need for long-term care services and lessen the extensive nature of the need for long-term care services as they arise. West Virginia is known as a state with a high incidence of chronic disease, obesity and elderly and disabled individuals. Research continues to place the state in the bottom three in most of these areas. Research also indicates that healthier lifestyles can impact the future needs of our population in the area of long-term care.

The Governor has recognized the importance of healthy living by his Healthy Lifestyles initiative. In July of 2005, the Legislature, in collaboration with the Governor, established the Healthy West Virginia Program in the Office of Healthy Lifestyles. The purpose of this new office is to assure consistency of the public health and private sector approach to dealing with programs that address the problems that affect overweight individuals, to provide a forum for discussing the issues that affect healthy lifestyles and to identify best practices to be replicated in the state. Further, the intention of this initiative is to have a broad comprehensive approach to improving the health of the citizens of the state through an organized collaborative approach for both the public and private sector. This is definitely a good starting point to bring consistent attention to the need to improve lifestyles and thereby, improve the health of the state.

Obviously, there is significant progress towards the goals of the Healthy West Virginia Program. Yet there continues to be a lack of healthy lifestyle programs for the disabled community throughout the state. There is no organized system of chronic disease management in the state and there is only a rudimentary beginning of the real need for each region of the state to make healthy living not only a health, but economic goal of the area. The ability to focus on creating a healthy environment for all of our citizens will be a challenge for years to come. Until there is major progress in this direction, there will be a continuing need to expand services and make available all of the support services needed for the elderly and disabled population, which, as previously indicated, is a growing percentage of the population in this state. It only makes good sense to really spend time and money on developing healthier communities which will have a long term and significant effect on the long-term care services needed in the future.

Medicaid does not support preventive health programs extensively, although with the passage of the Deficit Reduction Act of 2005, the federal government has certainly empowered states to reevaluate their programs and to focus on personal responsibility even in the early years of development. West Virginia has been one of the first states to take this challenge through their Medicaid redesign. This program places expectations on enrollees to be active participants in their care, establishes medical homes for the participants to have a team of providers focusing on improving health, and rewards participants who do take responsibility for their medical care. With these changes, there is a strong motivation to change the focus to prevention and early intervention rather than the more expensive end-of-life care services.

Recommended Actions

1. Direct the Healthy Lifestyles Coalition and all providers of health care services to provide incentives for local collaborations, including public health and the medical community, to actively promote healthy aging through preventive and chronic care for all age groups.
2. Develop and implement legislative and administrative initiatives to provide financial and other supports to caregivers to sustain natural caregivers.
3. Educate all community movers and shakers about the importance of early intervention and prevention with model programs made available after a nationwide review of best practices through the Healthy Lifestyles Coalition, the Bureau of Senior Services and the Bureau of Public Health.
4. Offer continuing education courses to educate the educators, the church leaders, the provider community and the public on how to bring healthy lifestyle opportunities by providing education and well developed programs to anyone in the state who is interested.
5. Ensure that as new communities are built, there are basic design components of every healthy community which include walking trails, biking trails, healthy foods and more.
6. Direct the Healthy Lifestyles Coalition to establish task forces to specifically develop programs for those interested in long-term care issues and how to include the elderly and people with disabilities in all of their planning efforts.
7. Request the legislature to make strong efforts to assure that funding is earmarked for "low end" or "light" long-term care services that can prevent both the elderly and people with disabilities from needing more extensive and costly long-term care services later. The governor recently earmarked seven million dollars to provide services to those who are not nursing home eligible but who have some basic service needs to prevent more extensive problems. This is an important step in the right direction and should be studied and expanded if the purpose proves successful in enabling more people to live in the community.
8. Request that the West Virginia Public Transit Association develop a plan to assure that transportation will be made available to the those with disabilities and the elderly for medical visits and other needed services as finances permit as a strong step towards preventing unnecessary complications from disease.
9. Promote the use of assistive technology for consumers and direct care workers/caregivers as a prevention tool.
10. Develop and implement chronic care protocols, including, but not limited to:
 - a. identifying abuse and

neglect, caregiver burnout and develop intervention strategies;

- b. Medication usage and the most effective strategies to assure safe administration in home and community-based settings and institutional settings when necessary; and
 - c. identifying chronic care management protocols that are considered models nationally that focus on health and save money.
11. Request that public health entities develop a broad based campaign focused on preventable illness targeted to older adults and also focused on resources available in the community that can assist in developing a healthy approach to living.
12. Require all state agencies to examine their existing programs to ensure that there are sufficient resources to enable people to make their homes accessible for their changing needs, to create community services to promote independent living and to assure that community settings are available for those who want congregate living.

