

Principles of the Ideal Long-Term Living System for Pennsylvania's Older Adults



The Southwestern Pennsylvania Partnership for Aging (SWPPA) is a 30+ year old, volunteer-led organization with a mission to serve as a catalyst to promote policy, program and systems change that improves the quality of life of older adults. SWPPA was created as a neutral forum for collaboration, information sharing, discussion and formulation of aging policy recommendations. Members include organizations and businesses, as well as individual members such as civic leaders, business owners, medical professionals, scholars, professionals in aging services, students and residents of all ages.

Principles of the Ideal Long-Term Living System for Pennsylvania's Older Adults

The Ideal Long-Term Living System for Pennsylvania's Older Adults Must Be...

1. Person-Centered
2. Able to Acknowledge that Risk Exists While Supporting Maximum Independence
3. Focused on Quality of Life and Quality of Care
4. Simple to Understand and Access
5. Coordinated, with Seamless Transitions through a Comprehensive Array of Services
6. Focused on Prevention, Wellness and Early Connection to Home and Community Based Services
7. Vested in a Viable and Competent Direct Care Workforce
8. Focused on Continued Learning and Quality Improvement
9. Financially Feasible and Encourage Public/Private Participation

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About the Southwestern Pennsylvania Partnership for Aging (SWPPA):

The Southwestern Pennsylvania Partnership for Aging (SWPPA) is a regional coalition of individuals, organizations, and businesses who are committed to the well-being of an aging population. In keeping with SWPPA's mission to serve as a catalyst to promote policies, programs and system change which will improve the quality of life for older adults, the purpose of this work is to initiate a dialogue across Pennsylvania about long term living. Although this document focuses on older adults, we hope to open discussion across Pennsylvania among the stakeholders in the long-term living system.

Currently, Pennsylvania's long-term care system is broken and changes are underway in Harrisburg to rebuild a more comprehensive and workable long term care system. Yet, little has been explicitly offered as the principles on which such a system should be based. This document proposes nine (9) principles which need to underlie any new, ideal Pennsylvania long term living system, and are based on the work of SWPPA's Futures Work Group.

Principle - a fundamental truth... or motivating force;

a rule of conduct, especially of right conduct

-Webster's New World Dictionary of the American Language

The Ideal Long-Term Living System for Pennsylvania's Older Adults Must Be...

1. Person-Centered

An ideal long-term living system must first and foremost advocate for the individual dignity, autonomy and choice of elders and support their right to make their own decisions directly or, when necessary, through their advocates. Each older adult has a unique history, preferences, needs and values and should access long term living services in a person-centered model that promotes optimal quality of life as defined by the individual his/herself.

Person-centered care is a philosophy and practice which promotes quality of life. It affirms the whole person—the physical, emotional, intellectual, social and spiritual dimensions and focuses on the person's preferences and abilities, while ensuring dignity and supporting independence. Person-centered services require stakeholders to put the quality of life of the older adult first, which occurs by knowing the whole person,

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including his or her strengths and abilities and not just limitations, illnesses or disabilities. From physicians, to hospitals, to long term care facilities, to community-based service providers, to government, to funders, to family caregivers, the long term care system will have to undergo significant philosophical discussions and practice changes to embrace person-centered care. Only with these discussions and practice changes can we transform the present institutional/provider/funding driven model into a service system that truly centers on the individual.

2. **Able to Acknowledge that Risk Exists While Supporting Maximum Independence**

The ideal long-term living system upholds the principle of Person-Centered care by acknowledging the inherent risks, challenges and opportunities of self-determination.

The long-term living system in Pennsylvania should support older adults, families and long-term living providers that are willing to perform true risk management. Alert and oriented older adults may make decisions that are not in their best interests from a professional point of view but exemplify the older adult's idea of "quality of life." In the current system, many providers are afraid to allow for risk because of fear of lawsuits, punishment and negative media attention.

