

## Revised Draft Washington Long Term Care Task Force Guiding Principles

This statement of principles, drafted by the Advisory Committees to the Long-Term Care Task Force, is intended to guide the work of the Task Force and provide criteria for evaluating recommended changes to the long term care system in Washington State. These principles focus on three equal and inter-related primary elements for the provision of services and supports for individuals throughout their life: 1) access; 2) appropriateness; and 3) acceptability. They are meant to apply to services and supports for individuals, regardless of funding source, age or degree of disability and promote the health and independence of individuals throughout their lives including programs on health promotion, disease prevention, early intervention and chronic care management. Policy recommendations and decisions regarding long term care must support autonomy, self-determination and individual choice, as well as support the role of informal caregivers/families, through access across the state to information and culturally appropriate, high quality services and supports.

- **Focus on individual self-determination and personal responsibility.**
  - Individuals, their families, and communities can fully engage, to the extent that they are able, in the design of the system through:
    - A process that includes all interested stakeholders in a community and makes a special effort to ensure representation of persons with chronic illnesses, individuals with disabilities, and their families.
  - Individuals not yet using LTC services
    - Receive care based on the chronic care model
    - Utilize a shared care plan to coordinate their care cost and systems
    - Have a health care directive
    - Have access to medical/ social support systems that promote prevention
  - Individuals with chronic or advanced illnesses or disabilities can plan and direct, to the extent that they are able, their services and supports through:
    - Person-centered planning, which includes identifying personal goals over his or her lifespan and develops services and supports to meet those goals
    - Educational opportunities to empower individuals in decision-making and self-management
  - Professionals that comprise the system (state policy makers, case managers, direct care workers and other service providers) support individuals by:
    - Organizing services around the individual and their “home”
    - Training professionals on person-centered services and self-determination with the assumption that individuals are capable of planning and self-direction
    - Recognizing the choice of individuals to include others in the planning and delivery of services and supports (e.g., family, friends, etc), subject to legal limitations

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- **Support informal caregivers/families through respite and other services, training, support groups and information.**
  - Include incentives in state policy and program rules that support families to provide care or pay for care
  
- **Guarantee access to information for all citizens of the state.**
  - Individuals know that information is available and how to access the information
    - Information should be accessible to people in locations and formats they can easily use
    - “Consultants/navigators/care managers” available to help individuals gain access to meaningful information
  - Individuals have the right to make informed choices about their service and support options, as well as planning for future needs and pursuing healthy behaviors through information systems meeting the following criteria:
    - Accessible regardless of age or disability status, culture or language, as desired by the individual
    - Reliable
    - Comprehensive
    - Community-oriented and culturally appropriate
    - Includes a full range of programs, services and support -- health and wellness, transportation, housing, employment support, palliative care, and personal care in varied settings (nursing facilities, adult family homes, assisted living and individual’s homes).
    - Information should be accessible to people in locations and formats they can easily use
    - Organized with the end-user in mind and to facilitate decision-making and self-determination
    - Integrates data systems and information to support the needs of individuals, providers and policy-makers
    - Details individual’s rights and responsibilities
  
- **Access to culturally appropriate, high quality services and supports.**
  - Timely access to appropriate services and supports within a reasonable distance from where individuals live. Considerations for appropriateness include:
    - Type and setting -- primary care, specialty providers, direct (formal) services workers, and informal supports
    - Availability of full range, including transportation, housing, employment support, personal care, adult day services, disease prevention, health promotion, chronic care management, family caregiver support services, health and wellness activities, and palliative care
    - Adequate and sustainable funding (i.e., Medicaid reimbursement sufficient to make the resource available and no unfunded mandates)
    - Language and appreciation for cultural diversity

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- Reasonable accommodations to meet an individual's needs and preferences
  - Adequate availability of a well-trained and competent workforce
  - Within available resources
  - Support individuals to meet their goals and honor their preferences and choices regarding quality of life by:
    - Including individual satisfaction and dignity in measures of quality
    - Integrating palliative care as a service and support option subject to a person's choice and preferences about quality of life
    - "Consultants/navigators/case managers" available to help individuals gain access to, understand, and make appropriate use of services
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- **State and system-wide effort to assure the delivery of high quality care and services in a cost-effective and efficient manner, that:**
  - Establish clear outcome goals and measurements (e.g., maintain health status; minimize acute episodes; avoid or delay more costly service use; reduce costs)
  - Use data systems and information to support individuals, as well as the needs of providers and policy-makers
  - Continually monitor progress toward meeting established performance goals and regularly reassesses, monitors, and reports on both the goals and measures
  - Improve or maintain cost-effectiveness and efficiency in delivery of services and supports, in the aggregate
  - Use evidence-based clinical guidelines and outcome-based interventions
  - Include consumer protection provisions
  - Include individual satisfaction and dignity measures in performance goals
  - Maximize the efficient use of available long term care programs, supports and services irrespective of funding sources
  - Ensure public dollars are spent on high quality care
  - Establish and evaluate various pilot programs to test the efficacy of state and system-wide efforts to assure the delivery of high quality care and services