Goal #5

On an ongoing basis, promote meaningful participation by consumers, their families and other interested parties by establishing a broad based LTC team both at the community level and at the state level authorized by the state health

plan on which there is active participation by consumers, families and interested parties in developing the LTC system as benchmarks are identified and achieved and goals are met and revised.

Current Issues

Currently there is no single entity which coordinates all long-term care activities in the state. In order to create a long-term care system based on consumer choice and control, consumers and their representatives must have a meaningful role in the development and oversight of a variety of programs located throughout state and local government. In West Virginia, although there are many efforts to have consumers represented on various boards and commissions, there is a continuing belief on the part of many consumers that their voices are not always heard. As discussions take place about person-centered care, an often-used phrase by funders and providers, there is a question about whether these interested individuals really understand the concept.

Because of the rural nature of the state and the geographic barriers that exist, many believe that the needs of certain geographic areas are quite different than other geographic areas and that these differences need to be considered during the decision making process to establish needed services. For example, Area Agencies on Aging in each county can have vastly different services as the needs of the local communities are considered.

Recommended Actions:

- 1. Establish regional long-term care task forces that are organized with the local providers and full representation of consumers and their families who are directed to

- review existing consumer surveys and do new surveys to establish what the primary needs of the communities are in the region as a starting point.
2. Establish a coordinated system of care with linkages between all services to make movement between the services seamless.
 3. Create a West Virginia Long-Term Care Commission at the state level with representation from all six regional task forces and all stakeholders in the system. The commission shall be appointed by the Governor and shall include representation of the regional task forces, fourteen consumers of which 50% are primary consumers and 50% are representatives of consumer organizations, seven provider organization representatives, three direct care workers and one member with expertise in long-term care research from a university. The Governor shall choose a member to chair the Long-Term Care commission. In addition, the Commissioner of the Bureau of Medical Services, the Director of the Bureau of Senior Services, the Commissioner of the Bureau of Behavioral Health Services, the Director of the Developmental Disabilities Council and the West Virginia Ombudsman shall be ex-officio non-voting members. The commission shall have the authority in partnership with the executive branch to do the following:
 - a. Develop and recommend policy regarding LTC programs including a public awareness and education campaign;
 - b. Participate in the development of the budget for the long-term care system and ensure that the budget supports the policies developed by the commission and work on the same with the Legislature;
 - c. Monitor spending and the budget implementation to make sure expenditures match policy decisions;
 - d. Help develop and approve quality assurance measures for the long-term care system;
 - e. Work diligently to rebalance the long-term care system;
 - f. Establish working groups on topics as the need arises to develop a comprehensive response to an identified need; and
 - g. Establish benchmarks to measure progress towards the established goals.
 4. Request that a small staff including an executive director, an analyst and a secretary be hired to carry on the work of the commission and coordinate their efforts. Consider funding this office with money earmarked for LTC in the recently passed table games bill.
- a. Develop and recommend policy regarding LTC programs including a public

Goal #6

In addition, develop and implement a

consumer education program that educates the public about long-term care issues, available resources and the ongoing need for planning by consumers and their families.

Current Issues

Currently, there are a number of efforts to educate the public about the importance of planning for long-term care needs in the state. AARP has a number of long-term care education programs. The Bureau of Senior Services offers educational programs and the Governor holds regular seminars on Aging each year to encourage planning and preparation for future needs. Programs to help consumers make LTC planning a common practice are not yet built into the curriculum for schools to assist young people to think about and prepare for the future. Often individuals make no plans until the need arises and then become dependent on others to take responsibility.

Recommended Actions

1. Increase awareness among consumers, future consumers, and other community organizations. Other community organizations can access information from a single point of entry system and consumers can choose from the array of long-term care services to support their needs from a person-centered planning process.
2. Assure that state employees involved in long-term care are provided mandatory training on the array of long-term care supports available, options for consumers to direct and control their care, and the importance of person-centered planning.

3. Provide orientation to legislators and their aides on the array of long-term care options and the value of person-centered planning.
4. Create and establish criteria for educational programs for children and adults to learn about the aspects of long-term care.
5. Develop and implement Disability History Week curriculum about long-term care.
6. Electronic resources should be made available so that people can get more information about how much money is needed to provide long-term care for themselves and the family making estimates based upon age and health status.
7. Develop an RFP to hire a marketing firm to develop a marketing and public awareness campaign, including web site design, toll free telephone number, public service announcements, print ads, brochures, and other educational materials that highlight the array of long-term care services available, the single point of entry, and providing information stressing available services to keep people independent and living healthy lives at home.
8. Establish criteria for the service providers that provide continuing education for a licensing and certification.
9. Request that the Legislature consider ways to provide incentives to citizens of the state to purchase long-term care insurance so that there will be more private funding available to

the system.