Stakeholders must also acknowledge the reality of declining mental and physical capacity in some older Pennsylvanians and the resulting risks of serving these individuals in the long-term living system. To uphold the principle of Person-Centered care, the system must recognize that some seniors, especially those with Alzheimer's disease or other dementias, need long term care due to safety issues, not physical limitations related to chronic medical conditions. Those living in the community with dementia are often the most difficult to serve with home and community-based supports. In some cases, aging service providers must assist seniors and their circles of support to consider and mitigate the risks of living independently. This includes assisting and sometimes taking the lead on navigating the various support options as an individual moves through the ranges of independence, interdependence and dependence while always seeking to achieve maximum quality of life and quality of care at each stage in the process.

3. **Focused on Quality of Life and Quality of Care**

The long-term living system would consider both quality of life and quality of care in the ideal system. Quality of life is a highly individualized experience that cannot be generalized across an entire population. Because quality of life is highly subjective and

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is sought by older adults, their caregivers and service providers, person-centered care as described in Principle #1 is paramount.

The Institute of Medicine defines Quality of Care as “the degree to which health care services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge.” Quality of care in long term living requires that services provided are comprehensive, consistent, coordinated, and reliable, having measurable outcomes. Consumers whose quality of life depends on the services they receive must be confident that the long term living system understands the need for both quality of life and quality of care. Provider staff competence is essential to high quality care. They must understand current standards of care and be proficient at delivering those services. Staff must also focus on continual improvement as standards of practice change. A long-term living system with high quality care not only supports consumer safety but also meets and strives to exceed consumer expectations.

The issues of quality of life, including the value of the individual's experiences and relationships, along with quality of care, including clinical aspects and knowledge, are interdependent and both must be present within the ideal system.

4. Simple to Understand and Access

An ideal long-term living system should be simple to understand even in the midst of a crisis, which is when many older adults enter the system. At present, Pennsylvania's health and long-term living system is confusing and difficult to navigate. When older people, their families or other advocates seek information or long-term care services, they often face new terms/language and a complex system of public and private options which are administered by a wide variety of providers operating under different, and sometimes conflicting, regulations and administrative procedures.

State government must eliminate the fragmented system that currently exists. An integrated approach to long term living should exist at local levels that directly impact a consumer's experience with accessing and navigating long term care. The importance of planning ahead for long term living must be emphasized as essential to facilitating access to services when they are needed. In recognition that most people will not plan in advance for long term living needs and will seek services during crisis, an immediate response, clear options, accurate information about the older adult's (and family's) rights and responsibilities and prompt access to services are essential.

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5. Coordinated, with Seamless Transitions through a Comprehensive Array of Services

Older adults should be able to access the services they need, when they need them, in the place they call home. Fragmentation of the long-term care system has a huge impact on both cost and quality. This collaborative approach requires fluidity and coordination of care by consumers, funders and providers of services, with minimal interruption in the flow of services received as seniors move throughout the long-term living system. To achieve this, current barriers such as confusing or over-burdensome eligibility requirements must be eliminated; providers across the continuum of care must work together to coordinate their services around the needs of each individual rather than around the needs of their individual organizations; and state government and regulatory departments must identify and tear down program "silos" that result in contradictory service provision and regulations.

6. Focused on Prevention, Wellness and Early Connection to Home and Community Based Services

The ideal long-term living system must focus on prevention. Most long-term support needs emerge from chronic conditions and injuries suffered as a result of a fall or other accident. Today at least 80 percent of adults 65 and over have one or more chronic conditions that can lead to serious illnesses and disabilities which dramatically raise health care costs.¹ While lifestyle changes and disease management can lessen the effects of disease, the current formal system of aging and long term care emphasizes reactive medical care and support services over wellness and prevention.