Goal 7

By 2010, establish a quality management system that's primary consideration is the evaluation of the person receiving supports and the desired outcomes.

Current Issues

Although quality is an important consideration in most programs that are offered in West Virginia and there are effective quality standards in some programs, there are not in others. A more systematic quality program developed with input from consumers and stakeholders that can be applied to all programs in the state would be of real benefit to the value of the system.

Recommended Actions

1. All state government agencies administering long-term care services should convene a working group including individuals needing long term care services and their families and service providers to research which person-centered quality measures are currently being utilized in various delivery systems, how they were developed and how they are used to measure and improve service quality.
2. Based on its research and study of best practices in other states, the working group should then recommend a quality system which focuses on evaluating whether the services delivered met the individual outcomes identified in the person-centered care plan.

3. The working group should research and recommend a quality system which directly asks consumers about the quality of the services and whether those services have met and are meeting their needs.

Goal #8

On an ongoing basis, develop a coordinated approach to all oversight by streamlining and integrating rules to assure the highest practical physical, mental and psychosocial wellbeing of the individual with a focus on outcomes.

Current Issues

Although there are many rules and regulations that have been developed over time in West Virginia, there continues to be competing regulations and in some cases inconsistent regulations that place providers in a quandary. There is a need for the oversight body to evaluate all rules and make them consistent and focused on quality. One set of standards needs to apply to each type of service so that the application is consistent and easily understood. The need to decrease unnecessary oversight will enable providers to focus on service and quality.

Recommended Actions

1. It is recommended that the long-term care commission establish a group to review state rules governing the provision of long-term care services in the state. The review should focus on which agencies regulate which services and the process used for that regulation. Focus should be placed on recommending ways to streamline existing regulations so that providers, consumer and other

stakeholders all understand what is expected from them and that regulations are focused on specific outcomes which benefit consumer health and well-being. There should be additional focus on ensuring that the outcomes for the regulations are consistent within and across state agencies.

2. It is recommended that state agency long-term care regulations include outcomes which focus on practices which ensure that consumers achieve the highest practical physical, mental and psychosocial health. The regulations should provide that system performance should be geared to helping consumers achieve individual person-centered plans.
3. It is recommended that the state's long-term care quality management system comply with the quality assurances given to the federal government and that consumers be regularly surveyed about the quality of the services they receive.
4. It is recommended that state entities which regulate and pay for long-term care services develop a system where providers know what is expected and are rewarded for excellent performance.

Goal #9

By 2009, develop and implement career building strategies to attract and recruit into LTC careers an increasing number of capable, committed workers and to retain the capable workers currently in the system with a focus on the development of this critical profession. In addition, develop needed supports for

informal caregivers to maintain their important role in long-term care services.

Current Issues

There is a huge concern that there is an inadequate number of workers to perform the needed services for long-term care. On a national basis there is a real concern about the number of trained professionals in this field. Working in this field is hard work and being able to advance is not always easy. There have been many studies in the state on the needs of long-term caregivers and what will make the professions more attractive. Currently there is one long-term care associate degree program in the state. Much work is needed in this area and it needs to be an immediate focus to decrease the expected shortages from occurring. Improving LTC worker retention to relieve current and future worker shortages, reduce labor-turnover costs and provide quality care and supports is essential. Salaries need to be competitive and working conditions need to improve. There are many ideas available and there needs to be a concerted effort to improve the career opportunities in this area.

Recommended Actions

1. It is recommended that the Long-term care commission in collaboration with other interested parties sponsor a campaign to focus on recruiting capable and committed workers to employment in long-term care giving, while stressing the importance of families in supporting individuals with needs of all ages. Workers are needed in all areas of long-term care and the campaign should focus on the growing opportunities to work in this field in a variety of settings. The campaign should use a variety of media to

reach potential workers including television, print and electronic advertising.

2. It is recommended that the long-term care commission convene representatives of educational training institutions, employer associations and labor unions, state and local government workforce entities, provider associations and consumers to help design and implement programs to increase the supply of needed workers. Candid conversations must be encouraged about wages and benefits, opportunities for advancement, education and training, workplace improvement, mentoring and management.
3. There is a major need for care givers to be educated about the needs of Alzheimer patients who have specialized care needs. There is a large population of Alzheimer patients who are currently struggling to find appropriate services in their own communities. Many community settings are not structured to deal with these patients due to their lack of training in the area. Many residents of facilities are being asked to leave due to their behavior which is not currently controlled in appropriate ways. This necessitates extensive training for providers and care givers to that these services are more readily available throughout the state.
4. State government must support this campaign by implementing programs to increase the supply and quality of paid care givers. Long-term care programs must ensure adequate

compensation and continued training and education for paid care givers through administrative rules and/or provider payment. Educational institutions must afford opportunities for training and continued education and schools should have curricula focused on the growing need for long-term care and the employment opportunities within the care giving profession.