Public policies and in effect reimbursement and other financial incentives must begin to focus on wellness and support prevention. Prevention is not financially supported in the current system and has not been a top priority. Wellness programs are often simple and effective, but they require increased community awareness and financial incentives for participation. Technology can play an important role in these efforts. Once a shift from a reactive to a proactive health and social service system is embraced, both significant quality of life enhancements and significant monetary savings can be realized.

¹ U.S. Administration on Aging Strategic Action Plan 2007-2012, p.11.
<http://www.aoa.gov/about/strategic/AoA%20Strategic%20Action%20Plan%202007-2012.pdf>

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7. Vested in a Viable and Competent Direct Care Workforce

A viable and competent direct care workforce is a core component of the ideal long-term living system. Direct care workers are the cornerstone of any long-term living system's success. Seven out of ten elder service workers in long term care are direct care workers. In the non-acute setting, eight out of every ten hours of paid services are not for doctors or nurses, but for direct care workers.² In the ideal system, providers could offer direct care workers a fair, living wage, basic benefits such as health insurance and paid time off, and opportunities for advancement and growth. The reality is that direct care workers within long term care settings are leaving the long term care system in large numbers—some 70 percent annually in nursing homes and 40-60 percent in home care.³ Home care providers across the system struggle to compete with acute and residential care as well as unrelated industries like retail and fast food for a shrinking pool of workers. With present reimbursement rates, providers simply cannot afford to offer comparable pay and benefits. To ensure an effective aging service workforce for the future, both state government and providers must invest in the workforce in the following ways: provide skills-based training to ensure workers have clinical and relational expertise to support the consumer, offer supportive work environments that include supervisors who set clear expectations and require accountability, offer a living or family sustaining wage, offer affordable health benefits, and provide connections to community services and public benefits.

8. Focused on Continued Learning and Quality Improvement

Government, all aging service providers and elders must embrace continual learning in order to respond and adapt to the constant changes in the long-term living environment. Continued learning and quality improvement will lead to growth and progress for providers and government, which ultimately benefit the older adults that long term living programs support. All stakeholders, including consumers, providers and government, in Pennsylvania's long-term living system should collect data to measure service outcomes and conduct surveys to assess consumer and worker satisfaction. The results should be used to improve services. Data that is already being collected by state government should be made available to long term living service consumers and providers for use in decision-making. Providers that achieve exemplary performance should be recognized.

² Recruitment and Retention of Paraprofessionals, Presentation to the Institute of Medicine's Cmtee on the Future of Healthcare Workforce for Older Americans, by Steven L. Dawson, Ph.D., President, Paraprofessional Healthcare Institute on June 28, 2007.

³ Ibid.

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9. Financially Feasible and Encourage Public/Private Participation

The ideal long-term living system should be financially feasible for both consumers and government. Pennsylvania faces a tremendous challenge in serving the needs of its rapidly expanding aging population. There are many deficiencies in the current long term living system including lack of person-centered practice, no formal acknowledgement of risk, lack of focus on quality of life and quality of care, significant barriers to understanding and accessing long term living, lack of a coordinated system with seamless transitions and a comprehensive array of services, lack of focus on prevention, inadequate direct care workforce in both numbers and competency and lack of focus on continued learning and quality improvement.

It is essential that fiscal concerns do not take preference over the other principles outlined in this document. When facing a financial crisis, the standards for evaluation for programs can be skewed or influenced too much by cost, placing quality at risk.

Creative thinking and new approaches are essential and should involve all stakeholders in long term living, encourage prevention and establish a level of personal accountability for long term living needs. Pennsylvanians should be expected to plan and pay for their own long-term living needs to the fullest extent possible. Innovative efforts around long term care insurance, such as the Long-Term Care Partnership with tax incentives for those who obtain long term care insurance, may be a key component of a longer-term solution and should begin in Pennsylvania as soon as possible.

Despite best efforts, personal responsibility will not be enough to fund the long term care services that some individuals need. This is when Pennsylvania's publicly funded long-term care services need to step in so that eligible persons who need help can receive the services they need, when they need them, in the place they call home.

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