5. State government must also support the campaign by developing more programs to support informal care givers. Unpaid care givers need services such as relief care (respite), education and training and support groups; however, they also need to be appreciated and supported in other ways. In addition to public media thanking family care givers, surveys should be completed of care giver needs throughout the state.

Goal #10

By 2009, begin the adaptation of financing structures that support a new system in a more equitable manner with more support of individuals having choices in the type and location of their care.

Current Issues

Funding the long-term care system is a challenge. There are many sources of funding but it is not coordinated in a rational manner. As the chaotic system becomes more functional, it is essential to better coordinate funding sources and fund those services that have been identified and are really needed. If people plan for their futures, there will be more private dollars available to support the system instead of

the significant dependency on state and federal dollars. Pulling resources into a system will be a challenge but will improve the currently fragmented system. As the Long-Term Care commission works to provide a coordinated system that is user friendly, the Legislature will have a roadmap to consider when making funding decisions.

Recommended Actions

1. The Bureau of Medical Services should enact a process of presumptive eligibility for long-term care services. This would require a determination that an individual is functionally, or medically eligible for services and would likely be financially eligible pending a further examination of income and assets with a provision for proper recoupment of funds if not eligible.
2. Government should continue to expand the opportunity for individuals to direct their own services and to make service choices based on an individualized budget.
3. Preference for funding of home and community-based services should be given.
4. Counseling and fiscal services must continue to be developed to ensure that the individualized budget system is supported and available to the largest number of eligible individuals.
5. Government should consider ways to maximize local match to capture additional federal Medicaid dollars for long-term care and supports.

6. Legislation should be enacted that promotes the purchase of long-term care insurance policies, including the provision of tax credits and tax deductions for the purchase of long-term care insurance policies for out of pocket costs.
7. The state must make a commitment to reinvest all dollars realized from cost savings identified within the long-term care system back into long-term care supports and services.

Goal 11

By 2009, require and implement person-centered advance care planning throughout the long-term care system. Person-centered advance care planning means a process for educating the person and family about end-of-life care options and offering assistance in completion of advance directives and the Physician Orders for Scope of Treatment form based on the person's preferences. This process empowers the individual to make informed choices about future medical treatment options while the person retains the capacity to decide what he or she wants. It honors the individual's preferences, choices, and abilities. This process involves families, friends, and professionals as the individual desires and requires. For persons who no longer possess decision-making capacity, planning for future medical contingencies is to be conducted with the person's medical power of attorney representative or health care surrogate based on the person's expressed wishes or, if these wishes are unknown, the person's best interest.

Current Issues

Although West Virginia has been acknowledged to have excellent health care advance directive forms, the majority of West Virginians have not completed them. The failure to complete them means that patients are likely to receive the default option in the health care system: aggressive treatment at the end-of-life that results in the patient dying in an intensive care unit on a breathing machine unable to communicate his or her wishes. Research shows that most West Virginians do not want this default option. Repeated surveys of West Virginians indicate consistently that three-quarters of state residents would prefer to live a shorter period of time rather than endure pain, suffering, and being kept alive on machines. These same surveys reveal that West Virginians by a large majority prefer to die at home. Currently the majority of West Virginians die in the hospital. There are only about 10 other states that have such a high percentage of citizens dying in the hospital. Just as options counseling provides knowledgeable L.C. specialists working with individuals and families to examine L.C. service choices, residential settings and financing, the same concept could be used to implement an advance care planning approach so that persons can learn about their options for end-of-life care and make informed choices while they still have the capacity to do so. Providing advance care planning in this way coordinates the health care preferences, needs, and treatments of the individual throughout the care system, rather than allowing the continuation of a fragmented series of encounters or episodic treatments, that is often the case for residents in L.C. settings at present.

Recommended Actions

1. It is recommended that a working group be convened including

representatives from the West Virginia Center for End-of-Life Care, the Bureau of Senior Services, the West Virginia Health Care Association, the state ombudsman program, and the Hospice Council of West Virginia to research the extent to which advance care planning is currently being conducted in L.C. facilities and by whom.

2. Based on its research and study of best practices in other states, the working group should recommend a new system of advance care planning which focuses on the needs and preferences of the persons residing in L.C. facilities.
3. It is recommended that the West Virginia Center for End-of-Life Care be allocated appropriate funding to provide training to health care professionals, including physicians, physician assistants, nurses, social workers, ombudsman, and others, with regard to the recommended practice of person-centered advance care planning so that this process is available to all residents in L.T.C. facilities in West Virginia.

Appendices

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Vision Shared Long Term Health Care Team-Continued

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